DOCTOR OF PHILOSOPHY

A critical analysis of the current postpartum care experiences of women with FGM using NHS services in the UK

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By

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A thesis submitted in partial fulfilment of the University's requirements for the Degree of Doctor of Philosophy

Ethical Approval

Certificate of Ethical Approval

Applicant:

Rebecca Seymour

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The Experiences and Needs of Women who have had FGM in the Post-partum Period.

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

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"Fall down seven times, stand up eight."

Japanese Proverb

Abstract

Female Genital Mutilation (FGM) affects approximately 200 million women worldwide (WHO, 2016), with 103,000 women and girls with FGM thought to be living in the UK. Of specific concern is pregnancy and childbirth due to the negative obstetric consequences caused by FGM. The transition to parenthood is challenging for new mothers and is known to be complicated by migration status. Thus, the research question for this thesis is: what are the post-partum experiences and needs of women with FGM using NHS services in the UK? A focused ethnographic (FE) approach conceptualized the postpartum experiences and needs of women with FGM. A FE approach ensured a culturally contextualized understanding of the phenomena and ensured contextual factors influencing women's experiences were understood and incorporated. A three-phase approach, reflecting the macro, meso and micro levels ensured contextual grounding in culture and a robust understanding of women's experiences throughout the pregnancy and postpartum journey.

A documentary analysis (DA) of health policies relating to FGM, showed a top-down approach to healthcare used by the UK government and health authorities. There was a heavy focus on antenatal and labour and birth and while culturally sensitive care was noted as important, guidance on implementation is lacking. Interviews with Key informants (KI) (Policy makers, Police, midwives) displayed the top-down approach to healthcare, resulting in tension between KI who had direct interaction with women with FGM, and those who did not. Women interviewed were happy with the care they received overall, but they voiced the dominance of the law during the antenatal period, and the top-down approach to healthcare provision. The importance of the postpartum period (PPP) was highlighted, and women expressed the need for additional support during this time.

This thesis highlights the top-down approach to maternity care for women with FGM used by the NHS, and how this approach decreases the ability of healthcare providers to deliver culturally sensitive care, silencing women's voices. A 'cradle model' is proposed to activate women and increase support mechanisms they feel are needed. This model lifts and supports women to achieve their best health outcomes. Limitations include the ethical restriction of allowing only English-speaking women to participate, the unknown degree of assimilation of women, and the small sample size. Strengths include the wide range of healthcare professionals interviewed, and the conceptualization of the issue from the macro, meso and micro levels providing a detailed context to women's experiences. This is the first study to exclusively research the postpartum experiences of women with FGM in the UK using NHS services. Women need a holistic approach to care, which extends to postpartum needs and considers individual circumstances and contexts beyond FGM. Recommendations for future policy and research include a mapping of maternity care for women with FGM; increased understanding of the importance of social networks for women who have migrated and understanding the experience of healthcare practitioners providing care to women with FGM. A Patient and Public Involvement and Engagement (PPIE) framework would ensure women's voices are heard.

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Abbreviations and Acronyms

AN	Antenatal
ARPs	Alternative Rites of Passage
BAME	Black, Asian and Minority Ethnic
BMA	British Medical Association
BME	Black and Minority Ethnic
BMI	Body Mass Index
CCG(s)	Clinical Commissioning Group(s)
CDC	Centres for Disease Control and Prevention (USA)
CEDAW	Convention on the Elimination of all forms of Discrimination Against Women
C-section	Caesarean-Section
CoE	Council of Europe (Human Rights Organization of the EU)
DA	Documentary Analysis
DHS	Demographic Health Survey
ECOSOC	United Nations Economic and Social Council
ECtHR	European Court of Human Rights
EIGE	European Institute for Gender Equality
EU	European Union
FGC	Female Genital Circumcision/Cutting
FGCS	Female Genital Cosmetic Surgery
FGM	Female Genital Mutilation
GBV	Gender-Based Violence

GDPR	General Data Protection Regulation
HCPs	Health Care Practitioners/Providers
KIs	Key Informants
L&B	Labour and Birth
MBRRACE-UK	Mothers and Babies: Reducing Risk through Audits and Confidential Enquires across the UK
MDE	Maternity Death Enquiry Ireland.
NGO (s)	Non-Governmental Organization(s)
NHS	National Health Service
NICE	National Institute of Health and Care Excellence
NIMACH	Northern Ireland Maternal and Child Health
NMC	Nursing and Midwifery Council (UK)
ONCHR	Office of the United Nations High Commissioner for Human Rights
PCHR	Personal Child Health Record
PIS	Participant Information Sheet
PP	Post-Partum
PPIE	Patient and Public Involvement and Engagement
PTSD	Post-Traumatic Stress Disorder
RCM	Royal College of Midwives
RCN	Royal College of Nurses
RCOG	Royal College of Obstetricians and Gynaecologists
REC	Research Ethics Committee
SCIE	Social Care Institute for Excellence

SES	Socio-economic Status
TR	Therapeutic Relationship
UHCW	University Hospital Coventry and Warwickshire NHS Trust
UK	United Kingdom
UKCC	UK General Council
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNECA	United Nations Economic Commission for Africa
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Fund
UNIFEM (UN Women)	United Nations Development Fund for Women
UNFPA	United Nations Population Fund
WHA	World Health Assembly
WHO	World Health Organization

Chapter 1 Introduction and Background

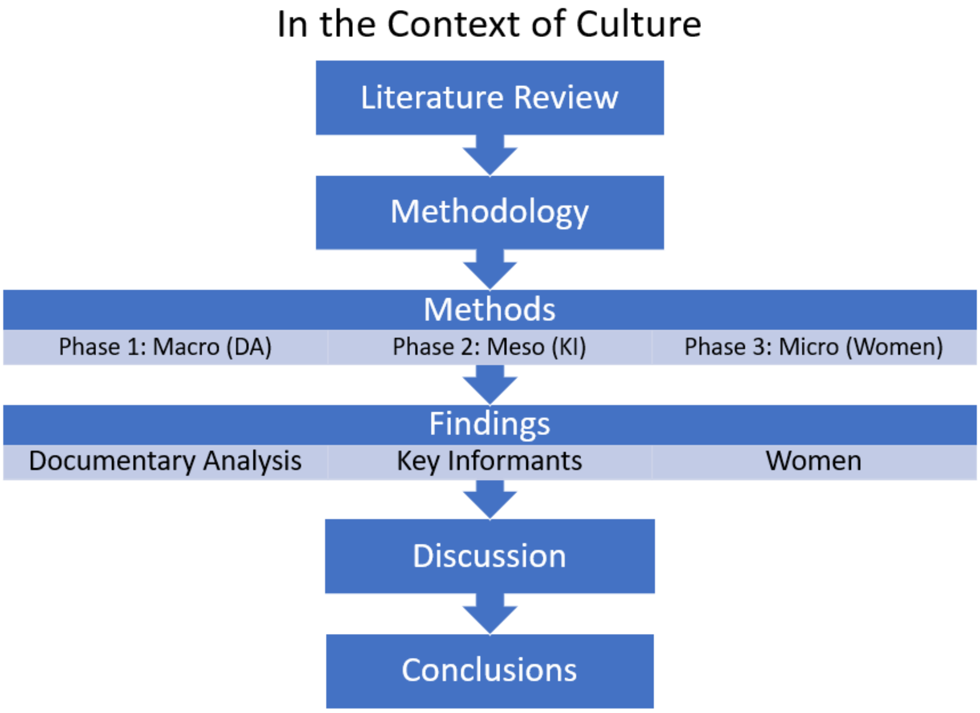
This introduction will provide the definitions of FGM, reasons for the practice, women’s perceptions of the practice, the female physical, psychological, and sexual health consequences, international and national policy, laws regarding FGM, and the prevalence and context of FGM within the UK. FGM is a diverse cultural practice and as such is influenced by attitudes and beliefs of those who practice it and those who do not. International and national policy and legal frameworks, and the degree to which these are implemented and acted upon also influence attitudes and behaviours. As UK policy has evolved in the past 30 years to reflect changing attitudes to FGM and set the tone for how the practice is viewed in the UK by the general public this is also outlined. Increased migration from FGM practicing countries has also impacted policy, though the level at which migrating populations who practice FGM integrate into UK society is unknown. The voices of women with FGM are not being heard and represent a crucial aspect of this issue. The following chapter includes a summary review of the literature regarding maternal health, FGM and the UK context. In this chapter, an exploration into the current maternity practices in the NHS, knowledge regarding migrant maternal health, and the health consequences of FGM specific to childbirth will be explored in detail for context to the study design. While not in the purview of this thesis, topics such as Alternative Rites of Passage (ARPs), Female genital cosmetic surgery (FGCS), male circumcision, and medicalization of FGM are major topics for discussion and provide understanding to the complex nature of the topic and complex opinions and experiences women with FGM may have. A brief introduction to these topics is available in Appendix 0.

The thesis will go on to present the methods used to address the identified research question and aims and is followed by three findings chapters representing how aims 1-3 of the research project were met. A discussion will be presented at the end of each findings chapter as well as an overall discussion in Chapter 6.

1.1 Thesis Structure

This thesis is structured around the context of culture, which is explained in Section 2.4 and throughout the thesis (Figure 1.1).

Figure 1.1: Structure of Thesis



1.2 Introduction to, and Context of Female Genital Mutilation in the United Kingdom (UK)

The practice of Female Genital Mutilation (FGM) is a complicated, contested issue with deep cultural and traditional roots. To say it is a multi-layered, multi-faceted, culturally-contextualized issue fails to convey the sheer depth of nuance associated with it. Discussions regarding FGM, its origins, continuation and means of ending the practice can be found in such diverse fields as anthropology, history, sociology, women’s studies, medicine, health, human rights, and the law. FGM is currently practiced in approximately 30 countries in Africa, the Middle East and Asia, affecting approximately 200 million women (UNICEF, 2016). This thesis focuses on a very specific time-point within the lives of women with FGM, exploring their postpartum experiences and needs. The term “FGM” will be used throughout this thesis as this is the term currently used by the World Health Organization (WHO) and United Kingdom (UK) government although it is acknowledged that other terms are used by different cultures. While it is not in the purview of this thesis to debate or pass judgment on the act of FGM itself, an introduction to the topic of FGM and the UK context will be given to ensure understanding of the significance of the contextualized findings and conclusions of the study.

1.3 Female Genital Mutilation

1.3.1 What is FGM?

In 1997, the WHO produced a new definition and classification system of FGM. The current definition for FGM used by the WHO, United Nations (UN) and UK government states FGM is comprised of: "all procedures involving partial or total removal of the external female genitalia or other injury to the female genital organs for non-medical reasons" (WHO, 1997). The WHO describes FGM as violating a "persons' rights to health, security and physical integrity, the right to be free from torture and cruel, inhuman or degrading treatment, and the right to life when the procedure results in death" (WHO, 2016).

Table 1.1: WHO Definition of Types of FGM
Type I — Partial or total removal of the clitoris and/or the prepuce (clitoridectomy). When it is important to distinguish between the major variations of Type I mutilation, the following subdivisions are proposed: • **Type Ia**, removal of the clitoral hood or prepuce only; • **Type Ib**, removal of the clitoris with the prepuce
Type II — Partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora (excision). When it is important to distinguish between the major variations that have been documented, the following subdivisions are proposed • **Type IIa**, removal of the labia minora only; • **Type IIb**, partial or total removal of the clitoris and the labia minora; • **Type IIc**, partial or total removal of the clitoris, the labia minora and the labia majora
Type III — Narrowing of the vaginal orifice with creation of a covering seal by cutting and appositioning the labia minora and/or the labia majora, with or without excision of the clitoris (infibulation). When it is important to distinguish between variations in infibulations, the following subdivisions are proposed: • **Type IIIa**, removal and apposition of the labia minora; • **Type IIIb**, removal and apposition of the labia majora *Re-infibulation can occur after childbirth
Type IV — All other harmful procedures to the female genitalia for non-medical purposes, for example: pricking, piercing, incising, scraping and cauterization

(Source: WHO, 2018, created from Section 1.3, p26-32) *Added by author

The types of FGM have been described in Table 1.1 and include clitoridectomy (Type I), excision (Type II), infibulation (Type III) and all other harmful procedures carried out on the female genitalia for non-medical reasons (Type IV) (WHO, 2008). Re-infibulation is "a procedure to narrow the vaginal opening again in a woman who has been de-infibulated. If it is done, it is usually completed after childbirth and is also known as ‘re-suturing’” (WHO, 2018, p219). Re-infibulation is considered Type III FGM. Diagrams showing the types of FGM compared to normal female external genitalia can be found in Figure 1.2. These drawings are used by healthcare professionals in clinical practice when explaining FGM to women.

The following images of normal external female genitalia and Type 1-4 of FGM are directly reproduced from: Royal College of Nursing (2019). *Female Genital Mutilation: An RCN Resource for Nursing and Midwifery Practice*. Fourth edition. London: RCN. Retrieved from: www.rcn.org.uk/professional-development/publications/pub-007833. (p16-17)

Figure 1.2: Clinical pictures of usual genitalia and types of FGM

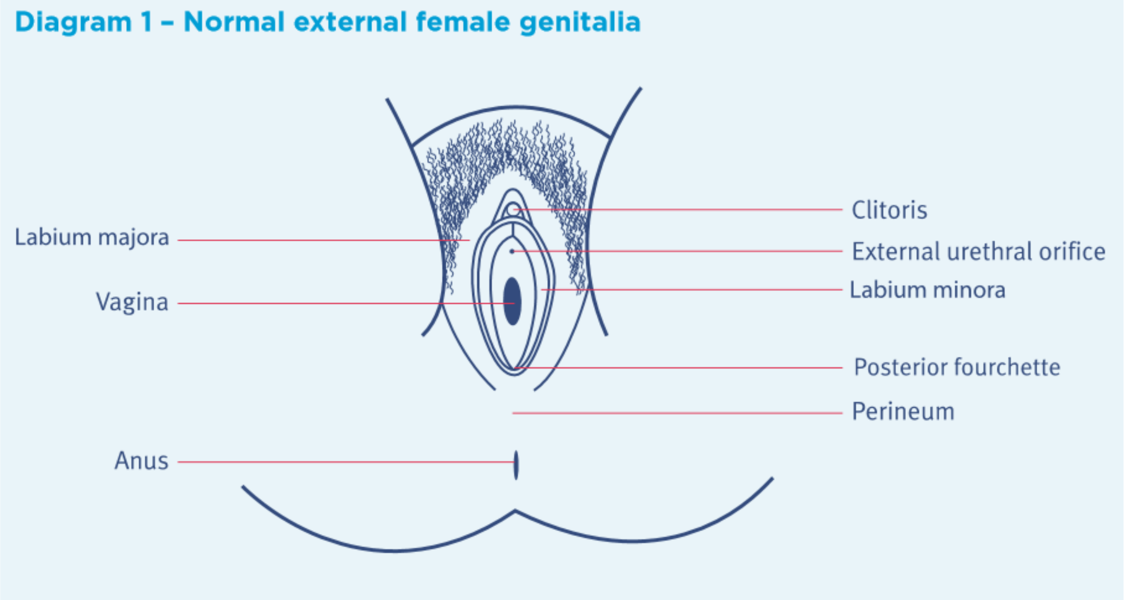


Diagram 2 – Type 1 FGM

When the clitoris or the clitoral hood is cut off

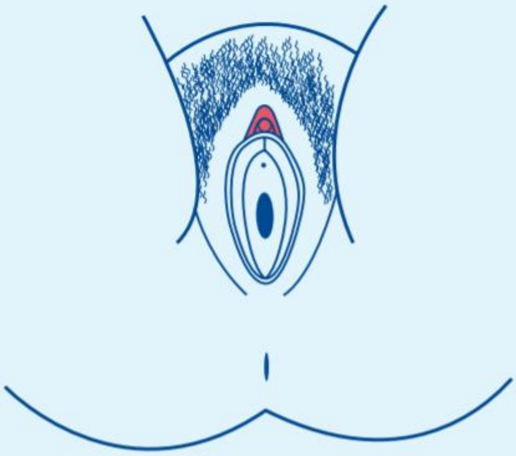


Diagram 3 – Type 2 FGM

When the clitoris and inner lips are cut off

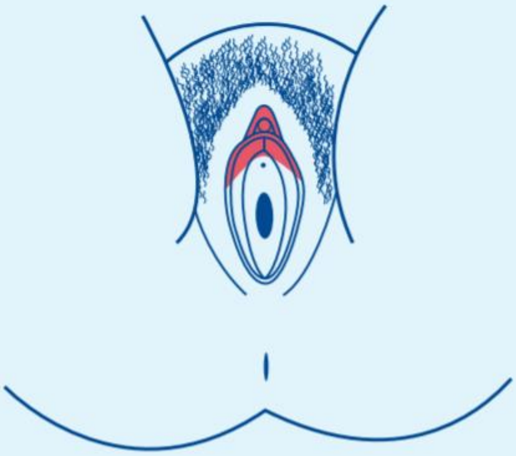


Diagram 4 and 5 – Type 3 FGM

When the clitoris, inner lips and outer lips are cut and sewn together

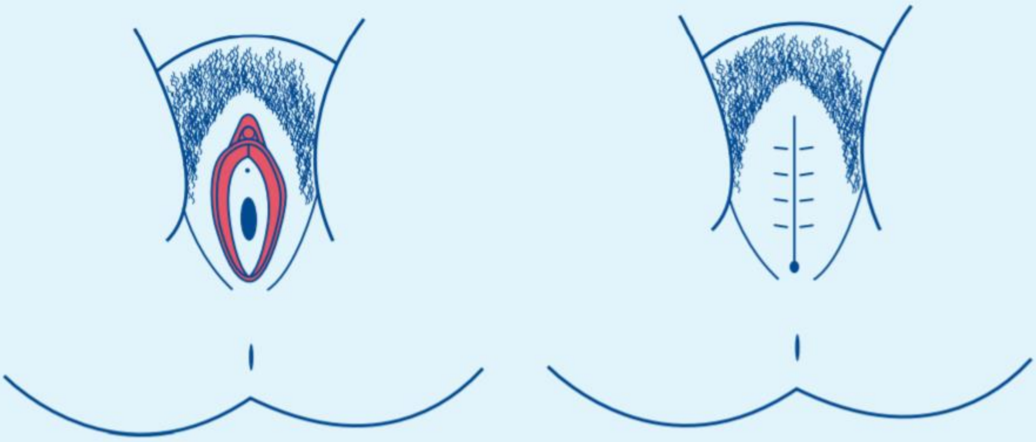
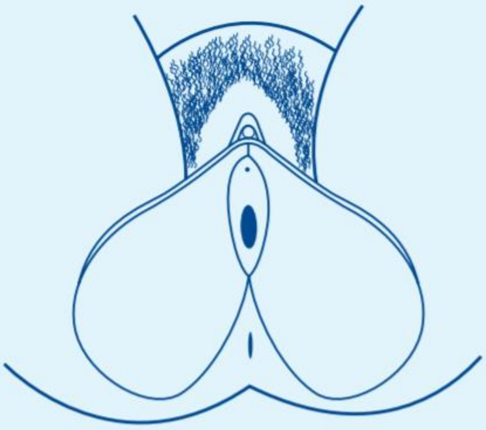


Diagram 6 – An example of type 4 FGM stretched labia

All other harmful pratices including stretching, pricking, piercing, cutting, scraping and burning



1.3.2 Reasons for the Practice of FGM.

The reasons FGM is practiced and continues are nuanced and context related, and can be divided into cultural, religious, sexual and health related. Although the WHO (2020) lists various reasons for the practice of FGM (see Table 1.2); it must be noted that for practicing communities FGM is practiced with good intentions and represents an act of caring by parents who desire to enhance and protect their daughters future prospects in life (Gruenbaum, 2001). The practice of FGM is highly contextualized, varies by geographic location and cultural groups, and is practiced for nuanced reasons within those groups. The WHO (1999) Mental Map of FGM (Figure 1.3) provides great insight into the layered and complex nature of the issue including the intersecting aspects of culture, religion, community cohesion and how they influence the perpetuation of feminine ideals. The Mental Map also displays how the continuation of FGM is supported from many aspects of a woman’s life, requiring numerous interventions to alter the practice.

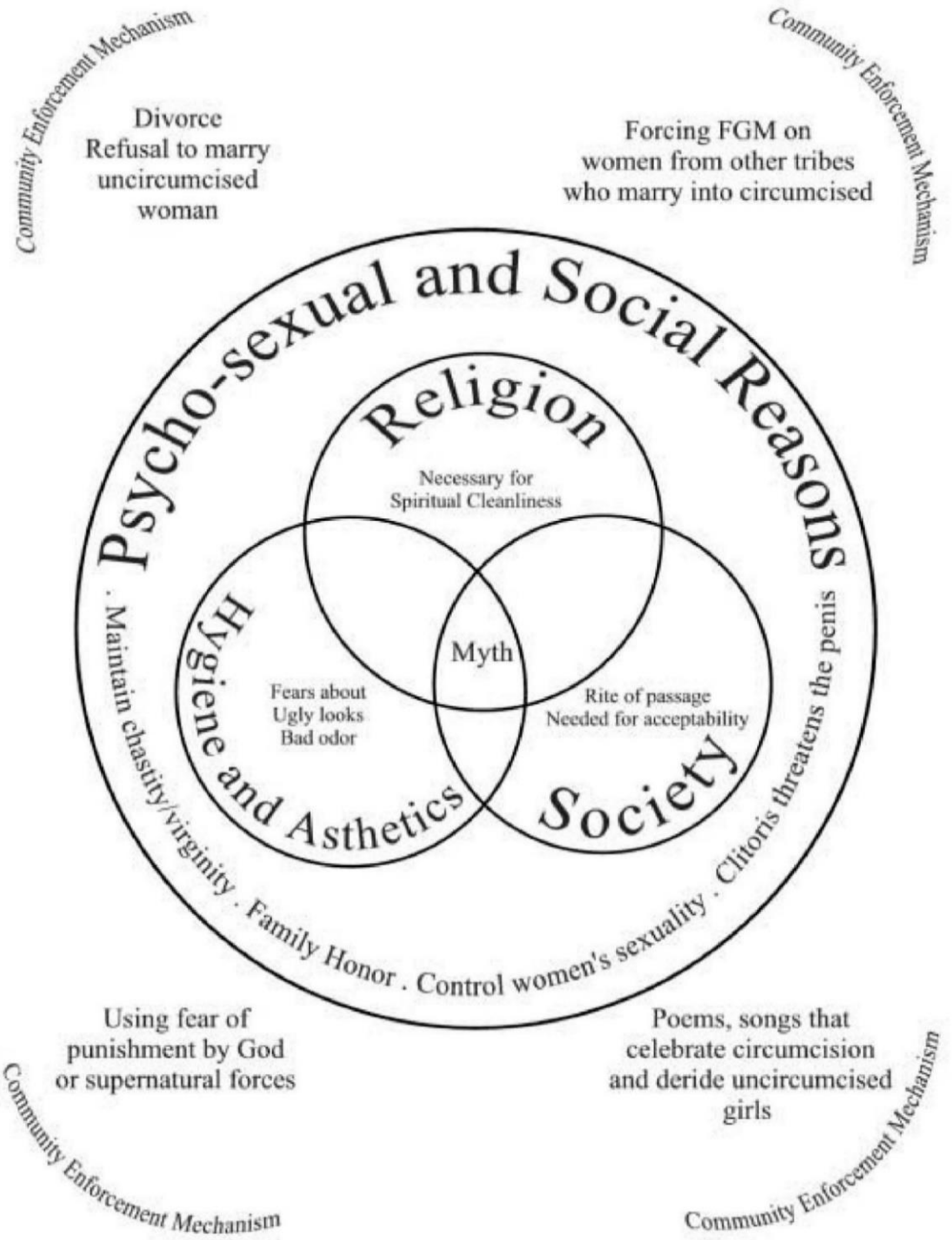
FGM is an ancient cultural practice with potentially life-threatening health consequences and long-term morbidities. No matter what the specific reasons for continuing the practice are, the impact of the act is always the burden of the individual and depends on experiences, attitudes and perceptions towards the practice, health outcomes and access to medical care.

Table 1.2: Reasons why FGM is practiced

1. Where FGM is a social convention (social norm), the social pressure to conform to what others do and have been doing, as well as the need to be accepted socially and the fear of being rejected by the community, are strong motivations to perpetuate the practice. In some communities, FGM is almost universally performed and unquestioned.
2. FGM is often considered a necessary part of raising a girl, and a way to prepare her for adulthood and marriage.
3. FGM is often motivated by beliefs about what is considered acceptable sexual behaviour. It aims to ensure premarital virginity and marital fidelity. FGM is in many communities believed to reduce a woman's libido and therefore believed to help her resist extramarital sexual acts. When a vaginal opening is covered or narrowed (Type 3), the fear of the pain of opening it, and the fear that this will be found out, is expected to further discourage extramarital sexual intercourse among women with this type of FGM.
4. Where it is believed that being cut increases marriageability, FGM is more likely to be carried out.
5. FGM is associated with cultural ideals of femininity and modesty, which include the notion that girls are clean and beautiful after removal of body parts that are considered unclean, unfeminine or male.
6. Though no religious scripts prescribe the practice, practitioners often believe the practice has religious support.
7. Religious leaders take varying positions with regard to FGM: some promote it, some consider it irrelevant to religion, and others contribute to its elimination.
8. Local structures of power and authority, such as community leaders, religious leaders, circumcisers, and even some medical personnel can contribute to upholding the practice. Likewise, when informed, they can be effective advocates for abandonment of FGM.
9. In most societies, where FGM is practised, it is considered a cultural tradition, which is often used as an argument for its continuation.
10. In some societies, recent adoption of the practice is linked to copying the traditions of neighbouring groups. Sometimes it has started as part of a wider religious or traditional revival movement.

Source: WHO, 2020b; https://www.who.int/news-room/fact-sheets/detail/female-genital-mutilation

Figure 1.3: Why the Practice of FGM Continues, Mental Map.
Reproduced from WHO (1999); Female Genital Mutilation, Programmes to Date, What Works and What Doesn’t, A review



1.3.3 Women’s experiences, attitudes, and perceptions towards FGM.

FGM is practiced in approximately 30 countries in Africa, the Middle East, and Asia, with an estimated 75 countries having women with FGM in their populations (Orchid Project, 2019). Literature on the topic of FGM originates from two main sources, Africa and countries with Western cultures who have affected migrant populations (e.g., the UK, Canada, Norway, Sweden). Though the literature is growing, less has been produced discussing the practice in the Middle East, with even less discussing FGM in Asia. Factors such as a woman’s and her partners views, beliefs and perceptions may impact how a woman experiences the Postpartum Period (PPP) and what needs she may have. Women’s individual perceptions of the practice and its consequences provide context to their experiences during the PPP. As men are an integral part of practicing societies and may act as partners and support structures for women with FGM, their perceptions are also noteworthy.

There is evidence that within FGM practicing countries there is a divergence in attitudes and perceptions towards the continuation of the practice (Masho & Matthews, 2009), and that there are many diverse reasons some cultures perpetuate the tradition of FGM. Indicators for the continuation of the practice include living in rural geographical areas (Masho & Matthews, 2009; Mohammed, Hassan, & Eyada, 2014), associating the practice with religion or tradition (WHO, 2020b), lower levels of education in women (Afifi & von Bothmer, 2007; Gage & Van Rossem, 2006), and having FGM and being married (Masho & Matthews, 2009). However, the severity of type may be decreasing from Type 3 to Type 2 or 1 as new generations with differing views have children reaching circumcision age (Almroth et al., 2001). Re-infibulation (Section 1.3.1) was also seen to be associated with social conformity over desire to continue the practice from women and men (Berggren et al., 2006). Studies show both younger generations of women and men have negative feelings towards the practice and while reasons such as religion and myths concerning female sexuality are difficult to dispel, lack of communication between sexes and within partnered relationships and how this effects subsequent perceptions towards FGM is noteworthy as FGM is seen as ‘women’s business’ (Almroth et al., 2001). The complexity and diversity of reasons for the perpetuation of FGM are unique to each practicing community (WHO, 2020b).

Women’s and men’s perceptions of FGM are complex and diverse, resulting in an internal dilemma for women. Although women report negative feelings towards the procedure and negative health outcomes as a result, the power of social conformity, tradition, and religion acts to perpetuate the practice while being contrasted with the resulting pain and fear. This may be further complicated by migration and the influence of new cultures as the amount of segregation or assimilation migrants experience may impact their perceptions of FGM (Johnsdotter & Essén, 2016). Increases in migration have resulted in women who have undergone FGM being seen in increasing numbers by healthcare services in traditionally non-practicing countries. Studies conducted in countries women migrate to report changing attitudes towards FGM. Litorp, Franck, and Almroth (2008) found 83% of women in their sample described no positive effects of FGM, with 89% reporting they would not let their daughters undergo the procedure. This section has discussed women’s experiences, attitudes and perceptions towards FGM; the next section discusses international FGM policy, human rights and laws.

1.3.4 International FGM policy, human rights, and laws.

International recognition and activism regarding FGM began circa 1976, with the signing of the International Covenant on Economic, Social, and Cultural Rights requiring countries to uphold standards of physical and mental health. In 1979, the ‘Convention on the Elimination of all forms of Discrimination Against Women’, which became known as the charter for women’s human rights was released (CEDAW, 1979). In 1990, the UN Committee on the elimination of violence against women classified FGM as a form of violence against women and made recommendations to member states for its elimination. In 1991, the UN changed the term ‘female genital cutting’ to ‘female genital mutilation’ upon recommendation of the WHO, using the medical term mutilation to highlight the removal of healthy tissue and has now been widely accepted in countries with Western cultures and Africa (Andro & Lesclingand, 2016; Gruenbaum, 2001).

All UN bodies, including UN Children’s Education Fund (UNICEF), UN Population Fund (UNFPA), UN Development Fund for Women (UNIFEM), and the WHO have declared an unyielding opposition towards FGM (Toubia & Sharief, 2003). This has been followed by an addendum in the African Charter on Human’s and People’s Rights to reflect this stance. On a national level, almost all African governments have created laws abolishing the practice (Toubia & Sharief, 2003). The European Academy of Paediatrics has condemned FGM as a devastating form of child abuse that must be abolished (Sauer & Neubauer, 2014).

In a review article, Toubia and Sharief (2003) note the lack of reliable data collected regarding FGM before 1995, and conclude more time is needed to assess the outcomes of the changes in the law. However, when the Sudan Fertility Survey conducted in 1979 is compared to the Sudan Demographic Health Survey (DHS) (1990), an overall decrease in prevalence can be seen in rates of FGM, 96% falling to 89% (Toubia & Sharief, 2003). A 10% shift was also seen from infibulation (Type 3) to clitoridectomy (Type 2). The Egyptian DHS between 1995-2000 also found daughters were 10% less likely to have undergone FGM than their mothers (Toubia & Sharief, 2003). Attitudes towards FGM have been seen to change when the determination to alter behaviour comes from within the practicing society (Toubia & Sharief, 2003). Toubia and Sharief (2003) provide little explanation surrounding data used and although a review article, the authors do not state where or how they gathered evidence, limiting the applicability of findings, and resulting in the need to use their information with caution.

In an article discussing the progress made in terms of abolishing FGM, Cottingham and Kismodi (2009) note a gradual increase in the recognition of the gravity of the practice, as well as the implications for women's health and position in society. The Fourth World Conference on Women held in Beijing in 1995 is noted as a great stride forward in progress and resulted in a strong commitment of 170 governments to eliminate FGM and other harmful practices (Cottingham & Kismodi, 2009). The authors note the importance and significance of recognizing FGM as a violation of human rights, with the African Charter on the Rights and Welfare of the Child, and the African Charter on the Human and People's Rights now containing sections regarding FGM. International organizations such as the WHO (WHO, 2008b), the UN (United Nations, 2015), the European Union (EU) (European Commission, 2013) have aided states and smaller organizations to act through their resolutions, policies and research focusing on the elimination of FGM. The UN Economic and Social Council (ECOSOC) and the World Health Assembly (WHA) Resolutions are also focusing on FGM (ECOSOC, 2007; World Health Assembly, 2008). Cottingham and Kismodi (2009) remark how locations that have succeeded in the abandonment of FGM on a large scale have done so through social change, where a significant number of families act as one in a community to ensure no single girl or family are deprived or ostracized due to not having their daughters undergo FGM.

In many African countries and most of Europe FGM is illegal. Unfortunately, enforcing these laws is difficult and risks the practice being conducted in secret as is assumed to happen in the UK and other European countries (Dixon et al., 2018). Some countries have advocated the less severe forms of Type I and II FGM, and promoted the procedure being conducted in a medical facility, however, the WHO and its affiliates have rejected the medicalization of FGM on the grounds that the harm is not reduced. Current international policy and laws ban the procedure of FGM; however, due to the nature of the practice, it is still being conducted in practicing communities and sometimes by healthcare providers (HCPs) (UNFPA, 2018). This section has discussed international FGM policy, laws and human rights. The next section discussed the prevalence of FGM in Europe and the UK.

1.3.5 Prevalence of FGM in Europe and the UK.

The WHO estimates approximately 200 million women are living with FGM, with three million at risk of having the procedure completed annually (UNICEF, 2016; WHO, 2016). With increased migration from practicing countries, FGM has become a global concern and is now seen in Canada, New Zealand, Australia, the USA, and Europe. It is estimated that 137,000 women in England and Wales are currently living with FGM, with a further 67,000 at risk for, or already having had the procedure completed (Macfarlane & Dorkenoo, 2015).

Estimating prevalence of FGM within a country is challenging, with the current methods used by many countries and the UK being the so called ‘extrapolation-of-

African-prevalence-data-method' (Leye, Mergaert, Arnaut, & O'Brien Green, 2014; Macfarlane & Dorkenoo, 2015). This method uses DHS survey data from FGM practicing countries and applies the prevalence of FGM to women who have migrated. The risk to female children is also calculated using 'having a parent with FGM' as the number one risk factor. Limitations of this method and its' use in the UK include the use of census data in the calculation as census data may not be representative of the affected population as female refugees and asylum seekers would not be included (Leye et al., 2014). The estimated prevalence of FGM in Africa varies widely across countries, does not follow country borders and is closely tied to ethnicity (Gruenbaum, 2001). The political, social and historical contexts of practicing communities and how country borders were created must be noted and reflects a variation in FGM practices despite geographical proximity (Sipsma et al., 2012). Although ethnicity may be a better predictor of risk for FGM, associated legal and ethical issues, such as ethnic profiling, prevent countries using this option (Johnsdotter, 2004).

The most important limitation to this method in the UK context is its' failure to consider the effects of migration. The reasons for migration are numerous and have a considerable impact on how much or how little women integrate into UK society (Giuntella, Kone, Ruiz, & Vargas-Silva, 2018). Johnsdotter (2004) recommends the following considerations be noted when calculating risk; number of immigrants from FGM practicing countries, ethnic community size and composition, socio-cultural logic of FGM, level of social pressure, level of state interference, preventative campaigns, level of integration or segregation, time of residence in host society, and parent individual background. This list is complex and interconnects many levels and aspects of society.

The importance of these factors led to the European Institute for Gender Equality (EIGE) publishing ‘Estimation of girls at risk of FGM in the European Union’ (EIGE, 2015), a step-by-step guide on how to calculate risk estimates now in its’ 2nd edition. This guide combines the extrapolation method discussed above with a ‘migration and acculturation impact factor’. Since its publication, numerous studies have used this method (e.g. Ziyada, Norberg-Schulz, & Johansen, 2015); while others have hypothesized different methods to enhance the EIGE method such as Van Baelen, Ortensi, and Leye (2016) who applied age specific FGM prevalence rates in migrants home countries in five-year intervals, and Ortensi, Farina, and Menonna(2015), and Ortensi, Farina, and Leye (2018), who devised and applied a ‘migrant selection-effect’ to account for migrant-selection resulting in younger, more educated and more urban migrants in EU countries having decreased risk. Kawous et al., (2020) applied a reduction factor to their risk estimates based on the effects of ‘migration and acculturation’ and ‘preventative measures’, arguing it enhanced the sensitivity of FGM risk estimates. More data is needed to fully understand the risk profile of migrants for FGM, but until then, current methods must suffice as they provide estimates used to initiate change and resource deployment. Until more data is acquired in the UK, current estimates, combined with mandatory reporting numbers while acknowledging the lack of individual context, is the best method available. The next section discusses FGM in the UK context.

1.4 The UK Context

In 1985, the practice of FGM was made illegal through the passing of the Female Circumcision Act (UK Parliment, 2020). The passing of the Female Genital Mutilation Act in 2003 provided further insight into how FGM was being managed in the UK with the adoption of the UN and WHO terminology of ‘mutilation’ rather than ‘circumcision’, while also making it illegal to take a child overseas to have FGM performed (UK Parliment, 2003).

In 2011 the UK signed the Council of Europe’s declaration on *Preventing and Combating Violence Against Women and Domestic Violence*; which provides a comprehensive framework based on prevention, prosecution and elimination of violence against women (Council of Europe, 2011). In the UK, FGM cannot occur based on the argument that a woman’s psychological health will suffer if she does not conform to her cultural expectations (Griffith, 2013). Penalties to those conducting FGM, or assisting in the completion of FGM, include imprisonment of 14 years, a fine, or both (Griffith, 2010). Midwives and HCPs have a duty to report, safeguard, advise and educate women and families, and district nurses must invoke child protection procedures and educate women and communities (Griffith, 2010).

The National Health Service (NHS) in the UK is a publicly funded universal healthcare system. In October 2015, a mandatory reporting (MR) duty for health and social care workers and teachers came into effect (Home Office, 2015), directly intertwining the law and healthcare in the context of FGM. These groups must report any known cases of FGM in girls under the age of 18 years to the Police, as well as any cases that arise during their practice (Home Office, 2015). In 2015, it also became mandatory for HCPs to use the FGM enhanced dataset to record any interaction with women or children with FGM. The enhanced data set includes the woman’s NHS number and other information about her FGM such as type, country where it was performed and age when it occurred (NHS England, 2015). In the UK it is best practice for HCPs to record FGM status in a woman’s healthcare record (NHS, 2014). During pregnancy, birth and the PPP; midwives record if there is a family history of FGM status in discharge summaries to General Practitioners (GPs) and health visitors, as well as the personal child health record (PCHR), also known as the ‘Red Book’ (NHS, 2014). Midwives must note a woman’s history of FGM and confirm they have advised her it is illegal in the UK and regarding the health implications of FGM (NHS England, 2020). The enhanced data set has caused controversy between the government and HCPs, with the government stating it needs such personal information as a woman’s NHS number to ensure the same case is not reported several times; however, HCPs argue it is an invasion of privacy and harms the therapeutic HCP- woman relationship, decreasing their ability to develop trust (Creighton et al., 2019; Dixon, 2019). Although female children of women who have had FGM are routinely referred to social services in the UK, to date there has been only one successful prosecution of an FGM case, resulting in the mother of the child serving a prison sentence, the father being acquitted and the ‘cutter’ remaining at large (BBC News, 2019). In 2013, the International Development Committee issued a report regarding the lack of prosecutions concerning FGM in the UK (Griffith, 2013). Poor understanding of the law, poor reporting of the procedure, and officials being “too politically correct” (p525) when investigating complaints were cited as the main reasons for the low prosecution rate (Griffith, 2013).

Table 1.3, provides a brief timeline of FGM laws and policies, adapted from EIGE, (2013). It is important to note the ‘enhanced FGM dataset’ is unique to the UK and represents a differing approach compared to EU and international contexts.

Note: each organization, EU and UN have worked separately producing policies and laws for its members. The UK was a member of the EU from 1969-2020 and has been a member of the UN since 1945.

Table 1.3: Timeline of UN and EU FGM Laws and Policies

Year	**UN**	**EU**	**UK**
1985			Female Circumcision Act bans female circumcision
1990	1st UN policy specifically dealt with FGM- General Recommendation No. 14 CEDAW (focused on health).		
1992	Word ‘mutilation’ appeared in CEDAW general recommendation No. 19 on violence against women (focused on health but featured gender inequalities and discrimination as factors of FGM).		
1994		Increased awareness leads to a non-binding policy change stating that FGM can be used as a reason to grant asylum (becomes legally binding in 2009).	
1997	UNHCR deems FGC a ‘harmful cultural practice’. This statement is endorsed by the WHO, UNFPA, and UNICEF, and represents the first joint statement on FGM.	DAPHNE Programme (I, II, III) begins	
1999		Treaty of Amsterdam: enactment of common European asylum legal order (based on 1951 Geneva Convention, status of refugees. Laid the groundwork for common FGM asylum	

Table 1.3: Timeline of UN and EU FGM Laws and Policies

Year	**UN**	**EU**	**UK**
		policy, information exchange and prevalence numbers. Common standards and greater equality across nations.	
2000		Charter of Fundamental Rights of the EU, right to life, human dignity, rights of the child and women, freedom from discrimination, torture, inhumane treatment, right of men and women to be treated equally.	
2001		Resolution 1247 on FGM is adopted. CoE acknowledges increased prevalence of FGM in EU due to migration. It states FGM should be considered inhumane and degrading treatment within the meaning of Article 3 of the European Convention of Human Rights (ECHR). (refugees cannot be retuned if there is risk of FGM).	
2000-2003		Daphne I Programme: Contribute to the protection of children, young people and women from violence.	
2003	1st annual Day of Zero Tolerance of FGM (February 6th)		UK FGM Act replaces earlier Act. The word ‘circumcision’ is replaced with ‘mutilation’, FGM cannot occur in other countries on UK residents or

Table 1.3: Timeline of UN and EU FGM Laws and Policies

Year	**UN**	**EU**	**UK**
			citizens, and the maximum prison sentence is increased to 14 years.
2004-2008		Daphne II: Continues work of Daphne I.	
2005			Scottish Prohibition of FGM Act.
2007-2013		Daphne III: Continues work of previous Daphne programs.	
2007		First FGM asylum case heard by the ECtHR	
2008	New statement released by the WHO replacing 1997 (UNHCR) statement highlighting the cross-sectorial and human right approach needed for FGM. Joint statement by: WHO, OHCHR, UNECA, UNHCR, UNAIDS, UNESCO, UNICEF, UNDP, UNFPA, UNIFEM.	European Commission Policy Plan on Asylum. Laid roadmap for Common European Asylum System (CEAS), including FGM. European Parliament included prosecution and education regarding FGM in the Convention of the Rights of the Child.	
2009	UN High Commissioner for refugees releases a Guidance Note on Refugee Claims Relating to FGM. Victims or potential victims of FGM can be considered as members of a particular social group. Statement also reiterates responsibilities covered under the Convention Against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment.	CoE enacts Resolution 1662- Action to Combat Gender-Based Human Rights Violations reaffirmed. Concrete actions must be taken to combat FGM at a National and International level. <u>National</u>: members must develop policies, prevent violations and punish perpetrators	

Table 1.3: Timeline of UN and EU FGM Laws and Policies

Year	**UN**	**EU**	**UK**
		International: members must promote women's rights and take action against gender-based violence. European Parliament pass Resolution on Combating FGM in the EU. New section includes asylum as it pertains to FGM. Stockholm Programme: First time FGM is noted in an EU Programme for Action (landmark policy).	
2010		European Council commits to the eradication of violence against women	
2011		Council of Europe: Istanbul Convention: First legally binding European instrument completely focused on violence against women; including FGM	
2012	UN General Assembly passes UNIFEM resolution banning FGM. Urges members to condemn FGM and harmful practices (women and girls), enforce legislation, raise awareness and allocate sufficient resources to the issue.	EU strategic Framework and Action Plan on Human Rights and Democracy. FGM is explicitly addressed. Members must take action by 2014. Victims' Rights Directive: outlines minimum standards that must be reached by members. Definition of	

Table 1.3: Timeline of UN and EU FGM Laws and Policies

Year	**UN**	**EU**	**UK**
	General Assembly passes resolution 67/146: Intensifying global efforts for the elimination of female genital mutilations	GBV includes FGM. Specialized support services must be developed and implemented.	
2013		European Commission: Support for EU member states in prosecuting FGM more effectively. European Commission Press release: “International Day for Elimination of Violence against Women: European Commission takes action to combat Female Genital Mutilation”	
2014	General Assembly passes resolution A/RES/69/150: Intensifying global efforts for the elimination of female genital mutilations	Council of the European Union: Justice and Home Affairs Council Meeting. Council conclusions - "Preventing and combating all forms of violence against women and girls, including female genital mutilation" Reaffirms stance of FGM, recommends actions for member states to take.	Acute NHS Trusts are mandated to report numbers of women and children seen with FGM to the Department of Heath
2015	Sustainable Development Goals: Goal 3: Ensure healthy lives and promote well-being for all at all ages Goal 5: Achieve gender equality and empower all women and girls		The Enhanced FGM dataset is released and all mandatory reporters are required to submit detailed information about service users with FGM, including NHS number, country of

Table 1.3: Timeline of UN and EU FGM Laws and Policies

Year	**UN**	**EU**	**UK**
	5.3: Eliminate all harmful practices, such as child, early and forced marriage and female genital mutilation		origin, type, country and age where cut took place.
October 2015			Mandatory Reporting for healthcare workers, social workers and teachers comes into effect (Home Office, 2016)
2016			Point 55 from the UK Government Violence against Women and Girls Strategy 2016-2020 action plan (HM Government, 2016) reads as follows: ‘Develop an approach to the collection of data recorded by Police Authorities in relation to Honour Based Violence (HBV), Forced Marriage (FM) and Female Genital Mutilation (FGM) in conjunction with the National Police Chiefs' Council. Consideration will be given to this data being recorded as part of the Annual Data Return.’ *(HM Government, 2016: 55)*
2017		European Commission: declared 2017 the European Year of focused action	

Table 1.3: Timeline of UN and EU FGM Laws and Policies

Year	**UN**	**EU**	**UK**
		to combat violence against women and girls	
2018	Report of the Secretary-General: Intensifying global efforts for the elimination of female genital mutilation (A/73/266)		
2020	UNFPA-UNICEF Policy Brief: Enabling Environments for Eliminating Female Genital Mutilation		

1.4.1 Health Consequences of FGM

Healthcare consequences can be divided into physical, psychological and sexual. Health consequences directly related to childbirth are reviewed in Section 1.5.

1.4.1.1 Female physical health consequences of FGM.

The female physical health consequences of FGM can be divided into immediate and long-term and are shown in Table 1.4.

Table 1.4: Short and Long-term Consequences of FGM

Immediate complications can include:

- severe pain
- excessive bleeding (haemorrhage)
- genital tissue swelling
- fever
- infections e.g., tetanus
- urinary problems
- wound healing problems
- injury to surrounding genital tissue
- shock
- death.

Long-term complications can include:

- urinary problems (painful urination, urinary tract infections)
- vaginal problems (discharge, itching, bacterial vaginosis and other infections)
- menstrual problems (painful menstruations, difficulty in passing menstrual blood, etc.)
- scar tissue and keloid
- sexual problems (pain during intercourse, decreased satisfaction, etc.)
- increased risk of childbirth complications (difficult delivery, excessive bleeding, caesarean section, need to resuscitate the baby, etc.) and newborn deaths
- need for later surgeries: for example, the sealing or narrowing of the vaginal opening (Type 3) may lead to the practice of cutting open the sealed vagina later to allow for sexual intercourse and childbirth (deinfibulation). Sometimes genital tissue is stitched again several times, including after childbirth, hence the woman goes through repeated opening and closing procedures, further increasing both immediate and long-term risks;
- psychological problems (depression, anxiety, post-traumatic stress disorder, low self-esteem, etc.)

Directly reproduced from WHO (2020a)

Female physical health consequences of FGM can be immediate or chronic and can interfere with many aspects of a woman’s daily life and fertility. A review of the literature was also conducted (Appendix 0) and shows the broad spectrum of health consequences that can be experienced by women depending on the type of FGM, who performed the FGM, and their access to healthcare. Although current data included studies with low methodological rigour, it reflects the difficulty of the topic to research. This is especially noteworthy when considering countries where FGM is outlawed but still practiced in some communities. What is evident is that FGM can cause physical health consequences for women that have immediate and long-term impacts. Berg et al. (2014) suggest it is impractical to focus on this area as it is unlikely to yield practical results as each woman’s experience is unique, and research and health authorities should turn their attention to safeguarding and caring for the consequences of FGM. The next section explores the female psychological consequences related to FGM.

1.4.1.2 *Female psychological consequences.*

Literature available on possible psychological consequences of FGM is conflicting and illustrates the complex nature of psychology (Appendix 0). In a 2010 systematic review using only quantitative studies (14 Cross-sectional comparative, 1 prospective case control and 1 case control), Berg et al., concluded there was insufficient evidence to draw any conclusions due to a paucity of high-quality evidence. However, the evidence that has been published presents a picture of significant issues that require more research to fully understand and includes depression and psychological trauma (Mulongo, Hollins Martin, & McAndrew, 2014; Toubia, 1994; Whitehorn, Ayonrinde, & Maingay, 2002).

In a cross-sectional survey of 66 women with FGM living in the Netherlands after migration from Africa, Knipscheer, Vloeberghs, van der Kwaak, and van den Muijsenbergh (2015) explored women's mental health status using several standardized questionnaires and found 20% met the inclusion criteria for PTSD, 33% for depression, 30% for anxiety, and 18% scored above for all three indicators. Type of circumcision, country of origin, source of income, vividness of recollection and coping style were significant contextual factors in mental health symptoms. Originating from Somalia was associated with decreased PTSD, less anxiety and depression. Infibulation, substance misuse, avoidance coping, and lack of income were associated with higher anxiety and depression scores. These results indicate a complicated picture with multiple contextual variables impacting outcomes. Noteworthy and needing further exploration is the protective effect of women originating from Somalia. Limitations include the method of data collection. Snowball sampling, while heavily used for hard-to-reach population may lend bias to results as groups of women who know each other and may share experiences could be over sampled. This study furthers our knowledge regarding psychological effects of FGM and shows post-migration effects may exacerbate or alleviate some symptoms.

Women who have FGM and have migrated to a country where the practice is outlawed and viewed as a human rights violation may develop adverse mental health reactions, such as fear, shame, guilt, or anger towards family members (Smith & Stein, 2017). While education and information about the practice is beneficial, it needs to be accompanied by appropriate resources to ensure women process the information in as healthy a manner as possible (Smith & Stein, 2017).

Barriers to collecting data in this area include stigma surrounding mental health present in many cultures. If a woman assumes she will be stigmatized from reporting mental health issues she may not participate in studies, possibly skewing results to more or less negative outcomes. Trauma is unique to each individual and results from many intertwining factors and life experiences. The conflicting results in studies may indicate the dual feelings women report experiencing about FGM, that it is an important, desired cultural practice, while also acknowledging that it is painful and has negative consequences. Social pressure may also play a role in minimizing reports of negative outcomes of FGM. Studies using questionnaires also risk reducing complex, layered feelings and experiences to scales. Although the evidence may be lacking in this area, available evidence does indicate that some women who have undergone FGM can suffer psychological consequences that may impact them throughout pregnancy and the PPP. The next section discusses the female sexual consequences of FGM.

1.4.1.3. Female sexual consequences of FGM.

FGM has a detripsychological effect on female sexuality (Appendix 0). The most comprehensive review of sexual consequences was completed by Berg et al. (2010) and found pain during intercourse (RR-1.52, 95% CI-1.15-2.0), reduced sexual satisfaction (SD -0.34, 95% CI. -0.56- -0.13), and reduced sexual desire (RR-2.15, 95% CI- 1.37-3.36) to be significant sexual consequences of FGM. Fifteen studies of varying quality were included. All 15 studies, except one reported negative consequences of FGM including dryness during intercourse, pain during intercourse, not enjoying sex, and never or rarely experiencing orgasm. The one study that opposed these results found pregnant women with Type 1 or 2 FGM reported negative sexual consequences less than women without FGM, with variables including: never initiating sexual activity, not experiencing orgasm, and not engaging in sexual intercourse in the last week or in the last month. This may suggest negative sexual consequences are increased in women with Type 3 FGM. Although a meta-analysis was conducted on several outcomes, the quality of the studies overall were deemed very low and suggest that while more research is needed in this area to draw any meaningful conclusions, HCPs should be aware of possible negative sexual consequences of FGM and provide care accordingly (Berg, Denison & Fretheim, 2010).

While current literature suggests there are sexual consequences of FGM, a more substantial body of literature is needed to understand the topic. The practicality of such research must be questioned as there are numerous variables to account for with typical methods not able to provide additional insight. Experience and sexual consequences of FGM are not only influenced by type of FGM, but also by cultural and social norms surrounding sex and marriage. The sexual partner is also a variable as is country of residence, access to education, mass media, and access to birth control. If the woman is a migrant, the amount of integration or segregation may also play a role in her sexual views and experiences. Assessing sexual consequences is complex and efforts may be better served engaging women in healthcare and assessing individualized needs. The next section explores the current research evidence regarding FGM.

1.4.1.4. Current Research Evidence

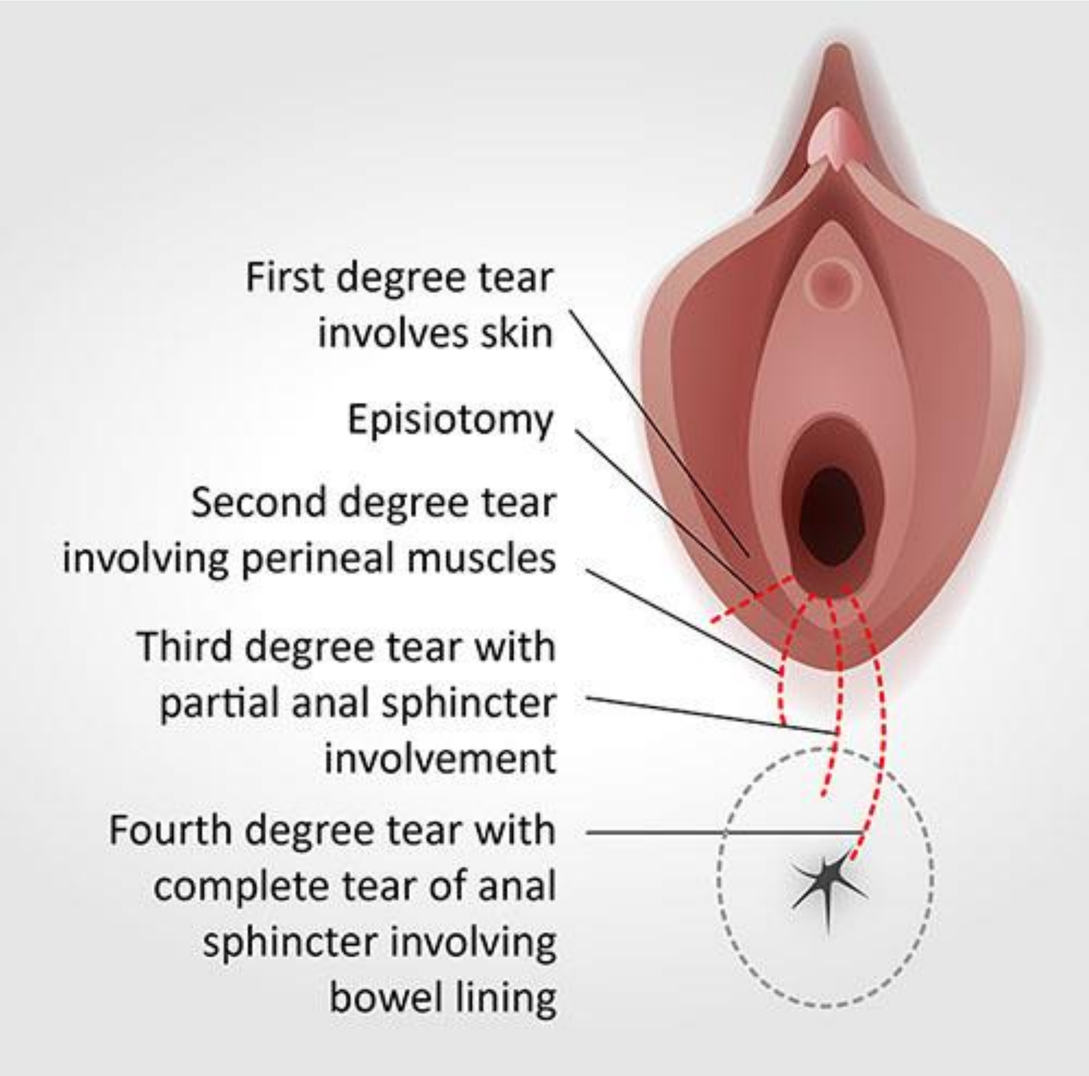
The quality of the available research is lacking, with clinical outcomes and empirical results focused on; an interesting but not unexpected finding as policy and guidelines are often based on quantitative research. Randomized controlled trials (RCT’s) are graded as the highest quality evidence by the National Institute of Health and Care Excellence (NICE) in their guidance manual (NICE, 2014) (see Chapter 3 for a discussion of guideline evidence). However, the varied, complex, and diverse outcomes of FGM make it a difficult topic to explore through questionnaires and tick-box descriptions. How FGM affects each individual woman is based on a myriad of complex, interconnecting variables that cannot be viewed in isolation. Recruitment of women with FGM is problematic and may create a bias in research where those women with possibly more negative health consequences and outcomes become representative of all women with FGM. The impact of the researcher must also be considered; including whether the researcher is from a practicing community, speaks the same language, or understands the contextual nuances of the woman’s experience. Overall FGM is a difficult topic to research, but with evidence of considerable poor health outcomes for some, research which seeks to understand the nuanced needs and experiences in order improve women’s health is needed. Women’s voices need to be heard if we are to fully understand the context of current clinical outcomes. Pregnancy and the PPP are opportune times to engage women with FGM and understand and address their health needs as they come into direct contact with health services for potentially the duration of their pregnancy and PPP, giving health services time to assess and address their needs. The next section discusses the maternal health consequences and experiences associated with FGM; including reproductive injuries, obstetrical health consequences and psychological consequences of FGM specific to childbirth.

1.5 Maternal Health Consequences and Experiences Associated with FGM

1.5.1 Reproductive Injuries Associated with FGM.

A woman’s perineum is the area between her vaginal opening and anus (RCOG, 2020). Perineal Tears, episiotomies and iatrogenic injuries may impact a woman with FGM and will now be discussed to provide context to the obstetric complications section that follows. A perineal tear occurs when the skin of the perineum tears during childbirth. There are four types of perineal tears described and illustrated in Figure 1.4 and described in Table 1.5.

Figure 1.4: Illustration of the four degrees of perineal tears. (Reproduced from RCOG, 2020; Retrieved from https://www.rcog.org.uk/en/patients/tears/tears-childbirth/ on 15/06/2020)



There are various reasons why a woman’s perineum might tear during childbirth which include; if the vaginal opening is not wide enough for the baby’s head to pass through, if instrumental delivery is required, as an extension of an episiotomy, and with presenting limbs (baby’s head to face) or cephalic (head) malpresentation. If the head is correctly deflexed, labour is controlled and the perineum normal, a minimal risk of perineal tears beyond Grade 1 exists.

Current UK data show 41.26% of women had a perineal laceration during delivery, with 1.28% experiencing an ‘other obstetric trauma’ which includes episiotomy and forceps delivery.

Table 1.5: Types of Perineal Tears

First Degree	First-degree tears are the least severe, involving only the skin around the vaginal opening or perineal skin. Although a woman might experience some mild burning or stinging with urination, first-degrees tears are not severely painful and heal within a few weeks. They may or may not require stitches.
Second Degree	Second-degree tears involve the perineal muscles-the muscles between the vagina and anus that help support the uterus, bladder and rectum. Second-degree tears typically require stitches and begin to heal within a few weeks.
Third Degree	Third-degree tears involve the perineal muscles and the muscle that surrounds the anus (anal sphincter). These tears sometimes require repair in an operating room-rather than the delivery room-and might take months to heal. Complications such as fecal incontinence and painful intercourse are possible.
Fourth Degree	Fourth-degree vaginal tears are the most severe. They involve the perineal muscles and anal sphincter as well as the tissue lining the rectum. Fourth-degree tears usually require repair in an operating room-rather than the delivery room-and might take months to heal. Complications such as fecal incontinence and painful intercourse are possible. Colostomy may also be required.

Source: Table created by author from: Mayo Clinic (2020), *Vaginal Tears in Childbirth: Slideshow*

An episiotomy is a surgical incision made to widen the vaginal opening for childbirth. An episiotomy is directed at a ‘mediolateral’ angle to direct any potential damage away from the rectum. An episiotomy may be done to facilitate an instrumental delivery, or to expedite birth if acute fetal distress in the second stage of labour occurs (OASI Care Bundle Project Team, 2018). There is currently a debate concerning whether the perineal tissue should be allowed to tear naturally, or to be cut surgically. Rates of episiotomy vary widely depending on country and range from 8% in the Netherlands, 14% in England, and 50% in the USA (RCOG, 2015). In some countries episiotomy is preformed routinely as it is believed to reduce severe perineal trauma to the woman and ease birth. Jiang, Qian, Carroli, and Garner (2017) conducted a systematic review comparing the effects on mother and baby of a policy of selective episiotomy (only if needed) compared with a policy of routine episiotomy (part of routine management) for vaginal births. The Cochrane Pregnancy and Childbirth’s Trial Register and reference lists of retrieved studies were searched. Only RCT’s were included. Two authors independently screened, extracted data and assessed risk of bias. The GRADE tool was used to assess quality. Eleven RCT trials (5977 women) from 10 different countries were included. Results found that where health staff were conducting selective episiotomy, there may be 30% fewer women with severe perineal trauma at birth; resulting in the use of routine episiotomy as a medical intervention not being justified as evidence-based (Jiang et al., 2017). Unfortunately, the evidence was graded as low-certainty; however, as routine episiotomy results in perineal trauma for women, this area desperately needs further research. There is a growing discourse on non-evidence-based, routine episiotomy as a form of FGM (Hartmann et al., 2005; Rodriguez, Seuc, Say, & Hindin, 2016; Weber & Meyn, 2002).

Iatrogenic injuries are defined as adverse effects or complications resulting from medical treatment and can include advice from HCPs and alternative forms of medicine (Khaskheli, Baloch, & Sheeba, 2014). In the context of FGM, iatrogenic injuries, such as increased healing time or infection may occur as an adverse event due to scar tissue.

Perineal tearing, episiotomies and iatrogenic injuries, can prolong the post-partum healing process leading to new mothers requiring greater resources. Iatrogenic injuries affect women's physical, mental and emotional wellbeing both immediately after birth and long-term. A systematic review by Frolich and Kettle (2015) explored incidence and severity of perineal trauma and short and long-term perineal pain, blood loss and quality of life (among others). Five electronic databases were searched and only published RCTs or systematic reviews of RCTs in the English language, at least single-blinded and containing more than 20 people of whom 80% or more were followed up were included. A GRADE evaluation of studies was completed regarding applicable outcomes. Confidence in the findings are high, with the authors finding 23-42% of women continue to experience pain and discomfort for 10-12 days post-partum; with 7-10% experiencing long-term pain at 3-18 months post-delivery in the UK. Dyspareunia has been reported in 23% of women at 3 months post-delivery, with 3-10% reporting faecal incontinence, and up to 24% experiencing urinary problems (Frolich & Kettle, 2015). As one can deduce, social and psychological concerns emerge from iatrogenic injuries including disruption to social and family life, breastfeeding and sexual relations (Frolich & Kettle, 2015). Regarding FGM, some women may experience an anterior episiotomy, which is distinct from de-infibulation as only the minimum required skin is cut to facilitate a wide enough opening for birth (Kalis, Laine, De Leeuw, Ismail, & Tincello, 2012). Anterior episiotomy opens an infibulated woman's scar tissue to the point of being able to see the vaginal opening and urethra only, leaving any further scarring intact (Royal College of Nursing, 2019). Anterior episiotomy can and is used in the USA instead of de-infibulation, where re-infibulation of autonomous adult women is also lawful (Kalis et al., 2012) and shows a distinct departure from laws regarding FGM in the majority of Westernized countries where re-infibulation is illegal.

Another factor relating specifically to FGM is the presence of keloid scarring around the perineum resulting in the need for episiotomy (Birge, Akbaş, Özbey, & Adıyeke, 2016). Keloid scarring results from an excess of collagen when a scar is forming, creating an excess amount of tissue around the scar which can appear as lumpy or domed. People of African descent are 15-times more likely to have keloid scarring than those of European decent, although the reason for this is currently unknown, it is thought to be a linked to a genetic predisposition (Meenakshi, Jayaraman, Ramakrishnan, & Babu, 2005). A genetic predisposition for keloid scarring, combined with FGM and repeated reinfibulations may result in keloid scar formation around the perineum, causing complications for de-infibulation and increasing the need for episiotomy (Birge et al., 2016). The avascular nature of scar tissue increases the risk of uncontrollable and severe tears. Episiotomies may be indicated if perineum keloid scarring is present (Birge et al., 2016).

Obstetric complications such as prolonged labour, perineal tearing, instrumental delivery, haemorrhage, and episiotomies have been found to affect women with FGM. However, the literature is varied based on location and type of FGM. Data from African countries suggests women with FGM have worse obstetric outcomes than women without FGM and this worsens based on type and severity of FGM (WHO, 2006). Studies conducted in migration countries suggest no worse outcomes for women with FGM than without and conclude access to high-quality healthcare reduces or eliminates complications (Abdulcadir, Dugerdil, Yaron, Irion, & Boulvain, 2016; Essén, Sjöberg, Gudmundsson, Östergren, & Lindqvist, 2005). However, studies conducted within the UK are conflicting, suggesting not only that the current outcome variables need to be considered, but additional factors such as

HCP level of education and competence, and availability of resources (Albert, Bailey, & Duaso, 2015; Bikoo, Davies, Richens, & Creighton, 2006; Paliwal, Ali, Bradshaw, Hughes, & Jolly, 2014). This could impact the decision about use and timing of episiotomy during labour and the effectiveness of de-infibulation. The above studies are discussed in more detail in Section 1.5.2.

Reproductive injuries associated with childbirth are also an important consideration when a woman has FGM as presence and extent of scar tissue could have negative consequences, including increasing the severity of perineal tears or necessitating an episiotomy. It is clear more data is needed to consider the nuances associated with each individual case of FGM and current evidence should be interpreted cautiously as definitive conclusions have not been reached. The next section discusses obstetrical health consequences associated with FGM.

1.5.2 Obstetrical health consequences associated with FGM

Since FGM concerns the reproductive tract there is strong potential for obstetrical complications to arise. The WHO (2017) lists the obstetrical consequences of FGM including increased risk for perineal tearing, need for episiotomies, prolonged labour, C-section, post-partum haemorrhage, instrumental childbirth and extended maternal hospital stay. The following is a summary of the available literature exploring reasons for potential increased obstetrical complications found in women with FGM (Table 1.6).

The WHO (2006) conducted a study of 28 obstetric centres in Burkina Faso, Ghana, Kenya, Nigeria, Senegal and Sudan. Prospective demographic, health, reproductive factors, and type of FGM (completed by genital examination) were collected through interviews during the antenatal period and women were followed until postpartum discharge from hospital. Prevalence of various factors according to FGM status, with x^2 tests for heterogeneity to identify potential confounding factors. Estimated risk of having specific adverse maternal or infant outcomes versus not having this specific outcome in women with type I, II and III FGM were compared separately with women who had not had FGM. Adjusted odds ratio and approximate relative risk were calculated by unconditional logistic regression. Results indicated women with FGM were at higher risk for C-section delivery, postpartum haemorrhage, extended maternal hospital stay, infant resuscitation, still-birth or neonatal death and low birth-weight (WHO, 2006). The study concluded that women with FGM are significantly more likely to have adverse obstetric outcomes than those without FGM. It is important to note that as severity of type of FGM increases (Type 1-3), the risks for adverse events increases. As this study was conducted in hospitals, women with high-risk, complicated pregnancies, and those able to afford hospital care are likely over-represented. While the overall findings of higher risk for complications for women in these countries is likely applicable, the authors note the frequency and effect of the complications will depend on many different factors.

A systematic review and meta-analysis by Berg and Underland (2013) searched 12 databases, grey literature and organizational websites for studies examining the obstetric consequences of FGM. Two investigators independently reviewed all studies before analysis took place. Studies were quality assessed using the GRADE tool. Overall, the quality of evidence found was very-low, and thus little confidence can be placed in the effect estimate calculated. Type of FGM were often reported together, thus it is unknown how much influence each type has. However, significant results were found, and the authors concluded FGM is a significant risk factor for prolonged labour, obstetric lacerations, instrumental delivery, obstetric haemorrhage, and difficult delivery. No significant increase in risk was found regarding C-section delivery or use of episiotomy. Although the evidence is of low-quality, the pattern of FGM exerting a negative impact on obstetric outcomes must be considered and studied further. Strengths of the studies included consist of many clinically based reports, enhancing validity.

Almroth et al. (2006) explored the connection between FGM and primary infertility through a hospital-based case control study in Sudan. Ninety-nine women with primary infertility not caused by hormonal or iatrogenic factors (e.g. previous abdominal surgery), or male-factor infertility were included. Socio-economic status, level of education, gonorrhoea and chlamydia were controlled for and women were compared with respect to having FGM and type of FGM. The study found that women with FGM Type III, or the most extensive form, had a significantly higher risk of primary infertility than controls (OR 4.69, 95% CI 1.49-19.7, p=0.003). The anatomical extent of FGM rather than whether the woman was ‘sewn closed’ or not was associated with primary fertility, supporting the proposition that FGM is so varied it is difficult to make assumptions based on WHO Type (Earp & Johnsdotter, 2020).

Larsen and Okonofua (2002) conducted a cross-sectional reproductive health survey and medical exams of 1836 women seeking antenatal care in three Nigerian hospitals. Forty-five percent were found to have FGM, with 95.7% having Type I or II. The authors found significantly higher rates of perineal tear when comparing non-FGM participants with those with Type II (OR 2.84, 95% CI. 1.43-5.68). This study suggests the extent of scar tissue is an important consideration in women with FGM. However, these results must be considered with caution as although type of FGM was clinically based (enhancing validity), pregnancy outcomes and complications were self-reported by women, introducing recall bias. The sample also excluded women with type 3 or 4 FGM, and the majority of the included sample was type 1. A larger sample of type 2,3 and 4 is needed, combined with clinically reported outcomes to confirm these results. Cross-sectional studies also only provide information for a specific time point in a certain location and this study must be viewed in this context.

Rodriguez, Seuc, Say and Hindin (2016) used data from the WHO (2006) study described above to conduct a secondary analysis to determine if type of episiotomy by FGM classification had a significant impact on key maternal outcomes of anal sphincter tears, intrapartum blood loss requiring intervention and postpartum haemorrhage. Cross tabulations and multivariable logistic regression were used. Women with FGM were more likely to have the most extensive types of episiotomies performed (anterior and posterior-lateral). Findings suggest de-infibulation (or anterior episiotomy) may protect against anal sphincter tearing and postpartum haemorrhage in women with Type 3 FGM and should be completed. Limitations of this study include those inherent in a secondary analysis, including any limitations of the original methodology and applying a research question to data not collected to answer it. In this study, timing and indication for episiotomy is unknown and may impact study outcomes by not being unrelated to the woman's FGM. Community deliveries were omitted and may bias outcomes towards women with worse obstetric outcomes as a hospital delivery may have been required. Indication for scheduled caesarean sections is also unknown and may have an impact on study outcomes as reasons may reference FGM. The majority of the sample was from Sudan, making generalizability difficult. The large study sample is a strength and provides useful information on episiotomy outcomes for women with Type 3 FGM.

Abdulcadir, Dugerdil, Yaron, Irion and Boulvain (2016) retrospectively reviewed medical charts of women with FGM who attended a specialized clinic and recorded outcome measures before comparing obstetric outcomes between groups of women based on type of FGM. Outcome measures included type of delivery, reason for C-section, assisted delivery, blood loss, episiotomy, perineal tear, duration of second stage of labour, postpartum complications, weight of the neonate and APGAR score- a test to check a new-born's health. Women with Type 3 FGM were compared to women with Type 1 and 2. No statistical differences were found between types of FGM, and no differences were found between women with FGM compared to women without FGM in Switzerland. This is an important finding that suggests obstetric health complications associated with FGM may be decreased or eliminated dependent on access to high quality culturally sensitive healthcare. Limitations of this study included the retrospective design and consequent lack of a control group. The small study sample also makes generalizability not possible. Strengths include providing more information on a current research gap, including women with all types of FGM from different countries and cultural backgrounds, providing a reflective sample of women in Switzerland, and reporting the reasons for caesarean and assisted deliveries taking place, a variable not often reported in studies on FGM.

Essén, Sjöberg, Gudmundsson, Östergren and Lindqvist (2005) compared second stage labour in women with (n=68) and without (n=2486) FGM in a high-income European country. Women with FGM were found to have a statistically significant shorter second stage of labour than women without FGM (median time 35/5 min, respectively, p<0.001), and a statistically significant lower risk of prolonged labour. Frequency for mediolateral episiotomy was 65% for women with FGM, and 40% for uncircumcised women. Circumcised women had c-sections due to fetal distress, preeclampsia, infection or breech presentation. These findings suggest prolonged labour is not associated with FGM in high-income countries with high standards of obstetric care where de-infibulation is routinely completed during labour. Limitations of this study include being unable to compare the circumcised women with uncircumcised women from the Horn of Africa, resulting in possible confounding variables due to ethnicity, though no evidence for this exists. These two studies suggest outcomes in migration countries could differ due to access and quality of obstetric care.

Three studies conducted in the UK were found to evaluate obstetric outcomes for women with FGM. A prospective cohort study by Bikoo, Davies, Richens and Creighton

(2006) found that all women in the UK, regardless of timing of de-infibulation had extremely and significantly high levels of perineal trauma compared to hospital and national rates. Episiotomy rate was also higher than expected (Bikoo et al., 2006). Albert, Bailey and Duaso (2015), conducted a retrospective study of UK medical records of 94 women. Infibulated women attending an antenatal clinic were offered de-infibulation at 20 weeks' gestation. Women were split into three groups, de-infibulated prior to pregnancy, de-infibulated antenatally, and de-infibulated before labour. Results demonstrated an increased relative risk of having an episiotomy and of increased length of hospital stay in women de-infibulated in labour. All women, regardless of timing of de-infibulation had higher than national rates of C-section, instrumental birth, episiotomy, and perineal damage; with London having higher rates of C-section deliveries than other areas. Limitations of this study include its retrospective nature and low numbers as women with FGM represent a difficult to reach population. The authors conclude that rates of perineal trauma are unacceptably high and warrant further investigation.

Paliwal, Ali, Bradshaw, Hughes and Jolly (2014), conducted a retrospective case analysis of patient records of women with Type 3 FGM in Birmingham, UK. The majority of women were de-infibulated from previous pregnancies. Thirty-nine women were found to be infibulated at their antenatal booking appointment, of which nine were de-infibulated antenatally. The remaining women chose to be de-infibulated during labour. Those de-infibulated during labour had higher than average blood loss and more perineal tears, however, both of these results were statistically insignificant. The findings of this study are inconclusive and require further research into any differences in outcomes regarding timing of de-infibulation.

The current literature is inconclusive but suggests that depending on type of FGM, location of childbirth and skill of attendants, women with FGM may experience increased obstetrical health consequences. The next section discusses the psychological consequences of FGM specific to childbirth.

Table 1.6: **Obstetrical Health Consequences of FGM**

Reference	**Aim**	**Methods**	**Results**	**Strengths/ Limitations**
(Larsen & Okonofua, 2002)	To examine whether complications at delivery are associated with FGM.	Cross-sectional reproductive health survey and a medical exam of women aged 15-49. Women had sought family planning or AN services at one of 3 hospitals. Predominantly rural. Referral hospitals. 1861 women selected, 99.5% participation rate (10 declined). Survey of SES, obs history, circumcision status, characteristics of circumcision and a physical exam to determine extent and type of FGM. A total of 1836 women included. Types 3 and 4 excluded due to low numbers (24, 11). Prevalence of self-reported complications at delivery was calculated for circumcised and uncircumcised women. logistic regression models used to calculate relative odds of complications for women, Wald test to determine significance.	Five main findings emerged from the analysis of circumcision and obstetric complications: -obstetric complications and stillbirth rates were higher at first pregnancy for circumcised and uncircumcised women 2. circumcised women had higher risks of tear and stillbirth controlling for confounders 3. circumcised and uncircumcised women did not have significantly different risks of prolonged labor, episiotomy and cesarean section in the adjusted models 4. women with type 1 or type 2 did not have significantly different risks of obstetric complications and stillbirth, although it appeared that women with type 2 suffered more tear (type 2 vs. uncircumcised: OR_2.84, 95%_1.43, 5.68.). 5. there was no evidence suggesting that the harmful effects of circumcision increased with parity.	Clinic reports about type of FGM-enhance validity of findings. Self-report findings: complications and outcomes at delivery decreases validity by recall. Sample: only type 1 and 2, and majority type 1. Need larger sample of other types of FGM, and clinical outcomes to strengthen results.
(Essén et al., 2005)	To assess “whether or not there is a tendency towards a longer duration of labour among circumcised women giving birth in a community with high standards of obstetrical care.”	68 nulliparous singletons circumcised women delivering in maternity unit in hospital in Malmo, Sweden. Compared to a cohort of 2486 non-circumcised, nulliparous women with singleton pregnancies. “Obstetrical information was provided by the hospital database. The medical records of all women of Ethiopian and Somali origin were identified and scrutinised for their genital status. The classification of circumcision was not always described with the terms of WHO’s classification.” Most often described was type 3. “A	Women with FGM were found to have a statistically significant shorter second stage of labour than women without FGM (median time 35/5 min, respectively, p<0.001), and a statistically significant lower risk of prolonged labour. Frequency for mediolateral episiotomy was 65% for women with FGM, and 40% for uncircumcised women. Circumcised women had c-sections due to fetal distress, preeclampsia, infection or breech presentation. These findings suggest prolonged labour is not associated with FGM in high-income countries with high standards of obstetric care where de-infibulation is routinely completed during labour.	Limitations of this study include being unable to compare the circumcised women with uncircumcised women from the Horn of Africa, resulting in possible confounding variables due to ethnicity, though no evidence for this exists. Possible impact of mental health status of women giving birth (anxiety? Being in another health system)

		Mann–Whitney test was used to compare differences between the groups. The relative risk of prolonged labour was estimated by means of odds ratios (OR), 95% confidence intervals (CIs) are reported. Multivariate analysis was performed by means of logistic regression. Prolonged labour was used as dependent variable and maternal age, epidural anaesthesia, episiotomy, augment with oxytocin and birthweight deviation as independent variables."		
(Almroth et al., 2006)	To test hypothesis that FGM during childhood causes ascending infections that present as primary infertility in young women. FGM that involves labia majora=more likely then milder forms. Forms that involve stitching of the vaginal opening particularly likely to cause primary infertility.	Hospital based. Age-matched case control. 99 women, regular menstrual cycles, regular sexual intercourse for past two years, who had never been pregnant, used an IUD or hormonal contraceptives. Recruited consecutively. Husband's semen tested normal. Controls=180 pregnant women expecting first child who had become pregnant within 2 years of regular intercourse. Interviewed, genital examinations, laboratory investigations for gonorrhoea, chlamydia, and blood flukes. Diagnostic laparoscopy and tubal patency tested. Subdivided into normal and adnexal pathology. Ethically approved. Received all medications, treatments and investigations free of charge. Oral consent as written not in education or culture. All data collection in clinical setting with specially trained doctor.	Women with primary infertility had a significantly higher risk of having undergone the most extensive form of FGM. OR 3.62 (95% CI, 1.46-10.3), p=0.003. But, WHO type 3 not significantly associated with infertility. There is a strong positive association between FGM involving labia minor and majora and infertility. Immediate complications to FGM reported by few. 3 cases and 7 controls reported fever and 2 cases and 6 controls=medical care. Reports of 3 or more UTI's significantly more in cases. No specific form of FGM linked. Person who did FGM could be confounder as less or more skilled.	Selection bias Defended oral consent procedure by citing education and culture. Large CI but significant and OR. Received all medications, treatments and investigations free of charge. Bias? Same person collected all data, specially trained in how to visualize FGM.
(Bikoo et al., 2006)	To determine the need for antenatal defibulation and subsequent obstetric outcome of	Prospective cohort study was carried out on all pregnant women with a history of FGM referred for antenatal assessment. Clinical assessment performed to confirm type of FGM. Demographic details including country of origin,	28 women attended, 26 completed study. Majority from Somalia (20/26), and all type 3 FGM. 24 examined in clinic, 2 declined. Defib recommended for 16 women before labour (67%). 10/16 agreed, 6 defib during labour. "Seven women (27%) underwent caesarean section which	Small study sample. All type 3. Clinical outcomes are a strength. No difference noted between 1st time mothers and multiparous women.

	women with a history of FGM presenting to a London obstetric unit.	timing of FGM, gestational details, parity, outcome of previous pregnancies. Obstetric notes, mode of delivery, deinfibulation, perineal trauma (tear or episiotomy).	is consistent with the expected rate in this hospital. Reasons for caesarean section were fetal distress (5), intrauterine growth restriction (1) failure to labour at 42+ weeks (2). None of these indications were considered to be due the FGM. Five women (19%) required a ventouse delivery and the rest had spontaneous vaginal deliveries. The overall rate of perineal trauma (episiotomy or tear) was 73% which is significantly higher than expected hospital or national rates. Episiotomy rate was 47% (higher than anticipated) Of five women who sustained perineal tears, there were two anterior clitoral tears, one first degree tear, one second degree tear and one third degree tear involving the anal sphincter which required follow-up in the birth injuries clinic." (p404).	
(World Health Organization (WHO), 2006)	The WHO (2006) conducted a study examining the effect of different types of FGM on obstetric outcome in women from 28 obstetric centres in Burkina Faso, Ghana, Kenya, Nigeria, Senegal and Sudan.	Prospective demographic, health, reproductive factors, and type of FGM (completed by genital examination) were collected through interviews during the antenatal period and women were followed until postpartum discharge from hospital. Prevalence of various factors according to FGM status, with x^2 tests for heterogeneity to identify potential confounding factors. Estimated risk of having specific adverse maternal or infant outcomes versus not having this specific outcome in women with type I, II and III FGM were compared separately with women who had not had FGM. Adjusted odds ratio and approximate relative risk were calculated by unconditional logistic regression.	Results indicated women with FGM were at higher risk for C-section delivery, postpartum haemorrhage, extended maternal hospital stay, infant resuscitation, still-birth or neonatal death and low birth-weight (WHO, 2006). The study concluded that women with FGM are significantly more likely to have adverse obstetric outcomes than those without FGM.	It is important to note that as severity of type of FGM increases (Type 1-3), the risks for adverse events increases. As this study was conducted in hospitals, women with high-risk, complicated pregnancies, and those able to afford hospital care are likely over-represented. While the overall findings of higher risk for complications for women in these countries is likely applicable, the authors note the frequency and effect of the complications will depend on many different factors.
(Berg & Underland, 2013)	Systematic review and meta-analysis on the obstetric consequences of FGM/C	Followed standards for SR, with input from stakeholders and a protocol published with PROSPERO. Detailed in another report. 12 databases searched, 3	Meta-analysis for: <u>Prolonger labour:</u> absolute risk difference was 3 more cases in women with FGM (95% CI= 0-8	Low quality of evidence does not allow a casual relationship to be determined between obstetric complications and FGM,

		grey literature and organizational websites. 2 investigators, independently, then joined. Used design specific extraction forms. Used GRADE.28 comparative studies included. Overall, quality of evidence is very low-very little confidence in the effect estimate, the true effect is likely to be substantially different from the estimate of effect.	more per 100 women) (RR=1.69, 95%CI=1.03,2.77) Obstetric tears/lacerations: AR: 1.5 more cases of lacerations among women with FGM/C (95% CI = 0–3 more per 100 women). Significant. C-section: no statistically significant difference for caesarean section was found (RR = 1.19, 95% CI = 0.94, 1.51). The absolute risk difference was 8 more cases of caesarean section among women with FGM/C (95% CI = 0–18 more per 100 women). episiotomy: No significant effect for this outcome was found (11 studies, RR = 1.26, 95% CI = 0.97, 1.64). The absolute risk difference was 6 more cases of episiotomy among women with FGM/C (95% CI = 1 fewer to 14 more per 100 women). Instrumental delivery (ventouse, forceps, operative, or instrumental delivery): women with FGM/C are more likely than women with no FGM/C to require instrumental delivery (RR = 1.65, 95% CI = 1.29, 2.12). The absolute risk difference was 2more cases of instrumental delivery among women with FGM/C (95% CI = 1–4more per 100 women). Conversely, registry studies, comparing Somali born women (likely FGM/C type III) and Western-born women without FGM/C showed no statistically significant difference between the two groups of women with respect to instrumental delivery (RR = 0.96, 95% CI = 0.59, 1.54). There was large, unexplained heterogeneity across the registry studies, but not the cross-sectional studies. Obstetric/postpartum haemorrhage: significant effect (RR = 2.04, 95% CI = 1.36, 3.05). The absolute risk difference was 5 more cases of obstetric haemorrhage among women with FGM/C (95%CI = 2–9more per 100 women). Women who had gone through FGM/C	however, does seem to exert negative impact. Date: newer studies may exist. Low quality of evidence, methodology weaknesses, wide confidence intervals. Definitions of outcomes varied. Strengths: many studies used gynecological exam to confirm FGM and type. Majority of outcomes were clinically based. Major differences between cross-sectional and registry studies.-unexplained. Data pools all types of FGM together so unknown how much influence different types have. Strong methods but weak data available. Publication bias.

			experienced a median of 50mL blood loss more than non-FGM/C women during labour. Difficult labour/dystocia: The pooled result from cross-sectional studies where the participants were selected from the same population shows that women with FGM/C are more likely than women with no FGM/C to experience difficult labour (RR = 3.35, 95% CI = 1.71, 6.55). The absolute risk difference was 5 more cases of difficult labour among women with FGM/C (95% CI = 1–12 more per 100 women). The registry study, comparing Somali-born women (likely FGM/C type III) and US-born women showed no statistically significant difference between the two groups of women regarding difficult labour (RR = 1.29, 95% CI=0.95, 1.74).	
(Paliwal et al., 2014)	-Provide a description of the population that uses the service -Audit the service against standards set by the trust -Describe the obstetric outcomes of women with FGM and to compare adverse outcomes between women who were deinfibulated prior to labour with those who opt for intrapartum deinfibulation	All women with type 3 FGM that delivered in Heartland's Hospital between January 2008 and December 2009 were included in the audit. 283 eligible women. 253 (89%) included only, due to incomplete records. Audit criteria: 1. Was FGM identified at booking? 2. Was UK law explained to the expectant mother? 3. Was deinfibulation offered at booking to women who were inflibulated? 4. Was deinfibulation carried out antenatally? 5. Was there documentation in the notes of normal genitalia for live female infants? 6. Was an African Women Tracker form completed in the notes?	253 women included in final analysis. 9 women defib antenatally, 18 during labour, 18 not deinfibulated at all (12= c-section, 4 elective), 208 deinfibulated in a previous pregnancy. Blood loss was lower in women previously deinfibulated (not significant). Perineal trauma (not significant) = women with antenatal deinfibulation were significantly more likely to have an episiotomy than women who chose not to be deinfibulated in the antenatal period. AN defib group (9) = 3 emergency c-section, remaining 6=episiotomy (none had spontaneous tear). 6 infibulated women were never deinfibulated: primi= second degree tear, 4th degree tear and episiotomy. Multi=2 second degree tears, 2 intact perinea. 208 women previously deinfibulated had a much lower episiotomy rate. No statistically significant findings.	Inconclusive findings and require further research into any differences in outcomes regarding timing of de-infibulation. No statistically significant results.
(Albert et al., 2015)	To provide evidence on which to base an informed discussion with women with type	Retrospective study of UK medical records of 94 women. Infibulated women attending an antenatal clinic were offered de-infibulation at 20 weeks' gestation.	Results demonstrated an increased relative risk of having an episiotomy and of increased length of hospital stay in women de-infibulated in labour. All women, regardless of timing of de-	Limitations: retrospective nature and low numbers as women with FGM represent a difficult to reach population. The authors

	3 FGM to enable them to decide the timing of their deinfibulation.	Women were split into three groups, de-infibulated prior to pregnancy, de-infibulated antenatally, and de-infibulated before labour.	infibulation had higher than national rates of C-section, instrumental birth, episiotomy, and perineal damage; with London having higher rates of C-section deliveries than other areas.	conclude that rates of perineal trauma are unacceptably high and warrant further investigation.
(Rodriguez et al., 2016)	To investigate the association between type of episiotomy and obstetric outcomes among 6,187 women with type 3 Female Genital Mutilation (FGM).	Secondary study using WHO, (2006) data. To determine if type of episiotomy by FGM classification had a significant impact on key maternal outcomes of anal sphincter tears, intrapartum blood loss requiring intervention and postpartum haemorrhage. Cross tabulations and multivariable logistic regression were used. Each type of episiotomy was compared with no episiotomy.	Women with FGM were more likely to have the most extensive types of episiotomies performed (anterior and posterior-lateral). Findings suggest de-infibulation (or anterior episiotomy) may protect against anal sphincter tearing and postpartum haemorrhage in women with Type 3 FGM and should be completed.	Limitations of the original methodology. Secondary analysis has inherent limitations as the study was not designed for the applied research question. Timing and indication for episiotomy is unknown and may have impacts on study outcomes. Community deliveries omitted, bias towards women with worse outcomes (hospital delivery needed). Women who had c-section-unknown why, may have impact. Majority of sample from Sudan (generalizability). Strength: large sample of women with type 3 FGM.
(Abdulcadir et al., 2016)	“The aim of the present study was to focus on the population of pregnant women attending the specialized clinic at HUG during its first 2 years of operation, evaluating their sociodemographic characteristics, the most frequent FGM types and their long-term complications, and the impact on obstetric outcomes.”	Retrospectively reviewed medical charts of women with FGM who attended a specialized clinic and recorded outcome measures before comparing obstetric outcomes between groups of women based on type of FGM. Outcome measures included type of delivery, reason for C-section, assisted delivery, blood loss, episiotomy, perineal tear, duration of second stage of labour, postpartum complications, weight of the neonate and APGAR score- a test to check a new-born’s health. Women with Type 3 FGM were compared to women with Type 1 and 2.	No statistical differences were found between types of FGM, and no differences were found between women with FGM compared to women without FGM in Switzerland. This is an important finding that suggests obstetric health complications associated with FGM may be decreased or eliminated dependent on access to high quality culturally sensitive healthcare.	Retrospective design, no control group. Small study sample, no generalizability possible. Strengths: Data double checked, women included from different countries, cultural backgrounds, different types of FGM. Reasons for cesarean and assisted deliveries rarely reported. Research gap, study improves knowledge in this area.

1.5.3 Psychological consequences of FGM specific to childbirth.

There is a lack of research focusing on the childbirth-related experiences of women with FGM from a psychological perspective. A study by Chibber, El-Saleh, and El Harmi, (2011) reported post-traumatic stress disorder (PTSD) and anxiety disorder being associated with women who have experienced Type 2 or 3 FGM, with 80% experiencing flashbacks of their FGM, feelings of helplessness and pain during childbirth. The study methods were poorly described however, with no numbers provided. Despite the low quality of this study, it is important to note because the idea of women experiencing flashbacks and trauma associated with their FGM procedure during childbirth is featured in awareness raising articles for HCPs (Rymer, 2003). It is also listed in reports about FGM from sources such as the Royal College of Nursing (2019), and the UK Department of Health (HM Government, 2016b); suggesting that while evidence for this experience is lacking it has infiltrated guidelines and is implemented in healthcare.

Glover, Liebling, Barrett and Goodman (2017) conducted a grounded theory study analysing the psychological and social impact of FGM. Twenty women were recruited from refugee centres and Non-Governmental Organizations (NGO’s) working with survivors of FGM in the UK. Women reported childbirth as a key stage of womanhood and expressed complex feelings towards the topic. Childbirth brought forth feelings of fear in women for themselves and their babies. Women feared the complications and the pain of childbirth, knowing it would be worse because of their FGM. Fear for the health of the baby was tragically realized in five of the women who had lost babies due to complications from FGM. Due to some chronic and longstanding physical pain arising from complications of childbirth, some women were unable to care for their child as they would have liked, resulting in feelings of resentment, anger, and compromised bonding and attachment. Women reported a lack of support from healthcare services and felt a lack of trust in HCPs. These findings highlight the complex repercussions of FGM.

Evidence regarding the psychological effects that women with FGM experience during childbirth is sparse. However, when reading policies and guidelines concerning FGM, the majority mention psychological consequences such as flashbacks, PTSD, depression, and anxiety specifically related to genital examinations and childbirth, due to being in a reclining position with legs spread, a similar position to the one used when FGM occurs. No evidence was found for this widely-held belief in primary studies except Chibber et al. (2011), which is of low quality. One study by Moxey and Jones (2016), and another by Glover et al. (2017) reported findings suggesting a lack of knowledge about FGM, childbirth and the healthcare system could be causing fear and anxiety around childbirth for women with FGM. More information is desperately needed in this area as if negative psychological consequences are occurring for women with FGM, healthcare systems need to respond appropriately to prevent chronic conditions arising. The next section explores maternity care within the NHS.

1.6 Maternity Care in the NHS,

The following sections explore core contextual factors needed to understand women’s experiences of their post-partum care using NHS services. The concepts of culture and maternity care are described to provide context to the reviews of migrant maternal healthcare and FGM maternal health care and complications. In order to provide context, the following is a focused scoping review as the topics presented are broad. The section concludes with an amalgamation of the information presented in the form of a model describing the current maternal care received by women with FGM by the NHS (). Search strategies can be found in Appendix 0.

The Better Births Report (National Maternity Review, 2016) highlighted the historic underfunding of postnatal care and the need to focus on this area to improve maternal outcomes and support women (National Maternity Review, 2016). Postpartum or postnatal care is often referred to as the ‘Cinderella of maternity services’ (Barker, 2013); with literature often showing the quality and value of postnatal care described in less optimistic terms than antenatal or labour and birth care (Guthrie et al., 2020; Rogers, 2018; The Royal College of Midwives, 2014). In a commentary article published in the British Journal of Midwifery, Rogers, (2018) describes interviewing women about their postnatal experiences and subsequently developing a booklet to improve care (The NW London Collaboration of Clinical Commissioning Groups, 2018). Women described inconsistent postnatal care and receiving information that was often conflicting and confusing. As this was not a peer-reviewed traditional scientific study the results must be taken with caution, however, data is being collected on the booklets’ use and will hopefully be available soon.

Commissioned by the National Childbirth Trust, Guthrie et al. (2020) are attempting to understand the pregnancy-related research landscape in the UK. Pregnancy-related research was identified through searches and requesting information from funders for the years 2013-2017. Data was screened by title award and abstract to classify based on their topic, funder, research approach, funding type and stage of pregnancy they address. A total of 580 awards were found. Although the project has not been completed yet, a summary report shows just 1.4% of UK research funds dedicated to pregnancy are used for postnatal care research. As this summary report focuses on the findings of a different aim, it does not describe the analysis methods, presenting a limitation. However this is an important finding and displays the lack of attention given to postpartum care research compared to other pregnancy issues and time points.

Between September and November 2013, the Royal College of Midwives surveyed their midwife, maternity support workers and student midwife members about their experiences of postnatal care (RCM, 2014). Mothers were also surveyed using a website frequented by mothers. While no other methods are stated, findings show a significant gap between what current policy states about postpartum care and what midwives do and women actually experience. Relevant findings include 65% of midwives reporting that organizational pressures influence the number of postnatal visits, rather than the needs of the woman. Another finding suggests 64% of women did not discuss a postnatal plan with midwives after the birth of their baby (RCM, 2014). Recommendations include more resources being dedicated to postnatal care. Although not a peer-reviewed study, this survey is important and reflects the lack of resources given to postpartum care.

This issue is not unique to the UK health system, but rather a lack of attention given to postnatal services globally, as reflected in the UN millennium goals (United Nations, 2015). The next section explores the organization of the NHS.

1.7 Organization of the NHS.

The NHS is the universal, public health care system used by the UK and provides maternity care for all women, except undocumented migrants and illegal migrants (National Maternity Review, 2016). However, it should be noted that no woman will be refused care for herself or her baby if she cannot pay at the time. Figure 1.5 shows the allocation of funding in the NHS for England, Northern Ireland, Scotland and Wales; and Figure 1.6 displays the organizational structure of the NHS.

Figure 1.5: How Funding Flows in the NHS (Reproduced from The King’s Fund (2020); Retrieved from: https://www.kingsfund.org.uk/sites/default/files/202004/NHS_Funding_Flow_April_2020.pdf. Accessed 02/08/2020)

Figure 1.6: The Organizational Structure of the NHS (Reproduced from: The Kings Fund (2020); retrieved from: https://www.kingsfund.org.uk/sites/default/files/2020-03/NHS_structure_March_2020.pdf. Accessed 27/08/2020)

FGM is outlawed by the EU and UN; and as the UK is a member of the UN, and was a member of the EU until 2020, it was required to abide by the international policies of these groups. Healthcare guidelines have been published to guide healthcare provision of women with FGM (WHO, 2018). International guidelines, including from the WHO have been adapted into UK law and health policy by the UK government, Department of Health and NHS England (RCOG, 2015). Each individual Trust within NHS England further adapts these guidelines to meet the needs of their specific population and resources. NHS England uses two independent bodies to provide monitoring and feedback on its’ care processes; NHS Improvement (NHS England, 2020b) oversees the financial viability of NHS Trusts, and the Care Quality Commission (2020) oversees patient care and experience. The Care Quality Commission (2020b) asks five key questions of the care practices provided; 1) are they safe? 2) are they effective? 3) are they caring? 4) are they responsive to people’s needs? 5) are they well led? Both bodies provide important oversight to the NHS and ensure quality care for all (NHS England, 2020b). The next section explores the biomedical model and the holistic midwifery model.

1.7.1 The biomedical model, and the holistic midwifery model and the medicalization of childbirth.

The current care model used by the NHS is anchored in the biomedical model, with a holistic approach used if resources allow. Although not in the purview of this thesis, it is important to note the historical origins and motivations for the traditional biomedical model of medicine, and the holistic model of midwifery. The former views the body in binary terms as either ill or healthy (Downe & McCourt, 2019). The ideal state is healthy, and if you are ill, medicine will attempt to restore a healthy state (Davies, 2019). The NHS was developed using a biomedical model of health.

The biopsychosocial model of health (Engel, 1977), and later the biopsychosocial-spiritual model of health (Sulmasy, 2002), attempts to expand the traditional biomedical model by including the psychological and social dimensions of a patient's experience, with many believing this should be expanded to include a patient's spiritual beliefs also (Saad, de Medeiros, & Mosini, 2017). Although these models are not used by the NHS or UK midwives, it is important to recognize their existence as they bridge the gap between the NHS and midwifery models of care and display different approaches to health provision. Though adapted to integrate new knowledge and technologies, the model remains the foundation through which the structure and medical provision of the NHS is delivered (Rivett, 2014).

In contrast, midwifery uses a holistic approach to pregnancy, birth and the PPP which has evolved with the profession that has its roots in community-based and untrained birth attendance. Where the medical model focuses on the risks, complications and need for interventions during childbirth; the midwifery model holds birth as a normal physiological event, focuses on choice, only using interventions when necessary, while also considering the woman's social environment and needs beyond pregnancy and birth (RCM, 2018). Theoretically these two models should work in a complimentary fashion, however, as medicine became the authority on health knowledge in UK society during the 19th and 20th centuries, and physicians became the knowledge keepers, a risk-reduction approach was taken regarding childbirth, with pregnancy and childbirth seen as unsafe and risky events rather than natural ones (Scamell, Stone, & Dahlen, 2019). This shift in thought was demonstrated by the move of births from the home to hospitals and the increasing levels of interventions in childbirth seen today (continuous foetal heart rate monitoring, epidural pain relief, Caesarean-sections (C-sections), episiotomies); with some interventions, such as episiotomies, becoming part of regular practice without indication warranted (Scamell et al., 2019). The practice of midwifery changed worldwide, some countries removed midwives from their system (North America), others merged with nursing (Canada), while in the UK, midwifery maintained its' autonomous profession while becoming legally regulated (Connerton, 2012). For an overview of midwifery care over time please see Appendix 0.

1.7.1.1 Current UK maternal health outcomes.

Public healthcare is inevitably organised in accordance with the needs of 'mainstream' populations. FGM is a culturally unfamiliar practice within the UK and therefore maternity services were not designed to accommodate it. Although it has never been safer to give birth in the UK, health disparities do exist between women based on ethnic background. The first Mothers and Babies: Reducing the Risk through Audits and Confidential Enquires Across the UK (MBRRACE-UK[1]) report (Knight et al., 2018) looked at maternal healthcare between 2014-2016, and found black women were five times more likely to die as a result of complications during pregnancy versus white women (40/100,000 versus 8/100,000). Asian women had a two-fold increase

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[1] MBRRACE-UK' is the collaboration appointed by the Healthcare Quality Improvement Partnership (HQIP) to run the national Maternal, Newborn and Infant clinical Outcome Review Programme (MNI-CORP) which continues the national programme of work conducting surveillance and investigating the causes of maternal deaths, stillbirths and infant deaths.

compared to white women (15/100,000). All maternal deaths are reported to MBRRACE-UK, Northern Ireland Maternal and Child Health (NIMACH) and Maternity Death Enquiry (MDE) Ireland. Identification of deaths is cross-checked with record from the ONS and National Records of Scotland. Full medical records are obtained for all women who die, as well as those identified for the Confidential Enquiry into Maternal Morbidity and anonymised before a confidential review is undertaken. The cause of death is reviewed by a pathologist, an obstetrician or physician as required. The care received by the woman is then reviewed by a range of experts including midwives, obstetricians, physicians, pathologists and psychiatrists (usually between 10 and 15 experts in total). The findings are then reviewed by a multidisciplinary writing group to gather main themes and develop recommendations resulting in very strong evidence.

The MBRRACE-UK report, coupled with the Better Births Report (National Maternity Review, 2016) released by NHS England, resulted in a focus being placed on improving maternity care in the UK. Better Births (National Maternity Review, 2016) described a vision of personalized maternity care and continuity of care provider. Personalised care is defined in the National Maternity Review as care “centred on the woman, her baby and her family, based around their needs and their decisions, where they have genuine choice, informed by unbiased information” (National Maternity Review, 2016, p8). With continuity of carer promoted to “ to ensure safe care based on a relationship of mutual trust and respect in line with the woman’s decisions” (National Maternity Review, 2016, p9). In practice, each woman should have a midwife who is based in the community, knows the woman and her family; and can provide continuity of care throughout the woman’s pregnancy, birth and her PPP (National Maternity

Review, 2016). If implemented, this care plan would ensure women's needs are understood and hopefully met throughout her pregnancy, birth and postpartum transitions, resulting in better healthcare for the woman and her baby.

The second MBRRACE-UK report (maternal deaths 2015-2017) (Knight et al., 2019) showed rates had persisted, and black women were still five times more likely to die as a result of complications during pregnancy compared with white women (38/100,000 vs. 7/100,000). Mixed race women were found to have a three-fold increased risk (23/100,000), and Asian women a two-fold increase (13/100,000) in risk relative to white women. Women who die during pregnancy or the PPP were found to have multiple complications including with their mental or physical health, or with complex social situations (Knight et al., 2019).

These health disparities trends have continued throughout the current COV-SARS- 2 pandemic. A recent study found that between March 1st and April 14th, 2020, over half (56%) of pregnant women hospitalized with COVID-19 were from Black or other ethnic minority groups (233/427) (Knight et al., 2020). Black ethnic groups were eight times more likely than White ethnic groups to be hospitalised (3.5/1000 versus 28.5/1000), with Asian ethnicity groups being four times more likely than White groups (13.9/1000) (Knight et al., 2020). This study highlights the continuation of health inequalities even in a pandemic. The next section discusses FGM and the NHS.

1.7.2 FGM and the NHS.

Contact with maternity services is often the first engagement with health services female migrants in the UK may have; and is seen as an ideal opportunity for identification of FGM and completion of safeguarding for both mother and baby.

Through mandatory reporting, healthcare providers are now required to record all incidences of FGM and report any girls under 18 years who are at risk or have had FGM, or if safeguarding concerns exist (Home Office, 2015). The aim of mandatory reporting is to safeguard women and children against FGM, and accurately record the prevalence rates within the UK to be better able to respond to the illegal perpetuation of the practice and distribute healthcare resources where needed.

The law, healthcare and FGM have become intertwined within the UK; an intentional feat driven by the law. The 2003 FGM Act (UK Parliment, 2003) instituted a mandatory reporting duty for all healthcare professionals. This was implemented through additional NHS safeguarding requirements specific to FGM to ensure legal responsibilities were met (NHS Safeguarding Team, NHS England, & NHS Improvement, 2019). Any healthcare professional who failed to complete their mandatory reporting duty was referred to their licensing body for ‘appropriate action’ (NHS Safeguarding Team et al., 2019). In this situation, the law is dictating requirements to healthcare, a unique circumstance in the UK with currently unknown impacts on those with FGM receiving healthcare. The law surrounding FGM (section 1.3.4), specifically impacts the context of this study. The transition to parenthood offers a unique time point to prevent the perpetuation of FGM through education and reinforcing that FGM is illegal in the UK. Women with FGM are invited to attend an appointment with an FGM specialist midwife. The purpose of the appointment is i) to assess if medical intervention is needed for birth and if so to create a FGM birth-plan, ii) to complete safeguarding for the woman and her family and iii) to complete mandatory reporting requirements. The FGM Safeguarding and Risk Assessment toolkit provided by the Department of Health for healthcare providers includes descriptions of how to complete a FGM risk assessment, safeguarding steps and education about FGM (Department of Health, 2016). Safeguarding process maps specific to each NHS trust , and checklist assessment tools are available (Department of Health, 2016 (Annex 1)). According to the Department of Health, the two most important questions for risk are whether a woman comes from a country that practices FGM, and whether she has been cut herself; and reflect how the UK assesses risk as discussed in Section 1.4. During this appointment, women are informed of the law and taught about the different types of FGM based on WHO guidelines. They are shown diagrams to illustrate the WHO 'Types' and if they consent, undergo a genital examination to determine what type they have. Genital examinations ensure the midwife can accurately create a birth-plan and refer for de-infibulation if necessary, while also ensuring an accurate type is listed for mandatory reporting. Antenatal de-infibulation is preferred to reduce the risk of birth injury and prevent foetal distress from an obstructed birth. Current NHS maternity care for women with FGM is based on WHO guidelines, which can be seen by guidelines referencing the WHO and using their terminology and care guidance (see Chapter 3). If this appointment is not attended, a referral to social care will be made to complete safeguarding risk assessments and referrals. Safeguarding procedures can also be completed during labour and birth. Community midwives may also complete safeguarding risk assessments during the PPP, as may health visitors, and GPs during the 6-week postnatal check. The current experiences of women with FGM receiving maternity care through NHS services is not well understood, though the impact of the law on those experiences must be noted and provides context to women's overall healthcare experiences. The next section explores the concept of personalized care within the NHS.

1.7.3 Personalized care within the NHS.

In 2019, NHS England released a report detailing how universal personalised care would be implemented across the UK, and defined personalized care as meaning: “people have choice and control over the way their care is planned and delivered, based on ‘what matters’ to them and their individual strengths, needs and preferences” (NHS England, 2019b, p16). Further description of personalized care can be found in Table 1.7.

Table 1.7: What Personalized Care Means in the NHS (NHS England, 2019b, p18)

1. Be seen as a whole person within the context of their whole life, valuing their skills, strengths and experience and important relationships.
2. Experience hope and feel confident that the care and support they receive will deliver what matters most to them.
3. Be able to access information and advice that is clear, timely and meets their individual information needs and preferences.
4. Be listened to and understood in a way that builds trusting and effective relationships with people.
5. Be valued as an active participant in conversations and decisions about their health and well-being.
6. Be supported to understand their care, treatment and support options and, where relevant, to set and achieve their goals.
7. Have access to a range of support options including peer support and community-based resources to help build knowledge, skills and confidence to manage their health and wellbeing.
8. Experience a coordinated approach that is transparent and empowering.

The report acknowledges there are variations regarding access and delivery to personalized care across the UK, and promotes a ten-year action plan to achieve continued improvement in this area (NHS England, 2019). A systematic review of randomized controlled trials and cluster-randomized trials involving adults with long-term conditions where the intervention included collaborative goal setting was conducted by Coulter et al., (2015). Two authors independently screened citations for inclusion, extracted data, and assessed risk of bias. Nineteen studies involving 10,856 participants were included. Primary outcomes included effects on physical health, psychological health, subjective health status, and capabilities for self-management. Overall personalized care planning was found to lead to improvements in certain indicators of physical and psychological health status, and people's capability to self-manage their condition when compared to usual care. However, the effects were not large, but do increase as the comprehensiveness, intensity and integration of the intervention into routine care increases (Coulter et al., 2015). This research evidence is corroborated by NHS surveys (NHS England, 2019). A recently completed systematic scoping literature review by Crowther, MacIver and Lau (2019) assessed empirical literature and government and professional documents to understand current postnatal care. Clear methods are described and as befits a scoping review, no quality assessment was completed as the aim was to explore all evidence available. The review concluded that although personalized care plans for women post-birth are recommended throughout policy and guidelines, there is a lack of evidence showing their implementation in practice.

1.8 Culture

Culture serves as the context for this study as FGM is an ancient cultural practice which holds great meaning for those who practice it (WHO, 2016). While there are many definitions of culture, and fierce debates surrounding its use (Jahoda, 2012; Mironenko & Sorokin, 2018), the definition by Spencer-Oatey (2008) will be used to guide this study; "culture is a fuzzy set of basic assumptions and values, orientations to life, beliefs, policies, procedures and behavioural conventions that are shared by a group of people, and that influence (but do not determine) each member's behaviour and his/her interpretations of the 'meaning' of other people's behaviour" (p3). This definition, while not a definitive definition of culture, encompasses the necessary ideas (basic assumptions, values, beliefs, behavioural conventions) required to understand the intertwined and fluid impacts culture has on the postpartum experiences of women with FGM. In order for the practice of FGM to stop; the cultural meanings associated with the practice must be understood, followed by consideration of how to influence the desired behaviour change. This study views culture as an essential contextual factor that cannot be ignored if the true postpartum needs and experiences of women with FGM are to be understood.

1.8.1 Culture and minority healthcare and health outcomes.

Culture is created and maintained by social, political and historical conventions (Burke, 2019). When taken together culture, healthcare and society form a distinctive intricate network, which impacts health in unique ways (Hollins, 2009). Cultural constructs of manhood and womanhood combined with the expression of gender identities merge with socioeconomic status such as education and income level to directly impact health outcomes (Airhihenbuwa & Liburd, 2006). FGM is one such cultural construct of femininity and womanhood, and there are many reasons given for its continuing practice despite the known health risks as discussed in Table 1.2. FGM has direct economic impacts such as eligibility for marriage and ability to work; as well as potentially restricting a woman’s ability to receive education (UN Human Rights, 2014). It has been shown that higher income and education equate to better healthcare access and health outcomes (UK House of Commons Health Committee, 2009), therefore it is extremely important to understand the connection between health and culture to improve healthcare for women in a culturally acceptable fashion.

In a cohort study, Aquino, Edge, and Smith (2015) explored midwives' experiences of providing care for Black and Minority Ethnic (BME) women, focussing on their views of maternal health inequalities and service delivery. Twenty semi-structured interviews took place over two months using a purposive sample in Manchester, UK. Thematic analysis revealed minority populations encounter difficulties receiving appropriate and timely maternity care due to language challenges, differing perspectives on health, medical care and expectations concerning diagnosis and treatment (Aquino et al., 2015). Strengths of this study include the diverse sample of midwives, and the diverse population they serve. Limitations include potential bias from participants as they volunteered, and one research site being used, limiting generalizability. Cultural differences can manifest in health disadvantages for ethnic minorities; an example can be seen in a Centers for Disease Control and Prevention (CDC) (2013) report from the US which found the pre-term rate for black infants (17.1%) was approximately 60% higher than for white infants (10.8%) . This report also found the rate for Asian infants was 13.6%, and Hispanic was 11.8%; with white infants having the lowest pre-term rate and coming from the dominant culture (CDC, 2013). The report cited socioeconomic status, prenatal care, maternity risk behaviours, infection, nutrition, preconception stress and genetics as contributing factors to the pre-term rates (CDC, 2013).

Health disparities were also found in a Finnish study comparing ethnic minority with non-ethnic minority women and their birth outcomes. The Finnish Medical Birth Register (MBR) records all births taking place in Finland. The register includes all live births and stillbirths of more than 22 weeks of gestation or weighing less than 500 grams. The coverage of the register is considered complete and administered by the

National Institute for Health and Welfare. The MBR data was linked to the Finnish Central Population Register by Statistics Finland using women's unique identifying numbers. The anonymised data was then sent to the researchers for analysis. Women of foreign origin (6,532) with singleton births were compared with Finish origin singletons (158,469). Statistical analysis found those of African origin had the most health problems during pregnancy and childbirth, and the worst perinatal outcomes; including perinatal mortality rates (Malin & Gissler, 2009). Low birth weight, babies 'small for gestational age', increased number of C-sections and interactions after birth were also recorded for women of ethnic minority (Malin & Gissler, 2009). A limit of this study may be the method of grouping migrants. Three groups were used due to sample numbers: Somali, African and North African. The Somali group was large enough to have stand-alone statistical significance. Placing all other 'Africans' in two groups may limit the applicability of findings due to decontextualizing different migrant experiences. However, this study does show statistically significant disparities in health outcomes between migrants and non-migrants which requires addressing in maternal care. These findings further the evidence that migrants may experience different care outcomes than non-migrants that may be caused by cultural differences.

The healthcare system can be viewed as a cultural system, with interactions between historical forces, economics, politics, geography, legal, and cultural systems and their subsequent effect on the delivery, access; and consequent health outcomes. Healthcare interactions can be especially revealing where the dominant culture of the healthcare system interacts with minority cultures (Kagawa Singer et al., 2016). Kagawa Singer et al. (2016) gathered a multidisciplinary team of experts from 7 different disciplines to develop a definition of culture to guide researchers in studying how cultural processes influence health behaviours and overall health. The 4-phase Delphi Process was used and resulted in not only a definition of culture but nine issues relating to conceptualisation and operationalisation that lead to an inability to reduce health disparities and can be seen in Table 1.8. Two points are particularly relevant for this study: “the assumed universality of the dominant culture's constructions of reality and salient domains, such as selfhood, family, fairness, and well-being, is problematic” and “the biomedical and behavioural sciences have focused primarily on the individual without accounting for the influence of the social, historical, and environmental context of the group(s) to which s/he belongs” as migration often leads to new meanings of family, culture and community (Johnsdotter & Essén, 2016).

Table 1.8: Barriers to the use of scientific definitions of culture (Kagawa Singer et al., 2016)

Conceptualization

1. The concept of culture is inadequately conceptualized and inconsistently applied.
2. Few studies demonstrate how culture affects health outcomes with clear definitions, measurable constructs, and conceptual models that indicate the interactions of the cultural processes.
3. Problems of diverse cultural groups are identified, but devoid of their historical, geographic, social, and political contexts, and the influence of such contextual factors on their positions in the societal power hierarchy.
4. The dynamic nature of culture is not reflected in most studies.
5. The role of culture in shaping the nature and conduct of health research in the U.S. is lacking.
6. The assumed universality of the dominant culture's constructions of reality and salient domains, such as selfhood, family, fairness, and well-being, is problematic.

Operationalization

7. The current practice of using nominal, dichotomous variables of race and/or ethnicity and/or ancestry to represent culture, is simplistic and inadequate.
8. The heterogeneity within the group of focus should be explicit and demonstrated in the description of the study sample.
9. The biomedical and behavioural sciences have focused primarily on the individual without accounting for the influence of the social, historical, and environmental context of the group(s) to which s/he belongs.

Health Disparities

10. The challenges listed in #1-9 contribute to the inability to effectively reduce health disparities

Johnsdotter and Essén (2016) explored the current knowledge regarding cultural change post-migration and FGM in a literature review including qualitative and quantitative studies, and grey literature. Reference lists were also checked, although no quality assessment was described. Findings suggest migration can change cultural norms regarding FGM as people reflect on their cultural values and question the reasons for the practice. The combination of exposure to others who are not circumcised, questioning religious reasons, legal bans, and the risk of ostracism erased due to migration may change peoples beliefs about the practice (Johnsdotter & Essén, 2016).

Tensions can manifest between tradition and modernity in many aspects, including gender roles and norms, resulting in generational dilemmas when family members are exposed to a new culture; leading to feelings of oscillating between two countries (Kalmijn, 2019). In a study examining how cultural and social aspects of integration affect parent-child relationships Kalmijn (2019) used data from a nationally representative survey of people living in the Netherlands where people of Turkish and Moroccan origins were systematically oversampled. The survey used a two-stage stratified random sample of individuals aged 15-45 living in the Netherlands in 2006. Respondents were interviewed in their homes and also completed a paper survey which contained questions on intergenerational relations and detailed measures on multiple dimensions of immigrant integration. Findings suggest that although intergenerational conflict is normal, in migrants it may have worse effects as parents feel that distance threatens solidarity with migrant group. Findings showed that when adult children are more integrated culturally and socially in host society, their generally have weaker ties to their parents. This is manifested in more conflict, especially between mothers when children have more liberal family views. Limitations include that links may arise from casual processes in two directions as it is unknown what degree parents are integrated. With many factors in play, the authors conclude that the presence and amount of conflict will depend on the individual, family members, and the level of cultural integration of each.

It is important to acknowledge the healthcare system is not designed from the cultural viewpoints of minority groups and the possible negative consequences that can result (Institute of Medicine, 2013), including healthcare systems unfamiliar with minority cultural practices, such as FGM (Phillimore, 2016).

An example of this is FGM in the UK as there is a fundamental mismatch in the belief system of the dominant culture (do not practice FGM) and the minority one (practice FGM), where FGM is believed by the dominant culture to be harmful to health and an unacceptable cultural practice and is thus illegal. This mismatch in beliefs may cause a lack of appropriate care and resources to be accessible due to a lack of knowledge by healthcare providers working in the NHS. This study increases the knowledge of women's postpartum experiences and highlights differences in provided and desired care delivery. Culture is an important contextual factor in healthcare provision. The next section discusses providing culturally competent care.

1.8.2 Providing culturally competent care.

Providing culturally competent care (CCC) is a method employed to reduce the inequalities in health outcomes of minority cultural groups (NHS Health Education England, 2020). When providing care to a woman of a different cultural background, midwives must display cultural competency, showing awareness of differences in expectations or traditions and adapt care accordingly (NHS Health Education England, 2020). Direct links are seen between improved cultural competency of healthcare staff and health care improvement for minority populations (Weech-Maldonado et al., 2012), with negative health outcomes resulting from culture being dismissed as an influencing factor (Napier et al., 2014). Weech-Maldonado et al. (2012) examined the relationship between hospital cultural competency and inpatient experiences with care in the USA. Using the ‘Comprehensive Framework and Preferred Practices for Measuring and Reporting Cultural Competency, the authors analysed six domains for hospital cultural competency: leadership, integration into management systems and operations, workforce diversity and training, community engagement, patient-provider communication and care delivery and supporting mechanisms. They subsequently created a statistical model that analysed these domains with the ‘Consumer Assessment of Healthcare Providers and Systems (CAHPS)’ survey to assess patient outcomes. Hospitals with greater cultural competency had greater patient outcome scores for doctor communication, hospital rating and hospital recommendation. Importantly, CAHPS scores for minorities were higher in hospitals with greater cultural competency levels in nurse communication, staff responsiveness, quiet room, and pain control. Overall patient experience was increased as cultural competency increased. These findings suggest cultural competency in HCP and healthcare institutions can improve patient experience and outcomes, especially in migrants (Weech-Maldonado et al., 2012).

Healthcare providers must attempt to provide culturally competent care; defined by NHS England as recognition and response to cultural components that affect care provision (NHS Health Education England, 2020). The Royal College of Midwives considers cultural competence as good practice and suggests it could improve care

(RCM, 2018). However, while some people may ascribe a great deal of cultural significance to healthcare interactions, others may not; it is therefore important for the healthcare provider to ascertain how and if culture colours a patients' healthcare interaction (NHS Health Education England, 2020). Culture is an important factor when considering healthcare interactions with minority groups, especially when it concerns a cultural tradition not seen in the dominant culture, such as FGM.

'Contextual consciousness' is a method for HCPs to achieve cultural competence and involves acknowledging the inherent power differentials encompassed in a person's social context and can include gender, race, socioeconomic status, and sexual orientation (Esmiol, Knudson-Martin, & Delgado, 2012). It includes sensitivity and acknowledgment of the patient's unique experiences in the above contexts and awareness of the intersection and interaction these factors can have in relation to health perceptions (Esmiol et al., 2012). When attempting to replace a harmful practice based on cultural belief with a harmless practice, it is important to explain the rationale thoroughly (Brown, Beecham, & Barrett, 2013); and for every provider to deliver a consistent message. Providing culturally competent care and understanding the cultural context allows HCP to deliver appropriate care to people from minority cultures.

Providers should learn effective interviewing techniques and use interpreters to illicit necessary information from patients to provide appropriate care (NHS England & Primary Care Commissioning, 2018). Effective communication allows patients to dictate how much or how little culture impacts their healthcare interactions (Phillimore, 2016). Phillimore (2016) conducted a mixed-methods semi-structured questionnaire co-designed with maternity professionals and migrant women to explore the reasons new migrant women book late and do not attend follow-up antenatal appointments. Eightytwo questionnaires were completed using snowball sampling through a community centre. Thirteen women were identified for in-depth interviews and findings were triangulated, with thematic analysis used for the qualitative data and SPSS for the quantitative data. A range of structural barriers to healthcare were found, including not understanding how to access maternity care, and not being able to due to poverty or onward dispersal. Time limitations exacerbated communication issues and resulted in an inability to form meaningful connections with HCPs. Caseload targets for HCPs are not adjusted when migrant women are accessing services and presents an institutional failure to recognize their need for additional time for communication. Limitations include recruitment from only one community centre, potentially missing women or biasing results based on friendship circles of women from similar backgrounds. The methods also lack clear description of how the 13 women were chosen for in-depth interviews. While communication is key to healthcare services being productive, HCPs and women must be given the resources to allow therapeutic communication to occur.

It is important for providers to be sensitive, non-judgemental and to learn about patients' cultural beliefs and practices (NHS Health Education England, 2020). HCPs must become aware, through reflection and understanding their own cultural identity; their own views and any bias and cultural characteristics they might present to patients (NHS Health Education England, 2020). A retrospective Q methodology study of Pakistani women following childbirth concluded cultural competency should be included in midwifery training to improve care (Cross-Sudworth, Williams, & Herron-Marx, 2011). Fifteen women completed semi-structured interviews and 16 women participated in the completion of Q-grid sorting. Translations were verified by a second, experienced translator. While a larger sample size is needed for future studies, this study showed that women need to be assessed on an individual basis as needs are dependent on many different factors, including culture, family support and information and support from HCP.

Although culturally competent care is heralded by policy and literature as a necessity for healthcare interactions, there is a lack of evidence regarding its' impact. Jongen, McCalman, Bainbridge, and Clifford (2018) conducted a scoping review of interventions strategies, outcomes and measures used to increased cultural competence in healthcare. peer-reviewed and grey literature published in English which evaluated interventions designed to improved cultural competence in healthcare for indigenous or minority groups in Australia, Canada, New Zealand or the United States were included. PRISMA guidelines and the CASP tool was used for quality assessment. Of the 16 studies included; 10 were found to be weak, 4 moderate and 2 strong. There was a lack of consistent terminology and a lack of quality evidence among the literature. Although HCPs reported positive effects from training such as improved knowledge and skills, there remains a lack of evidence regarding patient outcomes.

Currently the NHS provides an E-learning module dedicated to culturally competent care (NHS Health Education England, 2020), and the RCM provide statements noting the importance of culturally competent care in their Blue-Top professional guidance for 'Midwifery care in labour guidance for all women in all settings' (RCM, 2018). These statements include noting a woman's decision making process during labour may be influenced by her culture, and care may need to be tailored to accommodate a woman's cultural background (RCM, 2018). However, no information or policy could be found regarding formal training or evaluation of these education strategies, or their outcomes; suggesting a more formal approach may be warranted to evaluate training on both HCP's cultural awareness and any impact on women's maternity care (specific discussion of this topic in relation to migrant health can be found in Section 1.9).HCPs must also be able to look to institutional policy to provide a multi-culturally accepting environment for staff and women (Jongen et al., 2018). Effective communication coupled with culturally competent healthcare provision allows cultural mismatches to be explained in an appropriate and sensitive manner; promoting discussion and reaching mutually beneficial outcomes for all involved (Jongen et al., 2018; NHS Health Education England, 2020). Culture is an important contextual factor for this study as FGM is a cultural practice. Disadvantages are present for cultural minorities using the NHS and therefore ensuring adequate training for HCPs regarding culturally sensitive care is paramount to improving healthcare experiences for migrant and ethnic minority women. The next section explores migrant maternal health and healthcare experiences.

1.9 Migrant Maternal Health

FGM is a culturally unfamiliar practice in the UK and as such many of the women with FGM in the UK will have migrated at some point in their lives. Migrant status is an important factor to consider when exploring the health needs of women with FGM. The following section briefly discusses migrant maternal health. A thorough discussion on migrant maternal experiences can be found in Appendix A.8.

The MBRRACE-UK (Knight et al., 2019) report found that black women have a five-fold increase in risk of maternal mortality and morbidity compared to their white counterparts, with Asian women having a two-fold increase suggesting ethnic minority status is important to maternal health outcomes. This must be acknowledged when exploring the health experiences of women. In an editorial on migration and health from a global health perspective, Chung and Griffiths (2018) suggest that the health disparities are due to differences in exposure to social determinants of health such as physical and social environments, migrant-related policies, health services and health systems. However, placing all people who have migrated into one category oversimplifies a complex, layered topic, and reduces the role of individuals and context. Discrepancies between migrant groups within countries have been noted, with health risk profiles varying greatly (Crawshaw & Kirkbride, 2018).

Overall, migrant women experience worse maternal outcomes due to a complex interplay of factors relating to culture, resources and experiences with individual HCPs. Table 1.9 summarises the barriers women may face based on the above review.

Table 1.9: Potential barriers to healthcare for migrant women (Source: Author, 2020)

- Language barriers and lack of translation services (Merry et al., 2016; Rayment-Jones et al., 2019b)
- Transport (Boerleider, Wiegers, Manniën, Francke, & Devillé, 2013)
- Lack of support (family/partner) (Balaam et al., 2013; Owens, Dandy, & Hancock, 2016; Small et al., 2014)
- Access to childcare (Rayment-Jones et al., 2019a)
- Cultural differences in healthcare expectations versus reality (Balaam et al., 2013; Boerleider et al., 2013; Firdous, Darwin, & Hassan, 2020; Jomeen & Redshaw, 2013; Merry et al., 2016)
- Finances (Rayment-Jones et al., 2019a)
- Education (Raleigh, Hussey, Seccombe, & Hallt, 2010; Small et al., 2014)
- Socioeconomic status (SES) (Rayment-Jones et al., 2019a)
- Lack of trust in health service or HCP (Balaam et al., 2013; Boerleider et al., 2013; Firdous et al., 2020; Raleigh et al., 2010; Small et al., 2014)

Maternal experiences impact the trust women have in health services and when their expectations are not met, negative experiences occur. There is a lack of data on the postpartum experiences of migrant women and it is important to note the barriers present when researching migrant populations, including language, legal status and fear of being reported to authorities, access to participants, cultural norms surrounding childbirth, and adverse social conditions, complicating the establishment and maintenance of contact with participants. The next section explores the specific maternal health consequences of FGM.

1.10 UK Healthcare Experiences of Women with FGM

Three studies were located that specifically examined the maternity care experiences of women with FGM in the UK; Harper-Bulmam and McCourt, (2002), Moxey and Jones, (2016) and Straus, McEwen, and Hussein (2009). These will now be discussed to add context to the discussion of FGM maternity experiences.

A study by Harper-Bulmam and McCourt (2002) focused on communication and language barriers as this issue underpinned all others. Twelve Somali women using UK maternity services were interviewed or attended a focus group. Women reported interpretative services were good when available, but too many times women attended appointments without interpreters or had to provide their own. When interpretation was not adequate, women’s needs were not met. Women also reported a lack of support during labour, especially regarding pain management. Pain was not discussed antenatally and the study reported midwives as describing how Somali women were ‘more natural’ and only used Entonox (gas and air) or nothing for pain control during labour and birth.

Six women discussed FGM; one was happy due to discussions with a caseload midwife and birth plan, while three reported they had severe tears due to mismanagement and were unhappy with the healthcare provided. Women reported midwives had a lack of knowledge about FGM and communication by staff was lacking. One woman reported not being able to communicate her need for de-infibulation, and subsequently received a medio-lateral (downwards) episiotomy and severe tear. The authors noted a policy for labour and birth de-infibulation is in place but was not followed based on this woman’s description of her care experience. Women described staff attitudes as impersonal and task oriented. Continuity of carer resulted in positive experiences for women who received caseload midwifery care as midwives had more time, were able to get to know the woman, and subsequently the woman felt more comfortable. Women desired caring and kind midwives and noted how positive experiences could counteract negative ones. Language presented the biggest barrier in this study and the authors found that although midwives knew how to use interpretative services, most did not consider it necessary when the woman could speak broken English or had her own interpreter. Caseload midwives were better positioned to know whether language was a barrier. It was also noted that women did not like using a friend or relative as an interpreter, which is in line with the current NHS interpretation guidelines; but contradicts findings from Balaam et al. (2013) and illustrates the individualized nature of health experiences.

Moxey and Jones (2016) conducted a study to explore how Somali women with FGM experienced and perceived antenatal and intra-partum care in England. The authors conducted a descriptive, exploratory qualitative study using face-to-face semi-structured interviews. Purposeful, snowball sampling was used at two community centres in Birmingham. A sample of ten Somali women was recruited who had accessed the antenatal services in the previous five years. Informed verbal consent was collected, as well as interpreter confidentiality agreements. Semi-structured interviews took place in private rooms and were audiotaped. Questions were tested on the first four women to ensure they were understood as intended. The questionnaire expanded after the first four interviews. Inductive, thematic analysis occurred concurrently. Three themes emerged from the study findings; experiences of FGM during life, pregnancy and labour, experience of care from midwives, and adaption to English life (Moxey & Jones, 2016). Women explained how FGM had a traumatic, lasting impact on them both physically and mentally. They described having pre-existing expectations of having problems during labour, had a fear of giving birth, increased pain, infection, tearing and a more negative overall experience of pregnancy and childbirth. Women described more positive experiences after de-infibulation. Women wanted one procedure during labour, not two in order to minimize pain, rejecting antenatal de-infibulation (Moxey & Jones, 2016).

Women also reported hiding their FGM status from midwives. The study found that women who communicated with their midwives about their FGM had a more positive experience than women who did not. In regards to adaption to English life, women reported lacking understanding about how services worked, and worried that their child would be removed from their care because they had FGM (Moxey & Jones, 2016). The authors concluded that early identification of FGM to meet the healthcare needs of women, providing culturally sensitive care by midwives to ensure women disclose their FGM status, and also to alert women to the option of de-infibulation before conception are important needs of this group of women (Moxey & Jones, 2016). The authors note many women did not know about the option for pre-conception deinfibulation and would have preferred it (Moxey & Jones, 2016).

Perceptions and experiences of childbirth from Somali health workers in the UK were explored by Straus et al. (2009). In-depth, narrative interviews were conducted with eight Somali women (aged 23-57 years) who worked within the health sector, and/or as nurses in Somalia. Six had also given birth in the UK. Women described FGM as being mismanaged by HCPs who did not know how to care for a woman with FGM, did not listen to women when they requested an episiotomy, and unnecessarily advised women to undergo C-sections because HCPs believed they could not have a normal birth. A lack of suitable interpreters and the use of complicated medical terminology was also noted. A significant cultural difference was also noted in that Somali culture is largely oral communication focused, with woman desiring to talk and spend time with HCPs, not to receive leaflets and to be left alone during childbirth. Continuity of carer occurs in Somalia where women get to know their midwife and feel comfortable with her. This did not occur in the UK. Stereotyped judgement by HCPs was also described by women leading to negative birth experiences.

The above review focused on the experiences of women with FGM using UK maternity services. Communication and language were described as a major barrier to care by women, with HCPs underestimating the need for translation services, and lacking in knowledge about FGM in general. Expectations of care did not match reality and negative care experiences resulted. Increased culturally sensitive training, training about FGM and better communication is needed to improve care experiences for women with FGM. The reproductive, obstetrical and psychological complications associated with FGM have also been outlined. UK maternal healthcare experiences of women with FGM was explored and shows a disconnect between the expectations of women and the reality of their healthcare experiences. Women’s experiences must be considered when creating healthcare policy if their needs are to be met.

1.11 Summary of Literature

This background section has explored the contextual concepts of culture and maternal healthcare, exploring the history and organization of NHS maternity services women with FGM experience and showed a top-down approach to maternity care which followed a biomedical approach and based in a traditional British cultural context. The second section investigated the maternal health consequences and healthcare experiences of women with FGM in the UK and found a divergence between physical health outcomes and heath experiences of women; specifically, that while the physical aspects of care such as de-infibulation and childbirth had positive outcomes, women's healthcare experiences were less than ideal due to cultural or migratory status barriers. Taken together, women with FGM face a myriad of layered, context specific and individualized health needs and experiences. Specific health needs and experiences based on the impact of a woman's FGM, combined with ethnic minority health disparities, and the possible disconnect between the woman's culture and the culture of the NHS paints an incomplete picture and shows more research is needed to fully comprehend the intricate intertwining of various factors.

It is evident that FGM causes immediate and long-term health consequences for women. Unfortunately, due to the complexity of the topic, the diversity of the practice mixed with the hidden nature of FGM in practicing communities, it is difficult to collect and access high quality data. Clinical outcomes were used by all high-quality studies in Berg et al. (2014), and show how a bias in published literature may be occurring towards quantitative research methods, leading to a bias in public policy using only quantitative outcomes. Women who do not access care may be undocumented in such studies leading to an underestimation of health outcomes. Although there is evidence of negative outcomes, the practice is so divergent it is difficult to predict outcomes based on type. The current evidence must be interpreted cautiously. A lack of trust in HCPs was also seen in the literature, not only a lack of trust in their knowledge about FGM, but in their attitudes towards migrant women and women with FGM. This is an important and negative finding that may be compounded by the UK law regarding FGM and its impact on maternal care processes.

This section has provided a review of the relevant literature regarding reproductive injuries, obstetric consequences, and psychological consequences associated with FGM and childbirth. Taken together and added to the literature concerning migrant maternal health outcomes and disparities; this body of literature suggests women with FGM are at risk for adverse outcomes during childbirth. However, this statement must be taken in context of where the woman receives her maternity care. Regarding this study, current evidence suggests high-quality healthcare decreases the risk of adverse outcomes, however, psychological outcomes and socio-cultural outcomes due to migration may exist and require attention. Overall, a lack of evidence exists on the effects of migration for women with FGM and any psychological consequences experienced during childbirth. More evidence is needed on women’s postpartum experiences as current literature focuses on antenatal experiences and labour and birth. Women’s voices and experiences are missing in the majority of studies that tend to report largely clinical outcomes.

This chapter has critically analysed contextually relevant literature related to FGM, migrant maternal health and women’s maternal health, and the NHS, and provides a foundation of contextual knowledge within which to consider the following chapters of this thesis. This review showed that women with FGM are subject to numerous negative influences on their health including being an ethnic minority, being a migrant, and having FGM. Maternity care has been noted to compound these issues through a lack of culturally competent care with NHS FGM guidance stemming from a biomedical and legal framework with a strong antenatal focus. However, maternity care in the UK is also undergoing a transformation programme with a strong drive to personalised care delivery within the midwifery biosocial model with additional consideration of social determinants. The above review shows more research is needed concerning the PPP and provided the rationale for this study.

1.12 Rationale

It is proposed that women who have had FGM will require more resources during the PPP and forms the basis of the rationale for conducting this study. Current research relating to FGM focuses on the antenatal period, consequently, little is known about the postpartum experiences and needs of women with FGM. Although available literature suggests an increased rate in perineal trauma in women with FGM (WHO, 2006); there is a lack of research focusing on the PPP. Health consequences of FGM can manifest as physical, sexual, psychological, reproductive, and obstetrical and suggest worse maternal outcomes for women with FGM. Though research in this area is inconclusive, it does suggest the quality of healthcare in migration countries can decrease the negative obstetric complications of FGM. Migration presents unique factors associated with health outcomes and has been shown that ethnic health disparities do exist in the UK. Health disparities in ethnic minority populations during pregnancy occur as the minority culture interacts with the dominant healthcare culture. FGM may be an example of a health disparity manifesting due to culture and needs to be researched to explore the postpartum experience of women with FGM in order to ensure optimum care to women and their babies is provided.

From this knowledge, Figure 1.7was created to show the current top-down approach used by the NHS to provide maternity services to women with FGM. This figure combines to provide the rationale for the development of the research question and aims (Table 1.10).

Figure 1.7: Top-down approach to FGM maternity services used by the NHS in the UK

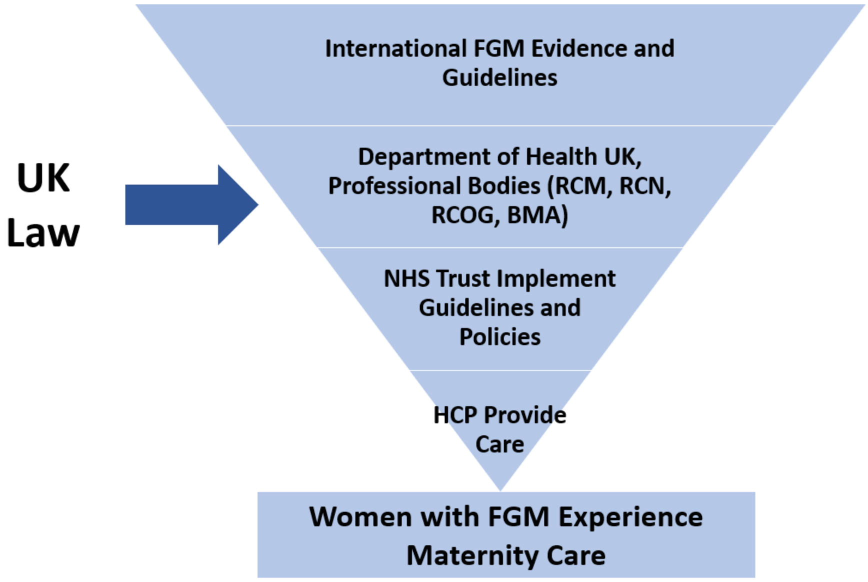


Table 1.10: Rationale for Study

- Negative health consequences associated with FGM (physical, psychological, sexual)
- Negative reproductive consequences associated with FGM (obstetrical and psychological)
- Migrant status leading to health disparities
- Maternal healthcare issues
    - Post-partum care historically underfunded
    - Focus shifts from woman to baby
    - Cultural differences and lack of practical support given to women
    - Expectation versus reality
- Lack of trust in healthcare system
- Lack of trust in HCP
- Barriers to healthcare (Table 2.2)
- Lack of data on post-partum experiences of women with FGM

1.13 Research Question and Aims

The research question for this study is:

What are the post-partum experiences and needs of women with FGM using NHS services in the UK?

Using a focused ethnographic approach, this study aims:

1. To identify and thematically analyse current international and national guidelines on FGM during pregnancy and the Postpartum Period
2. To examine and thematically analyse the role and views of key informants who influence the care received by women with FGM using NHS services
3. To critically evaluate the needs and explore the postpartum experiences of women who have FGM

This thesis seeks to give a voice to an often-unheard group of women in a sensitive and important time in their lives. In order to provide the best care possible to women with FGM, their needs and experiences must be understood. This research study will draw on women's voices to understand the experience of postpartum care in the UK for women with FGM. The findings may be used in the future to inform a post-partum support intervention to better care for women who have had FGM, and support staff providing the care. The research question and aims above were developed from the gap found in the above literature. The following chapter sets out the methods of the study, their justification and how the research question and aims were completed.

Chapter 2 Methodology and Methods; A Critical Examination and Application of Focused Ethnography

This chapter is divided into two sections, the first gives a focused discussion of the relevant knowledge required to understand how and why the specific methods were applied, including positionality; with the second section detailing the application of the methods in three phases, challenges and limitations, and recruitment and demographic results. Ethical considerations were of such import during this study a separate chapter (4) details the process of receiving ethical approval and the unique challenges this presented within the context of research regarding women with FGM.

2.1 A Focused Discussion of Ethnography in the Context of This Study

Ethnography is a qualitative methodology strongly identified with the acquisition of knowledge regarding distinct cultures foreign to the researcher (Gobo, 2008); and has been described as the most basic form of social research (Hammersley & Atkinson, 2007). The crucial foundation of ethnography is to understand the culture under study from the insider perspective (Gobo, 2008), and to examine the world from the subjects understanding of it (Hammersley & Atkinson, 2007). Ethnography, and subsequently focused ethnography, was chosen to conduct this study because it is the viewpoint of women who have FGM, and their postpartum experiences and needs, which is sought.

2.1.1 Focused ethnography

This study uses a focused ethnography approach because it investigates a subculture within a medical setting; women with FGM as a subculture of maternity service users and women experiencing the birth process. This study also investigates specific beliefs and practices regarding healthcare as held by 'patients' (Higginbottom, Pillay, & Boadu, 2013; Magilvy, McMahon, Bachman, Roark, & Evenson, 1987; Morse, 1987), reflecting a focused ethnographic approach.

Table 2.1 displays a comparison of traditional and focused ethnography methods. Focused ethnographies have emerged as a beneficial method in nursing and midwifery; with both professionals' and patients' experiences being sought (Cruz & Higginbottom, 2013), as practical problems can be addressed (Wall, 2015). Focused ethnography was chosen as the most effective method to use to address the research question as the desired outcome of this study is to enhance our understanding of the post-partum experience of women with FGM of the NHS from a cultural context.

Table 2.1: Comparison of focused ethnographies to traditional anthropologic ethnographies (Source: Adapted from Knoblauch, 2005)

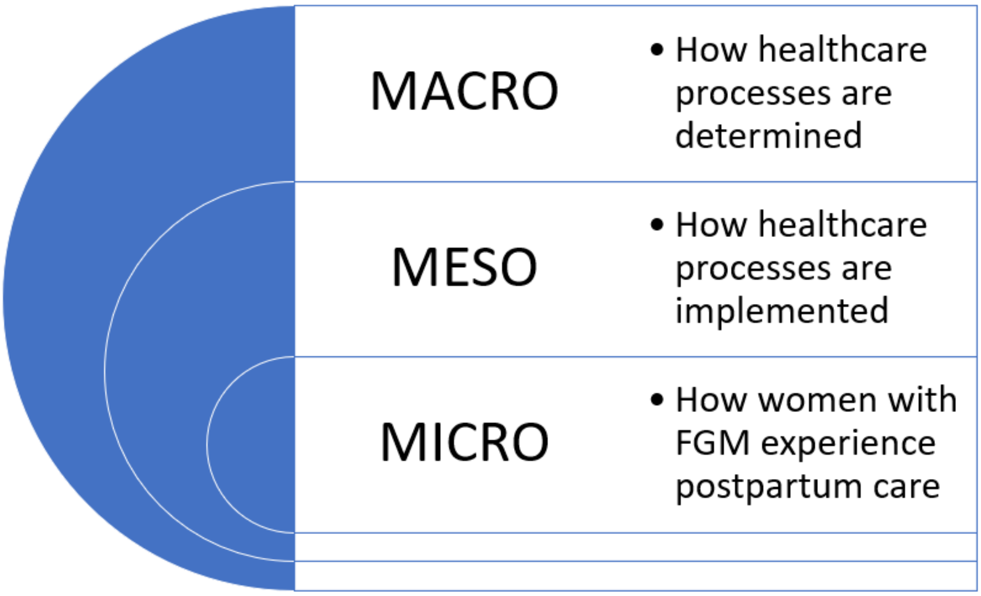
Traditional Ethnographies	**Focused Ethnographies**
Entire social field studied.	Specific aspect of field studies with purpose. e.g.: Charette, Goudreau, & Bourbonnais, 2019 -studied factors affecting *new graduate nurses* in *acute care* hospital settings.
Open field of investigation as determined through time.	Closed field of investigation as per research question. e.g.: Strandås, Wackerhausen, & Bondas, 2019 -Seen through the aim of the study: "to gain deeper understandings of *nurse–patient relationships* in the NPM era *by exploring meanings and values behind beliefs and practices* of nurses and patients in Norwegian public home care
Researcher gains insider knowledge from participatory engagement field.	Background knowledge usually informs research question. e.g.: Bikker et al., 2017 -Conducted a conceptual review to inform their focused ethnography

Participants are often those with whom the researcher has developed a close relationship.	Informants serve as key participants with their knowledge and experience. e.g.: Hales, De Vries, & Coombs, 2016 -Explored the culture and influences on doctors and nurses within the intensive care setting when caring for critically ill morbidly obese patients. Authors observed staff and interviewed them over four months.
Immersion during long-term, experiential-intense fieldwork.	Intermittent and purposeful field visits using particular timeframes or events, or may eliminate the observational aspect of the study e.g.: Dupuis-Blanchard, Neufeld, & Strang, 2009 -Sought the meaning of social engagement for adults who had recently moved to flats for older people and the types of relationships they developed in their new homes. Interview and demographic data were collected.
Narrative intensity.	Data analysis intensity often with numerous recording devices including video cameras, tape recorders and photo-cameras. e.g.: Garcia & Saewyc, 2007 Information from two interviews; pictures taken by participants, who had been given 24-exposure disposable cameras. Participant observation, field notes and journaling.
Individual data analysis.	Data sessions with a gathering of researchers knowledgeable of the research goals may be extensively useful for providing heightened perspective to the data analysis particularly of recorded data. e.g.: Taylor, Rush, & Robinson, 2015 -study was to explore ED nurses’ experiences of caring for the older adult. All authors participated in data analysis

While the focus on culture and sub-cultures is still present as in traditional ethnography; focused ethnographies are also framed within a specifically chosen phenomenon or context (Higginbottom et al., 2013; Morse, 1987); in this case, the postpartum experience of women with FGM using NHS services. Focused ethnographies have meaningful and applicable outcomes (Knoblauch, 2005), with medical focused ethnographies stemming from the desire to understand how culture impacts health beliefs with the intention of planning and delivering improved healthcare (Cruz & Higginbottom, 2013). An example of this is given by Sullivan, O'Brien, and Mwini-Nyaledzigbor (2016) who analysed sources of support for women with obstetric fistula in Ghana with the aim of improving support structures for these women. Similarly, Hales, De Vries, and Coombs (2016) conducted a study that "explored the culture and influences on doctors and nurses within the intensive care setting when caring for critically ill morbidly obese patients" (p83), with the intent to improve healthcare.

Focused ethnographies study situations in real-time, in natural settings seeking an in-depth perspective and are suitable for researching healthcare as the method provides a link between the micro, meso and macro events of life; the everyday versus wider cultural context (Savage, 2006). The macro, meso and micro levels were used to structure the analysis in this study and are considered useful in qualitative research (Creswell & Creswell, 2017; Jaspal, Carriere, & Moghaddam, 2015). While the focus of this study is on the micro (women's experiences, influenced by family and community), it is crucial to contextualize their experiences considering the interactions that shape those experiences on the meso (NHS), and macro (law, government, UK culture) levels (Rashid, Hodgson, & Luig, 2019). As relationships are at the centre of experiences, it is important to understand who women with FGM are in relationships with, and how this impacts their care experiences (Jerolmack & Khan, 2017). In this study the micro level constitutes the individual woman and potential influencing factors such as her family and community; the meso level represents the healthcare system; and the macro level focuses on structural aspects of society such as the law, government and dominant cultural norms (Caldwell & Mays, 2012). Caldwell and Mays (2012) published model has been applied in this study (Figure 2.1and Table 2.2).

Figure 2.1: The Macro, Meso and Micro levels of analysis (Source: Author, 2020; based on Caldwell & Mays, (2012))



An analysis of the cultural influences women with FGM may experience during healthcare interactions was conducted based on the knowledge gained from the background chapter, and shows multiple layers and systems are involved in how women's experiences are formed and impacted (Table 2.2) (Jaspal et al., 2015; Thurston & Vissandjée, 2005); and demonstrate the cultural lens used throughout this thesis An interaction of the multiple layers of culture present which influence how women with FGM experience maternity care and the PPP is sought including UK culture, NHS culture, women's assimilation with UK culture, and women's country of origin or ethnic culture. Women's individual culture influenced by both her ethnic culture and UK culture will shape her experiences of care within the culture of the NHS and the culture of the UK’s response to FGM. This study was designed to incorporate each level through Phases 1, 2 and 3 of the research design. This achieves the aims and objectives of the study and provides a culturally contextualised study, and therefore nuanced understanding of women’s experiences of care. This is typical of a focused ethnographic approach and increases the ability to apply findings and inform change (Rashid et al., 2019).

Table 2.2: Possible Cultural Influences on women’s perceptions of healthcare interactions (Source: Author, 2020; based on Caldwell & Mays, (2012))

Macro	UK societal norms concerning: • FGM • Child abuse • The law • The media • Ethics
Meso	The NHS: policy and practice regarding FGM • HCP: knowledge, perceptions of FGM and women with FGM
Micro	Woman and FGM: • Status • Support structures • Health knowledge • Personality • Attitudes towards healthcare • Socio-economic status • Level of segregation/assimilation • Years in country of origin • Years in UK Also influenced by: • Family: presence, education, health knowledge, SES, bond, importance of cultural traditions such as FGM • Community: presence, education, health knowledge, SES, bond, importance of cultural traditions such as FGM

Limitations of a focused ethnographic approach. Limitations of this method include queries at an ontological and epistemological level (Cruz & Higginbottom, 2013). Reservations about qualitative research in general, including issues such as lack of precision and definition, usefulness and scientific value due to lack of generalizability are also present and can be defended (Cruz & Higginbottom, 2013). Focused ethnographies are holistic in nature and seek to understand a specific issue from many different perspectives, including observations, interviews and documents (Cruz & Higginbottom, 2013). As an emerging method, focused ethnography is continuously developing (Higginbottom et al., 2013; Knoblauch, 2005) and its allure is the ability to adapt ethnographic research methods in order to answer a specific research question. The issue of generalizability in qualitative research is constantly presented (Carminati, 2018); however, qualitative research and subsequently focused ethnographies are not seeking to be able to apply their findings to the general population, but rather ‘zoom in’ on a specific issue, within a specific sub-culture and explore it (Cruz & Higginbottom, 2013).

2.1.2 Ethics, positionality, and reflexivity

As mentioned above, the unique and challenging ethical aspects of this study are detailed and discussed in Section 2.5 and 0. In this section positionality and reflexivity and their impact on the research are discussed.

Identifying and acknowledging one’s positionality is an essential component of ethnographic research. Positionality describes the perspective of the researcher that is shaped by their individual fusion of race, class, gender, nationality, sexuality and other identifiers (Mullings, 1999). Reflexivity refers to the researcher’s internalized beliefs (Higginbottom et al., 2013) and the critical analysis of how these beliefs shape who the researcher is and therefore the orientation of the research (Gobo, 2008). Taken together, reflexivity is the critical analysis and subsequent impacts of the researcher’s positionality. A researcher's positionality is multi-layered and transforms throughout the research project; a dynamic interaction between research participants and the researcher (Mullings, 1999). Bourke (2014) describes positionality and reflexivity as the critical reflection of the intersection of the collective identities of the researcher. The researcher becomes part of the research during a focused ethnography and must acknowledge and understand how this transforms not only the research, but themselves as a researcher.

When researching a culture different to one's own, it is important to reflect on one's own cultural identity. Researchers should label, reflect and discuss their power and privilege and engage with other backgrounds to increase knowledge and experience concerning different cultures (Esmiol et al., 2012). While accomplishing this and conducting the research, Esmiol et al. (2012) suggest developing a critical consciousness dialogue and interpersonal questioning; recording this through reflections. This was accomplished during this study through personal and research-focused reflections and discussions with research supervisors and peers.

Critical reflections of my positionality were conducted throughout the research project and included reflexive reflections of not only critical time points (design, ethics approval, data collection, data analysis); but also critical times during the research process where my positionality could influence the outcome of the research itself (recruitment and interviews). I am a white, middle-class female raised in Ireland and Canada. My parents are both alive and married and I have two sisters, one older and one younger. My professional background is in nursing within the publicly funded Canadian healthcare system. I have developed communication skills through training and practice and am confident addressing difficult, painful and uncomfortable topics. An internal conflict arose during my nursing practice as I could not balance the pragmatic, realist approach of the healthcare system, which due to limited resources results in focus on acute needs, with the holistic nursing approach to care which would ideally take all patient concerns into account. This prompted me to complete a master's degree in nursing where I developed my critical thinking skills and continued to develop my communication skills. I began this current project as an 'insider' (woman, migrant, in-depth knowledge of FGM) and an 'outsider' (have never experienced the PPP, have not experienced FGM, am not a member of a minority, and I migrated to a country with similar cultural norms). Throughout this project my desire has been to find how best to care for women holistically within a healthcare system using a biomedical model.

Throughout the research project my positionality was reflexively-reflected upon and detailed in critical reflections; through the implementation of ethical considerations (Section 2.5) and methodological rigour (Section 2.4), I do not believe my positionality had negative impacts on, or biased the findings of the study. My sincere interest and desire to improve care for women with FGM by listening to, and amplifying their voices, was the focus of every decision and interpretation made.

2.2 Summary

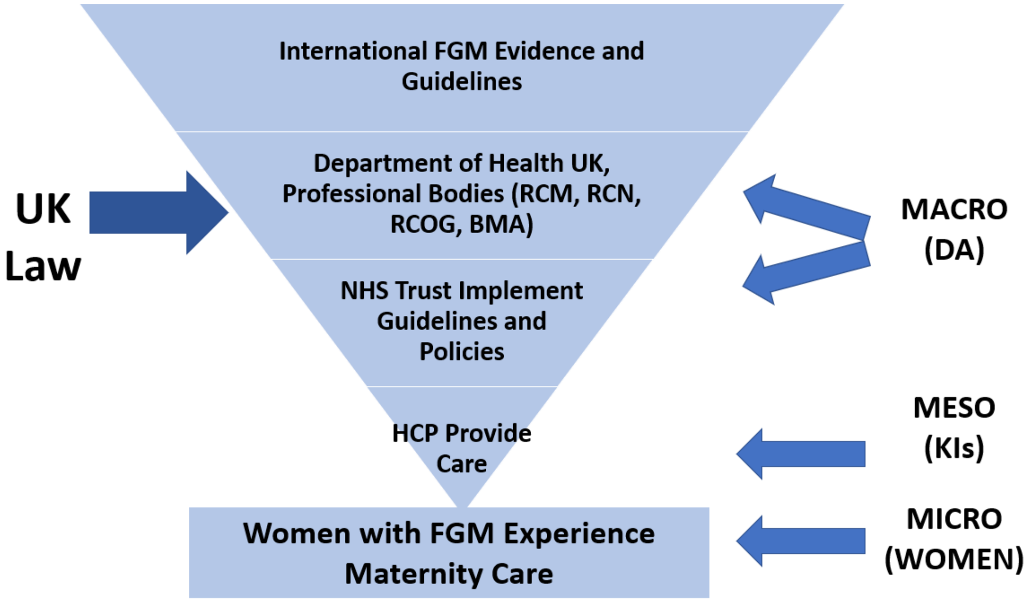
This section has described the application of the concepts of culture, positionality, and reflexivity in this focused ethnographic study. A focused ethnography was used in all aspects of the study design, data collection, analysis and reporting of the findings. Culture is considered a foundational aspect influencing women's postpartum care experiences and its influence can be seen on a macro, meso and micro level of analysis. A focused ethnographic approach is appropriate for this population and area of study as women with FGM who live in the UK have multiple cultures influencing their experiences, have been exposed to a cultural tradition not practiced in the culture they currently live in, live in the UK where FGM is illegal, have an alternative healthcare pathway compared to women without FGM, and can be viewed as a medical subculture within maternity services with unique needs. Using a focused ethnographic approach ensured a cultural context was used throughout the study, from the creation of the research question, choosing the methods and the cultural lens used during analysis. Focused ethnographies result in the cultural context of the phenomenon under study being weaved throughout.

2.3 The Three Phases

This research project was divided into three phases to achieve the aims and objectives and to explore the context in which women's experiences are situated. Common methods that were applied to multiple phases will be described first, with further details of each phase following. Each phase represents a layer of the current maternity model used by the NHS devised from the literature review (Chapter 1);

Phase One, the documentary analysis represents the macro level, Phase Two, interviews with Key Informants (KIs), the meso level, and Phase Three, interviews with women represent the micro level (Figure 2.2).

Figure 2.2: The three phases of research applied to the conceptualization of the top-down approach to healthcare within the NHS



2.3.1 Data collection

Interviews were used in Phase 2 and 3 of this study and as the development of the interview guides and the techniques for conducting the interviews were the same, they will be discussed together.

Interviews. Semi-structured, in-depth interviews were used in Phase 2, KIs, and Phase 3, women users of NHS maternity services who have experienced FGM, of this study and is typical for focused ethnography studies (Cruz & Higginbottom, 2013). Recorded interviews allowed for intense data collection and analysis to occur that mitigated the need for extended field visits (Cruz & Higginbottom, 2013; Knoblauch, 2005).

Interview guides. Interview guides were created from an in-depth review of the literature and discussions with members of the research team, and the FGM midwife was consulted regarding the Women interview guide Interview questions were specifically created to be open-ended and broad, allowing the participant to describe what aspects of their experience was important to them (Higginbottom et al., 2013). KIs were asked about their experiences working with women with FGM, their thoughts on the current care provided and any needs they believe women with FGM might have (see Appendix 0 for KIs interview guide). Women were asked to describe their postpartum experiences and any needs they had during this time (Appendix 0). Although questions were divided into four sections; it should be noted that after a general introduction, women were given the opportunity to tell their story and discuss what was important to them. This was achieved through an open-ended question asking women to describe their most recent birth experience. From this description, where applicable, follow-up semi-structured questions concerning medical experiences, role of partner (if applicable), and role of FGM in birth process experiences were asked. Questions were followed up with specific probes to gain an in-depth description of postpartum experiences for women with FGM. This process allowed women's voices to be heard and allowed women to direct the conversation and discuss what was important to them.

Although interviews were not officially piloted, confidence in them is high due to input by the research team, the consultation of the lead FGM midwife from the Coventry and Warwickshire NHS Trust clinic. Once interviews were commenced there was the option to refine and steer the approach as the interviews were semi-structured in approach. However, interviews flowed well with no misunderstanding or awkwardness was detected by the interviewer. The interviewer, while not having direct research interviewing experience, has interviewing experience from her role as nurse and is skilled in discussing sensitive healthcare topics.

Safety protocols were created for both KI and women interviews, and can be found in Appendix 0. The safety protocols ensured a plan was in place for adverse scenarios, such as resources to aid in any negative feelings caused by the interview, or a protocol to enact should a woman disclose the intent to have FGM conducted on any daughters. Please see Section 2.5 for more details on how an ethically sound and safe study was a top priority.

Probes. According to Gobo (2008), there are verbal, non-verbal and para-verbal probes. Verbal probes have five functions; encouraging the participant to talk, breaking down defences, increasing clarity, checking the researcher has understood the response correctly, and acquiring elaboration on stereotypical answers (Gobo, 2008). Verbal probes took many forms during interviews including: reforming the question, commenting on the participant’s response, repetition of responses, summaries of responses, requesting clarification, and deliberately misunderstanding the participants to cause them to confirm or revise their statement (Gobo, 2008). Non-verbal and para-verbal probes were used as appropriate including nods and smiles, and interjections such as ‘uh huh’, ‘mmm’ and ‘ah’ to illicit depth from interviews and obtain rich data (Gobo, 2008).

Field notes. Field notes were used for the duration of data collection and analysis. Field notes are a specific technique used in ethnographic research to enhance validity and were written by the researcher for self-utilization at a later date (Montgomery & Bailey, 2007). Field notes were divided into a field journal containing observations, analytic notes and personal notes on the research process, and a personal journal containing the researcher’s reactions to the data collected. Hammersley and

Atkinson (2007) note the importance of keeping field notes as ideas useful in analysis could occur during the creation of them, as well as developing the researchers internal dialogue; a key component of reflexive ethnography. The authors also note it is important to distinguish analytic notes from the researcher's observations and descriptions (Hammersley & Atkinson, 2007). This was accomplished by dividing the field journal into two sections: observations and analytic. The creation of field notes and the reflection it involves was essential in guiding the researcher through the data collection process, highlighting areas for further inquiry and conducting reflexive research (Hammersley & Atkinson, 2007). The creation of analytic notes were beneficial in initiating and maintaining productivity throughout the research process (Birks, Chapman, & Francis, 2008). Montgomery and Bailey (2007) recommend four questions to contemplate when making memos; what is happening within these lines of data? What underpins the action/event/statement? How does this code label relate to an earlier one? And how does this memo compare to that memo? These questions were considered when writing field notes throughout data collection and analysis, with the fourth question being especially relevant when analysing and triangulating between data sources. A title reflecting the content of the field note and the date were noted (e.g. 'First visit to FGM clinic' 9/9/2016) (Birks et al., 2008). The continuous creation of field notes also provides a record of thought on theory and methodology, and provides a record of decisions made throughout the research process (Glaser, 1998); which allowed the researcher to engage with the data at a higher level, and with a heightened sensitivity to the meanings hidden in the raw data (Birks et al., 2008).

The personal journal included the researcher's personal reactions to the research process (Hammersley & Atkinson, 2007). Feelings colour our social interactions and as such it is essential the researcher comprehends the impact their personal feelings have on the research (Hammersley & Atkinson, 2007). Feelings such as personal comfort, surprise, anxiety and disgust are of analytic import and were noted and reflected upon (Hammersley & Atkinson, 2007). The choice of what is note-worthy, deviant, and uninteresting was dictated by the researcher and displays the influence the researcher can have on data collection and analysis (Hammersley & Atkinson, 2007). This aspect of the research process underscores the importance of reflexivity in ethnography (Polit & Beck, 2008; Roper & Shapira, 2000). After each interview, a field note and reflective note were created, shared, and discussed with the research team. At the beginning of data collection, a detailed reflective note was written by the researcher containing their views on the literature related to FGM and their views on the practice of FGM. This was explored reflexively with the supervisory team to ensure data collection and analysis were not unduly influenced by the researcher's personal views and integrity was maintained. The field journals also created a component of the audit trail of the research, enhancing rigour (Montgomery & Bailey, 2007). An example of each type of note made, observation, analytic, personal research and personal feelings, can be found in Appendix 0.

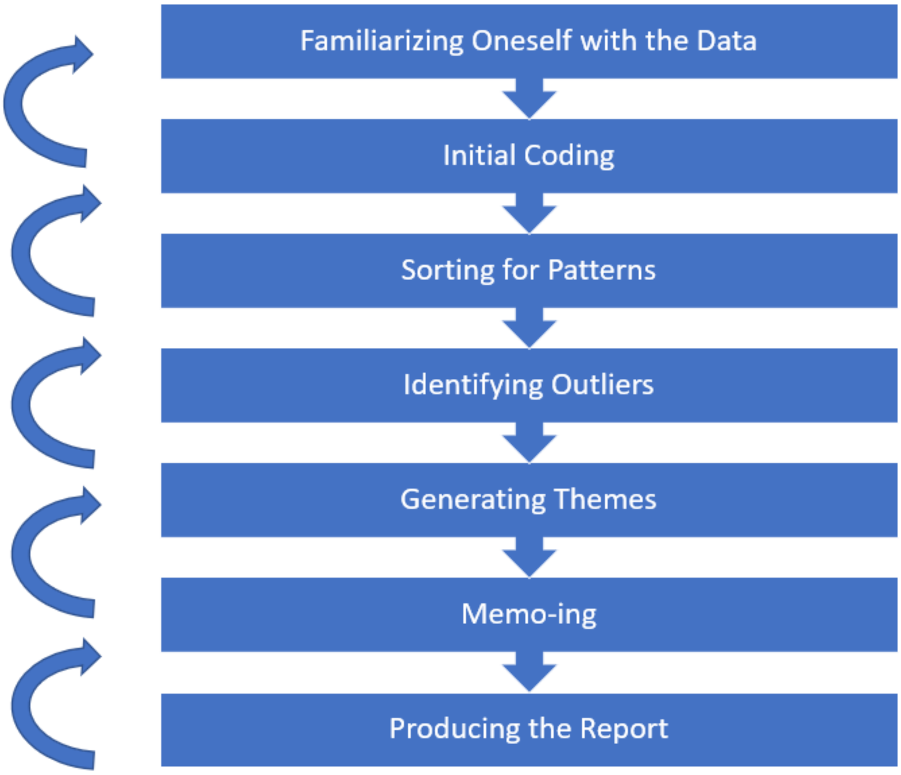
Data collection for key informants and women included the development of interview guides and field notes, and the use of probes. The next section looks at data analysis techniques.

2.3.2 Data Analysis

Analysis for the Documentary Analysis was completed in Microsoft Excel (Microsoft, 2004), with interviews being analysed using NVIVO 11 (QSR International, 2020). Data analysis in focused ethnographies is an iterative, systematic and reflective process (Higginbottom et al., 2013; Roper & Shapira, 2000) and the same approach was used for thematic analysis during phases 1, 2 and 3 of this study. As focused ethnographies are problem-oriented (Higginbottom et al., 2013); the desired findings lead to concrete recommendations for change in practice or the development of guidelines (Cruz & Higginbottom, 2013; Knoblauch, 2005).

The data analysis steps for ethnography produced by Roper and Shapira (2000) were combined with the thematic analysis steps outlined by Braun and Clarke (2006) to analyse data in this study during all phases of the research. These methods were combined for this study as a focus on ethnographic methods was sought, as well as the development of themes as a desired outcome from the data (Figure 2.3).

Figure 2.3: Data Analysis Process created from Braun and Clarke (2006), and Roper and Shapira (2000)



Authors from both methods agree analysis is a rigorous process, needing dedicated time and energy (Braun & Clarke, 2006; Roper & Shapira, 2000). Data analysis began by transcribing the data. During transcription, and subsequent checking and reading documents and interviews completely through twice, a sense of the whole was achieved, and initial thoughts and ideas were generated (Braun & Clarke, 2006). During Phase 2 and 3, which included interviews, transcriptions were completed by the researcher and initial thoughts were recorded through field-notes. Open-coding, where no certain answer is sought, followed the screening of documents in the documentary analysis and transcription of interviews and began once a sense of the whole document or interview was achieved. As documents or interviews were read, passages relating to the research aims and objectives were highlighted and ‘coded’ by assigning a descriptive label to them and to distinguish emerging concepts and patterns (Roper & Shapira, 2000). Each document and interview were read twice during coding to ensure no data was missed. Codes allow the data to be separated into smaller, manageable chunks, which are subsequently grouped in the following step.

Sorting for patterns and searching for themes reflects the same process as initial coding. Codes were grouped into categories based on a common phrase, pattern, event or process (Roper & Shapira, 2000). Memos and reflective notes were created to begin to explain emerging patterns and ideas (Roper & Shapira, 2000). Codes were grouped into categories of patterns before generation of themes completed analysis; and demonstrates the continued development of concepts from detailed codes to abstract themes (Braun & Clarke, 2006).

During abstraction and development of themes, meanings were sought, and theoretical understandings were constructed (Roper & Shapira, 2000). Themes were also viewed in relation to codes, categories and the entire data set to ensure the themes came from the data (Braun & Clarke, 2006); following an interpretivist focused ethnographic approach. Memo-ing and maintaining reflexive practice throughout was essential for the production of rigorous research, and was maintained throughout this research project through the creation of memos and recording ideas through a research journal (Braun & Clarke, 2006; Roper & Shapira, 2000).

2.3.3 Phase 1; Documentary Analysis (DA)

A documentary analysis was conducted to achieve objective 1; to identify and thematically analyse current international and national guidelines on FGM during the PPP, and to provide an understanding of the policies and guidelines impacting the postpartum care experiences of women with FGM. Documentary analyses are a data collection method used in ethnographies (Gobo, 2008), and allow the researcher to understand a wider perspective regarding the culture under study (Spradley, 1980). Documentary analyses are often used in conjunction with healthcare-based ethnography to provide contextual understanding (e.g: Agom, Poole, Allen, Onyeka, & Ominyi, 2019; Armstrong, Herbert, & Brewster, 2016). Understanding the healthcare and governmental guidelines and NHS policies provides insight into the healthcare culture associated with FGM, and illustrates the perspective of the dominant culture, who provides healthcare, towards a phenomenon only seen in practicing minority cultures. In order to fully comprehend the postpartum experience and needs of women with FGM, it is essential to understand the healthcare system they interact with; and analysis of guidelines and policy documents provides the perspective of the healthcare system. Acquired documents included clinical guidelines and international and national government policies and statements (Spradley, 1980; Wall, 2015).

Search Strategy. To identify European countries with laws against FGM, the EIGE website was searched for a list of countries with laws against FGM in Europe. The government websites of Australia, New Zealand, the USA and Canada were also included as these countries have comparable migration populations from FGM practicing countries as the UK.

Government websites of countries who had laws against FGM, comparable migration patterns and comparable healthcare systems were searched using the terms; female genital mutilation, female genital circumcision, female circumcision, FGM, FGC, FGM/C, mat* health, wom* health, birth, and preg*. Google Translate was used to translate the search terms into the countries' official languages. Health departments and health ministry websites within governing bodies were also searched. If no information on FGM could be found, contact was attempted through the websites contact feature to receive the information. If no response was received within two weeks, professional bodies for physicians, nurses and midwives were searched using the same search terms and contacted if no documents could be found. If no response was received within two weeks the country received a 'NO' to the question of 'Official publications by Government bodies or healthcare governing bodies'. If English translations were not available on the website, an email was sent to the contact person listed in an attempt to receive one. If no response was received within two weeks the country received a 'NO' for the question 'English (translation) available?'. If government websites referred the reader to another website or document, such as the WHO, this was noted and the referred document was included for screening.

Screening Procedure. Table 2.3show the inclusion and exclusion criteria and specific screening questions used on documents for analysis. The purpose of the DA was to not only understand what guidelines and policies were guiding FGM care, but to compare and contrast the UK guidance with comparable migration countries. Specific screening questions were developed from a review of the literature and to achieve research aims.

Screening Part 1: Application of inclusion and exclusion criteria.

Table 2.3: Screening Procedure for Documentary Analysis	
1) General Screening using inclusion and exclusion criteria	
Inclusion Criteria:	Exclusion Criteria:
a) Countries where FGM is illegal (compare with UK, likely to have healthcare guidance in place) b) Countries with comparable migration patterns from FGM practicing nations as the UK (to compare to UK) c) Nations with comparable healthcare services (compare to UK)	a) Not a migration destination country (unable to compare to UK) b) Countries where FGM is legal (unable to compare to UK) c) Nations using a non-Western medical system (unable to compare to UK)

Screening Part 2:

Countries that passed the inclusion criteria were then searched for documents.

Part two screening questions were then applied:

A. Official publications by Government bodies or healthcare governing bodies
B. English or English translation available (No funding available for translation services for documents not in English)
C. Focused on women and not child prevention/care

Screening Part 3:

Documents that passed screening part 2 were subsequently assessed to determine if they contained information about healthcare and FGM, and pregnancy, childbirth and FGM using the following questions:

a. Does the document contain information on FGM and healthcare?
b. Does the document contain information on FGM and antenatal care, pregnancy, labour and delivery, postpartum care? Or anything associated with pregnancy and childbirth?

Documents that passed screening part 3 were content and thematically analysed using the following questions as a guide:

- Mention of maternal services?
- Mention of perineal care?
- Mention of antenatal, birth, post-partum care?
- Discussion of needs specific to FGM?
- Discussion of education for healthcare professionals?
- Mention of resources for women with FGM
- Source material

Data Analysis. Data analysis for the documentary analysis included both content and thematic analysis (Section 2.3.2). Although all documents collected included information about FGM, specific information was sought, and content analysis was used to identify whether that specific information was contained in the document. Once documents passed the inclusion/exclusion criteria, they were screened using the specific questions created. Table 3.1, Table 3.2, and Table 3.3 in Chapter 3 display the results of the screening process. Thematic analysis was then used to identify themes in documents that passed screening level two. Thematic analysis was conducted in Microsoft Excel (Microsoft, 2004) and followed the procedure outlined in Section 2.3.2, Data analysis continued until data saturation was reached and no new themes or outliers were emerging.

2.3.4 Phase 2; Key Informants (KIs)

KIs represent the meso level of this study and were sought to provide insight into care provision in the NHS.

Setting. All KIs worked in the West Midlands or London regions of the UK. Both areas have high numbers of women with FGM.

Sample. Purposive and snowball sampling were used in this study because specific in-depth knowledge of an issue was sought, with data collection continuing until saturation was achieved (Cruz & Higginbottom, 2013). KIs were recruited for their insight into the research question and to fulfil Objective 3; to examine and thematically analyse the role and views of key informants who influence the care received by women with FGM using NHS services. KIs included specialist FGM midwives, obstetricians, gynaecologists, clinic managers, nurse home visitors, midwives, and community outreach coordinators (Table 3.4). These groups were chosen due to their experience caring for women with FGM in the PPP and to provide context in the healthcare setting.

Data Collection. Phone interviews occurred with all KIs who participated. Face-to-face interviews were presented as an option, however all KIs preferred phone interviews. Interviews began with the researcher reading the information sheet and informed consent forms, receiving informed consent and starting the recording. All interviews were audio recorded and lasted between 30 and 120 minutes. KIs were approached 6-8 weeks before interviews to ensure enough time was given to the decision to participate, as well as complete internal ethics forms. KIs were advised of the interview schedule and asked to complete the demographics and consent forms. At the end of each interview KIs were given the opportunity to ask any questions; and were given the researchers contact information in case any questions materialised after the interview. While focus groups were considered, the practicality of arranging them proved too difficult and could not be accomplished. Future studies could attempt focus groups to concentrate on certain aspects of the findings; however, as this was an exploratory study, individual interviews were preferred to allow KIs to discuss what was important to them.

Data Protection. Data protection procedures were the same for KI and Women. A list containing names, method of contact, and participant identification numbers linking to interview transcripts and demographics forms was stored on a password protected computer at Coventry University. This list was only accessible by the lead researcher and was created in case a participant wished to withdraw from the study. Once the data had been anonymized, participants were no longer able to withdraw from the study and the form was destroyed. Consent forms were stored in a locked locker on a card-access only floor at Coventry University with only the lead researcher having a key. No identifying characteristics of participants are reported during the study or in the dissemination of the work to ensure confidentiality and privacy of the research participants.

Recruitment. Convenience and snowball sampling were used to access KIs. The FGM steering group, based in Coventry and including HCPs, city council representatives, clinical commissioning groups (CCGs) and researchers was contacted through email. All listed specialized FGM clinics in the UK were contacted and invited to participate by phone and email, as well as charities, community groups and support groups Potential participants were sent up to three emails inviting them to participate. At the end of each interview, KIs were asked if they knew anyone who would be interested in participating, with five sending contact information for others.

Data Analysis. Interviews were transcribed verbatim by the researcher. After transcription was complete, interviews were printed and reviewed with the recording for any inconsistencies. Notations concerning expressions or pauses were added from interview notes. Clarifications were also added where needed.

KIs interviews followed the thematic analysis steps outlined above (Section 2.3.4). Interviews were read completely several times to get a sense of the whole before coding began. KIs were initially divided into three groups for analysis: policy KIs, direct care KIs and police. Once themes were identified in each group, it became evident similar themes appeared in each group. All three groups were then analysed together to understand any similarities and differences among them. As the aim of collecting data from KIs was to understand the context of the healthcare system that women with FGM engage in, it was decided to analyse all groups together. Though differences between groups could be seen depending on whether they interacted with women, and when that interaction occurred; antenatal, labour and birth, or post-partum. The overall culture and approach of the NHS and police were sought, and therefore all groups were analysed together as the focus of analysis was to understand the overall context. Data analysis was concluded when data saturation was reached, measured by no new themes or outliers arising from the analysis.

2.3.5 Phase 3; The post-partum care experiences of women with FGM

Women with FGM were interviewed concerning their postpartum experiences and needs, in order to achieve objective 3 of this study; to critically evaluate the postpartum needs and explore the experiences of women who have FGM using focused ethnography.

Setting. The setting for this study was Coventry, West Midlands, UK. Coventry is a city with the third highest prevalence of women with FGM in the UK after London and Birmingham (Macfarlane & Dorkenoo, 2015). Coventry was chosen as it was able to provide a rich population to sample, and it was believed women in Coventry would not have been included in research as often as FGM populations in Birmingham and London. Women attending the specialized FGM clinic varied in their type of FGM and country of origin. As the purpose of the research was to enhance understanding to improve care for all women with FGM in the UK, a rich and diverse sample was specifically sought, with diverse cultural backgrounds and differing types of FGM seen as enhancing the applicability of study findings.

The FGM clinic is located at University Hospital Coventry and Warwickshire NHS Trust (UHCW). It is led by a trained midwife with support from obstetrics and gynaecology. The clinic is an antenatal clinic for women with FGM, with the goal of ensuring a safe and healthy pregnancy and birth for mother and child. As per guidelines, de-infibulation is offered at 20 weeks gestation. Birth plans are created to ensure the best outcomes for mother and baby, with safeguarding and mandatory reporting also occurring.

Sample. Due to the desire to collect in-depth descriptions of a rare and understudied population, purposive sampling took place. Purposive sampling is common in qualitative research methods as researchers seek those who can answer the research question with depth and lived experience (Hammersley & Atkinson, 2007). Women attending the FGM clinic in Coventry provided an information rich population and were used at the first stage of sampling. Further sampling was attempted using snowball sampling; however, no women were recruited using this method.

Women with any type of FGM as defined by the WHO (Chapter 1) between the ages of 18 and 45 years were invited to participate in the study. Participants must have given birth in the UK, using UK NHS maternity services in the previous 18 months, and speak English. Only English speakers were invited due to ethical concerns by the ethical review board (see Chapter 2). While the researcher felt strongly about inclusivity and did not want to deny any women participating who wished to do so, the ethical review board’s request was accepted as it was believed this would not overly negatively impact women who wanted to participate, or the overall study findings. Participants were excluded if they lacked capacity to give consent, did not speak English, or did not use UK maternity services during their recent birth.

Recruitment. Recruitment took place weekly at the specialized FGM clinic in Coventry over a 12-month period (Figure 2.4) Approximately three women were scheduled per week (range two-four). Twelve months allowed for systematic recruitment of women who visited the clinic and permitted the highest level of fairness in opportunity for recruitment possible based on the inclusion restrictions and targeted sampling location. This method of recruitment also provided interesting observations on the use of the clinic, how many women were unable to participate due to language restrictions, and how many were lost to follow-up. Over the 12-month period, 18 women were recruited. Upon being contacted for an interview, nine women consented and participated.

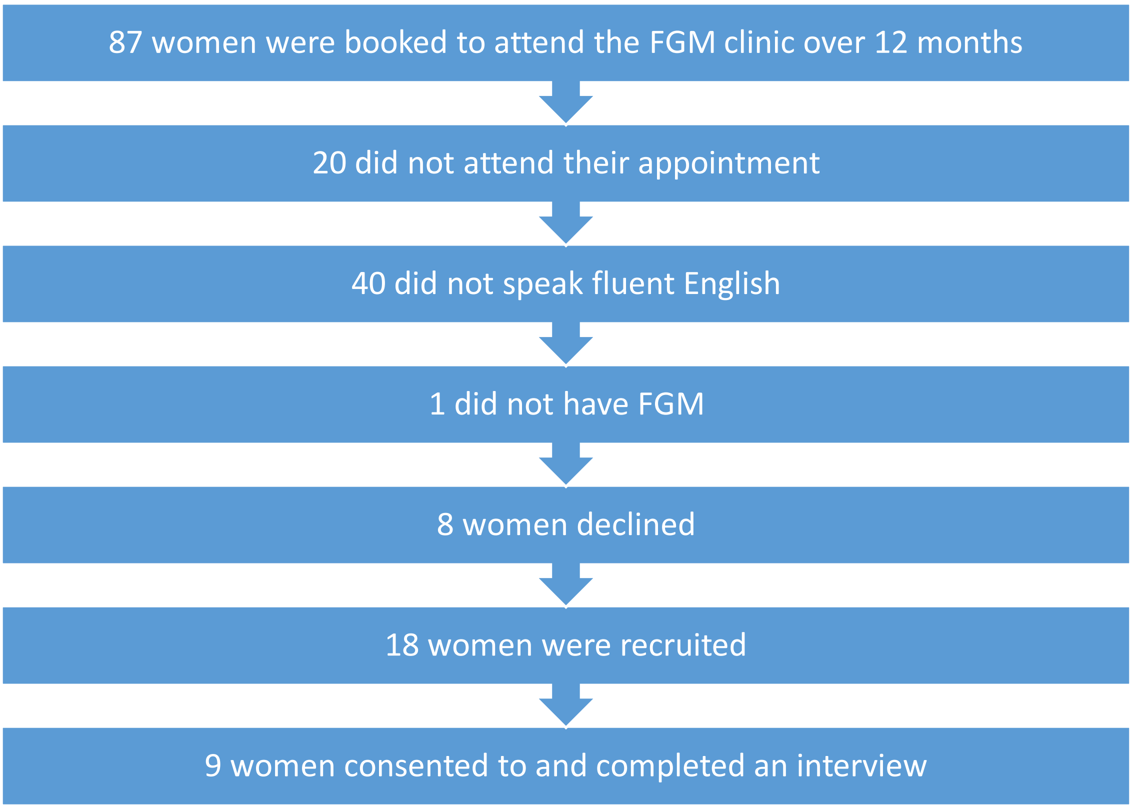


Figure 2.4: Women’s Recruitment Flowchart (Source: Author, 2019)

Two methods were used in the recruitment of participants. The lead midwife in the FGM clinic approached potential participants at the end of appointments and asked if they would like to hear about a study being conducted. If the woman agreed, she met with the researcher who gave a brief description of the study and asked for consent to call them for an interview. Women who agreed gave their name and preferred contact information. Women who did not want to meet the researcher were given a participant information sheet with the researchers contact information to look at in their own time. Secondly, participants were asked during interviews whether they knew anyone who could provide information about their post-partum experiences in the UK and may be willing to participate in the study. If so, participants were asked to give the researcher's contact information to the potential participant in order for them to call to receive more information. However, no women were recruited using snowball sampling. Although the term 'female genital mutilation' is used by the UK government and WHO, the term 'female genital circumcision (FGC)' was used in all the forms the participants would see, such as the participant information sheet and informed consent form. This was decided after consulting the literature and several FGM midwives who reported the majority of women use the word circumcision. FGM is a sensitive topic for some, and the terminology used by participants must be taken into consideration (Blee & Currier, 2011).

Data collection. Interviews were conducted with consenting women after their PPP had concluded and resulting in a minimum of 12-weeks between recruitment and data collection. Women agreed to take part in an interview via a phone call with the researcher. Although interviews were offered in person in a mutually agreed location, all but one woman requested phone interviews. Reasons given for this were transport and time restraints. Before interviews began, it was ensured the woman was comfortable discussing the topic in their homes and privacy could be maintained. Interviews, both in-person and by phone, began with an informal welcome and introduction of the researcher and woman, including the guarantee of anonymity within the research process. The woman was advised of the schedule of the interview, including the explanation of the study, demographic and consent forms, the interview itself and the conclusion (Appendix 0). If women agreed to continue, the audio recorder was started and the study information sheet, demographic and consent forms were presented and completed. Before the recording started, the in-person interview woman was taught how to press stop and play on the device in the event they wanted to stop the interview, or not answer one of the questions. Phone interviewees were informed they could stop the interview at any time or choose not to answer specific questions. The semi-structured interview then began with questions and probes. Each interview lasted approximately 60-90 minutes. At the end of each interview women were given the opportunity to ask any questions they might have. Women were also reminded of their right to privacy and confidentiality and were presented with the researcher’s contact information in the event further questions arose after the interview, or they decided to withdraw from the research.

Data Protection. Please see Section 2.3.4.

Data Analysis. Interviews were transcribed verbatim. After transcription was complete, interviews were printed and reviewed with the recording for any inconsistencies. Notations concerning expressions or pauses were added from interview notes. Clarifications were also added where needed. Interviews continued until saturation, or no new information, was forthcoming (Polit & Beck, 2008). This decision was reached after careful reflection of field notes, personal reflections, and analysis of data. Thematic data analysis was used following the steps outlined by Roper and Shapira (2000) and Braun and Clarke (2006) (Figure 2.3). Thematic analysis was the most suitable method to use as in-depth meaning of women's experiences was sought.

2.4 Rigour

Focused ethnographies maintain rigour using specific qualitative research methods such as those outlined by Lincoln and Guba (1985); with matters such as trustworthiness, credibility, transferability, dependability and confirmability being addressed by employing methods such as a precise methodological framework, triangulation of data sources, and providing a thick description of the population, context and environment (Higginbottom et al., 2013). This study ensured rigour throughout and the techniques used will now be discussed.

Table 2.4: Application of Rigour (Lincoln & Guba, 1985)

Trustworthiness	• Creation of an audit trail
Credibility	• Debriefing with supervisory team and peers • Achieving saturation • Triangulation of data sources
Transferability	• Thick description of the research process including setting, sample and the methodological processes followed
Dependability	• Audit trail • Reflexive field notes • Debriefing • Thick description of the population and methods • Triangulation of data sources • Transparency of research methods
Confirmability	• Audit trail

	- Reflexive field notes - Triangulation of data sources - Achieving trustworthiness, credibility, transferability, and dependability

Rigour was heightened in this study by ensuring trustworthiness, credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985) (Table 2.4). Trustworthiness describes the degree of confidence the reader has in the findings and the value they ascribe them (Lincoln & Guba, 1985) and was achieved in this study by the creation of an audit trail. The audit trail includes all field notes and produces a record of all steps and decisions made throughout the research process. This complete record allows the reader to view and understand what and when decisions were made, enhancing their trust in the methodological rigour of the study, and therefore, the validity of the findings.

Credibility is concerned with whether or not the study findings are plausible (Lincoln & Guba, 1985). The use of quotes from raw data as evidence for findings strengthens the credibility of this study by demonstrating where the findings came from (Graneheim & Lundman, 2004; Lincoln & Guba, 1985). Credibility was also enhanced through debriefing with peers and the supervisory team, which allowed new ideas to be explored, and promoted new insights into the research process (Guba, 1981). Debriefing occurred each week and as necessary to discuss concerns or challenges faced by the researcher, such as women reporting health concerns during interviews and one failing to seek care due to their traumatic birth experience. In this case confidentiality was breached with consent from the woman and the FGM clinic midwife was informed to ensure care for the participant was provided. Saturation was achieved during this study and promotes credibility by demonstrating data continued to be collected until no new information emerged from women and KIs. Saturation gives the reader confidence in the plausibility of the findings. Triangulation was used to verify findings between sources of data during the study. Through analysis and comparison between and among interviews with women, KIs and documents; findings were compared and contrasted to ensure credibility.

Transferability refers to the provision of sufficient contextual information to permit readers to evaluate whether the information is suitable and applies to their populations (Lincoln & Guba, 1985). This has been achieved through a thick description of the research process including setting, sample and the methodological processes followed.

Dependability discusses the consistency of findings (Guba, 1981), and relates to the question that if another researcher repeated the study using exactly the same methods, would their results be the same? Qualitative research involves both the participant and the researcher interacting together, with the researcher influencing the research process, however, to ensure rigour in qualitative research the impact of the researcher must be acknowledged and considered. Methods to ensure undue bias from the researcher did not impact findings are necessary and have been employed throughout this study through the use of an audit trail containing reflexive field notes, debriefing and thick description of the population and methods, and triangulation of data sources. During the coding process, Krefting (1991) describes how removing ones-self from the data for two weeks before recoding the same data can aid the researcher in determining whether findings are dependable as well as increasing rigour by completing intra-coder reliability, which was completed for all phases. A continuous, open-ended dialogue between the research team ensured findings were accurate (Lincoln & Guba, 1985). Transparency of research methods and process has been achieved and dependability has been accomplished in this study.

Confirmability addresses whether the findings and recommendations of the study are supported by the research process and data (Guba, 1981). When credibility, transferability and dependability are achieved, the study findings can be confirmed (Guba, 1981). The audit trail created for this study represents a record of the data, reflexive field notes, research decisions and thinking behind them, and serves to enhance the confirmability of the study findings (Guba, 1981). Triangulation of data sources also enriches study findings and recommendations.

2.5 Ethical Considerations

Qualitative research ethics are subtle and different to quantitative research ethics. Qualitative research often has an emergent and iterative design, and thus can have unpredictable outcomes (Orb, Eisenhauer, & Wynaden, 2001). The combination of culture and healthcare in this study raises unique ethical concerns and crosses the border between bioethics and sociology. The issue of vulnerability was explored fully throughout the ethics process and a detailed examination can be found in Appendix C. Following this it was assumed that vulnerability based on pregnancy or FGM status could be influenced by many additional individual factors and should be assessed at the informed consent stage. All pregnant women were considered potentially vulnerable in the immediate PPP due to the incidence of emotional and mental health issues in this period and the researcher was prepared to signpost women to resources if any concerns arose.

Recruitment outside of the NHS was a possibility and considered. Potential benefits to recruitment outside the NHS was to avoid the potential lengthy delay and additional procedures with NHS ethics due to time constraints, to potentially engage a wider group of women who did not use the Coventry FGM clinic; and to engage women who did not speak fluent English. Barriers to recruitment outside of the NHS included those focused on ethics, such as how to maintain confidentiality, safeguarding and access to medical support if needed. After deliberating, it was believed the best way to ensure women were protected throughout the study was to use the FGM clinic where safeguarding and specialist medical support was available. Using the clinic also ensured confidentiality. Due to this reasoning, the research protocol was altered to reflect the RECs recommendations, in particular recruiting only women who could speak English (for a detailed account of the NHS REC process see 0). I believe this hindered recruitment by not allowing translators to be used, as well as possibly skewing results to include a more settled, possibly more educated sample of women to participate. A detailed discussion regarding ethics is in Chapter 6.

2.6 Conclusion

This chapter described the methodology and described the specific methods applied in Phases 1 (DA), 2 (KIs) and 3 (Women) to achieve the aims and objectives of the research study. A focused ethnography was used to achieve a culturally focused understanding of the postpartum needs and experiences of women with FGM. Contextual understanding was sought and gained from completing a documentary analysis and interviews with KIs. Due to the unique nature of FGM and the layered ethical considerations involved, special consideration was given to the concept of vulnerability and how it applies in this study. The following chapters go on to discuss the findings of this study.

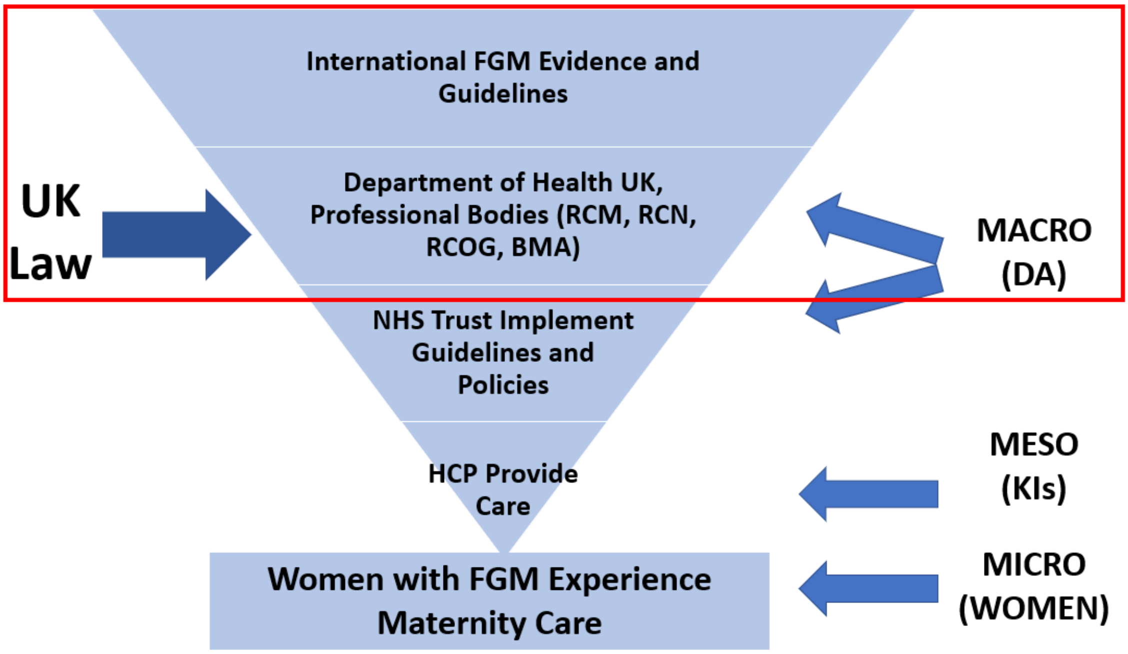
Chapter 3 A Documentary Analysis of International and UK National Guidelines Regarding Care of Women with FGM during Pregnancy, Labour and Birth, and the Postpartum Period

International recognition and activism regarding FGM began around 1976, with the signing of the International Covenant on Economic, Social, and Cultural Rights requiring countries to uphold standards of physical and mental health. In 1979, the ‘Convention on the Elimination of all forms of Discrimination Against Women’ (CEDAW), which became known as the Charter for Women’s Human Rights, was released (CEDAW, 2006). In 1990, the UN Committee on the elimination of violence against women classified FGM as a form of violence against women and made recommendations to member states for its elimination (United Nations Human Rights, 2014). In 1991, the UN changed the term ‘female genital cutting’ to ‘female genital mutilation’ upon recommendation of the WHO as using the medical term mutilation to highlight the removal of healthy tissue and has now been widely accepted in the Western world and Africa (Andro & Lesclingand, 2016; Gruenbaum, 2001). UNICEF, UNCHR, the World Medical Association, the WHO, the Organization of African Unity, the African Charter of Human Rights, the EU and the UK government have all stated their opposition to the practice with many countries, including the UK, creating laws banning the practice of FGM and creating healthcare policies to prevent the practice and provide care to women with FGM (OHCHR et al., 2008).

To understand the context of FGM in the UK, and the care provided to women with FGM; an assessment of the contents of policies and care guidelines is warranted. As the WHO is the leading health authority on FGM and is the basis of UK guidelines; WHO (e.g. Guidelines on the management of health complications from female genital mutilation

(WHO, 2016)) and international guidelines from comparable countries (e.g. Australia, Canada, Norway) were compared and contrasted with UK guidelines. This chapter accomplishes research objective 1; to identify and critically analyse current international and national guidelines on FGM and postpartum care; and focuses on the top two sections of the conceptual model presented in Chapter 1, as presented in Figure 3.1.

Figure 3.1: Conceptual Model Focus of Chapter 3 (Source: Author 2020)



3.1 Methods

A detailed description of the methods can be found in Section 2.3**.** Briefly, a three-part screening procedure was conducted on documents (Table 3.1, Table 3.2, and Table 3.3). Screening part one and two was composed of assessing inclusion and exclusion criteria, while screening level three assessed the content of the documents. Documents that passed screening part three were thematically analysed using a combination of Roper and Shapira (2000) and Braun and Clarke (2006) and compared to WHO publications regarding FGM.

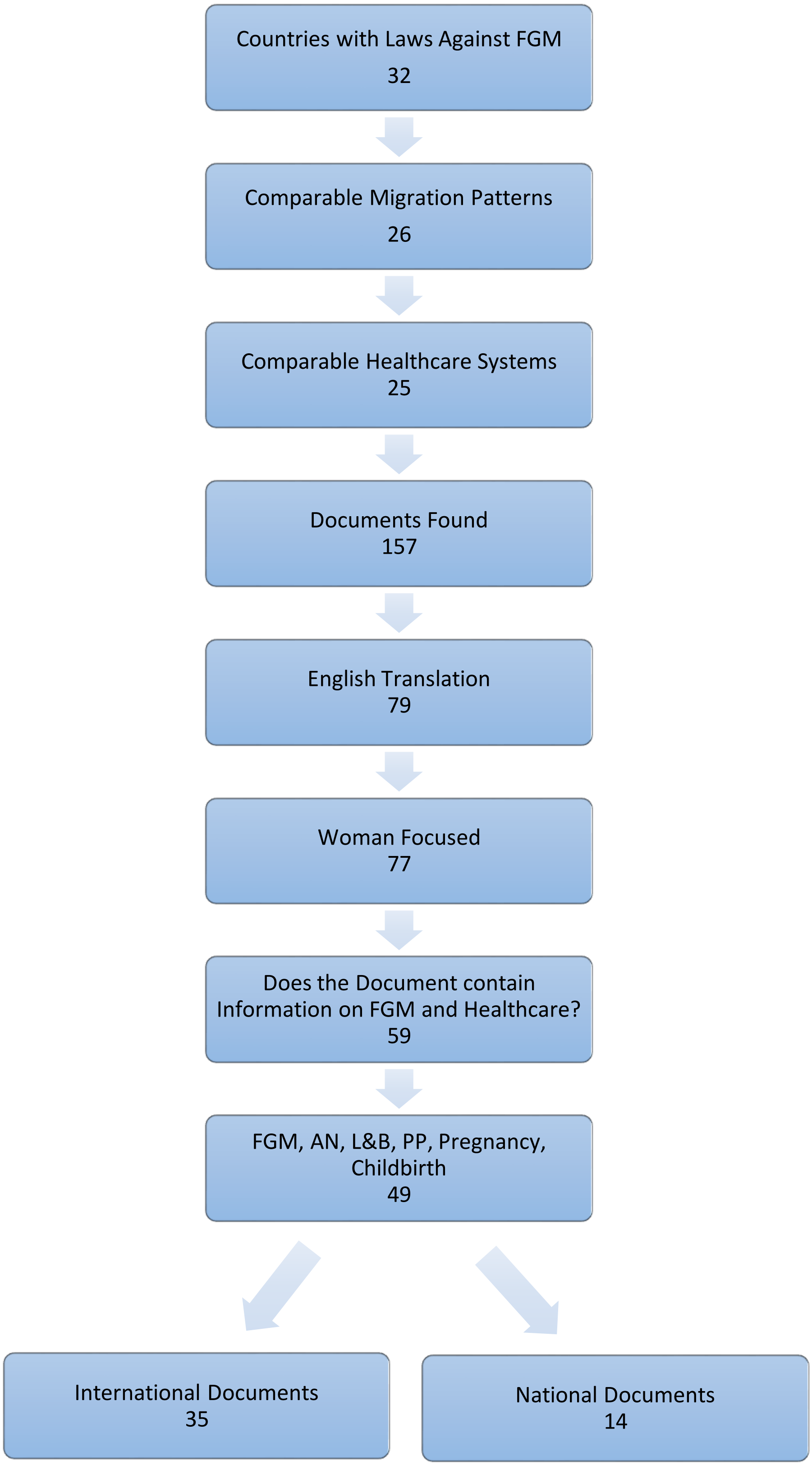
3.2 Results

The following section displays the results of the document screening procedure.

3.2.1 Screening Part 1, 2 and 3

Table 3.1 and Table 3.2, and Figure 3.2 and Figure 3.4 show the results after application of the inclusion and exclusion criteria on retrieved documents. Thirty-one countries, excluding the UK, were found to have laws against FGM. Twenty-five had comparable migration patterns, and 24 had comparable healthcare systems. From the 26 countries searched, 157 documents were retrieved from government and healthcare profession websites. Seventy-nine had English translations available, and 77 were focused on women rather than children. The 3rd level of screening included a content analysis (Section 2.3.3) resulted in 59 documents being found to include information on healthcare and FGM, with 49 (35 international and 14 UK) documents moving onto analysis and containing information about pregnancy, the antenatal period, labour and birth, the PPP or childbirth and FGM. Documents that did not, either focused on issues such as implementing government action plans against FGM (Norweigian Ministry of Children, 2013); or maternal healthcare guidelines applying to all women with no information specifically for women with FGM (NICE, 2014; NICE, 2010).

Figure 3.2: Search and Screening Results for International and National Documents



Results of Screening Part 1:

Table 3.1: Applying Inclusion/exclusion criteria Part 1		
Western Countries with laws against FGM	Countries with comparable migration patterns	Countries with comparable health systems
Australia	Y	Y
Austria	Y	Y
Belgium	Y	Y
Canada	Y	Y
Croatia	Y	Y
Cyprus	Y	Y
Czech Republic	N	NA
Denmark	Y	Y
Estonia	N	NA
Finland	Y	Y
France	Y	Y
Germany	Y	Y
Greece	Y	Y
Hungary	N	NA
Ireland	Y	Y
Italy	Y	Y
Latvia	N	NA
Luxemburg	Y	Y
Malta	Y	Y
Netherlands	Y	Y
New Zealand	Y	Y
Norway	Y	Y
Poland	N	NA
Portugal	Y	Y
Romania	N	NA
Slovakia	N	NA
Slovenia	N	NA
Spain	Y	Y
Sweden	Y	Y
Switzerland	Y	Y
United Kingdom	Y	Y
USA	Y	N
Totals: 32	**26**	**25**

Results of screening 2:

Table 3.2**: Applications of Inclusion and Exclusion Criteria (Part 2) International and National Documents**

Countries that met inclusion criteria Part 1	**Government and Healthcare Body websites searched**	**Documents Found**	**English version available**	**Woman focused?**
Australia	Federal Government: https://www.health.gov.au/	No results found	NA	N
	Australian Nursing and Midwifery Federation: https://www.anmf.org.au/	Policy statement: Female genital mutilation/cutting	Y	Y
	Australian Medical Association: https://ama.com.au/	Position statement: female genital mutilation	Y	Y
	New South Wales: https://www.nsw.gov.au/	1. Maternity-pregnancy and birthing care for women affected by female genital mutilation/cutting	Y	Y
		2. FGM is against the law in New South Wales (brochure)	Y	Y
		3. FGM (brochure)	Y	Y
		4. NSW education program on Female Genital Mutilation	Y	Y
	Queensland: https://www.health.qld.gov.au/	1. Perineal Care. Clinical guideline presentation v3.0	Y	Y
		2. Queensland Clinical Guidelines. Perineal Care	Y	Y
		3. Queensland Clinical Guidelines. Perineal Care Guideline Supplement	Y	Y
		4. Cultural dimensions of pregnancy, birth and post-natal care	Y	Y
		5. Community Profiles for Health Care Providers-Sudanese	Y	Y
		6. Antenatal and intrapartum perineal care-flowsheet	Y	Y
		7. Community Profiles for Health Care Providers-Ethiopia	Y	Y
		8. Perineal care and assessment flowchart	Y	Y
		9. Queensland Sexual Health Strategy 2016-2021	Y	Y
		10. Child and youth health practice Manual	Y	Y
	South Australia: https://www.sahealth.sa.gov.au/wps/wcm/connect /public+content/sa+health+internet	1. Female Genital Mutilation-SA Perinatal Practice Guidelines	Y	Y
		2. Preconception advice- SA Perinatal Practice Guidelines	Y	Y
		3. Refugee Health Service Comprehensive health assessments fact sheet	Y	Y
		4. Refugee Health Service Providing appropriate care fact sheet	Y	Y

Table 3.2**: Applications of Inclusion and Exclusion Criteria (Part 2) International and National Documents**

Countries that met inclusion criteria Part 1	**Government and Healthcare Body websites searched**	**Documents Found**	**English version available**	**Woman focused?**
	Tasmania: https://www.health.tas.gov.au/	1. Traditional cutting/female circumcision (https://www.health.tas.gov.au/pregnancy/a_healthy_pregnancy)	Y	Y
		2. Maternity Information Package. Your guide to Pregnancy, Birth and Early Parenting	Y	Y
	Victoria: https://www2.health.vic.gov.au/	No results found	NA	N
	Family Planning Victoria: https://www.fpv.org.au/professional-learning-support/resources/publications-research/fgmc	1. Improving the health care of women and girls affected by female genital mutilation/cutting. A service coordination guide.	Y	Y
		2. Improving the health care of women and girls affected by female genital mutilation/cutting. Care plan flow chart	Y	Y
		3. A tradition in Transition: female genital mutilation/cutting (literature review)	Y	Y
		4. Prevention Programs (Family Planning Victoria, 2013b)	Y	Y
	Government of Western Australia, Department of Health https://ww2.health.wa.gov.au/	1. Gender based violence in the CALD community (https://wnhs.health.wa.gov.au/Our-services/Service-directory/Womens-Health-Strategy-and-Programs/Gender-based-violence-in-the-CALD-community)	Y	Y
		2. International Day of Zero Tolerance for Female Genital Cutting/Mutilation (https://wnhs.health.wa.gov.au/About-us/News-and-events/International-Day-of-FGM)	Y	Y
		3. Female genital cutting/mutilation (FGC/M) Clinical Practice Guideline	Y	Y
		4. Female Genital Cutting/Mutilation. A guide for health professionals	Y	Y
		5. Female genital mutilation is a child protection issue.	Y	Y
		6. Female Genital mutilation/cutting eLearning package (https://nmhs.elearn.net.au/login/index.php) a. Staff login needed-unable to assess	Y	Y
	Australia Capital Territory: https://health.act.gov.au/	No results found	NA	N
	Jervis Bay Territory:	No health government website. Refers to other Territories	NA	N

Table 3.2**: Applications of Inclusion and Exclusion Criteria (Part 2) International and National Documents**

Countries that met inclusion criteria Part 1	**Government and Healthcare Body websites searched**	**Documents Found**	**English version available**	**Woman focused?**
	Northern Territory: https://health.nt.gov.au/	Department of Health and Community Resources. Female Genital Mutilation Resource Manual for Health Professionals	Y	Y
		NSW Education Program on Female Genital Mutilation (NSW College of Nursing, 2000)	Y	Y
Austria	Federal Ministry Republic of Austria: https://www.sozialministerium.at/en.html	No results found	N	N
	Austrian Medical Chamber: https://www.aerztekammer.at/ Results of search: 71 City of Vienna: 3 E-learning modules https://www.wien.gv.at/gesundheit-soziales/	Unable to assess due to language	N	N
Belgium	Official Government website: https://www.belgium.be/	No results found	NA	N
	Federal Public Service: Health, food chain safety and environment: https://www.health.belgium.be/	Ethical Aspects of Non-medical Circumcision Superior Health Council Annual Report 2009	Y	Y
	GAMS (Group for the Abolition of Female Genital Mutilation): http://gams.be/en/	Joint Shadow report, FGM in Belgium	Y	Y
Canada	Public Health Agency of Canada: https://www.canada.ca/en/public-health.html Family-cantered maternity and new-born care: national guidelines	Chapter 2. Preconception care	Y	Y
		Chapter 3. Care during pregnancy	Y	Y
		Chapter 4. Care during labour and birth	Y	Y
		Chapter 5. Postpartum care	Y	Y
	Alberta: https://www.albertahealthservices.ca/	Alberta Antenatal Pathway	Y	Y
	Alberta: College & Association of Registered Nurses of Alberta: https://nurses.ab.ca/	Joint Statement on Family Violence	Y	Y
	Alberta: College of Physicians and Surgeons of Alberta: https://cpsa.ca/	Proposals to amend the Health Professions Act	Y	Y
	British Columbia: https://www2.gov.bc.ca/gov/content/government	No results found	NA	N

Table 3.2**: Applications of Inclusion and Exclusion Criteria (Part 2) International and National Documents**

Countries that met inclusion criteria Part 1	**Government and Healthcare Body websites searched**	**Documents Found**	**English version available**	**Woman focused?**
	s/organizational-structure/ministries-organizations/ministries/health			
	British Columbia College of Nurses and Midwives: https://www.bccnm.ca/	No results found	NA	N
	College of Physicians and Surgeons of British Columbia	No results found	NA	N
	Manitoba: https://www.gov.mb.ca/health/	Refer to 'The Society of Obstetricians and Gynaecologists of Canada' guideline (Perron, Senikas, Burnett, & Davis, 2013)		
	Manitoba: College of Registered nurses of Manitoba: https://www.crnm.mb.ca/	No results found	NA	N
	Manitoba: The college of physicians and surgeons of Manitoba: http://www.cpsm.mb.ca/	No results found	NA	N
	New Brunswick: https://www2.gnb.ca/content/gnb/en/departments/health.html	No results found	NA	N
	New Brunswick: Nurses association of New Brunswick: http://www.nanb.nb.ca/	No results found	NA	N
	New Brunswick: College of Physicians and Surgeons of New Brunswick: https://cpsnb.org/en/	No results found	NA	N
	Newfoundland and Labrador: https://www.gov.nl.ca/	No results found	NA	N
	Newfoundland and Labrador: The College of Physicians and Surgeons of Newfoundland and Labrador: https://www.cpsnl.ca/web/cpsnl	No results found	NA	N
	Newfoundland and Labrador: College of registered nurses of Newfoundland and Labrador: https://www.crnnl.ca/	No results found	NA	N
	Northwest Territories: https://www.hss.gov.nt.ca/en	No results found	NA	N
	NWT: Society of Rural Physicians of Canada: https://srpc.ca/	No results found	NA	N

Table 3.2**: Applications of Inclusion and Exclusion Criteria (Part 2) International and National Documents**

Countries that met inclusion criteria Part 1	**Government and Healthcare Body websites searched**	**Documents Found**	**English version available**	**Woman focused?**
	NWT&N: Registered nurses association of the Northwest territories and Nunavut: https://rnantnu.ca/	No results found	NA	N
	Nova Scotia: http://www.nshealth.ca/	No results found	NA	N
	Nova Scotia College of Nursing: https://www.nscn.ca/	No results found	NA	N
	College of Physicians and surgeons of Nova Scotia: https://cpsns.ns.ca/	No results found	NA	N
	Nunavut: https://www.gov.nu.ca/	No results found	NA	N
	Nunavut Physicians: https://nuphysicians.ca/	No results found	NA	N
	Nunavut Nurses: https://www.nunavutnurses.ca/	No results found	NA	N
	Ontario: https://www.publichealthontario.ca/	No results found	NA	N
	Health Quality Ontario: https://www.hqontario.ca/	No results found	NA	N
	College of Nurses Ontario (CNO): https://www.cno.org/	No results found	NA	N
	Canadian Nurses Association (CNA): https://www.cna-aiic.ca/en/international-work/global-health-issues	'Global Health issues'	Y	Y
	College of Physicians and Surgeons Ontario: https://www.cpso.on.ca/	No results found	NA	N
	Prince Edward Island (PEI): https://www.princeedwardisland.ca/en/topic/health-pei	No results found	NA	N
	PEI: College of Registered Nurses: https://crnpei.ca/	No results found	NA	N
	PEI: College of Physicians and Surgeons: https://cpspei.ca/	No results found	NA	N
	Quebec: https://www.quebec.ca/en/health	No results found	NA	N
	Order of Nurses Quebec: https://www.oiiq.org/	No results found	NA	N
	College of Physicians Quebec: http://www.cmq.org/	No results found	NA	N

Table 3.2**: Applications of Inclusion and Exclusion Criteria (Part 2) International and National Documents**

Countries that met inclusion criteria Part 1	**Government and Healthcare Body websites searched**	**Documents Found**	**English version available**	**Woman focused?**
	Saskatchewan: https://www.saskhealthauthority.ca/	No results found	NA	N
	Saskatchewan Registered Nurses Association: https://www.srna.org/	No results found	NA	N
	College of Physicians and Surgeons of Saskatchewan: https://www.cps.sk.ca/imis	No results found	NA	N
	Yukon Department of Health and Social Services: https://yukon.ca/en/department-health-social-services	No results found	NA	N
	Yukon Registered Nurses Association: https://ncsbn.org/Yukon.htm	No results found	NA	N
	Yukon Medical Council: http://www.yukonmedicalcouncil.ca/index.html	No results found	NA	N
	Healthcare Body: The Society of Obstetricians and Gynaecologists of Canada: https://sogc.org/	Female Genital Cutting. Clinical Practice Guidelines (Perron et al., 2013)	Y	Y
Croatia	Ministry of health: https://eunethta.eu/miz/	N	NA	N
	Croatian Nursing Council: http://www.hkms.hr/	N	NA	N
	Croatian Nurses Association: https://hums.hr/	N	NA	N
	Croatian Medical Chamber: http://www.hlikom.hr/	N	NA	N
	Croatian Medical Association: https://www.hlz.hr/	N	NA	N
Cyprus	Ministry of Health: https://www.moh.gov.cy/moh/moh.nsf/index_en/index_en	No results found	NA	N
	The Cyprus Nursing and Midwives Association: https://cyna.org/	No results found	NA	N
	Cyprus Medical Association: www.cyma.org.cy	No results found	NA	N
Denmark	Ministry of health: https://sum.dk/english	Unable to assess due to language	NA	N
	Danish Nurses Association: https://dsr.dk/om-dsr/kontakt-dsr/welcome-to-dno	Unable to assess due to language	NA	N
	Danish Medical Association: https://www.laeger.dk/english	No results found	NA	N

Table 3.2**: Applications of Inclusion and Exclusion Criteria (Part 2) International and National Documents**

Countries that met inclusion criteria Part 1	**Government and Healthcare Body websites searched**	**Documents Found**	**English version available**	**Woman focused?**
Finland	Ministry of Social Affairs and Health: https://stm.fi/en/frontpage	13 results. 7 in Finnish. 5 in English. All Government statements or action plans.	Y/N	N
	Finnish Nurses Association: https://www.nurses.fi/	No results found	NA	N
	Finnish Medical Association: https://www.laakariliitto.fi/en/	No results found	NA	N
France	Ministry of Health: https://solidarites-sante.gouv.fr/	Unable to assess due to language	NA	N
Germany	German Ministry of Health: https://www.bundesgesundheitsministerium.de/	German Medical Association brochure	Y	Y
		Part 2	Y	Y
	German Medical Association: https://www.bundesaerztekammer.de/	Same as above	NA	NA
	The German Nurses Association: https://www.dbfk.de/de/ueber-uns/English.php	No results found	NA	N
Greece	Ministry of Health Greece: https://www.moh.gov.gr/	No results found	NA	N
	Hellenic Nurses' Association: https://www.esne.gr/	No results found	NA	N
	Panhellenic Medical Association: https://pis.gr/	No results found	NA	N
Ireland	National Office for Social Inclusion: https://www.hse.ie/	Female Genital Mutilation; Information for Health-care Professionals Working in Ireland	Y	Y
		Towards a National Action Plan to Combat Female Genital Mutilation	Y	Y
	Irish Nurses and Midwives Organisation: https://www.inmo.ie/	Midwifery matters - The challenges of FGM	Y	Y
	Irish Medical Organisation: https://www.imo.ie/	No results found	NA	N
	Irish College of General Practitioners: https://www.icgp.ie/	Unable to access	NA	N
Italy	Italian Ministry of Health: https://www.salute.gov.it/	No results found	NA	N
	CNAI (Italian Nurses Association) https://www.cnai.pro/	No results found	NA	N

Table 3.2**: Applications of Inclusion and Exclusion Criteria (Part 2) International and National Documents**

Countries that met inclusion criteria Part 1	**Government and Healthcare Body websites searched**	**Documents Found**	**English version available**	**Woman focused?**
	Italian Academy of Family Physicians: http://www.aimef.org/	No results found	NA	N
Luxemburg	Ministry of health: https://msan.gouvernement.lu/en.html https://sante.public.lu/	No results found	NA	N
Malta	Ministry of Health: https://deputyprimeminister.gov.mt//en/health-promotion/pages/home.aspx	Migrant Health unit, Female Genital Mutilation	Y	Y
	Primary Healthcare Malta: https://deputyprimeminister.gov.mt/en/phc/Pages/Home.aspx	Female Genital Mutilation in Malta, A research study	Y	Y
	Medical Association of Malta: http://www.mam.org.mt/	No results found	NA	N
Netherlands	Ministry of Health: https://www.government.nl/ministries/ministry-of-health-welfare-and-sport	19 results. None Health specific	Y	N
	Pharos (Dutch centre of expertise on health disparities: https://www.pharos.nl/english/	8 results. 3 in Dutch. 1 health related. Veiled Pain	Y	Y
	Dutch Professional Nursing Organisation: https://venvnvs.nl/	Unable to assess due to language	NA	N
	Royal Dutch Medical Association: https://www.knmg.nl/over-knmg/about-knmg/about-knmg.htm	No results found	NA	N
New Zealand	Ministry of Health: https://www.health.govt.nz/	Links to: FGM NZ website	Y	Y
		FGM Clinical Care Deinfibulation Guidelines (NZ FGM Education Program, 2009a)	Y	Y
		FGM clinical care; antenatal, labour and birth and postnatal guidelines (NZ FGM Education Program, 2009b)	Y	Y
		Refugee Health Care: A handbook for health professionals (Ministry of Health New Zealand, 2012)	Y	Y

Table 3.2**: Applications of Inclusion and Exclusion Criteria (Part 2) International and National Documents**

Countries that met inclusion criteria Part 1	**Government and Healthcare Body websites searched**	**Documents Found**	**English version available**	**Woman focused?**
	Healthcare Body: RANZCOG https://ranzcog.edu.au/	Royal Australian and New Zealand College of Obstetricians and Gynaecologists *(RANZCOG)*: Female Genital Mutilation (FGM) 2017 (RANZCOG, 2017)	Y	Y
Norway	Ministry of Health: https://www.regjeringen.no/en/dep/hod/id421/	8 results. 7 statements, 1 action plan Norway's International Strategy to Eliminate Harmful Practices 2019-2023	Y	Y
	Norway Ministry of Children and Families: https://www.regjeringen.no/en/dep/bfd/id298/	A national Clinical Guideline for antenatal care: short version-recommendations (Holan, Mathiesen, & Petersen, 2005)	Y	Y
		Action Plan for Combating Female Genital Mutilation (2008-2011) (Norwegian Ministries, 2011)	Y	N
		Action plan against forced marriage, female genital mutilation and severe restrictions on young people's freedom (2013–2016) (Norweigian Ministry of Children, 2013)	Y	N
Portugal	Ministry of Health Portugal: https://www.dgs.pt/	Unable to assess due to language	NA	NA
	Portuguese Nursing Association: https://www.ordemenfermeiros.pt/	Unable to assess due to language	NA	NA
	Portuguese medical Association: https://www.anmsp.pt/	Unable to assess due to language	NA	NA
Spain	Ministry of Health: https://www.mscbs.gob.es/en/home.htm	4 results: 1 in English. Common protocol for a healthcare response to Female Genital Mutilation (FGM) (Ministry of Health Social Services and Equality, 2015)	Y	Y
Sweden	Ministry of Health and Social Affairs: https://www.government.se/government-of-sweden/ministry-of-health-and-social-affairs/	25 results, government strategy and speeches.	NA	N
	Swedish Association for Health Professionals: https://www.vardforbundet.se/	Refer to WHO and other external websites for more information.	NA	N
	Swedish Medical Association: https://slf.se/in-english/	No results found	NA	N
Switzerland	Federal Office of Public Health: https://www.bag.admin.ch/bag/en/home.html	2 results. Both Government statements.	NA	N
United Kingdom	Department of Health	Commissioning services to support women and girls with female genital mutilation (UK Department of Health, 2015)	Y	Y

Table 3.2**: Applications of Inclusion and Exclusion Criteria (Part 2) International and National Documents**

Countries that met inclusion criteria Part 1	**Government and Healthcare Body websites searched**	**Documents Found**	**English version available**	**Woman focused?**
		All Wales Clinical Pathway – Female Genital Mutilation (FGM) (Public Health Wales, 2015)	Y	Y
		Multi-agency statutory guidance on female genital mutilation (HM Government, 2016b)	Y	Y
		Scotland's national action plan to prevent and eradicate female genital mutilation (FGM) 2016-2020 (Scottish Government, 2016)	Y	Y
		Scotland's National Action Plan to Prevent and Eradicate Female Genital Mutilation (FGM) – Year Three Progress Report (Scottish Government, 2019)	Y	Y
	NICE	NICE Postnatal care up to 8 weeks after birth Clinical guideline (NICE, 2006)	Y	Y
		Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors (NICE, 2010)	Y	Y
		Antenatal and postnatal mental health: clinical management and service Guidance Clinical guideline NICE (NICE, 2014)	Y	Y
		Postnatal care overview-NICE clinical guideline (NICE, 2017)	Y	Y
	BMA	Female Genital Mutilation: Caring for patients and safeguarding children Guidance from the British Medical Association (BMA, 2011)	Y	Y
	RCM	Evidence Based Guidelines *for Midwifery-Led Care in Labour* Care of the Perineum (The Royal College of Midwives, 2012)	Y	Y
	RCOG	The Management of Third- and Fourth-Degree Perineal Tears Green-top Guideline No. 29 June 2015 (Royal College of Obstetricians and Gynaecologists, 2015b)	Y	Y
		Female Genital Mutilation and its Management Green-top Guideline No. 53 (Royal College of Obstetricians and Gynaecologists, 2015a)	Y	Y
	RCN	Female Genital Mutilation An RCN resource for nursing and midwifery practice (Fourth edition) (Royal College of Nursing, 2019)	Y	Y
		Totals: 157	79	75

The WHO and EU websites were also searched and resulted in 16 documents from the WHO and 1 document from the EU. After screening, 11 documents were included in analysis (Figure 3.3, Table 3.3)

Figure 3.3: Search and Screening Results for WHO and EU Documents

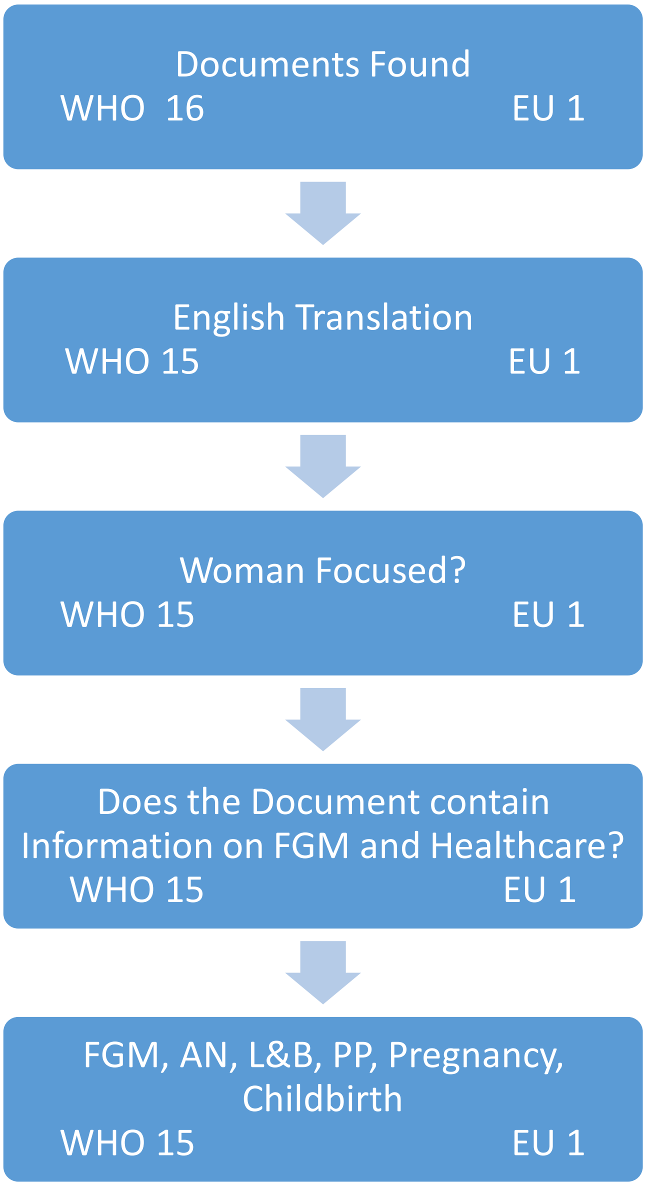


Table 3.3**: Application of Inclusion and Exclusion Criteria (Part 2) WHO and EU**

International Agency	**Documents found**	**English version available**	**Woman focused?**
WHO: https://www.who.int/publications/i?healthtopics=b3387754-2f0a-48a4-93f7-8d4cae10087b	WHO guidelines on the management of health complications from female genital mutilation	Y	Y
	Effects of FGM on childbirth in Africa (2006) (WHO, 2008)	Y	Y
	Who guidelines on the management of health complications from female genital mutilation; policy brief	Y	Y
	Care of girls and women living with female genital mutilation; a clinical handbook	Y	Y
	Female genital mutilation evidence brief	Y	Y
	Eliminating female genital mutilation, an interagency statement	Y	Y
	Estimating the obstetric costs of female genital mutilation in six African countries	Y	Y
	Sociocultural motivations for female genital mutilation: matrimonial strategies, family motivations and religious justifications among the Al Pulaar and the Soninké in the River Senegal Valley	Y	Y
	An update on WHO's work on female genital mutilation (FGM) progress report	Y	Y
	Female genital mutilation programmes to date: what works and what doesn't	Y	Y
	Men's and women's perceptions of the relationship between female genital mutilation and women's sexuality in three communities in Egypt	Y	Y
	Global strategy to stop health-care providers from performing female genital mutilation	Y	Y
	Female genital mutilation a teachers guide	Y	Y
	Mutilations sexuelles feminines	N	NA
	Gender differences in the epidemiology of affective disorder and schizophrenia	Y	Y
EU (https://europa.eu/)	Communication from the commission to the European parliament and the council. Towards elimination of FGM (European Commission, 2013)	Y	Y
	Totals: 16	15	15

International and National documents Screening 3:

Table 3.4**: Applications of Inclusion and Exclusion Criteria (Part 3) International and National Documents**

Countries that met inclusion criteria Part 2	**Government or Healthcare Body Publication**	**Document**	**3A) Does the document contain information on FGM and healthcare? (Y/N)**	**3B) Does the document contain information on FGM and antenatal care, pregnancy, labour and delivery, postpartum care? Or anything associated with pregnancy and childbirth? (Y/N)**
Australia	Healthcare Body	*Australian Nursing and Midwifery Federation:* Policy statement: Female genital mutilation/cutting (Australian Nursing & Midwifery Federation, 2021)	Y	Y
		Australian Medical Association: Position statement: female genital mutilation (Australian Medical Association, 2017)	Y	Y
		Multicultural Centre for Women's Health: NETFA Best Practice Guide for Working with Communities Affected by FGM/C (Multicultural Centre For Women's Health, 2019)	Y	N
	Government	*New South Wales:* Maternity-pregnancy and birthing care for women affected by female genital mutilation/cutting (NSW Kids and Families, 2014)	Y	Y
		New South Wales: FGM is against the law in New South Wales (brochure) (New South Wales Health, 2021)	Y	Y
		New South Wales: FGM (brochure) (NSW Education Program on FGM, 2013)	N	N
		New South Wales: Education Program on Female Genital Mutilation (NSW Education Program on FGM, 2014)	N	N
		Queensland: Queensland Clinical Guidelines: Perineal Care (presentation) (Queensland Clinical Guidelines, 2018c.)	Y	Y
		Queensland: Queensland Clinical Guidelines. Perineal Care (Queensland Clinical Guidelines, 2018b)	Y	Y
		Queensland: Queensland Clinical Guidelines. Perineal Care Guideline Supplement (Queensland Clinical Guidelines, 2018a)	Y	Y
		Queensland: Cultural dimensions of pregnancy, birth and post-natal care (Queensland Health, 2009)	Y	Y

Table 3.4**: Applications of Inclusion and Exclusion Criteria (Part 3) International and National Documents**

Countries that met inclusion criteria Part 2	**Government or Healthcare Body Publication**	**Document**	**3A) Does the document contain information on FGM and healthcare? (Y/N)**	**3B) Does the document contain information on FGM and antenatal care, pregnancy, labour and delivery, postpartum care? Or anything associated with pregnancy and childbirth? (Y/N)**
		Queensland: Community Profiles for Health Care Providers-Sudanese (Queensland Health, 2011a)	Y	Y
		Queensland: Antenatal and intrapartum perineal care-flowsheet (Queensland Health, 2018a)	Y	Y
		Queensland: Community Profiles for Health Care Providers-Ethiopia (Queensland Health, 2011b)	Y	Y
		Queensland: Perineal assessment and repair flowchart (Queensland Health, 2018b)	Y	Y
		Queensland: Queensland Sexual Health Strategy 2016-2021(Queensland Health, 2016)	Y	N
		Queensland: Child and youth health practice Manual (Children's Health Queensland Hospital and Health Service, 2014)	N	N
		South Australia: Female Genital Mutilation-SA Perinatal Practice Guidelines (SA Maternal Neonatal & Gynaecology Community of Practice, 2018)	Y	Y
		South Australia: Preconception advice- SA Perinatal Practice Guidelines (SA Maternal & Neonatal Clinical Network, 2015)	Y	N
		South Australia: Refugee Health Service Comprehensive health assessments fact sheet (Central Adelaide Local Health Network, 2020)	Y	N
		South Australia: Refugee Health Service Providing appropriate care fact sheet (Central Adelaide Local Health Network, 2020b)	N	N
	Government	Tasmania: Traditional cutting/female circumcision (Government of Tasmania, 2021)	Y	Y
		Tasmania: Maternity Information Package. Your guide to Pregnancy, Birth and Early Parenting (Women's Adolescent and Children's Services Tasmania, 2020)	N	N
		Victoria: Improving the health care of women and girls affected by female genital mutilation/cutting. A service coordination guide. (Family Planning Victoria, 2012b)	Y	Y

Table 3.4**: Applications of Inclusion and Exclusion Criteria (Part 3) International and National Documents**

Countries that met inclusion criteria Part 2	**Government or Healthcare Body Publication**	**Document**	**3A) Does the document contain information on FGM and healthcare? (Y/N)**	**3B) Does the document contain information on FGM and antenatal care, pregnancy, labour and delivery, postpartum care? Or anything associated with pregnancy and childbirth? (Y/N)**
		Victoria: Improving the health care of women and girls affected by female genital mutilation/cutting. Care plan flow chart (Family Planning Victoria, 2012a)	Y	Y
		Victoria: Prevention Programs (Family Planning Victoria, 2013b)	N	N
		Victoria: A tradition in Transition: female genital mutilation/cutting (Family Planning Victoria, 2013a)	Y	N
		Western Australia: Gender based violence in the CALD community (WA Health, 2021a)	Y	N
		Western Australia: International Day of Zero Tolerance for Female Genital Cutting/Mutilation (WA Health, 2021b)	Y	N
		Western Australia: Female genital cutting/mutilation (FGC/M) Clinical Practice Guideline (Women's Health Coordinator (CaLD), 2015)	Y	Y
		Western Australia: Female Genital Cutting/Mutilation. A guide for health professionals (Australian Red Cross Society, 2016)	Y	Y
		Western Australia: Female Genital Cutting/Mutilation. A guide for health professionals	Y	Y
		Western Australia: Female genital mutilation is a child protection issue. (WA Health, 2005)	N	N
		Western Australia: Female Genital mutilation/cutting eLearning package (https://nmhs.elearn.net.au/login/index.php) Staff login needed-**unable to assess**	NA	NA
		Northern Territory: Department of Health and Community Resources. Female Genital Mutilation Resource Manual for Health Professionals (NT Women's Health Strategy Unit, 2006)	Y	Y
		Northern Territory: NSW Education Program on Female Genital Mutilation (NSW College of Nursing, 2000)	Y	Y

Table 3.4**: Applications of Inclusion and Exclusion Criteria (Part 3) International and National Documents**

Countries that met inclusion criteria Part 2	**Government or Healthcare Body Publication**	**Document**	**3A) Does the document contain information on FGM and healthcare? (Y/N)**	**3B) Does the document contain information on FGM and antenatal care, pregnancy, labour and delivery, postpartum care? Or anything associated with pregnancy and childbirth? (Y/N)**
Belgium	Government	Ethical Aspects of Non-medical Circumcision Superior Health Council Annual Report 2009 (Belgian Advisory Committee on Bioethics, 2017)	N	N
	Healthcare Body	GAMS: Joint Shadow report, FGM in Belgium (GAMS; INTACT; End FGM European Network, 2019)	N	N
Canada	Government	Family-cantered maternity and new-born care: national guidelines Chapter 2. Preconception care (Public Health Agency of Canada, 2019a)	N	N
		Family-cantered maternity and new-born care: national guidelines Chapter 3. Care during pregnancy (Public Health Agency of Canada, 2019b)	Y	Y
		Family-cantered maternity and new-born care: national guidelines Chapter 4. Care during labour and birth (Public Health Agency of Canada, 2018)	Y	Y
		Family-cantered maternity and new-born care: national guidelines Chapter 5. Postpartum care (Public Health Agency of Canada, 2020)	Y	Y
		Alberta Antenatal Pathway (Alberta Health Services, 2020)	Y	N
	Healthcare Body	*College & Association of Registered Nurses of Alberta:* Joint Statement on Family Violence (College and Association of Registered Nurses of Alberta; & College of Licensed Practical Nurses of Alberta; College of Registered Psychiatric Nurses of Alberta, 2008)	N	N
		College of Physicians and Surgeons of Alberta: Proposals to amend the Health Professions Act (College of Physicians & Surgeons of Alberta, 2020)	N	N
		Canadian Nurses Association (CNA): 'Global Health issues' (Canadian Nurses Association, 2021)	N	N
		Female Genital Cutting. Clinical Practice Guidelines (Perron et al., 2013)	Y	Y
		Canadian Paediatric Society: Immigrant & Refugee Women's Cultural Health Practices A guide for health care professionals Project (Kongnetiman & Okafor, 2005)	N	N
Germany	Healthcare Body	German Medical Association brochure (German Medical Association, 2016)	Y	Y

Table 3.4**: Applications of Inclusion and Exclusion Criteria (Part 3) International and National Documents**

Countries that met inclusion criteria Part 2	**Government or Healthcare Body Publication**	**Document**	**3A) Does the document contain information on FGM and healthcare? (Y/N)**	**3B) Does the document contain information on FGM and antenatal care, pregnancy, labour and delivery, postpartum care? Or anything associated with pregnancy and childbirth? (Y/N)**
		German Medical Association: Recommendations on the management of patients with a history of female genital mutilation (German Medical Association, 2005)	Y	Y
Ireland	Government	Female Genital Mutilation; Information for Health-care Professionals Working in Ireland (Bansal, Breckwoldt, O'Brien Green, Mbugua, & Reilly, 2013)	Y	Y
		Towards a National Action Plan to Combat Female Genital Mutilation (AkiDwA, 2016)	Y	N
	Healthcare Body	Midwifery matters - The challenges of FGM (O'Connell, 2014)	Y	Y
Malta	Government	Migrant Health unit, Female Genital Mutilation (Migrant Health Unit, 2009)	Y	Y
	Healthcare Body	Female Genital Mutilation in Malta, A research study (NCPE, 2013)	Y	Y
Netherlands	Healthcare Body	Veiled Pain (Vloeberghs, Knipscheer, van der Kwaak, Naleie, & van den Muijsenbergh, 2011)	N	N
New Zealand	Government	FGM Clinical Care Deinfibulation Guidelines (NZ FGM Education Program, 2009a)	Y	Y
		FGM clinical care; antenatal, labour and birth and postnatal guidelines (NZ FGM Education Program, 2009b)	Y	Y
		Refugee Health Care: A handbook for health professionals (Ministry of Health New Zealand, 2012)	Y	Y
	Healthcare Body	Royal Australian and New Zealand College of Obstetricians and Gynaecologists *(RANZCOG)*: Female Genital Mutilation (FGM) 2017 (RANZCOG, 2017)	Y	Y
Norway	Government	Norway's International Strategy to Eliminate Harmful Practices 2019-2023 (Norwegian Ministry of Foreign Affairs, 2019)	N	N
		A national Clinical Guideline for antenatal care: short version-recommendations (Holan et al., 2005)	Y	Y

Table 3.4**: Applications of Inclusion and Exclusion Criteria (Part 3) International and National Documents**

Countries that met inclusion criteria Part 2	**Government or Healthcare Body Publication**	**Document**	**3A) Does the document contain information on FGM and healthcare? (Y/N)**	**3B) Does the document contain information on FGM and antenatal care, pregnancy, labour and delivery, postpartum care? Or anything associated with pregnancy and childbirth? (Y/N)**
Spain	Government	Common protocol for a healthcare response to Female Genital Mutilation (FGM) (Ministry of Health Social Services and Equality, 2015)	Y	Y
United Kingdom	Department of Health (DoH)	Commissioning services to support women and girls with female genital mutilation (UK Department of Health, 2015)	Y	Y
		All Wales Clinical Pathway – Female Genital Mutilation (FGM) (Public Health Wales, 2015)	Y	Y
		Multi-agency statutory guidance on female genital mutilation (HM Government, 2016b)	Y	Y
		Scotland's national action plan to prevent and eradicate female genital mutilation (FGM) 2016-2020 (Scottish Government, 2016)	Y	Y
		Scotland's National Action Plan to Prevent and Eradicate Female Genital Mutilation (FGM) – Year Three Progress Report (Scottish Government, 2019)	Y	Y
	National Institute for Health and Care Excellence (NICE)	NICE Postnatal care up to 8 weeks after birth Clinical guideline (NICE, 2006)	N	N
		Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors (NICE, 2010)	Y	N
		Antenatal and postnatal mental health: clinical management and service Guidance Clinical guideline NICE (NICE, 2014)	Y	Y
		Postnatal care overview-NICE clinical guideline (NICE, 2017)	Y	Y
	British Medical Association (BMA)	Female Genital Mutilation: Caring for patients and safeguarding children Guidance from the British Medical Association (BMA, 2011)	Y	Y
	Royal College of Midwives (RCM)	Evidence Based Guidelines *for Midwifery-Led Care in Labour* Care of the Perineum (The Royal College of Midwives, 2012)	Y	Y
	Royal College of Obstetricians and	The Management of Third- and Fourth-Degree Perineal Tears Green-top Guideline No. 29 June 2015 (Royal College of Obstetricians and Gynaecologists, 2015b)	Y	Y

Table 3.4**: Applications of Inclusion and Exclusion Criteria (Part 3) International and National Documents**

Countries that met inclusion criteria Part 2	**Government or Healthcare Body Publication**	**Document**	**3A) Does the document contain information on FGM and healthcare? (Y/N)**	**3B) Does the document contain information on FGM and antenatal care, pregnancy, labour and delivery, postpartum care? Or anything associated with pregnancy and childbirth? (Y/N)**
	Gynaecologists (RCOG)	Female Genital Mutilation and its Management Green-top Guideline No. 53 (Royal College of Obstetricians and Gynaecologists, 2015a)	Y	Y
	Royal College of Nurses (RCN)	Female Genital Mutilation An RCN resource for nursing and midwifery practice (Fourth edition) (Royal College of Nursing, 2019)	Y	Y
		Totals: 77	59	49

Table 3.5**: Application of Inclusion and Exclusion Criteria (Part 3) WHO and EU**

International Agency	**Documents found**	**3A) Does the document contain information on FGM and healthcare? (Y/N)**	**3B) Does the document contain information on FGM and antenatal care, pregnancy, labour and delivery, postpartum care? Or anything associated with pregnancy and childbirth? (Y/N)**
WHO	Gender differences in the epidemiology of affective disorder and schizophrenia (Piccinelli & Gomez Homen, 1997)	N	N
	Female genital mutilation programmes to date: what works and what doesn't (WHO, 1999)	Y	N
	Female genital mutilation a teachers guide (WHO, 2000)	Y	Y
	Effects of FGM on childbirth in Africa (2006) (WHO, 2008)	Y	Y
	Eliminating female genital mutilation, an interagency statement (WHO, 2008b)	N	N
	Men's and women's perceptions of the relationship between female genital mutilation and women's sexuality in three communities in Egypt (WHO, 2010b)	N	N
	Global strategy to stop health-care providers from performing female genital mutilation (WHO, 2010a)	Y	Y

Table 3.5**: Application of Inclusion and Exclusion Criteria (Part 3) WHO and EU**

International Agency	**Documents found**	**3A) Does the document contain information on FGM and healthcare? (Y/N)**	**3B) Does the document contain information on FGM and antenatal care, pregnancy, labour and delivery, postpartum care? Or anything associated with pregnancy and childbirth? (Y/N)**
	Sociocultural motivations for female genital mutilation: matrimonial strategies, family motivations and religious justifications among the Al Pulaar and the Soninké in the River Senegal Valley (WHO, 2011)	N	N
	An update on WHO's work on female genital mutilation (FGM) progress report (WHO, 2011a)	Y	Y
	Estimating the obstetric costs of female genital mutilation in six African countries (WHO, 2011b)	Y	Y
	WHO guidelines on the management of health complications from female genital mutilation (WHO, 2016)	Y	Y
	Who guidelines on the management of health complications from female genital mutilation; policy brief (WHO, 2016a)	Y	Y
	Care of girls and women living with female genital mutilation; a clinical handbook (WHO, 2018)	Y	Y
	Female genital mutilation evidence brief (WHO, 2019)	Y	N
EU	Communication from the commission to the European parliament and the council. Towards elimination of FGM (European Commission, 2013)	Y	Y
	Totals: 15	15	15

3.3 Findings

As the WHO is the United Nations directing and coordinating authority on international health (WHO, 2020), international and national guidelines were compared and contrasted against FGM guidelines published by the WHO. Upon completion of analysis, two critical time points, the antenatal period, and labour and birth, were found to be the focus of the majority of documents, with postpartum care mentioned briefly. Education regarding FGM, the law and culturally sensitive care were overarching themes that were seen throughout documents (Table 3.6). The focus of the antenatal period was identification, the creation of a birth plan, and de-infibulation if required. The focus of labour and birth was de-infibulation if necessary and perineal support; while the focus of the PPP was the time immediately after birth. The findings are presented by stating what the WHO guidelines suggest, what the international guidelines dictate, and finally what the national UK documents state and how this compares to the other two groups.

<table>
<tr><th colspan="3">Table 3.6: Documentary Analysis Themes</th></tr>
<tr><td colspan="3">Overarching:
• Sources of information
• Culturally sensitive care
• The law
• Education about FGM: Women and HCP</td></tr>
<tr><td>Antenatal:
• Identification
• Creation of a birth plan
• De-infibulation</td><td>Labour and Birth:
• De-infibulation
• Perineal support</td><td>Postpartum:
• Perineal support
• Immediate care</td></tr>
</table>

Documents that met the inclusion and exclusion criteria were both content and thematically analysed based on the predetermined questions (Table 2.3, Section 2.3.3)

International Documents:

Table 3.7: **Application of specific analysis questions to International documents**

Country	**Document**	**Mention of maternal services?**	**Mention of perineal care?**	**Mention of antenatal, birth, post-partum care?**	**Mention of specific postpartum care needs for women with FGM?**	**Discussion of needs specific to FGM?**	**Discussion of education for healthcare professionals ?**	**Mention of resources for women with FGM**
Australia	*New South Wales (NSW):* Maternity-Pregnancy and Birthing Care for Women Affected by Female Genital Mutilation / Cutting (NSW Kids and Families, 2014)	Y	Y	Y	Y	Y	Y	N
	New South Wales: FGM is against the law in New South Wales (brochure) (New South Wales Health, 2021)	Y	N	N	N	Y	N	N
	Australian Nursing and Midwifery Federation: Policy statement: Female genital mutilation/cutting (Australian Nursing & Midwifery Federation, 2021)	Y	N	Y	N	Y	Y	N
	Australian Medical Association: Position statement: female genital mutilation (Australian Medical Association, 2017)	Y	N	Y	N	Y	Y	N
	Western Australia (WA): Clinical Practice Guideline; Female genital cutting / mutilation (FGC/M) (Women's Health Coordinator (CaLD), 2015)	Y	Y	Y	Y	Y	Y	N
	Western Australia: Female Genital Cutting/Mutilation. A guide for health professionals (Australian Red Cross Society, 2016)	Y	Y	Y	N	Y	Y	N
	Queensland: Cultural dimensions of pregnancy, birth and post-natal care (Queensland Health, 2009)	Y	Y	Y	N	Y	Y	Y
	Queensland: Community Profiles for Health Care Providers-Sudanese (Queensland Health, 2011a)	N	N	N	N	Y	Y	N

Table 3.7: **Application of specific analysis questions to International documents**

Country	Document	Mention of maternal services?	Mention of perineal care?	Mention of antenatal, birth, post-partum care?	Mention of specific postpartum care needs for women with FGM?	Discussion of needs specific to FGM?	Discussion of education for healthcare professionals ?	Mention of resources for women with FGM
	Queensland: Community Profiles for Health Care Providers-Ethiopia (Queensland Health, 2011b)	N	N	N	N	Y	Y	N
	Queensland: Maternity and Neonatal Clinical Guideline; Perineal Care (Queensland Clinical Guidelines, 2018b)	Y	Y	Y	Y	Y	Y	N
	Queensland: Maternity and Neonatal Clinical Guideline Supplement: Perineal care (Queensland Clinical Guidelines, 2018a)	Y	Y	Y	Y	Y	Y	N
	Queensland: Queensland Clinical Guidelines: Perineal Care (presentation) (Queensland Clinical Guidelines, 2018c.)	Y	Y	Y	Y	Y	Y	N
	Queensland: Antenatal and intrapartum perineal care-flowsheet (Queensland Health, 2018a)	Y	Y	Y	N	Y	Y	N
	Queensland: Perineal assessment and repair flowchart (Queensland Health, 2018b)	Y	Y	Y	N	Y	Y	N
	South Australia (SA): South Australian Perinatal Practice Guideline Female Genital Mutilation (SA Maternal Neonatal & Gynaecology Community of Practice, 2018)	Y	Y	Y	Y	Y	Y	N
	Victoria: Improving the health care of women and girls affected by female genital mutilation/cutting. A service coordination guide. (Family Planning Victoria, 2012b)	N	N	Y	N	Y	N	N
	Victoria: Improving the health care of women and girls affected by female genital mutilation/cutting. Care plan flow chart (Family Planning Victoria, 2012a)	N	N	Y	N	Y	N	N
	Northern Territory (NT): Female Genital Mutilation Resource Manual for Health	Y	Y	Y	Y	Y	Y	Y

Table 3.7: **Application of specific analysis questions to International documents**

Country	Document	Mention of maternal services?	Mention of perineal care?	Mention of antenatal, birth, post-partum care?	Mention of specific postpartum care needs for women with FGM?	Discussion of needs specific to FGM?	Discussion of education for healthcare professionals ?	Mention of resources for women with FGM
	Professionals (NSW College of Nursing, 2000)							
	Northern Territory: Department of Health and Community Resources. Female Genital Mutilation Resource Manual for Health Professionals (NT Women's Health Strategy Unit, 2006)	N	N	Y	N	Y	Y	N
	Tasmania: Traditional cutting/female circumcision (Government of Tasmania, 2021)	Y	N	Y	N	Y	N	Y
Canada	FGC, Clinical practice guidelines (Perron et al., 2013)	Y	Y	Y	Y	Y	Y	N
	Family-cantered maternity and new-born care: national guidelines Chapter 4. Care during labour and birth (Public Health Agency of Canada, 2018)	Y	Y	Y	N	Y	Y	Y
	Family-cantered maternity and new-born care: national guidelines Chapter 3. Care during pregnancy (Public Health Agency of Canada, 2019b)	Y	Y	Y	N	Y	Y	Y
	Family-cantered maternity and new-born care: national guidelines Chapter 5. Postpartum care (Public Health Agency of Canada, 2020)	Y	Y	Y	Y	Y	Y	Y
Germany	German Medical Association: Recommendations on the management of patients with a history of female genital mutilation (German Medical Association, 2005)	Y	Y	Y	Y	Y	Y	N
	Recommendations on the management of patients with a history of female genital	Y	Y	Y	Y	Y	Y	N

Table 3.7: **Application of specific analysis questions to International documents**

Country	**Document**	**Mention of maternal services?**	**Mention of perineal care?**	**Mention of antenatal, birth, post-partum care?**	**Mention of specific postpartum care needs for women with FGM?**	**Discussion of needs specific to FGM?**	**Discussion of education for healthcare professionals ?**	**Mention of resources for women with FGM**
	mutilation (FGM) (German Medical Association, 2016)							
Ireland	Female Genital Mutilation. Information for Health-care Professionals Working in Ireland (2nd Edition) (Bansal et al., 2013)	Y	Y	Y	Y	Y	Y	N
	Midwifery matters - The challenges of FGM (O’Connell, 2014)	Y	Y	N	N	Y	Y	Y
Malta	Female Genital Mutilation in Malta, A research study (NCPE, 2013)	N	N	N	N	Y	N	N
New Zealand	FGM Clinical Care Deinfibulation Guidelines (NZ FGM Education Program, 2009a)	N	Y	Y	Y	Y	Y	N
	FGM clinical care; antenatal, labour and birth and postnatal guidelines (NZ FGM Education Program, 2009b)	Y	Y	Y	Y	Y	Y	N
	Refugee Health Care: A handbook for health professionals (Ministry of Health New Zealand, 2012)	Y	Y	Y	N	Y	Y	N
	Royal Australian and New Zealand College of Obstetricians and Gynaecologists ***(****RANZCOG)*: Female Genital Mutilation (FGM) 2017 (RANZCOG, 2017)	Y	Y	Y	N	Y	Y	N
Norway	A national Clinical Guideline for antenatal care: short version-recommendations (Holan et al., 2005)	Y	N	Y	N	Y	Y	Y
Spain	Common protocol for a healthcare response to Female Genital Mutilation (FGM) (Ministry of Health Social Services and Equality, 2015)	Y	Y	Y	Y	Y	Y	N
	Totals:	28/35	24/35	30/35	15/35	35/35	30/35	8/35

National Documents:

Table 3.8: Application of specific analysis questions to National documents

Country	**Document**	**Mention of maternal services?**	**Mention of perineal care?**	**Mention of antenatal, birth, post-partum care?**	**Mention of specific postpartum care needs for women with FGM?**	**Discussion of needs specific to FGM?**	**Discussion of education for healthcare professionals?**	**Mention of resources for women with FGM**
DoH	Commissioning services to support women and girls with female genital mutilation (UK Department of Health, 2015)	Y	Y	Y	Y	Y	Y	N
	All Wales Clinical Pathway – Female Genital Mutilation (FGM) (Public Health Wales, 2015)	Y	N	N	N	Y	Y	N
	Multi-agency statutory guidance on female genital mutilation (HM Government, 2016b)	Y	N	N	N	Y	Y	N
	Scotland's national action plan to prevent and eradicate female genital mutilation (FGM) 2016-2020 (Scottish Government, 2016)	Y	N	N	N	Y	N	N
	Scotland's National Action Plan to Prevent and Eradicate Female Genital Mutilation (FGM) – Year Three Progress Report (Scottish Government, 2019)	Y	N	N	N	Y	N	N
NICE	NICE Postnatal care up to 8 weeks after birth Clinical guideline (NICE, 2006)	Y	Y	Y	N	N	N	N
	Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors (NICE, 2010)	Y	Y	Y	N	N	N	N
	Antenatal and postnatal mental health: clinical management and service Guidance Clinical guideline NICE (NICE, 2014)	Y	Y	Y	N	N	N	N
	Postnatal care overview-NICE clinical guideline (NICE, 2017)	Y	Y	Y	N	N	N	N
BMA	Female Genital Mutilation: Caring for patients and safeguarding children Guidance from the British Medical Association (BMA, 2011)	Y	N	N	N	Y	Y	Y

RCM	Evidence Based Guidelines *for Midwifery-Led Care in Labour* Care of the Perineum (The Royal College of Midwives, 2012)	Y	Y	Y	N	N	Y	N
RCOG	The Management of Third- and Fourth-Degree Perineal Tears Green-top Guideline No. 29 June 2015 (Royal College of Obstetricians and Gynaecologists, 2015b)	Y	Y	Y	N	N	Y	N
	Female Genital Mutilation and its Management Green-top Guideline No. 53 (Royal College of Obstetricians and Gynaecologists, 2015a)	Y	Y	Y	Y	Y	Y	N
RCN	Female Genital Mutilation An RCN resource for nursing and midwifery practice (Fourth edition) (Royal College of Nursing, 2019)	Y	Y	Y	Y	Y	Y	N
	Totals:	14/14	9/14	9/14	3/14	8/14	8/14	1/14

Table 3.9: **Application of specific analysis questions to WHO and EU documents**

Organization	**Document**	**Mention of maternal services?**	**Mention of perineal care?**	**Mention of antenatal, birth, post-partum care?**	**Mention of specific postpartum care needs for women with FGM?**	**Discussion of needs specific to FGM?**	**Discussion of education for healthcare professionals?**	**Mention of resources for women with FGM**
WHO	Female genital mutilation a teachers guide (WHO, 2000)	Y	Y	Y	Y	Y	Y	N
	Effects of FGM on childbirth in Africa (2006) (WHO, 2008)	Y	Y	N	Y	Y	N	N
	Global strategy to stop health-care providers from performing female genital mutilation (WHO, 2010)	Y	N	Y	N	Y	Y	N
	Global strategy to stop health-care providers from performing female genital mutilation (WHO, 2010a)	Y	N	Y	N	Y	Y	N
	An update on WHO's work on FGM progress report 2011 (WHO, 2011)	N	N	N	N	N	N	N
	Estimating the obstetric costs of female genital mutilation in six African countries (WHO, 2011b)	Y	N	Y	N	Y	N	N
	Postnatal Care of Mother and Newborn (2013) (WHO, 2013) *(Specific publications on FGM are separate)*	Y	Y	Y	N	N	N	N
	Guidelines on the management of health complications from female genital mutilation (WHO, 2016)	Y	Y	Y	Y	Y	Y	N
	Managing complications in pregnancy and childbirth: a guide for midwives and doctors (WHO, 2017) *(Specific publications on FGM are separate)*	N	N	N	N	N	N	N
	Care of girls and women living with female genital mutilation. A Clinical Handbook (WHO, 2018)	Y	Y	Y	Y	Y	Y	Y-not country specific
EU	Communication from the commission to the European parliament and the council. Towards elimination of FGM (European Commission, 2013)	Y	N	Y	N	Y	Y	N
	Totals: 11	9	5	8	4	8	6	1

3.3.1 Sources

An interesting and noteworthy finding is the common sources used by documents. The WHO uses original publications and peer-reviewed literature for health guidelines; the UN for information on laws and human rights, and UNICEF for prevalence data (WHO, 2018). International documents use primarily the WHO, peer-reviewed literature, the UN for laws and UNICEF for prevalence data. However, they also heavily use the RCOG guidance (2015a), and the RCOG guideline on the management of third and fourth degree perineal tears (2015b). noteworthy as many countries are using the UK as source material. Documents have many aspects to them, including tone; and exhibit the culture of the country that writes them. FGM is illegal in the UK, with the law and healthcare intertwined in a unique manner. This context is contained in all documents published by the UK as an undercurrent, and therefore may be influencing other countries view on FGM (already a divergent cultural practice). This is highlighted in the documents discussions of the specific criminal laws against FGM in the UK (Section 3.3; Culturally Sensitive Care).

Table 3.10 below shows which international guidelines use UK Literature.

Table 3.10: International Guidelines for FGM using UK Literature as Source Material

- RCOG Green-top Guideline No.53
    - RANZCOG, Ireland suggested reading
    - *SA:* South Australian Perinatal Practice Guideline Female Genital Mutilation (SA Maternal Neonatal & Gynaecology Community of Practice, 2018) as source
    - *WA:* Clinical Practice Guideline; Female genital cutting / mutilation (FGC/M) (Women's Health Coordinator (CaLD), 2015)
    - *Queensland:* Maternity and Neonatal Clinical Guideline; Perineal Care (Queensland Clinical Guidelines, 2018b)
    - Maternity and Neonatal Clinical Guideline Supplement: Perineal care (Queensland Clinical Guidelines, 2018a)
- RCOG Green-top Guideline No. 29
    - *SA:* South Australian Perinatal Practice Guideline Female Genital Mutilation (SA Maternal Neonatal & Gynaecology Community of Practice, 2018)
    - *Queensland:* Maternity and Neonatal Clinical Guideline; Perineal Care (Queensland Clinical Guidelines, 2018b)
    - Suggested reading Ireland

  - Maternity and Neonatal Clinical Guideline Supplement: Perineal care (Queensland Clinical Guidelines, 2018a)
- Royal College of Midwives. Evidence based guidelines for midwifery-led care in labour: Suturing the perineum. 2012
  - *Queensland:* Maternity and Neonatal Clinical Guideline; Perineal Care (Queensland Clinical Guidelines, 2018b)
- RCM (Tackling FGM in the UK)
  - Spain: Common protocol for a healthcare response to Female Genital Mutilation (FGM) (Ministry of Health Social Services and Equality, 2015)

UK documents use the WHO, UN and UNICEF sources for health, law and prevalence data respectively (BMA, 2011; HM Government, 2016; RCN, 2019; RCOG, 2015a); as well as the UK charity FORWARD for UK prevalence data (BMA, 2011; RCN, 2019; RCOG, 2015a). Peer-review published literature was also used (BMA, 2011; HM Government, 2016; RCN, 2019; RCOG, 2015a).

3.3.2 Culturally sensitive care

Providing culturally sensitive maternity care was described by the WHO as care *"organized for and provided to all women in a manner that maintains their dignity, privacy and confidentiality, ensures freedom from harm and mistreatment, and enables informed choice and continuous support during labour and childbirth"* (WHO, 2018, p183). Culturally sensitive issues such as engaging in a restricted diet, interpreters and female HCPs were discussed by international documents. An issue raised by several international documents was the potential for women with FGM to restrict their diet during pregnancy to reduce the size of the baby and subsequently reduce any negative impacts during birth (NSW Kids and Families, 2014; NZ FGM Education Program, 2009b; Women's Health Coordinator (CaLD), 2015). The use of interpretation services and appropriate interpreters was also discussed in international documents; with some highlighting the possible need for interpretation services (NZ FGM Education Program, 2009b; Perron et al., 2013); while others provided more detailed instruction including using a female interpreter when possible, and stating *"use of a family member for the purpose of interpreting is never appropriate"* (NSW Kids and

Families, 2014, p5). The Western Australia guideline further advised *"it is important to note that many interpreters are part of the community that the patient is from; therefore it is highly recommended that a phone interpreter be engaged to ensure confidentiality"* (Women's Health Coordinator (CaLD), 2015, p4). Female clinicians where possible were advised by many documents (Bansal et al., 2013; Ministry of Health Social Services and Equality, 2015; NSW Kids and Families, 2014; NZ FGM Education Program, 2009b; Perron et al., 2013; SA Maternal Neonatal & Gynaecology Community of Practice, 2018; Women's Health Coordinator (CaLD), 2015) and suggested seeking women's gender preference on care provider to enhance culturally sensitive care provision. One document noted the importance of terminology, suggesting clinicians refer to the practice as female genital cutting/mutilation, to ensure sensitivity and inclusivity of all communities (Women's Health Coordinator (CaLD), 2015).

National documents also discussed providing culturally sensitive care in relation to interpreters and the importance of communication about FGM by HCPs. Interpreters *"should ideally be appropriately trained in relation to FGM, and in all cases should not be a family member, not be known to the individual, and not be someone with influence in the individual's community"* (HM Government, 2016, p45). The RCN noted interpreters should be involved as necessary (RCN, 2019). Sensitive communication about FGM was also noted; with the RCOG Green Top No. 53, describing how the impact of *"FGM on labour and delivery should be sensitively discussed and a plan of care agreed"* (RCOG, 2015a, p5); however, specifics on how this was to be achieved were not provided.

While documents stated HCPs should ensure communication with women with FGM was culturally sensitive, the multi-agency statement also stated:

> *"cultural sensitivities must not get in the way of tackling FGM, but communicating about it in the wrong way can undermine and damage efforts. It is important to highlight that*

> *FGM is illegal, child abuse, a form of violence against women and girls, a human rights violation and a manifestation of gender inequality. However, communication on FGM also needs to be framed respectfully"* (HM Government, 2016, p45).

No specific training was suggested for HCPs to accomplish this mammoth task.

Both international and national documents addressed the need for culturally sensitive care provision, including the use of appropriate interpreters. However, differences in approaches can be seen in what information is provided to women and how the communication is given. International documents focused on health consequences of FGM and gently persuading women that FGM, while being against specific criminal laws, was negative for their health. National documents, while also focusing on the importance of interpretation services and sensitive communication about FGM, strongly focused on the law aspects of FGM. The multi-agency statement signed by the RCOG, BMA, RCN and RCM among others (HM Government, 2016b) is the only document analysed that suggests informing women with FGM, that the practice is considered a form of violence against women and girls, a human rights violation, and a manifestation of gender inequality. All other documents suggest HCPs discuss the health consequences of FGM, and the specific criminal laws against it. The above statement is a strongly worded one which shows the views of the UK government and professional organizations regarding FGM and should be noted as it is a very influential document cited by many others in the UK.

All documents discussed the need for healthcare practitioners to be educated about FGM and to be able to support women in a culturally sensitive and safe way, adapting assessments to include topics specific to FGM, such as the need for possible psychological support (NZ FGM Education Program, 2009b) and the law (Women's Health Coordinator (CaLD), 2015). Although referred to as a crucial aspect of care, specific education or examples were not provided in many documents. Documents that did discuss specifics warned practitioners not to show signs of shock or disgust when visually inspecting a woman’s genitals (NSW Kids and Families, 2014). ‘Othering’ the woman, though not expressly labelled as such, was warned against (NZ FGM Education Program, 2009b; RCN, 2019), as all women should feel comfortable and confident in their healthcare experience.

3.3.3 The Law

Although many countries across the world have outlawed the practice of FGM, some have not. Therefore the WHO Handbook (WHO, 2018) suggests HCPs be aware of their country’s laws to do with FGM and ensure they are abided by. All documents analysed discussed the law regarding FGM as all documents originated from countries where FGM is illegal. However, a distinctive difference is seen between documents in their approach to discussions about FGM and the law with women, the documentation required, and the overall tone discussions of the law have within documents. Also interesting to note are the timepoints where discussion of the law takes place; the antenatal period and PPP.

Although FGM is against the law in the countries represented, most of the international healthcare documents approached the topic of FGM from a predominantly health perspective. For example, in Australia (NSW Kids and Families, 2014) and New Zealand (NZ FGM Education Program, 2009b), the woman is given the choice of whether her FGM status appears on her medical record and it is only placed there to prevent further duplicate assessments and examinations taking place. All international documents noted the negative health consequences of FGM, both short and long-term and advised HCPs to educate women about them (German Medical Association, 2016; NSW College of Nursing, 2000; NZ FGM Education Program, 2009b; Women’s Health Coordinator (CaLD), 2015). Although international documents stated the importance of documenting care provision and discussions of the law, no additional documentation was required. This is in contrast with the unique mandatory reporting requirement of HCPs in the UK (Section 1.3).

Overall, the tone of the international documents were health focused and referred the woman to social work or a maternal child community nurse for safeguarding assessment, resulting in no assessment called for during pregnancy or birth (NSW Kids and Families, 2014; NZ FGM Education Program, 2009b). Some documents discussed the law at the beginning of the document (Women's Health Coordinator (CaLD), 2015), while others discussed the law throughout and specifically related the law to timepoints during care where the HCP may need to act (NZ FGM Education Program, 2009b). One document bolded any discussion concerning the law to highlight it's importance for HCPs (SA Maternal Neonatal & Gynaecology Community of Practice, 2018). Ensuring a healthy birth for mother and baby was the goal of all documents, and the law, while important and noted, did not take the spotlight away from health needs.

International documents suggest the antenatal period is a key timepoint during healthcare interactions to discuss the law and FGM with women. During antenatal appointments, practitioners were required to discuss the law regarding FGM and document they had done so (NSW College of Nursing, 2000; NSW Kids and Families, 2014; NZ FGM Education Program, 2009b; Perron et al., 2013; SA Maternal Neonatal & Gynaecology Community of Practice, 2018); with the Southern Australian guideline stating it *"is preferable that health care professionals initiate discussion around deinfibulation and the law antenatally"* (SA Maternal, 2018, p11).

The PPP was also seen as an important timepoint for discussions concerning the law from both HCPs and women's points of view. HCPs were reminded of the illegality of re-infibulation and cautioned to ensure any wound management regarding perineal trauma was not to resemble re-infibulation (German Medical Association, 2016). HCP were mandated to advise women that re-infibulation was illegal and having FGM done to a child was also illegal (German Medical Association, 2016; NSW College of Nursing, 2000; NSW Kids and

Families, 2014; NZ FGM Education Program, 2009b; Perron et al., 2013; SA Maternal Neonatal & Gynaecology Community of Practice, 2018; Women's Health Coordinator (CaLD), 2015).

All documents referred to infibulation and the law. The WHO also suggests that having laws enables easier discussions about FGM and re-infibulation with women as HCPs can not only refer to the negative health consequences, but also the legal ramifications of conducting FGM on a child or getting re-infibulated post-pregnancy. Other approaches seen in international documents was the focus on the illegality of re-infibulation (German Medical Association, 2016; NSW College of Nursing, 2000; NSW Kids and Families, 2014; NZ FGM Education Program, 2009b; Queensland Clinical Guidelines, 2018a; SA Maternal Neonatal & Gynaecology Community of Practice, 2018); both from a woman's perspective and the HCP perspective. HCPs were warned that conducting re-infibulation was against the law (German Medical Association, 2016; NSW College of Nursing, 2000; NZ FGM Education Program, 2009b).

Whether referrals were mandatory or not differed between documents, with one making it mandatory that all women with FGM see a social worker before discharge during the PPP (Women's Health Coordinator (CaLD), 2015), while others making sure HCP are aware it is the woman's choice; for example the Australian Northern Territory guideline states *"a Social Assessment should be made at the first antenatal visit and referral made to the FGM Liaison Officer for support, advocacy and referral to other appropriate services with all actions clearly documented. Please note it is the women's choice to take up the referral options"* (NSW College of Nursing, 2000, p11).

All UK national documents discussed the illegality of FGM in the UK (BMA, 2011; HM Government, 2016; Public Health Wales, 2018; RCN, 2019). Discussion of the law pertained to having FGM done to a child, the safeguarding and social work procedures involved and the act of re-infibulation after childbirth. Why re-infibulation cannot happen, and the need to tell the woman’s partner or family and community was also mentioned (BMA, 2011). Strong emphasis was placed on ensuring HCPs knew what procedures should be carried out regarding safeguarding, mandatory reporting and referrals (BMA, 2011; Public Health Wales, 2018; RCN, 2019; RCOG, 2015a; UK Department of Health, 2015). The law in the UK mandates that every women with FGM is reported (Section 1.3). This is enacted by healthcare providers conducting safeguarding assessments on all women attending maternity care appointments and collecting data (such as NHS number, type of FGM, country where the FGM occurred etc…). Safeguarding during maternity appointments includes the woman and her intent for re-infibulation, if applicable, and her intent to have FGM done if her baby is a girl. The distinction between noting on a woman’s chart whether she has FGM to prevent repetition of assessment (e.g. New Zealand) versus noting it because the law mandates it is significant, as one is healthcare driven and the other is law driven.

While healthcare providers in other countries conduct a safeguarding assessment and provide education, it is clear in the tone of the international documents that healthcare is the focus of the appointments. In contrast, there is a clear tone of the law first in the UK documents, with the RCOG (2015a) document discussing the law as the second section, giving it a page in the executive summary where other health-related topics received bullet points, and bolded the majority of the information concerning the law and professional requirements. While documentation is crucial in healthcare and is essential to providing good-quality care, documenting FGM in the UK is a legal requirement and thus a part of a healthcare assessment that is not health focused.

3.3.4 Education for HCPs

All documents noted the need for HCPs to be educated regarding the health consequences of FGM, the laws in their countries and how to educate and provide care to women. All guidelines were educational tools for HCPs; however, WHO and international documents did not specify exactly what education HCPs needed, how often it should be given, and how knowledge be evaluated.

Many documents discussed the importance of the healthcare interaction as a prevention mechanism and implored healthcare practitioners to take the opportunity an appointment provided and deliver as much education as possible (BMA, 2011; HM Government, 2016; NSW Kids and Families, 2014; NZ FGM Education Program, 2009a; Perron et al., 2013; RANZCOG, 2017; RCN, 2019; RCOG, 2015a). Many documents described the need for culturally sensitive care in this situation to ensure the woman and her family were not offended and did not withdraw from care (Bansal et al., 2013; BMA, 2011; NZ FGM Education Program, 2009b; Perron et al., 2013; RCN, 2019). All documents contained lists of health complications related to FGM; short term, long term and obstetric. Healthcare providers were expected to be knowledgeable about these complications and advise women about them and the healthcare they could access to alleviate symptoms (Bansal et al., 2013; Ministry of Health Social Services and Equality, 2015; RANZCOG, 2017; RCN, 2019; RCOG, 2015a). Educating women and their partners was noted by one document as a method of educating the wider community in the hopes of preventing re-infibulation and FGM on girls and other women (NSW Kids and Families, 2014); though the effectiveness of this kind of intervention has not been established. The importance of the healthcare provider status in the community and the respect it earned was seen as an opportunity to educate the community regarding FGM in one document (NSW Kids and Families, 2014), however, this can only be seen as an assumption of the guideline (NSW Kids and Families, 2014).

The UK documents referred to the NHS FGM e-learning (NHS England E-Learning, 2020), for all HCPs, and also referred HCPs to FGM leads for their Trusts when more knowledge was needed. Designated consultants and midwives should be available to provide care for women with FGM (RCN, 2019; RCOG, 2015a; UK Department of Health, 2015). Each Trust in the UK has an adult and child safeguarding lead for FGM, and maternity safeguarding and FGM leads. Additional reading was given by the majority of UK documents to ensure HCPs had resources to consult (BMA, 2011; HM Government, 2016; RCN, 2019; RCOG, 2015a). Apart from FGM itself, there was a heavy focus on HCPs knowing the law and how to complete mandatory reporting in the UK documents (BMA, 2011; HM Government, 2016; Public Health Wales, 2018; RCN, 2019; RCOG, 2015a). The Multi-Agency statement (HM Government, 2016b) suggests the following topics for HCP education: *"an overview of FGM (what it is, when and where it is performed); the UK law on FGM and child protection; the potential consequences of FGM; what to do when FGM is suspected or has been performed; and the role of different professionals and the importance of multi-agency working"* (p30). All documents served as educational tools for HCPs but no formal education except the NHS E-learning was stipulated.

3.3.5 Antenatal

During the antenatal period, the focus of the WHO Handbook (2018) is personalized care, identification and the creation of a birth plan and discusses it as a critical timepoint of interaction between women and healthcare systems. Specific information regarding women with FGM is detailed, and included: genital examination, visual recording of FGM type, pregnancy related FGM health consequences, such as increased risk of perineal trauma during birth; and includes a specific section on assessment of type 3 FGM and subsequent de-infibulation (WHO, 2018). Additionally, the usual information given to all pregnant women is also noted such as diet, hygiene, and regular check-ups with their HCP (WHO, 2018).

International documents reflected the WHO guidance and focused on the identification of women with FGM (European Commission, 2013; Holan et al., 2005; RANZCOG, 2017; SA Maternal Neonatal & Gynaecology Community of Practice, 2018;

Women's Health Coordinator (CaLD), 2015), and the creation of a personalized birth plan (German Medical Association, 2016; Holan et al., 2005; Ministry of Health Social Services and Equality, 2015; NSW College of Nursing, 2000; NSW Kids and Families, 2014; RANZCOG, 2017; SA Maternal Neonatal & Gynaecology Community of Practice, 2018; Women's Health Coordinator (CaLD), 2015). Birth plans were created to provide needed information to HCPs during labour and birth, and to enable HCPs to provide culturally sensitive care, while also ensuring the woman knew what to expect regarding de-infibulation if necessary. The RANZCOG (2017) guideline, and subsequently the NZ and Australian guidelines also discussed the importance of detailed documentation by HCPs; stating *"examination findings (including diagrams if appropriate) and management plan should be carefully documented in the patient record in order to reduce the need for unnecessary repeat examinations"* (RANZCOG, 2017, p3). HCPs were encouraged to create birth plans in partnership with the woman and her family (NSW College of Nursing, 2000; NSW Kids and Families, 2014; Perron et al., 2013; Women's Health Coordinator (CaLD), 2015); for example the Western Australian guideline states *"it is essential that the woman's husband or partner is involved in the discussions"* (Women's Health Coordinator (CaLD), 2015, p5), and the Canadian guideline echoes this point *"the focus should be on developing a detailed birth plan with her and her family"* (Perron et al., 2013, p1039). One guideline noted some women may experience psychological consequences of FGM during pregnancy and may *"develop a fear of childbirth as a result of post-traumatic stress disorder, anxiety and depression related to their experience of FGM/C"* (NSW Kids and Families, 2014, p4). It was advised that HCPs be aware of potential psychological consequences and refer accordingly. This was not noted in the antenatal period by the WHO or other international guidelines.

The UK documents also focused on the identification of women with FGM (RCN, 2019) and the creation of a birth plan (HM Government, 2016; RCOG, 2015a), however, this had equal importance to the safeguarding and mandatory reporting duties HCPs also had (HM Government, 2016; RCN, 2019; RCOG, 2015a). This is important to note, as whereas the international documents were health focused and included education regarding the law; the UK documents can be seen as law and health focused, highlighted in Figure 5.3 which displays the current flowchart of care recommended by RCOG (2015a) and giving equal importance to safeguarding, mandatory reporting and clinical management. As with international documents, UK documents also focused on Type 3 FGM and de-infibulation during the antenatal period; noting HCPs know and educate women regarding the law against re-infibulation (HM Government, 2016; RCN, 2019; RCOG, 2015a). As stated in international documents, UK documents also encouraged the inclusion of partners when creating a birth plan, stating *"partners should be involved in decision making when the woman is willing for this to happen. It is important to work out an agreed care plan with the woman early in pregnancy, and to involve interpreters as necessary"* (RCN, 2019, p32).

As with the New South Wales (NSW Kids and Families, 2014) guideline, the Multi-agency statutory guidance (HM Government, 2016b) and RCN (2019) both describe the possibility of women with FGM having flashbacks and the potential need for mental health services. HCPs should offer referral for psychological assessment where needed (RCOG, 2015a).

De-infibulation

The WHO Handbook (2018) provides detailed instructions and diagrams teaching HCPs how to conduct a de-infibulation procedure. The WHO suggests de-infibulation be carried out as soon as a woman is identified as being infibulated, during or outside of pregnancy. During pregnancy three timepoints for de-infibulation are available, each having their own advantages and disadvantages (Table 3.11); the second trimester (20-28 weeks), the first stage of labour, or the second stage of labour.

De-infibulation was a major focus of both International and National UK documents, which followed WHO guidance on de-infibulation procedures and techniques. Guidelines followed WHO guidance and recommended during de-infibulation *“the incision should extend anteriorly enough to allow visualisation of the external urethral meatus but not far enough to injure the buried clitoris or clitoral stump (potential for heavy bleeding)”* (RANZCOG, 2017, p4). De-infibulation during the antenatal period was recommended *“in women where antenatal assessment indicates that adequate vaginal examination is unlikely to be possible due to introital narrowing”* (RANZCOG, 2017, p4).

Figure 3.4: Flowchart of care for women with FGM in pregnancy. (Direct reproduction from: RCOG, 2015a, p24)

Table 3.11: De-infibulation timepoints and their advantages and disadvantages
Source: Created by Author from WHO (2018), Box 6.1 A and B (p210-211).

Timing of de-infibulation	Advantages	Disadvantages
During pregnancy	It facilitates several medical procedures required during pregnancy and labour: – performing vaginal examination if needed – obtaining clean samples of urine – investigating conditions such as vaginal infections, premature rupture of membranes and antepartum vaginal bleeding if they occur. • It allows time for healing before childbirth. • It gives the woman time to adjust to the physiological changes after de-infibulation • The woman will arrive at childbirth with an unobstructed vaginal opening	It requires performing a minor surgical procedure during pregnancy. • The woman will need to return to the healthcare facility for postoperative follow-up. • Women must be able to rest and take good care of the wound for a week after the procedure.
During Labour and Birth	If deinfibulation was not advisable or not performed during pregnancy, this will be the only opportunity to open the infibulation in a woman with type III FGM in order to facilitate unobstructed vaginal childbirth. • It facilitates the evaluation of the progression of labour, and also facilitates medical procedures required during childbirth.	Anatomical conditions that arise during labour, such as tissue oedema and distortion, may pose difficulties when performing intrapartum de-infibulation – especially for less-experienced health-care professionals • There is a risk of injuring the baby during the procedure. • While dealing with the pain of contractions during labour, it may be difficult for the woman to keep still during the deinfibulation procedure. • In cases when labour progresses fast, there may not be time to perform deinfibulation. This puts women at risk of severe perineal tears.

The majority of documents stated the desired time for de-infibulation was during pregnancy (20-28 weeks) (Bansal et al., 2013; NSW Kids and Families, 2014; NZ FGM Education Program, 2009b; SA Maternal Neonatal & Gynaecology Community of Practice, 2018; Women's Health Coordinator (CaLD), 2015). This timepoint is not based on specific evidence, but rather a consensus as it is not in the first trimester (risk of spontaneous abortion), and early enough to allow full healing before labour and birth. However, the RANZCOG (2017) guidelines stated de-infibulation could be carried out at any time during pregnancy; which is against the WHO recommendation of not de-infibulating during the first trimester due to the general increased risk of spontaneous abortion during this time (WHO, 2018); and important to note as the Australian and New Zealand guidelines both cite RANZCOG (2017) as a main source. Elective de-infibulation should be offered to women if an unexpected c-section occurs during labour and birth (NSW College of Nursing, 2000). While many documents simply stated when de-infibulation could and should occur, the Southern Australian guideline (SA Maternal Neonatal & Gynaecology Community of Practice, 2018) was the only document to provide details about how HCPs should come to the decision of when to de-infibulate, stating;

> *"The timing [of defib] should be based on the following factors:*
> *•The woman's preference*
> *•Obstetric history*
> *•Access to healthcare*
> *•Place of birth, and;*
> *•The skill of the healthcare provider.*
>
> *Detailed records (including diagrams) of the genital examination should be kept and shared with other health care professionals as required. This should be coupled with a detailed history identifying any complications the woman may have experienced because of her FGM including psychological distress. A care plan for labour should be developed with the woman. The woman's wishes regarding perioperative deinfibulation should be clearly documented in case of the need for a caesarean section during labour, particularly in the event of an*

> *obstetric emergency (deinfibulation may also be required to perform urinary catheterisation)"* (SA Maternal, 2018, p11-12).

De-infibulation during the second stage of labour was discussed as the preferred time by the Spanish and Canadian guidelines (Ministry of Health Social Services and Equality, 2015; Perron et al., 2013). Germany was the only country to recommend de-infibulation only take place during labour to prevent two operations happening (German Medical Association, 2016).

Skilled midwives or senior doctors were suggested to carry out de-infibulation (German Medical Association, 2016; NSW College of Nursing, 2000; NSW Kids and Families, 2014; NZ FGM Education Program, 2009a; Perron et al., 2013; Queensland Clinical Guidelines, 2018a; SA Maternal Neonatal & Gynaecology Community of Practice, 2018), with the South Australian guideline stating *"Intrapartum deinfibulation is performed by a senior doctor or midwife skilled in deinfibulation or under the direct supervision of a skilled doctor or midwife and following the woman's consent"* (SA Maternal, 2018, p12).

After care of women who had been de-infibulated was mentioned in a few documents (NSW College of Nursing, 2000; NZ FGM Education Program, 2009b; Perron et al., 2013; Women's Health Coordinator (CaLD), 2015); although specifics about care provision was lacking. The Northern Territory (NSW College of Nursing, 2000), New Zealand (NZ FGM Education Program, 2009b, 2009a) and Canadian (Perron et al., 2013) guidelines all mentioned the possible psychological impacts of being de-infibulated women might experience and suggested referrals to appropriate services. The Western Australian guideline stated HCPs should provide advice on perineal healing and hygiene but did not state what specific advice should be given and did not refer to another document (Women's Health Coordinator (CaLD), 2015). Other documents, such as the Canadian guideline suggest readers refer to the WHO guideline for additional information. The Australian guidelines (NSW College of Nursing, 2000; NSW Kids and Families, 2014; Queensland Clinical Guidelines, 2018a; SA Maternal Neonatal & Gynaecology Community of Practice, 2018; Women's Health Coordinator (CaLD), 2015) suggest readers refer to the RANZCOG (2017) guideline which in turn guides HCPs to provide care based on usual perineal injury care plans.

The UK guidance also suggests that during pregnancy, de-infibulation take place during the second trimester of pregnancy (RCN, 2019; RCOG, 2015a). The RCOG recommends *"all gynaecologists, obstetricians and midwives should receive mandatory training on FGM and its management, including the technique of de-infibulation. They should complete the programme of FGM e-modules developed by Health Education England"* (RCOG, 2015a, p13). One of the main foci of the antenatal period was de-infibulation for UK documents. This ensured a skilled HCP was available to complete the procedure, whereas if the woman waited until labour and birth, an experienced HCP may not be available; showing that although the above recommendation exists, not all gynaecologists, obstetricians and midwives are suitably skilled or experienced (RCN, 2019; RCOG, 2015a). Outside of pregnancy, de-infibulation is recommended as soon as it is identified (BMA, 2011; RCN, 2019; RCOG, 2015a). After-care of women who had been de-infibulated was not mentioned in either the RCOG Green-top No. 53 (2015a) or the RCN (2019) guideline.

All documents noted and focused on the adverse outcomes associated with waiting until labour to complete de-infibulation including increased risk of foetal and maternal death, increased risk of tearing, postpartum haemorrhage, and perineum instability (NSW Kids and Families, 2014; NZ FGM Education Program, 2009b; RCN, 2019; RCOG, 2015a; SA Maternal, 2018). The de-infibulation procedure was discussed in detail with the majority of documents including detailed instructions with diagrams within the documents or as an appendix (NSW Kids and Families, 2014; NZ FGM Education Program, 2009b; RANZCOG, 2017; Royal College of Obstetricians and Gynaecologists, 2015a; Women's Health Coordinator (CaLD), 2015). Personalized care was described as essential and variations of the de-infibulation procedure, from day surgery with general anaesthesia to an outpatient procedure with local anaesthesia were described (NSW College of Nursing, 2000; RCOG, 2015a; Women's Health Coordinator (CaLD), 2015). The de-infibulation procedure was also seen as an important time to discuss the law prohibiting re-infibulation with women, and describing how, after they birthed their baby, they would not be medically re-infibulated (German Medical Association, 2016; Holan et al., 2005; NZ FGM Education Program, 2009b; RANZCOG, 2017; RCOG, 2015a). De-infibulation was also seen as a major educational opportunity for the changes in the woman's body post-de-infibulation, with essential information such as differences in voiding, menstruation and appearance being discussed (NSW Kids and Families, 2014; NZ FGM Education Program, 2009b; RCN, 2019; RCOG, 2015a; Women's Health Coordinator (CaLD), 2015).

The antenatal period is focused on identification, de-infibulation if necessary, and the creation of a birth plan. A difference was seen between international and national documents on their focus on health and the law regarding FGM. The next section compares and contrasts documents with a focus on the timepoint of labour and birth.

3.3.6 Labour and birth

The focus of labour and birth regarding FGM was found to be de-infibulation (if necessary and not already completed), and the prevention of perineal tears and the use and need of episiotomies. As de-infibulation has been discussed above, this section focuses on perineal support.

Perineal support.

The WHO gives detailed guidance on steps HCPs should follow during labour and birth for women with FGM (WHO, 2018, p182); including taking a thorough history of the woman and assessing the perineum. The WHO discussed perineal care in the context of de-infibulation, and scar tissue leading to increased perineal tearing during birth and stated that

> *"if during the [perineal] assessment it is possible to introduce a finger but impossible to stretch the opening at all because of resistance due to scar tissue, inform the woman that it will be necessary to open up the vaginal opening during childbirth by performing a medio-lateral episiotomy"* (WHO, 2018, p189)[2].

Avascular scar tissue may prevent the perineum from adequately stretching during childbirth and thus necessitate an episiotomy, preventing a potentially severe uncontrolled tear. Regarding episiotomy; the WHO states:

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[2] A medio-lateral episiotomy is a cut that starts at the posterior of the vaginal opening and extends towards the buttocks at a 45-degree angle. Directing the cut away from the rectal area is considered to reduce the risk of injury to the anal muscles and is a standard approach for episiotomy when required (RCOG, 2015).

> *"once the woman has been de-infibulated, it may be possible for her to give birth with the perineum intact. Episiotomy should only be carried out if the scarring due to FGM has caused extensive inelasticity of the skin around the vagina. As in other women during childbirth, episiotomy should not be performed routinely"* (WHO, 2018, p191).

International documents noted *"the intrapartum issues related to FGM are directly correlated to the degree of narrowing and scarring of the vaginal introitus"* (RANZCOG, 2017, p3). The RANZCOG guideline also noted the current data used to guide intrapartum care was collected in low-income countries and questions whether the associations of increased perineal tearing and episiotomy rates persist after migration to high-income countries (RANZCOG, 2017). International guidelines also note issues concerning the inelastic scar tissue that may be present in women with FGM (German Medical Association, 2016; Holan et al., 2005; Ministry of Health Social Services and Equality, 2015; NSW Kids and Families, 2014; NZ FGM Education Program, 2009b; Perron et al., 2013; Queensland Clinical Guidelines, 2018a; SA Maternal Neonatal & Gynaecology Community of Practice, 2018; Women's Health Coordinator (CaLD), 2015), with the New Zealand guideline stating:

> *"Perineal Assessment: Raw edges will retract and the baby's head will begin to crown. Care must be taken to ensure the perineum is stretching adequately. FGM Scar tissue may not stretch under pressure of the baby's crowning head. Should the perineum appear tight consider performing a medio-lateral episiotomy. Note: posterior episiotomies alone are not recommended as the anterior scar tissue and anterior vaginal wall may tear and cause excessive perineal trauma. Control the birth of the emerging head to avoid a precipitate birth. Continuous assessment of*

> *perineal stretching is required throughout this stage"* (NZ FGM Education Program, 2009b, p4).

There was little consensus on the language used to describe perineal tears in international documents; e.g. mild to severe (German Medical Association, 2016; RANZCOG, 2017), spontaneous lacerations (SA Maternal Neonatal & Gynaecology Community of Practice, 2018), 'blow-out' (Perron et al., 2013); and shows the different international approaches. International documents recommended the use of a medio-lateral episiotomy if clinically indicated (NSW Kids and Families, 2014; Queensland Clinical Guidelines, 2018a; Women's Health Coordinator (CaLD), 2015); and noted if the woman has been de-infibulated previously, HCPs should proceed as with a woman without FGM (NZ FGM Education Program, 2009b). Only the Canadian guideline (Perron et al., 2013) suggested an episiotomy be carried out as standard care when de-infibulation takes place during labour; stating *"if defibulation is performed intrapartum, an episiotomy performed at the same time facilitates delivery and minimizes vaginal tearing"* (Perron et al., 2013, p13). This is against current WHO policy, and current international and UK policy.

UK documents state perineal assessment, the decision to perform an episiotomy and treatment of any perineal tears should follow routine guidelines for all women (RCOG, 2015a); and refer to the RCOG guidelines on perineal care (RCOG, 2015b). However, the RCOG guideline does note the increased risk women with FGM have for episiotomy due to scar tissue, regardless of type of FGM and whether they have been previously de-infibulated (RCOG, 2015a). The RCN guideline also noted how

> *"midwives need to watch women who have undergone type 3 FGM closely during the second stage of labour, even when the woman's introitus has*

previously been assessed as adequate for the birth; unexpected problems may occur with descent of the fetal head or stretching of the perineum because the scar tissue around the vagina and perineum may be unstable" (RCN, 2019, p34).

If needed, a medio-lateral episiotomy should be used (RCN, 2019; RCOG, 2015a). HCPs were reminded to ensure the woman and her family were aware of the laws against FGM and re-infibulation in the UK (HM Government, 2016; RCN, 2019; RCOG, 2015a); and to complete mandatory reporting and safeguarding duties (BMA, 2011; Public Health Wales, 2018; RCN, 2019; RCOG, 2015a).

The focus of the labour and birth sections in documents were de-infibulation and perineal support. FGM is a highly unique procedure and HCPs were advised to assess and watch closely the perineum to prevent uncontrolled tears due to inelastic scar tissue that may be present.

3.3.7 Postpartum

The PPP was given the least space within documents and information focused on immediate after-birth care. The WHO divides the PPP into immediate, after childbirth and follow-up (WHO, 2018). Immediate postpartum health consequences include: *"postpartum haemorrhage, excessive blood loss and injury to neighbouring structures, urine retention, damage to neighbouring structures, infection of sutured perineal tears, extensive perineal tears and/or vesico/vaginal fistulae or recto-vaginal fistulae, psychological problems"* (WHO, 2018, p197). Immediate care provision includes assessment and repairing perineal injuries (WHO, 2018). After childbirth and follow-up care is identical to the care provided to women without FGM, with additional information focused on women with Type 3 FGM such as counselling regarding changes to the appearance of genitals, no re-infibulation, the benefits of de-infibulation and abstaining from sex for four-six weeks until the woman has healed and feels ready (WHO, 2018). HCPs are encouraged to make themselves available for follow-up questions and are reminded the *"PPP is an ideal opportunity to advocate for the prevention of FGM!"* (WHO, 2018, p197). Any women who give birth to baby girls should be counselled about the negative health consequences associated with FGM; with partners and family members also included in all care discussions (WHO, 2018). A 6-week GP postnatal check-up for woman and baby is advised (WHO, 2018).

International guidelines focused on physical changes and wound care due to de-infibulation (German Medical Association, 2016; Ministry of Health Social Services and Equality, 2015; NSW College of Nursing, 2000; NSW Kids and Families, 2014; SA Maternal Neonatal & Gynaecology Community of Practice, 2018). As stated above, guidelines instructed HCPs to provide perineal care and education as usual (German Medical Association, 2016; Perron et al., 2013; Queensland Clinical Guidelines, 2018a; RANZCOG, 2017), with only the NSW and Spanish guideline suggesting extra perineal checks should be conducted at home for women with FGM to ensure appropriate healing. Partners should be involved in all discussions (Ministry of Health Social Services and Equality, 2015; NSW College of Nursing, 2000; NSW Kids and Families, 2014); and counselling should be referred as necessary (Ministry of Health Social Services and Equality, 2015; NSW College of Nursing, 2000; NSW Kids and Families, 2014; NZ FGM Education Program, 2009b). As suggested by the WHO, a 6-week postnatal check with a GP is advised (Ministry of Health Social Services and Equality, 2015; NSW College of Nursing, 2000; NSW Kids and Families, 2014; Perron et al., 2013; Queensland Clinical Guidelines, 2018a; RANZCOG, 2017). A referral to a community health nurse should be considered with the woman's consent (NSW College of Nursing, 2000).

The New South Wales (NSW Kids and Families, 2014) guideline was the only document to provide detailed information about care for the first seven days postpartum, including providing education on issues such as pain and pain relief, infection and mental health, changes after de-infibulation, advice on care for vulval, perineal or vaginal wounds, and encouraging the woman to abstain from sex for 4-6 weeks. HCPs were advised to assess the perineum daily for seven days following birth to ensure wounds were healing appropriately, and to *"ensure that the woman has information about support services in the community that are relevant to her needs such as refugee health workers, family planning, women's health nursing and/or physiotherapy as required"* (NSW Kids and Families, 2014, p12).

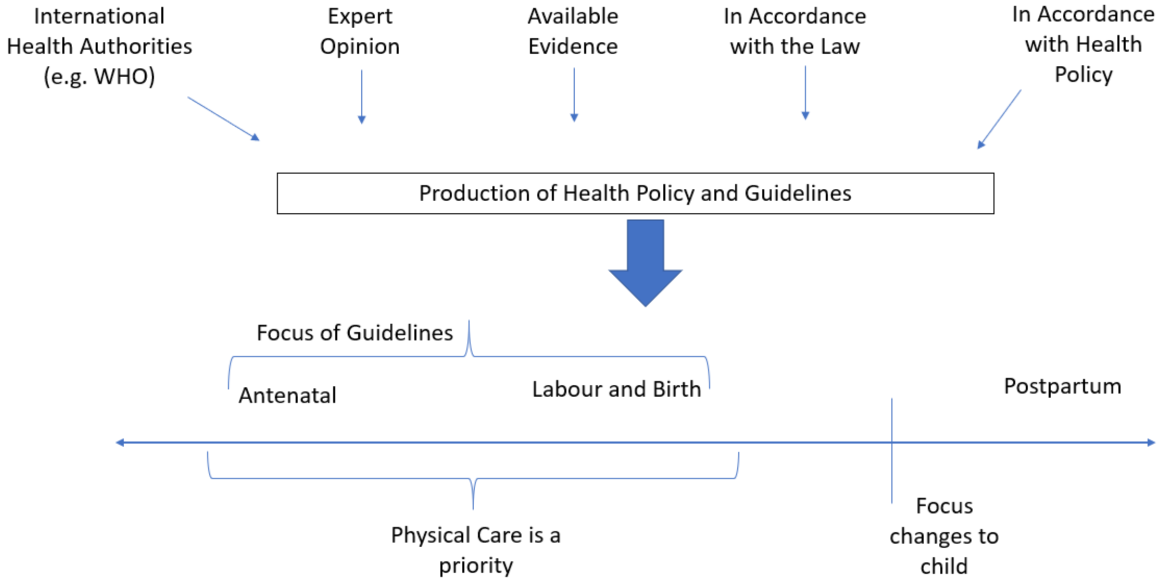
The law; specifically no re-infibulation or FGM performed on children, was also a focus of international documents (Ministry of Health Social Services and Equality, 2015; NSW College of Nursing, 2000; NSW Kids and Families, 2014; NZ FGM Education Program, 2009b; SA Maternal Neonatal & Gynaecology Community of Practice, 2018; Women's Health Coordinator (CaLD), 2015); with the German guideline discussing the need for HCPs to understand the difference between wound management and re-infibulation, listing the legal consequences to HCPs if re-infibulation was performed (German Medical Association, 2016). The Western Australian guideline was the only guideline to reiterate the laws against FGM and the procedures HCPs must follow in the postpartum healthcare section and shows a legal focus of this document's approach to postpartum care (Women's Health Coordinator (CaLD), 2015).

Although little health information was present in postpartum sections of UK guidelines, the law was heavily focused on, with guidelines ensuring HCPs knew their legal requirements and what penalties they would face if they did not (RCN, 2019; RCOG, 2015a). HCPs were reminded to ensure all legal requirements were completed before discharge, and health visitors and GP’s were notified if the woman gave birth to a girl (RCN, 2019; RCOG, 2015a). Postpartum care once discharged was briefly alluded to in one national document describing how “a discharge plan will be prepared offering support and facilities required for providing care at home” (UK Department of Health, 2015) and *"it is necessary to follow up with the woman during the postnatal period. Support, information and counselling continue to be very important”* (RCN, 2019, p33). During the PPP, ongoing information and support should be given, however no information on what this entailed was given. Some documents stated women should be referred to community organizations but did not specify who should refer or when. De-infibulation, if not conducted before birth or during labour, should be completed during the PPP (RCN, 2019; RCOG, 2015a; UK Department of Health, 2015). Women should also be provided education about the law and FGM in the UK (Royal College of Nursing, 2019; Royal College of Obstetricians and Gynaecologists, 2015a; UK Department of Health, 2015). Usual postpartum care pathways should be followed (RCOG, 2015a; UK Department of Health, 2015). In the UK this includes home visits by midwives and a health visitor, and a 6-week GP antenatal check-up. Although international documents did not specify what postpartum care provision specifically entailed; the 6-week postnatal GP check-up is a common feature and recommended by the WHO for all women experiencing the PPP.

3.4 Discussion.

The above analysis displays a top-down approach to the creation and desired implementation of guidelines for healthcare regarding FGM and has been conceptualized in Figure 3.5.

Figure 3.5: Conceptualization of Documentary Analysis Findings (Source: Author, 2020)



Current methods of creating guidelines, such as those used by NICE (2014), are thorough but can only use available evidence. An example of this is the RCOG (2015a) guideline, which makes recommendations based predominantly on expert opinion and case studies or reports, and thus is based on evidence receiving a Grade D, or a ‘good practice point’ mark from their evaluation methods, and thus constitutes low-quality evidence. Unfortunately, there is a lack of evidence in this area, and when combined with difficulties developing clinical trials, expert opinion is sought. Although expert opinion is a reasonable alternative, the choice of experts may be wanting, namely academics and clinicians rather than women with FGM and community experts. Currently NICE (2014) states guideline committees include stakeholders, which can include members of affected communities; however, no community members were used in the creation of the RCOG (2015a) guideline; a major limitation based on the literature discussed in Chapter 1. According to the NICE guideline manual, experts are chosen through a rigorous recruitment process, though details on what this included were not given (NICE, 2014). This is important to note as the UK guidelines are heavily used as source material for international guidelines (see Table 3.10). Guidelines from international bodies such as the WHO use amalgamated data from many countries and may not be applicable to the UK context due to differences in law, specifically mandatory reporting, or due to healthcare practices already in place for women without FGM as the UK has high-quality maternal healthcare (Knight et al., 2019), and the possible effects of migration on women's attitudes and experiences of FGM. The effects of migration on perceptions of healthcare for women with FGM are difficult to assess as many intertwining factors contribute to what cultural importance women accord FGM, and how this changes after migration (Isman, Ekéus, & Berggren, 2013), and provide another reason why women with FGM should be consulted involving the creation of FGM healthcare guidelines.

Hassanen, Okubatsion Woldu, and Mkuu, (2019) explored men's and women's perceptions of FGM after migration from the Horn of Africa to Melbourne, Australia, and found men and women believed migration had given them a new perspective on the practice of FGM. The authors reported that the majority of women in their sample (23/25) felt FGM was a harmful cultural practice and were happy they could oppose it in Australia (Hassanen et al., 2019). Johansen (2017) explored whether perceptions changed towards premarital de-infibulation for Sudanese and Somali women and men living in Norway and found that while the negative health consequences were known, cultural ideals of virginity and virtue persist and restrict the uptake of premarital de-infibulation offered for this population. The above studies suggest women with FGM living in the UK should be consulted concerning FGM healthcare guidelines as they could provide insight pertaining to their specific needs as migrants in the UK.

General migration effects are also difficult to apply as migration appears as an umbrella term within the literature and studies included varied populations of 'migrants'; including those who have lived the majority of their lives in the new country, and those that have recently arrived (Johnsdotter & Essén, 2016). Recent migration to the UK has been included in the NICE (2010) guideline on pregnancy and complex social factors and discusses the need for HCPs to educate women regarding the NHS services available to them, as well as ensuring interpreters are available if needed. The mode and reason for arrival is also of great importance when considering healthcare needs and experiences. Refugee and asylum-seeking women will have vastly different health needs compared to women who are migrating for study or to join already established family members (e.g. a pregnant woman traveling alone and seeking asylum versus a pregnant woman traveling with family members to a country where people she knows are already established and willing to help her settle) (Giuntella et al., 2018; NICE, 2010). Context is of great importance when considering the postpartum needs of women with FGM, with more studies needed to assess the current experiences, needs and perceptions of women with FGM experiencing the birth process; in addition to increased consultation regarding the creation and evaluation of healthcare guidelines affecting them. A more detailed discussion of the influence of knowledge pathways follows in the wider discussion (Section 6.2.2).

The documents contained in this analysis display the focus on the antenatal, labour and birth stages of the birth process by the healthcare system. This is a known phenomenon and has been written about by various nursing and midwifery authors (e.g. Barker, 2013; Bird, 2014) with some naming the PPP the ‘Cinderella’ of the birth process due to its lack of attention for both physical and mental health (McCalmont, Brown, Mills, & Lees, 2010; Rogers, 2018). This represents an interesting and complicated intersection for the healthcare system and its users. The NHS uses a pragmatic approach to healthcare traditionally focused on the physical health needs of people (Grosios, Gahan, & Burbidge, 2010). Knowing this, it appears reasonable that in the context of FGM, the majority of focus would be on the antenatal period, preparing for labour and birth through assessing the need for de-infibulation, and labour and birth, where increased risk of perineal damage and postpartum haemorrhage among other complications, can occur (Section 1.10). Unfortunately, focusing on the physical needs leads to a lack of postpartum care considerations appearing in guidelines, with usual postpartum care being advised for women with FGM (RCN, 2019; RCOG, 2015a; WHO, 2018). Although current evidence is sparse on the experiences and needs of women with FGM in general, and those who have been de-infibulated during pregnancy or labour, it is an important area requiring further study due to the uniqueness of each experience and potential additional needs. With current literature suggesting women with FGM have worse outcomes than women without FGM during pregnancy and birth (Albert, Bailey, & Duaso, 2015; Glover, Liebling, Barrett, & Goodman, 2017; WHO, 2018), it is wise to assume these women face unique issues during the PPP (Abdulcadir, Rodriguez, & Say, 2015), due to the potential for intersecting needs based on migration status and reason, general health, socio-economic status, in addition to the potential negative outcomes FGM can cause during birth and therefore the PPP (please see Chapter 1, section 1.5 for a description of the negative obstetric outcomes due to FGM). Noting that the majority of maternal deaths occur in the PPP (Knight et al., 2019) may enhance the awareness of HCPs of this possibility while more research is conducted to increase the knowledge regarding what the specific postpartum needs of women with FGM are in the UK context.

Passing comments concerning discharge planning and immediate after-birth affects were made but lacked substance. Documents did not focus on or contain details pertaining to the PPP once the woman and baby were discharged home and directed healthcare providers to follow routine protocols for perineal tears and episiotomies with regular follow-up care (RANZCOG, 2017; RCOG, 2015a). In addition to the medical aspects of care, there was a lack of specific guidance for enacting culturally sensitive care. Although all guidelines discussed culturally sensitive care in terms of terminology, interpreters and female clinicians, no mention of asking women what their expectations of care were, was made. Literature shows migrants expectations of care often do not match reality (Balaam et al., 2013; Firdous et al., 2020; Jomeen & Redshaw, 2013), and suggests further discussions between HCPs and women, as well as research is needed. Overall, a trend throughout the documents was a lack of attention given to the PPP in the presence of FGM.

Postpartum care was not given unique coverage, except in one document; the New South-Wales Australian guideline (NSW Kids and Families, 2014), which discussed daily checks of the perineum for seven days post-delivery. The feasibility of such measures in the NHS would need to be researched, but also the need as visual checks of the perineum after the experience of childbirth may be unwanted by women, and unnecessary. While visual checks may ensure no infection is occurring, education and continuity of care with one midwife may act as a more feasible and acceptable approach to assessing care needs in the PPP. Most documents discussing pregnancy did not mention the PPP, and those that did focused on the law, immediate after-birth issues, or as an opportunity for community wide education (NSW Kids and Families, 2014; RANZCOG, 2017; SA Maternal Neonatal & Gynaecology Community of Practice, 2018)

Although heavy focus is placed on de-infibulation to ensure an unobstructed birth; it is acknowledged by the literature (Berg & Underland, 2013; Larsen & Okonofua, 2002) and expressed throughout the documents analysed that women with FGM have an increased risk of perineal trauma during birth which is not dependent on type of FGM or if they have been de-infibulated (WHO, 2018). With this knowledge it is surprising more attention is not paid to the perineum during the antenatal period. While it is true there are not many interventions, except caesarean birth, which can minimize the risk of perineal damage (for that one birth episode) (RCN, 2019; WHO, 2018); education and preparation of the woman may promote a feeling of control over their care, an important feature of positive birth experiences (Downe & McCourt, 2019). The importance of antenatal de-infibulation was discussed extensively, and while the focus was on reducing possible complications and time restrictions during labour; traditionally within FGM practicing communities, de-infibulation occurs during labour by midwives (Gruenbaum, 2001), which may make the focus of antenatal de-infibulation by Western healthcare systems perplexing and anxiety causing for women (Almroth et al., 2001). A systematic review using PRISMA guidelines conducted by

Esu, Udo, Okusanya, Agamse, and Meremikwu (2017) found only two studies to analyse, both discussed above (Albert et al., 2015; Paliwal et al., 2014); and concluded there is no statistically significant difference between the clinical outcomes of women with Type 3 FGM who underwent de-infibulation during the antenatal period versus during labour. The review analysed the clinical outcomes of duration of labour, perineal lacerations, episiotomies, postpartum haemorrhage and caesarean delivery (Esu et al., 2017); suggesting the focus of antenatal de-infibulation is to ensure trained HCPs are available for de-infibulation and to decrease adding this task during birth. Limitations include the inclusion of only two retrospective studies conducted in the UK, resulting in generalisability inappropriate at this time. Limitations from the original studies are carried into systematic reviews and must also be acknowledged, such as the retrospective nature and small sample sizes. More research, such as observational studies which include women's views on their experiences would progress the limited knowledge in this area.

Interestingly, while mental health was discussed as a potential source of concern during labour and delivery, it was only mentioned in a few documents as a concern during the PPP (Ministry of Health Social Services and Equality, 2015; NSW College of Nursing, 2000; NZ FGM Education Program, 2009b). If psychological difficulties arise during labour and delivery, and perhaps during the antenatal period following de-infibulation; it stands to reason that psychological care will be needed during the PPP when the woman is not only caring for herself, but a new-born and possibly others as well. Mental health should be a priority in all mothers in the PPP (National Collaborating Center for Mental Health, 2018), however particular attention should be paid to women with FGM during this time due to specific matters such as the possible effects of their genitals changed appearance (WHO, 2018), the experience of giving birth using a potentially unfamiliar culture’s healthcare system, and possible social and cultural ramifications from not being re-infibulated following birth (Braddy & Files, 2007); in addition to not having the usual support networks present if recently settled in the UK.

Healthcare provider education and training needs were discussed by all documents. As documents were all retrieved from nations where FGM is a culturally unfamiliar practice, many healthcare providers do not have satisfactory knowledge concerning how to provide care for women with FGM. A systematic review assessing literature on healthcare students and providers knowledge, attitudes and practice regarding FGM was conducted by Abdulcadir, Say, and Pallitto (2017). Published and grey literature was searched using two online databases. Twenty-nine studies met the inclusion criteria, with only 19 evaluation tools analysed due to access. Included studies originated from low/middle income countries and high-income countries and included a wide range of participants including university students, nurses, midwives, physicians (differing specialities), social workers and public health workers. No systematic means of evaluating HCPs knowledge, attitudes and practice regarding FGM was found. Of particular interest was the lack of knowledge regarding the assessment and clinical management of women with FGM to prevent and treat associated consequences. With no evaluation of HCP interaction with women with FGM it is difficult to assess educational needs and their impact on practice. The authors conclude a universal evaluation tool would allow comparisons in different settings, as well as adaptation to the educational needs and resources of each setting.

While none of the documents in this analysis specifically stated what training should include, when all documents are taken together, the topics of: consequences of FGM, tearing, repair of tears, de-infibulation, mandatory reporting, laws associated with FGM, safeguarding, community support and opportunity to educate can be pieced together to provide a list of the essential topics that should be covered (Table 3.12). Not only do healthcare providers need to know the medical processes and care involved, including the referral pathways, procedures, and community supports available, they also need to be aware of the cultural significance and meaning FGM has to those who practice it, and any impacts this may have on not only the population’s access to care, but their acceptance of the care itself (Carolan & Cassar, 2010). FGM is not practiced by the dominant culture of the healthcare services these documents guide. Special attention should be given to the differences in care between what is expected by women and what is provided by the healthcare system (WHO, 2018), with this lacking in the documents analysed.

Table 3.12: Healthcare Provider Training; potential topics

1) FGM basics
2) FGM health implications
3) Tearing/ episiotomy/repair during birth and after-effects
4) De-infibulation
5) Mandatory reporting
6) The law regarding FGM
7) Safeguarding
8) Community support
    a) Opportunity to educate

3.5 Conclusion

There is currently a dearth of knowledge regarding the PPP for women with FGM, and it is an area which needs further research (Abdulcadir et al., 2015). While health consequences are known (WHO, 2016), and a few studies have reported worse perineal outcomes for women with FGM (e.g. Albert et al., 2015; Berg, Underland, Odgaard-Jensen, Fretheim, & Vist, 2014; Lockhat, 2004; WHO, 2006), more knowledge is needed. This study analysed International and National guidelines and policies directing how maternity care should be given to women with FGM. However, most guidelines did not focus on the PPP, and those that did failed to acknowledge the specific needs of women with FGM during this time. Only one guideline (NSW Kids and Families, 2014) provided a specific care pathway for women with FGM in the PPP. Guidelines provide essential evidence-based information for healthcare providers to follow and set the tone of care provided. If current guidelines do not view women with FGM as having specific needs during the PPP, healthcare providers cannot be expected to; resulting in potentially inadequate care being given. It is still unknown if women with FGM experience extra needs during the PPP, and if they do, what those needs are. The following chapters seek to answer those questions.

The medical issues of inelastic and avascular scar tissue combined with pregnancy and birth prompting potential mental health concerns; coupled with the cultural issues of differences in healthcare provision and a potential lack of community or family support due to migration create a potential for adverse outcomes. More information is required on the experiences and needs of women with FGM in the PPP and this issue is therefore the focus of the following study. Findings will improve our understanding of the experience of postpartum care from the women’s and the healthcare system perspective and potentially support the development of evidence-based, standardized policies. Pregnancy is an important and life changing transition event in women’s lives and represents a key contact point for healthcare providers.

This chapter has achieved objective 1: to identify and thematically analyse current international and national guidelines on FGM during pregnancy and the PPP and provides context and understanding of the current healthcare provision for women with FGM using NHS maternity services. This chapter has shown the intertwining of the law and healthcare practices associated with FGM, and the lack of attention paid to the PPP and possible health needs of women during this time. The next chapter investigates the experiences and perceptions of Key Informants providing care for women with FGM.

Chapter 4 Key Informant Findings

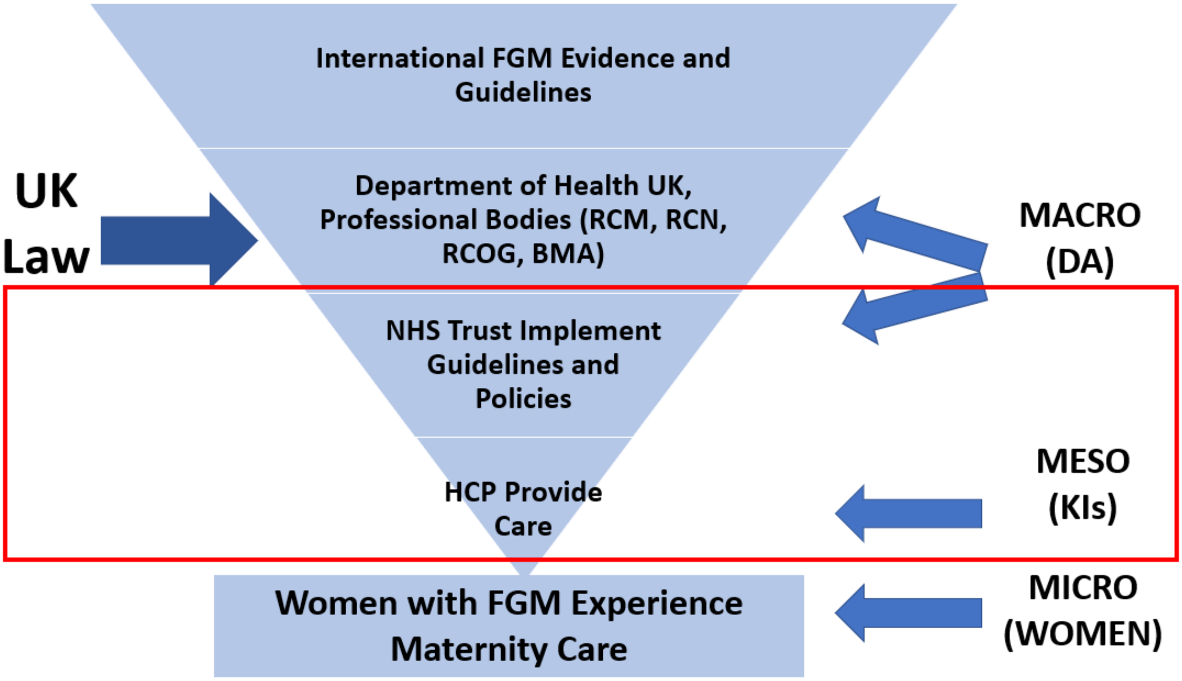
"I think, you know, the, the general comment I would make is I think postnatal care, whether you're from a culture where FGM is practiced or not is, is poorly resourced" (201803SD)

In order to understand women's experiences, the roles and views of Key Informants (KIs) working within the NHS was needed. This is not a complete data set and was never intended to be, however, it does provide context to the women's experiences by providing information about who women with FGM might come into contact with during the birth process and what resources are available. In doing so it reflects the ethnographic process of viewing women in their natural contexts and enhances the ability to understand the relationship pregnant women have with the healthcare system.

KIs provided much needed context to women's experiences throughout the birth process. KIs were divided into policy KIs, direct care KIs and police KIs. Policy KIs were defined as those not having direct interaction with healthcare service users and included safeguarding leads, research nurses, and CCGs. Direct care KIs were defined as having direct interaction with healthcare service users and included GPs, health visitors and midwives. The Police were defined separately as even though they do not provide healthcare or influence care for women directly, they can be intertwined with healthcare experiences if safeguarding issues arise.

These groups coupled with the documentary analysis (Chapter 3) and women's experiences (Chapter 5) provide deep understanding of the birth experience for women with FGM at each level of the healthcare system. This chapter achieves research objective 2, 'to examine and thematically analyse the role and views of key informants who influence the care received by women with FGM using NHS services' and focuses on the overlap of the macro and meso areas of the conceptual model presented in Chapter 1, as shown in Figure 4.1.

Figure 4.1: Conceptual Model Focus of Chapter 4 (Source: Author, 2020)



4.1 Demographics

Table 4.1: Key Informant Demographics

Policy KIs	Police	Direct Care KIs
• Clinical Commissioning Groups (2) • Public Health (1) • Research Nursing (1) • Charity Employee (1) • Hospital Adult Safeguarding Lead (1)	• Subject expert on FGM for Police (2)	• FGM Specialist Midwife (4) • General Practitioner (3) • Nurse Home Visitor (1)
Total=6	**Total=2**	**Total=8**

Over the course of 18 months, 16 interviews were conducted (Table 4.1). KIs interviews achieved the aim of providing context to the women's experiences and understanding how the healthcare system and community cares for them, reflecting a focused ethnographic approach. All but three KIs worked within the West Midlands. Three specialist FGM midwives were located in London and offer an important comparison of population and resources, although it should be noted that nationally there are few specialist midwives. While a complete list of specialist FGM midwives could not be found; a list of FGM clinics is available on the NHS webpage 'National FGM Support Clinics' (NHS England, 2020a) and lists nine FGM pregnancy clinics in London, two in the Midlands, one in the South, and one in the North of England (all clinics were contacted). As all women who participated were from the West Midlands, having KIs working within the region added specific context of care provision. This is not a complete data set and was never intended to be, however, it does provide context to the women's experiences by providing information about who women with FGM might come into contact with during the birth process and what resources are available.

4.2 Findings

Four themes emerged from the KIs group as a whole as significant aspects to care for each group: *community and taboo*, *time restraints*, *training* and *passion*. Three themes are seen only in the 'direct care' group and show the unique issues experienced by front-line healthcare providers. These are *language*, *building* trust and *'not FGM'*. Two important contextual themes were also found and represent vital contextual information for women's experiences of their birth process; they are '*postpartum care*' and *'partner support'*. Please refer to Section 2.3.4 for a discussion of the methods used in the analysis.

4.2.1 Themes discussed by all KIs.

Community and Taboo. KIs described how FGM is a taboo topic experienced by a close community and reported there is a negative relationship between the FGM community and healthcare services due to the law surrounding FGM. KIs described barriers to providing care to the FGM community while also noting the important community resources currently available. Although each KIs group interacts with the FGM community differently, each group saw the FGM community as an underutilized resource to improve care and prevent the practice of FGM. KIs noted FGM is *"a hidden issue" (201805SID),* with a definite *"absence of men." (201814SID);* while another stated:

> *This is an honour-based crime, where if you speak about it, you're going to be isolated potentially unless you've got full supportive family. So understandably people don't want to talk out about it and so we need to be able to provide that support to them to enable them and empower them to speak out. So for me, my answer to your question would be, well it's everybody, it's everybody's business to... to speak out about it and say this isn't right (201804SP).*

While KIs reported they perceived women to be happy to attend medical appointments, discussion of FGM in the community is still unacceptable in many situations, as one KIs noted it continues to be a taboo topic and must be discussed in an appropriate context;

> *They follow-up the hospital appointments, especially when they're pregnant, because obviously it's that medical influence that you need to go to this appointment. What we do struggle with is about getting mums to attend these counselling groups if you definitely promote them as FGM support groups, so what we try to do is try to promote them as more of a befriending groups for refugees and*

> *a…you know for isolation, for a way to get them into these supportive groups and then have the undertones of support for FGM but I find that if we promote it as an FGM survivors group they don't attend (201806SD).*

KIs described the importance and impact of culture regarding the FGM community and noted that while women may integrate into British society well, culture plays a prominent position when selecting marriage partners and reflects how women identify themselves.

> *I think that the FGM population are a quite a close community in general… community is kind of everything and em, I mean […] not much extra-marital marriage* [marriage outside of FGM community], *[…] even kind of young feisty women who've you know, English as me, and they've been here since they were 6 years old, they often end up with it seems a Somali or an Eritrean, or a Kenyan, or a...you know, someone from their own culture. There doesn't seem to be that many mixed eh, marriages. (201802SD).*

KIs collectively believe in building relationships with the FGM community to encourage engagement and understanding that while FGM is against the law in the UK, the healthcare system and the police are available to help and care for the community, rather than acting against them. Community engagement was seen as a method to break barriers created by mandatory reporting;

> *For me again it's seen as about community engagement as well, […] we're going to start recruiting for the community advocate, you know, if you have somebody within the community advocating, hopefully they can see that, you know, we're on their side, versus we're opposed to them, because then, when all this mandatory reporting and reporting to the police came in duty, the community*

> *were absolutely, upset about it, quite rightly, we're 4-5 years, we're 4 years down the line, I think, and people pretty much know that that's what we're going to do, however, I also feel that we have to engage the community, in a way that is positive, as opposed to negative …but, you've got to build those community relations, even though you may be an Acute Trust (201815SID)* [Acute Trusts in the UK represent hospitals. Here the speaker is suggesting that even though Acute Trusts may not see patients regularly, they must still build trusting relationships with communities].

Language is a barrier identified by all KIs to providing care to women with FGM, and for women to access care. Language will be discussed in more depth later, however, it was highlighted how important community groups are for women when language is a barrier, potentially causing social isolation. One KI noted;

> *Yea, definitely because they don't speak, you know, a lot of them have come, are newly over from the countries they were here, sort of 2018, 2017, and they don't speak very good English and that is going to socially isolate anybody isn't it, so, yea, I believe that some of them are socially isolated and that's why I try to get them to go to this, like a, coffee morning in the library every other week, for women, you know, migrant women and things like...I always try to tell them about things like that, just to try and say to them that there's a big population of say, new over from Eritrean, and a big Eritrean population here and I try to sort of signpost them to people that they can, you know, become friends with, so that they're not so isolated. (201812SD).*

How the FGM community views the police appears to be mixed and based on experience and type of interaction. Community members engaged in community groups and who are anti-FGM were seen as happy to interact with police. This contrasts with community members who were not happy interacting with police services due to reasons such as, having experienced a visit from social services, were seen as pro-FGM, or believe myths about children being removed from families due to FGM. Previous policies in the UK saw all women with FGM reported to social services and this seems to have resulted in a lack of trust between the police, social care, and the FGM community:

> *I think, it's a really difficult one isn't it, trying to get people to do it because there's a lot of urban myths that go round as well [...] people still see us as the agency that take children away, and a lot of urban myths with FGM [...] so it's about challenging some of them comments that people make, and eh, empowering professionals [to say] that's not true, we don't take children from families, it is trying to keep families together, ideally (201808SP).*

Other barriers raised by KIs regarding community engagement included the lack of mental health services available specifically tailored to FGM survivors;

> *but I think across the board, the counselling provision is quite limited and that's eh something that a lot of the, people who are victims of, FGM seek and need, but I think that's across the board [...] ...a definite need for increased counselling provision (201809SID).*

The risk of creating FGM fatigue among women, an emotional numbing to the topic due to constant and unnecessary repetitions and over exposure to the message, was also a concern raised by KIs. KIs worried that too much focus on one aspect of women’s lives, instead of offering a holistic support structure might cause disengagement from health services, as seen in the following quote:

> *fatigue and women don't want to keep being targeted for support because of their FGM status as well, and so you know, how do you offer support in a holistic manner, and FGM is part of it, you know, because it might be that actually it's not the biggest problem, that they've got right now (201813SID)*

KIs felt confident that awareness of FGM was growing among communities and professionals because of "o*ngoing learning, that ongoing development" (201807SID)* that is now part of professional development within the police and healthcare system. Raising awareness among healthcare staff and the police ensures appropriate responses;

> *that in order to tackle FGM we need to take a partnership approach and make sure that all of our… all of our partners who are having contact with you know, potential women and girls that have experienced FGM, know how to respond appropriately and therefore that that training element and awareness raising element is really important (201807SID).*

That are not wholly focused on maternity:

> *as I said that is not maternity-centric, it is Trust wide, so, you know it means that the message is out there, the Trust, the training that we've delivered and I've managed to get the training on the mand [mandatory]...the inductions, the induction study day so that was actually, I had to fight for that because again I thought that if people have statutory obligation to do ABC, then as you're coming into the Trust you need to know (201815SID).*

City council initiatives were also seen to help to increase community and healthcare professional awareness:

> *probably 10, 12 years ago that we really got trained and we started asking about it and then, there's… there's been sort of various initiatives from various*

> *sides and then finally a few years back it was [name of group] that had a big campaign [...] which was really raising awareness among all of the health professionals and the community and having lots of training sessions, and forums and so on, so [...] we didn't start out at the beginning being so conscious and screening for it as we do now (201810SD)*

Awareness of FGM and the associated health consequences was also seen to be increasing in the community. Women's groups were described as providing education and creating self-awareness in a safe environment while teaching women about their bodies:

> *joined the women's group and got involved in their discussions, and then in their general kind of issues that they talk in the women's group, I gather that FGM is kind of, kind of, introduced from the side, and then women kind of gradually open up and it becomes a real interesting thing to talk about and exchange views on, I think that, that sounds really interesting, and that's how women would get to have the self-knowledge because that would be the great thing, if women knew their own bodies, and they knew more about their FGM and what the effect, what is, what is FGM all about, in, you know, and they've talked about it with other women and they you know, kind of internalized, you know, what has it meant to me, then they would have a lot more to bring to that question of, you know, how are things postpartum, and hopefully they would maybe say something, maybe I've got a physical problem because of FGM, what do you think doctor? or, they might say even something about their psychological issues, I, I think yea, I think that would be really great, you know, thinking, thinking more about kind of patient empowerment (201810SD).*

However, KIs expressed how more education among women with FGM is needed, and support for some women could be creating awareness of the impact of FGM. The impact of FGM is not defined by the type however, and the health consequences should be focused upon, as seen in the following quote:

> *I don't think across the board there is a huge knowledge and awareness of FGM, they may say, they may know the different types but then actually all the different factors that contribute so [...] and so her support may be in recognizing that and how those sorts of basic questions are asked maybe aid then and awareness of the impact on that person's health [increases] (201809SID).*

Reported community engagement includes *"training of champions in this kind of work" (201808SP)* and using community members to educate the community;

> *we have survivors in our facilitation team, who help deliver schools training, and who are really the spokespeople for the charity along with young people, and so all of our training is delivered by at least one facilitator from an affected community who may or may not have had FGM, but can speak, you know, about FGM in real terms and how it affects families and communities, so there's no pressure at all for anyone to ever share a personal story, but, just having lived in an affected community means that people have got that extra understanding (201814SID).*

A more reasoned response; Coventry, a case study

As many KIs discussed Coventry specifically, it became apparent that Coventry is unique in its research and community-based approach to FGM. This is due to a specific research project conducted in Coventry that was able to alter their health and social care response while still ensuring any legal requirements were addressed:

> *yea, I co-wrote them with...for our city anyway utilizing the em the model [...]* [which came] *from a very much community-based rather than a you know referring everybody to social care and the police, actually having a more em, eh, a more informed approach, to, to addressing the issue for us as a city, [...] and that's a multi-agency protocol then utilizing and underpinned by the research. (201805SID).*

> *we've merged kind of the statutory requirements along the FGM reporting system alongside what is a more reasoned response from health and social care, and education (201805SID).*

> *so it's definitely the researchers have impacted on our commissioned arrangements here, directly, and [name] is part of the you know, the eh, operational FGM group here in Coventry and is able to share directly, we've also got counsellors on it as well, [...] we've actually got, you know, a whole gamut of people trying to think about this, [...] it's quite a complex issues, it's different from other safeguarding issues, cos its, cos of the cultural beliefs that underpin it, and em, you know the approach if it's too punitive then, you know, just drives the practice underground so, there's quite an art to get the balance right. (201805SID).*

KIs believe community resources are suitable and available but are underutilized and represent an unexploited resource that could aid women and health services in delivering care for women with FGM. KIs expressed the need for awareness raising initiatives. Awareness raising initiatives are needed to increase women's utilization of current services, as expressed in the following quote;

> *it highlighted the fact that the [name] clinic did an absolute brilliant service but not enough people knew about it, so, that led to some awareness raising work (201814SID).*

And:

> *yea, there is a lot of community support if they know to access it, there is, there's community champions in Coventry, they're really quite proactive, there's a few women's groups that are good, dedicated FGM champions in communities, so yea, there definitely is support there if women need to access it (201812SD).*

KIs experiences of interacting with the FGM community were described as positive. Many KIs reported building relationships with the FGM community and women within the community through healthcare interactions, noting the preference for community-based settings compared to hospital ones;

> *very well attended, people feel very safe to come back here, em, I suppose it's kind of the relationship that they form with us, coz we've seen them from antenatally up until the child is 5 years old, they develop a close relationship with us, and I also work closely with their GP [...] so this is a very safe place and it's not in a clinic setting, it's not in a health centre it's in a community-based kind-of location, so which they prefer (201806SD).*

FGM is considered by KIs as a hidden issue in a close community; creating barriers for the utilization of healthcare and community resources. Current mandatory reporting procedures, previous policies regarding FGM and social services, myths concerning the removal of children from homes, mental health services and language were all discussed as barriers to providing care to the FGM community. KIs described barriers being broken down by community groups led by community champions, increased interaction with specialized law enforcement and training of healthcare professionals. However, KIs felt confident in the community resources currently available and noted how awareness of FGM was increasing in healthcare professionals and community members themselves. The importance of the community to women with FGM was also noted by KIs and seen as a means to promote services and prevent future FGM practice. KIs described how current community resources are underutilized by the FGM community due to barriers and lack of awareness, however, KIs also described their desire to rectify this.

Time constraints. A pragmatic approach to service provision is taken by the NHS and police, with resources being based on population numbers. While all KIs stated they would like more time to complete their work, they understood how resources were distributed, stating;

> *oh gosh yes, and then some* [more time], *yea, absolutely, there's so much, so, so much that we could do and, but obviously what I don't want to do is get quoted to say that you know....it is, it is justifiably not a full-time role at the moment, but I'm sure, that given...if we had the money and the officers, then there's nothing, for all areas of business, not just FGM but honour based abuse, force marriage,*

> *CSE, human trafficking, county lines that are merging, you know all of these things which we know that are happening within child abuse, you know to have somebody dedicated to do some absolute dedicated proactive work around it would be ideal, yea (201804SP).*

Although KIs reported understanding resource challenges, time constraints were described as stress inducing and limited what they could achieve, leaving many feeling pressured to complete their workload. One midwife commented:

> *The challenge [...]* [is] *I'm not given full-time for this job, it's a 3-day service, I need full-time hours because it's grown and grown over the 15 years, I'm seeing more women now, I'm expected to do training and things like that as well, which I'm happy to do, but there's not enough hours in the day really, and that's a challenge for me, because I need more time (201801SD).*

And another stating:

> *they want me to do the role in 2 days instead of 3, so they're putting a lot of pressure on, not just me, all of the midwives and specialist midwives to do more and more and more (201802SD).*

With others feeling services could be better with more time;

> *I obviously haven't got enough time to cover everything I would like to and the service could be much better, you know, eh, unfortunately, you know, I'm two days and you can do what you can do (201816SD).*

Midwives reported logistical difficulties when clinics ran only on specific days, and women missed appointments and needed to reschedule;

> *I mean my clinic runs every two-weeks, I mean it would be great, because a lot of women you know, if they miss appointments and then I'm very restricted, with appointments to reappoint, so you know, it would be wonderful if I could have my clinic every week, so it would just give a bit more room and movement, you know, for the women to turn up to the clinic, so again, it's all down to, you know, money and resources (201816SD).*

Time constraints regarding access to appointments was also noted by GPs;

> *I mean there's enormous barriers for anybody in the mainstream trying to get an appointment these days, I mean just anybody trying to get an appointment, you get one in 3 weeks' time after a lot of struggle and if you've got an urgent problem it's really difficult (201810SD).*

Especially regarding mental health;

> *[Name] are brilliant, fabulous, they do the best possible counselling for people who've been sexually abused, they've got that specialist remit and they do it superbly, the problem is they get assessed and there might be a wait, maybe 6 weeks, or something like that, a reasonable wait to get assessed, they do the assessment, a lot of our patients, get the assessment and then they are told by [Name], yes, we would like to take you on to our counselling waiting list because you're absolutely fit, you know, you know, the bill, and, and then now, at the moment, it's a 9-12 month wait (201810SD).*

During appointments, time constraints were described as stress provoking for KIs, who found it difficult to complete assessments in the appointment times provided. KIs not only have to complete their assessments, but also allow the woman time to discuss any relevant issues, complete safeguarding, and potentially use a translator if the woman does not speak English. One KI noted how short usual appointments were for a subject such as FGM, stating;

> *it's very, very hard to fully understand even if you've got half an hour or forty minutes or...of a consultation, you know, what it all means to them and their cultural context which is a very big thing (201810SD).*

KIs commented on the individual nature of women with FGM and how some needed longer appointments, while others did not. As one midwife noted:

> *it's challenging because they're time, timekeeping, it makes it really long, you know, she's doing all the talking and examination and I could have about ten women on the list, they all turn up in their times, and then if I'm in the room for 20 minutes or half an hour, some women need more time, you know, it's challenging with timekeeping as well, very challenging, in a clinic that is (201816SD).*

FGM was described as a difficult topic to discuss due to not knowing what reaction the woman may have, while also being able to provide appropriate resources;

> *I think just giving the patients the time to talk about it is probably, and that availability that if they want to talk they can talk, and if they think that it's*

> *nothing then I don't want to open up a can of worms for them that doesn't need to be opened up you know? (201812SD).*

Language and the need for translation presented another layer of difficulty for KIs and women, and can impact the care women receive due to time constraints, as described by KIs;

> *when you have a discussion with a woman that doesn't speak English, you've got a translator there, in general it's going to take double the time to have that conversation, mmm, if you're in a hurry and you've got 5 women who're in your caseload that speak no English, it's very likely that you will… it's easier to just have a short conversation and not go through in detail labour, antenatal care, intrapartum care, all of those things, than it is to, you know, that if she speaks English for example. (201802SD)*

And

> *it is challenging because most women, you know their English language is not their first language, so, I have to use interpreters, I do have, we have like a link worker working with us, eh, in (name) hospital, so, that's really good because she's consistent, she's there you know, every clinic, so she's very familiar with the clinic, but sometimes, you know, if we have a Somalian lady or a Tigrenian we have to use outside interpreters, so what I mean like different agencies, so that would be, so that is more challenging, because interpreters not aware about themselves.. we haven't been trained in this field, you know, of*

> *FGM, or in general in maternity, um, so it's very challenging yes, using the interpreters as well, it's not easy (201816SD).*

Although many KIs reported time constraints as a difficult aspect of their work, one midwife felt they had enough time with women and their experience of interactions and care provision was more positive, with one midwife stating;

> *I think the community midwife probably can do the safeguarding assessment but I think with them, it's a time issue, because they don't get very long slots to see the patients, so I do think it's beneficial for them to always come* [to the FGM clinic] *because I will have that chat with them about the law in the UK, you know, because I've got that little bit more time with them [...] I get half an hour just to talk about, about this issue, I think that's probably quite, nobody else does, and I think that's probably quite beneficial, you know I have the time to sit there and talk about the law in the UK and how they feel, how does your husband feel about this? You know, do you spend much time with your aunts and your mother, are they in this country or are they still living abroad? (201812SD).*

Time constraints were identified by the majority of KIs as a barrier to care for women with FGM. Direct care KIs described feeling increased pressure to complete their workload in the time allotted, with usual appointment times given for a very variable issue. The sensitive, potentially traumatic nature of the issue of FGM may need longer to discuss, especially if language translation is needed. While KIs reported understanding how resources were distributed, time did affect their work experience and the care they provided for women with FGM. Time is described as important to the quality of the healthcare experience for both women and HCPs.

Confidence through Training. Training of healthcare providers regarding FGM, mandatory reporting and available resources is completed, however; many KIs described the need for more access to and additional training. KIs described how training builds confidence in their ability to engage with women who have FGM effectively. KIs noted how interacting with women and ensuring women are supported by healthcare providers when using health services is *"about confidence" (201815SID)* and

> *about the confidence of the staff in terms of understanding FGM, understanding cultural difference and supporting women who have undergone it as opposed to blaming them because after all they didn't have a hand in saying that I want this done, you know they probably had it done when they were kids so, it's about making sure they are supported through the service (201815SID).*

KIs noted the need for ongoing training to ensure information is up-to-date and increase awareness about FGM throughout the healthcare services. The importance of supporting women through HCP training was discussed as potentially leading to more personalized care of women with FGM, as noted by the following KIs;

> *on-going kind-of eh process of kind-of education, eh, and support to all clinicians, not just in house but across the board really because then that will support the...any potential victims they come across can get a kind-of equal service (201809SID)*

And

> *perhaps there ought to be at least an annual big conference and training session, outreach for all the professionals and you know, the medical students, and midwifery students [...] out in the community, amongst...you know by the [Women's Aid Group], by other people, you know, with, with, the people themselves, to kind of educate them, inform, empower and do that [...] I think if there was a bit more on the general community side that could feed into the general health professional's training, a bit more, so we don't have quite such a narrow view (201810SD).*

Midwives discussed the need for special midwifery and obstetrics training, specifically surrounding de-infibulation and episiotomy. Several midwives reported women receiving episiotomies instead of de-infibulation and described this as being due to the lack of knowledge or confidence of HCP, stating;

> *so what they do is they perform an episiotomy instead of doing the de-infib, yea, so they deliver the baby, episiotomy, stitched back together, the woman is back to square one with the same problem as type 3 (201816SD)*

KIs did acknowledge receiving training for a specific skill not often seen is sometimes challenging:

> *perhaps being taught how to de-infibulate has been a slight challenge, though that seems to be becoming rectified, just by chance, the consultant that does it now seems to be happy for me to observe that (201812SD).*

Knowledge about de-infibulation, what it looks like, how to do it and what extra precautions need to be taken after childbirth were described as areas for additional training for midwives. FGM specialist midwives reported often being asked to consult with community midwives if they are unsure regarding postpartum health needs. KIs noted how training would provide confidence and knowledge in this area, as noted by a midwife;

> *you know for episiotomy because that's where we've been trained, but not all midwives can eh...really...they do, you know, this is what happened with the other ladies the other midwives been there and they seen the de-infibulation site, but they all rang me, saying (name) I'm not sure if that de-infibulation site is infected or not, I'm not sure, could you go and see this lady. It's a little bit difficult for the midwives, someone who hasn't been trained in that area, you see (201816SD).*

KIs reported training regarding the law and FGM is given to healthcare staff with a focus on safeguarding and mandatory reporting. KIs described the need for increased training to increase knowledge about FGM and the nuance of the topic while also increasing HCP confidence to address the subject with women. Specific knowledge is needed by midwives, foremost surrounding de-infibulation; how to complete it and how to care for the wound post de-infibulation and birth, and the associated healthcare education. While training of healthcare professionals regarding FGM is completed, KIs expressed the belief that a more contextualized approach would provide greater understanding of the needs of women with FGM and subsequently more personalized care.

Passionate about providing care. Although KIs described facing difficulties in their roles due to time constraints and the often-emotional labour of their work, each KI reported feeling passionate about the work they do and admiring women they come into contact with. A sense of reward for their work was also experienced by many. Expressions such as ***“****passionate about it” (201803SD); “very rewarding” (201801SD);* and *“end FGM in a generation, I mean, isn't that all our aim” (201808SP)* were echoed by many KIs. When KIs discussed the negative aspects of their roles they ended on a positive note, stating *“its fine, I love it very much” (201808SP).* KIs spoke about their personal motivation for completing their roles, stating;

> *I am personally very, very passionate about it […] so it can be rewarding, you know as much as the press talk about prosecution and yes we would all like to see a cutter prosecuted, or parent where it's appropriate, but you know, at the end of the day you know, if we could stop a girl undergoing FGM in the first place then that's is just fabulous, and really, really rewarding... (201804SP)*
>
> And:
>
> *oh, absolutely, I do not need to do this work at all, in fact, it probably causes me a lot of stress, if I didn't go home every evening thinking oh my God, I've done that training with the [Group Name] today, and now I have to give 3 hours back because I've not done the emails for my normal job, yea, you know what I mean? it's, and you know, I’m a white Northern woman, it's not my community so to speak, but when you listen to victims stories and you listen to survivors, it lights a fire in you, you release passion to want to help support victims to stop it*

> *happening to little girls and to women, and you want to fight the prejudice of people, you want to, you just want to make a difference don't you? (201808SP).*

Making a difference and helping women was described as an important motivator for KIs, with many stating;

> *I suppose that's what my drive is, is to try and make a bit of a difference really, to the most vulnerable (201805SID)*

Citing internal passion as a driver:

> *there's very little external, no, no parent who's child is on the child protection registry is going to thank me for doing anything […] this is definitely an internal driver, it's a vocation that's for sure (201805SID);*

And:

> *So, being, you know, when you, when you've burnt the candle late into the night trying to write business cases of [indiscernible], you tend to have to have some form of passion to drive it (201803SD).*

KIs reported admiring the women they work with and for and described this as providing motivation for their work;

> *I think the women are amazing, absolutely amazing people, women, very strong women and they're an absolute pleasure to work with the community that I work with, I really admire them, very, very much (201801SD).*

Despite stress, time restraints and pressure to complete their workload in the time allotted; KIs describe finding their roles rewarding and are passionate about making a difference and helping women who have experienced FGM.

4.2.2 Themes and Important Findings Discussed by Direct KIs Only.

Direct care providers have different experiences than policy-maker KIs and their experiences provide insight into the care provided to women with FGM that cannot be known without direct contact with women. The element of patient interaction provides context that cannot be overlooked. Three themes and two significant findings were only discussed or elaborated on by KIs who provided direct care to women; language, building trust and ‘not FGM’ represent themes, while ‘postpartum care’ and ‘partner support’ constitute significant findings in the context of this study.

Language as a barrier to care provision. Direct KIs described language and language barriers as a key component of their work and was a focus of direct KIs because of the direct interaction they have with women with FGM. Language barriers were reported as increasing the difficulty of providing care due to the need for interpretation services. The vulnerability of women with FGM is increased during the birth process if they cannot communicate their wants and needs effectively, possibly leading to reduced care provision, thus making this finding significant.

Direct-care KIs found women to have a mixed ability to speak English, stating;

We do get ladies that are new to the country and you know but they don't speak English and we have to have interpreting services for that, but a lot of the

> *women do speak English, yea. A lot of them speak several language to be fair, yea, they put me to shame (201801SD)*

Although they always try to learn and speak English, impressing midwives;

> *yea, I'm really impressed, like some of them are really impressive with how they try to learn different languages [...] I always find that patients that I see, they're always trying to make an effort to speak English if they don't already (201812SD)*

Direct-care KIs reported FGM as being a difficult topic to discuss with patients regardless, however, the addition of language barriers and the need for interpreters increased this difficulty a great deal. One KIs described the difficulty of communicating the need for a private examination;

> *They don't necessarily speak the language. They're not familiar with the healthcare system. And they're very fearful of intervention in the vaginal area. And so, their behaviour, they haven't been able to discuss their fears or concerns, which then just further just deepens their anxieties for examinations and so forth (201803SD)*

And:

> *it is challenging because, most women, you know their English language is not their first language [...] using the interpreters as well, it's not easy, and it's challenging. (201816SD).*

Direct-care KIs reported that being able to book female interpreters can also be difficult for KIs and provides a barrier to care for women with FGM;

> *On occasions, language barriers is a challenge, and getting female interpreters can be a bit of a challenge (201811SD)*

Direct-care KIs described being in the state of pregnancy as increasing a woman's vulnerability. Added to this, KIs report women possibly being new to the country and not understanding the NHS birth services. If language is a subsequent barrier, these women could have layered vulnerabilities preventing them from receiving equal care to women without FGM. One KIs observed;

> *I think women with FGM are vulnerable as well as FGM, and I think it's very difficult for them to go through the system knowing, or being able to sort of access the best care possible, if you see what I mean, whereas I think perhaps, someone who, sort of, speaks English and is used to dealing with the NHS, I mean I think all women actually find that during childbirth, it's a bit of a learning curve, particularly if you haven't used NHS services much beforehand, but I think then their doubling as susceptible and vulnerable, so things like accessing the birth centre, I mean we've, we tell women about the birth centre, no one evens bothered to tell them about it (201802SD).*

Language presents a healthcare barrier for women with FGM as reported by direct-care KIs. Increased difficulty for healthcare providers in understanding women, providing care and time restraints increases the vulnerability of women in an already vulnerable state, possibly resulting in their wants and needs not being adequately addressed.

Building trust between HCPs and women. An important part of healthcare interactions is the trust between woman and HCP. Direct-care KIs described methods they use to break down barriers to building trust with women such as having flexible appointment times, being responsive to their needs and being respectful of their culture. Unfortunately, previous healthcare policies regarding FGM saw an automatic referral to social services when FGM was identified and social services would arrive with a police officer to women's homes. Current healthcare policy in England is to complete a safeguarding assessment first and refer onwards as needed. However, when non-healthcare institutions, such as schools, report a suspected case of FGM, an immediate referral to social care and the police is still current policy. This has created a negative relationship between the FGM community and the healthcare system. One KIs described the policy as follows:

> *there would be an automatic referral into social care, so a social worker and a police officer would go and see this lady at home, she's just had birth, she's given birth-to have the chat about you know, FGM is illegal. you know you can just imagine this lady is a victim anyway and then she feels like she's being stigmatized further and has a police officer comes to their house, we've changed our practice now [...] so they would finding they were being further victimized really (201806SD).*

Although the law and policies are well-intentioned; KIs described how the implementation can be negatively perceived by women in the community. Direct-care HCP reported working hard to build trust with women when not all women agree with the mandatory reporting policies;

> *Building trust is a big thing. And you know, there's a current well-intentioned drive towards improving awareness around FGM, but unfortunately there's been very few from legislation that's come out, where women aren't always happy about how their information is being handled (201803SD).*

Building trust was described as important for direct-care KIs to be able to fulfil their roles of providing healthcare and safeguarding. As one KIs noted, *"well we know that actually clients will need to form a relationship with you and have a trust issue to be honest, so it's over that time where you would explore further issues"* (201806SD). Positive relationships result in women feeling "*safe*" and coming "*back again and again*" (201806SD) for care. FGM specialist midwives also noted how FGM was not the only topic discussed at appointments and reported conducting a holistic antenatal appointment, describing their approach as follows;

> *I don't see them and talk about FGM continuously, I'll talk to them about their babies and the birth of their babies and previous deliveries, and so...listening to their babies, and making it a little bit more, sort of, a general antenatal examination. They appreciate that I think. I can also do little other things for them, I can chase their bloods up, or you know, I can do their bloods for them or, just so it's not, I don't want it to feel like they're coming to sort of be told off, or lectured to (201812SD).*

A dilemma exists for direct-care KIs when they must confront their dual roles of providing healthcare and safeguarding when interacting with women with FGM. Many discussed the difficulties they face discussing FGM, and how they worry about alienating women;

> *then kind-of lead up to why they came to the UK and what happened to them on the way and then go into the FGM, and I suppose that's the best way to do it, not to just go in cold because you know, it's the things, we were talking about at the beginning, it's not necessarily what they're most concerned with and they may have a feeling you're kind-of homing in on something which really isn't that important for them, or, or, they may feel that, you're kind-of, it's an invasion of privacy, and I, certainly feel a sense of, you know, worry about whether when I ask, isn't that what I'm doing and this may put them off, so, they feel inhibited in answering but also because you're a GP and you want to start off on a good footing with new patients because it's going to be an ongoing relationship you don't want to put them at the start by having embarrassed them or you know, made them feel they were having to tell you private things, or things they're a bit confused about so, so I, think, I think that's a fairly big thing with me, I, and I have a sense that it's not as, you know, it's not as satisfactory as it could be, and then there's this dilemma of having to have, to tell people as part of the kind-of spiel if you like, or the agenda that we're supposed to follow, that it is illegal, and so on [...] there's so many aspects and so many dimensions that you don't know [...] it's so multidimensional and you as the practitioner really want to be sympathetic but also you've got an agenda (201810SD).*

Building trust and rapport was described as essential to the creation of the therapeutic relationship. It is essential in sensitive topics to create trust to allow people to discuss their issues honestly. Safeguarding and the law surrounding FGM were reported to impact this by introducing the idea of surveillance and ulterior motives for contact not associated with health, with KIs describing how trust may be broken if the need to report arises.

Not FGM. A significant distinguishing topic between KIs groups was the theme titled ‘Not FGM’. All direct-care KIs discussed how the issues facing women with FGM are mostly not about the FGM itself, but what having FGM is a sign of, namely migrant status. Many comments were made discussing the other issues faced by women with FGM including the *“day-to-day things that they want help with is the basic needs, food, shelter, warmth, clothing, once we've got those established, then we can address the further kind-of issues that they have” (201806SD).* KIs also discussed the link between poverty and migration status;

> *there's loads of issues that come up to be honest, immigration is a massive one, usually it's the poverty, being an asylum seeker and on very small amounts of money, so the main concerns that they're dealing with is that initial period, they're not getting their payments on time, still about 5-6 months after that baby is born, so they're surviving off £35 for themselves and a baby, so if you think £10 for nappies, £10 for formula, they've not got very little to live on, so the biggest concern they've got is with immigration and payment of living in isolation and poverty to be honest so I do lots of food bank vouchers, lots of liaison with the refugee centre and the Home Office to sort their payments out, but the Home Office don't get back to anyone and it takes as long as it takes for them to be honest. So biggest concerns are that and it's, you know, obviously you have the low mood as well, you know that, you know, all this kind of like contributes to, but if you think is it the FGM? That's not one of the real concerns*

> *that come out, it's the other things so once they get their status they may talk about the FGM later, so... (201806SD).*

Direct-care KIs reported women having different priorities and being more focused on social needs than their FGM status. KIs noted how FGM was not always the defining need the women experienced, and often was not a priority for them at all. As one KIs observed;

> *and this is not because of their FGM necessarily it's more to do with them being perhaps not very good English speakers, and immigrants, but I don't think they're getting as much general good care, so not to do with FGM, but things like breastfeeding support, you know, help with um, benefits application, we've had two women that are homeless in the last month coming to our clinic, you know, if they spoke English, or had somebody who would help them, they wouldn't have been in that situation on the streets or...you know, so, it's all the other social stuff, women with special needs children who haven't accessed help with that, and I think in general women are terrified of social services (201802SD)*

KIs described the difficulty they often found in broaching the topic of FGM, especially when they worried about alienating the woman by focusing on a topic that was not relevant to her at the time, but might be relevant to her healthcare as a pregnant woman. KIs described often feeling women were unconcerned by their FGM status and pondered whether the UK focuses too much attention on it;

> *I think that the women that have FGM and the women that don't have FGM come from the...are fleeing, or migrating, I think they all have similar issues, it really probably doesn't matter too much whether they've had FGM or not. They usually fleeing and that lifestyle aren't they and... where that will come [...]and accessing healthcare probably is more of an issue that, whether they've had FGM or not, I don't know, is possibly not, not that relevant [...] I think it's more the situation they're in, rather then what's been done to them in the past, because a lot of people just put it away in a box, that's the past, that's what happened to them in the past, and they've probably closed the door on it [...] yea, and I think you have got to be a bit careful about opening up a can of worms, because I think in British society, we're not, probably that great about just moving on from stuff are we, we're like, maybe like to over-analyse things a little bit, whereas I don't find these women do that (201812SD).*

And stating that most issues facing women with FGM are "*not necessarily anything to do with the fact that they've had FGM" (201812SD).*

All direct KIs noted there are many issues facing women with FGM, and that the majority of women have more pressing priorities, such as social support, than their FGM status. KIs also noted the significant impact migrant status has on women's health needs (see Chapter 2, Section 2.3 for a review of maternal migrant health and the NHS structure, Section 1.7).

Postpartum Care. Direct-care KIs reported postpartum care for women with FGM as following the usual NHS care plan for all women after birth. If a woman has not seen the FGM specialist midwife during the antenatal period, then an appointment will be made to complete a safeguarding assessment;

> *to be honest I think it's just normal postpartum care, I mean if the woman hasn't gone to the FGM clinic then they should make me a referral and I will try and see her post-natally or on the ward but generally speaking, other than that it will be normal intrapartum care, eh, postpartum care (201802SD).*

Direct-care KIs described how a woman would be seen during the PPP if there are any concerns about healing, or if the woman has had de-infibulation during labour, or declined de-infibulation during the antenatal period;

> *yea, so the ladies who are Type 3 who ask for the de-infibulation procedure, that can be done and in the antenatal period, or it can be done in labour, so if they've chosen to have it done in labour, I will usually see them 2 or 3 weeks post-delivery to make sure that everything has healed well, and how they're getting on, you know, with the changes in their body, so I'll see them then. sometimes I'll see ladies if they have not been referred antenatally or like they've been a late transfer from a different Trust maybe, and I've not managed to catch up with them before the baby's born, then I might see them postnatally but it's not many I see, postnatally its predominately in the antenatal (201801SD)*

> *I would probably do the home visit, to go and review them, just to see what happened [...] so it would be ideal for them women really to be seen by myself and you know, do home-visit, with a link worker, appropriately, offer her examination, just to double check what's gone on, actually did she have that de-*

> *infib in labour or not, or because some women get mixed up, sometimes the doctors or midwife preform episiotomy, if they're cut down you see, then that cut is stitched back together because its episiotomy (201816SD).*

Although women can book to see the specialist FGM midwife during the PPP, no midwife reported a woman had done so.

The majority of direct-care KIs reported feeling positive about the current postpartum care provided; describing good, accessible services by community midwives, health visitors and GPs. Negative comments concerning postpartum care included issues such as language, time and resources. However, these comments applied across postpartum care and not just concerning women with FGM. One midwife noted;

> *I think, you know, the, the general comment I would make is I think postnatal care, whether you're from a culture where FGM is practiced or not is, is poorly resourced (201803SD).*

Direct-care KIs were asked what care they would like to provide during the PPP if they could and reported the desire to discuss wound healing, postnatal depression, and specific changes to a woman's body after de-infibulation. Perineal healing was only discussed by midwives if women had been de-infibulated; *"em, no. Only if they are de-infibulated, or need de-infibulation do we start talking about perineal healing"* (201802SD). One midwife described the education she would like to give women after de-infibulation;

> *Just, as I said, the ladies that I do see tends to be ones that have been de-infibulated in labour, so it will be that...the issues that they'll have is the change*

> *in their bodies, em, as in like passing urine and menstruation, well obviously they're not going to menstruate but they are going to lose blood following delivery and obviously the changes, you know, when they do start having intercourse again, so it's like, that's what I talk about, and I also talk about cervical screening, and contraception, which they'll be able to access different forms of contraception now from having the de-infibulation procedure (201801SD)*

If a woman has not attended a FGM antenatal appointment it is important for specialist midwives to see them during the PPP to complete their safeguarding assessment;

> *if they hadn't been to the FGM clinic then they haven't really had a safeguarding assessment, so that should mean that the midwife should refer them to me, or give me their details so I can contact them, if, wound healings, so something to do with the perineum, eh, that would be another reason why, I would, might suggest they send them to see me again, you know, 6 weeks after the baby's born, something like that, and again if there's any sort of safeguarding concerns then I would, might need to follow-up (201802SD)*

The majority of direct-care KIs felt the current postpartum care is meeting the needs of women with FGM. FGM specialist midwives report women can return and visit them during the PPP but never do and therefore assumed there was no need. They also report being contacted by community midwives to ask questions about perineal wound healing, however those interactions are rare and have resulted in antibiotics for infections being prescribed. The postpartum care experiences of women with FGM is the focus of this study, and interviews were constructed around this time-point in the women's birth process. It is noteworthy that postpartum care was a contextual theme only and reflects the focus of the healthcare system on the safe development and birth of the child, as well as the decrease in healthcare support during this time. Overall, direct care KIs felt postpartum care is poorly resourced for not only women with FGM, but for all women and suggested increased care could be given to all women.

Partner Support. Direct KIs discussed the role of partners during their interviews. The majority described a family structure made of traditional gender roles, with the man's duties focused outside the house, and the woman managing the house and children. KIs could only report their experiences based on partners they interacted with during appointments and what women told them. Men who attended appointments with their partners were described as supportive and caring about their partner's wishes and wellbeing, with one midwife noting;

> *I've done one this morning and I've asked the lady and she said that her partner, her husband was really supportive to her and anything that could be done to help her then he will support, so (201801SD)*

KIs reported asking about partners during their assessments to safeguard against domestic abuse and to understand the woman's family structure to aid in referral to any additional services required. KIs reported women with FGM receive a significant amount of care and support from other women in their community, stating;

> *I would say there’s a significant amount of care – it’s, it’s community-*based in a *way that the women who give birth tend to get the support from other women... (201803SD)*

And;

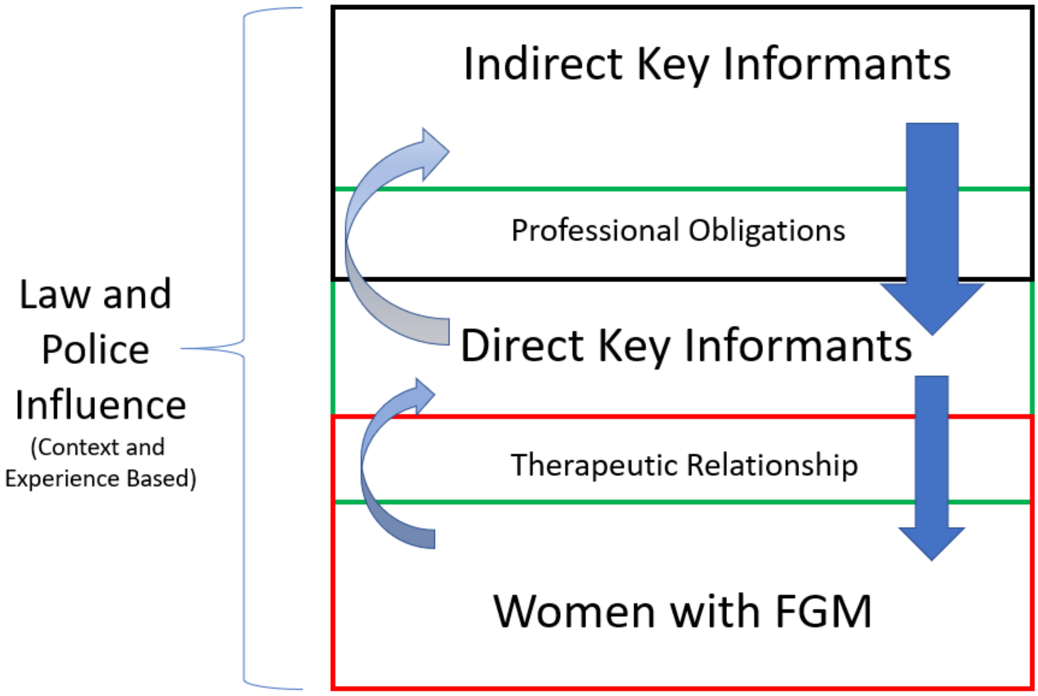
> *because the culture, the women usually do all the cooking and household chores and everything else, so I probably see more would be their mum, or their sisters or their aunties, whose supporting, you know, and providing some help around the house, because usually the women live with extended families, as well, so, they have support from the female family members. (201816SD)*

KIs believe traditional gender roles exist in the culture’s women are from where the men work outside the home and women manage the home and children. Women receive support in raising their children from female relatives or community members. Partner support is important to be able to understand the culture of women with FGM and how and where they receive support during the PPP. It is significant to identify what KIs know about the support structures of women with FGM to provide context for women’s experiences using NHS services. It is also notable this finding was only discussed by direct care KIs and may reflect a lack of understanding of the cultural context by policy KIs and the police. Support is vital during the PPP to help prevent feelings of isolation and postnatal depression in women.

4.3 Discussion

From the above findings the following conceptualization was produced and represents Phase 2 of the research study (Figure 4.2).

Figure 4.2: Conceptualization of findings in context of law and police (Source: Author 2020)



The above figure displays the top-down approach of the health services in the UK found in the DA (see Chapter 3), being implemented, resulting in the loss of women's voices. A tension between indirect and direct KI, with contextual influence from the law and police services is evident. Indirect KI feel resources are adequate and women's needs are being met, whereas direct KI feel current resources do not enable them to complete their workload, including to provide culturally sensitive care. This suggests a disconnect between different sectors of the NHS system resulting in a tension felt by direct KI to complete their professional obligations while providing holistic care in what they describe as an under-resourced area.

4.3.1 The influence of guidelines on KIs

The majority of guidelines use international literature and guidance from the WHO regarding FGM. The majority of international literature is from Africa, however, more studies are appearing from migration countries (e.g. Isman et al., 2013). Currently there is little data from the UK about maternal health experiences of women with FGM, with only four studies found on this topic (Albert et al., 2015; Glover et al., 2017; Harper-Bulmam & McCourt, 2002; Paliwal et al., 2014). This presents a difficulty for UK health services to provide culturally appropriate care within the UK context as migration may alter experiences, needs and outcomes. Currently the NHS system focuses on the physical aspects of FGM, seen in the DA with the focus on antenatal identification and de-infibulation, and seen in this chapter where KI described implementing health policy. It is here that one can see why a divergence is taking place between indirect KI and direct KI as if the NHS focuses on the physical aspects of FGM, safeguarding and mandatory reporting, the completion of these tasks by direct KI will be sufficient to meet expectations. However, direct KI described a different picture of care provision, one where they find it difficult, within current resource allocation, to complete their role to their satisfaction within the holistic model of midwifery care. Direct KI described issues such as language, trust and time as major obstacles in their roles resulting in descriptions of stress and burnout. An update on the 2002 report by the RCM titled ‘Why do midwives leave?’ found that the top three reasons midwives are leaving their profession are staffing levels, increased workload and not having enough time to spend with women (RCM, 2016), a finding reflected in this study. Continued NHS resource restraints have created a challenging environment for midwives to flourish (RCM, 2016). Direct-KI described providing care to women with FGM as challenging at this time due to the unique nature of appointments with women with

FGM for various reasons. Antenatal FGM midwives described challenges creating a therapeutic relationship with women when they only see them once and are mandated to complete many tasks within a short appointment. As described in Chapter 1, FGM is an intensely unique experience for women, and midwives not only have to complete safeguarding, mandatory reporting and a possible genital examination, but they have to complete these tasks upon a first meeting with a woman who did not know what the appointment was for upon entering the room, and they must do it within a short appointment time, possibly with an interpreter. Other direct-KI, such as family physicians and health visitors also discussed their difficulties in approaching the topic of FGM, at once needing to complete their professional obligations, while also wanting to provide care to women and not jeopardize the therapeutic relationship. This displays an important and alarming disconnect between how indirect-KI and direct-KI view the care given and received by women with FGM, resulting in a tension between indirect and direct KI, and the possibility for negative health interactions, stress and burnout of health professionals.

4.3.2 The Therapeutic Relationship (TR)

The importance of the therapeutic relationship (TR) has long been observed and established as an essential component to the delivery of safe and effective care (Peplau, 1952). However, the ability to create and maintain a TR within midwifery care is challenged by systematic factors such as staffing levels, organizational structure and workload (RCM, 2016). The importance of the TR in healthcare experiences is well known within the fields of nursing and midwifery (Bradfield, Duggan, Hauck, & Kelly, 2018; Feo, Rasmussen, Wiechula, Conroy, & Kitson, 2017) and is a cornerstone of midwifery care as seen in several Codes of Conduct for midwifery practice around the world (College of Midwives of Ontario, 2018; Nursing and Midwifery Board of Australia (NMBA), 2018; Professionl Standards Authority for Health and Social Care, 2020). The importance of the TR can be readily seen for migrant populations who are often vulnerable and may not be aware of how their new healthcare system works (Almeida, Caldas, Ayres-De-Campos, Salcedo-Barrientos, & Dias, 2013). Maternity care provides a unique and important time for positive healthcare interactions and the creation and maintenance of a TR with a midwife improves positive experiences of birth for women (Lewis, Jones, & Hunter, 2017). KI described trust, language and time as the most important aspects of the TR affected by the presence of FGM when interacting with women.

4.3.2.1 Trust.

Studies previously discussed (section 1.9) highlighted trust as an important yet unachieved component of healthcare experiences for women with FGM, with studies from the UK consistently showing this finding (Glover et al., 2017; Harper-Bulmam & McCourt, 2002; Moxey & Jones, 2016; Straus et al., 2009). In Glover et al. (2017), three-quarters of women felt a lack of trust in health services and the authors noted the unique mandatory reporting in the UK may contribute to this. Larger studies such as the Bristol PEER (Hussein, 2010), the Essex PEER (Norman, Gegzabher, & Otoo-Oyortey, 2016), and the AFRUCA study (AFRUCA, 2015), which all explored healthcare the experiences of women with FGM in the UK, it is clear many women lack trust in healthcare services, making the formation of a therapeutic relationship difficult.

Turkmani, Homer and Dawson (2020) used an Appreciative Inquiry approach to identify approaches to achieve culturally safe and high-quality care for women affected by FGM. With a member of the community involved throughout, 23 individual interviews and three focus groups were conducted with English speaking migrant and refugee women with FGM. Positive maternity care included being provided with respectful care and a feeling of having a safe service. Trust was directly related to the providers competence. Women dreamed of personalized care from a provider with a similar background. Provider knowledge was viewed as a need by women who felt more culturally sensitive care would improve their experiences. Women also indicated that building trust occurred over time and endorsed continuity of care for this reason. Limitations in this study include the issue of generalizability as the study was conducted in Sydney, which has a high migrant population and is well resourced. Women also had to be English speaking, possibly skewing the results in favour of more settled migrants. Using chain referral sampling also may introduce a bias by recruitment of women who wanted to participate and discuss specific topics. However, this study provides important information based on a collaborative method, enhancing the validity of the findings.

In a study exploring midwives experiences providing care to women with FGM related problems in Somalia, Isman, Mahmoud Warsame, Johansson, Fried and Berggren (2013) conducted 8 semi-structured explorative qualitative interviews. Each midwife had experience providing care for women with FGM. Relevant findings surround the issue of trust, as even though midwives were from the same culture and all but one was against getting their daughter cut, they still expressed the need to spend time gaining women’s trust and developing a relationship with them before the women would discuss their FGM related issues. FGM was described as a cultural issue, and thus midwives were seen as subverting Somali culture by counselling against it in general and specifically against infibulation. Midwives reported that sharing a common experience with women positively helped establishing a trusting relationship. Interviews were conducted in the midwives native language, before being translated to English by a professional translator and checked by a second translator. This represents a strength of this study. A limitation might include the small sample size, however the authors report saturation was reached and the interview guide was piloted, enhancing validity of the findings. As all midwives worked for an NGO network against FGM, any personal views that clashed with the organizational ones may have been withheld, causing a bias in the results. However, as midwives reported being ambivalent towards type 1 and 2 FGM, and only completely against Type 3, this is most likely not relevant.

Dixon et al. (2021) conducted a realist literature synthesis using 10 electronic databases, citation chasing, and grey literature to explore what influences how and when GP’s discuss FGM with their patients. Although limited evidence for research directly relating to primary care was found; studies exploring healthcare settings were used to synthesize themes. The authors concluded that four themes may influence when and how GP’s respond to FGM; 1) the amount of FGM knowledge and awareness they have; 2) their communication skill and comfort level; 3) the role of guidelines and service provision, and 4) mandatory reporting requirements. Trust and communication were highlighted as critical factors in maintaining relationships with the FGM community and ensuring women engaged with health services as needed.

Smith and Stein (2017) performed a synthesis summarizing the evidence on women’s values, preferences, and the context and conditions that are needed for psychological counselling interventions for women with FGM. Although just five studies were found and evaluated using the CASP tool, the findings suggest counselling interventions may be beneficial for women and girls with FGM. Too many variables (age of FGM, associated memories etc…) exist to ascertain who may benefit, however, the authors found evidence that long-term mental health problems related to FGM occur and psychological interventions may help women. Included studies also found respect and trust between HCPs and women is an essential component of interventions, especially in high-income migration countries where HCP are unlikely to have experienced FGM themselves. More research is needed in this area, however this study reinforces the available evidence of the importance of the therapeutic relationship, especially respect and trust for impactful care for women with FGM.

Evans et al. (2019) conducted a systematic review exploring the experiences of women and girls with FGM receiving and accessing FGM-related healthcare. ENTREQ guidelines were followed and the study protocol was published to enhance transparency. Eleven electronic databases were searched, as well as grey literatures and references (forward and backward). The JBI-QARI qualitative assessment tool was used to assess quality of included studies. Although no studies were rejected based on quality, their impact on the synthesis and subsequent confidence in the findings was assessed using the GRADE-CERQual tool, adding validity to the review findings. Although the majority of finding were associated with communication; an important finding worth highlighting is how women described ‘good care encounters’ as leading to trust with their HCP and opened up communication. Two studies linked good therapeutic relationships to continuity of care models. As with all systematic reviews, the quality of the original studies impacts the quality of the review. However, the rigorous methods of this robust review led to high credibility and trustworthiness in the findings. Trust is an essential component of the TR and creating healthcare interactions that aid in the creation of trust should be a priority for the NHS as evidence suggests it may enhance care experiences.

4.3.2.2. Language and Terminology

KI in this study reported language barriers as an issue in their care provision for women with FGM. KI described difficulties organizing translators and using them as it disturbed the private nature of the appointment. KI also reported some women who needed translators did not acknowledge this need when booking their appointment, and thus no translation service was organized, resulting in a fruitless healthcare meeting.

Language barriers may lead to inconsistent health services, further increasing any vulnerabilities women with FGM may have. Suphanchaimat, Kantamaturapoj, Putthasri, and Prakongsai, (2015) conducted a systematic review of the perceptions and attitudes of healthcare providers in managing care for migrants and also explored practice barriers. Three electronic databases were searched including the WHO website and grey literature. Thirty-seven articles were included, and quality assessment was performed using the CASP tool. While the quality of included studies varied substantially, and the definitions used for ‘migrant’ included documented and undocumented; consistent findings regarded language barriers and cultural challenges. Lack of healthcare resources resulted in language and interpretation issues for migrants and provided challenges for HCP in providing care. While the quality of the included studies varied, it is important to note almost all studies reflected uniform findings and found implementing culturally competent care within current healthcare resources was a constant challenge. While maternity care experiences depend on many different factors, information and support from HCP is important, and impacts women’s ability to make informed decisions regarding their health (Cross-Sudworth et al., 2011). Insensitivity and improper care were cited as a likely cause of increased C-sections in women with FGM in a review by Merry, Vangen, and Small (2016) (discussed in section 1.9). improving the quality of health information provided to women with FGM was suggested as a means to decrease C-sections and improve maternity experiences (Merry et al., 2016).

The ability of the woman to communicate with HCP during labour is essential. Often translators are not present in the birthing room, either by choice of the woman to have a family member or partner translate, or inability to coordinate one. Who is in the birthing room has an impact on women's experiences and mood, and was explored by Crowther, Smythe, and Spence (2014) in a phenomenological study involving mothers, midwives, birth partners and obstetricians. Fourteen hour-long interviews were conducted following purposive, snowball sampling. The authors found a positively construed mood of joy is present at birth which midwives seek to preserve and view as sacred. Disturbances, such as unwanted people in the room, or the women's expectations not being met during birth can disturb this mood. In this study, women preferred having partners translate for them rather than a translator to preserve the intimacy of the moment, potentially leading to communication barriers. Appropriate communication is essential throughout the birth process. HCP have an essential role in the birthing room and can influence the mood of birth. Culturally competent care is a method to preserve the joy of birth and maintain the spiritual nature of this unique experience for all involved.

Language was found to be the greatest barrier in communication between HCP and women in a study by Binder, Borné, Johnsdotter, and Essén (2012). Thirty-nine immigrant Somali women, 11 from Ghana and 10 White British women were interviewed, along with HCP. Women could participate in individual interviews or focus groups with semi-structured, open-ended questions. Translators were used where necessary and thematic analysis was performed. Language barriers were reported as women’s largest concern with care, with both immigrant and White British women experiencing difficulty with communication. HCP that spoke the same language as women, whether immigrant or White, reported increased comfort with care provision. HCP questioned interpreter’s familiarity with medical terminology and desired uniform training for translators. Time-constraints, the ability to access translators in emergency situations, and some women claiming better English proficiency then they had were also described as communication barriers by HCP. Women expressed different opinions on the use of translators which may be based on culture. Somali women reported being more comfortable with using family as translators as they were trusted, a finding also expressed by HCP. However, women from Ghana were happy to use provided translators. Limitations in this study include the potential bias of the recruitment method as Somali culture is strongly orally focused and any shared healthcare knowledge may bias women’s opinions. More information on data analysis methods would also have improved the reliability of the study findings.

Although asking the woman what her translator preference is, either family or trained professional, may enhance personalized care, issues such as domestic violence must be considered and current NHS policy is for non-family members to translate (National Health Service England & Primary Care Commissioning, 2018). Specialist midwifery services and CoC could support this issue by creating TR between HCP and women, allowing greater depth to develop over time.

KI in this study discussed the impact of family and cultural norms on women’s ideas surrounding childbirth, and how these are linked to maternity services matters to women. Downe, Finlayson, Oladapo, Bonet, & Gülmezoglu (2018) explored what matters to women during childbirth in a systematic review using seven electronic databases and reference lists. A meta-ethnographic technique was used for analysis and synthesis. Thirty-five studies from 19 countries were included. Quality of studies was assessed using the GRADE-CERQual tool. Confidence in most results were moderate to high. Although this review included all women, relevant findings for this study include the impact of culture on women’s experiences of childbirth. Women desired giving birth to a healthy baby in a safe environment. Their values and expectations of what a safe environment meant to them was based in their culture and highlights the necessity of culturally competent care.

4.3.2.3 Time allowed for appointments.

While everyone in healthcare would like more time, it is a critical aspect of developing a TR between midwives and women and their ability to provide a holistic needs assessment (Lewis et al., 2017). There was a difference between midwife experiences based on location in this study; those areas with higher populations overall, and areas where they have a higher incidence of Type 3 FGM versus lower population areas. Midwives in lower population areas noted they enjoyed their roles and felt they had adequate time to discuss women’s needs. In contrast, midwives in high population areas, and with increased Type 3 demographics described feeling rushed and as safeguarding has to be assessed and mandatory reporting completed, resulting in less time being spent in other areas. This reflects the current literature that suggests midwives are leaving the profession due to lack of time (RCM, 2016). Time is of vital importance if trust is to be established and an effective TR created (Bradfield et al., 2018; Feo et al., 2017). NHS organizations could review staffing levels and workload, or allow midwives more autonomy on how they spend their working time, to potentially increase work satisfaction among midwives (RCM, 2016).

Midwives discussed the difficulty of building rapport with women when confronted with short appointment times, language difficulties and the lack of trust in the healthcare service. Unfortunately, lack of time in general, and lack of trust between migrant populations and HCP is not a novel finding (Hussein, 2010). Continuity models of care do not necessarily work when specialist services are needed, however, the woman's relationship with the healthcare system could be strengthened with each interaction. This is especially important for maternity services, where care is provided during a unique life event that is health-based, not illness-based, and where a natural process is occurring with the added knowledge and support of healthcare professionals (Downe & McCourt, 2019).

4.3.2.4 Summary of TR

Personalized care, continuity of carer and culturally competent care are all goals of current NHS guidelines. In an editorial based on the authors research and nursing experience working with women with FGM; Odemerho and Baier (2012) describe how cultural competence requires HCP to have the ability to assess the impact of their own culture on patients during interactions. The authors also highlight this requires HCPs to be motivated and compassionate and to be a patient advocate. Cultural humility requires a life-long reflection by HCP that bring awareness to their care provision and the inherent power imbalances that exist (Odemerho & Baier, 2012). The authors conclude that both cultural competence and cultural humility are needed if effective communication is to occur (Odemerho & Baier, 2012).

The therapeutic relationship is a cornerstone of midwifery holistic care. The building and maintenance of the therapeutic relationship is important for the health and wellbeing of both woman and midwife (Professionl Standards Authority for Health and Social Care, 2020). The current model of maternity care does not allow for maintenance with the same midwife, although efforts continue for continuity of care, it does allow for maintaining a therapeutic relationship with the healthcare system at large, and specifically the maternity care system during the birth process. Findings from reports such as Better Births (National Maternity Review, 2016) and MBBRACE (Knight et al., 2019) have endorsed continuity of care as a much-needed goal of maternity services. Currently the NHS is trying to implement teams of community midwives where women would see one of a team and would therefore be more likely to see familiar faces and have a dedicated team knowing them (NHS England, 2017). Evidence strongly suggests trust is an important factor in the creation and maintenance of the TR (Kennedy, Beasley, Bradley, & Moore, 2010; Professionl Standards Authority for Health and Social Care, 2020) and may enhance care experiences for women with FGM if made a priority (Evans et al., 2019).

4.3.3 The Law

The impact of the law, and HCP being mandatory reporters raises questions about the impact on the TR between woman and midwife. Questions must be asked concerning whether it is useful to potentially negatively impact the TR and isolate women during a significant life transition. More research is needed to evaluate the impact of the law on healthcare practices, but also the impact on HCP and their perceptions, feelings and experiences providing care.

Other countries have approached the legal aspects of FGM using varying methods. Leye and Deblonde (2004) conducted a comparative analysis of different legal approaches in five countries; Belgium, France, Spain, Sweden and the UK. Each country has different legal approached and judicial outcomes. Methods included a documentary analysis of archival records concerning FGM cases, and a case study aimed at identifying whether legislation applicable to FGM was implemented, and also to identify any barriers to legislation implementation. No evidence was found to suggest that specific criminal laws are needed or are more successfully implemented than general criminal law provisions. However, the authors note that as criminal laws have a child protection preventative function, it is impossible to know their full impact and suggest more focus should be placed on prevention rather than persecution. In the context of this study, the UK data are currently out-of-date due mandatory reporting requirements brought in in 2016. Changes to KI roles may have impacted the implementation of the law. Incomplete data sets create difficulties in assessing the current prevalence of FGM in the UK, however, to date only two cases of FGM have been brought to court, with one conviction.

In an opinion article, Berer (2015) described the history of the law against FGM in the UK and questions how it can be implemented when genital cutting for other reasons such as cancer, gender reassignment surgery and cosmetic surgery are allowed to take place. They question how the act of cutting can be separated from the cultural meaning behind it and suggests a community, educational focused response to FGM is required. Johnsdotter (2019) also questions the usefulness of current laws and discusses whether compulsory genital examinations are useful in identifying cases of FGM. In an ongoing longitudinal study, 122 police files were examined and sorted by whether a genital examination took place or not. Findings show that no illegal FGM cases have been identified and brought to prosecution as a result of compulsory genital examinations. Of the two cases that reached court, both originated from girls who told their stories to authorities. The author concludes that building trust is a superior method to identify and prevent FGM than punitive action.

In the UK, a level of deception also occurs during the antenatal period between health services and women; and was also described in the purpose of community groups. Women are sent a generic antenatal clinic letter for the FGM clinic. This was noted by several KI to be because ‘otherwise they wouldn’t come’. The NHS should not deceive women and expect trust in return. Women with FGM and their communities must be treated with respect, and respect is shown through honesty and integrity. By deceiving women in this manner, and surprising them with an appointment dedicated to FGM, a topic the midwife does not know how they feel about, is a flawed approach to creating trust. Community groups that focus on FGM but present themselves as a ‘woman’s health group’ may be inadvertently creating barriers to women discussing FGM by surprising women with a topic they do not wish to discuss.

Taking a health focused approach to appointments concerning FGM is a method to create trust and provide holistic resources to meet women’s needs. Removing women’s autonomy from knowing what an appointment is for is not appropriate and would not be tolerated in any other area of the health service. Why it is allowed regarding FGM can only be seen as the dominance of the law over healthcare and ensuring safeguarding takes place. Again, this can be seen in the fact that if a woman does not attend her antenatal FGM appointment no healthcare referral is made, but a referral to social services is, showing this appointment is far more concerned with implementing the law and collecting data than the creation of a birth plan. Women are not fooled by this and the negative impact on their perceptions of the healthcare system should not be overlooked (Evans et al., 2019). When synthesizing the current literature and KI results from this study, one must question whether the law is having a negative effect on healthcare interactions between women with FGM and HCP, hindering their access to, and quality of healthcare provided. The health system must start approaching FGM with honest, culturally sensitive care that ensures the woman remains autonomous throughout healthcare interactions.

4.3.4 Not FGM

Direct-care KI described women having more pressing needs than FGM and noted the majority of women did not raise concerns about their FGM spontaneously. Although a holistic, personalized approach is described in guidelines and the midwifery model (NMC, 2019), currently there are not enough resources for implementation (RCM, 2016). Again, more information on women and HCP’s experience of receiving and providing care in the presence of FGM is needed.

Many KI noted other issues women with FGM are concerned with and one questions whether FGM should be the focus of a separate appointment. There is a broad spectrum of potential consequences to FGM. Due to the design of healthcare systems they respond with a ‘worst-case scenario’ mindset within hospitals to ensure that if it is a worst-case scenario they are prepared (Scamell et al., 2019). In the case of FGM, the focus of the antenatal appointment from a healthcare perspective is to create a birth plan, which includes assessing the type of FGM and the need for de-infibulation. The other component of the appointment is law and safeguarding based. Other physical health consequences can only be dealt with during labour and birth. While the antenatal midwife can note on the birth plan the extent of scar tissue and the fact that the woman has experienced FGM, the potential birth consequences, such as whether tearing and how much will occur, cannot be known in advance, suggesting each woman will need individualized care and a prepared birth team. Mental health consequences of FGM can and should be identified and supported during the antenatal period. Rather than a specific FGM appointment for all women with FGM, a community midwife could assess degree of scar tissue and need for de-infibulation and refer only those who need specialized care; relieving pressure on specialists and providing more time to those who need it most.

KI discussed other issues women were confronted with, such as housing, lack of support, poverty or immigration issues. These issues will only become more prominent with the addition of a child, or another child into the woman's life. The antenatal period is an opportunity to complete a holistic assessment and plan for the transition home and to parenthood after birth. FGM, while a focus of maternity services due to the possibility of negative health outcomes during birth and the law, should focus on a woman's needs from a holistic standpoint and recognize that FGM may not be a priority compared to other issues present (Puthussery, 2016).

The creation and maintenance of the therapeutic woman-HCP relationship is needed to promote positive birth outcomes. A holistic assessment is needed to ensure a positive birth experience and transition home following birth as other issues may be of greater import in women's lives than FGM. A difference in perspective exists between policy makers and direct-care KI suggesting more communication about needs, experiences and resources are needed. A potential for front-line staff to experience moral dilemmas exists when law and healthcare intertwine. Limited time and resources result in safeguarding and the lawful requirements being met over the creation of a TR with women. This potentially has meso and macro level effects through the woman disengaging from healthcare services and relating her story to community members. Migrant communities distrusting health services is not beneficial for society. The KI findings provide insight into the implementation of guidelines through the health service perspective.

4.3.4.1 Potential enhancement of the vulnerability of migrant women

From the above discussion, one point is very clear; the vulnerability of migrant women may be increased by their experiences and interactions with health services. From the top-down approach of guidelines and the impact of the law on appointment content, to the appointments themselves and their lack of time to build the therapeutic relationship, have appropriate translators and provide culturally sensitive care, to the women themselves reporting more urgent matters to discuss then their FGM status. As discussed in Chapter 1, Black women have a five-fold increase in risk of maternal mortality and morbidity, with Asian women having a two-fold increase in risk (Marian Knight et al., 2018). Vulnerability stemming from socio-economic status, migrant related policy, health services and health systems (Chung & Griffiths, 2018); accumulate with individual factors and differences between migrant groups and reasons for migration (Giuntella et al., 2018), culminating in a clear disadvantage for migrant mothers in many clinical outcomes including increased risk for low birth rate, pre-term delivery, perinatal mortality, and congenital malformations (Bollini, Pampallona, Wanner, & Kupelnick, 2009). These compounded vulnerabilities may be increased during healthcare interactions focused on FGM by not approaching women regarding topics that are meaningful to them. Addressing issues such as family support, loneliness, depression, isolation and identity insecurities (Straus et al., 2009); would provide a holistic approach to maternity care and help women to help themselves after they leave the care of maternity services. Personalized healthcare, meeting women ‘where they are’ may alleviate vulnerabilities migrant women encounter when they engage with maternity services.

4.3.5 Police opinion

The police form an interesting group within this study and represent an important contextual aspect being at once an external influence on health services (the law), and a direct influence on health processes and experiences (implementing the law). The police officers who participated in this study discussed their desire and passion to protect children against FGM and did this through education and building community relations. However, the integration of the law and healthcare regarding FGM results in a level of deception between health services, police services and women with FGM was observed. Policy and police KI noted how urban myths about the removal of children due to FGM needs to be dispelled, and yes, what the KI were referring to was the idea that if the police or the NHS learn a woman has FGM they will immediately remove your children, and while that thought is not true, under some cases, e.g. if there is a high risk for FGM, the children may be removed (Creighton, Samuel, Otoo-Oyortey, & Hodes, 2019). A tension exists between wanting to engage the community, and build trusting relations, while also completing the role of keeping children safe. This can result in healthcare workers experiencing moral dilemmas leading to moral distress (Leinweber & Rowe, 2010).

4.4 Strengths and limitations of sample

Limitations of the sample include the number of participants and the locations they worked in. Rigorous attempts were made to recruit as many KIs as possible, with all FGM clinics in the UK being contacted, as well as charities, community groups and women's support groups, several times by phone and email with a request to participate. Snowball sampling was also used. Confidence in the findings are high as KIs worked in areas with high FGM populations. Strengths of the sample include the wide range of KIs who participated, including GP's, a health visitor, midwives, policy makers, CCGs, and the police. This wide range of professionals gives depth and breadth to the findings and enhances our understanding of the interconnected healthcare experience women with FGM receive.

Phase 2 achieved objective 2 of this study; to examine and thematically analyse the role and views of KIs who influence the care received by women with FGM using NHS services. Semi-structured interviews were used to gain insight and depth of experience of KIs working in the field of FGM and provided context for Phase 3, the post-partum care experiences of women with FGM.

4.5 Conclusion

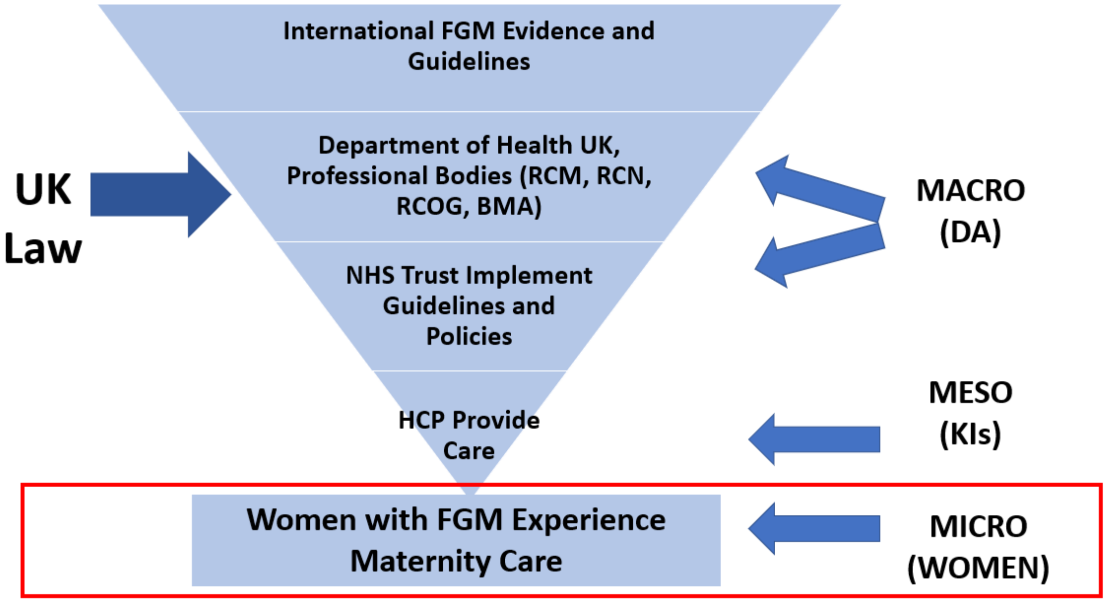
Four themes emerged from all KI groups; community, time restraints, training and a passion for the work they do resulting in job and personal satisfaction. Themes that emerged from direct-care KI groups only included language, building trust, partner support, postpartum care, and 'not FGM'. These latter themes are very important as they represent insight only gained from direct interaction with women with FGM. In order to understand the experiences of women with FGM, it is important to explore the healthcare system providing that care. This analysis has discovered a tension exists between policy-making KI and direct-care KI caused by an inability of direct-KI to implement policy due to practical issues such as time, language and building trust. This tension results in a focus on FGM to fulfil requirements of the law, while other health concerns may be a priority for both women and direct-healthcare providers. Building trust was seen as essential to creating a good healthcare provider-woman relationship and direct-KI described how current resources do not allow for this. Building trust requires time, and direct-KI and police reported time restraints were present in their work. To provide personalized, holistic care to women, more time is needed during appointments to focus on healthcare needs rather than the law.

The KI descriptions of care reflect the implementation of the top-down approach to healthcare seen in documents in the DA. A top-down approach to care silences women's voices as they are on the bottom and care is given 'to them' and received 'by them' rather than a joint experience of women directing their care within available resources and with the aid of specialized health knowledge. It is important to remember that the birth process is a natural event in a woman's life and does not represent a state of illness. As such it may require a unique framework guiding care rather than the standard framework used for treating illness (e.g. the biomedical model used in the UK). An expected finding was the lack of attention paid to the PPP for women with FGM and reflects the policy documents analysed in the DA. Guidelines, and their subsequent implementation by HCP, focus on the physical aspects of the birth process, namely the preparation in the antenatal period and the birth itself during labour and birth. However, this negates to consider the possible unique needs of women with FGM during the PPP; and from the above findings that describe women with FGM experiencing many issues regarding migration (housing, money, support), this area needs to be explored. The PPP is a transition period for women; not only from pregnancy to having a child, but also a transition from increased healthcare support to decreased and eventual absence of healthcare support. How women experience this transition and what their needs are is the focus of the following chapter.

Chapter 5 Postpartum care experiences of women with FGM using NHS services

This chapter explores the findings of the semi-structured interviews conducted with women with FGM. Although general areas of interest were directed by the interview questions, including postpartum experience and role of the partner; the experiences women shared, and their perception of the questions differed and resulted in varied discussions throughout the nine interviews. During analysis it was found that to understand the context of the postpartum experience, the entire pregnancy experience needed to be acknowledged. This study focused on women with the intention of understanding their experiences by listening to their voices, their stories, in the hope of identifying if and how the health service can be improved. This chapter describes the context of FGM, the themes that emerged from analysis and concludes with a discussion of the findings. For a description of the methods and recruitment, please see Section 2.3.5. This chapter achieves objective 3; to critically evaluate the needs and explore the postpartum experiences of women who have FGM and focuses on the micro level of the conceptual model presented in Chapter 1, as shown in Figure 5.1.

Figure 5.1: Conceptual model focus of Chapter 5 (Source: Author, 2020)



5.1The Antenatal Care Pathway for Women with and without FGM

The following diagram (Figure 5.2) illustrates how the journey through the NHS from pregnancy to postpartum differs for women who have FGM and those who do not. The differences in the pathways should be noted as they provide context to the findings that follow.

The 'healthcare birth process' encompasses antenatal, labour and birth, and postpartum care provided by the NHS. Each stage impacted the next and provides nuanced understanding to women's experiences and perceptions of events. The 'healthcare birth process', like the woman herself, must be seen in a holistic context in order to provide the best healthcare possible and meet her needs

Figure 5.2: The Antenatal Process for those with and without FGM (Adapted from: NICE care for uncomplicated pregnancies: schedule of appointments (NICE, 2020, retrieved from: https://pathways.nice.org.uk/pathways/antenatal-care-for-uncomplicated-pregnancies/antenatal-care-for-uncomplicated-pregnancies-schedule-of-appointments)

5.2 Demographics.

The demographics of the women can be seen in Table 5.1. Women were aged between 30 and 38 years old, which reflects the current average age of women giving birth in the UK (Office for National Statistics, 2019). Their most recent children were aged between eight weeks old and 11 months old at time of interview. The number of children women had, varied from one to five, with three women being first time mothers, two women having their second child, and one woman each having their third, fourth and fifth child. Three women had planned C-sections, one woman had an emergency C-section after spontaneous labour, four women delivered after spontaneous labour and one woman was induced.

Women originated from Nigeria (5), Sudan (2), Zambia (1) and Eritrea (1). Type of FGM was self-reported and ranged from Type 1 to Type 3. Neither of the two women who had Type 3 were first time mothers and both had previously been de-infibulated. Country of origin did not predict type of FGM and reflected the cultural nature of FGM, that it is dictated by cultural group and not country boundaries (WHO, 2016). First time mothers were all over 30 years of age (34, 38 and 32), which may reflect education level as trends show the more education a woman has the older she becomes a mother and the less children she will bear (Berrington, Stone, & Beaujouan, 2015). Seven of the nine women had postsecondary education and reflects the rising level of postsecondary education among women (Department of Education, 2019). The level of education in the sample could also contain a bias due to the English language requirement of the study. All women reported being a member of a religious group, with eight of the nine attending a place of worship regularly. The ninth woman was new to the country and had not found a Church yet but intended to do so.

Further demographic analysis was conducted to aid in providing context to the women's experiences during their 'birth process' (Table 5.2). Three women had planned C-sections and thus have been removed from analysis of factors occurring during vaginal birth. Four of the six women who birthed vaginally experienced tearing. Episiotomies occurred for two out of six women, with one woman having both a tear and episiotomy due to a forceps-assisted birth. There was no observed pattern between tear or episiotomy during previous births and current birth experience, and no observable association was found between suffering a tear or episiotomy and type of FGM.

The standard care in the UK during the PPP is three midwife home visits and one at-home visit from a health visitor (NICE, 2006). Seven of the nine women received three midwife visits at home. One woman received two visits, and one received one visit. The woman who received one visit spent four days in hospital after birth which could explain this finding as the majority of the midwife home-checks would have already been completed. However, the woman expressed a desire for more home visits. Health visitor at-home visits ranged from zero to two and followed no discernible pattern. Those who received two visits included a woman very new to the UK, an emergency C-section, and a planned C-section. Those who received no home-visits included a planned C-section, a forceps birth and spontaneous labour births. This finding may reflect the current budget restrictions on health visitors in the NHS. Eight out of nine women attended a health visitor clinic for assessment and discharge, with one woman having this visit at home. All women attended their six-week post-natal check-up with their GP.

Table 5.1**: Women with FGM Participant Demographics**

Code	**1W**	**2W**	**3W**	**4W**	**5W**	**6W**	**7W**	**8W**	**9W**
Age	34	31	38	30	32	35	34	35	33
Age of most recent child born in UK	8wks	10wks	12wks	8wks	5mon	10wks	6mon	4mon	11mon
Sex of child	M	M	F	F	F	F	F	F	M
# of children	1	2	1	2	1	5	2	4	3
Marital status	Married	Married	Single	Married	Married	Married	Married	Divorced	Single
Country of Origin	Eritrea	Nigeria	Nigeria	Nigeria	Zambia	Sudan	Sudan	Nigeria	Nigeria
Ethnicity	Eritrean	Nigerian	Nigerian	Nigerian	Zambian	English	Sudanese	Nigerian	Nigerian
Religion/Faith	Orthodox Christian	Christian / Catholic	Christian	Christian	Islam	Islam	Islam	Christian	Christian
First language	Tigrigna	English	English	English	Mandega	Sudanese / English	Arabic	Yoruba	English
Education Level	College	University	Masters	University	University	University	Secondary School	Secondary School	University (currently)
Employment status	Mother	Employed	Mother	Employed	Employed	Mother	Mother	Mother	Mother & student
Type	3 (1,2)	4	2	2	1	1	3	2	3

Table 5.2**: Demographics Providing Contextual Understanding to Women's Experiences**

Code	**1W**	**2W**	**3W**	**4W**	**5W**	**6W**	**7W**	**8W**	**9W**
Natural start or induced?	Natural	Natural	Induced	Natural	C-Section (planned fibroids)	Natural	Emergency C-section following induction	Planned C-section	Planned C-section
Hospital stay	4 days	24 hrs	6 days	2 days	24 hrs		3 days	3 days	3 days
Tear	No	2nd	No	1st	NA	Yes, UK	Yes	NA	NA
Episiotomy	Yes	No	No	No	NA	Yes, metal forceps	UK	NA	NA
Previous tear during birth	NA	No	NA	2nd degree	NA	Yes (stitches)	Yes	Yes, small, in Africa	NA
Previous episiotomy during birth	NA	Yes	NA	Yes, shoulder dystocia	NA	No	Unknown	No	NA
Previous C-Section	0	0	0	0	2	0	1st = I → EC	2	1st = EC 2nd = PC
Number of midwife visits	3	3	1	3	3	2	3	3	3
Health visitor visits at home	2	1	0	0	0	0	2	2	0
Health centre visit	1	1	1	1	1	1	1	Home	1
Health centre discharge	1	1	1	1	1	1	1	Home	1
GP 6-week check	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
FGC have impact?	No	No	No	No	No	No	No	No	No
Partner present	Y	Y	Y	Y	Y	Y	Y	Y	Y

Reasons for women having planned C-sections included the presence of fibroids, and women's request due to previous C-sections. The third planned C-section was for unknown reasons. The woman had delivered her first child in Africa vaginally before delivering her subsequent children by C-section in the UK. She did not know why she had C-sections in the UK and had type 2 FGM. The woman who requested a C-section had had two previous ones in Africa. She did not state the reason for the initial C-section but stated that once she had the first one, she requested the following ones.

5.3 Findings

Three interconnecting themes emerged from the analysis of women's interviews: FGM, pain and support. Due to the intertwining nature of the experiences, the data will be presented in a chronological order to highlight the different aspects of FGM, pain and support that were present and how they were experienced at different times during the birth process (Figure 5.1). At each time-point, the antenatal, labour and birth, and the PPP, there are different acute needs. It is important to note the cross-cutting nature of the women's experiences, and how no experience should be seen in isolation but as part of the woman's holistic journey through the pregnancy and birth process. Each experience impacts the next, including previous birth experiences, and is why the findings have been presented reflecting the woman's journey through the healthcare birth process.

It is important to note the intensely emotional and stressful time pregnancy, childbirth and the PPP can be for women (Buckley & Moberg, 2019). Perceptions of events can be affected by this stress and thus it is significant to observe that interviews took place a minimum of eight weeks after birth, allowing women not only time to reflect on their experiences, but also allow healing time, and their hormones and bodies to regain balance. The cross-cutting nature of the themes is deliberated on in the discussion for this chapter (Section 5.4).

5.3.1 FGM context setting

To understand the postpartum experiences and needs of women with FGM, it is first important to acknowledge the context of their beliefs and thoughts about FGM. This personal knowledge, thoughts and beliefs provide the contextual base of how women with FGM will perceive their experiences. The following section is divided into three areas where women expressed their personal thoughts and experiences about FGM outside of the birth process.

Age. No woman remembered having FGM done to her, describing how they did not remember *"because I was very, I was like a baby, small baby"* (08). Women stated it occurred **"***when I was very young"* (01), and that *"we in Africa, we circumcise, I was circumcised back home, when I was a baby"* (09). As noted in Section 1.3, there are a range of ages when the FGM procedure is carried out dependent on cultural traditions.

Against the practice of FGM. All women reported they were against the practice of FGM. Women stated they accepted *"it's illegal now"* (01), and they *"agreed with that"* (01). Another woman described how she will not have her daughter cut "*because I'm still suffering and I'm not going to do that with my daughter, it impacts lives*" (06). One woman described how attitudes in home countries were changing and stated **"***but this time everything is stop, even our government is stop for the female, it's not allowed except for the boy…not good right, but it's our generation maybe, they don't have any indicate that's why"* (01); suggesting a reason for the change in attitudes surrounding FGM was from the current generation seeing no need for it. Some women spoke about FGM being a practice of culture, carried out by parents, and therefore not a needed practice in a country where it was not part of the culture, as described by the following quote,

> *I know what the law is in this country and I don't, even if the law doesn't say, I don't believe in it, it was done by my parents when I was a baby and that is the culture where I was born, so em, it's not a concern to me but, my baby girl is not circumcised because I don't believe in it* (04).

FGM was described as an *"African mentality"* (08), and women understood there was a difference in 'mentality' in the UK, stating: *"that's their own mentality, but here, it's not actually good anyway, so, I understand"* (08).

Non-pregnancy related sexual impacts of FGM. Two women noted negative sexual experiences and stated FGM was the cause. One woman described encountering difficulties during intercourse causing anxiety:

> *My husband doesn't really talk about it, though we, we, we, we, we usually encounter some, some issues, because sexually – well...we just manage through it. […] the only anxiety I have is just about – it's really having – taking its toll on my – on my, on our sexual lives*. (02)

Another described not particularly enjoying sexual intercourse, stating *"the only problem is, I don't really like sex, maybe it's because of that (the FGM)"* (08). Neither woman spoke about seeking help for their concerns and would not elaborate, suggesting they were uncomfortable discussing the topic and so this was not pursued.

Women described having limited knowledge about when their FGM occurred. Apart from two women who connected negative sexual experiences with their FGM, no other woman reported issues relating to FGM. All women reported being against FGM, suggesting perceived attitudes may be changing.

5.3.2 Antenatal Experiences

During the antenatal period, women with FGM are requested to attend a specialized FGM clinic with a specialized FGM midwife or consultant. The clinic’s purpose is three-fold, to create a birth plan for the woman, complete a safeguarding assessment and complete mandatory reporting. The clinic the women in this study attended is run by a specialist midwife but was previously run by a consultant gynaecologist specialized in women’s health. The focus of this section is the women’s experiences of their antenatal period. Overall women were happy with their antenatal care and FGM clinic visit. They learned new information, asked questions and one woman made friends at her appointment that she has maintained contact with. Although views on the necessity of the FGM clinic varied, women understood the midwife was required to ask questions about FGM and complete her safeguarding assessment. However, understanding does not mean acceptance and a few women reported feeling negative emotions towards the clinic process.

Type of FGM does not matter to women. In order to create a birth plan, the midwife must assess the type of FGM a woman has. The NHS uses the WHO typing of FGM (Section 1.3). FGM can be assessed through discussion with visual aids, or a genital check. When asked about type of FGM, women responded:

> *I can't remember that...I don't know...I remember one of the nurses was speaking about it, but in a general context, and not with it specifically to me. So, I don't even know that yea* (09)
>
> *I don't know exactly* (06)
>
> *Initially saw the consultant prior to me having my first child, em, I know the detail, but I can't remember what it is now* (04)

One woman discovered she was circumcised at her antenatal appointment and described her feelings about FGM as follows:

> **“***hey may have said something at the hospital, but I wasn't paying attention to them em... I know they told me the first time about it when I attended the clinic specifically what type they said it was to be honest because I didn't know, I didn't know I was circumcised until I did come from my check I don't know what check it was they did and they realized it... I just thought as long as it wasn't affecting me in any way then I'm like I don't really need to know much about it so, so I didn't put myself in a depressed state of mind* (03)

Although the NHS places great importance on knowing what Type of FGM a woman has, it must be acknowledged that the women themselves do not seem to and it was seen as inconsequential.

FGM Antenatal Clinic Experience. While the FGM antenatal clinic experience can be uncomfortable, the midwife support was valued, with women stating they were *“really, really, really satisfied with my antenatal”* (02) and describing their clinic appointment as *“lovely, yea, lovely”* (09).

Women expressed the need for the FGM clinic because of the information they received, stating: *“it gives me lots of instruction”* (06); provided details about FGM that were previously unknown; *“yea, they give me some information that I ask, that I need to know, which...they give me some drawings, I need to know that”* (08) and about different types of FGM, *“I never knew there were other degrees of it, I just thought I was the only type of circumcision available”* (04). The midwife provided resources for future reading which women appreciated, describing: *“because they told me a lot of things I didn't know before...if...I am in country I didn't know a lot of information like* *this, yea, they told me a lot, and they give me a leaflet"* (07). Before this, women reported trying to gain information to increase their knowledge of FGM from TV and the internet with little success as shown in the quote below:

> *I tried searching the internet, but I didn't get any more information because it's not legal, it's illegal over here so that's why, so I didn't see all the stuff. I see some TV, in our country TV, it's far away from our village, yea I saw the cut for the small baby, she was like 2 or 3 years she was crying, they using by a knife or like that one, but I didn't see carefully that one so I don't have any idea, I was trying to see but I can't see clearly* (01).

Women thought the clinic was necessary to educate others about the law and FGM in the UK, saying *"yea, it's necessary [to go] because some people, they don't know about the law in this country and don't know they harm their daughters [...], they need to tell them yea, they need to tell them, to advise it"* (06). Returning to the clinic during subsequent pregnancies was valued by some women who stated they did *"learn something"* (08) and felt it was *"it was absolutely helpful, as simple as that"* (07). One woman described meeting friends, stating; *"[I met] some friends there, so we are still keeping up to date so...em, so we stick together you know"* (08). Although the FGM antenatal clinic can be an uncomfortable experience, women appreciated the health teaching and support from the midwife and described understanding the necessity and value of attending.

Negative FGM antenatal clinic experiences. Some women reported negative aspects to their antenatal care, including not knowing what the FGM clinic appointment was for, feeling uncomfortable with the examination, feeling it was unnecessary to go to the clinic again during subsequent pregnancies and feeling victimized by discussions of the law. An important issue worth noting described by women was the idea of the NHS 'allowing normal birth' (described in the section 'Allowing normal birth' below).

Not knowing what FGM clinic appointment was for. The current appointment letter for the FGM antenatal clinic is a generic antenatal appointment letter indicating time and place but not the reason for the visit. A few women described being upset by this and would have preferred to know what type of appointment it was. One woman described: *"I just saw appointment at antenatal, I didn't know that's what it was about until I got to the lady and that was the time I knew that kind-of appointment I was having"* (05), and went on to say:

> *I didn't think it was necessary for me because em, I was going through caesarean, not natural birth and then if it were about sensitizing me because I have girl children, that has been done with my previous pregnancies and I signed papers that I'm not going to take my...do any FGM on my kids so I didn't think that that em, that appointment was necessary to be fair* (05).

This shows that mixed feelings about the FGM clinic are present among women. Some women feel it is important to attend during all pregnancies and learn something new each time, while others do not and feel it is purely to create a birth plan.

Not feeling comfortable with genital exam. Many women, with or without FGM are uncomfortable having a gynaecological examination (Moser, Patnick & Beral, 2016). Some women reported feeling uncomfortable being examined at the FGM clinic, while also understanding it was necessary. One woman, who had been previously de-infibulated in the UK was examined at her appointment and stated it was *"...uncomfortable but...it's so helpful for me"* (07). Although not stated, a possible reason for re-examination could have been to check for re-infibulation, or a lack of clear documentation or access to records within maternity services. While some women did feel uncomfortable, they prioritized the creation of a sound birth plan.

Discussions and focus on the law. All women were aware of and agreed with the law against FGM in the UK, stating, *"I know I'm not going to do with my daughter you know, because I know how bad it hurts [...] it's necessary to combat the cut. Some people they don't know, you know, so you have to advise it"* (06). There was a variety of responses to discussions focusing on law during appointments, with some women feeling happy to discuss the topic:

> *I'm very comfortable talking about it because eh, everyone even right inside my country, people are already, you know, campaigning against it…I am one of, em, I'm a sufferer of it so I am one of the eh...supporters and all that, so, that I know* (09).

While others, although expressing understanding of the role of the midwife described discussing the law in negative terms, *"eh, I slightly feel bad, I felt bad, though, but they have to do that and am I going to do for my daughter I said no, no it's not right, I can't, so..."* (08); and *"I'm... not going to say it's helpful here because I've been experienced of FGM I'm not going to try to get my daughter [cut]"* (07); while others felt exasperated,

> *that it is not allowed in this country, so told them that I know that already because I have a 12 years old girl, so she's not circumcised, so I know that right from time, and the, also, in my course of studies, so I also learnt that, so, yea [...] that it's not allowed and all that, I said I know* (09).

"Allowing normal birth". The issues of the law and FGM, while described as accepted and adhered to by the women in this study, shows how important communication by HCPs is. This is highlighted in the following description of two women feeling as though the healthcare system had the power to tell them how they were able to give birth. The first woman describes feeling victimized and intimidated. The experience, although with a previous pregnancy, clearly still impacts her thoughts and feelings about her most recent pregnancy and the NHS:

> *The consultant saw that it* [the baby] *was a very small one, there was no concern about it and he was happy for me to have a normal birth [...] I think the only thing I would potentially say will get a circumcision because I remember my first child eh, I think it's a bit daunting when they say because you're circumcised you have to go and see a consultant and they have to see if you can have a natural birth, I think it can sound quite intimidating em, with regards to that because eh it was my first child and I was told I needed to go and see this consultant to see if I could have a normal birth, and it just kind-of seemed my fate was hanging by this consultant to decide if I could deliver my baby safely or not, so I'm not sure if the consultant had seen me and had a different level of circumcision if they would...I don't know what sort of em, birth method they would have recommended but I think the whole process...it just made you feel like a victim at that point, that was just the only way I felt [...] and I just remember thinking, what have I done wrong? [...] It was the referral I had a letter in the post saying em I'd been referred to to go and see this consultant... so I went to the appointment and the consultant examined me and that was when the consultant said 'oh I think you're fine, you can have normal birth', and that was it. and then they just went on to advise to say that in this country it's illegal to circumcise the child, bla bla bla, so yeah [...] I don't know how I could feel*

> *less of a victim [...] I think maybe it would, like you, you said, maybe more information and maybe more information in how em, being circumcised could affect you know, the safety of your birth, maybe more information on that so you feel less of a victim you feel more....you want to help me, you want me to have the safest birth as possible rather then it be, it sounds more like a finger-pointing or being segregated to one side because oh, yea, she's been circumcised, we have to know she's gonna have a normal birth or not* (04).

Although not as intimidating as the above described experience, the idea of the consultant 'allowing normal birth' was also seen in another woman's description of her antenatal appointment:

> *I just had my appointment with the gynaecologist to see if I can have the baby naturally but when I got to the gynaecologist and they said, you know, I can see on your notes that you are booked for caesarean, classical caesarean because of your fibroids, so I don't think it's necessary for you to have that examination* (05)

Outlier: Social worker, what for? An outlier, albeit impactful and necessary experience to note, describes one woman's interaction with social work and the police force during a previous pregnancy. Although this was a unique case in this sample, it requires attention due to the reported negative impact. After attending the antenatal FGM clinic a social worker called to set up a meeting. The woman's account follows:

> *because when I, when I went for my antenatal clinic in my other pregnancy, em, I was just, I had just received a call em from the social worker, oh it's me the social worker, and I said social worker, what for? she said no mam, don't be panicked, em, now it's the rule that when you book at the clinic we have to be*

> *aware that you book at the clinic but I would like to set up an appointment with you, I need to come over to your house to speak to you and see how your living conditions at home and the like, I said ok. But, to my surprise I just opened my door and saw a policeman in uniform, and I wasn't informed about it. With forms, this lady said I need to sign them, and the like, so it's like, we were victims of circumstance, but now it's a threat, I don't understand* (05).

Miscommunication and poor communication between HCPs and women can leave lasting impressions and negative feelings. Although this experience occurred during a previous pregnancy, the woman felt the need to share her experience when discussing why she was hesitant to return to the antenatal clinic for subsequent pregnancies.

Pregnancy is an important contact point for healthcare interactions (Better Births, 2016). There is the potential of causing women to disengage from the conversations and losing an opportunity for effective safeguarding if not approached in a sensitive manner. Overall women were happy with the midwifery support and knowledge received. Communication about the need for the appointment, and a focus on health instead of the law were identified as potential methods to increase women's satisfaction with their antenatal experience. Focusing on the law risks blunting the issue and alienating women with FGM. While the antenatal time is dominated by FGM from a healthcare perspective, with the focus being on the law and ensuring a woman can have a safe birth, notably assessing whether a woman has Type 3 FGM and requires deinfibulation; it was not described as a focus for women in this study. Women with FGM, like women without FGM, focus on the health of their baby and planning a safe birth without focusing on their FGM. The themes of FGM, support and pain are present in the antenatal period. While FGM can be seen as the acute need from a healthcare perspective, support was described as the acute need from the women's perspective. On a positive note, pain was not a factor in the antenatal period.

5.3.3 Labour and Birth

The experience of labour and birth can be emotional, stressful, tiring and painful. Three women had planned C-sections, one woman had an emergency C-section following spontaneous labour, one woman was induced, and four women had vaginal births following spontaneous onset of labour. For most women, pain was an intrinsic part of their experience and represents the 'acute need' for this time in their birth process. The themes of support and FGM are also experienced during labour and birth but are not as prominent as pain. Although pain is an accepted aspect of birth by all women, women with FGM can have different experiences due to contextual factors regarding FGM, migration and culture. The following section details women's labour and birth experiences and provide contextual understanding of their postpartum experiences.

Pain during labour and birth. Women described pain as an accepted part of labour and childbirth. This theme describes women's pain experiences during labour and birth.

Positive feelings regarding pain. Some women reported positive feelings regarding their pain management, stating:

> *yes, it was under control because I was given some pain killers and to em reduce the pain and some medication so I think it was, the doctors, the nurses they know what to do, they give me the right medication because I'm also in the care*

> *setting and the, I don't in the hospital that's where I work as well, so I knew they were doing the right thing, so* (09).

Negative feelings regarding pain: 'No, it's not good'. Many women described having negative pain management experiences both during labour and the time in the hospital until discharge. Negative experiences resulted from epidurals not being effective, not feeling listened to, and delay in receiving pain medication after birth.

Epidurals. Several women reported feeling the epidurals they received were not effective, stating, *"I had an epidural for the labour but still eh, it's painful"* (06), and comparing their experience to previous births:

> *no, it's not good this time, yea, I'm looking for, you know they give me a leg injection, but the side effect was so bad, different from the one I had before, you know, I have dizzy, I can't control myself and after that I'm asking them to give me an epidural, and this time the epidural felt different as well, you know it's not killed the pain completely, but before, you know, if they give you an epidural, it kills the pain, you can't feel anything, but this time, it's different, you have to control it and ask every time, you have to press the machine to give you a little bit of pain relief, it doesn't work, it should be like a previous epidural, yea, even one of my friends who had it, she told me this time it's not good, they change it, you know, five years ago when I go, you know the epidurals are good but I think they change the system, this is not good, it's not helping you know* (06).

Pain management was also compared to experiences in home countries, with women reporting:

> *I actually realized that in Nigeria, they give a much higher dose at initial stage of – at initial – yeah, the dose of the epidural, and that really helped me [...]*

> *Yeah. But here I think it's actually titrated and then you have to take it as, as it once – as soon you have a pain or something. It's quite different, and there was still a lot of pain, and it, it didn't really help me to settle into my second stage...to, to, to the, to the pushing fully, yeah […] With this birth. I – yes, I, I wasn't in so much control like I was in, in my – at my first birth* (02).

Not feeling listened to. Negative pain experiences were not limited to women who delivered their babies vaginally, but also those who had C-sections; *"I had to caesarean section […] eh, it was so horrible […] so painful"* (07). Experiencing pain led some women to feel they were not listened to. Although they felt they communicated their feelings, their pain management expectations were not met. One woman described her experience during vaginal delivery, stating: *"I don't know, but I told them that I thought the drug doesn't work with me, you know I told them what I'm feeling"* (06), while another stated,

> *Because I, I had had issue with my first child and I've explained to my midwife about it, about my labour being really short and how I wanted to be managed […] So, it's been like, my, my information being, being get – you know, to be acted upon quickly* (02)

This led to her feeling out of control and subsequently as if she had let herself down.

> *Well, because the pain management wasn't enough. I wasn't in control […]. [I felt] like, like I let myself down, because I've, I've played it over and over in my head, and because I had an experience of, of, of being in control...of second stage, I know what to expect. But this time around, it wasn't like that. So, I was just, I was just in everywhere […] I wasn't in control at all.* (02).

Wait times. Wait times for pain medication after birth were also a concern for some women who reported waiting hours for midwives to return, describing how

> *for pain, you wait, sometimes more than is fitting and then sometimes like when there is an emergency you have to wait until after the emergency, so that change of schedule, it makes you more anxious, and the like so...* (05).

Although women were understanding, it contributed to a negative pain management experience.

> *I think probably what could be improved is and I know NHS is stretched so I totally understand but I felt from the time I had my first child to the second one I feel the care has dropped slightly, eh, with regards to you know, if you say, can I have a painkiller, you know that person would go for maybe 2-3 hours before coming back with a painkiller and I understand that potentially that maybe the midwife is covering about double of the number of patients that they should normally be covering hence why eh, the turnaround time is quite long, and that's the only thing but I guess the only way they could improve that is by hiring more staff but it's all down to budget and stuff, so... that's the only thing potentially that they could, we could improve on cos I feel that I understand the demand because I work in that environment but someone else who doesn't would have felt that that was a totally poor service* (04)

A lack of support from the healthcare system was described by some women because they were required to acquire or bring their own non-prescription pain medication. This was a decrease in the level of care from previous births and described thusly: *"Yea because they say they don't give pain medicine, I have to go and get* *paracetamol by myself […] yea, they say they don't give pain so I have to go get it myself"* (08) and

> *I remember that when I had my other two, em, previously, em, the first milk and all that...you, you get from the hospital, but these days you have to bring in your baby's first milk to the hospital, you have to bring your baby clothes to the hospital, so, em, some of those benefits, em, are no longer there* (09)

While pain is an intrinsic part of childbirth, it can be alleviated by effective pain management, and ensuring the woman feels listened to.

5.3.4 Support during Labour and Birth

Support during labour and birth, although not the 'acute need' of the mother, did have a significant impact on women's experiences. This section contains descriptions of women's experiences of support by midwives and their partners, and what that support meant to them.

Midwifery support. All women were happy with and appreciated their midwives during labour and birth, describing them as *"helpful"* (08). Supportive behaviours included remaining beside women throughout the birth as described by several women; *"… I really appreciate them… they help me if I call them also in the middle they come in to help me what I want and what I ask I get it"* (01); and:

> *As soon as I, I felt I was being – going to be in second stage, I – she, she was about going for a coffee or a tea, but I just – she just – I just told her, you – I'm not sure you can have that. She, she was like, oh yes, these things, things are changing. She was with me all through…. So, she, she didn't, she didn't leave my side at all. She, she, she couldn't even move* (02)

And:

> *"And then, at birth, having a midwife with you all along and you don't, you don't have to wait for the doctor to make decisions regarding your care. You have – you had – it's, it's been made – with you right there with the midwife. It was good and nice, also. There wasn't any waiting. There wasn't any delay in anything. Everything was dealt with immediately. It was – that, that is – that was really, really good also* (02)

Helpful behaviours such as responding to women's requests and supporting the woman as needed was also noted by several women and can be seen in the following quotes:

> *Midwives and they were really, really good they were good… I...yea... the labour ward were super they were actually the best* (03)

> *I'm happy they help me, they do their best to help me you know* (06)

> *So helpful, because I got a caesarean, they help me a lot, they helped my daughter and my son, and helped me with all of the things, all of my things* (07)

> *They were quite lovely, if I asked for anything, they would em, they would help me with it, em, and they were quite informative to say, to give me the information on what to expect at different times of the day* (04)

> *Oh they are lovely, they, they, they give me all the stuff when I need it…whenever I needed anything [...] they'll get it for me, they check my baby to*

> *make sure everything was ok, so, they did all the necessary...gave my baby all the necessary vaccines … they were always there, just normal, I don't think anything differently because for me I just feel they were doing their job and they did everything right to the best of their knowledge* (09)

'They listen to me'. Good communication was described as important to women during their hospital stay. Women expressed happiness at the amount of information given by healthcare staff, including information before birth *"they give me every information also before I deliver"* (01), during a change of plan from vaginal to C-section *"they explain to me sort of, how, if, because I decided to give up the birth she explain to me em how to give birth after caesarean section, sort of, and the risks"* (07), and information about what to expect after a C-section *"yea they gave me and they also gave me a leaflet for that and how to manage my pain when I go home and the exercises to do and all that, yea, they did speak to me about it and give me a leaflet to guide me and all that"* (09). Staff were responsive to women's needs, with women describing how *"they help me if I call them also in the middle they come in to help me what I want and what I ask I get it"* (01), and *"when I shout for help they listen to me"* (06).

While the pain management and wait times were not always ideal for women, they never questioned the support of the midwives and appreciated it.

'I was cared for'. Overall women described a positive healthcare experience and voiced their satisfaction with the healthcare received. Women reported getting *"whatever I want from the hospital and I appreciate that"* (01) and being *"so happy with everything that happened"* (07). Women described hospital staff as *"lovely [...] they give me all the stuff when I need it [...] they were very helpful and responsive"* (09) and commenting *"the way they treat the patient is good I think, nothing bad...I*

didn't see anything bad in them"(06). When asked what made the experience good, one woman stated, *"because everything went fine, and I was cared for"* (01).

Negative communication experiences. A few women reported negative communication experiences. Many were associated with pain and have been categorized in the pain section above. Two women discussed poor communication by staff in the hospital not relating to pain. One woman needed a forceps birth and did not feel staff communicated their actions well when she requested help, stating

> *because they tell me to force myself to push, but I tell them that I am tired, and they need to help me, I ask for it, but I don't...I don't know they were going to cut and take the baby out with a cut, because I didn't have that before yea, but I'm happy they help me, they do their best to help me you know* (06).

This quote shows how the woman perceived staff failed to communicate the necessity for an episiotomy during a forceps birth. The woman described a long healing process and attributed this to the episiotomy.

Another woman's experience shows how poor communication by staff can be felt very personally. A woman described her experience being moved from labour and birth to the post-birth ward. Initially she was given a single room as she was experiencing heavy bleeding, however, after a few hours she was moved to a multiple occupancy room directly opposite her previous room and was told another woman needed the single room more than her. The single room was not occupied for a long time and the woman was enraged. Her account follows:

> *when I got there they did put me in a private room so when they put me in a private room it wasn't because I was recovering it was because I was actually struggling and there was blood so I was proper struggling it wasn't even after 2*

> *hours after I was trying to settle in and I mean I had a shower cleaned myself up a lot and they just come to move me out of the room and say or someone else need this room more than you do and I'm thinking so why put me here in the first place because I was choking I was so incensed and I needed this space, I needed to clean myself off to get used to it, you get what I mean so they did that not once but twice and they just put me, and I don't have a problem being in a general Ward but I, but I mean is there a proper… I don't know, I know there are emergencies that you have but I just felt a bit… and that room wasn't occupied until much later at night or early the next day so why put me there kick me off when I was still trying to recover and I was struggling because I was proper struggling cos I've lost so much blood why put me there in the first place? and then you take me out in less than an hour and tell me [..] someone needs the room more than I do and then you put me in the general Ward right opposite myself at the bay so I can see nobody occupied that room until like early hours of the morning (03)*

This experience has been highlighted to show how poor communication was perceived as a personal attack on the woman. This woman was a first-time, single mother who felt she was struggling. Better communication about why the single room was needed and later not occupied may have alleviated her feelings of upset. While both these women’s experiences are unique in this data set, it is important to acknowledge how negative communication experiences can impact women during the birth process and can have lasting repercussions.

5.3.5 Partner Support

Partner support was very important during labour and birth. Although two women did not cohabitate with their partners, all women reported having a partner present at birth. Partners provided support in the form of company, as described:

The whole day and whole night, he was the one who stand with me […] yea, yea he support me. Starting from Friday until deliver, he was with me. Because I know only him. He's only the one who support me, that's why we get the lovely baby also (01),

Support was also shown through caring for the baby, allowing the woman to rest;

> *em, so I was, I gave birth sort of midnight and I was settled in the eh birth room, eh and as I was very exhausted, so I was there with my husband who...Em, so my husband took care of the baby, as well as the midwife that was at the birth unit, and I rested* (04).

Being an advocate for the woman during labour was also an important supportive behaviour displayed by partners and was described by women as helpful and meaningful:

> *He was, he was just trying to get things sorted. He was trying to, you know, speak on, on my behalf to, to the midwives and, and he was, he was very supportive […] Because when I'm in labour, I don't like being touched. I don't really like – I, I just listen to music or just – yeah. I don't like being touched at all, but he understood me very well, and he was, he was right on top of it and all the situation happening.* (02).

Support from midwives was very much appreciated by women who felt listened to and cared for during labour and birth. While poor communication did occur, women understood the staffing pressures faced by midwives, and overall women reported positive feelings about their midwifery support. Partner support was also vital for reassurance and company, advocacy and ability to rest, and shows how support grows in importance throughout the birth process.

Experiences regarding FGM during labour and birth. FGM was reported by all women not to have had an impact on birth, whether this birth or previous births. All women except one had had a vaginal birth at some point. When asked whether they thought their FGM had an impact on their birth, women responded, *"no, no, it was normal"* (01); *"no I don't think so, it's not something they told me at all so I don't think so"* (03); *"I don't think it had"* (04); *"no, none at all"* (09); and *"no, because my cut is not too bad […] not too much because I'm not feeling like it was a problem in labour"* (06). One woman who reported experiencing a tear stated it was due to staff being ill-prepared and not her FGM; *"I had a first degree, and that was because of, you know, the, the – they weren't really prepared"* (02).

During labour and birth, pain is the most prominent and acute need for women. Labour and birth can be painful experiences and can be remembered negatively if pain is not controlled. While multiple women described painful experiences, this was alleviated by supportive behaviours from midwives and partners. Although pain can be seen as the acute need during labour and birth, support is secondary, and its importance should not be overlooked. According to all women, FGM did not have an impact on their birth experience or birth outcomes. This is a noteworthy finding based on the importance placed on FGM by the NHS and guidelines and may reflect the impact of the law on UK healthcare policies. It also emphasises that all women should be seen as women first and not defined by potentially erroneous conceptions of their needs. Labour and birth experiences for women with FGM provide important understanding of previous experiences that may affect their postpartum experiences.

5.3.6 Postpartum Experiences

In the PPP support becomes the acute need over pain or FGM. During the PPP women reported receiving support from healthcare professionals, partners, family, their Church and community. Pain was a secondary concern for most women, with FGM becoming only an issue when healthcare professionals inquired about it.

5.3.6.1 Postpartum Healthcare Support.

Midwives. Midwives have the most contact with women during the PPP from a healthcare standpoint. Standard care (Figure 5.2) includes three home visits with midwives. During these visits, women reported receiving advice, knowledge, and reinforcement of feelings. Midwives conducted health assessments on women and their babies and also completed health teaching. Midwives were supportive throughout the PPP and women described their appreciation through statements such as *"oh, I mean, it was, it was really nice. It was – I've been one-on-one with the midwife. It was, like, amazing"* (02). Support by midwives can be described as sharing information, advice and displays of supportive behaviours.

Midwives play an important role in women's experiences of the birth process. Midwives were seen as authority figures and women desired them to provide positive reinforcement for their thoughts and actions, with one woman revealing: *"And they gave me lots of information about support groups, psychological support; if I'm feeling down, depressed, what to do. And it was, it was reassuring that you have someone who* *really cares about how you feel"* (02). One woman believed she had a tear on her urinary tract and expressed that she would have *"loved if the, the midwife visited me at home after, after birth, you know. And she actually recognized that there was a little tear around the urinary tract, which was making the urine quite painful urination. If she had been able to make a decision and probably repair or, you know, do something at that point"* (02). This woman was experiencing painful urination and wanted the midwife to acknowledge, reinforce her feelings, and provide or refer for treatment

Advice and Information. Women were pleased to receive advice from midwives about topics such as support, *"…they give me many advice and they make sure I have some friends coming in or someone to help me with the baby"* (06); and exercise after C-sections, *"give me the exercise you know, they just asked me to go and do some exercise"* (08). Information given by midwives included numbers to call if women had any concerns, *"...yea, they give me a number yea, to call if I need them, the baby, the pain or infection or anything I have to call them"* (06).

Health assessments. Midwives conducted health assessments on women and their babies, ensuring healing and development were progressing. Women reported midwifery interactions positively, stating,

> "*leaving the hospital that we were told that there would be a midwife coming to see us the following day, em, and she did, so she came and she introduced herself... she introduced herself and she weighed the baby em, checked the cord, make sure I was cleaning it with water, and make sure that there was no sign of infection."*(04)
>
> And

> *I then, left the hospital, and the midwife come to see me twice at home, and they help me how to breastfeed the baby, because I have...pain in my nipple, stuff like that, and they checked me, and they tell me once that I need to go to the[name] centre for the check for me and the baby [...] they touch my, you know, they touch my womb, to see if it's the right way, and they ask me about the bleeding, what does the bleeding look like, and if I have any infection, or something like that, and even they still look to make sure it's healing better* (06).

Midwives checked the perineum for those women who had tears or episiotomies, ensuring no infection was present and healing was progressing; *"even the midwife also she was checking me 2 or 3 times and she also help with that one, she told me everything is fine and scabbed normally"* (01), and *"she just come home and see the stitches, she said she want to make sure I don't have an infection or...probably just wants to watch the area"* (06).

Health teaching. Health teaching included topics such as breastfeeding: **"***when she came the baby how to breast, and how to wash and how to dressing and everything. Then I get some knowledge from them then I try by myself"* (01), how to care for your baby,

> *And they were able to actually tell me about, you know, how to, to, to care for the baby at home with, with minimal support, because back home, I have the luxury of my, my, my, my parents and my, my, my aunties, but here, I'm just on my own, and it's very new for me. So, though with them, they were able to tell me how to go about it, do this, do that.* (02),

Putting the baby to bed:

> *Oh, she came and asked...she talked me through the process of, you know, putting baby to bed, and what not to have in babies cot, and how to support myself, and the exercise to do and if I need any help where to go, and, she left her phone number with me as well, and yea, all that, yea* (09)

and wound care for women who had C-sections, *"the midwifes, they asking me about my surgery, and my baby, and then ask me about my wounds and check my wounds and my baby's bits"* (07), and

> *They were, I was asking them about, em, how to call the...about the injections, whether I have to do them all for the 6 weeks, and then, yea, and they said yea, it's very important that I have them, and then I did ask about the stitches, for them to change, to look at the wound side, everything was ok* (05)

Women felt midwives were supportive and described being comfortable with them, stating *"she cover everything that I needed to know and some things I never knew, you know [...] she was very, very supportive and eh, I was very free with her, you could say, she was so friendly as well."* (09).

Women prefer home visits. Most women stated they preferred home visits and appreciated their midwives visiting them at home, *"yea I do appreciate them coming, I do" (08),* with some answering *"yes, I would – yeah, yes, yes"* (02) to the question of wanting more home-visits, especially after a C-section where women greatly appreciated midwives coming to their homes *"because I can't go there because I can't really walk, it's just like six-weeks before I can do anything, 6-weeks"* (08).

Outlier. One woman received only one home visit and one health visitor discharge from a clinic. However, the woman spent four days in the hospital after she birthed her baby, and this could provide context as most midwifery checks would have already been completed. What this does display is a lack of communication from staff about what care will be received and why. The woman was confused about why she did not receive more midwife visits and expressed feelings of depression surrounding the perceived lack of care;

> *I've asked a few other people who have had babies about the same time as I have they've had 2 to 3 midwives the Midwives come like 2 to 3 times I'm not really sure why they haven't come after the first one* (03)
>
> *I don't want to use the word annoying but I'd like to say it was depressing... that when you know these people are supposed to come see you... they're not there and you, you think someone just had a baby the day before and they go oh they come back to 2-3 times, so I think oh did I do anything wrong? Or is something wrong somewhere* (03)

The same woman was the only one to discuss feelings of anxiety when at home. A single, first-time mum, this woman discussed what concerns she had and how she had to ‘learn’ by herself. She described her experiences here:

> *Initially it was just a bit... being the first one and the first time and a first-time mum was just a bit em... I can't find the word... it was strange it was a bit unusual fitting in and all of that... trying to settle in and then... but as soon as I did settle in...it did take some time...so I had like almost a week of that and then all the anxiety started and I couldn't sleep, it seemed like I had to be awake to make sure the little one was alright, so there was a bit of anxiety for like a week.*

> *then when I was sure she we were settled in then it's settled a little bit and em, my concern majorly was the fact I wasn't lactating properly because I did have quite a few antibiotics while I was in the hospital as they thought that I was prone to infection at the time so it was a bit hard at the time so I had to keep doing milk you know but I tried combinations though I did realise that whenever she had the breast milk she still did cry so that meant to me that she wasn't fooled so at that point I had to introduce milk, but in general terms I would say it wasn't too bad but just the unknowns and having to learn by myself (03).*

GP and health visitor. All women had a GP and attended a six-week postnatal appointment. All women went to a health visitor clinic and stated the health visitor was helpful by answering questions and displaying supportive behaviours. One woman received *"advice about em, breastfeeding"* (06).

Healthcare support is very important during the PPP, especially as a source of knowledge and education for women and is essential for women who do not have family or community support post-migration. Women reported feeling comfortable with their midwives and were very appreciative of any home care provided. Overall, women described feeling well cared for and their needs being met.

5.3.7 Non-healthcare Support during the PPP

Partner Support. Partner support during the PPP is shown through behaviours and when re-engaging in sexual relations. Supportive behaviours include partners caring for the baby,

> *change the nappy, feed the baby, rock the baby and then at, you know, ask me to go and have a rest or a sleep, em, so at least I can get some rest and times where*

> *he would make dinners well so I could rest, and then make things a lot easier for me* (04),

And *"helping me with the kids, changing nappies, helping with the kids, the other ones, taking them to school, making their lunch boxes, that sort of thing"* (05), as well as, *"he walk with my kids, brings them to school, and collects them sometimes he help me with the cooking and give me some food and clean the house, play with the kids sometimes"* (06).

Preparing food was another valued supportive behaviour:

> *and he help me and support me at home also, when I was busy with baby and he do the cooking and he bring some food, that's how. the whole day he's in work but even he didn't say tired and something like that once, if, when he come and he make something cooking or he washing, like that way, he's supporting the baby* (01)

As was doing household chores, *"he'll change the baby and do the homework, ironing, cleaning"* (07). Women reported feeling supported by their partners' presence, stating *"he took two weeks paternity leave. He was at home with us for two weeks"* (02), and *"he is really being there for me, yea"* (07). Supportive behaviours were described as giving women the ability to rest and bond with their baby.

Re-engaging in sex. Partners were also supportive when couples attempted to re-engage in sex after the birth of their baby. While the majority of women had re-engaged in sex without issues, three women reported concerns, with two not having re-engaged in sex at the time of interview. FGM was not described as the cause of this, with women stating *"I think, I think it will just happen naturally, that's what...it's because we're both preoccupied getting used to the child...yea [...] I don't see it as a problem, no"* (04), and *"yea, it was not the best around the cutting area, a bit sore, it's not so strong yet"* (06). Partner support was exemplified by giving the woman time to heal, *"it's a little bit sore when he tries to penetrate. So, yeah. But we've been giving each other time"* (02). Length of time from childbirth to re-engaging in sexual relations is very personal and can depend on a variety of factors. Partners can support the woman in this situation by ensuring they are comfortable and allowing them to dictate when re-engaging occurs.

Partner support is greatly appreciated by women in the PPP allowing women to heal, rest and bond with their baby. This is especially important when the woman lacks family and community support post-migration.

Family. Family support is wanted, as described by some women: *"I want more family"* (01), *"I had some, some period of cries and wishing my family was, was here or I could just travel home, something like that"* (02) and needed, *"oh, absolutely if I could have more of my family here that would be perfect"* (04). It is evident the women's cultures are ones of sharing experience and community. Women looked for family for their experience, *"but I was looking for my mother and my sister also [...] when I was pregnant because I didn't know how to care the baby, how to breast, how to just... I asked my mother and my sister"* (01); and support, stating

> *I guess there would be if I had all my family here then you know, you know, instead of having one pair of hands I would have quite a few, so that would be a big, big impact on how em, the support I have and even the, my relation with them as well, because certainly means my children would have potential of seeing their cousins more often rather then you know, just a couple of times, and you know in the culture in Nigeria where if you have more family members*

> *around we bring up the children em together so I've a big family compared to em quite a micro-family that we have here* (04)

And *"I had my mum around for a bit so that did help and, and I got support from her so, that did help"* (03). Women felt a vast difference between the UK and the home countries in terms of family support and were pleased the healthcare system was able to fill some gaps, *"With, with minimal support, because back home, I have the luxury of my, my, my, my parents and my, my, my aunties, but here, I'm just on my own, and it's very new for me"* (02).

Family and partner support bring emotional security at a time of high emotion, allowing rest,

> *like I, I only have access to baby when I want to breastfeed her, my aunty spent two weeks in my house so she was always bathing the baby, dressing the baby, and they, they, always with the baby for me to have enough rest [...] I was able to manage myself because em, this was not the first time I have it, I have support from my family, they were with me, my partner was, you know, he's always around me [...] I have enough rest at home* (09).

Family support also results in more family time, *"more family time really, em, that's the support I would get from them"* (04) and less stress,

> *yea, I think because of the support I have from family em, and from my partner it does make me more secure emotionally em, I guess if I didn't have that support then potentially you know the task of looking after two children might be a bit a bit overwhelming at that point. but I think, I feel secure and supported and I know if I've got too much on my plate or I feel stressed because of the demand of the job of parentage I know I can always say you know, can you watch them and

> *you know both of my kids have got godparents who live em locally to me so they always pop over you know, here and there and support, you know they help with house work or they might take the older one to the park or to a play area just to give me some time to sort of bond with the little one as well* (04)

It may be that healthcare need can be decreased if support is available at home. The next quote shows how a woman was able to manage experiencing baby-blues because of family support:

> *I didn't because I had support, my family were here, my partner, my Aunty, everybody was around me so I wasn't in the mood to talk to any of them, I was in the low mood, crying, you know, so, because my Aunty is, also involved, so she knew, she know what I was going through, so she was there to support me* (09).

Comparisons of support received in their country of origin versus the UK were made by some women, explaining the differences as:

> *Like, how you are dealing with pain. Because that's a major difference from what is back home and here; back home, there's a lot of supports. Like, you're, you're just resting physically. But here, so much, so much is, is taken out work of the hand. I have, I have, the house to take care of and I have, then – with the baby also, so, it's, it, it was a lot at the initial stage. And it was quite nice with the midwives coming often. And the health visitor* (02)

Family support allows the woman to rest, have companionship and help, and also feel more emotionally secure. Having support at home can decrease reliance on midwives for knowledge and reassurance. Due to migration, women with FGM may lack family and community support, enhancing their need and reliance on healthcare.

Assessing and increasing support networks may alleviate reliance on healthcare for women with FGM.

Community support. Community and church support were spoken about interchangeably by women. Church and community support was important for gaining experience, with women revealing: *“Yea, I have, yea, from my country, I have some friends around…they visit me and even they give me some experience also”* (01); *“it’s very helpful, you know that you, you are not alone and that the, you share experiences and it's helpful”* (05); and company; *“I have a lot of friends and a community around me […] my friend’s yea, they always come to my house to support me, you know, spend nice time with me”* (06), and *“yea, coffee, sometimes dinner, sometimes breakfast”* (07). Community support is shown through help with chores: *“yes, they are, I know most people from my Church so em, people keep, people come around, help out with house chores and then leave again, yea, so yea, they are supportive”* (04) and an overall feeling of people being there in times of need: *“very supportive, very helpful, they are always there when you need them, that's important”* (09). Women had differing opinions on mother support groups, including feeling a lack of time prevented participation,

> *I’ll take my time to look into one, it depends on what it's about, I don't think I want to be in a group, where maybe there's a group chat and that they keep bomping my phone unless* it didn't*, when I’m supposed to be taking care of my little one and stuff like that but if it’s something I want I’m sure I’ll find someone nice but for now I’m just fine with Church you know* (03)

And

> *mummy group, I tried to sort something like that to go you know, but I don't really have time, I drop my daughter up from school, check the boys to their school, look after the very small one, it's too much, I can't, I can't attend* (08)

while others wanted more community support, stating:

> *here, yes, only me. because if you have a lot of social and a lot of friends you can get a lot of experience also from them because we have lots of baby, so that's why I want more friends* (01),

and *"no, not really, no. I'm, I'm very new to, to this area. I don't really have any friends" (*02). A community provides a support network for women, with many women believing more community support would benefit them.

Women described support as meaning sharing experiences, sharing knowledge, reassurance (supporting while ensuring autonomy) and social company; and results in increased emotional wellbeing, increased mental health, decreased pain and increased ability to manage pain. When a lack of support is experienced, feelings of isolation can occur. The following two quotes demonstrate the needs of a single mother and the feelings of a woman when her husband returned to work.

> *Just for support just in case I have to cancel anything if I have to go, if I have to go to anything if that if I have to go here. just on my wish-list I wouldn't mind a live-in nanny not to care for her 100% but just to you know just keep an eye on her while I run around because I do things faster if I had someone that would like hold for, for a bit well I get things done but, but hey it's fine it's not that bad* (03)

And

> *yes tired, em, stressed. my husband was on paternity leave for a couple of weeks so I was technically only by myself for about em a week and a bit, yes, so but I did feel the difference being all by myself em doing everything because at that point there were times where I struggled to have my shower because she needed feeding every time and as soon as I put her down she was crying so not until my husband gets home at night, that was the time I had to I was able to have a good long shower or bath so I do feel the difference when em I do have the support there because then at least I can have a shower, at least I have some proper food em, and then that would help me mentally as well [...] I was in the house most of that week yes* (04)

Support from partners, family and community were seen to enhance positive experiences when present and were wished for when absent. The cultural differences and comparisons are clearly seen in this section of desired support versus reality for women with FGM and shows an important element that could enhance positive experiences.

5.3.8 Pain

Pain is highly personal and highly variable depending on birth experience, support and individual pain tolerance. In this study there was a spectrum of pain being experienced during the PPP from days to months. Some women felt pain for a few days after returning home;

> *a little bit pain, for my baby it's everything is fine, even the midwife is come like after 3 days, 4 days like that one to check for my baby and for me also, it's only for 4 days, it's pain, then it's nothing* (01),

And *“the pain was...it was fine with the before 3 days, like if I didn't take the pain killers, I do feel unbearable pain but after that I was fine with taking it only once or not, nothing at all”* (05). One woman had a forceps birth and has taken months to heal, stating the pain was *“very bad, yes, it’s taken two months to heal you know, and even until now sometimes I feel pain you know”* (06). Another woman had experienced trauma with a previous birth and did not feel able to return to the hospital when advised by the midwife due to a potential tear on her urinary tract. She reported her experience was

> *it really was – it was really painful. I had, I had lots of pain. I actually felt there was some bruise on my, my, my urinary tract. The midwife came home to check, and she said probably there is. Though she, she, she advised me to go back to the hospital, but I just couldn’t, I just couldn’t stand it. So, I had to just continue with warm baths at home and just personal hygiene and [...] it just went, yeah, and healed on its own.* (02)

Other women were so happy about their baby they did not emphasize the pain, stating *“I’m so happy with everything that happened”* (07); while another presented a calm attitude towards pain, stating *“I think I was able to manage because it's just pain, and it was there, and later it went, and that was it”* (09).

5.3.9 No infection

No women got an infection after they birthed their baby: *“yea they stitched it up and they give me some medicine and for 4 or 5 days when I came to home, they say everything is fine...it's gone normal”* (01). All women healed well after their childbirth experience. While some took longer than others, no woman reported healing concerns.

5.3.10 FGM

Two women stated that FGM had been discussed during the PPP by midwives. One woman found this helpful and indicated *"I just need to be clarified on what is acceptable in the UK"* (02), while the other woman seemed exasperated by the line of questioning and stated that the midwives said *"that it's not allowed and all that, I said I know"* (09).

5.3.10.1 Outlier: Continuity of care.

One woman expressed she would like continuity of care by midwives and stated she

> *would have been more comfortable with the midwife who I had my antenatal with. Yeah, because we already had, had, had the relationship, and you know, she, she knows a lot about me. So, it would have been more easy – much easier, you know, just having to, to, to continue with her* (02).

No other woman mentioned desiring continuity of care.

Support is the acute need in the PPP. Sources of support that were mentioned included healthcare providers, partners, family, Church or community. When women feel they have concrete non-healthcare support, it can decrease their reliance on midwives. When partner and family support is not enough, women rely on healthcare more and can feel isolated when it does not meet their needs.

5.3.11 Additional Subthemes

5.3.11.1 Factors influencing healthcare experiences.

Many factors influence people's abilities to access healthcare services. Issues brought up by women included increased wait times for appointments, transport, childcare, support from family of friends and lack of time. Appointments and waiting times were an issue for several women, with some stating waiting times had increased from previous pregnancies,

> *the only thing I think that is a problem is the waiting time, yes, the waiting time compared to 12 years ago, the waiting time now is so ridiculous that they give you appointment that they make, and the appointment time is past it, up to 30 minutes to one hour* (09)

and that going to appointments caused stress; *"a bit stressful you know, going to appointments every time, every time, it's stressful"* (08). It was sometimes difficult organizing child pick-ups as described by one woman:

> *I remember one of my appointments, I had to go to school run and my appointment was em, for 1.30, half one, so I'm there, and I was like oh ok fine, I will still have enough time to pick up the kids, so, and the kids go late to 3 o'clock, so I had my partner cover for me and help me pick them up because I was running late* (09)

Overall, women were understanding of the pressures on the NHS, expressing; *"I don't think there is anything I would change to my experience for now, yea, the NHS is trying, and that's what I would say, all of the facilities, the equipment, the staff"* (04).

5.3.11.2 Outliers.

Outlier issues included previous birth trauma and living conditions. Previous birth trauma was experienced by one woman and influenced her decision to seek medical attention when advised by the midwife.

Previous birth trauma. One woman described how a previous birth trauma experience influenced her decision not to seek medical attention when advised:

> *I wasn't really – well, I wasn't ready to transport. In, in the, the first it was just – it was my experience back home, I had repair of my episiotomy twice. Which I did once [didn't want to repeat itself] quite, very, very scared about – and any some of – repair down there, now. And then, the other thing was – it was, it was only my husband and I here. We didn't have – we don't have so much support and I don't want him to be left alone with the baby and my daughter, and them. Just so they – I just don't want so much stress anymore.* (02).

Previous birth trauma should be noted by midwives and appropriate resources given.

Living conditions. Less than optimal living conditions were a cause of stress for two women.

> *my problem is the house you know we are living, sharing, like that one, we are living, 1,2 3, and 4 [...], and yea, that's why I'm afraid also to my baby, because I'm not living alone, we are living, sharing with some cousin here when I bring my baby just I get scared because we have breathing all of the cooking, we have the same kitchen, the same table, the same bathroom [...] only the sadness is about that one...the sharing...* (01)

And *"I think that one I'm dealing with, I'm staying in temporary accommodation, with the council, they are still looking for me, looking for the house for me"* (08). Living conditions should not be overlooked as a cause of stress for new mothers.

Advice for others.

Women were asked if they had any advice for others going through the same experience. Their advice ranged from self-advocacy, not doing FGM to their daughters, ensuring you have enough support, remembering that everybody is different and promoting de-infibulation during the antenatal period.

No FGM. Women advised others not to have FGM done to their daughters, stating:

> *for my friends for example if they get a baby girl I don't want a lot of them to cut for that baby, it's not allowed and I will give some explanation also about how I care for my baby if that's only the first one that's all, I want to share everything with them...yea…but the only, the first one I don't allow them to cut if it's a girl baby. that's difficult, even its not legally...that I want to give them that advice also* (01).

Self-advocacy. Women encouraged others to self-advocate and express their questions, concerns and feelings throughout the birth process.

> *Just that next time I, I, I would be much more adamant on what I want and totally I would, I would just put my foot down on things I want to be done…And anything she feels uncomfortable with or not going well, she should voice it out as soon as possible* (02)

and

> *I just telling her don't take the epidural, because it doesn't work, and, eh, take your time, you know, I don't like this time you know, because I get a different*

pain killer, get an injection or gas and air, when the epidural doesn't work I use the gas and air (06)

and

well I would just tell her to be calm, and ask questions if she, she's not sure, because the nurses and the doctors, they are willing to help, so, I would tell them that there's no question that is stupid or foolish, if she is not sure of anything she should ask (09)

Support. Women encouraged others to ensure they had enough support when returning home.

I would just tell her to, probably, get a support […] make sure she has a lot of support ready, aside from her husband, probably. If she's going to be alone, she should be looking out to having more than her husband and get someone from home or a relative around. And I would encourage her to stick more to her birth plan (04)

'Everybody's different'. Women expressed the thought that every woman has a different birth experience and to not compare yourself with others.

I'd say it's different for everyone I'd just say take more time to prepare yourself, it's ok to be anxious, it's ok to be nervous but don't be scared, that's what I was feeling because all the people I did speak to about their experiences because I just wanted to know what it was like it's all different, my happened so differently […] So, there's no point going around and asking people how they need to do things because it's different for everyone and everyone says it different. so that's my advice like just *prepare yourself physically, spiritually, emotionally and otherwise and don't compare your experiences with another person's [...]so it's completely different so I just say it's a unique experience* (03)

*De-infibulation***.** One woman advised having de-infibulation during the antenatal period to allow women to have a better chance at having a vaginal birth go smoothly.

> *there's a certain belief that some ladies don't want to cut before they have their babies, they thought if you gonna have a baby you have to cut after, when you have the baby, but I'm thinking it is best, you have to do the cut before your birth time, yea, because it's really helpful for if you're going to try* (07)

The law. Women advised following the law of the country and to ask questions if unsure, stating, *"just to make sure they follow the, make sure they follow the rules and regulations of the country and the hospital as well"* (05)

Women openly shared advice for others, indicating that a peer-support group for women with FGM during pregnancy and post-partum would be welcomed and beneficial.

5.3.11.3 *Knowledge Needs*.

New mothers have many questions about a variety of topics. Midwives should continue to signpost resources. Women had varying knowledge needs and resource wants, including *"how to go about the circumcision of my boy. I had to go on the Internet to know, because based on our culture and religion, it's something that has to be done"* (02); where to access help regarding sexual issues, *"but I don't know how to probably explain that to my GP. I don't know if it's part of what services to ask for"* (02). Information about different types of birth control was also desired: *"I tried to watch a DVD to find about the contraception, but when they, I want to get the coil,* *because I think it's a good way, but when they treat the coil"* (06). General questions about the baby's development and reassurance of progress was also stated as a want: *"in general terms I would say it wasn't too bad but just the unknowns and having to learn by myself"* (03). Women expressed desiring knowledge about breastfeeding, ***"I** then, left the hospital, and the midwife come to see me twice at home, and they help me how to breastfeed the baby, because I have...pain in my nipple, stuff like that"* (06).

5.3.11.4 Resources.

A peer support group for the PPP to give information on what to expect was desired,

> *there's usually, like, like, a support group in all hospitals. Like, the hospital I used, there, there, there are, there are women or mothers, or sometimes matrons who must be around talking to mothers before leaving the hospital, about what to expect. And probably at that point, I would have asked about what if I have to come back to the hospital for repairs or something like that.* (02)

General baby resources in a small living area were also desired, suggesting increased community support could be a method of sharing resources among families and new mothers.

5.3.11.5 Look to healthcare to fill gaps.

The differences between support between home countries and the UK often leaves gaps in critical times. One woman spoke of her stress and concern about beginning labour during the night, and who was going to look after her other children. This would not have been a concern in her home country. When asked how the healthcare system could help, she suggested child minding support.

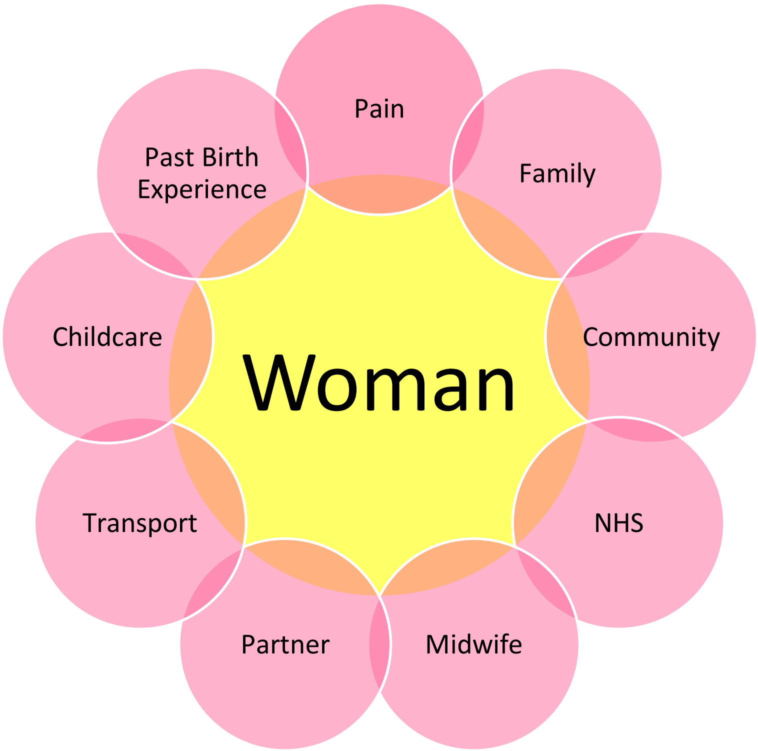
> *I don't know, I think it's...obviously with the birth suite they only say no other children but I totally understand why kids are not allowed em, I don't think there's any other way the NHS could help I don't think so, thinking that they, cause you know if they...in an ideal world, we would love you know, an NHS that has a creche onsite where if for anything you could just drop the other child there while you know em, you're having a baby and then you could pick that child up at that point after em, the whole thing was over that would be the ideal thing but I don't know how feasible that would be* (04)

The women's descriptions of additional factors influencing their healthcare decisions and ability to access services, as well as their advice to other women are revealing. Pregnancy is an important contact point for health services. Wait times, logistics surrounding child-care and knowledge of how to access health resources are areas for improvement.

5.4 Discussion

The 'healthcare birth process' a woman follows theoretically provides care throughout pregnancy and the PPP. However, the focus is not necessarily on the woman, but the protection and health of the foetus and child. Medical terms used display this by defining the birth process by foetal, new-born and child checkpoints, pre-NATAL, ante-NATAL, birth of the child, and post-NATAL period. This was evident during interviews with KIs by the use of these terms (Chapter 4), and literature searches where the PPP is referred to as the post-natal period, even when specifically discussing the woman. The birth process is focused on the creation and development of a healthy child, but to have healthy babies, you need healthy mothers (Knight et al., 2019). Key findings within this chapter include the influence of the law, FGM not being a priority for women and the importance of support. These will now be discussed in turn. A conceptualization of the chapter findings has been created (Figure 5.3).

Figure 5.3: Conceptualization of the postpartum experiences of women with FGM (Source Author, 2020)



5.4.1 The Law

As noted in the DA and KI interviews, the law is heavily impacting antenatal healthcare interactions regarding FGM and was described by women as setting the tone of the interactions with midwives during their antenatal appointment. There is not much known about women's perceptions regarding the interaction of the law and healthcare interactions, however, this study highlights the need for expansion in this research area. This study found women experienced interesting and at times conflicting feelings about the care they received; at once reporting being appreciative of midwife support, while also feeling ‘othered’ and not in control of their birth process during the antenatal care pathway.

The impact of the law and mandatory reporting cannot be underestimated regarding FGM and healthcare. Women discussed the law and how it made them feel like victims and perpetrators simultaneously, a feat the healthcare service should not strive for. Women’s experiences with health services regarding FGM show women do not feel all their needs are being met, which is reflected in current literature (Glover et al., 2017; Moxey & Jones, 2016). The consequences of negative maternity experiences should not be underestimated, especially in migrant and minority populations (Hussein, 2010). Women feeling victimized (Evans et al., 2019; Hussein, 2010), like bad mothers (Evans et al., 2019), and feeling blamed for their FGM (Glover et al., 2017) is a known negative experience for women with FGM.

The message that FGM is illegal in the UK has been heard and understood by the women in this study, however, a pilot study by Larsson, Cohen, Hann, Creighton and Hodes (2018) that surveyed 51 women and 3 men about their attitudes and knowledge towards FGM found only 72% of respondents knew FGM was illegal in the UK and 15% reported FGM posed no danger to women’s health, or they were unaware if it did; suggesting that not all people know FGM is against the law in the UK and/or causes negative health effects for women. Larsson et al’s (2018) study was conducted in London which has the largest FGM-affected population in the UK, and must be viewed in the context of the differences in demographics between migration groups; such as those who have lived in the UK for many years and those who have not. Larsson et al. (2018) reported a mean time spent in the UK of 10 years (SD 5.9 years, range 1–26 years).

5.4.2 Not FGM

Women in this study did not associate any birth outcomes with their FGM, either positive or negative. This is an interesting finding as current literature reporting on clinical outcomes suggests otherwise (WHO, 2018). Qualitative studies conducted in the UK (Harper-Bulmam & McCourt, 2002; Moxey & Jones, 2016; Straus et al., 2009) did not report type of FGM the women had and so no comparison on type can be made. However, Straus did report experiences with Type 3 FGM and its' impact on birth, including de-infibulation. As no women in this study were de-infibulated for this birth, a difference in experiences is expected. Other studies have reported women with previous de-infibulation or antenatal de-infibulation to have better outcomes compared to women who have intrapartum de-infibulation.

This may be due to the current methods of collecting data on FGM, where that data originates from (see Section 1.3.5), high-quality maternity healthcare or the particular sample used in this study. Women also described their feelings about the 'types' of FGM. The WHO classification, while perhaps useful as a tool for HCPs to understand the general extent of FGM a woman has experienced, is not helpful or wanted by women. FGM comprises many different procedures based not only on 'type' practiced within communities, but also based on who carries out the procedure. The method and skill individual midwives or cutters use can be seen as a signature. When combined with the woman's individual anatomy and the 'type' practiced by the community, many variations of the practice exist (WHO, 2016).

The WHO classifications are intended for use by HCPs as a form of reference to potential health complications and needs. The media has taken the classification into the public sphere, and the nuance of the variations have been ignored (Johnsdotter &

Mestre, 2017). Reducing a culturally-contextualized, multi-layered phenomenon to ‘four types’ alters the public conversation and attempts to create distinctive lines and boxes within a practice with many variations and unique health consequences. Attention is focused on the ‘worst type’ and women are told by the media that they are victims of a terrible crime (Boyle & Hoeschen, 2001; Johnsdotter & Mestre, 2017; Sobel, 2015). Women in this study reported not caring about what type of FGM they have. Again, FGM must be seen as a spectrum of procedures, with a broad spectrum of health consequences. While for some women with FGM it may help to characterize what procedure they had to help process trauma associated with FGM; this should not be applied to all women with FGM, concluding an individualized approach is warranted.

The focus on type of FGM and the concurrent media messages women are exposed could negatively impact not only the women’s lives, but also their support network. If a woman does not experience any negative health consequences from her FGM and does not consider herself a victim of mutilation; media, law and healthcare messages to the contrary could have a negative effect. This may lead to negative feelings towards family members and cause rifts. It also displays the top-down approach of the healthcare system and has the potential to change what a holistic midwifery assessment into a tick-box assessment. Having a health focused approach, listening to the woman, and responding to her individual needs may prevent this.

This suggests a closer evaluation and acknowledgement of where data is coming from is needed, with healthcare systems assessing the applicability of evidence within their specific contexts. Western medical systems may not have the same outcomes as non-western medical systems. Studies conducted in the UK are inconclusive and display the varied nature of FGM (Harper-Bulmam & McCourt, 2002; Larsson et al., 2018; Moxey & Jones, 2016; Straus et al., 2009).

The experience of having FGM and the type of procedure completed is unique to each woman. The majority of women in this study reported type 1 or 2 FGM. The women who reported type 3 had been previously de-infibulated. This study focused on women's experiences of the 'birth process', and specifically the PPP and if or how their FGM had an impact. While women in this study did not report their FGM had impacted their birth, either physically or psychologically, there is evidence many women with FGM are permanently affected mentally and physically, and have worse birth outcomes. A systematic review by Berg, Denison, and Fretheim, (2010) stated no firm conclusions could be drawn regarding the psychological impacts of FGM due to the low quality and number of studies found, and inconsistencies in collecting data regarding mental health. Qualitative studies including Glover et al., (2017) describe women experiencing life-long negative mental health impacts from their FGM experiences.

Many factors may be influencing women's reactions to the experience of FGM, including the cultural embeddedness of the practice possibly providing a protective influence on how women process the experience. Age may also be a factor, with younger girls not remembering the event. Pre-pubescent girls who have experienced FGM may be unaware of how their anatomy and function may have changed. In this study, women could be creating bias by the majority being Type 2 or having previous de-infibulation before this most recent pregnancy; however, this was a rigorous recruitment within the Coventry clinic and represents the current population in Coventry who consented to participate and met inclusion criteria (see Section 2.3.5). As a qualitative approach was used, generalizability was not expected. This study has uncovered how FGM is experienced within an individual context and thus the aim of studies to produce generalizable results through classification such as those used by the WHO may be unfeasible. The idea of generalizability and FGM requires further deliberation.

What can be concluded is that FGM is a unique experience for each woman and healthcare providers should ask women how they have been affected, and how and if they would like to explore interventions. More information is needed on those that did not participate and a larger sample from many different clinics would enhance understanding of the UK context.

5.4.3 Support

The importance of support during the birth process by HCP, partners, family and friends is well established and is reflected in current government health documents, guidelines, and literature (National Maternity Review, 2016; Sandall, 2016). Less attention is paid to the PPP and represents an area requiring further study. Women in this study described the importance of partner support and, although included women represent a small study, it was seen that the two women in the sample who did not cohabit with their partners described more negative feelings towards their care than did women with live-in partners. This has been reported in studies such as Raleigh, Hussey, Seccombe and Hallt (2010), who found single mothers were more likely to spend over 24 hours in hospital following a vaginal delivery, less likely to breastfeed, and are more negative about food choices. Single mothers in this study were also less likely to report feeling respected or feeling their dignity remained intact, less likely to say they saw a midwife as often as they would have liked, and less likely to report attending a postnatal check-up than women with partners. These are serious concerns, and the importance of support should be acknowledged and prioritized in guidelines.

Women also discussed the cultural differences between their home country and the UK in terms of family support and described wanting that level of support in the UK. This finding is reflected in literature where women describe a disconnect between their expectations and the reality of support during the birth process and during the PPP, with women wishing they had more family present to support them (Rayment-Jones et al., 2019; McCourt & Pearce, 2000). More attention needs to be paid to the PPP support structures women use, have access to, and want to understand the expectations of women with FGM. Attempts to meet those expectations or informing women what actual care and support is available would allow women and midwives to create a support plan for the PPP.

It is apparent that support plays a major role in the wellbeing of women with FGM experiencing the birth process. What that support looks like and who provides the support changes throughout the birth process. Pregnancy, labour and birth, and the PPP are times in a woman’s life when she needs healthcare education and knowledge (RCM, 2016).

The addition of healthcare support during this time is necessary to ensure a safe and healthy process for mother and child. During the pregnancy there are appointments and increased interest in the woman as she develops her child within her and prepares for birth. The healthcare system is focused on a safe birth for mother and baby and it can seem that the birth is the climax of the process, but it should be seen as the beginning. The woman’s life is changed in many ways and many ways that perhaps cannot or were not anticipated. As discussed in Section 1.1, maternity care focuses on the antenatal period and labour and birth, often neglecting the importance of the PPP (RCM, 2014).

While this will be especially felt for first time mothers, the addition of more children into a household will also always present a time of transition. A woman's support transitions from family, partner, and community to healthcare and back again, except that when it goes back again there is a new-born baby and a mother who is recovering from the effects of birth. While the transition during the antenatal period is an addition of support, the transition during the PPP is a removal of support (from a healthcare perspective). New mothers need support to heal after pregnancy and birth, while also caring for a new-born.

Narrative story-telling is a technique used for therapeutic reasons and can trace its' origins to Freud's theory of Psychoanalysis (Jacobs, 2003). It is currently unknown whether women with FGM might benefit from this technique, and what those benefits might be, specifically as a research participant. Participating in research has been shown as beneficial and rewarding for participants (Cox & McDonald, 2013; Kost et al., 2013) and women sharing their birth stories is a common feature of the birth experience (Farley & Widmann, 2001). Using an inductive thematic analysis, Johnson et al. (2020), analysed 22 womens motivations for sharing their birth stories across five focus groups and two one-to-one interviews. One primary theme 'building mother wisdom' was found, with the authors concluding women gained therapeutic benefits from sharing their birth stories, which may help women maintain and improve mental health during the PPP (Johnson et al., 2020). Limitations of this study include participants from similar socio-economic and educational backgrounds. While the population may not be similar to women with FGM; the beneficial therapeutic effects should not be discounted. More research on the therapeutic effects of sharing birth stories on diverse populations is needed. The unique situation women with FGM using NHS services in the UK experience has not been researched until this study, and how their participation through telling their birth stories during interviews was experienced by them is currently unknown. While one can hypothesize beneficial outcomes may result from women with FGM being able to tell their birth stories; individual variables are numerous and must be approached in an individual and holistic manner. More research is needed before conclusions can be drawn.

A focus on the postpartum transition during the antenatal period may ensure a woman has support prepared or allow time for referrals and postpartum care plans if she does not. The postpartum transition from healthcare support to partner, family and community support is very important and needs attention.

5.5 Strengths and limitations of the sample and methods.

The attempted recruitment of all women attending the antenatal FGM clinic over 12 months shows a robust effort to include all eligible women. The sample was hindered by ethical constraints (see appendix….), lack of access to other clinics and women who declined. Allowing women to choose in person (location of choice) or by phone gave agency and promoted comfort during interviews, which may have provided richer data. Providing the choice of phone interviews allowed participants to talk about sensitive topics they may not have felt comfortable discussing in person and may have allowed more women to participate as new mothers are very busy and transport was mentioned as a barrier to participation. The researcher was not involved in healthcare provision for the women which may have allowed women to feel more comfortable reporting experiences honestly, both positive and negative, as no healthcare repercussions could have occurred.

Limitations of the sample and method include those that were ethically imposed by the NHS ethics review board, including language restrictions, and not allowing the researcher to visit the homes of women to conduct interviews. See Section 2.5 for a detailed discussion of the ethical issues associated with this study. Women who did not respond to phone calls to arrange interviews could be a source of sample bias and may represent women who were less able to afford calls, uneasy about discussing the topic due to their experiences, feared the interview impacting their healthcare, or did not have time due to socio-economic reasons, childcare, or lack of social or family support. Other reasons could include their views regarding FGM, being fatigued by constant discussions about FGM, disinterest, cultural barriers such as discussing the matter of FGM with someone outside their healthcare team, or fear of being reported, which may be especially relevant for refugees, undocumented migrants, or asylum seekers. Women may not have reported some issues because of language barriers and not understanding Western medical terminology, or poor communication by staff during their antenatal or labour and birth experiences. Using observation as a method to triangulate the data obtained from interviews could have enhanced the understanding of the findings, however, this was not conducted due to privacy concerns, and fear of putting pressure on women to participate. As the study was focused on the postpartum experiences of women this was deemed an acceptable limitation. For the purposes of this research, the sample size was adequate and reached saturation, however, future research may benefit from recruitment from several FGM clinics to get a broader picture of women’s needs and experiences.

5.6 Conclusion

This chapter has described the experiences and needs during the birth process of women with FGM. While the PPP was the key focus of the study, it was found that the women's experiences of the entire birth process must be looked at holistically to understand their postpartum needs and experiences. The cross-cutting and developing nature of women's experiences cannot be viewed in isolation and must be seen as a process, with each experience influencing and impacting the next. Three themes emerged at each time-period during the birth process: FGM, pain and support. An acute need was seen in each stage of antenatal, labour and birth and postpartum; with the theme of support growing in importance throughout the birth process. Support is essential for women during the PPP, and when it is not received, feelings of anxiety and depression can occur. Support through the healthcare system dominated the antenatal and labour and birth stages but decreased slowly during the PPP. This can be seen to reflect the focus of the healthcare system on the birth of a healthy baby. Once that birth has taken place and the baby has passed its health assessments at home, healthcare is decreased and changed to an as-needed basis. However, it is during this time that support for the woman and new mother should become paramount. If the mother is supported the baby will have better outcomes (MBBRACE, 2017). This chapter describes the growing importance of support throughout the birth process as described by women who shared their stories. New insight and knowledge has been gained through their voices and has elevated wider contextual issues above FGM, having a significant impact on the study and how their experiences are understood. The next chapter will provide an overall discussion of the findings from each findings chapter (Chapter 3, Chapter 4, and Chapter 5).

Chapter 6 Discussion

This chapter brings together the findings of the documentary analysis, KIs and women interviews in a discussion of the overarching factors influencing the postpartum experiences and needs of women with FGM. A reminder of the research aims, and conceptual framework is given before the findings are applied and a model is proposed and described.

The research question for this study was: What are the post-partum experiences and needs of women with FGM using NHS services in the UK? With the research objectives being to:1) to identify and thematically analyse current international and national guidelines on FGM during pregnancy and the PPP (Chapter 3); 2) to examine and thematically analyse the role and views of key informants who influence the care received by women with FGM using NHS services (Chapter 4); and 3) to critically evaluate the needs and explore the postpartum experiences of women who have FGM (Chapter 5). A conceptual framework of the current care processes used within the NHS was constructed (Figure 1.7) and is shown again below (Figure 6.1). This framework led to the exploration of the postpartum experiences of women with FGM using a focused ethnographic approach from the macro, meso and micro levels of society and allowed the concept and impact of culture to be explored on multiple levels (Table 2.1). Figure 2.1 is presented again as a reminder and illustration of how the discussion is structured (Figure 6.2), and Figure 6.3 reminds readers of key findings the discussion is grounded in. The following discussion combines all three findings chapters to develop a proposed model for postpartum care for women with FGM (Figure 6.4).

Figure 6.1: Top-down approach to FGM maternity services used by the NHS in the UK

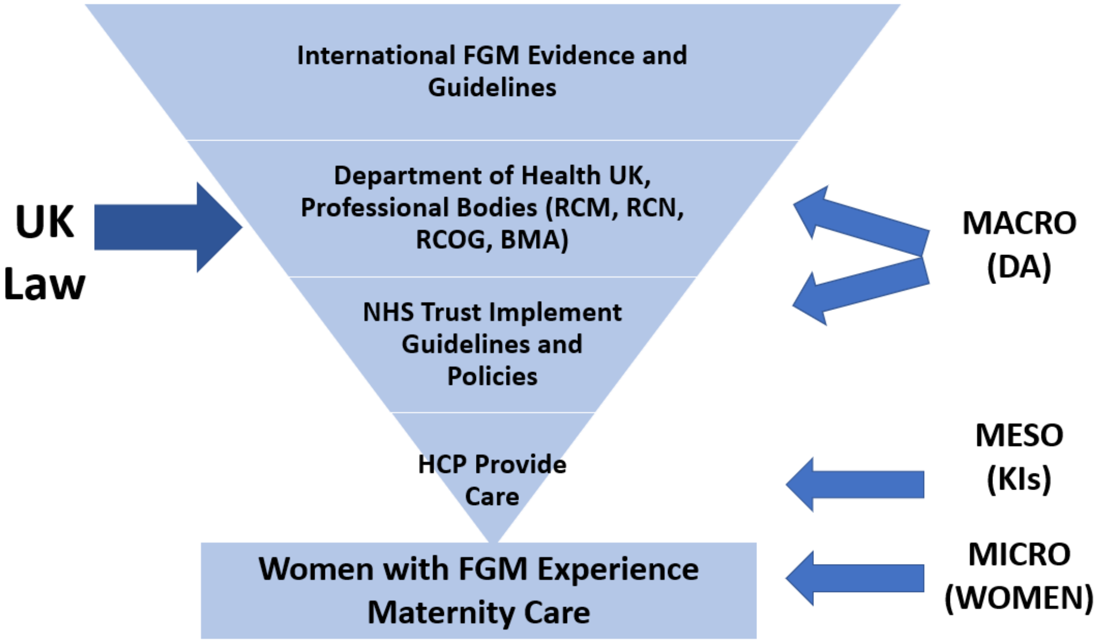
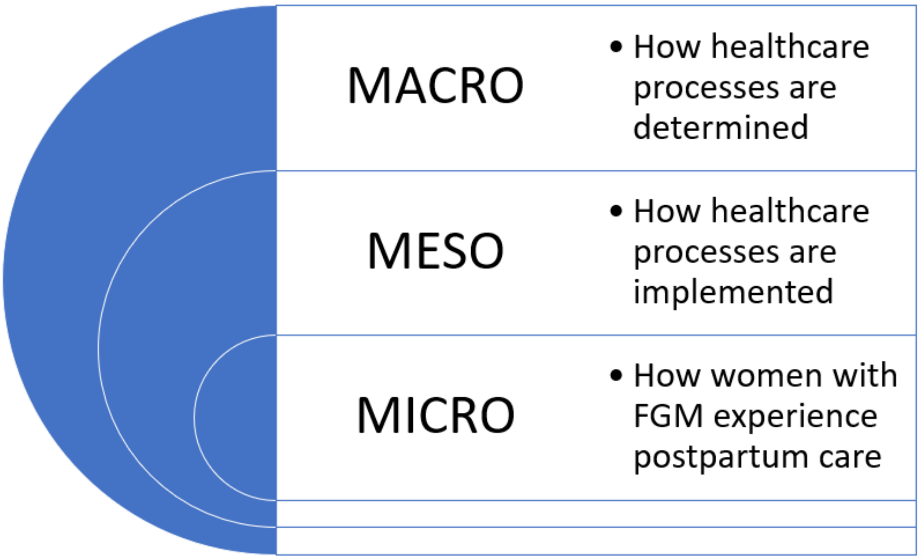


Figure 6.2: The Macro, Meso and Micro Levels of Analysis (Source: Author, 2020)



6.1 A Reminder of the Key Findings of the Documentary Analysis, Key Informant Interviews and Women Interviews

The following is a brief reminder of the main findings of the documentary analysis (Chapter 3), the Key Informant interviews (Chapter 4) and the Women interviews (Chapter 5) (Figure 6.3). The documentary analysis displayed a top-down approach to care within the NHS. The production of health policy and guidelines in the UK were found to be based on international health authorities, expert opinion, available evidence, and to be in accordance with the law and health policy. Limitations of this method include the lack of information available on the effects of migration on the practice of FGM, and the continued lack of attention paid to the PPP. A focus on the antenatal period and labour and birth was found in guidelines and policies regarding FGM; promoting the medical focus of healthcare while not recognizing the importance of the PPP. While culturally sensitive care was recognized as an important factor in the care of women with FGM throughout documents, implementing this care practice requires further investigation.

Interviews with key informants revealed a tension between those who provided indirect and direct care to women with FGM. A top-down approach was described by KI, with direct care KI describing a dual role whereby they balanced providing holistic care to women with FGM while completing their professional responsibilities of mandatory reporting and safeguarding specifically for FGM. Most direct care KI described difficulties providing holistic and culturally sensitive care within current resources, and described the PPP as receiving the least attention within maternity services. The police and law were found to have a contextual influence over the healthcare process. The woman might have direct interaction with police or interact with the law during healthcare appointments that include safeguarding and mandatory reporting. Although the law against FGM has benefits, its impact on healthcare processes and potential negative influence on the therapeutic midwife-woman relationship must be acknowledged.

Interviews with women with FGM described the implementation of the top-down approach whereby some women felt they were ‘allowed’ to have a ‘normal birth’. This emerged from descriptions of antenatal appointments where women felt they were assessed for their ability to birth their child with respect to their FGM. While overall women were happy with their care, negative aspects included the antenatal focus on the law and the reality of care versus the expectation of culturally sensitive care. The importance of postpartum support to women was highlighted as an area needing further investigation and resources as this is the time when healthcare support is phased out.

When the above findings are analysed together and applied to the Macro, Meso and Micro model, several overarching themes emerge and relate to the possible underlying processes occurring and allow further understanding and context of the findings. Overarching themes for the Macro level include: ‘health system authority over healthcare’, ‘the idea of risk within the NHS’ and the ‘application of policy and guidelines’. Meso themes include: ‘implementing the medical model and the law’, ‘mandatory reporting’, ‘typing of FGM’ and ‘autonomous midwifery (holistic model). Micro themes include: ‘unmet cultural expectations’, ‘culturally competent care’ and ‘support of the woman’. These will now be discussed in detail.

Figure 6.3: Reminder of Key findings from the Documentary Analysis, Key Informant and Women interviews

DA

- Top-down approach
- Evidence pathways/ sources of information
- Lack of knowledge about effects of migration (may not apply to UK context)
- Antenatal and Labour &Birth focus
- Culturally sensitive care (CSC) important
- Lack of attention on PPP

KIs

- Top-down approach
- Tension between indirect and direct KI
- Dual role of DKI to provide care for women and complete professional requirements
- Police have influence: direct impact individual, law and overall police impact contextual to women's experiences
- Difficulty implementing policy of culturally-sensitive care with current resources
- Postpartum period receives least attention during birth process

Women

- Top-down approach
- 'Allow normal birth'
- Reality versus expectation of care (CSC)
- Happy with care
- Not happy with Antenatal focus on law and FGM data sources, impacts on women of law, media and health policy
- Importance of support to women (CSC) (would like more practical support)
- Postpartum period transition phase when healthcare support is phased out

6.2 MACRO: Authority over healthcare inherent within the NHS.

The Macro level in this study represents the structural aspects of society including the law, government and dominant social norms. When the findings from each phase of the study were analysed together, the overarching concepts of the ‘health system authority over healthcare’, ‘the idea of risk’, ‘risk and the law’, and ‘the application of policy and guidelines’ emerged and provide context to the findings of each study, adding depth and meaning to the findings. Each overarching concept reflects and reinforces the dominant cultural norms of the UK where FGM is viewed as a severe form of gender-based violence and child abuse. As discussed in Section 1.8, culture influences behaviour and behaviour influences culture, resulting in a potential reinforcement loop. This dominant cultural norm provides essential context to each overarching concept, without which understanding is impossible.

6.2.1. Health system authority over healthcare

The current structure of the birth process is medically driven (Perez-Botella, van Lessen, Morano, & de Jonge, 2019) using a top-down approach as illustrated in this study through the DA, KI interviews and women feeling ‘told’ if they could have a ‘normal’ birth. The healthcare system is seen as an authority over the knowledge and skills surrounding childbirth, a sense of authority that is so well established it is seen as part of the natural order (Downe & McCourt, 2019). This was seen by women’s descriptions of their antenatal appointments where they described feeling the midwife had the ability and power to decide how they were ‘allowed’ to give birth. These descriptions of power and health decisions being made ‘for’ women display the inherent sense of authority the health system has over women as although the women did not feel comfortable with this authority over their birth decisions, they also did not question it or seek to oppose it. This displays the top-down approach to healthcare taken in the UK and implemented by healthcare providers that results in authority over one’s health appearing to be controlled by the government and NHS rather than with women experiencing maternity care.

The medicalization of birth and the shift of authority over one’s health from the person to the healthcare system, and the subsequent increase in medical interventions seen has not gone unnoticed (Phelan & O’Connell, 2015). Although not in the purview of this thesis, a brief exploration of interventions during childbirth shows an increase in the use of C-sections for women with FGM (Berg et al., 2014); and whether this is woman driven, or health system driven is debatable, due to the potential for increased negative obstetric outcomes reported in women with FGM (Berg & Underland, 2013). For many interventions the evidence for their effectiveness is currently mixed (Tracy & Page, 2019), with literature suggesting a greater understanding of the birth process is needed to fully comprehend the impact interventions have (Cheyne & Duff, 2019).

Many issues arise when a health system is seen as having authority over people’s health; with the most prominent being the health system setting the tone of how society views health and illness and how people interact with health services, creating a power imbalance where the NHS is the authority figure, and the woman a submissive recipient. As discussed in Section 0, the NHS uses the biomedical model of health, which views people as having an illness and needing treatment. When this model is applied to the birth process, it defines birth as an unnatural event that needs to take place under medical supervision. When birth is seen as an unnatural, medical event, clinical factors are focused on over other aspects such as the social, cultural, and spiritual elements (Scamell et al., 2019), potentially leading to a silencing of women's voices, and a lack of culturally sensitive care.

The Idea of Risk within the NHS.

As discussed in Section 1.3.2, estimating risk of FGM is challenging. Methods are continuously evolving as new variables, such as acculturation, are included (see Ortensi et al., 2018; EIGE, 2015). Current UK risk estimates are based on a study byMacfarlane and Dorkenoo (2015), with official statistics released quarterly by NHS Digital (NHS Digital, 2021) for England based on mandatory reporting data. Unfortunately, limitations such as incomplete reporting are present within the MR data resulting in difficulties analysing and using the results. The idea of risk, from the perspective of the NHS, associated with women with FGM experiencing the birth process can be divided into two categories; the risk of adverse birth events (focused on Type 3 and de-infibulation), and the risk of FGM being perpetuated on the child (safeguarding and mandatory reporting). Care provided by maternity services is determined by the potential risk to the unborn child (Downe, Byrom, & Topalidou, 2019), and dominates the current literature on childbirth (MacKenzie Bryers & van Teijlingen, 2010; Maclean, 2014; Skinner & Maude, 2016; Smith, Devane, & Murphy-Lawless, 2012). This can be seen in the antenatal appointment where equal weight is given to safeguarding (child focused), mandatory reporting (child focused) and clinical assessment (mother and child focused). Risk, while once seen as both positive and negative (Beck, 1992; Scamell et al., 2019), is now largely regarded as negative; and opposed to positive outcomes (Hill & Firth, 2018). This can be seen in the language used by NHS documents discussing risk where the words 'risk management' and 'risk mitigation' are used. (Prerana, Kanani, & Pritchard, 2020). The definition of risk given by Oxford University Hospitals NHS: “a risk is the chance of something happening that will have an *adverse impact* on the achievement of the Trust’s objectives and the delivery of high quality care” (Oxford University Hospitals, 2015) (emphasis added). By viewing risk as inherently negative, and accepting healthcare systems as authority figures over health knowledge, the ability to define risk becomes a tool by which to control the discourse surrounding a topic (Scamell, 2016). By controlling the discourse surrounding FGM, the NHS is arguably silencing women with FGM.

An example of this is reducing the birth process to care plans and protocols designed to avoid risk, as is seen during antenatal appointments for women with FGM and birth and postpartum checklists. By doing so, the healthcare system focuses on a worst-case scenario and acts to prevent it (proactive), instead of designing care focused on evidence and a ‘wait and see’ (reactive) approach (Healy, Humphreys, & Kennedy, 2017). When a health system defines risk and presents it as negative, those who do not conform to care-plans are viewed as deviant, and to be a good mother, you must conform (Scamell et al., 2019). Women with FGM are immediately seen as different and needing specific intervention, not only to give birth, but to safeguard their children (Creighton et al., 2019). As seen in Section 3.3, one of the main reasons given for timing of deinfibulation is to ensure it occurs in a planned, controlled environment versus during labour where unforeseen events can occur; though current evidence suggests no difference in outcomes of timing of deinfibulation based on the caveat of high-quality care being received (Albert et al., 2015; Esu et al., 2017; Paliwal et al., 2014). Safeguarding a baby whose sex is unknown at the majority of antenatal appointments can be seen as monitoring the morality of women with FGM, as they are not automatically trusted to ensure the safety of their children. The morality of a healthcare system reflects that of the dominant culture, which in the UK has deemed FGM as morally wrong and a form of child abuse. Safeguarding implies a risk which has not been quantified for FGM and represents an assumed risk based on less-than ideal methods of data collection and analysis. Although there is a statistical correlation between mothers having FGM and their daughters undergoing the procedure (Cappa, Thomson, & Murray, 2020), the effects of migration are not well understood, and current literature on the matter suggests migration alters parents views on FGM (Johnsdotter & Essén, 2016; Karlsen, Carver, Mogilnicka, & Pantazis, 2019).

How risk is thought of and assessed needs to be rethought and discussed to ensure the NHS does not alienate women with FGM by appearing to have an accusatory manner during their interactions with maternity services as reported by women during their antenatal appointment in this study. Current FGM risk assessment tools (Department of Health, 2016) may result in alienation from healthcare and support services, representing a possible ‘risk’ to the welfare of children who could be impacted by avoidance of public health and social support measures in their early years. Although no evidence of this has been published, literature does show the importance of social inclusion for healthcare use and outcomes in vulnerable mothers (Katz & Gagnon, 2002), and has shown women with FGM avoid healthcare due to the associated stigma (Karlsen et al., 2019). Degree of acculturation and assimilation should be considered, as these will affect the likelihood of women desiring FGM for their daughters (Mesplé-Somps, 2016). The current NHS strategy of risk avoidance shows the top-down approach of the NHS and how it assumes authority over maternity healthcare for women with FGM. What affected communities believe should be the resulting healthcare needs and research priorities (S. Dixon et al., 2018), resulting in a responsive, holistic assessment and elevating the voices of women with FGM.

Risk and the Law.

Both law and healthcare are macro institutions within all societies. The law upholds healthcare and healthcare upholds the law, as seen in issues such as abortion (legal impact on healthcare), termination of life (healthcare seeks ruling by law), forced c-sections (healthcare seeks approval by law), and reporting FGM (law enforced by healthcare). There is a presumption of innocence in UK law, however, the current use of risk regarding FGM results in women with FGM becoming suspects in a potential crime. It is difficult to find a similar situation where women are at once told they are victims of mutilation and potential child abusers. The influence of the law in maternity care for women with FGM shows the inherent authority of the healthcare system bolstered by the inherent authority of the law and results in a top-down authority-driven health experience for women with FGM. The influence of the law should not be underestimated and has been found to negatively impact women’s trust in health services, with most reporting feeling uncomfortable when confiding in their HCP about FGM (Hussein, 2010). Mandatory reporting may also impact women’s experiences of healthcare interactions and negatively impact the creation and maintenance of the therapeutic relationship (Salisbury & Dixon, 2015). The KIs (who implement the law) in this study discussed the need and importance of repairing relations between the Police and FGM community due to previous damaging policy regarding social care and Police visits and displays the negative impact the law is currently having on health interactions. The current response is disproportionate compared to other forms of child abuse and risks alienating women (Creighton et al., 2019). The authority of the law and healthcare systems are reinforcing a top-down authoritative approach to maternal healthcare for women with FGM, resulting in their voices being lost and needs being misunderstood.

6.2.2 Application of policy and guidelines.

The NHS works on an ability to generalize care in order to be able to apply care to a large population using limited resources; and is carried out through the use of guidelines, protocols and care plans (Downe & McCourt, 2019), as seen in the DA and the policies implemented by the KIs in this study. A concern with this approach is the creation of a boundary between HCPs and women, a line in the sand that reinforces the health system as a knowledge authority on one side, and women experiencing the birth process as passive users on the other. This is exemplified in the DA by the creation of protocols for HCPs to implement, with only a few documents suggesting women had choice in their care provision, and with the majority of documents describing care ‘given to’ or ‘provided for’ women with very little discussion of women’s preferences. This is also reflected in the global influence of the WHO and how they are currently viewed by all DA documents as the authority in knowledge regarding FGM. A divide is created between who has the specialist knowledge that is needed to ensure a safe birth and who does not; a type of ‘othering’ ensues and maintains the authority of the healthcare system. The presence of FGM represents an additional layer of complexity within this dynamic between the NHS and women. FGM is seen as a defining characteristic of the woman, with statistics from literature being used to inform policies and care guidelines. Using general statistics regarding women with FGM reduces the context and autonomy of the individual woman and ignores factors that can support and diminish the effects of the FGM. Current literature concerning FGM often does not distinguish between types, or if it does, focuses on type 3 FGM, as type 3 is the most medically concerning, however, this may not reflect the woman's point of view. Another limitation of current policy and guidelines is the lack of inclusion of women with FGM, community-based organizations and charities in their development. As discussed in Section 3.4, guidelines such as those produced by NICE use academic and clinical experts when expert opinion is sought, rather than members of affected communities (NICE, 2014). McEwan and Bedford (2021) created an app called 'Let's talk FGM' for both HCP and women. The app is an education tool to help HCP and women discuss FGM with each other. HCP are given training regarding approaching FGM in a culturally competent manner, while women are helped with phrases and health literacy to better communicate their needs with HCP. A participatory method was used and the authors state that without the inclusion of women in the research study, the app would not have achieved its' goal (McEwan & Bedford, 2021). Co-creating guidelines and policies with those directly affected by them and community organizations could assist in progressing guidelines and policy towards a more woman-focused, personalized care experience and is discussed further in Section 6.5.. The application of policies and guidelines continues to display the top-down nature of the NHS and global health authority in general, eclipsing women's voices.

Summary of MACRO

The Macro level represents societal structures and currently reflects a top-down approach to healthcare implemented by the NHS. The medicalization of childbirth, combined with how risk is defined within the NHS results in healthcare authority over childbirth. The current risk of FGM in the UK is unknown, with current data being incomplete and risk estimates needing updating. The current EIGE risk estimate could provide a method for achieving this, however, limitations in this method are present as each woman’s risk profile is unique. Regardless, the influence of the law on healthcare processes concerning FGM have resulted in potentially negative healthcare interactions with FGM communities (Evans et al., 2019; Hussein, 2010). The authority of the health system and how it implements policies and guidelines through a top-down approach results in silencing of women with FGM. Women with FGM must be included in the creation of policy regarding their care. Top-down approaches obscure context and silence the voices of women with FGM, leading to de-contextualized policies that fail to meet their needs by failing to understand what they are.

6.3 The MESO: Maternity Care for Women with FGM

As defined in Section 2.1.1, the Meso layer represents the healthcare system and consists of the implementation of the Macro (authority over healthcare, idea of risk, the law) policies and guidelines by healthcare providers. Each phase of this study was analysed together and overarching themes relating to the MESO layer were found to be how guidelines and policy are implemented using the medical model with influence from the law; and the tension between autonomous midwifery care and the implementation of guidelines and policies.

6.3.1 Implementing the medical model and the law

The top-down approach of the NHS as seen through the implementation of guidelines, policies and protocols not only silences the voices of women with FGM, but also prioritizes the law over healthcare. This is exemplified in the antenatal care pathway for women with FGM, where if they fail to attend their antenatal appointment, they are referred to social services, but no follow-up medical appointment is demanded. The impact of the top-down approach not only affects women experiencing care, but also the HCPs who are required to enact policy and guidelines in their professional roles, demonstrated by the KIs in this study. KIs in this study discussed not only the difficulty implementing policies within current resources, but also how current policies constrain their relationships with women and communities. The current focus on the AN period, specifically safeguarding and mandatory reporting being given equal importance (as seen in the DA), represents an inattentiveness to the individualized needs of women with FGM and displays the focus of the NHS on avoiding risk and attempting to control the need and outcomes of de-infibulation before labour and birth occur. Risk avoidance is expected by the NHS and displays implementation of policy.

Using HCPs, such as the KIs in this study, as a means to discharge the law in the context of FGM has become idealistic (Section 6.2.1). By ‘othering’ women with FGM, the NHS is not only othering a cultural practice, but an entire culture, perpetuating stereotypes and preventing women from seeking care (Hussein, 2010). Safeguarding is also a patriarchal and patronizing practice (Gosselin, 2000), where society has deemed the person at risk of committing a crime. In no other area are women accused of child abuse before the child is born, reflecting the current human rights laws governing maternal healthcare that state the foetus has no separate legal recognition from the mother, and therefore “women are free to make choices against medical advice and cannot be forced to accept treatment whether or not it is said to be in the unborn child’s interest” (Birthrights & Birth Companions, 2019, p12).

As such, women who engage in negative health practices such as smoking or alcohol consumption are not reported to the authorities, though it could be argued they are negatively impacting the health of their unborn children, whereas women with FGM are not. This demonstrates an inequality in healthcare provision for women with FGM resulting from the influence of the law on healthcare. The result is a silencing of women, and an unnecessary tension created between HCPs and women, hindering the TR and potentially negatively affecting care.

While this thesis argues the UK law is having a potentially negative effect on healthcare interactions during the birth process; it is important to note the benefits of national laws against FGM including awareness, dedicated resources, multisector approaches, protection orders and providing a legal framework for HCP to refuse to perform FGM or reinfibulation. All women in this study reported knowing about the law against FGM, and all KI noted women they care for knew about the law also. This is an important feat to recognize and could be an important driver in the prevention of FGM. The WHO encourages countries to outlaw FGM and states it shows support on a national level to end the practice (WHO, 2020). Laws against FGM may also aid women and families in opposing the practice as they can cite fear of prosecution (Home, Rowland, Gerry, Proudman, & Walton, 2020). A ‘loophole’ in the UK law was closed in 2015 when it became illegal to take a girl overseas to have FGM done (Home Office, 2015). This addition to the law may also aid families who wish to end the practice but fear opposition from wider family or community members in their country of origin (Creighton et al., 2019). Another benefit of the law against FGM is the dedicated resources provided to address the issue. Although more resources were requested by KI in this study, it must be noted how knowledge and services regarding FGM have increased substantially in the UK over the past two decades. Charities such as Forward (Forward UK, 2021) and Daughters of Eve (Daughters of Eve, 2021) are dedicated to helping African women and focus on FGM. The NHS has also dedicated national FGM support clinics for women with FGM throughout England (NHS England, 2020a).

Coupled with increased resources dedicated to the prevention of FGM is the multisector approach being used (HM Government, 2016b). Charities, human rights groups, universities, the police, social care, schools, and the NHS are all working together to prevent FGM. Within the NHS, social care and education sector; employees are considered mandatory reporters. Awareness raising campaigns have been launched by the Police and human rights groups, such as the Red Triangle Campaign in 2017 where the police partnered with the Freedom Chairty (Freedom Charity, 2021). FGM police protection orders (FGMPO's) provide an additional resource for police to prevent FGM and serve to stop FGM occurring in a situation deemed high risk. FGMPO's can include the forced surrendering of passports, preventing people taking girls out of the UK to be cut (HM Government, 2016a). Although it is rarely possible to understand the full impact of the law on preventing FGM; the positive aspects of the law need to be noted. Debates surround FGM laws in the UK and often center on the possible adverse effects on girls and families (Creighton et al., 2019). A tension between the pros and cons of the law exists and requires further exploration. Regarding this thesis, it was found that the impacts of the law on healthcare interactions may be negative, however, more research is needed to understand how the law in the UK affects women with FGM, their families and communities outside of healthcare.

Mandatory reporting.

As discussed in section (Section 1.7.2) a mandatory reporting (MR) duty for healthcare providers came into effect in 2015, with an enhanced data set requirement enforced in 2016. The enhanced data set requires HCP to record details regarding a woman's FGM such as age, country of origin, country where FGM took place and type of FGM. It also records the woman's NHS number to prevent recording the same data twice. The mandatory reporting enhanced FGM dataset was developed to increase knowledge regarding FGM, however, no data on specific rates of FGM in maternity settings are available as the MR is not completed effectively and often excludes data needed to identify trends (NHS Digital, 2019). FGM represents a small population when compared to migrant women, and all women using maternity services (NHS Digital, 2019).

The current enhanced FGM data set produced from HCP mandatory reporting is resulting in massive numbers of ‘new cases’ of FGM, however this is not true, and ‘new cases’ in this context represent ‘newly reported’ cases; a distinction lost in media translation. In a commentary on this topic, Creighton et al. (2019) discuss how of the 4495 newly recorded cases from the 2017-18 FGM enhanced dataset, 83% related to pregnant women who had been cut before entering the UK. Unfortunately, this is being reported by the media in headlines such as “More than 5,000 new cases of FGM in UK last year” (ITV News, 2018, https://www.itv.com/news/2018-02-06/more-than-5-000-new-cases-of-fgm-in-uk-last-year), with the following article suggesting these new cases represent women being cut in the UK. This gives the impression that FGM is widespread and therefore a greater concern than it actually is (Creighton et al., 2019).

A shift needs to occur from focus on FGM to a focus on providing culturally sensitive care. A qualitative systematic review and meta synthesis with the aim of understanding the sociocultural and health needs of women with FGM was conducted by Turkmani, Homer, and Dawson (2019). Nine electronic databases were searched for peer-reviewed, English language studies from 2000-2016. Reference lists were checked by hand. Twenty-two studies met inclusion criteria and were evaluated for quality using the CASP tool. Six studies were omitted due to methodological quality concerns.

Sixteen peer-reviewed studies were analysed and four major themes emerged; 1) living with fear, stigma, and anxiety; 2) feelings of vulnerability, distrust, and discrimination; 3) dealing with past and present ways of life after resettlement; and 4) seeking support and involvement in health care. The authors suggest a key method to improve maternity care is to enhance trust between HCPs and women, and to provide women-focused care. Limitations of this study include the majority of included women being Somali, decreasing the generalizability of results. The authors also note some women spoke about their experiences in general terms rather than specifically discussing their maternity experiences. Including only English language studies could have resulted in missing important literature published in different languages. As with all systematic review, the quality of the findings is determined by the quality of the original studies, using the CASP tool, the authors increased the rigour of the study and the trustworthiness of the findings. The findings in the above study are reflective of the findings in this thesis and demonstrates how trust is essential to the provision of culturally sensitive maternity care (Evans et al., 2019). Individualized care will also highlight the most pressing concerns the woman has, which may not be her FGM, as found in this study, and an insight that only becomes apparent through individualized care.

Typing of FGM.

Currently the NHS uses the WHO typing of FGM to characterize women. Typing is based on prevailing healthcare ideals that situations must be standardized (Tracy & Page, 2019). By defining and organizing FGM into ‘neat little boxes’ the healthcare system feels in control of the situation and uses these categories to design protocols, policies and documents that attempt to meet the needs of categorised women with FGM. The ‘needs of women with FGM’ are defined by the healthcare system as a healthy mother and baby, mainly physical health, as even though mental health is assessed, resources are often not available (National Maternity Review, 2016). The social and emotional health of the mother and baby are referred onwards and occur within the family and community, outside of the hospital. By categorizing FGM, the healthcare system is objectifying women’s bodies and reducing them to the appearance and function of their genitals.

This pattern of reducing women and their experiences to building blocks can be seen throughout maternity care where the woman is seen as a machine (Downe et al., 2019). By defining women as a particular type of FGM the NHS is reducing their experiences to a tick mark. The importance of language used in maternity experiences is known and debated, with providers being urged to use language that will empower women (Astrup, 2018; Mobbs, Williams, & Weeks, 2018). FGM experiences exist on a spectrum, with some women having no memory or health complications resulting from it, while others experience a myriad of physical, mental and social health complications during their life and any birth processes they experience (Section 1.9). Categorizing FGM constrains the topic and accepts the woman’s genitals are ‘mutilated’, but for the women they are ‘normal’ and defining type is largely unhelpful, does not accurately reflect the situation, and does not consider all aspects influencing women’s care experiences and needs. It also reflects a medical term that signals the HCP, usually a midwife, has power to ‘define’ part of the identity of women, displaying power over her. Terminology is very powerful and demonstrates the nature of the relationship between HCP and woman (Mobbs et al., 2018); by defining ‘type of FGM’, the HCP is exhibiting an unequal relationship. A holistic assessment, which encompasses all areas of a woman’s life and assesses her individual needs is required to ensure care and support are provided in the way it is needed by that individual woman at that time (Byrom, 2020).

Women should not be labelled by the healthcare system. There is a risk of women returning to their family and questioning relatives about FGM, or googling FGM and creating the thought that her genitals are mutilated, as stated by one woman in this study. They are normal to her, and without solid evidence that reconstructive surgery works, there is no ‘treatment’, so one questions the benefit of a diagnosis, an area for future research consideration. This categorization of FGM is for HCPs and should stay facing away from women if continued to be used, with the creation of a descriptive system based on women’s opinions and values to be used when discussing the issue with women. A holistic assessment should be designed and completed, without necessarily including type of FGM, rather a description of the needs of the woman and an analysis based on need for de-infibulation and presence of scar tissue. This would include a description of the alteration of her genitals, of any adverse effects that could be related to FGM. If the woman is not traumatized by her experience, the healthcare system should not potentially traumatize her by giving her a label and perpetuating the ‘othering’ of women with FGM present throughout the NHS. It can be concluded from this study that women do not care about the type of FGM they have because their genitals are their own and will not change. No studies were found that included women’s thoughts or feelings about the WHO typing. More research in this area is needed.

6.3.2 Autonomous Midwifery (Holistic Model)

UK midwifery autonomy is defined by the legal status of the midwife practising within the regulation of the Nursing and Midwifery Council and being the primary care providers of maternity care. This means that midwives are autonomous as they can manage a whole pregnancy care episode from initial consultation through to post-partum discharge without the need to consult an obstetrician at all, unless there is an apparent deviation from ‘normal’ pregnancy at which point they are required to refer. UK midwives have the legal right to ‘witness’ a notifiable birth for birth registration (Appendix 0). However, the term autonomy is often also used in the context of the degree to which midwives can exercise their discretion in providing individualised care and to work outside of set protocols and guidance and within professional responsibility (International Confederation of Midwives, 2017; Royal College of Midwives, 2020). Midwives working within a medical model, in the NHS with limited resources, must abide by the regulations of the NHS. This results in the de-personalization of care and an inability to carry out autonomous holistic care (Skinner & Maude, 2016), as seen in this study. Direct-care KIs in this study reported numerous challenges when providing care for women with FGM, including time constraints. One KI was an outlier in this regard and due to having limited appointments felt they had enough time to discuss the woman’s individual needs. This midwife also primarily saw women with type 2 FGM, displaying a potential geographical difference in care to areas with high prevalence of type 3 FGM, such as London.

A study by Prowse and Prowse (2008) found the current role-redesign occurring in the NHS, whereby midwives are taking on roles traditionally completed by doctors, and their preferred roles of providing individualized, compassionate midwifery care are being completed by healthcare assistants was causing unhappiness among midwives who felt their autonomy was being removed. By placing the midwifery holistic model of care within a medical model structure, core aspects of midwifery, such as time taken with individual women, support, and the building of trust and the therapeutic relationship are hindered (Prowse & Prowse, 2008). Time constraints represented the most challenging factor as much of direct care KIs time was used by the completion of professional obligations of safeguarding and mandatory reporting; with time constraints being a known issue perpetuating the number of midwives leaving the profession (RCM, 2016). Knowing these tasks must be completed, coupled with already limited time for appointments, KIs described feeling uncomfortable with how to approach FGM in a sensitive manner, especially if an interpreter was required, a finding reflected in current literature (Evans et al., 2019; Phillimore, 2016) Directing how direct care KI, especially how midwives allocate their time is a removal of professional autonomy and hinders their ability to provide individualized care. FGM may be a very sensitive topic for women and midwives should be allowed to autonomously decide how best to allocate their time based on women's needs.

The medicalization of birth has decreased the ability of midwives to provide holistic care because they are under-resourced and must complete care based on protocols designed from a medical model perspective (Downe & McCourt, 2019). This is especially important and relevant for women who have FGM as their voices are lost and their unique context and capacity are not focused on or used to their potential. A recent report highlighted the dire need for additional support for nurses and midwives in the NHS to prevent long-term mental health issues and burnout (Kinman, Teoh, & Harriss, 2020), and suggests a redesign of care practices is needed to not only improve care provided by midwives, but also to ensure the care needs of women with FGM are met.

Healthcare, and the responsibility for health needs to be returned into the community and with the women themselves. Activating women, their support networks and communities to understand their health needs and the resources available is needed, reflecting a community assets based approach supported by Public Health England (UK Government, 2017). This approach focuses on building social capital within communities to redress health inequalities (Johnstone, 2017), and has been shown to improve women's maternal health (Gabbe et al., 2017). Women and the birth process should be seen as one continuous event, not divided into time points as in the current model.

6.3.3 Summary of Meso

Healthcare systems can only provide care within the available resources. The above discussion displays how care is impacted by local priorities, possible geographical, and financial pressures in maternity services across the UK (Sandall et al., 2016), and this must be accounted for when designing care plans and implementing guidelines. NHS England expects individual Health Trusts to adapt and implement guidelines within their resource capacity (DoH, 2015). Unfortunately, this results in resources focused on a safe delivery for mother and baby and usual care in other aspects. Therefore, activation of the woman and her support network and community is essential and should be integral to the woman's care plan.

6.4 MICRO: The postpartum needs and experiences of women with FGM

The Micro level combines the concepts of social isolation, culturally competent care, and support for women to discuss the postpartum needs and experiences of women with FGM.

6.4.1 Unmet Cultural Needs Related to Pregnancy, Birth and Postpartum Care

An important finding, and crucial aspect in the understanding of women's experiences and needs was the negative effect of social isolation in the form of unmet cultural needs. In the literature, social isolation is often seen as part of social deprivation in maternity settings (Gonthier et al., 2017) and is noted for its negative effect on maternal outcomes. In this study women experienced social isolation in the form of missing support from immediate and extended family and community groups that were normal for their culture and would be present in their country of origin. Many women expressed missing family and described how this negatively impacted their postpartum experiences, with practical support and knowledge sharing highlighted by women as unmet needs. A systematic review by Fair et al. (2020) reflected this key finding when they explored migrant women's experiences of pregnancy, childbirth and maternity care in their destination European countries. Five electronic databases were searched with citation tracking and two independent researchers screening titles and abstracts. The qualitative NICE critique tool was used, along with the CERQual tool to assess confidence in the findings. Forty-seven studies were included, with 43 being qualitative and four utilizing mixed-methods. Data collection methods included individual interviews, focus groups and surveys. Relevant findings to this study include the theme 'my needs go beyond being pregnant'; where women described challenges with finances and rearing other children while being pregnant and caring for a newborn. The burden of traumatic experiences was also highlighted as a continuing issue for women post-migration. Women specifically wanted family members to be present and missed them if they were not. Women wanted their mothers to help with advice and domestic duties. Contact with family was very important to women and if family were not present, or contact was difficult, women reported feeling lonely, isolated and hopeless. These feelings in turn caused tension within their marital relationships as new roles and duties were placed upon women. Another important finding to note is how a trusting relationship with HCP empowered women and could overcome their lack of social networks and support. Continuity of care and individualized care models were highlighted as methods to attain a trusting relationship with HCP.

Women with FGM face the potential for layered vulnerabilities in their maternal experiences including FGM, migration status and possibly their socio-economic status. Rayment-Jones, Harris, Harden, Khan, and Sandall (2019) conclude from their realist synthesis exploring how women with social risk factors experience maternity care in the UK, that being native to a country or not may have less bearing than being seen as different by the dominant culture. Applied to women with FGM, this conclusion may mean that health inequalities may persist even if acculturation occurs and that if the NHS views women with FGM as different they may be at greater risk for health inequalities. Currently the NHS employs a unique health pathway for women with FGM and thus it may be that women with FGM are starting with a health disadvantage that has nothing to do with their FGM, but rather how the NHS perceives them. This is compounded by a lack of postpartum resources as noted by the RCM Pressure Points report (2014) which found two-thirds of midwives reported the most important factor influencing the number of postnatal visits they conducted was service pressures and not women’s needs.

However, there is hope. Community based care has been shown to increase access to care and increase antenatal care in Black and Minority Ethnic women in the UK (Hollowell et al., 2012), and combined with culturally competent care (Evans et al., 2019; Odemerho & Baier, 2012) has the potential to increase maternal health experiences for women with FGM and is an area for further research. Midwifery care in this context was seen as extremely important to women in this study and was very powerful for women who received it, as it provided support they were missing from family members. The negative effects of unmet cultural needs cannot be underestimated. Adversity can be overcome with practical and emotional support, but loneliness and isolation due to missing family is pervasive and a known contributor to postpartum depression (Escribà-Agüir & Artazcoz, 2011). Individualized care and listening to women should be incorporated into policy to identify and plan interventions to meet the cultural needs of women with FGM.

6.4.2 Culturally Competent Care

A theme running throughout this thesis is the concept of culturally competent care (CCC), or culturally sensitive care as some documents refer to it. As set out in Section 0, culturally competent care is used by the NHS to reduce the inequalities in health outcomes of minority cultural groups (NHS Health Education England, 2020), and suggested as good practice by the RCM (2018). Although found to be an overarching theme in the documentary analysis, current implementation was described as difficult by KI within current resource restrictions and was not experienced by women in this study, who reported too much focus given to their FGM and preferred a holistic approach. The above presents a conundrum within healthcare where evidence suggests women want culturally competent care (Cross-Sudworth et al., 2011; Evans et al., 2019), policy dictates it (UK Department of Health, 2015), HCP report positive benefits of training (Jongen et al., 2018; Reibel & Walker, 2010) but women do not experience it, or if they do there are few studies evaluating outcomes (Chae, Kim, Kim, Lee, & Park, 2020). As FGM is a cultural practice, it is imperative HCP provide CCC to create and maintain the therapeutic relationship, the importance of which was detailed in Section 5.4.

A TR inclusive of trust and understanding results in CCC; but how that trust and understanding is achieved needs further exploration (Baillot, Murray, Connelly, & Howard, 2018). Using a scoping review and KI interviews, Baillot et al. (2018) explored FGM prevention and responses to interventions in Europe. Five electronic databases and key journals were searched. KI were interviewed followed by a thematic analysis. Key findings include the need to include affected women and communities in the development of interventions. Participatory research frameworks were seen as positive in both the literature and interviews as they fully involved women. However, limitations of these methods were also noted as having small, purposive samples, focusing on certain communities, or coming from communities already addressing FGM (Baillot et al., 2018). More research is needed to evaluate these methods and reduce their limitations, increasing generalizability and implementation of interventions. In a consistent findings with Chae et al. (2020), the authors found minimal evaluation of current interventions. As this was a scoping review, the authors did not conduct a quality assessment and findings should be interpreted with this caution.

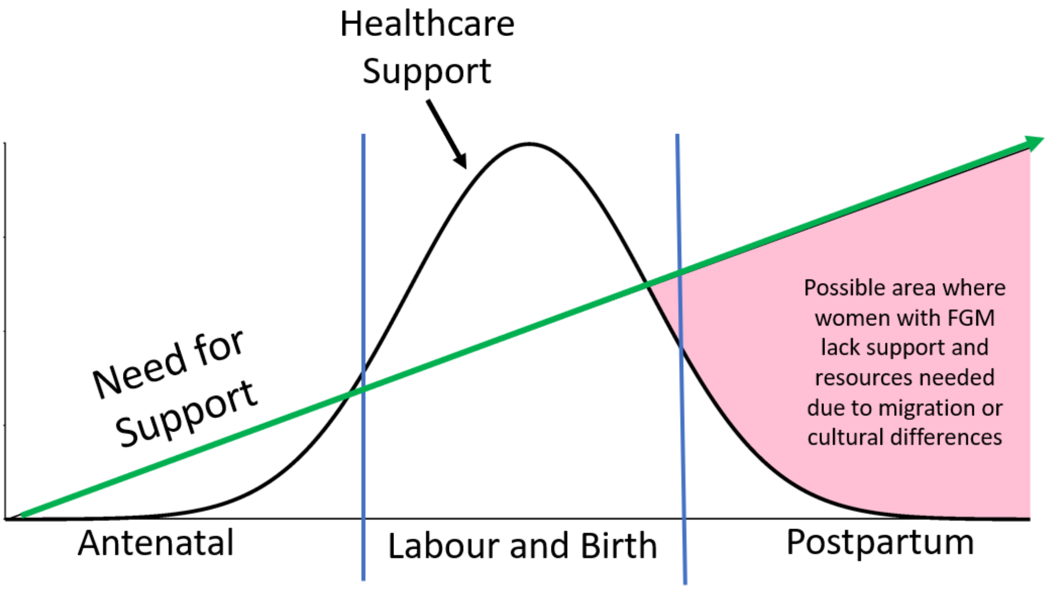
Current research is lacking and conclusions on how to implement CCC cannot be drawn (Jongen et al., 2018). While women appreciated and were generally happy with the midwifery and healthcare support they received in this study, more support was desired and women were not always happy about the FGM aspect of their care, reflecting the literature and suggesting a greater understanding and provision of culturally competent care (Evans et al., 2019), as well as a revision of FGM policy is warranted (Creighton et al., 2019). Creating a therapeutic healthcare environment may be one method of achieving CCC, which is especially important for women with FGM due to their reported negative experiences of care (Evans et al., 2019), and to facilitate trust with HCPs (Odemerho & Baier, 2012). This theme displays the top-down nature of the NHS and suggests a woman-focused approach is warranted to improve care experiences.

6.4.3 Support of the woman

Support is always needed by women; what that support is comprised of, and where it comes from should be based on the needs and wants of the woman. Where support comes from changes throughout the birth experience, transitioning from family and community to healthcare and back again. Although the birth experience is viewed as separate events by the healthcare system, antenatal, labour and birth, and postnatal; for women in this study it is one continuous event that changes their lives. The PPP is a unique time where both woman and baby need support, and it is essential that this transition from healthcare intense support to family and community support is not overlooked and support networks are in place.

Women in this study experienced the birth process on a continuum of experiences throughout her life. Before pregnancy, her support may come from a partner, family, or the community. During pregnancy, birth and the PPP, additional healthcare support is given. After birth and the PPP, healthcare support is diminished and available on an at-need basis. The transition and addition of healthcare support at the beginning of the birth process is welcome and required as women in this study needed midwifery support for education and checkpoints, with education and healthcare support desired by women, a finding supported by literature (Glover et al., 2017). A key finding by Karlström, Nystedt, and Hildingsson (2015) was the need for all pregnant women to be seen and heard. Based on the findings in this study a conceptual figure (Figure 6.4) showing the curve of needs of women with FGM was created.

Figure 6.4: Curve of Needs of Women with FGM during the birth experience (Source: Author, 2020)



The importance of culturally competent support for women with FGM due to cultural differences cannot be underestimated and was a key finding of this study as women described missing practical and knowledge sharing support from female relatives. Other studies have shown positive birth experiences increase with one-to-one continuous support during labour and birth (Bohren, Hofmeyr, Sakala, Fukuzawa, & Cuthbert, 2017). Escribà-Agüir and Artazcoz (2011) measured social support in the 12 months following birth using the Duke-UNC Functional Social Support Questionnaire and found incidence of postpartum depression was higher in women who self-reported low affective social support (measured by positive affective expressions) and low confidant social support. Mondy, Fenwick, Leap, and Foureur (2016) found women have more positive birth experiences when they are in an environment they can control versus feeling like passive patients. The importance and benefits of support should not be underestimated and should be a key measure in research (Bohren et al., 2017).

Support planning should be encouraged during the antenatal period for women with FGM, directed by women and facilitated by HCPs, to ensure adequate supports are in place for labour and birth, and the PPP. All women should be assessed for their individualised support needs and a personalised care plan developed. Migrant communities may have an increased risk due to cultural differences and associated barriers such as language, poverty, level of assimilation, job opportunities, family structure and health literacy. FGM presents an additional layer of potential vulnerability, potential for adverse obstetric outcomes, history of or current emotional trauma associated with their FGM, cultural ideals of FGM conflicting with UK laws and culture, and NHS processed potentially negatively impacting birth experiences and interactions with health services.

HCP support should be seen in combination with and used to enhance the woman’s personal support network. Trusting, respectful relationships between women and HCPs have been shown to increase feelings of safety (National Maternity Review, 2016), decrease negative emotions associated with birth (Sandall, 2016), and decrease pain (Dempsey, 2013). Unfortunately, current healthcare system protocols and rigid patterns of care often do not allow a therapeutic relationship to form between HCP and woman during labour and birth, or the PPP (RCM, 2014). Lack of time and a preoccupation with risk avoidance often lead to women's experiences being deprioritized over completing tasks as dictated by protocols (Crowther et al., 2019).

One method being implemented in NHS policy upon recommendation by the 'Better Births Review' (National Maternity Review, 2016) and supported by the findings of this study is continuity of care models (NHS England, 2017), which seeks to pair women with the same care giver before, during and after pregnancy. The 'Better Births' review not only found this was an evidence-based recommendation, but also the greatest request from women who wanted to forge a strong relationship with one midwife throughout their birth experience. The 'Better Births' Review included the first 10-14 days postpartum only, which is when usual midwifery care ends, and does not include care provided by health visitors or the GP six-week check. Although the NHS is confident continuity of care will improve maternal outcomes, a lack of attention is still present on the PPP and beyond, and has been a source of criticism from practitioners (Bick, Duff, & Shakespeare, 2020; Shakespeare et al., 2020). Bick et al. (2020) questions why the NHS is convinced of the evidence that continuity of care models are effective when the evidence used in the 'Better Births Review' was from one Cochrane review of 15 trials with 17,000 low risk pregnant women, with only five trials from the UK (Sandall, Soltani, Gates, Shennan, & Devane, 2016). Shakespeare et al. (2020) also laments the lack of attention given to postpartum care and questions why the GP six-week check is not considered part of postpartum care under NHS funding, and questions why the PPP ends on day 14 when both health visitors and GP's provide maternal healthcare. Both authors argue greater attention needs to be paid to the PPP and additional models of care should be evaluated.

Although continuity of care has been shown to have positive outcomes, its applicability within the NHS and how the model is to be achieved at the intersection of primary and secondary care that the PPP represents, needs further investigation. Additionally, no specific data on FGM and continuity of care models is available. How women with FGM, with potentially increased needs for services while possibly having a negative perception of those services experience continuity of care models is unknown. Women in this study did not express comments spontaneously wishing they had the same midwife, and it was not directly asked. Further research is needed in this area; however, continuity of care models present a potential model to improve maternity healthcare for women with FGM.

6.4.4 Summary of MICRO

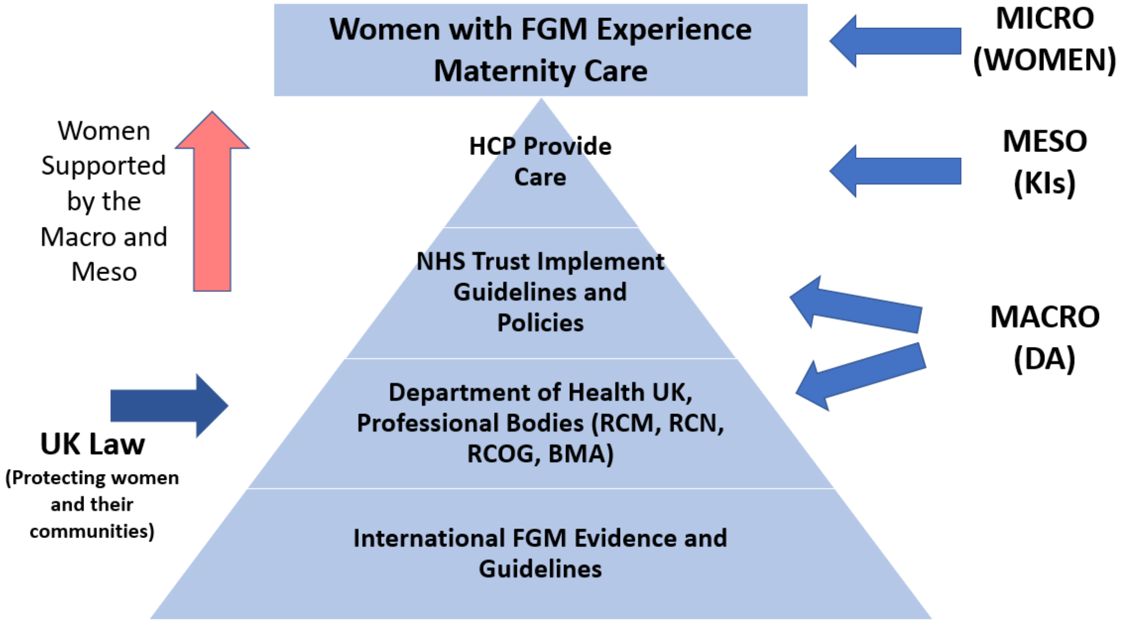
The transition during the PPP, returning to the woman’s original support structure but with the addition of a new-born baby should be focused on. Postpartum transition support should be addressed and planned for during the antenatal period to ensure referrals are made in adequate time and women have a support structure in place when they leave the hospital and are discharged from community services.

6.5 Bringing it all together: The Cradle Model of Care for women with FGM experiencing the birth process

The top-down approach used by the NHS resulting in HCPs implementing the law and generalized healthcare for women with FGM results in a straining of the therapeutic relationship, a lack of individualized care, potential burnout and stress of

HCPs and a silencing of women's voices. The current top-down model needs to be inverted (Figure 6.5) placing the woman at the top, being supported by the meso and macro structures of the NHS and the implementation of its policies, and the UK law serving to protect her and her community. By inverting the triangle, women's voices are elevated, and they direct their care; alleviating the tension between HCPs and women, and hopefully improving her care experiences. From this inverted triangle, the Cradle Model was created.

Figure 6.5: Inverted 'top-down' approach to healthcare for women with FGM (Source: Author, 2020)



The Cradle Model of Care for women with FGM experiencing the birth process (Figure 6.6) was created from the findings of this study. This model provides a visual displaying that although care considerations might originate from different levels (Macro, meso, micro), they intertwine seamlessly in women's lives. The model also allows women to dictate the importance of each care factor and their presence at different time periods throughout the birth process, and elevates the woman so she is supported by the macro, meso and micro level influences.

Figure 6.6: The Cradle Model of Care for Women with FGM (Source: Author, 2020)

When viewed together, these findings show the PPP is a crucial timepoint in the birth process for both mother and child. While overall outcomes might be the same, the birth of a baby, interacting elements and processes that produce outcomes (micro and meso level) are not as simple. Opinions, feelings, values, expectations, preferences, social, cultural and political influences produce a complexity of experience that not even the woman with FGM will be completely aware of or expecting during the birth process (Haines, Rubertsson, Pallant, & Hildingsson, 2012; Noseworthy, Phibbs, & Benn, 2013). Part of the definition of midwifery is to strengthen women's own capabilities allowing her to feel control over her own health, and adapt it to her needs (Renfrew et al., 2014). Individualized care allows women to enhance and activate her support features while navigating any negative aspects as best she can.

Individualized care is suggested in many guidelines, such as Better Births (National Maternity Review, 2016) and the MBBRACE Report (Knight et al., 2019); as well as the holistic midwifery model (Sandall, 2016). Although guidelines already recommend an individualized approach, how to adapt and enact this approach is not well understood.

Using the findings of this study and combining them with current literature, a 'CRADLE' model of care for women with FGM experiencing the birth process was created. The current hierarchical nature of how evidence is created, the healthcare system, law and culture have massive impacts on how women with FGM experience postpartum care in the UK. However, these systems are also unlikely to change quickly, and so the model is situated within the meso (NHS and community) and micro (women) levels of the ecological model, levels where intervention would be immediately experienced by the woman. A strengths-based approach that consciously maximizes women's strengths is endorsed (Coulter & Collins, 2011). A strengths-based approach is defined by the Social Care Institute for Excellence (SCIE) and NICE as focusing on "what individuals and communities have and how they can work together rather than on what individuals don't have or can't do" (King, 2019, p1). This is currently the NHS approach to social care and supporters of the approach believe it should be used throughout NHS services (Coulter et al., 2015; Coulter & Collins, 2011). Using a strengths-based approach, the Cradle model provides personalized care while activating women and their support networks to achieve the woman’s needs. One method of operationalizing this model would be the placement of a nurse and midwife in a community centre. Having a dedicated nurse and midwife present would potentially result in familiarity with women, continuity of care, the formation of a trusting relationship, and referrals made as needed. How this model could impact care throughout the birth process has been hypothesized in Table 6.1. The CRADLE Model approach could also be used to inform the implementation of continuity of carer in the context of maternity transformation in the UK. The model could also be adopted by healthcare services outside the UK seeking to frame the emphasis of maternity care on individualized care and in situating the women within additional support needs.

Table 6.1: Example of Specific Changes in Care Based on CRADLE Model (Source: Author; 2021)

Antenatal	• Full needs assessment based on culture o what does birth mean to the woman? o What cultural expectations does she have regarding the experience? People present? Healthcare provided? • FGM: o Planning for birth; how FGM might impact the woman's birth plans/birth choices. o Antenatal deinfibulation • Support structures identified and assessed (family and friends, childcare, household needs (tasks such as cleaning, cooking, washing clothes after birth) • Money available to pay for transport to appointments if required and to prepare for the baby at home • Living arrangements o Are they secure? o Are they safe? • Follow-up with referrals as appropriate
Labour and Birth	• As per needs assessment; o Female consultant preferred? o Translation: family member or professional required/desired? o Cultural expectations and rituals woman expects to take place- communication of a birth plan/birth choices • Money available to pay for transport to birth centre/hospital if required
Postpartum	• Understanding how post-natal care will be organised (home visits, post-natal clinics, links to GP, transition to Health Visiting services) and how to raise concerns over birth recovery • Preparation for postpartum emotional and mental health • Support activated based on needs assessment; o Family, friends, childcare o Money available to pay for transport to appointments if required • Knowledge provided based on needs; breastfeeding, sleeping safety, equipment (eg: cot for baby, pram)

Within the CRADLE Model the midwife has the autonomy to suggest additional antenatal and postpartum visits as per their judgment, their assessment of the needs of their wider caseload, and management of their time. This would depend on midwife numbers and feasible caseloads, however, as evidenced by direct-KIs in this study, attempts are already being made. While this model may be effective, a feasibility study is needed as although effective for women, there may be a personal cost to midwives potentially leading to burnout and compassion fatigue.

There is a gap between policy makers and direct-care HCPs reflective of the top down approach that needs to be addressed. Direct-care HCPs and women's voices need to be heard and guidelines need to be adapted to include them and reach a balance between top-down and bottom-up approaches to care. There is a desire and a need to provide individualized care, however there are resource constraints and individualized care and activation would take this into account. Parents are the biggest KI group when it comes to children, and advocating for a women-driven care plan takes into account the voices of parents and especially women regarding their care (Drandic, Hill, & Fisher, 2019).

Women need to be 'cradled' by support during the birth process and especially the PPP where healthcare support transitions to family and community support. Community, family, healthcare, and the woman all need to be dynamically and holistically interacting to meet the needs of the woman and her baby. Interactions between HCPs and women should be evidence-based and driven by women and consider the interactions of systems and relationships within the healthcare system and the woman's life. Individualized care allows for divergent birth experiences.

7 Conclusion

Postpartum care is an extremely important time for new mothers as they transition into parenthood, or transition to an additional child at home. More evidence is needed to explore the cultural impacts on women’s perceptions of FGM healthcare and changes in attitudes to cultural practices surrounding FGM. This study illuminated the need for a unique approach to women with FGM experiencing the birth process that considers the unique intersection and impacts of various factors such as culture, migration experiences, healthcare experiences, support structures and individual assets and needs. An individualized, strengths-based approach is warranted to enhance women’s experiences and ensure their needs are met.

7.4 Contributions to Knowledge

This is the first study to exclusively focus on the postpartum experiences of women with FGM in the UK using NHS services and represents a unique contribution to knowledge of this thesis. This study applied a focused ethnographic approach to FGM, and while other studies have used this method, this study applied it to not only women with FGM and their health needs, but to a specific and very important life transition post-migration. This study expanded the knowledge on women’s health needs and examined their experiences from a holistic perspective, broadening the scope of knowledge concerning women’s needs and combining the biomedical, cultural, and social aspects of their lives. This study encourages healthcare institutions to refocus their care processes surrounding pregnancy, childbirth, and the PPP from a medical event to a natural transitional event in the woman’s life that requires support outside of traditional healthcare institutions. A documentary analysis on current FGM policy and guidelines has not been completed before and shows a unique contribution to the literature regarding FGM and exemplifies issues concerning data sources and potential issues with policies lacking specific country-context for women with FGM. The Key Informant study represents a unique analysis of a wide range of healthcare professionals and Police providing vital understanding of contextual influences impacting women with FGM using maternity services. Although women's voices were the heart of this research, the DA and KI studies considered the contextual influencing factors of their experiences at different levels from different players and provided a full picture of women's experiences.

The theoretical and methodological contributions to knowledge, while not unique, represent noteworthy contributions to the current knowledge and methods used when researching the healthcare experiences and needs of women with FGM and have been discussed throughout this thesis (layering of vulnerabilities, using focused ethnography in the context of FGM). The layering of vulnerabilities women with FGM may experience, and the meeting of the biosocial, cultural, and medical aspects of healthcare enhance understanding of healthcare experiences of women with FGM.

7.5 We need to talk; implications for policy, practice and research

7.2.1 Implications for policy

Findings suggest a 'mapping' of current maternity care is warranted for women with FGM, as suggested by the NICE guideline 'Pregnancy and complex social factors', which suggests: "developing a clear and detailed map of existing services in the UK for pregnant women with complex social factors, and the effectiveness of these services" (NICE, 2010, p25), and would enable NHS Trusts to create a benchmark understanding of their current care provision for women with FGM. Once the current situation is understood, efforts should be made to establish a stakeholder-led group to assess the needs of women with FGM and how they can be met within current available healthcare resources. A stakeholder-led group could include women with FGM, partners of women with FGM, community organizations, charities that specialize in FGM, academics, clinical experts and policy makers.

Using a Patient and Public Involvement and Engagement (PPIE) framework combined with qualitative and quantitative methods should promote practical and applicable solutions to current unmet needs. Morgan, Thomson, Crossland, Dykes and Hoddinott (2016) achieved success combining PPIE and qualitative methods and concluded the benefits included increased access to underheard populations, sample diversity, trust, engagement, and creative approaches to problems over using either method alone. Combining these approaches with quantitative methods would attempt to meet the NHS and women's needs simultaneously and find the compromise between a realist system and an individualized approach to care.

A review of current FGM policy is warranted as it was found to have a negative effect on care experiences in this study, and has been critiqued by many as causing harm and alienating women (Creighton et al., 2019; Karlsen et al., 2019). A greater understanding of the risk of FGM post-migration is needed, and an evolving policy that considers migration and world FGM trends is needed. An individualized approach to risk assessment to prevent alienation of women and communities should be created and evaluated. Policy should also seek to understand the impact of the law on views of healthcare for women with FGM, and whether women's use of maternity services is impacted by the influence of the law of current care processes. The need to provide culturally competent care was a major finding of this study and although it is noted in guidelines and current policy (NICE, 2010; RCOG, 2015); specific understanding of what culturally competent care means to women with FGM and how to effectively implement and evaluate it is currently not understood.

7.2.2 Implications for practice

The importance of social networks postmigration should also be assessed and evaluated as a policy objective moving forward. The importance of social networks for women in the PPP is known and was shown in this study. HCPs need to proactively assess support structures and bring women with FGM into contact with women who can share their experiences through community and women's groups. Co-creation of women focussed personalized birth plans created with a focus on postpartum and early childhood support for mother and baby may be a method to achieve this. Time, and lack thereof was an important yet expected findings in this study. While it is unlikely resources will increase to allow longer appointment times, efficiency of appointments can be increased by increasing health literacy of women with FGM and enhancing their support networks through the above suggestions and implementation of the Cradle model. Language was also found to be a barrier to care provision in this study. Increased appointment times for women who need interpreters should be established, as well as possibly using health advocates, or lay advocates to increase communication effectiveness between women, the FGM community and the NHS.

The other aspect of practice is the HCPs who provide care. This study found direct-care KIs are exhibiting signs of stress and burnout, suggesting more attention and research focused on front-line healthcare staff experiences is needed, and how to create a more positive work environment within budgetary constraints should be evaluated.

7.2.3 Implications for research

There is currently a lack of research and therefore understanding of the maternity experiences of women with FGM using the NHS. Future research should use a PPIE approach to ensure women’s voices are heard, and their needs direct future policy. A PPIE approach would involve stakeholders, specifically women with FGM, in every step of the research process. The research question and methods would be co-created, as well as outcomes and how to apply the findings to ensure meaningful change was made within resource capacity. A standard PPIE framework does not exist as each study and population create and adjust frameworks based on their desired outcomes. However, the National Institute for Health Research (NIHR) has developed six guiding principles: 1) building on people’s existing capabilities, 2) promoting mutuality and reciprocity, 3) developing peer support networks, 4) breaking down boundaries, 5) facilitating as well as delivering, and 6) recognising people and their experiences as assets (NIHR, 2018). Working with women is essential.

A PPIE approach may have altered the direction of this study by focusing on areas decided by women with FGM and not the researcher; and certainly would have supported the ethics of conducting the study by ensuring women’s autonomy and informed consent in the research process.

The findings suggest women are silenced through the top-down approach currently used. Consulting women throughout policy development would elevate their voices and improve care.

Overall, a lack of women’s voices is present in policy, practice, and research. Using women as the starting point for all care decisions and policy development would create a compromise between individualized care using the current realist NHS system resources. Until the current situation is mapped, and the needs of women understood, meaningful changes cannot be implemented.

7.2.4 Ethical Implications

There is evident tension between research ethics committees and researchers, especially those who use qualitative methods. The Declaration of Helsinki (2001) was created for medical research and practitioners concerning research with human participants (World Medical Association, 2001). The subsequent ethics committees empowered with deciding what research can be conducted and by whom, were not designed for qualitative research methods (Hannigan & Allen, 2003). A tension has been created whereby ethics committees are seen as oppressive and researchers as ‘suffering angels’ who are only trying to help society (Guta, Nixon, & Wilson, 2013). Committees are seen as having excessive demands, inappropriate conservatism and impeding or obstructing research (Allen, 2008; Angell, Bryman, Ashcroft, & Dixon-Woods, 2008), while employing maximum protection for all conceivable risk (Campbell, 2003). The fact that ethics committees have the final say on whether research occurs or not has led to much animosity over their growing power by researchers, and is what Haggerty (2004) termed the ‘ethics creep’ of research ethics committees (Appendix 0).

Since first describing ‘ethics creep’ a vast amount of articles have been published by researchers discussing the topic (Bosk, 2004; Edwards, Kirchin, & Huxtable, 2004; Martyn Hammersley, 2009; Israel & Hay, 2006; van den Hoonaard, 2001). Haggerty (2004) described the increasing remit of ethics committees to comment on methods and not only ethical considerations. He also lamented the formalization of the procedure, creating endless repetitive forms that were not fit for qualitative research (Haggerty, 2004). The decision that all research needed to be ethically reviewed within institution, when before only medium or high risk research needed this level of review led to the idea of institutionalized distrust of the researcher, who needed ethical oversight in order to act ethically (Haggerty, 2004). The author concludes it is currently easier to produce research as a journalist than an academic (Haggerty, 2004).

Moving Forward.

Since publication of that first article (Haggerty, 2004), the ‘ethics creep’ discussion has continued and while I agree with and have experienced many of the stated complaints, I believe a structural change in the approach to qualitative research ethics with respect to healthcare research needs to occur. While no one is contesting the need for ethical research practices to be implemented, the current methods are not suitable. A new framework is needed that reflects qualitative research and is accepting of a wide range of methodologies and methods (Rivière, 2011; van den Hoonaard, 2001). Regarding ethics committees, more training concerning research methods and the practical ethical considerations needs to occur (Ramcharan & Cutcliffe, 2001), as well as training in cultural awareness and cultural competence for both ethics committees and researchers (Quigley, 2016). Du Bois et al. (2012) recommend ethics committees make evidence informed decisions, and do not rely on “stereotypes and untested assumptions” to guide development of ethical safeguards (p2223). Reflexivity and being a mindful researcher should be included in research design (Allen, 2008). Reflexivity helps to prepare researchers for day-to-day ethical issues that arise (Guillemin & Gillam, 2004), and encourages critical examination of all aspects of the research process (González-López, 2011). Context is essential in qualitative research and Quigley (2016) suggests considering all aspects of participants lives, including the impact on the community. Reflecting on the participants lives ensures that methods guarantee easy access to research participation (González-López, 2011). Van den Hoonaard (2001) suggests allowing verbal consent that is indicated on audiotape as a means to prevent the formalizing tone set by consent forms. Placing more emphasis on the benefits of research for society and gathering evidence on actual risk versus possible risk should also be included in the framework (Aldred, 2008). These additions to a new framework of research ethics for qualitative methods would enhance rigor and suitability of ethical oversight for research projects.

Specifically, for my research, in future studies women should be seen as autonomous and able to give informed consent until there is evidence to the contrary for individuals. Translators should be acceptable if consented to by the women, and the status of "vulnerable" should be considered in context. Ethics committees must become culturally competent and more comfortable with 'taboo' or 'delicate' topics, and if needed, request an information sheet on the population from the researcher. Research should not be hindered by fear of harm where no practical risk is real.

Diversifying and increasing research knowledge among REC members would also improve the process. A 2009 survey of 225 lay REC members found 51% were 61 years old or older; 92% were white; 2% were Asian, 2% were black, and 83% reported being heterosexual (Simons, Wren, & Buckland, 2009). Other interesting findings include 33% of respondents having healthcare professional experience, 38% having research experience (unknown whether quantitative or qualitative), and 44% stating their primary perspective brought to the REC was that of a service user (Simons et al., 2009). This survey shows a lack of diversity on ethics committees and exposes a desperate need for minority representation for ethnicities, sexual orientations, and disabilities, as well as a focus on qualitative research expertise.

7.2.5 Limitations in the context of the findings

A detailed review of study limitations completes descriptions of each phase of the research study and are located in Chapter 3, Chapter 4, and Chapter 5, with specific ethics related limitations found in section 2.5. Possible limitations include the unknown degree of assimilation or segregation of women participants. The degree of assimilation may alter care experiences and move women towards having similar outcomes to non-migrant populations versus migrant populations. This could be seen in housing issues, amount of community support and integration, knowledge and expectations of healthcare processes and familiarity with the law and FGM in the UK. However, issues of racism would still exist as all women in the sample were Black and originally from African countries. Similarly, any discrimination due to religious affiliation may be unaffected, though depending on how long the woman has been in the UK, a religious support network could counteract or alleviate issues of religious discrimination and lack of support from family due to migration. Although reflexivity and debriefing occurred throughout analysis, professional biases of mine as a researcher that may have impacted the study findings include a belief in the importance of public health and a professional background in nursing, leading to the desire to successfully provide care using a holistic care model within a realist system.

The limits of qualitative research and FE as a method are discussed in Chapter 2, section 2.1.1. Limitations of FE that must be acknowledged for this study are the lack of precision and definition of the methods, emphasizing a limit of qualitative research in general (Cruz & Higginbottom, 2013). The ability to tailor methods to answer a particular research question results in increased specificity and thus decreased generalizability. Generalizability is a continuous issue for qualitative research (Carminati, 2018); however, in the context of this study generalizability was not an aim. As this study is the first to explore the postpartum experiences of women with FGM, an exploratory method was required. Using this data, further studies, both qualitative and quantitative, can further knowledge in this area and enhance generalizability of findings to potentially a national level. FE was the most appropriate method to use to answer the research question. Nevertheless, related questions regarding the theoretical process of how women experience care and integrate their experiences into their identity or discovering the cultural matrix women use to navigate their care experiences are yet to be explored and would be more suited to methodologies such as grounded theory.

A quantitative study may have discovered trends in birth experiences of women with FGM, such as how many attended antenatal appointments, how many had episiotomies or tears, or how many appointments women had with midwives at home during the PPP. However, while these numbers may be useful in assessing women's access to care, how they experience that care would not be known. A follow-up study could use a mixed-methods approach to determine why specific healthcare trends occur and provide more generalizable findings. Yet, it must always be remembered how unique the practice of FGM is, how it differs from culture to culture, and how varied the effects are, physically, mentally, and sexually, making generalizability very difficult.

7.3 Concluding Remarks

This thesis explored the postpartum experiences and needs of women with FGM. Three phases of research were designed to meet study objectives and included a documentary analysis, and semi-structured in-depth interviews with both KIs and women with FGM. Findings reaffirm the top-down approach taken by the NHS, and the potential for this approach to silence women’s voices or focus on issues of unimportance to them. Interviews with KIs showed a challenging dynamic between different areas of the NHS is present, with policymakers and those who do not have direct interaction with patients having different experiences and thoughts about care than front-line HCPs. This disconnect results in a tension between HCPs within the healthcare system and a difference in focus and assessment of what women’s needs are. This tension and difference of focus is compounded by the influence of the law on the healthcare provision of women with FGM. The influence of the law could be seen throughout each phase of the study and provides important context to how women perceive their healthcare interactions. Both women and HCPs reported discontent with the impact of the law on healthcare practices, suggesting an immediate need to critically assess the current impact of the law regarding FGM and its impact on healthcare interactions. The importance of maternity healthcare interactions during the PPP cannot be underestimated, especially in migrant populations who have known decreased positive perceptions and experiences of healthcare (Balaam et al., 2013; Evans et al., 2019). The potential negative consequences of mandatory reporting and safeguarding process in the antenatal period should be assessed and evaluated in the context of actual risk to potentially female children. Currently the risk of FGM to children cannot be assessed, but what can, and has been, is the impact of risk prevention strategies on women experiencing NHS care. New guidelines and protocols should be developed jointly with women with FGM, their families and communities.

Women reported positive experiences with midwives when their care was focused on the health needs of the woman and her baby. Negative emotions were described by some during their antenatal clinic interaction and when they did not feel listened to. The antenatal clinic interaction is dominated by the law, the completion of MR and safeguarding. When the law eclipses discussions of health needs at a healthcare appointment, something has gone awry. Women stated they were aware of the law and described feeling victimized and 'othered' by the NHS, with some describing they felt the HCP had the authority and power to allow or disallow them to have a vaginal delivery. Concurrently women reported no adverse effects of their FGM during their birth process, displaying a disconnect between the focal point of women and health services. The NHS should aim to meet the healthcare needs of women with FGM, thus further study of women's experiences is needed to enhance care practices. An individualized care approach would amplify women's voices in this aspect of their care and provide a much needed holistic, woman focused approach to care. The degree to which the successful implementation of better births and continuity of care models impacts this remains to be seen,

A focused ethnographic method was used that identified women with FGM as a subculture of maternity service users. This method is well suited for exploring healthcare interactions, especially when investigating perceptions of care at the intersection of different cultures. Focused ethnography also seeks to find solutions to clinical issues and was used effectively for this purpose in this study. Using focused ethnography ensured culture, a core aspect of human identity, and therefore a crux of healthcare interactions, was observed as paramount to provide contextual understanding to findings. As medical advances are made, the focus of medicine has been able to expand to include the person as a whole, and not only resolutely focused on fixing immediate, life threatening events. Unfortunately, due to an ever-expanding population, resources are limited. Constrained resources combined with people reaching more advanced ages results in a unique confluence of personal healthcare needs. However, people do not live in seclusion and need to be viewed as part of family, community and societal networks and systems. Not only do these networks impact perceptions of care, they can also enhance care by providing support. The need to feel supported was a key finding in this study and is needed by women with FGM during the PPP. This particular life transition into motherhood, or the addition of more children into a household represents a unique time period in a woman's life and results in unique support needs. Due to the emerging needs and experiences during this time, a confluence of factors occurs that cannot be understood if dissected, they must be viewed as a whole. The only method to ensure holistic care is provided that fits the needs of women and ensures their voices are heard is an individualized approach to healthcare. An iterative process between HCP and woman needs to take place, mediated by women's cultural beliefs.

This study is the first to exclusively focus on the postpartum experiences of women with FGM using NHS maternity services using various methods to achieve its aim including a documentary analysis, interviews with a wide range of key informants and women with FGM. Currently a top-down approach to healthcare is occurring, silencing women's voices, and directing their care from a medical perspective. The findings from the study show women with FGM have unique needs in the PPP due to various factors relating to culture and migration; and the importance of support cannot be underestimated. This study showed that support was the most important factor of birthing care and was potentially the largest gap in postpartum care needs (Figure 6.4).

A new approach which considers the interwoven nature of women’s lives with internal and external factors at the macro, meso and micro level is needed and presented in the ‘Cradle Model’. Maternal experiences of women with FGM using NHS services represents a convergence of the social, cultural, and biomedical aspects of their lives and a suitable model of healthcare acknowledging these interlacing aspects is needed. FGM is a multi-layered, intertwining, context-driven healthcare topic; policy directed at providing maternity healthcare for women with FGM must consider that how a problem is defined is not necessarily how the solution should be framed.

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Appendix A Appendices for Chapter 1

A.1 Perceptions, experiences, and attitudes of women with FGM towards the practice

Table A.1: Perception, experiences, and attitudes of women with FGM towards the practice

Author	Country	Methods	Perception, Experiences, Attitudes Towards FGM
Masho & Matthews, 2009	Ethiopia	Secondary analysis of data from the 2005 Demographic Health Survey (DHS) 11,375 datasets analysed.	66.7% of women believed the practice of FGM should not continue. Women who lived in rural locations, who identified as Muslim, who received no formal education, were not exposed to mass media, were married, and who themselves had been circumcised were between 1-3 times more likely to support the continuation of FGM
Mohammed et al., 2014	Egypt	Cross-sectional study of 2,106 sexually active women who had undergone FGM, and their male partners	Significantly more women from rural locations, with less education and who themselves had been circumcised believed the practice should continue. However, no women without FGM nor their male partners were willing to have their daughters undergo FGM. While most males reported to prefer to marry a woman with FGM, they also reported being unsatisfied with their overall sex life and preferred to practice sexual intercourse with women without FGM (55.6%). Tradition, cleanliness and maintaining virginity were described as the reasons for continuing the practice. Uncircumcised women reported that tradition rather than religion was the main pillar for continuing the practice
Almroth et al., (2001)	Sudan	Conducted a survey of grandparents and parents (women	Results showed a significant association between higher education and lack of support for the continuation of FGM.

		<30 years old, men <35 years old) in a Sudanese village of 3,600 people. In total, 30 young women, 30 grandmothers, 29 young men, and 30 grandfathers were interviewed.	Interestingly, this association was only seen in young women, not young men. Education had no bearing on young men's perceptions on the continuation of FGM, rather, the belief that there was religious support for FGM determined young men's acceptance of the practice. Although all women except one were infibulated (Type III FGM), young men reported only clitoridectomy was supported by Islam, and was preferred by them. This reflected a significant difference between the attitudes of young and old, with both young men and women preferring clitoridectomy, versus grandparents preferring infibulation. All grandparents had had their daughters undergo FGM. In the younger generation, 30% of young women, and 38% of young men believed their daughters should undergo FGM, while 50% of young women, and 38% of young men believed the practice should not continue and would not get their daughters circumcised. When discussing general reasons for the continuation of FGM, young women reported motives such as to satisfy their husband, it being for the future husband, and men preferring it. Men did not discuss any of these reasons.
Afifi and Bothmer, 2007	Egypt	2005 Egyptian Demographic and Health Survey (EDHS)	Results showed 95.6% of participants were circumcised, and 75.8% intended to have daughters circumcised. Reasons for continuing the practice included the

		Mixed-methods study. Results of the EDHS were combined with interviews. A subsample of 5,249 currently married women were interviewed regarding whether they used physical punishment on their children.	belief by women that husbands preferred women with FGM (60%), that it prevents adultery (51.5%), and that it is a religious issue (60.5%). Over 34% were aware it could lead to death from haemorrhage during childbirth, while 42.1% had a high school or higher education. The authors do not report whether those with higher education supported FGM for their daughters, which would have led to more informative results. On detailed reading concerning the methods of the paper, the authors appear to have created a profile describing a range of behaviours of women and attempted to link the profiled behaviour on the women's views on FGM. The authors do not present this information clearly and the results are open to misinterpretation.
Goge and Rossem, 2005	Guinea	1851 men aged 15—59 and 6364 women aged 15—49 who were interviewed in the 1999 Guinea DHS. Face-to-face interviews were conducted.	Reported an association between education and belief in the discontinuation of FGM. For each year of education, belief in discontinuation increased, (men-OR=1.08, $p<0.001$, women-OR=1.10, $p<0.001$). Religion was the main motivation for men (61%) and women (74%) in this study, followed by social approval; (men (53%) and women (65%)). An association was also found between women never being married, increased household wealth and wanting an end to the practice of FGM. Men living in urban areas were also more likely not to support FGM than men living in rural locations.
Berggren et al., 2006	Sudan	Explorative interviews with women and men	Findings indicate both men and women place blame on each other for the continuation of re-infibulation. For both sexes, it is a

			complicated matter. Women want to see their genitals as ‘normal’, while also not wanting to be re-infibulated, with women also feeling they have limited influence over the practice. Men report suffering the consequences of re-infibulation through the time it takes the woman to heal and observing the pain it causes her, while trying to balance the negative sexual effects. Men described striving in vain to change female traditions.
Chalmers and Hashi, 2000	Somalian women’s perceptions of healthcare during pregnancy and birth in Canada.	Qualitative focus groups	Revealed women’s reasons for continuing FGM included religious requirements, tradition, protection of virginity, ensuring marriageability and beauty. Women reported being included in initiating FGM, planning the event, and described being pleased and excited before the procedure. However, women also described being afraid, having little idea about what was to happen, and reported not wanting FGM to be done. After the procedure women described experiencing severe pain, being extremely ill, feeling fear, and unhappiness. These negative feelings are juxtaposed with positive feelings about the outcomes of FGM such as being pure, proud, more beautiful, more faithful to future husbands, and pleased for their future husbands, leading to overall feelings of happiness. When discussing sexual intercourse and the wedding night, 75% of women reported fearing the wedding night, and reported being hurt, not enjoying sexual experiences, and described it as being traumatic with the majority (67.8%) reporting their wedding

			night was worse than anticipated. Despite this, when women were asked whether they would have their daughters circumcised, 48.8% said yes, while reporting only 35.7% of their husbands desired it. Feelings about having their daughters circumcised ranged from happiness and praise, to fear of criticism from the community for failing to do it. Discussions concerning re-infibulation revealed 69.9% of women would prefer to be 'left open' post-birth, with 33.3% believing it was a woman's decision, 36.3% believing it was a man's decision, and 21.8% the doctors decision.
Lithorp, Franck and Almroth, 2008	Women with FGM living in Sweden	Women who attended a clinic for antenatal care and contraceptive advice participated in interviews and physical exams.	Reasons for FGM being perpetuated included tradition, sexual control and religion. Eighty-three percent of women reported there being no positive effects of FGM, and discussed negative obstetric, sexual and menstruating consequences. Eighty-nine percent of participants would not let daughters undergo FGM, with reasons including FGM being 'not good', associated complications, no religious support, 'not natural', own negative experience, no need, forbidden and husband being against the procedure. Results of this study must be viewed in context; women sought care and contraceptive use which may provide a bias toward women with increased health complications, women who desired reproductive freedom and those who could access healthcare.

A.2 Female Physical Health Consequences of FGM

Table A.2: Female Physical Health Consequences of FGM

Author	**Country**	**Methods**	**Findings**
Berg et al., 2014	High income migration countries	Systematic Review	Immediate complications: bleeding, shock, genital tissue swelling, fever, infections, problems with urination and wound healing, and pain Genitourinary complications: genital tissue damage, vaginal discharge and itching, urological complications and infections, an increased risk for burning or painful urination. Women who had undergone FGM were also found to be at greater risk of menstrual problems, including: dysmenorrhea, difficulty in menstruation, irregular menses and difficulty passing menstrual blood.
Karimi & Loghmani, 2008	Iran	Cross-sectional study of 340 women; interviews, physical exams, demographic data	Immediate complications: 57% reported immediate complications of bleeding, shock, wound infection and swelling. 32% of women with FGM experienced painful and difficult menstruation, pelvic infections and recurrent UTI’s.
Almroth et al., 2005	Sudan	Interviews	Explored paediatric complications of FGM. Two-hundred and forty-nine girls were recruited from an ER ward in Sudan. Fifty-two (20%) had undergone FGM. Of those, 73% reported being bedridden for a week or more after the procedure, though only 5% reported having any immediate complications including urine retention and fever, shock with unconsciousness, and wound infection.
Amin, Rasheed and Salem, 2013	Egypt	Cross-sectional study assessing the effect of FGM on prevalence of lower urinary-tract symptoms	Reported prevalence of all lower urinary-tract symptoms being significantly higher in women with FGM than non-cut counterparts. Participants experienced storage of urine, urination, and post-urinating problems. Symptoms included: urgency, frequency and nocturia; incontinence, intermittency including

			terminal dribbling, straining and slow stream, and incomplete emptying of the bladder
Iavazzo, Sardi and Gkegkes, 2013	Global literature included	Systematic review of infections and FGM	Twenty-one articles were included in the study, and of those 21 articles, seven reported acute local trauma infections, and three reported UTI's. Genitourinary tract infections were reported in six studies and HIV infection was reported in five. Septicaemia and abscess formation were both reported in one study only. The authors note that most infections resulted from having Type III FGM. Sexually transmitted and bacterial infections ranged from 1-5 studies and included: HIV, clostridium tetani, chlamydia trachomatis, Neisseria gonorrhoeae, treponema pallidum, candida albicans, trichomonas vaginalis, HSV-2, pseudomonas pyocyanin, and staphylococcus aureus.

A.3 Female Psychological Consequences of FGM

Table A.3: Female Psychological Consequences of FGM

Author	**Country**	**Methods**	**Findings**
Berg et al., 2010	International databases	Systematic Review	Insufficient evidence to draw any conclusions due to a paucity of high-quality evidence
Al-Krenawi, 1999	Bedouin Arab women in Israel	Presented a questionnaire and interviewed 24 women	Twelve had undergone FGM, while the other 12 knew about the procedure but had not undergone it. An interesting dissonance between body and social image was found. The authors reported women answered the questionnaire as their cultural norms dictated, supporting FGM and discussing its role in society. However, when discussing FGM in the interviews, they expressed fear, shame, anger, and helplessness concerning the experience and consequences. They directed

			these feelings towards their parents and husbands or future husbands. This dissonance between what women described on paper versus verbally displayed the struggle women with FGM have when processing the event. Women want to be seen as pure, worthy and as a good candidate for marriage, while also not wanting the obligation of conforming to the body image ideal of FGM. Women who had not undergone the procedure did not support the tradition.
Chibber, El-Saleh and El Harmi, 2010	Kuwait	Studied 4,800 pregnant women in Kuwait over 4 years.	38% had undergone FGM. Of those 80% experienced flashbacks of the event, 58% had a psychiatric disorder, 38% had an anxiety disorder, and 30% had PTSD.
Vloeberghs et al., 2012	Women with FGM who had migrated to the Netherlands	Mixed methods, interviews, and questionnaire	Participants reported experiencing recurrent bad memories, nightmares, pain, tension, fear and feelings of powerlessness and apathy. Feelings of anger, shame, guilt and feeling excluded were also common. PTSD was indicated in almost 15%1/6 of the group, and almost 33% displayed signs of anxiety.
Behrendt et al., 2005	Senegalese women in Dakar	Conducted neuropsychiatric interviews to assess traumatization and psychiatric illnesses in 23 women who had undergone FGM. Twenty-four women without FGM acted as controls.	All participants except one remembered the day their FGM procedure was done as extremely appalling and traumatizing. Over 90% described feelings of intense fear, helplessness, horror, and severe pain. Over 80% reported suffering from intrusive re-experiences of their mutilation. Those with FGM experienced PTSD (30.4%), other anxiety disorders (26.2%), affective disorders (21.7%). Only 21.7% had no psychiatric disorder, compared to 95.8% of

			controls. PTSD was also associated with declarative memory dysfunction when the Rey Figure Test was conducted.
Parikh, Saruchera & Liao, 2018	UK	Interviewed 13 women recruited from an African well-woman clinic and with a snowballing approach and asked them about their experiences and feelings about their FGM.	Three themes were described by women. Women described ‘feeling different’ and like they were ‘missing something’. They also reported associating sexuality milestones such as menstruation and marriage with their FGM. Although women worked to salvage relationships with their families and mothers, forgiveness had to be negotiated, and ultimately culture was blamed for the practice. Women acknowledged the cultural power of the practice and understood parents perpetuated it for their own good. Women also reported UK society treated them as ‘guilty until proven innocent’ with regards to their FGM status and their beliefs about the practice.

A.4 Female and Male Sexual Consequences of FGM

Table A.4: Female and Male Sexual Consequences of FGM

Author	**Country**	**Methods**	**Findings**
Alsibiani et al., 2010	Saudi Arabia	prospective case-control study by 130 sexually active women with FGM, and 130 sexually active women without FGM in Saudi Arabia completed the Female Sexual Function Index (FSFI) questionnaire; a measure of sexual functioning in women by scoring desire, arousal, lubrication,	No statistically significant differences were found concerning desire and pain. Statistically significant negative differences were found in arousal, lubrication, orgasm, satisfaction, and overall sexual score. Pain scores for both groups were moderate (3.5±1 for FGM group and 3.8±1.1 for control group), and therefore, while statistically the groups did not differ significantly, pain was present

		orgasm, satisfaction and pain.	during intercourse. This is a disturbing and noteworthy finding perhaps more reflective of women's sexual experiences in general versus related to FGM. Having FGM was associated with sexual dysfunction. <u>Limitation</u>: the authors did not consider the level of FGM in their analysis which represents a flaw in the study, thus limiting the value of the results. This study must therefore be viewed in context of its' methods, with results indicating that study participants experienced pain during intercourse and overall differences were found between the FGM and control groups.
El-Defrawi et al., 2001	Ismailia	Semi-structured psychiatric interviews based on the Arabic version of the Sexual Behaviour Assessment Schedule-Adult (SEBAS-A).	Of 250 women attending a family planning clinic, 200 (80%) women had undergone FGM. Statistically significant differences were reported by the participants with FGM regarding a lack of sexual desire, less frequent sexual desire per week, less initiation of sex with husbands, being less pleased by sexual intercourse, being less orgasmic, dryness during intercourse, having difficulty in timing of orgasms with husbands, and symptoms of dysmenorrhea. Foreplay before sexual intercourse did not differ between groups. Attitudes towards FGM revealed 69% believed it was harmful, while 31% believed it was beneficial. When asked whether participants would circumcise daughters, 38.5% said yes, and 61.5% said no.
Berg et al., 2010	International databases	Systematic Review	Findings: pain during intercourse (RR-1.52, 95% CI-1.15-2.0), reduced sexual satisfaction (SD -

			0.34, 95% CI. -0.56- -0.13), and reduced sexual desire (RR-2.15, 95% CI- 1.37-3.36) to be significant sexual consequences of FGM. Fifteen studies of varying quality were included. All 15 studies, except one reported negative consequences of FGM including dryness during intercourse, pain during intercourse, not enjoying sex, and never or rarely experiencing orgasm. The one study that opposed these results found pregnant women with Type 1 or 2 FGM reported negative sexual consequences less than women without FGM, with variables including: never initiating sexual activity, not experiencing orgasm, and not engaging in sexual intercourse in the last week or in the last month. This may suggest negative sexual consequences are increased in women with Type 3 FGM. Although a meta-analysis was conducted on several outcomes, the quality of the studies overall were deemed very low and suggest that while more research is needed in this area to draw any meaningful conclusions, HCP should be aware of possible negative sexual consequences of FGM and provide care accordingly.
Epstein, Graham and Rimza, 2001	Somalian migrant to the USA	Case study on a woman with Type III FGM.	The woman presented with lower abdominal pain and a three-year history of severe dysmenorrhea, heavy bleeding with menses, dysuria, and prolonged micturition. Doctors advised reconstruction of the perineal anatomy. The woman rejected this idea as it was custom for the husband to ‘break through’ on the wedding night. Two weeks

			after her marriage she returned to the clinic as her new husband could not ‘break through’. The surgery was completed and follow-up showed the wound healed well, the kidneys and bladder showed resolution of calicectasis (inflammation of part of the kidney), and the time it took to pass urine was greatly reduced, with no dysuria or dyspareunia.
Fazari et al., 2013	Sudan	Case study	Described the removal of a vulval mass to allow penetration. The cyst was successfully removed, and the genitals reconstructed. No post-operative complications occurred. The patient reported being very satisfied with the procedure, especially concerning her sexual life.
Krause et al., 2011	Switzerland	Focused on infibulated women (FGM Type 3) in Switzerland. Women who approached the hospital department of Urogynaecology for de-infibulation were asked to participate. Women who did not speak English, Italian, French or German (Swiss national languages), or had a history of urinary incontinence, or were unwilling to fill out questionnaires were excluded, resulting in 18 participants. Study participants completed the Female Sexual Function Index (FSFI) questionnaire before de-infibulation surgery and six months afterwards.	Pain was the main reason women sought the surgery. Post-surgery, significant improvements were seen in the domains of desire, arousal, sexual satisfaction, and decreased pain, while lubrication and orgasm remained the same.

Vital et al., 2016	France	Observational, prospective, single-centre pilot study. Twelve women receiving clitoral reconstructive surgery. The FSFI was completed pre-surgery, and at three- and six-month's post-surgery.	The median scores (17, range 13-21) pre-surgery suggested sexual dysfunction was present. At six month's there was a significant improvement in scores seen (29, range 24-34) across all domains. Ninety-two percent of participants reported being happy with surgery, discussing how it increased their satisfaction with their genital appearance and sense of femininity.
Almroth et al., 2001	Sudan	Conducted interviews with married men of the youngest parental generation, and grandfathers. Participants were randomly chosen from a village in the Gezira Scheme along the Blue Nile in Sudan. Twenty-nine younger generation, and 30 grandfathers participated.	Most men described difficulty in penetration, wounds and infections on the penis, and psychological problems. With regards to psychological problems, men from both groups reported being upset at the thought of hurting their wives and knowing that she suffers during sexual intercourse. Men reported being aware of the decreased sexual desire and enjoyment felt by women and did not appreciate this result of FGM. Participants discussed the increased cost of medical care for their wives and themselves due to FGM, especially after re-infibulation.

A.5 An Overview of Midwifery Regulation Over Time

Regulation of professions is not a negative process; however, one must be aware of who is deciding what and who is regulated. In this context, midwifery practice in the UK is regulated based on the historical authority of physicians, who originally regulated what is now the Nursing and Midwifery Council (Connerton, 2012).

As medicine grew in knowledge and became the authority for health information, it assumed authority over childbirth. This began in the 18th century with wealthy women hiring physicians instead of having birth attendants or midwives. The move from childbirth occurring in the home to the hospital marked a shift in perspective (Scamell et al., 2019). Home birth was seen as ‘unsafe’ and medical interventions were deemed highly likely to be necessary, thus requiring women to be ready for an adverse event and be in a hospital. Midwifery became regulated in the UK in 1902 with the first Supervision of Midwifery Act (Thomas & Richarson, 2016). Under this Act, midwives were required to register their intent to practice with a local regional supervising authority, and be willing to have their practice scrutinized and receive complaints from the public, with original oversight being by obstetricians (Thomas & Richarson, 2016). It was not until 1920 that midwives were allowed to sit on the midwifery board to influence the care given by midwives and the regulation of their profession, however, they were strictly forbidden from forming a majority, and an obstetrician acted as Chair (Thomas & Richarson, 2016). At this time midwives were only regulated to attend normal, uncomplicated births. If any complication occurred, an obstetrician would provide care and intervention. The NHS was developed in 1948 to provide healthcare to all, with people paying as taxpayers rather than when receiving care (Rivett, 2014). The General Nursing Council (1979), and subsequently the United Kingdom General Council (UKCC) in 1983 regulated nurses, midwives and health visitors. However, this Council did not have a clear overall remit for regulation and was replaced by the Nursing and Midwifery Council (NMC) in 2002 (Nursing and Midwifery Order, 2001). Midwives continued to self-regulate through supervision until 2016 when midwifery supervision was deemed not fit for purpose after a number of failings (Ford, 2015). Currently all midwives in the UK are regulated under the same framework as nurses (Professionl Standards Authority for Health and Social Care, 2020).

As discussed above, safe birth at home became a contentious topic between physicians and midwives; and the mainstream media did not help matters. Media began to present birth in a highly dramatic fashion (Luce et al., 2016) and subsequently, fear of childbirth became more prominent among women (Hundley, Duff, Dewberry, & Luce, 2014). Luce et al. (2016) conducted a scoping review to investigate the current gaps in the literature around media and childbirth. Electronic databases were searched and yielded 38 articles that met inclusion criteria (12 qualitative, 5 quantitative, 3 unpublished, 18 grey). Three themes emerged; 'medicalization of childbirth' which includes birth being depicted as dangerous and risky; 'media is the dominant method women learn about childbirth', even though it is mostly negative; and 'birth being missing as an everyday 'normal' life event'. These themes suggest current media representation of childbirth may lead to women developing feelings of fear associated with it. The author notes that although it must be acknowledged that women are influenced by media, there are many other influences on women's choices and while more research is needed. Midwives must engage with media and advocate on behalf of women for more accurate representation (Luce et al., 2016). Limitations include those of a scoping review, namely that no quality assessment was conducted and thus the quality of included evidence must be taken with caution. Maclean (2014) also explored media representation of childbirth using grounded theory by examining first-person stories of childbirth published in 23 leading British newspapers covering the political spectrum. Themes included 'fear', 'ordeal pain', 'effective staff and gratitude', and 'malicious staff'. Articles describing poor experience often involved extreme cases, staff negligence or celebrities with emotive language used (Maclean, 2014). Limitations include only one researched conducting the study. Although reflexivity was used and methods were clearly described; unknowable biases may be present. Women's magazines were also considered beyond the scope of the study and may have altered findings. Taken together the above studies suggest birth depictions in media are negative and dramatic, and may induce feelings of fear and anxiety for women. This fear may also translate into policy where more interventions in childbirth are used as perceived risk drives decisions rather than real risk.

A.6 Brief Introduction to Alternative Rites of Passage (ARPs), Female Genital Cosmetic Surgery (FGCS), and the Medicalization of FGM

Alternative rites of passage (ARP)

Original attempts to encourage abandonment of FGM focused on education regarding health complications combined with Western values and legislation, however, this approach failed to consider culture and the diverse reasons for the practice of FGM (Johansen, Diop, Laverack, & Leye, 2013).

Johansen et al., (2013) conducted a review of ARPs and found several common approaches are used; education about health risks, conversion of excisors, training of HCP as change agents, alternative rituals, community-led approaches, public statements, and legal measures. The authors note several challenges with current approaches; 1) the documentation and evaluation of ARPs are not systematic, 2) multiple interventions are used at the same time resulting in an inability to know what is working, and 3) although a goal, the total abandonment of FGM is not regularly cited as an overall objective of ARPs. Although all approaches of ARPs have their advantages and disadvantages, a lack of thorough evaluations causes difficulty in knowing the effectiveness of programs, however, the authors did note the importance of community-wide acceptance of whichever method was used is needed if any change is likely to occur.

Graamans et al. (2019) conducted a review into lessons learned from the current Amref Health Africa ARPs which began in 2007. Results indicate that reasons communities do not adhere to ARPs include: risk of exclusion, perceived loss of cultural identity, changing meanings ascribed to cultural practices, lack of precise knowledge about subjective (sexual) experience, and negative stereotyping. Areas for concern were noted by the authors as: role confusion with follow-up on policing, perceived outsider interference and the intended prolonging of the transition phase into womanhood not being explicated and embedded within ARPs. Areas for enhancement of programs include education and school curriculum development, male involvement, new stylization of love relationships, monitoring and evaluation, inclusive aspects of religion. Education and the access to schools for women and girls was also noted as important by Boyden, Pankhurst, and Tafere (2012). The importance of community acceptance must also be noted as without community-wide acceptance, no change is likely to occur.

Hughes (2018) notes an issue with ARPs is the lack of a meaning given to culture within the context of the ARP. Culture should be viewed as changing rather than static and defined in terms of ethnic difference (Hughes, 2018). Changing this perception may help communities to accept and embrace change within their culture. Mackie (2009) also raises this point and argues a community approach is necessary as the practice of FGM is a social convention required for many aspects of life, including the community standing of the family. Any method towards abandonment must understand the community context and why the practice is perpetuated. The use and implementation of ARPs also evokes debate regarding cultural relativism because it asks the question of who decides what an appropriate cultural substitute is (Prazak, 2007). It is evident that if ARPs are to succeed, they must consider the cultural context and include community members input during the design process. Another method for decreasing the harm associated with FGM is the ‘medicalization’ of FGM. Providing information and education regarding FGM risks increasing the extent of FGM being performed by HCP as they are seen as a safer option to continue the practice (Johansen et al., 2013). A concern with this is the potential for the practice to be institutionalized through medical systems and for the ultimate continuation of FGM through healthcare systems (Johansen et al., 2013). Medicalization of FGM, and the two opposing viewpoints will be discussed in the next section.

Medicalization of FGM

FGM is and was traditionally practiced within communities by women called ‘cutters’ (Gruenbaum, 2001). However, with the advancement of healthcare, access to healthcare, and education concerning the health consequences of FGM, many parents are using HCP to perform the practice. This not only effects the economic prospects of the women ‘cutters’, but also raises unique ethical issues within medical ethics. A joint technical consultation on the medicalization of FGM was conducted by the WHO, UNICEF, and the UNFPA and in 2009 the medicalization of FGM was condemned by the participating bodies (UNFPA, 2018). Recent demographic and health surveys conducted in Egypt, Guinea, Kenya, Nigeria, North Sudan, Mali, Yemen and Indonesia have shown a substantial increase in the rate of FGM performed by HCPs (Serour, 2013) and demonstrates a trend towards the practice.

Leye, Van Eekert, Shamu, Esho, and Barrett (2019) argue against the medicalization of FGM and discusses the ethically difficult situation Western HCP experience. The author contends it is difficult to avoid damaging the clitoris when performing an incision, especially on non-fully developed genitalia, and that complications such as shock, infections, sepsis and bleeding are difficult to avoid even with an incision using medical instruments. FGM incisions are performed for cultural and traditional reasons and have no medical basis, opposing the medical rule of ‘do no harm’ with the resulting incision remaining a violation of the human rights of girls and women. One reason for promoting medicalization is often to avoid the traditional cutters who will perform a more severe form of FGM with unsterile and unskilled techniques. Leye et al. (2019) argues that in some communities girls are checked to ensure the appropriate type of FGM has been completed and if they find it has not been, traditional cutters will ‘redo’ the girls. Leye et al. (2019) argues promotion of a less severe form of FGM maintains the acceptability and legitimizes the practice. The author contends culture is dynamic and changes over time, therefore ARPs can be found to replace FGM. Referring to FGM as ‘sunna’ is dangerous as not only can it imply various degrees of FGM, including infibulation, it also means tradition in a religious sense. Giving FGM religious connotation is dangerous as it suggests the practice is acceptable on religious grounds and is positive.

In conclusion, Leye et al. (2019) discusses that while medicalization may be viewed as a less harmful method of FGM, it should not be condoned or performed by HCP who have taken the Hippocratic oath ‘first do no harm’. In the UK any form of FGM is illegal. HCPs’ focus should include support, information, counselling, deinfibulation, specialist midwives and appropriate care for women with FGM.

Opposing this viewpoint, Shell-Duncan and Herniund (2006) encourages the medicalization of FGM. The author states there is no empirical evidence showing that medicalization of FGM will counteract elimination efforts. Shell-Duncan and Herniund (2006) describe medicalization as a ‘harm reduction strategy’ as it minimizes the potential negative health consequences by providing clean, sterile environments and instruments for each woman, prophylactic antibiotics and trained professionals completing the procedure (Shell-Duncan & Herniund, 2006). By involving healthcare professionals, there is an opportunity for education, advice and resources regarding FGM (Shell-Duncan & Herniund, 2006). While healthcare professionals should council against FGM, it is safer for women to have the procedure done in a medical facility (Shell-Duncan & Herniund, 2006). Healthcare professionals can also decrease the amount of cutting as the literature suggests there are fewer complications with Type I and II FGM compared to Type III (Shell-Duncan & Herniund, 2006). Johansen et al. (2013) report medicalization may lead to a change in type of FGM performed as seen in Somalia and Sudan.

Methods to diminish and abandon the practice of FGM are in use and have reported some success. Issues with systematic collection of data to analyse efficiency and what methods are working is lacking. There is currently a debate between scholars regarding the medicalization of FGM, with some arguing a complete ban is the only method to lead towards abandonment, while others argue for a harm reduction approach. More data is needed before any conclusions are reached.

Female Genital Cosmetic Surgery and Male Circumcision

Female genital surgery and male circumcision are not in the purview of this thesis; however, they must be acknowledged as they have theoretical and ethical implications for the topic of FGM. Female genital surgeries began as a medical treatment for conditions such as lesbianism, hysteria, debility, masturbation and nymphomania (Donohoe, 2006). Circumcisions were performed and included removal of the hood of the clitoris and clitoridectomies (S. W. Rodriguez, 2008). As medical knowledge increased throughout the 19th century, these ‘treatments’ were discontinued and outlawed (S. W. Rodriguez, 2008). However, other forms of genital alteration have emerged throughout the last century. Between 1954 and 1966, Dr. James Burt in the USA altered episiotomy repairs and reduced the size of the vaginal opening in what would become known as adding a ‘husband stitch’ (Rodriguez, 2013). This procedure was conducted without consent and without medical directive because Dr. Burt believed the clitoris and vagina were too far apart for women to experience sexual satisfaction (Rodriguez, 2013). Current surgical procedures altering women’s genitals include labiaplasty, recreation of the hymen and vaginal rejuvenation after childbirth (Davis, 2002) and are referred to as female genital cosmetic surgeries (FGCS). Some argue there is a clear hypocrisy when adult women are allowed to consent to genital surgeries but not allowed to consent to re-infibulation (Wellsch, 2019); as occurs in the NHS. This argument is compounded when it is known that the NHS allows labiaplasty on women under the age of 18 for mental health reasons but FGM is against the law in all cases. Cosmetic surgery on female genitals is viewed as therapeutic with a psychological benefit. FGM is prohibited in adult consenting women based on the argument that, “they lack autonomy, agency and are victims of oppressive patriarchal rituals that revel in inflicting pain and servitude and destroy women’s natural sexual embodiment” (Kennedy, 2009, p211). Genital modification, they argue, should not be allowed for one group and not the other.

The other comparison supporters of FGM make is to male circumcision (B. Earp, 2015). Male circumcision is currently not medically indicated for infants (NHS, 2018), however there are no laws against it and currently a high proportion of infant boys in the Western world are circumcised. As it is not medically indicated, any removal of genital tissue must be seen as for non-medical reasons, which is identical to the FGM definition (B. Earp, 2015). Many scholars claim Western society is hypocritical and current evidence does not suggest FGM should be seen in such negative terms (The Public Policy Advisory Network on Female Genital Surgeries in Afirca, 2012).

While both of these comparisons and an in-depth discussion of the theoretical and ethical implications associated with FGM are not relevant to the discussion in this thesis, it should be noted that women with FGM may feel ‘othered’ by current laws in the UK concerning FGCS and male circumcision, and wonder why FGM is targeted.

A.7 Search Strategies used in Scoping Literature Review

A.7.1 Search Strategy

A general initial search was conducted to get a sense of the overall literature on FGM; migrant health, culture and maternal health, before a more specific search was conducted using focused terms. Search engines used included PubMed, CINAHL, Web of Science, Google Scholar and OVID. This was followed by searches using specific search terms including: Backwards and forwards searches were conducted on included papers. The following sections give a robust review of the available literature relating on the health consequences of FGM.

Table A.5: Search terms used

Concept	Linked search terms
Female genital mutilation; female genital circumcision; female cutting; FGM; and FGC.	types*; UK*; Europe*; NHS; WHO*; UN*; risk factors*; health* profession*; experience*; pregnan*; post-partum*; female*; male*; matern* care*; statistic*; prevalence*; and standard* of care*; percept*; perceive*; outcome*
Migrant Health Migrant*; immigrant*	NHS; WHO*; UN*; World*; glob*; pregnan*; postnat*; post-partum*; matern* care; experience*; percept*; perceive*; statistic*; prevalen*; and standard* of care*; outcome*; risk factor*; risk indicator*; outcome*
Culture; belief*; group ident*	UK*; Europe*; NHS; WHO*; UN*; glob*; risk factor*; risk indicator*; health profession*; experience*; pregnan*; post-partum*; female*; male*; matern* care*; statistics*; prevalen*; and standard* of care*; percept*; perceive*; outcome*
Maternal Health pregnan*; postnat*; post-partum*; matern* care;	UK*; Europe*; NHS; WHO*; UN*; glob*; risk factor*; risk indicator*; health profession*; experience*; female*; male*; statistics*; prevalen*; and standard* of care*; percept*; perceive*; migrant*; immigrant*; outcome*

A.8 Migrant Maternal Health

A study by Giuntella et al. (2018) using the UK's quarterly Labour Forces Survey (LFS) to complete a cross-sectional analysis of health outcomes and reasons for migration. Results showed substantial heterogeneity in health outcomes of migrants across reasons for migration; with migration for employment and study respondents less likely to report a long-lasting condition compared to local counterparts, whereas asylum seekers were much more likely to report long-lasting conditions. Although migrants for study and employment were seen to report greater health than the non-migrant population, this effect converged with non-migrant health reports as amount of time spent in the UK increased. This is an important finding for HCPs, as health needs could be masked by a 'healthy migrant' attitude or belief (Giuntella et al., 2018). However, as this is a cross-sectional study, the results only show a specific time and cannot be generalized. Cohort studies would be better suited to display outcomes across time periods. This is a significant finding and shows the differences in health of migrants may be determined in part by reason for migration and amount of time spent in the host country.

Differences in migrant health also extend to maternal health. Maternal clinical health outcomes have been explored in the literature and overall suggest worse outcomes for migrant women. Merry, Vangen, and Small (2016) completed a systematic review analysing rates of C-section among migrant women in high-income countries. Results showed migrant women from sub-Saharan Africa consistently show an increased risk for C-section birth. The most common reason cited was repeat C-section and failure to progress during second stage labour. Poor maternal health was also cited as a reason and divided into six explanatory categories including high body mass index (BMI) and gestational diabetes, women’s cultural attitudes and expectations, FGM, language, cultural barriers, and quality of care. The authors concluded that both medical and non-medical factors were involved and should be acknowledged. A limitation of this study is the lack of information on included studies. It is unknown what type of studies were included, and thus impossible to evaluate their potential biases or appropriateness for inclusion.

Bollini, Pampallona, Wanner and Kupelnick (2009) also conducted a systematic review assessing maternal outcomes of migrant women using epidemiological studies (cross-sectional studies, case-control studies and follow-up studies) conducted in European countries comparing pregnancy outcomes of migrant and non-migrant women. Sixty-five studies were included, with 12 countries represented, and 26 studies assessed being from the UK. Results showed, that compared to non-migrant women, migrant women showed a clear disadvantage for all outcomes considered. Migrant women had a 43% higher risk of low birth weight, 24% higher risk of pre-term delivery, 50% higher risk of perinatal mortality, and 61% higher risk of congenital malformations. Risks were clearly and significantly reduced in countries with strong immigrant integration policies; such as Belgium, Denmark, the Netherlands, Norway and Sweden. Strong immigrant integration policies were defined as “a multidimensional social policy that increases protection, economic integration and participation in social life” (Bollini et al., 2009, p453); fostering equity and social cohesion, and demonstrated by naturalization rates and ease of naturalization. This trend was maintained after the authors adjusted for age at delivery and parity. Bollini et al. (2009) concluded integration policies serve as a protective feature for migrants as they decrease stress and discrimination. The UK was viewed as having a weak integration policy by this review (Bollini et al., 2009).

The two reviews described above focused on clinical outcomes and migrant status, however, by only focusing on clinical data, much of the context and interconnecting factors may be lost. Women’s experiences of maternity care are also important and provide key insight into why some women access care more than others or have more positive birth experiences. Literature on how women experience their maternity care will now be discussed.

Factors affecting the use of antenatal care by non-Western women in Western countries was analysed in a systematic review by Boerleider, Wiegers, Manniën, Francke and Devillé (2013). Eleven databases were searched for relevant peer-reviewed articles published between 1995- 2012. Quantitative and qualitative studies were included and quality was assessed using the Mixed Methods Appraisal Tool. Systemic and organizational barriers included incompatible opening hours, arriving to the country late in pregnancy, language, dependency on husband, financial constraints, unemployment, low socioeconomic status, isolated community, family norms not matching with healthcare system, transport issues, lack of culturally sensitive HCP, indirect discrimination and the feeling of being treated badly by the HCP directly influenced women’s decisions to access care (Boerleider et al., 2013). Limitations include the large number of qualitative studies included, making generalization problematic. Included study quality was also noted by the authors as some studies were of low quality. Low quality studies were included to ensure no relevant factors were missed. Results from high- and low-quality studies were similar, strengthening the confidence in the findings. The restriction to countries with universal healthcare makes the findings more relevant to the UK and the context of this study. This review shows the importance of both individual and organizational factors in the provision and acceptance of health care for migrant women.

Owens, Dandy and Hancock (2016) explored women's perceptions of pregnancy experiences when using a community-based antenatal service in Perth, Western Australia. A phenomenological framework was used to explore the perceptions of care experience of refugee and migrant women who participated in a community-based antenatal programme specializing in maternity care of multicultural women. Using semi-structured interviews and interpreters if needed, twelve women (aged 23-44) participated. A bicultural worker and interpreter were used as needed. The bicultural worker was an employee f the health centre and may introduce some bias as women may exhibit different levels of trust in them. The translator was arranged through a government service and may also introduce bias as women may be concerned about what they reported. However, the authors noted this and reported using alternative translators as requested by women or viewed by the authors as warranted due to women's behaviour during interviews. Thematic analysis was used and all authors checked themes, enhancing rigour. A thorough description of methods provides confidence to the findings of this study. Themes included: social support, gaining of knowledge, a holistic service, and new opportunities. Using a maternity service specializing in the needs of multicultural women increased positive perceptions of maternity care; with the authors concluding that cultural context and needs are very important to women's satisfaction with maternity care (Owens et al., 2016).

A pilot study by Katz and Gagnon (2002) explored the adequacy of postpartum care for migrant women in Canada using a descriptive, cross-sectional design. The authors gathered data from hospital and community health centre records of migrant women who had been found to have health or social problems requiring a longer than usual postpartum hospital stay (more than 36hrs); 90.9% of eligible women were included, from 20 families. For all 20 pairs of mothers and babies, hospital nurses recorded having addressed the issue, however, in 80% of cases there was no evidence the issue had been resolved prior to discharge (Katz & Gagnon, 2002). For 55%, no evidence was found that the issue was resolved during community follow-up appointments (Katz & Gagnon, 2002). A lack of referrals and follow-ups were noted and suggest no resolution of issues occurred. Although this study had a small sample size and sampled from just one hospital, this pilot suggests that sub-optimal care is being provided and the PPP may represent a key area where women fail to get their health needs met.

A.8.1 Migrant women's experiences of healthcare in high-income migration countries.

Small et al. (2014) conducted a systematic review of migrant and non-migrant women's experiences of maternity care by comparing available population-based studies with studies conducted within those countries of migrant women's maternity experiences. Australia, Canada, Sweden, the UK and the USA had population-based studies and were included. Twenty-two migrant studies were found within those countries with all using qualitative interviews for data collection. No quality assessment was conducted on the migrant studies as the authors wanted all information included and most were small and qualitative. Studies included the antenatal period, labour and birth, and the postnatal period within the hospital. A descriptive thematic analysis was conducted. Results show migrant and non-migrant women desire the same pregnancy and birth outcomes, a healthy and safe delivery. Migrant women were found to be more likely to report negative maternity care experiences however, including feeling staff were rushed and there were not enough staff. Staff behaviour was also a factor and some women described a lack of attention paid to their needs, inadequate levels of support and advice, lack of sufficient information and explanation regarding baby care and the women's own physical and emotional health after birth (Small et al., 2014). Although described as important by women, a lack of attention to or restrictions on traditional cultural practices by caregivers were not the principal focus of women's descriptions of negative aspects of the maternity care they received post migration (Small et al., 2014). Miscommunication and discriminatory or negative caregiver attitudes appeared to be a more critical area of concern for women. Limitations of this study include the studies included within it as they were small and qualitative in nature, resulting in less generalizable findings. However, it is important to note that women from each analysed country expressed the same concerns and issues with their care, suggesting that while more data is needed, maternity care issues are global. Being treated with kindness and respect was essential to having a positive birth experience.

In a systematic review, Almeida, Caldas, Ayres-De-Campos, Salcedo-Barrientos and Dias (2013) explored migrant mothers' perceptions of postpartum care in Western countries including the USA, Canada, Australia and various European countries including Scotland. Medline and Scopus databases were searched for original articles in English, Spanish, French or Portuguese published between 1990-2012, including citation searches of discovered articles. One author conducted the search and applied the inclusion and exclusion criteria, while independent data extraction was competed by three researchers. No quality assessment was completed on included studies (30 in total). Although migrant mothers had equivalent levels of contact with HCPs in the first three months postpartum, they were less likely to report being asked about their emotional well-being or about social or family support. Great variation in maternal outcomes were found, including; increased risk of co-morbidities, reduced access to health facilities particularly for illegal migrants, poor communication between women and HCPs, a lower rate of obstetrical interventions, a higher incidence of stillbirth and early neonatal death, an increased risk of maternal death, and a higher incidence of postpartum depression. The authors note the lack of quality in some studies (though no formal assessment was completed) and the representativeness of the sample. Barriers to this area of research include access to participants, language barriers and ethical concerns such as ensuring adequate healthcare support is available if needs arise. Findings from this study must be considered with caution, however, do provide future research directions and indicate a person's health status has many factors and must be looked at individually if care needs are to be met.

Balaam et al. (2013) conducted a qualitative review of migrant women's perceptions of their needs and experiences related to pregnancy and childbirth. Four databases were searched for published articles between 1996-2010. References were checked and several journals were manually searched. Sixteen articles were included following quality appraisal (specific tool used not stated), five from Sweden, six from the UK, two from Switzerland, and one each from Norway, Ireland, and Greece. The overall theme was described as preserving one's integrity in the new country, and included subthemes: communication and connection, striving to cope and manage, struggling to achieve a safe pregnancy and birth, and maintaining bodily integrity (Balaam et al., 2013). Two key aspects were also described; struggling to find meaning and caring relationships with subsections: sources of strength, organizational barriers to maternity care and the nature and quality of caring relationships. Caring relationships, including HCP and family was seen as a source of strength by women. Several women reported missing their family and highlights the need for other support structure during the birth process for migrant women. Women’s interaction with the healthcare system was negative and described as: not being taken seriously, feeling insecure about being exposed, shyness, embarrassed, ashamed, breaking with traditional norms, and using technology over religion. Several studies contained evidence suggesting that maternity care services in Europe can be patriarchal (Balaam et al., 2013). When advice was provided, it was experienced as unhelpful, frightening or not matching with the woman’s reality. When the woman had FGM, they expected HCPs to have knowledge and discuss the topic before delivery and were disappointed when this did not occur. Women also described being unprepared for the lack of practical help and support in postnatal care (Balaam et al., 2013).

In an interesting finding, women reported preferring relatives, children, and friends to help with translation rather than strangers (Balaam et al., 2013). Current policy in the UK advises against using a familiar person for translation services where possible to ensure privacy and accuracy as it is thought unlikely a woman will be able to disclose risk for domestic violence or mental health issues with a family member interpreting (NHS England & Primary Care Commissioning, 2018). Women should be seen alone and screened at least twice for domestic violence and mental health issues during their antenatal care (NHS England & Primary Care Commissioning, 2018). Continuity of care and individualized information was desired. Limitations include the use of qualitative studies and the inherent issues of generalizability when combining results from different countries and specific groups. Another limitation of the findings, and this area of research in general is the focus on micro-level experiences. Follow-up and longitudinal studies are needed to understand if experiences are changing and interventions are having desired effects.

Barriers and facilitators to attending follow-up care appointments were analysed by Gagnon et al (2010) using semi-structured interviews with 25 women in Montreal, Canada. Women included refugees, asylum seekers, migrants and one Canadian born. Interviews were conducted with interpreters where necessary. Barriers included language ‘barriers’, absence of husband, lack of childcare, perceived inappropriate referrals, and cultural differences (Gagnon et al., 2010). Facilitators include HCP follow-up, appropriate services, HCP empathy, and being given information early. Limitations include a time lag between referral and interview, possible resulting in problems with memory recall.

HCPs are in a position to provide healthcare in a culturally sensitive and compassionate manner. This review shows the importance of the therapeutic relationship (TR), trust in the healthcare system, and the provision of culturally sensitive care.

A.8.2 Migrant maternity healthcare experiences in the UK.

Rayment-Jones, Harris, Harden, Khan and Sandall (2019), conducted a realist synthesis regarding how women with social risk factors experience maternity care in the UK. ‘Social risk factors’ were divided into two categories; women who find services hard to access, and women needing multiagency services. ‘Women who find services hard to access’ include risks such as poverty, low socioeconomic status, social isolation, refugee/asylum seekers, non-native language speakers, victims of abuse, sex workers, young mothers, single mothers, and those from a travelling community (Rayment-Jones et al., 2019a). Women needing ‘multiagency services’ included those with FGM, who were HIV-positive, perinatal mental health issues, physical/emotional and/or learning disabilities, substance and/or alcohol abuse, or safeguarding concerns (Rayment-Jones et al., 2019a). The authors found that women with social risk factors are more likely to experience paternalistic care and highlighted the impact of HCPs' assumptions based on race, class, ability, age, and other sources of oppression. The authors suggest these negative experiences could be mitigated through a trusting therapeutic relationship with HCPs and increased HCP cultural training. Trust was key to building a relationship with HCPs and regaining trust in the NHS. The authors suggest adequate access to maternity services, appropriate antenatal education, interpreter services, practical support, and continuity of care would enhance care experienced for migrant women. Limitations in the context of this study include the lack of studies reporting women’s specific socioeconomic status, and programs to improve women’s care drawn from negative experiences and inverted. Future studies should include women’s socioeconomic status as it has bearing on how maternity care is experienced, and also ask women what went right in their maternity care.

Jomeen and Redshaw (2013) explored ethnic minority women’s experience of maternity services in England. A random sample of 4800 women selected by the Office for National Statistics using birth registration records were mailed surveys three months after giving birth. An overall response rate of 63% was achieved included 13% of women from BME groups. A leaflet in a wide array of languages and a phone number was included and allowed women to participate with interpreters and by phone if desired. Qualitative thematic analysis was used to analyse three open-ended free text questions concerning their labour, birth and postnatal experiences, and anything else they wished to express. Of those asked, 60% responded with free text, and 40% were born in the UK. A key finding was the dissonance between expectation and reality of care. Women desired kindness and feeling well cared for and felt their experiences fell short. The authors also note how experiences with staff varies with each individual and can negatively or positively impact a woman’s experience. Postnatal care was also described as a ‘let down’ after the intensity of antenatal and labour and birth care (Jomeen & Redshaw, 2013). A limitation includes the method of data collection as it is acknowledged women who respond to free text are generally less satisfied with their experience. A second limitation is inherent with secondary analysis as it must be acknowledged the data was not originally collected for this studies purpose.

Raleigh, Hussey, Seccombe and Hallt (2010) conducted a survey of women’s maternity experiences drawn from a sample of 149 acute care trusts and two primary care trusts. Questions selected for this studies analysis included the topics of antenatal care, labour and birth care, care in hospital after birth, care at home after discharge, and overall care rating. The survey was piloting to ensure validity. Multiple logistic regression was used to examine inequalities in women’s responses after controlling for independent variables such as age, ethnic origin, relationship status and education level. The authors found ethnic minorities were less likely to report adequate pain relief during labour and birth, and were less likely to have complete confidence and trust in staff. These findings were compounded when the woman was single. Women without a partner were more negative about care during labour and birth, pain relief, having trust and confidence in staff, and being treated with respect and dignity. Single women were also more likely to spend over 24 hours in hospital after a vaginal birth and less likely to initiate breastfeeding, or to say they saw a midwife as often as they wanted and that they had a postnatal check-up.

Maternity experiences of ethnic minority women in the UK were analysed and an overall increase in adverse outcomes was found (Raleigh et al., 2010). During the antenatal period, ethnic minority women were less likely to have seen a HCP or had a booking appointment within 12 weeks of becoming pregnant, had a scan at 20 weeks, or attended NHS antenatal classes (Raleigh et al., 2010). The survey found they were more likely to have a pregnancy related hospital stay, respond more negatively to questions about choice of place of birth and being treated with dignity and respect (Raleigh et al., 2010). During labour and delivery, women from ethnic minorities were less likely to report they received adequate pain relief, had complete trust in staff, and were never left alone when worried (Raleigh et al., 2010). They were more likely to report unplanned C-sections than their non-ethnic minority counterparts (Raleigh et al., 2010).

The hospital experience after birth was also analysed and women from ethnic minority backgrounds were found to be less likely to report initiating breastfeeding, staying in hospital more than 24 hours post vaginal birth, or having a pre-discharge baby check-up; than white British women (Raleigh et al., 2010). Upon being discharged, ethnic minority women reported being more positive about receiving help and advice regarding baby feeding and health; but less likely to have post-natal check-ups, rather, they reported seeing the midwife whenever they chose to do so (Raleigh et al., 2010). Level of education was found to have an effect, with higher education leading to less favourable opinions concerning respect and dignity, but also resulting in higher rates of breastfeeding (Raleigh et al., 2010). Limitations include numbers from some ethnic minority groups being low, which may have resulted in some factors being missed. The authors also used age at completing full-time education as a proxy for social class, which may be misleading. Strengths include the size of the survey and including the majority of maternity units in the UK, giving added confidence to findings. The survey findings show the differences in opinions of ethnic minority women compared to white British women in their experiences of NHS maternity care; and are an example of how health discrepancies based on culture can manifest.

Firdous, Darwin and Hassan (2020) conducted a qualitative systematic review exploring Muslim women's experiences of maternity services in the UK. Electronic database searches (5), along with grey literature and citation tracking resulted in the inclusion of six studies. The CASP tool was used to critically appraise included studies. Two authors applied the inclusion criteria and CASP tool, while one author completed the thematic analysis. Only two included studies were peer reviewed journal articles; with three being doctoral dissertations and one being a book chapter. Study quality was variable; an expected finding due to the lack of peer reviewed studies included. Five themes were found showing the importance of understanding the impact of religion on the birth process. Experiences such as men attending antenatal classes, unacceptable meals, language, and insensitive care created barriers for women, whereas individualized care and compassionate midwifery enhanced care experiences (Firdous et al., 2020).

From the above literature it is difficult to make broad conclusions because of the varied reasons for migration and varied experiences of women. The majority of factors explored were pregnancy related outcomes (Gagnon & Redden, 2016), meaning that non-pregnancy related healthcare experiences could result in different experiences and should be researched to produce a holistic understanding of women's experiences. The

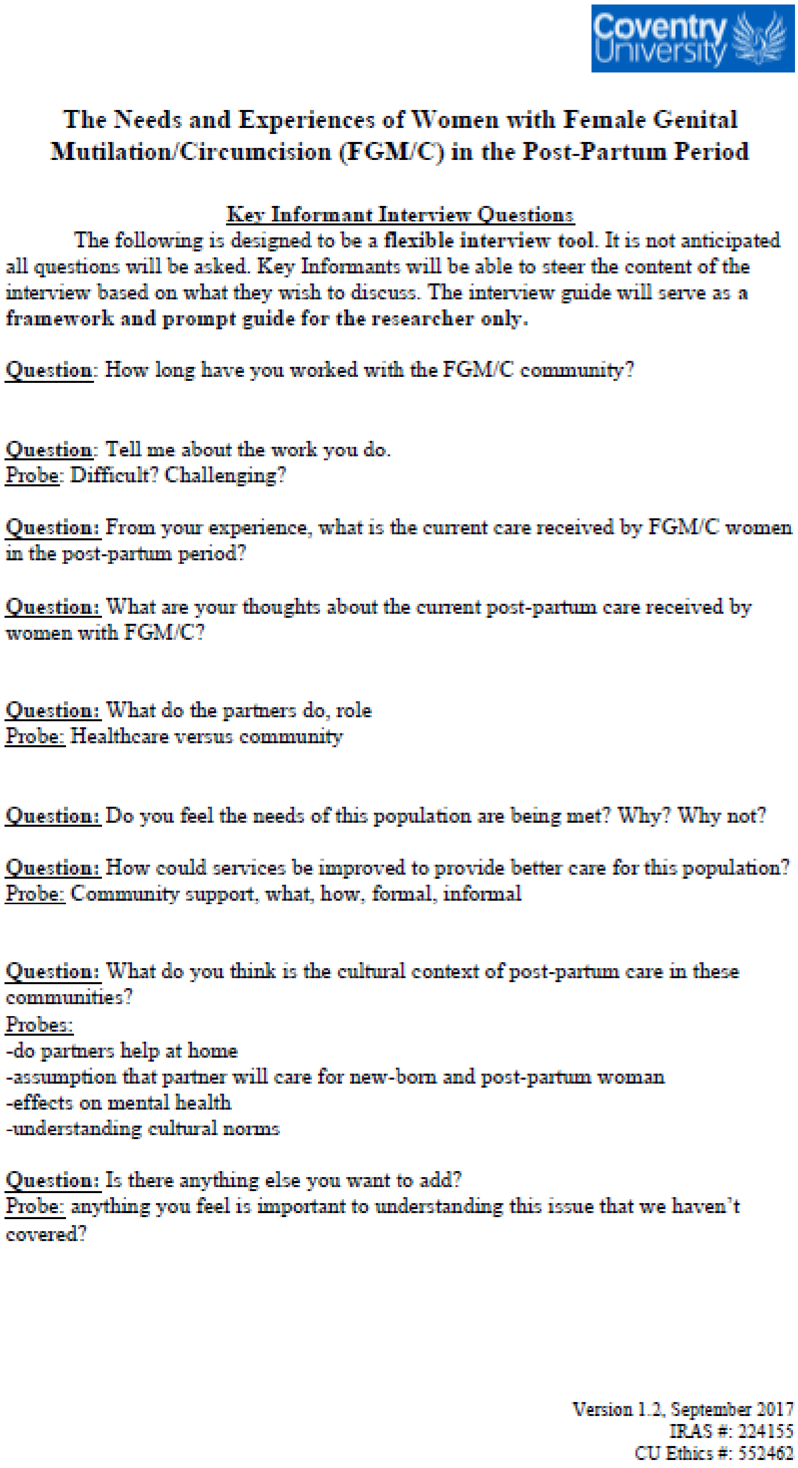
UK has developed a free migrant health guide online tool for HCPs which contains four sections; 1) migrants and the NHS: access and entitlements, 2) assessing patients: checklist for initial healthcare assessments and advice for patients travelling abroad to visit friends or relatives, 3) countries: country specific advice, infectious diseases, women's health and nutritional and metabolic concerns, and 4) health topics: information about communicable and non-communicable diseases and other health issues (Crawshaw & Kirkbride, 2018). As women in this study may be recent migrants to the UK, it is important to understand the context of their experiences.

Migrant healthcare is a difficult topic to explore as the definition of migrant differs between countries and research studies. The reason for migration and the degree of segregation or assimilation is not considered and can result in very different outcomes for different groups of women. This lack of context may lead to an oversimplification of causes, potentially ignoring important factors for women with FGM. Language barriers for healthcare and research present problems collecting accurate data and information. Guidelines regarding providing culturally sensitive care do exist (Douglas et al., 2014; E-Learning for Healthcare, 2020; RCM, 2018; Schouler-Ocak et al., 2015); but lack of data on evaluation and implementation leaves many questions regarding their effectiveness (Chae et al., 2020; Oikarainen et al., 2019). In a systematic review exploring the effectiveness of cultural competence training on HCPs and patient outcomes, Chae et al., (2020) found positive outcomes for HCPs but a dearth in knowledge regarding patient outcomes. Seven electronic databases, including four Korean databases were searched for randomized and non-randomized controlled trials. Eleven studies were included following screening and quality assessment. Findings are presented in a narrative review and describe positive outcomes for HCPs include job satisfaction; however, it should be noted each study included used a different self- report evaluation tool, and the evaluation pertained to the cultural competence training, not its implementation. In a similar systematic review by Oikarainen et al. (2019); four electronic databases were searched for studies using quasi-experimental design or randomized controlled trial published between 2000-2018. Search terms were enhanced after consultation with a specialist. Two authors completed screening and used the JBI Critical Appraisal Checklist for RCTs and Critical Appraisal Checklist for Quasi-Experimental Studies to appraise the quality of the included studies. Limitations of this review include the lack of methodological rigour of the studies included, many of which lacked a control group, or did not report proper randomization techniques. Another issue was the studies being heterogenous in outcome and interventions, hindering statistical synthesis. Increased evidence of the validity of the used tools is needed also. Relevant findings from this study show researchers used different self-report evaluation tools and did not include effects on patient outcomes, resulting in no evidence that cultural training has impacts on patient outcomes. No information regarding implementation or effects on patient outcomes of the training were evaluated by studies in either systematic review; revealing a gap in the literature in this area.

Maternal experiences impact the trust women have in health services and when their expectations are not met, negative experiences occur. In a survey of pregnant women attending antenatal services in Sydney, Australia, Porter et al., (2016) asked women where they were born, and whether they identified with any cultural group or ethnicity, and if so, which one. An inductive, thematic analysis was conducted on ethnicity text responses. The survey achieved a 92% response rate. Results show country of birth and ethnicity should not be used interchangeably in maternity care. Researchers should specify their aim in collecting data to ensure their purpose is met as women’s ethnic and cultural identities are complex. Individualized, culturally sensitive care is needed. Ethnicity and cultural group identity are complex concepts, and country of birth may not be a reliable indicator (Porter et al., 2016). Women-centred care should involve migrant women in care planning(Jentsch, Durham, Hundley, & Hussein, 2007).

Appendix B Appendices for Chapter 2

B.1 Key Informant Interview Guide



Coventry University

The Needs and Experiences of Women with Female Genital Mutilation/Circumcision (FGM/C) in the Post-Partum Period

Key Informant Interview Questions

The following is designed to be a **flexible interview tool**. It is not anticipated all questions will be asked. Key Informants will be able to steer the content of the interview based on what they wish to discuss. The interview guide will serve as a **framework and prompt guide for the researcher only.**

Question: How long have you worked with the FGM/C community?

Question: Tell me about the work you do.
Probe: Difficult? Challenging?

Question: From your experience, what is the current care received by FGM/C women in the post-partum period?

Question: What are your thoughts about the current post-partum care received by women with FGM/C?

Question: What do the partners do, role
Probe: Healthcare versus community

Question: Do you feel the needs of this population are being met? Why? Why not?

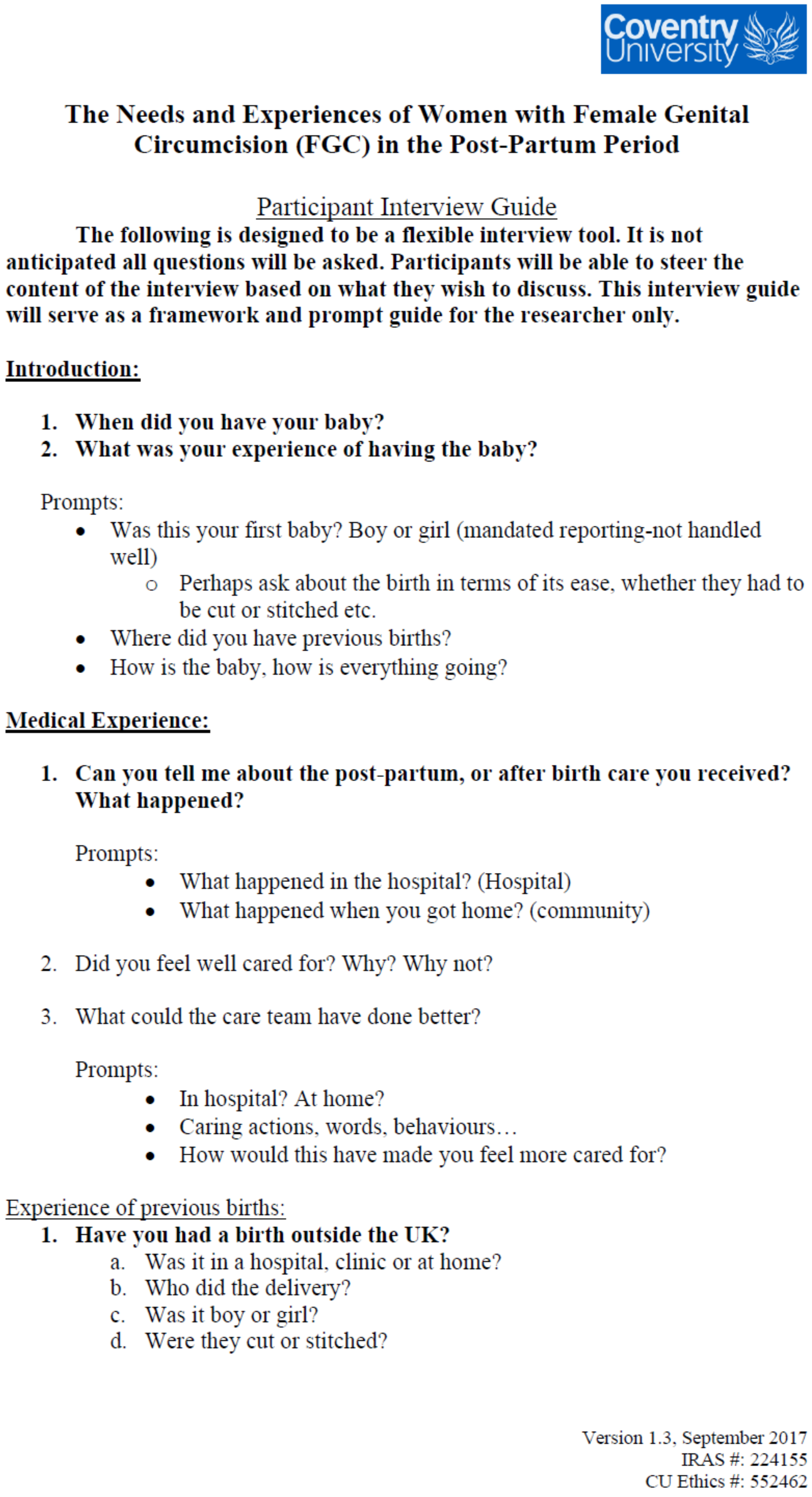
Question: How could services be improved to provide better care for this population?
Probe: Community support, what, how, formal, informal

Question: What do you think is the cultural context of post-partum care in these communities?
Probes:
-do partners help at home
-assumption that partner will care for new-born and post-partum woman
-effects on mental health
-understanding cultural norms

Question: Is there anything else you want to add?
Probe: anything you feel is important to understanding this issue that we haven't covered?

Version 1.2, September 2017
IRAS #: 224155
CU Ethics #: 552462

B.2 Interview Guide used for Women with FGM



The Needs and Experiences of Women with Female Genital Circumcision (FGC) in the Post-Partum Period

Participant Interview Guide

The following is designed to be a flexible interview tool. It is not anticipated all questions will be asked. Participants will be able to steer the content of the interview based on what they wish to discuss. This interview guide will serve as a framework and prompt guide for the researcher only.

Introduction:

1. **When did you have your baby?**
2. **What was your experience of having the baby?**

Prompts:

- Was this your first baby? Boy or girl (mandated reporting-not handled well)
  - Perhaps ask about the birth in terms of its ease, whether they had to be cut or stitched etc.
- Where did you have previous births?
- How is the baby, how is everything going?

Medical Experience:

1. **Can you tell me about the post-partum, or after birth care you received? What happened?**

   Prompts:
   - What happened in the hospital? (Hospital)
   - What happened when you got home? (community)

2. Did you feel well cared for? Why? Why not?

3. What could the care team have done better?

   Prompts:
   - In hospital? At home?
   - Caring actions, words, behaviours…
   - How would this have made you feel more cared for?

Experience of previous births:

1. **Have you had a birth outside the UK?**
   a. Was it in a hospital, clinic or at home?
   b. Who did the delivery?
   c. Was it boy or girl?
   d. Were they cut or stitched?

Version 1.3, September 2017
IRAS #: 224155
CU Ethics #: 552462

2. How did the care you received in the UK differ from the care you received in your country of origin? /where you previously gave birth?

   Prompts:
   - What was different?
   - What was better? What was worse?
   - Role of medical staff? Role of female/male relatives?

3. Was the care you received in the UK different than you expected?

   Prompts:
   - How was it different?
   - Was it better/worse? (expectations versus reality)
   - Do you have any examples you could share?

Role of the partner:

1. Do you have a partner?

2. Were they present at the birth?

3. Do/did you feel supported by your partner?

   Prompts:
   - Have they helped with the baby?
   - Have they helped with other children?
   - Have they helped with housework?
     (Mental and physical well-being)
   - What has he done that you liked? / Made you feel supported?
     - How did this help you?
   - What support would you have liked from your partner that you didn't get?
     - How would this have helped you?

FGC:

1. There are different ways in which women can be cut, and these are given category names or types, do you know what type you have? (medical diagrams to show them if they don't know)
   - Did anyone discuss with you how your FGC might impact the birth of your baby?
   - If needed to be opened: when did this happen? Were you happy with the discussions about how and when you were to be opened?
     - Did you feel informed about the process?
2. Are you aware that the practice of FGC is illegal in the UK? Are you aware of the mandatory reporting system in the UK? What is your experience of this?

3. FGC and birth experience (including C-sections)

- Was there any additional problems/damage/cuts made/tearing…from the birth?
- Were you cut at the time the baby was born?
- Did anyone discuss what kind of damage it was – sometimes called 2nd/3rd or 4th degree tear?
- Did you need stitches? Was this done by the midwife or the doctor? Was it done in the birth room or the operating theatre?
- Did you feel you had adequate pain relief during the repair?
- How has the recovery gone? Any ongoing pain or discomfort?
- Who helped you during the recovery? Did you need extra help from a midwife or home visitor?
- How do you think this will influence future pregnancies?

4. How do you feel about the care you were given by the NHS?
    - How do you see the NHS for future pregnancies?
    - Post-natal depression, flashbacks/trauma/anxiety, OCD, any mental health issues?
        - If no, do you know anyone who experienced anxiety? Or very negative emotions at any time?
    - What happened?
    - How did it make you feel?
    - Do you think your FGC was a factor? / had an impact?
    - How could things have gone better?
    - What would you change?
5. If you were talking to a friend who was just about to have a baby and had been cut, what advice would you give her?

Ending:

1. Anything you would have liked to have happened that didn't happen?

2. Anything else you would like to say more about? Anything we didn't cover

B.3 Examples of Notes and Reflections Used in this Study (Observation, analytic, personal research, personal feeling)

Research logbook entry on design of study (5/8/2016)

After completing the literature review and reading everything I can find on FGM I think the voices of women with FGM are missing. Much of the data is based on clinical outcomes and not how the women experience care. Postpartum outcomes are not mentioned much/at all in the data as women with FGM would be included in the regular attendees of the OASIS clinic. If we think more tearing is occurring, and subsequently worse birth outcomes are happening that may not be reported, then we need to talk to women and find out. Find out if there are additional needs and if there are, what they are. Interviews will be the best way to do this. Focus groups would also work but I am unsure whether women would have the time/resources to attend a focus group, or they would feel comfortable attending one and discussing a private matter. Until we know whether women have similar experiences it is probably better to interview individually. Individual interviews will also allow the interview to take place when and where is convenient for the woman. I think more data is needed before focus groups would be suitable.

Research logbook entry on culture (7/9/2016)

I have decided an ethnographic approach is best suited for this study due to the fact that FGM is a cultural practice and therefore culture underlies decisions and feelings about FGM. Receiving care in the NHS, where it is against the law and safeguarding takes place also adds another dimension to the issue where two cultures are clashing; one saying it's a traditional practice and the other saying it is child abuse. Will look into cultural relativism as a theoretical basis for the study. Have found a study from Sweden looking at women with type 3 FGM using a medical ethnography. A friend also told me about focused ethnography, so will research these and hopefully one will work. A traditional ethnography would not work as I'm looking at a specific timepoint in the women's lives and not their entire life or social structure, though that would be a very interesting study- how women with FGM integrate into UK society, maybe postdoc.

Research logbook entry on Focused Ethnography (10/9/2016)

After reading all about ethnography and the different forms it can take I've decided a focused ethnographic approach is the way to go. It allows me to define the population as a medical subculture, a subculture of women with FGM during the maternity process, using maternity services. This allows an ethnographic approach (focused on culture), while also allowing a specific timepoint and experience to be studied. It also allows for individual interviews and thematic analysis.

Research logbook entry on data analysis (11/11/2019)

I have decided to reanalyse the KI data as one group and see what the outcome is. I began dividing the groups into direct-care, policy KI and the police, but after analysing them in their groups I feel it is not the best way to answer the research question and inform the findings from the women. The women are the focus of the study, their experiences and needs, the KI are contributing to understanding the context the women's experiences occur within. By dividing them into groups the focus has become about the differences between the groups, and not about how the groups interact and impact the women's experiences. I am going to put them all into one group and analyse based on how women's experiences are impacted by the supporting structures of the NHS, police, and city councils.

Reflection: Attending the FGM Clinic for the first time (11/10/2017)

The FGM clinic is held on a Friday afternoon. Today there were three patients. All spoke fluent English, had been in the country for many years and were in committed relationships. All were excited to be pregnant and had planned the pregnancy. All knew about FGM but did not know what specific type they had (if any) although they did know they didn't have type 3 (bad type). They refereed to type 1 & 2 as sunna. One patient did not know what type or even if she did have FGM. When asked by the midwife why she ticked the box, she said she assumed she did because it was in her culture, but had no memory of it and it was never discussed in her family. When it was revealed she had Type 2 she was surprised and wasn't sure what this meant. She said she was going to call her sister and discuss it before calling her mother. All patients said they and their partners were against FGM and any girl children would not have it done.

It was an intense experience on many levels. Arriving and interacting with patients and potential participants made the research seem real, it was finally actually going to move from the computer to real data collection, real people. The force of acknowledging that FGM had occurred to these women, even though they reported no side effects and their birth plan remained regular, was intense. It brought everything I had read in the literature and made it real. This practice really happens and still happens to children. I cried when I got home.

Another thought that struck me during the observation was that the women who didn’t know whether she had FGM or not got informed she did and the Type, but nothing else. No resources were given on where to find information, and no mental health resources were offered. This disclosure had the potential to cause distress as the woman was just informed she had been mutilated as a child. It was a strange experience to be a part of, and leads me to think that this situation requires more attention and care. I will add this to future recommendations for research.

Interview reflection 201805-S

Interview was first one with upper management who has no direct contact with population. Develops and writes policies based on evidence. Believes Coventry is unique in it’s approach and an exemplar for the country. Coventry uses a community and medical approach with committees composed of many healthcare providers including direct and indirect care points. Did not feel their role needed more resources (this is opposed to direct care HCP feelings). Felt Coventry was doing really well. Noted it was difficult to assess change as have no baseline data or actual numbers to compare to. Referrals have gone down but we don’t know whether that’s a good thing or a bad thing as we don’t have data on why…is it because our interventions are working…or people not reporting/accessing care…?

Interesting perspective from other stakeholders interviewed to date. Difference in opinion between direct care professionals and policy management? Even though they sit on committees together? Will need more stakeholders on this level to clarify this finding.

Interview 201801S: 22/01/18

From a personal perspective this was my first interview and I was very nervous. I feel I rushed the questions and went to prompts too early. Something I noted and didn't do in the second interview. The interview itself went well and the KI was happy to chat. When I asked about the work she did, she brought up and focused on the challenges she faced while listening to the women's stories and providing a psychologist role for the women. This was draining for her and mentally tiring and I got a clear sense of burnout and compassion fatigue. Interestingly when I asked about resources available for her, she said her manager was available for debriefing if she needed, but she didn't use it and as a nurse and midwife, you just 'get on with it'. So while she admitted it takes a toll on her mental health, she wasn't actively using available resources or seeking them. From a postpartum perspective unless the women had an issue they were released into normal care. Women with type 3 would be potentially seen by midwife 2-3weeks after delivery, or if late transfer. Mention of flashbacks during de-infibulation. The focus for the midwife was the antenatal period for ensuring a smooth birth and safeguarding. Safeguarding was the major focus. De-infibulation occurred ante-natally or during delivery. There was no mention of the healing process being any different for women with FGM versus not, and unless there was an issue, the FGM midwife wouldn't see the women except in the antenatal period.

Overall thoughts: focus on antenatal period, normal care post-birth, midwife burnout and compassion fatigue. All immigrants.

Interview 201802S: 22/01/18

I felt more confident during the second interview and used less prompts, allowing the KI to talk in whatever direction she took the question. The interview was longer and I feel I got valuable information. Midwife does pregnant and non-pregnant clinics. No recognition of the care that they give. No realization of the demands and work midwives are putting in to this population. Constant funding cuts and clinic closures. Normal care in PPP unless issue comes up during labour. Normal wound healing (approx. 6wks). Vulnerable are falling through gaps in care. Acknowledged more likely to tear but no difference in pp care. In general though intrapartum and pp care not good. Intrapartum not good was causing pp not to be good, and problems to arise that didn't need to be there. Suggested needed more hand-holding and guidance through the system by people who speak the language because the midwives don't have time to explain everything. Midwives need more training and it needs to start in school so they feel comfortable doing it. Psych care being totally ignored. Women having flashbacks during labour. Language huge issue. Misconceptions about services. Noted that she didn't know whether mandatory reporting was a good or bad thing because the women scared and feel they had done something wrong. The funding isn't sustainable. Safeguarding is the main issue.

Overall thoughts: safeguarding is main role. Antenatal care is focus. Prepare birth plan and de-infibulation if needed. Postpartum only if an issue comes up, otherwise normal care plan.

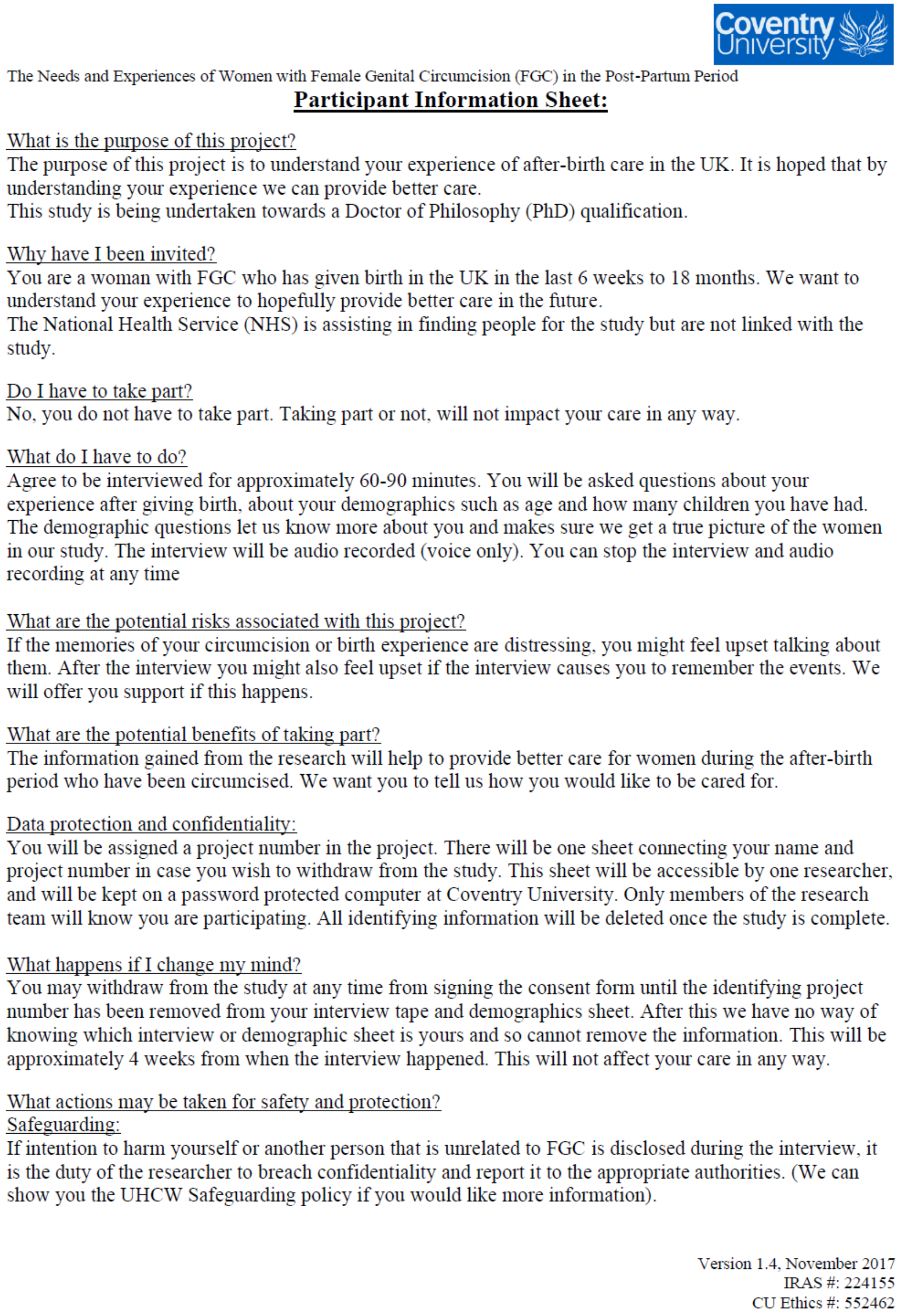
Personal Reflection 8/10/2017

I am getting increasingly frustrated with the ethics process. I understand the need for ethics but I am unsure it is being appropriately implemented with this population. I feel there was a lot of stereotyping of women with FGM going on in the rejection letter, and once again the voices of the actual women are being silenced by a society that thinks ‘it knows better’, that these women are victims and cannot understand or appreciate that fact, so we have to keep them safe. I think I have designed the study with all ethical implications thoroughly thought out. I don’t think it’s fair to tell someone they are a victim, or unable to make a decision to participate in a study when they are judged sound enough to look after children and make all decisions about their healthcare. The reaction from the ethics committee shows me how lay people get their views on topics from the media. The media has demonized the practice and demonized the women with FGM as potential child abusers and the biggest risk to their daughters. I think for future ethics application a qualitative process is needed that takes into account sensitive topics and allows for a detailed explanation of the unbiased situation versus allowing ethics committees to make decisions based on un-educated views. Mostly I am frustrated that women who need their voices heard will not be allowed to participate. How are we supposed to advance care and provide care to women if we can’t speak to them about what they need? How is this not further alienating women in a healthcare system not designed for their specific needs?

Personal Reflection 4/4/2019

Data collection has finished. It has seemed like a colossal task and has really shown me how difficult qualitative research can be. Even though I used the FGM clinic to reach women and recruited for 12 months it still was just enough. I feel we have reached saturation with the current data, however, more data would have allowed me to possibly split the women into groups by type, but, but…I am unsure whether that would have been appropriate as it has become apparent it is about much more than FGM, and that FGM isn't really a focus for women. I think it would have been very interesting to hear from women who don't speak fluent English, because if the current findings of women feeling alienated by the NHS are coming from women who speak English, I can only imagine how women who don't speak English feel and how they communicate their needs during the pregnancy and PPPs. I feel good about another milestone being reached and hope my future research projects can include women who need translation services.

B.4 Participant Information Sheet (PIS) for Women with FGM



The Needs and Experiences of Women with Female Genital Circumcision (FGC) in the Post-Partum Period

Participant Information Sheet:

What is the purpose of this project?

The purpose of this project is to understand your experience of after-birth care in the UK. It is hoped that by understanding your experience we can provide better care.
This study is being undertaken towards a Doctor of Philosophy (PhD) qualification.

Why have I been invited?

You are a woman with FGC who has given birth in the UK in the last 6 weeks to 18 months. We want to understand your experience to hopefully provide better care in the future.
The National Health Service (NHS) is assisting in finding people for the study but are not linked with the study.

Do I have to take part?

No, you do not have to take part. Taking part or not, will not impact your care in any way.

What do I have to do?

Agree to be interviewed for approximately 60-90 minutes. You will be asked questions about your experience after giving birth, about your demographics such as age and how many children you have had. The demographic questions let us know more about you and makes sure we get a true picture of the women in our study. The interview will be audio recorded (voice only). You can stop the interview and audio recording at any time

What are the potential risks associated with this project?

If the memories of your circumcision or birth experience are distressing, you might feel upset talking about them. After the interview you might also feel upset if the interview causes you to remember the events. We will offer you support if this happens.

What are the potential benefits of taking part?

The information gained from the research will help to provide better care for women during the after-birth period who have been circumcised. We want you to tell us how you would like to be cared for.

Data protection and confidentiality:

You will be assigned a project number in the project. There will be one sheet connecting your name and project number in case you wish to withdraw from the study. This sheet will be accessible by one researcher, and will be kept on a password protected computer at Coventry University. Only members of the research team will know you are participating. All identifying information will be deleted once the study is complete.

What happens if I change my mind?

You may withdraw from the study at any time from signing the consent form until the identifying project number has been removed from your interview tape and demographics sheet. After this we have no way of knowing which interview or demographic sheet is yours and so cannot remove the information. This will be approximately 4 weeks from when the interview happened. This will not affect your care in any way.

What actions may be taken for safety and protection?

Safeguarding:

If intention to harm yourself or another person that is unrelated to FGC is disclosed during the interview, it is the duty of the researcher to breach confidentiality and report it to the appropriate authorities. (We can show you the UHCW Safeguarding policy if you would like more information).

Version 1.4, November 2017
IRAS #: 224155
CU Ethics #: 552462

Mandatory Reporting:

UK law requires health professionals to report any incidence of FGC or intention to have FGC happen to yourself or another woman/girl as this is illegal. If you discuss the intention to arrange to have FGC done to yourself or another person during the interview the researcher will stop the interview and will be required to tell the clinic midwife and report it to authorities. If the risk is considered high, the UHCW safeguarding team will be contacted, and social services may become involved. If this happens, all information you have given will be removed from the study

What if things go wrong? Who to complain to:

Content removed on data protection grounds

What will happen with the results of the study?

The results of the study will be published and used to guide care of circumcised women in the after-birth period. We hope to improve care by understanding the needs of circumcised women during this time.

Do you want your GP to know about your participation?

If you would like us to contact your GP to let them know that you have agreed to participate in our study we can send them a letter about the study.

Who has reviewed this study?

This study has been reviewed by the National Health Service (NHS) Health Research Authority (HRA) West Midlands - Coventry & Warwickshire Research Ethics Committee (17/WM/0409) and Coventry University Ethics.

If you have questions about participating in research, the Patient Advice and Liaison Service (PALS) can help

- PALS gives you confidential support, help and information on health-related matters
- PALS University Hospital Coventry and Warwickshire NHS Trust
- Phone: 0800 028 4203
- Address: Clifford Bridge Rd, Coventry, Warwickshire, CV2 2DX

Further information/key contact details:

Content removed on data protection grounds

B.5 Safety Protocols for Women and KI Safety Protocol for Women

ID number: ___________________
Version 1.0, September 2017
CU Ethics #: 552462
IRAS #: 224155

The Needs and Experiences of Women with Female Genital Mutilation/ Circumcision (FGC) in the PPP

Participant Safeguarding Protocol:

- If the participant becomes distressed the interviewer will ask if they would like to stop the interview
- If the interview is stopped the interviewer will provide emotional support and ensure the comfort of the Participant while maintaining professional boundaries (such as calling someone, cup of tea…)
- The interviewer will offer to reschedule the interview if desired
- An information sheet on available resources will be given to Participants to ensure they can access support once they leave the interview.
- If consent is given, the interviewer will alert the Lead Midwife of the FGM clinic that the Participant became distressed to ensure appropriate support can be accessed.
- If consent is given, the interviewer will contact the Participants by their chosen method a few days after the interview to ensure their well-being.

B.6 Safety Protocol for KI

ID number: ___________________
Version 1.0, September 2017
CU Ethics #: 552462
IRAS #: 224155

The Needs and Experiences of Women with Female Genital Mutilation/ Circumcision (FGM/C) in the PPP

Key Informant Safeguarding Protocol:

- If Key Informant becomes distressed the interviewer will ask if they would like to stop the interview
- If the interview is stopped the interviewer will provide emotional support and ensure the comfort of the Key Informant while maintaining professional boundaries (such as calling someone, cup of tea…)
- The interviewer will offer to reschedule the interview if desired
- An information sheet on available resources will be given to the Key Informant to ensure they can access support once they leave the interview.
- If consent is given, the interviewer will contact the Key Informant by their chosen method a few days after the interview to ensure their well-being.

B.7 Principles of research Ethics

Medical research ethics became paramount after the atrocities of World War II were made public during the Nuremburg Trials. Scientists were found to have conducted horrific experiments on human subjects leading to grave disability or death (World Medical Association, 2001). A code of research ethics was ratified in the Declaration of Helsinki (1964), and most recently in Scotland in 2000, and outlines principles of ethics for medical practitioners and medical research involving human participants (The Health Research Authority, 2017). The Declaration of Helsinki (World Medical Association, 2001) is based on the ethical principles of autonomy, beneficence and justice. These intersecting concepts, along with the unique issues identified for women with FGM living in the UK, provided the basis for developing the research protocol.

The concept of autonomy includes the overlapping concepts of informed consent, the relationship between the research participant and the researcher, and coercion (Aita & Richer, 2005). To ensure autonomy, the potential participant must be given adequate information to allow for an informed choice to be made, including what is involved in and any potential effects of participation (Aita & Richer, 2005). Informed consent is achieved through a thorough and clear participant information sheet (PIS) and the experience of recruitment must be free from coercion. A person's ability to consent to participating in research depends on many factors and will be discussed in detail in Section 4.4. The social characteristics and potential emotional reaction to the research must also be considered for both the participants and the researcher (Butler, 2003). Healthcare research must acknowledge the unique power imbalance present between healthcare provider and patient and seek to eliminate this through the designing of the study protocol.

The application of the principle of beneficence guarantees the benefits of the research outweigh the harms to the participants and wider society, while also ensuring people are represented appropriately in the study sample (Holloway & Galvin, 2017). Beneficence ensures no harm through confidentiality, safeguarding, and the creation of an audit trail. Fair selection of participants is important and study samples must reflect their study population appropriately.

Achieving justice within a study includes fairness of participation, recognizing vulnerabilities, veracity of the researcher and creating a space for, and resolving complaints. In multicultural societies applying the principle of justice and ensuring beneficence includes appropriate representation of the population, including minorities and respect for diversity (Department of Health, 2005).

The benefits of participating in research were also considered in the harm/benefit assessment and included feeling heard (Cox & McDonald, 2013); potential for having a positive experience (Kost et al., 2013; Newman, Willard, Sinclair, &

Kaloupek, 2001); feeling helpful (Staphorst, Hunfeld, & van de Vathorst, 2017) and benefiting others (Fry & Dwyer, 2001).

B.8 Vulnerability

When I first contemplated ethical concerns for this study I did not consider the population to be vulnerable. The population was designated as autonomous and able to give informed consent. After consulting with Coventry University Ethics, I was advised my population were considered vulnerable due to being in the state of pregnancy during recruitment, and the potential for data collection soon after childbirth. A review of the literature was conducted to understand why pregnancy and the PPP, natural states for a woman, would deem her vulnerable, as this seemed to be the defining factor for vulnerable status according to ethics committees.

Definitions of vulnerable persons include: ‘incompetent persons,’’ ‘‘persons susceptible to coercion,’’ ‘‘persons who will not derive direct benefits from participation’’, “members of communities unfamiliar with modern medical concepts” and ‘‘persons for whom research is mixed with clinical care’’ (Weisser-Lohmann, 2012, p158). From these definitions one could argue my participants were susceptible to coercion due to being recruited in a healthcare setting, however, I argue that with informed consent, an approved information sheet and months in between recruitment and interviews, the risk of participants feeling coercion was unlikely. My participants could not be deemed “incompetent persons” and meet the inclusion criteria. It could be said that the participants may not derive direct benefits from the research, however it could also be argued that it is unknown whether the research will impact care, and if it does, it is unknown whether the women will have further children and benefit from the research or not. Additionally, participants can benefit from the involvement and contribution to research, without experiencing direct benefits from research outcomes. Although women may have emigrated from different countries and be unsure of NHS healthcare processes, they must have had some understanding and experience of it as the only method to be recruited involved using NHS maternity services; and I believe that in defining them as competent to give informed consent, it negates the risk of coercion. Table 4.1 was created to assess the specific vulnerabilities my population could be at risk for after reviewing the literature and consulting experts. It is believed the practical ethical considerations were judged and built into the research protocol.

In this context, the word, “vulnerability” ultimately means a person is unable to protect their own interests in deciding whether or not to participate in research (Bracken-Roche, Bell, Macdonald, & Racine, 2017). I do not believe this was the case in my research. Context is fundamental when examining ethical concerns, however, the current ethics forms do not take context into account and assume risk based on traditional clinical science studies (Dingwall, 2006; Haggerty, 2004); as seen by the IRAS application form (Appendix 0), and I do not believe the women participants would have defined themselves as vulnerable.

Current literature on the issue of vulnerability during pregnancy classifies pregnancy as a vulnerable status because women have to think about not only themselves, but their unborn child; as well as pregnancy being a potentially stressful time with hormonal influxes and variations, leading to a risk of coercion (Bracken-Roche et al., 2017; van der Zande, van der Graaf, Oudijk, & van Delden, 2017; Wild, 2012). According to Shivayogi (2013), the vulnerable status during pregnancy stems from “scientific and social concerns of anticipated risks to [the] embryo, foetus and neonate” (p.55). This is in conflict with the formal legal position of the European Court of Human Rights (2019) and the Royal College of Obstetricians and Gynaecologists (RCOG) (Schiller, 2017) that does not consider the foetus to have human rights before birth and therefore is legally afforded no special protection in-utero. This is also in conflict with medical ethics which favours the preservation of maternal life over foetal life (British Medical Association, 2018). In my study there was no practical risk to the embryo, foetus, or neonate. Although recruitment occurred in the antenatal period, the focus of the vulnerability assessment was on the PPP, after which the interview took place. Receiving consent and interviews took place after the PPP had concluded and healthcare interventions, such as midwifery home visits and the GP six-week new-born checks were complete. After the PPP women are discharged from most healthcare initiatives and the health focus turned to the child’s development and vaccinations, leading me to conclude my population was not vulnerable within the context of pregnancy.

All women are at risk of mental health issues in the PPP. Such issues were considered in the approach to post-partum interviews taken by the researcher and the potential for needing to signpost available support resources. This was based on the evidence of prevalence of maternal mental health issues in the literature; however, this seemed to be overlooked by the ethics committee as no feedback was received regarding this issue. Anokye, Acheampong, Budu-Ainooson, Obeng, and Akwasi (2018) found a postpartum depression incidence of 7% in a study of women in Ghana. Women are more vulnerable in the PPP than the antenatal period due to healthcare focus shifting to the child, even though the child is no less dependent on the mother, as well as the risk of post-partum depression.

Within ethnographic methods, culture and context are essential foundations of designing a study. When the context is removed and restrictions are imposed based on lack of understanding and false assumptions, research quality suffers. I believe it is paternalistic of ethics committees to deem my population as vulnerable and I would question whether it is ethical to label such whole populations as vulnerable (e.g. women with FGM, pregnant women). As a nurse I have experienced working on a surgical ward where I would bear witness and safeguard patients consenting to surgery. As a researcher with an in-depth knowledge of this population and with a supervisory team containing internationally recognized experts in FGM, I would not describe this population (pregnant women; women with FGM) as a whole as vulnerable, rather, an individual vulnerability assessment needs to occur. Research benefits should be accessible to all participants if they have autonomy to give consent; by restricting access to populations by deeming them vulnerable, ethics committees are gatekeeping research and its potential benefits based on impractical ethical risk concerns (Finnegan & O'Donoghue, 2019).

Table B.1: Assessment of Vulnerability of Women with FGM Accessing NHS Maternity Services (Source: Author, 2019)

Vulnerability Classification	**Potential Issues**	**Research Adaptations and Research Solutions**
Minority	Coercion (Scott-Jones, 2000) Recruited in a healthcare setting	• Time between recruitment and interview (8 Weeks-5 Months) • Participants were told on a number of occasions that they had the right to withdraw at any time and to refuse to answer any question without giving a reason (informed consent form). • Researcher no role in direct care. This was explained in the Participant Information Sheet and discussed with participants face to face.

Table B.1: Assessment of Vulnerability of Women with FGM Accessing NHS Maternity Services (Source: Author, 2019)

Vulnerability Classification	**Potential Issues**	**Research Adaptations and Research Solutions**
		• Confidential participation (informed consent form) • Anonymity protected in representation of data • Participant Information Sheet given out, explained and any questions answered. • Contact details of independent others to contact about the study in the PIS • Informed consent form explained and signed.
English as second language	Ability to understand information sheet and consent form (Harper-Bulmam & McCourt, 2002)	• Did not require translation services whilst attending NHS clinic or for NHS interventions. • Ability to give informed consent evaluated by researcher during verbal interaction with participants during recruitment and before interviews • Audit trail: maintained trustworthiness and confirmability of findings.
Pregnant status when recruited	Pregnancy and the PPP are designated as vulnerable time periods for women. (Shivayogi, 2013)	• Ethical boards designated population as vulnerable • Considerations to ensure safety in design of study o Safety protocols o Time between recruitment and interviews o Private location for interviews o Time and place of woman’s choosing o Researcher assessment of ability to give informed consent

Table B.1: Assessment of Vulnerability of Women with FGM Accessing NHS Maternity Services (Source: Author, 2019)

Vulnerability Classification	**Potential Issues**	**Research Adaptations and Research Solutions**
Recent childbirth when interviewed	Debate in literature, deemed vulnerable by ethics review boards. -Stressful time -Postnatal depression risk -Hormonal influx due to childbirth (Bracken-Roche et al., 2017; van der Zande et al., 2017; Wild, 2012)	• Safety protocols in place and considered throughout design and implementation of research o Safety protocols designed for interviews including safeguarding information, support services for women and follow-up contact to ensure wellbeing • Informed consent form signed by participants and followed up verbally by researcher during interviews to ensure participants were still willing to participate.
FGM	Potential physical and mental health effects • Obstetrical consequences including increased risk for perineal tearing, need for episiotomies, prolonged labour, C-section, post-partum haemorrhage, instrumental childbirth and extended maternal hospital stay, may result in trauma when recalling experiences (WHO, 2006) • Psychological trauma resulting from FGM (Jungari, 2016; Mulongo et al., 2014) could resurface during pregnancy and childbirth	• Voluntary participation • Informed consent • All over 18 years of age • Could speak English • Interviewed as individuals (not with partners, family members or friends) • Study idea introduced by FGM midwife. Allowed women to decline or agree to hearing further information about the study from the researcher after it was outlined by the FGM midwife. • Given PIS which included details of where they could access confidential help and advice concerning FGM
Legal status	Access to NHS funds Uncertainty over legal status of immigration	• Only women who attended appointments at the FGM clinic were recruited, therefore were deemed not to have any uncertainty concerning their migration status and right to access NHS services.

Table B.1: Assessment of Vulnerability of Women with FGM Accessing NHS Maternity Services (Source: Author, 2019)

Vulnerability Classification	**Potential Issues**	**Research Adaptations and Research Solutions**
Unfamiliar with NHS and processes	Not attending appointments Not receiving care that is available to them (Gagnon et al., 2010)	• Only women who attended appointments at the FGM clinic were recruited.
Vulnerable to discrimination	Societal and institutional (M Knight et al., 2019)	• Institutional by NHS because women may not understand different cultural processes of healthcare as the NHS is based on a Western influenced approach to childbirth • Potential for societal racism to be present o Recruitment took place over 12 months allowing all women who attended the clinic and met inclusion criteria to participate o Snowball sampling was used to engage women who did not use the clinic (however, no women were recruited using this method)

B.9 Initial Protocol Design and Ethical Considerations.

The combination of undertaking ethnographic research concerning healthcare experiences presented unique ethical concerns about the relationship between the participant and researcher, such as; would the participant view the researcher as a healthcare professional, and seek care from them? Due to recruitment occurring in a healthcare setting, would the participant answer questions as they would to a healthcare professional but not a researcher, thinking it was part of their care? I am a professionally registered nurse, would my role as a nurse conflict with my role as a researcher? When interviewing participants, would I make comments from a nursing perspective instead of from a researcher perspective? The principles of ethics and specific ethical concerns associated with ethnography and healthcare were considered, debated and deliberated on during the creation of the research protocol and the implementation of the research study. My positionality as a researcher was assessed and is discussed in Chapter 2, Section 2.1.2.

A major ethical concern for the impact on the participant was the possibility of recalling negative events either associated with their experience of having FGM, or their experiences of childbirth (including birth trauma), with the potential of causing re-traumatization. Re-traumatisation was not expected to occur during interviews as I would not specifically be asking the women to recount their experience of having undergone FGM; however, I did recognise the personal and private nature of the topic and considered it might be difficult to discuss with a stranger.

The impact of participating, on the women’s social and home life was also considered. Would family members know of their participation? Would they approve? The literature discusses FGM as a taboo topic that is not discussed openly; this concern, coupled with the fact that undertaking or procuring FGM is illegal in the UK (Chapter 1, Section1.3) might have presented an issue for participants if their family or social circle discovered it and did not approve. Although I did not need community gatekeepers to access potential participants, the effect on the community was considered. If several participants belonged to the same community, there was a possibility that women might discuss the research, which might have unknown impacts on the community. While this was a considered risk, as women were deemed autonomous, and participation confidential, it was decided that the women, as members of the community and participants in the research would retain the power to decide whether to discuss the research within their community or not.

B.9.1 Autonomy

I designated the population as autonomous and able to give informed consent throughout the creation of the protocol. The principle of autonomy included three issues; informed consent, the creation of a trust relationship between the researcher and participant, and issues associated with possible coercion. The exclusion criteria for the study were enacted if the participant was deemed unfit based on the Mental Health Act 2005 (UK Parliment, 2005), as assessed by the FGM clinic midwife and myself at the time of the interview.

Informed consent was ensured by the presentation and discussion of the PIS. The PIS clearly described why the woman was being invited to participate, what the study concerned and what was expected with regard to participation; confidentiality, data protection, safeguarding and research contacts for questions and complaints (Appendix 0). A consent form signed by the researcher and woman ensured proof of informed consent, with the participant being given a copy for her records. The FGM specialist midwife introduced the study before the potential participant met the researcher, thus providing an opportunity to decline.

The relationship between the researcher and the participant was recognized and reflected upon by the researcher. The researcher was not in the participant’s circle of care, and the time between recruitment and participation in the interview varied between at least eight weeks and several months, giving the participant time to decide whether they wanted to participate and also freeing them from coercion as their care within the hospital for their pregnancy would be near completion.

The timing of recruitment and access via the NHS was considered and assessed under the concept of coercion. It was essential that women did not feel forced to participate. Recruiting through the NHS brought the possibility of perceived coercion that women might feel compelled to consent to being contacted for an interview for fear of healthcare being terminated. There was also a possibility that participants could feel obligated to participate because a healthcare professional, the FGM specialist midwife, introduced the researcher. Myths about social workers and social care are prevalent in migrant communities (Bright Network, 2020; The College of Social Work, 2020) and there was a concern that participants may fear social care becoming involved as a consequence of participation in the research. Anonymity and data protection were explained to potential participants during recruitment and again before interviews; allowing women to ask questions and ensuring they felt secure knowing the two reasons for breach of confidentiality would result from disclosure to commit FGM or harm to another person or themselves (see Appendix 0, What actions may be taken for safety and protection?).

B.9.2 Beneficence

To guarantee beneficence, safety protocols for women and KIs were produced to ensure that in the case of an adverse response to the interview, their wellbeing would be guarded. Although the term “female genital mutilation” is used by the UK government and World Health Organisation, the term ‘female genital circumcision’ was used in all the forms the participants would see, such as the participant information sheet and informed consent form to ensure sensitivity was shown to women and they could use their preferred term during interviews. Safeguarding was also considered in the wording of the safeguarding and mandatory reporting sections in the PIS. A clear description of the role of the researcher in safeguarding issues, and the safeguarding process were given. Confidentiality was ensured through data protection protocols (Chapter 2, Section 2.3.4). Confidentiality would only be broken in the instance where a participant divulged the intent to have FGM done to herself or another person and was included in the PIS and explained to participants verbally at the time of recruitment and before interviews occurred to ensure informed consent was achieved.

B.9.3 Justice

Justice was ensured by fairness of participation; all women who attended the FGM clinic and met the inclusion criteria were invited to participate over the course of twelve months. Recognizing vulnerability was also essential to ensuring justice and was implemented through safety protocols and informed consent. The veracity of the researcher and the research was ensured by the creation of an audit trail (See Chapter 2, Section 2.4), by professional nursing obligation and by the oversight of the supervisory team, ensuring fairness and quality in the research process and outcomes.

B.9.4 KIs and researcher Ethical Concerns.

KIs and researcher ethical implications were also deliberated and will be discussed in turn. KIs also had the potential of recalling past negative events when discussing their experience and care of women with FGM. There was also a potential that KIs themselves could have had FGM and would recall negative events associated with it. Vicarious trauma occurs in healthcare professionals when traumatic stories from their patients transfer to themselves, causing symptoms of trauma to be experienced even though the traumatic event did not happen to them (Mathieu, 2012). Moral distress can also occur in healthcare professionals when their actions do not match their values and beliefs (Epstein, Whitehead, Prompahakul, Thacker, & Hamric, 2019). This could occur if a KIs had an experience of mandatory reporting when they did not agree with the law. Performing or procuring FGM is illegal in the UK and healthcare professionals have a duty to report it.

Researchers must also break confidentiality if intent to have FGM done is discussed. Vicarious trauma and moral distress were also a possibility for me as a researcher if women recalled traumatic events, or I was forced to break confidentiality for safeguarding reasons. A safety protocol developed for me included debriefing with the research team after each interview, completing a research and personal journal, and access to mental health support if needed.

B.10 Coventry University Ethics Approval.

The Coventry University Faculty of Health and Life Sciences Ethics Standards were consulted and implemented in the research design (Coventry University, 2008, 2010, 2019). When questions arose during the creation of the protocol, these were addressed to the faculty ethics specialist and the answers were acted upon. Ethics approval was received by Coventry University (P52462) and the NHS Coventry and Warwickshire Research Ethics Committee (REC) (IRAS 224155). This study also adhered to general data protection regulation (GDPR). A timeline of ethical approval can be seen in Figure B.1 below. Coventry University ethics was acquired first and was approved with minor amendments required. To be an ethics evaluator at Coventry University an internal ethics training is combined with being selected as a reviewer by the ethics team based on either topic experience, research methods or both. The anonymous evaluator commented on how detailed, clear, and sound the protocol was.

Figure B.1: Process and Timeline of Ethical Approval (Source: Author, 2019)

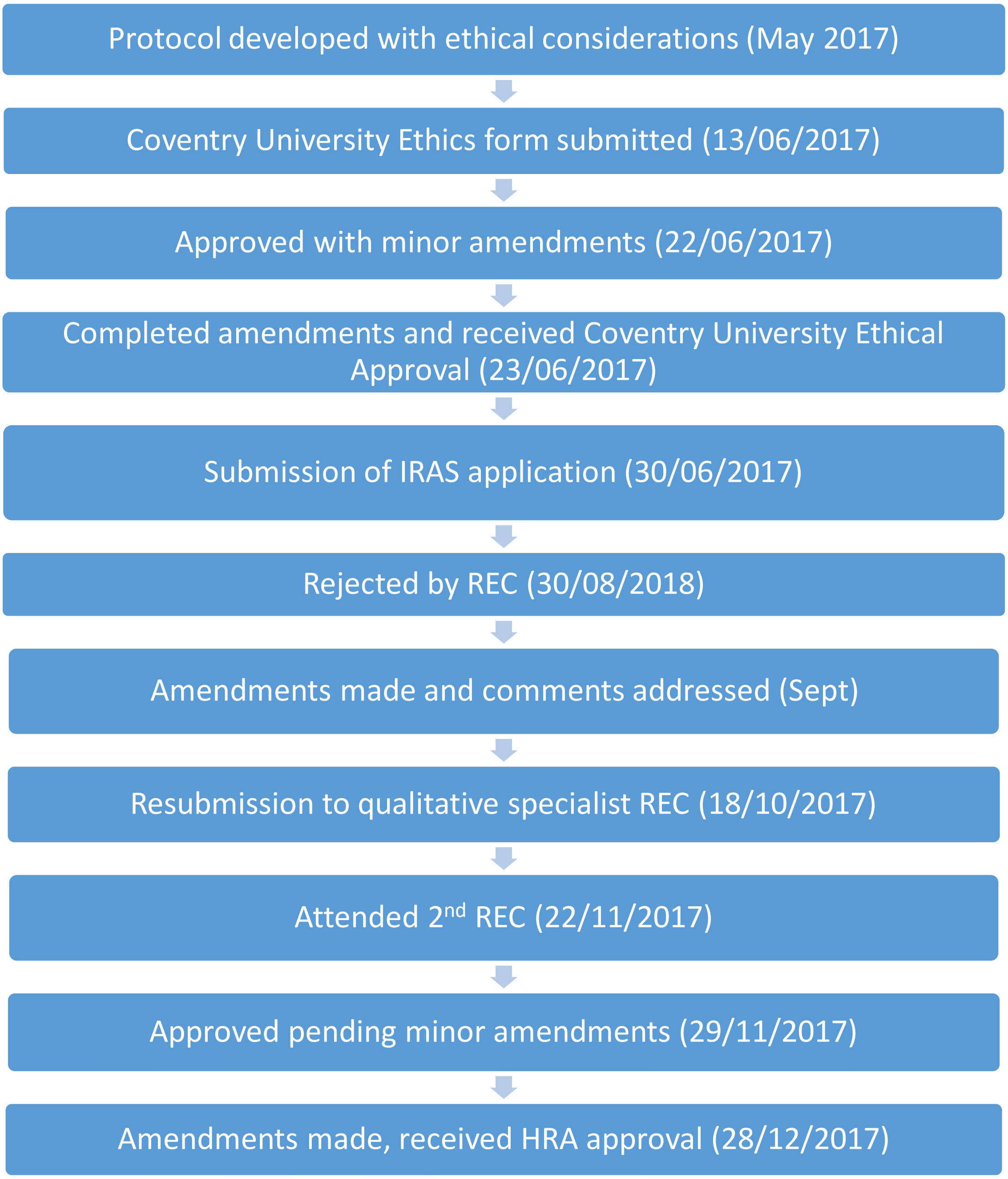


Table B.1 Application of Ethical Principles in Creation of the Research Protocol for Women with FGM, KIs and Researcher

Ethical Principle	**Issue**	**Solution**
Autonomy	Informed consent	• Participant information sheet ○ Included data protection, confidentiality and available

Ethical Principle	**Issue**	**Solution**

		supports to ensure women had enough information to be able to consent to participate
		- Informed consent form
		  - Ensured proof of consent for ethical research process
		- Midwife introducing study
		  - Allowed midwife to assess woman's ability to consent
		- Excluded from study if fell under Mental Capacity Act (2005)

	Relationship of researcher/researched	- Recognizing power in researcher/researched relationship
		  - Reflexive reflections were completed and debriefs with research team occurred after each interview
		- Researcher not being in circle of care
		- Months to consider participation (8 weeks to 5 months between recruitment and interviews)
		- PIS outlining ability to withdraw or stop interview at any time
		  - Woman was reminded of this before the interview began
		- Informed consent achieved before interview

	Coercion	- PIS-confidentiality
		  - Ensured woman knew how her information would be stored and used.
		  - Included section on how confidentiality would be broken if safeguarding was needed
		- Study idea introduced by FGM midwife. Allowed women to decline or agree to hearing further information about the study from the researcher after it was outlined by the FGM midwife.
		- Not in care circle
		  - Researcher could not influence care
		- Nobody in care circle would know about participation in research

Ethical Principle	**Issue**	**Solution**
		○ Midwife was not informed whether the woman agreed to be interviewed or not • Time between recruitment and interview (months)
Beneficence	Do no harm	• Safety protocols implemented for women and researcher ○ Debriefing ○ Well-being call ○ Support services available for mental wellbeing, FGM and domestic abuse • Researcher training ○ Registered nurse • Receiving ethical approval ○ From Coventry University and the NHS
	Terms used (Blee & Currier, 2011)	• FGC or circumcision used on all forms participants would see. During interviews participants were asked what term they would like to be used. ○ Ensured no harm was caused by the use of undesired terms
	Confidentiality	• Data protection protocols (Section 2.3.4) • Lead researcher only person with access to names and data stored on password protected computers or in locked lockers. • Broken if mandatory reporting must take place • Women made aware on PIS and consent form
	Mandatory reporting/ Concern for participants or someone else's safety	• Legal obligation to report illegal behaviour or intent • Safety protocols created and followed • Informed consent obtained by women • Women informed of procedure at beginning of interview
	Anonymity	• Data protection protocols (Section 2.3.4) ○ Confidentiality ensured
	Audit trail (Section 2.4)	• Ensure quality of research and protection of women ○ Confirmability and trustworthiness of research

Ethical Principle	**Issue**	**Solution**
		ensured by journals logging every step of the research process
	Vicarious trauma for KIs (Mathieu, 2012)	• Safety protocols created for women and KIs • Informed consent obtained after explaining risks through PIS
	Vicarious trauma for researcher (Mathieu, 2012) Moral distress (Epstein et al., 2019)	• Safety protocols created for researcher • Reflexive reflections (Holloway, 2017) • Debriefs with research team • Mental health support available if needed
	Participation in research Cox & McDonald, 2013 (feeling heard) Kost et al., 2013 (positive experience) Fry & Dwyer, 2001 (benefit to others is motivation) Newman et al., 2001 (most report positive experience)	• Goal of providing better care for women with FGM • Recruitment over 12 months to ensure as many women could participate as wanted. • Attempted snowball sampling to reach more women • Asked women about their care experiences and needs and if they could be improved Provided a non-judgemental space for women to discuss their post-partum and maternity care experiences
Justice	Fairness of participation	• Everyone who came to the clinic and fit the inclusion criteria was invited to participate. • Recruitment occurred over 12 months Snowball sampling was attempted
	English speaking only	• Safety protocols created and followed • Communication training received by researcher through nursing and Master’s education • Informed consent received by autonomous participants • PIS outlining risks of research (potential of recalling negative events or emotions) o Contact information for support services given to participants o Follow-up call one week after interview to ensure well-being
	Veracity of researcher	• Audit trail (Section 2.4) • Professional obligation o Registered nurse and PhD student of Coventry University

Ethical Principle	**Issue**	**Solution**
		Research team supervised process to ensure rigour
	Complaints	Information of who to contact in the event of a complaint is located on the PIS and did not include anyone on the research team

B.11 IRAS Application Form

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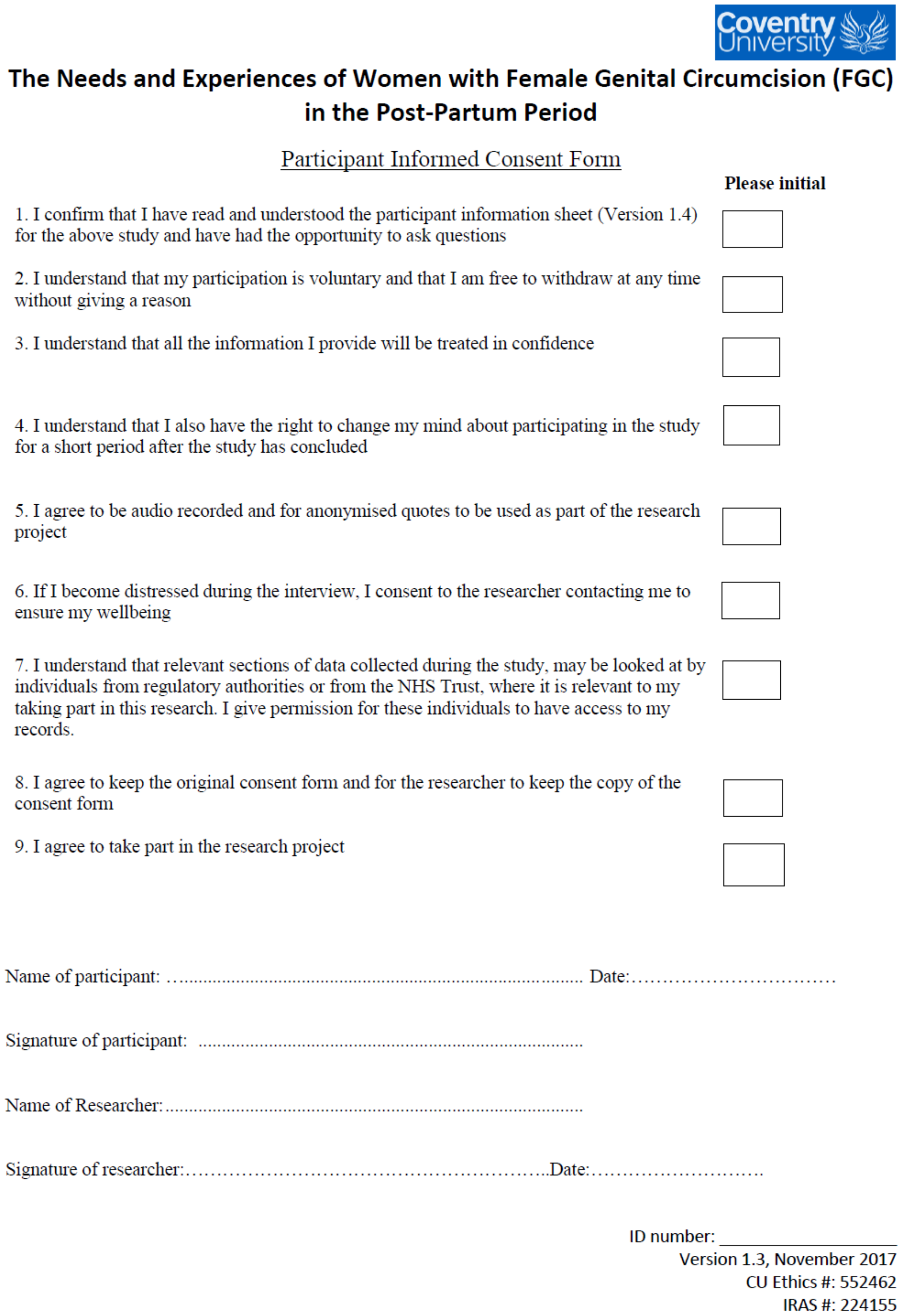
B.12 Informed Consent Form for Women with FGM



Coventry University

The Needs and Experiences of Women with Female Genital Circumcision (FGC) in the Post-Partum Period

Participant Informed Consent Form

Please initial

1. I confirm that I have read and understood the participant information sheet (Version 1.4) for the above study and have had the opportunity to ask questions ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason ☐
3. I understand that all the information I provide will be treated in confidence ☐
4. I understand that I also have the right to change my mind about participating in the study for a short period after the study has concluded ☐
5. I agree to be audio recorded and for anonymised quotes to be used as part of the research project ☐
6. If I become distressed during the interview, I consent to the researcher contacting me to ensure my wellbeing ☐
7. I understand that relevant sections of data collected during the study, may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
8. I agree to keep the original consent form and for the researcher to keep the copy of the consent form ☐
9. I agree to take part in the research project ☐

Name of participant: ….. Date:……………………………

Signature of participant: ....

Name of Researcher:..

Signature of researcher:…………………………………………………..Date:……………………….

ID number: ____________________

Version 1.3, November 2017

CU Ethics #: 552462

IRAS #: 224155

B.13 The NHS HRA Process

While a descriptive and detailed discussion of the NHS HRA process can be found in Appendix 0; here I highlight the focus on risk and safeguarding, and the subsequent removal of autonomy this produced (Table B.2).

The NHS Integrated Research Application System (IRAS) was used to complete the ethical approval steps and included: a form, signatures from Coventry University management and the research team, additional documents, and booking a date to appear before an ethics committee. The form was difficult to complete as it was clearly designed for clinical research and not ethnographic qualitative research. Several areas were repetitive, and clarification had to be sought when sections were not applicable. The IRAS form was completed and all members of the supervisory team approved submission. My director of studies and I attended the ethics committee meeting and received a rejection. This initial rejection displayed a lack of knowledge concerning the topic of FGM, and an ignorance of qualitative research methods. My ability as a researcher was also questioned. Amendments were completed where compulsory and justification was expanded upon where the researcher felt the rigour of the study would be negatively impacted by changes. The process followed and considerations can be seen in Figure B.1 and Table B.1.

The updated IRAS application was resubmitted to a qualitative specialist REC. The application was approved with minor amendments. Compulsory amendments were completed and HRA ethical approval obtained.

Table B.2: Highlight’s of the IRAS Ethical Approval Process and Implications for the Research Study (Source: Author 2020)

REC amendment	**Implication for study**

Add more information about the risks involved in participation and the possibility for distress to the PIS	**Focus on risk**: benefits not highlighted, only risk. Ensured the NHS would not be blamed for any negative outcomes of the research.
Interviews may not occur at the woman’s home under any circumstances	**Focus on risk** and **removal of autonomy** of women. If women preferred to speak about a private issue in their homes’, they could not. NHS midwives and health visitors conduct home visits, suggesting greater care was taken to prevent risk associated with research.
Women may not be called at home; a mobile number must be used	**Focus on risk** and **removal of autonomy**. If women preferred to give their home phone number or did not have a mobile, they could not participate. **Reduced the application of justice** in the study.
Women defined as vulnerable at a population level	Women were **defined as vulnerable** not only because of their pregnant state but also because they had FGM. There is no reason a woman with FGM should be seen as vulnerable simply by virtue of having FGM, if she has been designated as able to give informed consent.
Only fluent English speakers may participate	**Reduced the application of Justice** in the study by not allowing women who could not speak English to participate where language support could have been offered.
Questioned appropriateness of research design	Unnecessary and unwarranted implication Coventry University had not done its’ due diligence in producing the IRAS application and receiving Coventry University Ethical approval. Reflects gatekeeping approach of NHS ethics as seeing all subject groups as ‘patients’ who are always vulnerable. Pregnant women are not sick and therefore should not be subject to the same ethical approach as patients within hospitals. The first REC also did not appear to fully understand the nature of qualitative research.
Referred to ‘types’ of FGM as ‘levels’	Displays a lack of understanding concerning FGM and the different forms it can take. Suggests each ‘level’ of FGM fits nicely into a

	box when this is not an accurate representation of the phenomenon. It is not necessary to stratify by 'level'(type) as this is not important of qualitative research where no generalisability is expected.

From the above Table (Table B.2), I concluded the REC had a lack of understanding regarding the study population, the topic of FGM, and qualitative research methods. Several comments made revealed stereotypical assumptions regarding the study population, including; "interpreters had to be acceptable to the women because FGC is a very private matter particularly for those who *had fled conflict zones or who had left a relationship and feared being found*" (emphasis added). While it is true there was a possibility of a woman who was in this position attending the FGM clinic, it shows a stereotypical understanding of the study population and defines FGM as a 'very private matter' for women, rather than allowing women to decide how they feel about FGM. It also suggests this population had a high likelihood of being asylum seekers and refuges when the majority of the FGM population in the UK are settled migrants. The focus on risk avoidance can be seen in the above quote, and the following one; "assurance needs to be provided that the Department of Health's defined guidelines on FGM will be adhered to and are also fully understood by the applicants"; where again the capability of the research team, an intense focus on obeying the law and a lack of knowledge concerning NHS maternity FGM protocols can be seen. While this is required, the heavy focus and the insistence that mandatory reporting and safeguarding be separate sections in the PIS was unnecessary. To be referred to the FGM clinic a woman must identify herself as having undergone FGM. Once this information is on their file, safeguarding assessments are done regularly at health visits, including at the FGM clinic, any other antenatal appointments, during labour and delivery, during midwifery home visits, during the GP six-week new-born check, and at any health visitor appointments, as by recruiting directly from the FGM clinic, it was known women would be receiving these other interventions as well. By continuously repeating that FGM is against the law it is possible to stop women seeking answers to genuine questions regarding a cultural practice that until recently was deemed acceptable and desirable in many cultures. It also enhances the risk of women 'saying what you want to hear' as described by several KIs. Although this is a highly contested ethical topic, we must allow women to speak, listen to and accept what they say and to seek to understand their beliefs.

Overall, the NHS REC displayed a conflicting ideology and application of autonomy towards women with FGM. Women were autonomous enough to decide they could participate in the research but not autonomous enough to decide whether the interview could occur in their homes, that they could be called using their preferred number, or that they could use NHS interpreters; leading one to ask does the NHS REC see these women as autonomous or not?

B.14 The IRAS REC Process

The NHS' Integrated Research Application System (IRAS) was used to complete the ethical approval steps and included; a form, signatures from Coventry University management and the research team, additional documents, and booking a date to appear before an ethics committee. The form was difficult to complete as it was clearly designed for clinical research and not ethnographic qualitative research. Several areas were repetitive, and clarification had to be sought when sections were not applicable. The IRAS form was completed and all members of the supervisory team approved submission. My director of studies and I attended the ethics committee meeting and received a rejection. This initial rejection displayed a lack of knowledge concerning the topic of FGM, and an ignorance of qualitative research methods. My ability as a researcher was also questioned. Amendments were completed where compulsory and justification was expanded upon where the researcher felt the rigour of the study would be negatively impacted by changes. The process followed and considerations can be seen in Figure B.1 and Table B.1.

The updated IRAS application was resubmitted to a qualitative specialist Research Ethics Committee (REC). The application was approved with minor amendments. Compulsory amendments were completed and HRA ethical approval obtained. The following section details how the specific and pertinent issues of: autonomy, coercion, the decision to include non-English speakers, the wording on the PIS concerning safeguarding, and how the language used throughout the protocol was deliberate; were addressed in the design of the study. The responses and subsequent amendments required by each REC are evaluated and a discussion of the implications of these changes for the overall study findings concludes this section.

B.14.1 Ethical Issues.

Autonomy

Coercion. In protocol, neither REC had issues, lack of appreciation for perinatal mental health displayed.

1) Protocol development: risk of coercion due to vulnerable status, being recruited through NHS
2) REC 1: No comments
3) Amendments: NA
4) REC 2: No comments
5) Implications: Lack of appreciation for perinatal mental health and post-partum depression

Vulnerable Status.

1) Protocol development: vulnerable due to Coventry University Ethics guidelines of being pregnant during any part of the research process, also stipulated by HRA. Specific vulnerabilities assessed. Interview to be held in mutually agreed upon location. Telephone potential participants using preferred contact number to schedule interview.
2) REC 1: vulnerable status, add more information about risk of participation
3) Amendments:
    a. Focus on risk for participants. Added more information about safeguarding, created safety flowchart for participant, KIs and researcher
4) REC 2: vulnerable status, interviews cannot take place in home, potential participants cannot be called at home
5) Amendments: interviews to be held in mutually agreed public spaces. Potential participants' mobile number requested.
6) Implication: lack of autonomy shown to participants
    a. Removing autonomy of participant to judge whether they are safe conducting interview at home. Applying risk management to researcher above that required of NHS staff
    b. Removing autonomy of participant to judge whether they are safe to use their preferred contact method.

By requiring "the telephoning of potential participants at home to gauge interest in the project be removed from the study design", the REC removed autonomy from women to give informed consent using the paternalistic and stereotyped notion that women were at risk from family or community backlash if they participated in the research. The study design accounted for this, albeit impractical ethical concern, by recruiting while at a healthcare setting to keep confidentiality of participation. Women were then given information about the study and if consented, gave their preferred contact information. If a woman were at risk it is unlikely she would consent to participate, and if she wanted to do so, she was able to give her preferred method of contact. Taking the decision to participate into their own hands, the REC removed autonomy from women, took away their voices, and acted on media-driven 'what if' scenarios that had no basis in evidence or common sense. This study was designed with the aim of giving women voice and ensuring they received the best healthcare available;

and leaves one to wonder how healthcare expected to improve without consideration of the viewpoints of those receiving it.

Healthcare professionals working for the NHS routinely visit patients at home; including GP’s, district nurses, midwives and health visitors. Yet the REC stipulated “The study interviews should not be conducted in the participant’s own home under any circumstances, even if the participant expresses this preference.” As FGM and birth experiences are sensitive topics, it was thought a suitable place to conduct an interview would be the participant’s home where their comfort and privacy could be ensured. Once again, the REC displayed a paternalistic quality in deciding that even if participants wished to be interviewed at home, the REC ‘knew better’ and did not allow it on assumptions they were safeguarding from family and/or community backlash. Autonomy for personal safety for the participant should have been given to the participant, and a safety protocol, the same that NHS staff use when home visiting would be followed by the researcher.

Beneficence.

Safeguarding.

1) Protocol development:
   Mandatory Reporting. UK law requires health professionals to report any incidence of FGM or intention to have FGM happen to yourself or another girl or woman. If you discuss having FGM done to yourself or another person during the interview the researcher will be forced to tell the clinic midwife who will report it to authorities.

2) REC 1:

Please add information about safeguarding procedures for women to be followed to the Participant Information Sheet, Informed Consent Form and Protocol

Please add information about the process to be followed in the event of a participant becoming distressed to the Participant Information Sheet and the Protocol

3) Amendments and response: NHS safeguarding procedures will be active for participants already as they are activated by the Lead Midwife of the FGM clinic upon attendance at the clinic. Details have now been added to the PIS, Consent Form and Protocol. Safety flowcharts for participants, KIs and the researcher have been created.
4) REC 2:
    a. Assurance needs to be provided that the Department of Health's defined guidelines on FGM will be adhered to and are also fully understood by the applicants.
    b. The separation between safeguarding issues and the research itself needs to be made very clear. In addition the issues surrounding safeguarding in general need to be detailed in broader terms.
5) Amendments:
    a. The Department of Health's defined guidelines on FGM are instituted and adhered to by the NHS. NHS care pathways, as defined by the Department of Health guidelines will have been activated by NHS employees before any interviews take place. The applicants understand the care pathways used by the NHS in the care of women with FGM, the healthcare professionals involved, and the safeguarding policies in place. The applicants wish to convey that in a non-emergency situation, the most appropriate person to contact regarding issues of safeguarding is the lead midwife of the clinic who is an NHS employee, has access to medical records and who has rapport with participants. In emergency situations the applicants are aware of safeguarding procedures within the NHS and, if necessary, the police. The UHCW switchboard number is 024 7696 4000, and will be aware of who the safeguarding on-call staff member is. This information is contained in the attached flowcharts.
    b. A new section concerning safeguarding has been added to the participant information sheet (Version 1.4-November). It reads:

"Safeguarding. If intention to harm yourself or another person that is unrelated to FGC is disclosed during the interview, it is the duty of the researcher to breach confidentiality and report it to the appropriate authorities. (Please see the UHCW Safeguarding policy for more information)."

The mandatory reporting section of the PIS has also been changed to reflect safeguarding actions.

Mandatory Reporting:

"UK law requires health professionals to report any incidence of FGC or intention to have FGC happen to yourself or another woman/girl. If you discuss having FGC done to yourself or another person during the interview the researcher will stop the interview and will be required to tell the clinic midwife who will report it to authorities. If the risk is considered high, UHCW safeguarding will be contacted. If this happens, all information you have given will be removed from the study."

6) Implications: focus on risk and legal requirements.

The next statement I want to highlight displays the heavy focus the REC had on safeguarding issues and enforcing the law of mandatory reporting, should it arise. The REC stated: "Assurance needs to be provided that the Department of Health's defined guidelines on FGM will be adhered to and are also fully understood by the applicants". It was clearly evident the REC was concerned about safeguarding and maintaining lawful practice. While this is required, the heavy focus and the insistence that mandatory reporting and safeguarding be separate sections in the information sheet was unnecessary. To be referred to the FGM clinic a woman must identify herself as having undergone FGM. Once this information is on their file, safeguarding assessments are done regularly at health visits, including at the FGM clinic, any other antenatal appointments, during labour and delivery, during midwifery home visits, during the GP six-week new-born check, and at any health visitor appointments, as it was assumed if women attended the FGM clinic appointment, they would be receiving these other interventions as well. While it is understood that in order to receive informed consent the participants must be aware that the researcher will break confidentiality if the intent to have FGM performed, is needed, the formality of the statements caused an unnecessary and undesired tone at the beginning of the interview. It also appeared the REC was ensuring no legal action could be taken against them in the event of any negative consequences from the research. By continuously repeating that FGM is against the law it is possible to stop women seeking answers to genuine questions regarding a cultural practice that until recently was deemed acceptable and desirable in many cultures. It also enhances the risk of women ‘saying what you want to hear’ as described by several KIs. Although this is a highly contested ethical topic, we must allow women to speak, listen to and accept what they say and to seek to understand their beliefs.

Language.

1) Protocol development: FGM on research-facing documents, FGC on participant-facing documents
2) REC 1: "The study confuses FGM and FGC and as the way in which the study is written could appear judgemental and insufficiently neutral"
   Please review all documents and change reference to FGM to FGC

3) Response and Amendments: While opinions vary on whether FGM is a form of mutilation or a form of female circumcision, it is the consensus of the research team to use the official medical and legal term for the practice which is also used by the RCOG, WHO and UK government, during this study. During recruitment, interviews and on documents given to participants, the term female genital circumcision (FGC) will be used to mitigate any chance of causing offense. During interviews the lead researcher will seek guidance from participants on their preferred term and use it throughout the interview. However, in all other documents (documents the participants will not see), the term FGM will be used as this is the official term.
   Please note that participants will have attended the FGM clinic before being recruited. During initial visits the Lead Midwife of the FGM clinic explains the laws surrounding FGM in the UK, and women are enrolled in the NHS safeguarding protocols. The purpose of this study is to understand the needs and experiences of

women with FGM in the PPP in order to provide better care. The study focuses on the post-partum outcomes and impact due to FGM. FGM as a topic in and of itself is not a focus of this study and will not be approached by the researcher. If the topic does arise during interviews it will be in the context of the participants experience during the PPP only.

4) REC 2: no comments
5) Amendments: NA
6) Implication: displays a lack of understanding of nuance and context of topic.

Justice.

Include non-English Speakers.

1) Protocol development:
    a. The research team believes the data would be incomplete if only women who spoke English were invited to participate. However, from our correspondence with the Lead midwife at the UHCW FGM clinic, and the findings of the extensive report on FGM by Macfalane and Dorkenoo (2015), "many [women] are highly educated and reported English as their first language on their census forms" (p7).
    b. As participants are self-selecting and have been judged to have the ability to give informed consent, the research team feels it is only appropriate to give the participants the choice of what they deem acceptable by way of language support.

Inclusion criteria to include all women, translation services will be used if necessary.

The following paragraph was written in my IRAS form in response to the question "what arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? (E.g. translation, use of interpreters)"

"Participants:

If translators are needed and used, the confidentiality between the translator and participant will be explained. While the research team does not expect many participants will need translators, they will be available if needed and accessible. Only female translators will be present during face-to-face interviews with participants consent. If no female translators are available, participants will be asked for consent to have a male translator over the phone. No face-to-face interviews will occur with male translators. While the research team will do its utmost to only use female translators, it is believed that with informed consent, it should be the participants decision to complete the interview with a male translator over the phone or not. The research team believes the data would be incomplete if only women who spoke English were invited to participate. However, from our correspondence with the Lead Midwife at the UHCW FGM clinic, and the findings of the extensive report on FGM by Macfarlane and Dorkenoo (2015), the majority of women with FGM in England and Wales report English as their first language."

2) REC 1: Translators must be acceptable to women, accuracy and confidentiality of translation must be ensured
    a. "interpreters had to be acceptable to the women because FGC is a very private matter particularly for those who had fled conflict zones or who had left a relationship and feared being found"
3) AMMENDMENTS: I responded to the criticisms of including the choice of male interpreters (only used if consented to by women and located in a different room and connected over the phone) in the study design.

"Translators will be used if necessary. Translators will be unknown to participants. If translators are used, the confidentiality between the translator and participant will be explained. While the research team does not expect many participants will need translators, they will be available if needed and accessible. Ideally, we would aim to use female translators during face-to-face interviews with participants consent. If no female translators are available, participants will be asked for consent to have a male translator over the phone. While the research team will do its utmost to only use female translators, it is believed that with informed consent, it should be the participants decision to complete the interview with a male translator over the phone or not. It is also of note that female interpreters may be from the same culture or country of birth as the participants who require a specific language and as such may have experience of FGM themselves or within their families. This may result in interpreting on this topic difficult or embarrassing to them. As such we will aim to use interpreters that are known to the local FGM services and are aware of the aims of the study, or offer male interpreters over the phone.

The research team believes the data would be incomplete if only women who spoke English were invited to participate. However, from our correspondence with the Lead midwife at the UHCW FGM clinic, and the findings of the extensive report on FGM by Macfarlane and Dorkenoo (2015), “many [women] are highly educated and reported English as their first language on their census forms” (p7).

From correspondence with the Lead Midwife of the FGM clinic at UHCW, the majority of women seen there are well educated, legal migrants who have lived in England for many years and are not fleeing war zones.

As participants are self-selecting and have been judged to have the ability to give informed consent, the research team feels it is only appropriate to give the participants the choice of what they deem acceptable by way of language support.”

Who would check on the accuracy of the interpreting?

The research team does not expect to need many translation services based on our correspondence with the Lead midwife at the UHCW FGM clinic, and the findings of the extensive report on FGM by Macfalane and Dorkenoo (2015), “many [women] are highly educated and reported English as their first language on their census forms” (p7). However, if translation services are required, translations will be checked by a second translator who, with the informed consent of the participant, will listen to the tape recording and ensure accurate translation was achieved.

4) REC 2: Remove possibility of using male or female translators even with women’s consent
    a. The study interviews should not be conducted in the participant’s own home under any circumstances, even if the participant expresses this preference.
    b. The telephoning of potential participants at home to gauge interest in the project should be removed from the study design.
    c. The use of interpreters should also be removed from the study design.
5) Amendments:
    a. To receive HRA ethical approval the inclusion criteria had to be changed to include fluent English speakers only.
    b. Study interviews will never be conducted in a participant’s home, even if requested. Interviews will be held in mutually agreed upon public spaces where privacy can be ensured, and the participant feels comfortable.
    c. Participants will only be called if they have agreed to receive a call from the researcher. Agreement will occur when the lead midwife of the FGM clinic presents the study information and requests consent for the researcher to call to schedule an interview. During the call the researcher will confirm continued interest in participation of the study, not initial interest, to ensure the participant wishes to schedule an interview.
    d. Only fluent English speakers will be recruited for the study. This has been changed in the protocol.
6) Implication: bias of sample

By removing non-English speakers from the study the REC possibly skewed the results of the study from new migrants to a more settled sample who spoke English well enough to be included, or native English speakers. This possibly caused a bias in the findings as women who spoke English fluently could have different experiences than women who did not, such as easier access to healthcare and support. The REC took away the opportunity to hear these women’s voices concerning a vital part of healthcare received during the PPP. As a researcher, the aim was to be as inclusive as possible and empower women by giving them a voice, exampling the ethical principle of justice by attempting to recruit an accurate and fair sample from the population. The decision by the ethics committee prevented this.

The assumption that FGM would be a particularly private matter for women who were fleeing conflict zones or who had left a relationship and feared being found was made by the ethics committee and one can only assume was based on mainstream media. Although FGM is not present in traditional British culture, many of the women attending the FGM clinic in Coventry had either been born in the UK, or been living in the UK for many years. I wonder whether the REC questions translators in research with all women, or just ones that have stereotypes of leaving conflict zones and being victims of domestic assault. The interpreters used in this study would have been the same interpreters the NHS uses. Why are interpreters approved for NHS healthcare appointments not suitable for research with NHS patients?

B.15 IRAS Ethical Approval Process and Implications for the Research Study

Table B.3: IRAS Ethical Approval Process and Implications for the Research Study

Protocol	**REC 1**	**Response**	**REC 2**	**Response**	**Implication for study**
Assumed autonomous, defined as vulnerable due to ethics process	Defined as Vulnerable	No change	Defined as vulnerable	No Change	Autonomy of participant questioned
Steps included in event that participant becomes distressed	Add more information about risk of distress on PIS	Completed	No comment		Focus on risk
Interview to be held in mutually agreed upon location	No comments		Interviews cannot take place at home even if this is participants preferred location	Interviews only held in public mutually agreed locations	Removing autonomy of participant to judge whether they are safe conducting interview at home. Applying risk management to researcher above that required of NHS staff
Telephone potential participants on preferred contact number to schedule interview	No comments		Not allowed to call home number even if this is the participants preferred contact number	Potential participants mobile number requested	Removing autonomy of participant to judge whether they are safe to use their preferred contact method

Risk of participant feeling coerced to participate due to recruitment during pregnancy and through NHS	No comments		No comments		Lack of appreciation for perinatal mental health
Decision to include non-English speakers in study	Translators must be acceptable to women Accuracy and confidentiality of translation must be ensured	Consent to use translator emphasized. Accuracy would be checked by 2nd translator. Translators would be NHS approved.	Remove possibility of using a translator, Participants must be English speaking only	English speaking only added to inclusion criteria	Possible bias created due to ability to speak English Inability to hear all non-fluent-English speaking women's voices concerning FGM experiences
NHS FGM Safeguarding protocols already active. Report any issues to lead midwife of FGM clinic or safeguarding team	Add additional information to PIS, consent form and protocol	Additional information added to ensure understanding by participants	Need to make separation of safeguarding and mandatory reporting on PIS very clear. Add more detail.	PIS changed to reflect comments. Separate section for safeguarding and mandatory reporting	Change in section Focus on risk and legal obligation Created lengthy PIS that stifled beginning of interview
DoH defined guidelines for safeguarding and mandatory reporting of FGM followed	No comment		Requested research ensures guidelines and legal obligations are followed	Care and safeguarding pathways already active at time of interview. Women	Safety flowchart created, safeguarding and mandatory reporting sections in PIS altered

				aware of law. Safety flowchart created	
Terms: FGM on official documents FGC on all participant facing documents	Study confuses FGM and FGC and could appear judgemental and insufficiently neutral	Explained further. FGM official term used by government, FGC on all participant facing documents	No comments		Displays lack of understand-ding of nuance and context of topic
Flexible semi-structured interview schedule- not all questions intended for use, emerging design	Interview questions are too structured	Clarified flexible nature of interview, not expected all questions will be asked, emergent design	No comments		Difficulty of having to construct an interview guide for research with emerging designs
Researcher qualified, informed by supervisory team, will attend training to ensure suitability	Questioned ability of researcher	Researcher able, supervisory team in place, training to ensure preparedness, previous experience	Accepted		Lack of confidence shown in researcher ability due to 'highly sensitive' topic and vulnerable population
Research designed with feedback from supervisory team	Suggested experts in FGM should be consulted for peer review before resubmit-ssion	Quality of the research design defended	Accepted		Questioning research design on topic clearly unfamiliar with. Unnecessary to suggest Coventry University ethics and supervisory team did not

					do due diligence
Demographics sheet included number of previous pregnancies	Additional 'variable' questioned	Needed information due to possible previous de-infibulation, or experience of tears/episiotomies impacting current birth outcomes	Accepted		Displays a lack of understand-ding concerning the specifics of the topic and the population context
All types of FGM included as the NHS does not distinguish care by type and applicable findings desired	Having all 'levels' of FGM is too wide reaching	NHS does not distinguish, and findings aimed at improving care	Accepted		Displays a lack of understand-ding concerning the specifics of the topic and the population context
All women with FGM who attend the FGM clinic and meet inclusion criteria invited to participate	Suggested define group; e.g. refugees, Somali migrants (non-binding suggestion)	NHS does not distinguish between ethnicities or legal status, and findings aimed at improving care	Accepted		Displays a lack of understand-ding concerning the specifics of the topic and the population context
Format based on Coventry University templates	Rewrite PIS in HRA format	Made applicable changes	Accepted		HRA format was not conducive to emerging designs and not applicable
	Add regulatory paragraph	Added	Accepted		Difficult to explain in interviews

	for data on research and audit purposes				as appeared to be a break of confidentiality to participants

Appendix C Appendices for Chapter 3

C.1 References for Documents used in Documentary Analysis

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