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Perceptions and experiences of patients and clinicians in anal cytology screening and high resolution anoscopy
a hermeneutic phenomenological study

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Perceptions and Experiences of Patients and Clinicians in Anal Cytology Screening and High Resolution Anoscopy: A Hermeneutic Phenomenological Study

By

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Author’s declaration

I declare that all material in this thesis is original, is all my own work, and has not been presented previously.

Abstract

Background

Anal Intraepithelial Neoplasia (AIN) is a well-recognised precursor for invasive squamous anal cancer. The prevalence of anal cancer is increasing in people living with HIV. This hermeneutic phenomenology study explores the perceptions and experiences of patients and clinicians in anal cytology screening and high resolution anoscopy in sexual health clinics in the UK.

Methods

This study was conducted in the interpretative paradigm using hermeneutic phenomenology informed by Heidegger. A purposive sample comprising 14 patients and 8 clinicians was recruited. In-depth unstructured interviews were conducted between May and June 2014. Interpretive phenomenological analysis (IPA) was used to develop in depth interpretations of participants' perceptions and experiences of anal cancer screening. Data were analysed using the six stages in the analysis process i.e. immersion, understanding, abstraction, synthesis and theme development, illumination and illustration of phenomena, integration and critique.

Findings

Five themes emerged from the data from both patients and clinicians: psychological effects of anal cancer screening, screening procedures, education, knowledge and training, social and sexual activity, guidelines and practices. Findings of this study demonstrate that anal cancer screening is acceptable, but tolerability is variable; education, knowledge and information on anal cancer screening is limited to the media, press, magazines and those clinicians offering screening at their sexual health clinics in the UK. Although the social life of most patients was not affected, their sexual activity was affected. This study suggests that a screening program as part of routine HIV care in an outpatient sexual health clinic.

Conclusion

Anal cancer screening benefits outweigh any psychological harm caused by tests and diagnostic procedures for people living with HIV. The emotional responses highlighted were not associated with significant psychological harm. Anal cancer screening should be considered in future guidelines in the UK for people living with HIV.

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Abbreviations and Notes

AIDS	Acquired Immune Deficiency Syndrome
AIN	Anal Intraepithelial Neoplasia
AIN 1	Mild dysplasia
AIN 2	Moderate dysplasia
AIN 3	Severe dysplasia (sometimes referred to as carcinoma in situ)
Anal Pap/Anal cytology	A screening test that involved inserting a swab into the anal canal to secure fixed cell samples for cytological examination.
ANALOGY	A study looking at screening for anal cancer
Anal Intraepithelial Neoplasia (AIN)	An abnormal cell growth that may develop into cancer
ANCHOR	Anal cancer HSIL Outcomes Research
Anoscopy	A technique to view the inside of the anus or rectum
ASIL	Atypical Squamous Intraepithelial Lesion

BHIVA	British HIV Association
BSCC	British Society of Clinical cytologists
CIN	Cervical Intraepithelial Neoplasia
CIS	Carcinoma in Situ
CRUK	Cancer Research United Kingdom
CSP	Cancer Screening Programs
DARE	Digital Anorectal Examination
Dysplasia	The proliferation of abnormal cells
EACS	European Aids Clinical Society
Efficacy	Ability to produce the desired affect
Epidemic	Spreading rapidly and extensively
Epidemiology	The branch of medicine that deals with the study of the causes, distribution, and control of disease in populations
ESMO	European Society for Medical Oncology

ESRC	Economic Social Research Council
EVVA	Cohort study on the evaluation of HIV, HPV and AIN in women
HANS	Homerton Anal Neoplasia Society
Histology	Study of tissue structure
HIV	Human Immunodeficiency Virus
HRA	High Resolution Anoscopy
HSIL	High-grade Squamous Intraepithelial Lesion
HPV	Human papillomavirus
IANS	International Anal Neoplasia Society
Incidence	Frequency of a disease
LBC	Liquid Based Cytology
LOPAC	Laser Ablation versus Observations to prevent anal cancer
Morbidity	The rate of incidence of a disease

MSM	Men who have sex with men
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NRES	National Research Ethics Service
PEO	Population/Problem, Exposure, Outcomes
Prevalence	Number of cases of a disease
PSA	Prostate Specific Antigen
RRM	Risk reducing mastectomy
SPANC	Study of Prevention of Anal Cancer
UK	United Kingdom
USA	United States of America

1 Introduction

I developed an interest in anal cancer due to a personal life experience with a family member and this has inspired and challenged my interest for this study. The human immunodeficiency virus (HIV) and human papilloma virus are both infections that can be transmitted through sexual activity and there is no link medically between the two infections, however, the sexual behaviors that put someone at risk of contracting HIV can also raise the risk for getting HPV. According to Tong et al (2013), anal cancer is one of the most common non-AIDS-defining malignancies in the era of combination antiretroviral therapy; its precursor lesion, anal intraepithelial neoplasia (AIN), is highly prevalent in HIV-infected populations and more than 90% of anal squamous cell cancers are attributable to human papillomavirus. The purpose of my study was to explore the perceptions and experiences of patients who have had anal cytology and high resolution anoscopy and clinicians undertaking anal cancer screening within sexual health clinics around the UK. My study was to inform clinical practice and contribute to the evidence needed for the development of future guidelines for anal cancer screening in the UK. My study also included clinicians in sexual health clinics undertaking anal cancer screening in people living with HIV. Hermeneutic (interpretive) phenomenology, the philosophy of interpretation embraces and seeks meanings embedded in patients and

clinicians' experiences, guides my study through the lived experience of each individual.

My study is a Heideggerian Hermeneutic Phenomenology using interpretative analysis to analyse the data on the perceptions and experiences of patients and clinicians in anal cancer screening. Nursing research is conducted with the aim of developing the knowledge base that underpins the stability and growth of the discipline therefore nurse researchers have adopted and adapted a range of research methods from the human, social and natural sciences to examine questions of relevance to their practice (Mackey, 2005). I chose the interpretive approach for my study as nursing is a caring professional concerned with delivering quality of care and understanding individuals. I appreciate the unique experiences of individuals and understand the individual experience as a whole being. Nurse researchers have found the interpretive approaches more likely than the

positivist approach to reveal the depth and diversity of nursing knowledge therefore interpretive approaches allow for research which aims for understanding, rather than explanation of human phenomena; they allow for research that is conducted in a natural, uncontrolled setting which utilises the knowledge embedded in experience (Mackey, 2005). As a nurse, I find this particularly important as the interpretive approach is critical to examine the implications this may have on patients and clinicians in anal cancer screening as well as the impact it may have on practice. Furthermore, I am a nurse practitioner undertaking anal screening and my practice is embedded in my experience as an anoscopist. In keeping with the aims of my study in exploring the perceptions and experience of patients and clinicians in anal cancer screening, I can find meaning in and understand their experiences in their clinical environment and communicate this understanding to inform clinical practice.

I chose to write in the first person "I" as I am an integral part of the research process (Hamill, 1999) and this is a personal account of my journey. The essence of good first-person narrative is sharing an experience, letting the reader see and feel it (Paquin, 2001). As a researcher, I recognised my pre-understandings of "being in the world" as a lived experience is an important element for my study. This relation or connectedness required self-reflexivity so that the research I produce must be credible, trustworthy and transferable in the world of research. In other words, being self-reflexive means that I had to be cognisant of my views and social position as a researcher to understand how this will affect the research process and those being researched. This according to Allen (2004) gives researchers the opportunity to reflect on their own histories and theoretical stances as well as the way in which it may influence the research.

This Chapter introduces my study by:

- Introducing my story and in anal cancer screening with self reflexivity and reflexivity
- Setting the scene discussing the background of anal intraepithelial neoplasia
- Understanding anatomy and where AIN is detected
- Discussing the process and procedure of anal cytology
- Explaining the grading of anal dysplasia
- Explaining digital anorectal examination
- Explaining high resolution anoscopy
- Discussing the prevalence of AIN

- Introducing anal cancer screening programs, anal cancer screening guidelines and the impact of publicity about celebrities in anal, breast and cervical cancer screening as well as the cost effectiveness if anal cancer screening
- Presenting the purpose, research ains and research questions

This introduction is set out to provide background information on anal intraepithelial neoplasia, anal screening and existing literature highlighting the psychological effects of anal screening in the UK. To provide further context, reflexivity is discussed as a process I undertook in my chosen methodology and my personal background is included. Attia and Edge (2017) mentions that such reflexive processes will have a powerful impact on one's development as a researcher, raise awareness about the coherent expression of one's values as a whole person who conducts, and ensures that research practice consistently reflects the principles the researcher embraces.

1.1 Self-reflexivity and Reflexivity: my story and interest in anal screening

I am a registered nurse for over 24 years and working in sexual health and HIV for the last 21 years. I spent the last 17 years working in and specialising in Genito Urinary Medicine and HIV. My father in law was diagnosed with anal cancer in 1999 and ended up having a colostomy and subsequently had chemotherapy treatment which was successful. He lived in an economically developing country, and in the late 1990's there was no anal cancer screening available which meant that my father in law had a tumour that grew up to 8cm which was invasive in nature and required large bowel excision. It was difficult to detect AIN or anal cancer unless a person had symptoms which often are too late.

I worked in a speciality area of patients living with HIV in an outpatient clinic and pursued training in anal cytology at a local NHS trust in 2009. My interests started growing in detecting AIN and I used to chaperone a consultant undertaking high resolution anoscopy (HRA). From this point on I knew I wanted to pursue a special interest in a nurse led service in anal cancer screening and engaged with the head of school at Buckinghamshire New University about this new area of work in the UK. I was excited and overwhelmed at

the prospect of a new research idea which could potentially help inform clinical practice and guidelines for the UK once my study is published.

In 2011, I moved to my current hospital trust due to family commitments, started a professional doctorate with Buckinghamshire New University and in 2012 I went on to train to undertake high resolution anoscopy with an experienced consultant. In 2013, I went to San Francisco to formally train and completed an accredited course on Colposcopy and High Resolution Anoscopy. This was the only course offered in the world at that time. In November 2013, I attended the International Anal Neoplasia Society (IANS) scientific meeting and in that same year I registered to be a member of the International Neoplasia Society and I continue to be a member of the Society. I was the first UK nurse to register with IANS and attend the scientific meetings every two years. In March of 2015 I was accepted for two oral presentations which I presented to an international audience at the IANS scientific meeting in Atlanta.

I currently run a nurse led service providing an anoscopy service weekly, at my employing trust. I took great interest in exploring patients and clinicians' perceptions and experiences in anal cancer screening. This is a new field of study in the UK and I found this a great opportunity to produce research and utilise a hermeneutic phenomenological approach to examine the implications for development of knowledge in practice.

Reflexivity is an important process in research as it has an impact on the researcher (Spencer et al, 2003). I managed my position as a researcher in the reflexive process as it is widely acknowledged that the assumptions and beliefs of the researcher will influence how data is collected and analysed therefore, it is important to be clear about what these assumptions and beliefs are and to own one's own perspective in qualitative research (Elliot et al,1999 & Elliot, 2015). I chose to use a reflexive approach where I could consciously acknowledge that reflexivity challenged my personal assumptions, clarified individual beliefs and any subjectiveness I faced, as alluded to by Ortlipp (2008). This approach of reflexivity has become a tool for the development of my thesis.

In Hermeneutic (interpretative) phenomenology, reflexivity is a person's reflection on and experience of a situation that can help in interpreting the meanings discovered in the interpretations or even add value to a study (Sloane & Bowe, 2014). Reflexivity is the

process where the researchers are conscious of and reflective about the ways in which questions, methods and subject position might impact on the data or the psychological knowledge produced in a study (Langdridge, 2007). Without explanation or analyses, the means of describing essence may best be provided by the researcher's personal reflection (Cohen et al, 2007).

1.2 Background of Anal Intraepithelial Neoplasia: setting the scene

Anal intraepithelial neoplasia (AIN) is a premalignant or precancerous lesion of the anal canal and the risk factors for AIN and anal cancer consist of clinical factors and behaviours that are associated with the acquisition of persistent Human Papilloma virus (HPV) (Roberts et al 2017). AIN is a well-recognised precursor of anal squamous cell carcinoma and the incidence is increasing dramatically, especially in high risk groups, in particular, men who have sex with men (MSM) and those people living with human immunodeficiency virus (HIV) (Ajaz et al, 2007). Documented evidence shows that there is a relationship between AIN and HPV (Hoots et al, 2009). The natural history of AIN is still unclear although there is an assumption, that it is similar to cervical intraepithelial neoplasia (CIN) (Ajaz et al, 2007). Cervical and anal cancers are caused by HPV virus which is a viral infection; belonging to a family of approximately 100 different types of viruses and can present as genital warts to cancers (Aidsmap, 2011). HPV causes almost 100% of cervical cancers (Bouvard et al, 2009) and 80% of anal cancer (De Vuyst et al, 2009). Like cervical cancer, squamous-cell anal cancer is caused predominantly by high-risk, oncogenic strains of HPV and occurs at a squamocolumnar transition zone (figure 1); HPV infects basal cells of the cervix and anal canal, causing progressive dysplasia (Swedish et al, 2011). High-grade anal intraepithelial neoplasia (HGAIN) is believed to be the precursor to squamous-cell anal carcinoma (Darragh & Winkler, 2011). Anal cancer is caused by the HPV type 16 or 18 and is graded as high grade (grade 2 & 3) anal intraepithelial neoplasia (Palefsky et al, 2011).

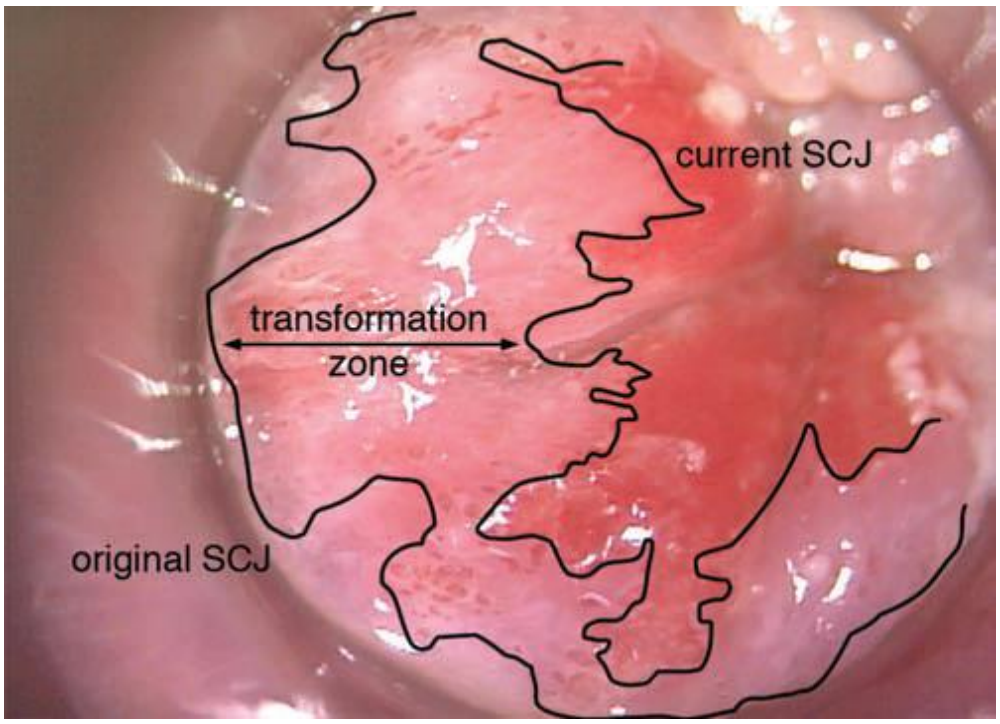


Figure 1 An illustration of the Transformation zone

Figure 1 is a partial view of the anal transformation zone indicating the transformation zone between the original and current anal squamous columnar Junction (Darragh et al, 2011)

Anal cytology screening is similar to cervical screening where the Papanicolaou (Pap) staining is used. According to Leeds and Fang (2016), a number of similarities exist between squamous cell anal cancer and cervical cancer; both occur at squamocolumnar junction epithelium; the transformation zones of the anal canal and the cervix are both characterized by high turnover epithelium that is thought to be particularly vulnerable to malignancy-inducing genetic alterations. In the UK clinicians have used this very model for screening since 1999. When I started to practice and undertook anal cancer screening, screening tools were already established in collaboration with the histoplathologists, clinicans and international colleagues. The first cancer screening test was developed in 1943 by George Papanicolaou, whose monograph provided a method for identifying both precancerous and malignant cervical cells (Wardle et al, 2015). Cervical and anal Pap smears share histopathologic features and they share similarities in the genital areas such as the transformation zone in the cervix and rectum (Lindsey & DeCristofaro, 2009). The transformation zone (figure 1) is an area where cells change and can develop into abnormal cells which can be detected with a Pap smear. These abnormal cell changes

are called dysplasia (mild, moderate, and severe). Almost all anal cancers develop in the transitional zone, where atypical, dysplastic and in-situ lesions are identifiable Histologically (Leiman, 2005).

Anal squamous cell carcinoma is similar to cervical cancer caused by cancer-causing strains of HPV, which infects basal cells of the cervix and anal canal resulting in dysplasia; thus, high grade AIN is assumed to cause squamous cell anal carcinoma (Darragh & Winkler, 2011). The study findings by Kristin et al (2011) showed that screening of high-grade intraepithelial neoplasia and appropriate treatment could prevent its progression to squamous cell anal cancer. Lindsey et al (2009) stresses the importance of healthcare providers including cytology screening during health promotion practices as information from anal cytology can provide opportunities for early diagnosis of anal lesions; for observation and treatment to prevent anal cancer. Data from a cohort study in the USA have indicated anal screening is useful in detecting AIN (Palefsky, 2011). Fox et al (2006) suggested that there is a need for large prospective cohort studies in men who have sex with men and HIV-positive patients to further our understanding of this disease and to evaluate treatment strategies. Rosa-Cunha et al (2011) provides an argument from their pilot study that anal cytology screening is feasible as part of the patient's routine HIV care visits.

The incidence of cervical cancer has decreased by more than 50% (Leeds and Fang, 2016). According to van Oortmarssen and Habbema (1995), this public health success story is largely attributed to the widespread and routine use of cervical cancer screening, primarily employing the cytology-based cervical Papanicolaou (Pap) test. It is thought that a similar screening effort applied to anal cancer could potentially reverse the disturbing recent trends in disease incidence (Leeds and Fang, 2016). The introduction of National Health Service's (NHS) organized cervical screening programme in 1988, the consistent increase in anal cancer incidence was noted in both men (from 0.88 to 1.06) and women (from 0.81 to 1.18) (Robinson et al, 2009). In specific groups, such as HIV-positive patients, the risk of anal cancer is 60 per 100 000 patient-years (mean value, 1984– 2003) and increased from 35 in the pre-highly active antiretroviral therapy (HAART) era (1984–1995) to 92 in the post-HAART era (1996–2003) (Bower et al, 2004). According to van der Zee et al (2013), incidence rates of anal cancer have increased in practically all Western countries during the last decades. Infection with oncogenic HPV is the most important

aetiological factor. Several risk factors and risk groups for anal cancer have been identified during the last decennia, in particular smoking, men who have sex with men (MSM), MSM practising receptive anal intercourse, a history of sexually transmitted diseases, having had more than 15 sexual partners, HIV-positive MSM, organ transplant recipients and women with a history of cervical cancer or cervical intraepithelial neoplasia.

The cervical screening model has led to its use as a template for anal cancer screening in high risks groups. The parallels between the models for anal cancer screening and cervical cancer screening are based on the biologic and morphologic similarities between anal intraepithelial neoplasia (AIN) and cervical intraepithelial neoplasia (CIN) (Darragh & Winkler, 2011). Anal cytology was first introduced into the College of American Pathologists (CAP) Interlaboratory Comparison program for gynaecology in 2005. If cytological results from anal Pap smear are abnormal, which means there are squamous epithelial cell abnormalities, then patients undergo high resolution ansocopy (HRA) (Nayar et al, 2014). The most accurate method for examining the anal canal is anoscopy as two prospective studies found that anoscopy detects higher percentage of lesions in the anorectal canal as compared to a sigmoidoscopy (Alonso-Coello & Castillejo, 2003). HRA is a procedure similar to colposcopy and is performed as part of a diagnostic evaluation, therefore clinicians have to have proper equipment and specialised training (Lindsey et al, 2009).

A study by Nathan et al (2010) in the UK demonstrates that the performance of anal cytology was assessed by comparing against HRA and histology was useful in the clinical setting. This study was a retrospective analysis of prospectively collected data. Cytology samples from 395 patients were used of whom 212 were HIV positive. They found that the sensitivity of anal cytology was dependent on the area of disease and HIV infection. This study concludes that anal cytology is a good predictor of anal cancer warranting further investigation with high resolution anoscopy if the patient has a positive smear. This study also supports the introduction of early screening in HIV positive patients. The performance of anal cytology was assessed by comparing against HRA and histology. For comparison with histology, two separate definitions were used. The first defined a positive biopsy to be any abnormalities detected on biopsy. Anal cytology was read by experienced cytopathologists, and all histology was read similarly in the same institution. All histology was interpreted using a system derived from National Health Service cervical screening

programme (NHSCSP, 1999), which provides guidelines for reporting histopathology, including cervical intraepithelial neoplasia (CIN) in cervical screening in the UK, and classified as AIN1, AIN2 and AIN3 for anal screening (Hamilton and Aaltonen, 2000).

The psychological implications of cervical cancer screening have been demonstrated by many studies. In cervical screening, it has been reported that there has been an increase in anxiety and worry about cancer which can be detrimental to sexual well-being (French et al, 2004; Gray et al, 2006; Landstra et al, 2013; Wardle et al, 1995). Evidence shows that not only do high grade intraepithelial neoplasia (dysplasia) results have an adverse impact on individuals (Wardle et al, 1995) but low- grade intraepithelial neoplasia results have shown to have a negative psychological impact too. Low grade intraepithelial neoplasia represents only mild dysplasia or abnormal cell growth and is confined to the basal 1/3 of the epithelium. This usually corresponds to infection with HPV and has a high rate of regression back to normal cells. High grade intraepithelial neoplasia or severe dysplasia has undifferentiated neoplastic cells that span more than 2/3 of the epithelium and may involve the full thickness of the epithelium. This lesion may sometimes also be referred to as cervical carcinoma in situ (Agorastos, 2005).

Inadequate specimen results are associated with increased anxiety (Gray et al, 2006) and those patients most anxious are those who are not recalled for repeat testing even after a negative or normal Pap smear (French et al, 2004). An inadequate test result means that the test must be done again because the laboratory was not able to see the cells properly to give a result (CSP, 2012). In breast screening similar results as for cervical screening were found, however worry about breast cancer persists even after receiving reassurance of a false positive mammogram (Brett et al, 2005). In prostate cancer screening findings show that worry about cancer persisted amongst a group of men after they receive negative biopsy results, these patients sought more medical follow up with their clinician compared to the control group who did not have a biopsy. These patients were still anxious about a negative biopsy result and needed reassurance therefore made follow up appointments with their clinician (Fowler et al, 2006; McNaughton-Collins et al, 2004; Pickles et al, 2007). Cervical, breast and prostate cancer screening studies show that participants have demonstrated levels of anxiety and worry. This is related to any type of result whether results are low grade or high-grade neoplasia, inadequate or a negative result, this can have an impact on their psychological well-being.

Screening and treatment studies have been conducted around the world, but little research has focused on the psychological aspects of the anal cancer screening process, therefore there is a need to assess this under more naturalistic settings, i.e. researchers study the phenomena as they are without changing or manipulating the environment (Ching-Hong et al, 2008). Landstra et al (2012) carried out a study in Australia to explore the psychological consequences of anal cancer screening. Reponses from participants included anxiety, worry about cancer, lower sexual well-being; changes in behaviours such as, increased or reduced medical follow up; a person's knowledge about screening and disease and how this can influence psychological response to screening. This study concluded that anal cancer screening had no significant effect on general mental health but increased their worry of having anal cancer. A study by Tinmouth et al (2011) in Canada concluded that anal cancer is not associated with greater adverse psychological impact in most men who have sex with men.

It is evident from the literature that there is limited evidence in the UK to support anal cancer screening. This needs to be developed and included in the British HIV Association (BHIVA) guidelines like the way it has been included in the HIV guidelines in New York, where screening is well established and documented (The New York State Department of Health AIDS Institute, 2018). The psychological effects of anal cancer screening need to be explored as there are only few studies published so far.

1.3 Understanding Anatomy: Where AIN is detected

The anal canal is approximately 2.3-3.5 cm long and is the terminal part of the large intestine (figure 2) (Darragh, 2011). It extends from the upper aspect of the pelvic diaphragm to the anus. The anal canal extends from the perianal skin or anal verge to the rectal mucosa. The dentate or pectinate line is an important landmark as it represents the end of the squamous mucosa and beginning of transition from squamous to the absence of squamous mucosa (Uronis & Bendell, 2007). The transformation zone in the anal canal separates the columnar epithelium of the rectum from the keratinising anal squamous mucosa which lies above the dentate line. This is a site where anal intraepithelial neoplasms occur (Palefsky, 1994).

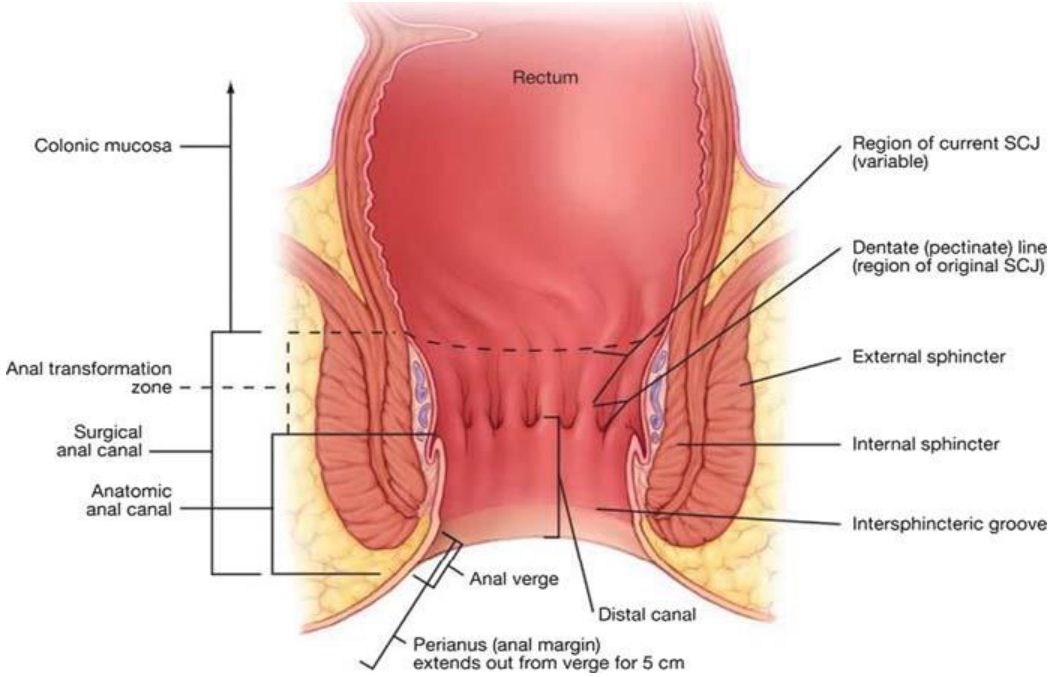


Figure 2 Anatomy of the anal canal and perianus (Darragh & Winkler, 2011).

Figure 2: The anus is the opening to the lower gastrointestinal (GI) tract and connects to the rectum, which connects to the colon, which traveling backwards connects to the small intestine, then the stomach, then the oesophagus and finally the mouth. The squamocolumnar junction is the area most commonly affected by HPV and where many of the lesions are likely to arise (Darragh & Winkler, 2011).

1.4 Process and Procedure of Anal Cytology

Anal cytology screening involves a Papanicolaou (Pap) smear from the anal canal where a moisten Dacron swab is rotated in the anal canal with gentle pressure on the walls, and slowly withdrawn and placed into Liquid Based Cytology (LBC) preservative. Experts recommend a Dacron swab to be used for anal cytology, which is a synthetic polyester fibre swab used for cell collection in anal canal while cotton swabs should not be used; cells adhere more to the cotton and are not as easily transferred to the glass slide or vial for liquid-based cytology (Darragh et al, 2011). The Dacron swab is inserted blindly approximately 5 cm beyond the anal verge and withdrawn over 30 seconds in a circular rotational motion to harvest cells from the epithelium in mucosal folds of the anal canal circumferentially (Wiley et al, 2013), so that adequate cells are collected using this this method. The UK National Screening Committee (UK NSC, 2010) state that anal

cytology screening is similar to cervical smear therefore referred to as anal Pap smear. In the UK, Liquid Base Cytology (LBC) has replaced conventional Pap smear method and LBC is used as the primary means of processing samples in cervical screening programme in England and Wales (NICE, 2003). Liquid based cytology increases the cell yield while decreases the faecal contamination and air-drying artefact common on direct smears (Darragh & Winkler, 2011).

1.5 Grading of Anal Dysplasia

Anal dysplasia is a pre-cancerous condition which occurs when the cells of the lining of the anal canal undergo abnormal changes. Anal dysplasia may progress from low-grade changes to high-grade changes before it turns into cancer. According to Wies (2017), High-grade anal intraepithelial neoplasia (HGAIN), the precursor of anal cancer, is identified by clinicians providing care for patients with anorectal disease and is increasingly being identified during screening of immunosuppressed patients for anal dysplasia. Anal cytology is currently one mode of screening for AIN (Roberts et al, 2017).

Cytology tests are reported using the Bethesda (2001) classification system where smears are evaluated according to the morphological features of the cells which indicate the degree of cellular abnormality. In the UK smears (NICE, 2003) are categorised using the British Society of Clinical Cytologists (BSCC) guidelines as negative cytology, borderline, mild, moderate, severe dysplasia, '? glandular neoplasia' or inadequate (Appendix 1). In the US (Appendix 1), the Bethesda system is used to classify smears as low grade squamous intraepithelial lesion (LSIL), high grade intraepithelial neoplasia (HSIL) and atypical squamous cells of undetermined significance (ASCUS) (Mallari et al, 2012). Histology findings after a biopsy are reported as AIN1, AIN 2, AIN 3 and CIS (carcinoma in situ) (Nayar et al, 2015).

1.6 Digital Anorectal Examination (DARE)

The DARE is performed as an essential part of the anal cancer screening process after the anal cytology has been taken but before HRA. The goal is to detect any palpable abnormalities which may guide the evaluation of anoscopic examinations and biopsies (Darragh et al, 2011). Although DARE is carried out by clinicians which is a painless procedure, the British HIV Association recommends that patients should be encouraged to check and report any lumps they notice in the anal canal (BHIVA, 2014). A water-soluble lubricant gel and lidocaine gel of 2%-5% is used for lubrication so that a gloved finger is inserted into the anus slowly with ease. The entire circumference and length of the anal canal staring at the rectum is palpated; then the mucosa over the internal sphincter and walls of the distal canal is palpated for warts, masses, areas of induration, discomfort and pain. Once DARE is completed in a systematic way, the perianal area is palpated and visually examined. Any findings on DARE should correlate with the visual examination. If there are hard firm, indurated immobile areas it should be noted as it could suspicious for cancer. Warts present a soft mobile, nodular and gritty to palpation (Darragh et al, 2011).

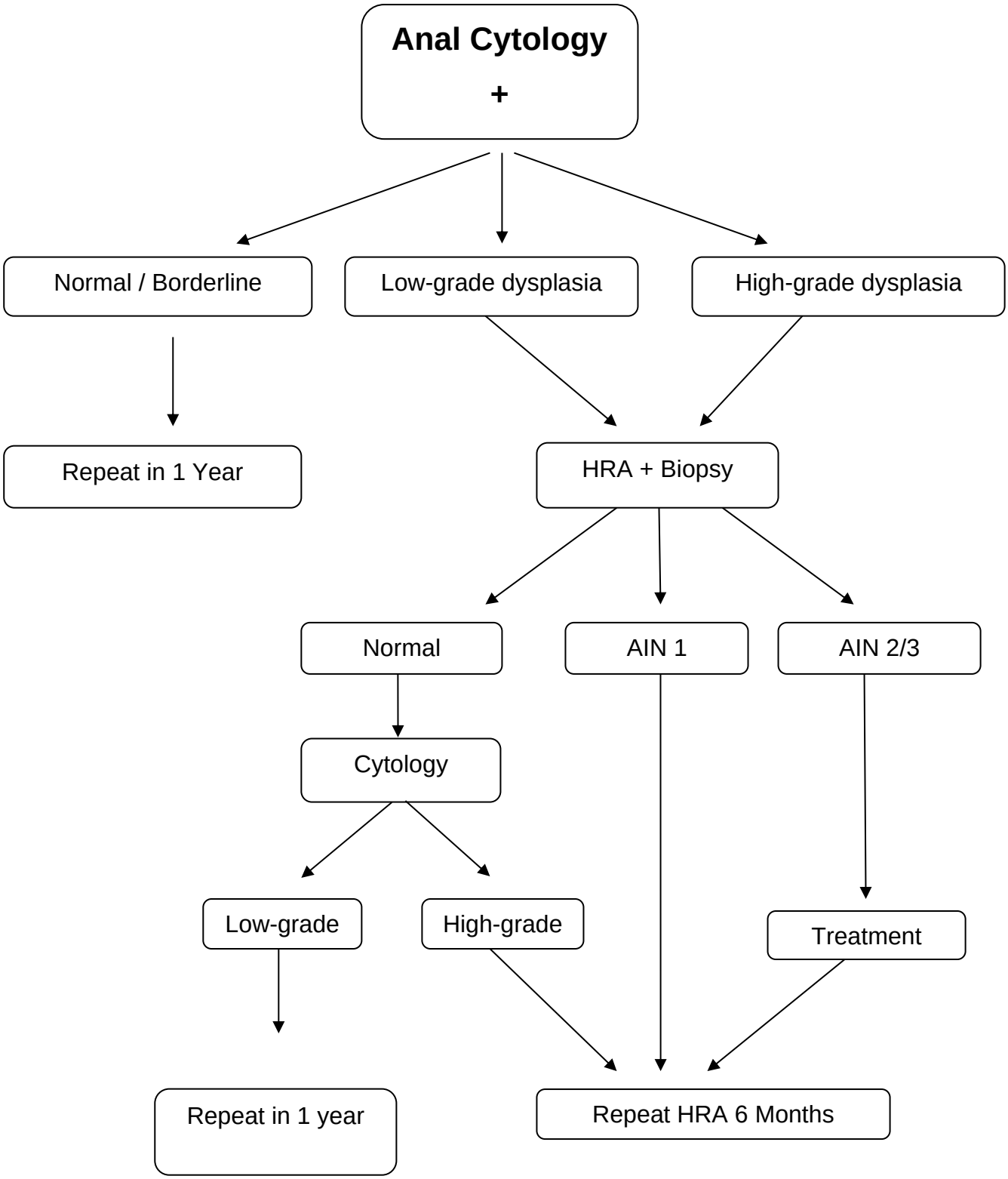
1.7 High Resolution Anoscopy

High-resolution anoscopy (HRA) is a procedure where patients with an increased risk of anal cancer and is fundamental procedure to detect high-grade lesions (Goldstone et al, 2014). An anoscope is introduced into the anal canal with a water-soluble lubricant and a gauze padded swab soaked in 3% to 5% acetic acid is passed through the anoscope. The anoscope is withdrawn and the gauze swab left in anal canal for 1-2 minutes before removing it and reintroducing the anoscope. Once the lubricated anoscope is reinserted into the anal canal, a colposcope is used with magnification and bright light is used to visualise abnormalities. Biopsies are usually performed where acetowhite lesions showed punctuation, friability and highly vascularised appearances. Biopsies are performed using endoscopic forceps (Wiley et al, 2013).

In the UK, the laboratory reports cytology, as low, moderate, or high-grade dysplasia, as categorised, by the BSCC (NICE, 2003). All patients living with HIV are offered anal cytology as part of their HIV care in the HIV outpatient department at the NHS trust sexual health clinic. I developed an algorithm in figure 3 which I adapted from Park and Palefsky (2010).

for the HIV outpatient anal cancer screening process. For my practice I set up this algorithm for anal cancer screening and currently use this to guide practice locally. I also took into account the updated guidelines International Guidelines for Practice Standards in the Detection of Anal Cancer Precursors (AINS, 2016). This is the proposed guidelines for practice standards in the detection of anal cancer precursors was developed using anal cytology and HRA. If anal cytology results are normal or borderline, the cytology is repeated in 1 year and monitored. Cytology results with low grade dysplasia HRA and biopsy undertaken. If on HRA the results are normal, and cytology indicates low grade dysplasia, the cytology can be repeated in a year. However, if HRA was normal and but cytology result is high grade dysplasia, HRA is repeated in 6 months. High grade dysplasia on cytology warrants HRA and biopsy and follow up for AIN1, AIN 2/3 is 6 monthly HRA and monitoring (figure 3).

Figure 3: Anal Cancer Screening algorithm



(Algorithm I developed for anal cancer screening which I adapted from Park & Palefsky, 2010).

1.8 Prevalence and Incidence of AIN

Anal squamous cell carcinomas are relatively uncommon tumours; there are between 350 and 400 new cases per year in England and Wales (Scholefield & Nugent, 2011). According to cancer research UK (CRUK, 2018) there are around 1,400 new anal cancer cases in the UK every year, that's nearly 4 every day which are statistics between 2013-2015. In the UK, 33% of anal cancer cases are in males, and 67% are in females (CRUK, 2015).

Anal cancer although considered to be a rare tumour, has been rising over the last 25 years where it was once thought that anal cancer develops as a result of chronic irritation in the anal canal (Uronis & Bendell, 2007). People living with HIV and AIDS suffer from anal cancers, much more often than the HIV-negative population and persistent HPV infection is the basis for the development of malignancy (Oette et al, 2017). Nowadays this is not the case as multiple risk factors such as HPV infection, infection with multiple HPV genotypes, cervical dysplasia or cancer, anoreceptive intercourse, smoking, immunosuppression following solid organ transplant and HIV infection is associated with anal cancer as more HIV positive patients are being diagnosed with this disease (Welton et al, 2004).

Observational studies reviewed by Simpson and Scholefield (2011) have indicated that individuals with HPV infection, those immunocompromised, and those living with HIV are more at risk of developing anal cancer. Several studies presented show that HPV is a risk factor for developing anal cell carcinoma which affects people living with HIV, MSM, and immunocompromised people. According to Swedish et al (2011) anal cancer is rapidly increasing in people living with HIV while Berry et al (2009) argues that irrespective of an individual's HIV status, HPV is a risk factor for developing anal cancer. Berry et al (2004) mentions, that although anal cancer is increasing across the world, especially in people living with HIV, it is well documented in homosexual men. However, the incidence of anal squamous-cell carcinoma is increasing rapidly among MSM, those infected with HIV, and other immunosuppressed people (Park et al, 2010 & Salit et al, 2010). HIV-positive MSM are at greatest risk, with a reported incidence of squamous-cell anal carcinoma ranging from 60 to 160 per 100,000 (Crum-Cianfliane et al, 2010 & D'Souza et al, 2010). The National Cancer Institute (2010) estimated in the United States (US), anal carcinoma

would be diagnosed in 5260 men and women and that 720 men and women would die of anal cancer in 2010.

It has been estimated that approximately 14 500 cases of anal squamous cell cancer in women and 12 500 in men occurred in 2008 worldwide. Previous studies have reported a relatively rapid increase in the incidence rate in some very high-income countries, including Australia, Canada, Denmark, France, the Netherlands, the UK and the USA (Islami et al, 2017). The incidence rates of anal squamous cell carcinoma are approximately 2 per 100 000 in the general population globally in both men and women (Grulich et al, 2012). This represents a two-fold increase compared to 30 years ago, and is attributed to populations at high risk, primarily MSM and immunocompromised people. There has been a steady rise in anal cancer among MSM concurrent with the HIV epidemic in the 1980's and does not seem to decline with HIV infected individuals living longer with antiretroviral therapy. Prior to the HIV epidemic (mid-to-late 1970's), the incidence of anal cancer was 35 per 100 000 presumed to be MSM (Daling et al, 1987). More recent data show that the incidence of anal cancer among HIV infected MSM is 60 per 100 000 and at the time of an AIDS diagnosis is 137 per 100 000 (D'Souza et al, 2008) while women who are infected with HIV; there is seven-fold higher risk of anal cancer after the diagnosis of AIDS (Frisch, 2000). There have been marked increases in anal squamous cell carcinoma (SCC) in recent decade with an annual rate of greater than 5 per 100 000 reported in Australians with 48% of cases diagnosed in people over 65. The increasing incidence of anal SCC in the general population may be related to changing sexual practices over time, such as earlier age of sexual intercourse and higher number of life time partners (Grulich et al, 2012). The increase in anal SCC in Denmark commenced in the 1960's and was greater in women than in men including residents of Copenhagen (Frisch et al, 1993, Nielsen et al, 2012). In the US, between the years of 1998-2003 anal SCC increased by an average of 2.6% per year and this trend was similar in men and women (Joseph et al, 2008).

The prevalence and incidence of anal squamous cell carcinoma is on the increase in the studies from UK, Australia, America and Denmark primarily in high risk groups like MSM and immunocompromised individuals.

1.9 Anal Cancer Screening

Most of the anal cancer is squamous cell carcinoma (Roberts et al, 2017). Several anal cancer screening techniques can be used to screen for anal cancer and lesions which may develop into anal cancers. Potential screening modalities include digital anorectal exam, anal Papanicolaou testing, human papilloma virus co-testing, and high-resolution anoscopy (Leeds and Fang, 2016). Pre-cancerous lesions are generally called Anal Intra-epithelial Neoplasia (AIN). The combination of anal cytology, possibly paired with anal HPV molecular testing, followed by HRA in individuals with positive results, represents a reasonable strategy to screen for AIN (Roberts et al, 2017). All types of AIN need monitoring and anal cancers need High Resolution Anoscopy to obtain a visual image of the anal canal and for biopsies to be taken to define exactly what the lesion is. All types of AIN (AIN 1-3) or anal precancers are very susceptible to treatment and have a good prognosis. Prior to the 1970's anal cancer was treated with abdominoperineal resection but the standard of care these days is concurrent chemoradiation therapy with surgery reserved for patients with residual disease (Uronis & Bendell, 2007). According to Weis (2013) HGAIN can then be ablated with several modalities, including infrared coagulation, CO2 laser, and electrocautery. These methods for HGAIN ablation can be performed with local anaesthesia in an outpatient clinic and are relatively well tolerated. Another treatment approach for HGAIN is topical treatment, principally with 5-fluorouracil or imiquimod.

1.9.1 Anal Cancer Screening Programs

The goals of anal cancer screening programs are to detect those patients with high grade AIN (HGAIN), locate these lesions, and treat lesions before it develops into cancer. The tools for anal cancer screening have been adapted from the tools used to screen and detect cervical lesions (Palefsky et al, 1997). The first clinic for anal dysplasia was established in 1993 at University of California, San Francisco, and this became the model for development of clinics in other cities throughout North America, Europe, Australia and New Zealand as the recognition of anal cancer screening is growing, and Jay et al (2011) states that anal cancer screening should be considered for HIV infected patients. Some clinicians have adopted a similar model of screening in the UK, but services are limited. According to a survey by Vera et al (2013), 15(21%) of the sexual health clinics in the who responded to the survey, are planning to set up a screening service in the future, while

other clinics are waiting for national guidelines.

The decrease in cervical cancers prior to cytology screening from 35 per 100 000 to its current incidence of 9 per 100 000 is attributed to the implementation of cervical cytology screening followed by colposcopy for identification and treatment of high grade CIN, thus preventing its progression to cancer (Watson et al, 2009). However, cervical screening programs were established on assumptions and without proof of efficacy, but still led to a decline in cervical cancers (Rotkin, 1967). Colposcopy enables the clinician to locate suspicious areas using a powerful light source and magnification, and colposcopy-directed biopsies remain the gold standard of diagnosis for cervical disease (Jay et al 1997). Colposcopy was first used in anal canal lesions in 1977 (O'Connor, 1977), and in 1997 the colposcopic descriptors and terminology were validated for anal lesions. Lesions (descriptors) were characterized by colour, contour, surface configuration, and vascular patterns using colposcopic criteria standardized for the cervix. Terminology for example for cervical high-grade squamous intraepithelial lesion (HSIL), was adapted and used for anal HSIL as this is analogous to precursor for cervical cancer (Jay et al, 1997). High resolution anoscopy (HRA) was the term used to describe anal colposcopy more than 15 years ago, by a colorectal surgeon in the US and was first published in literature in 2001 (Goldstone et al, 2001). In San Francisco, many at risk patients receive anal cancer screening and rates of HGAIN detection have increased. This can be attributed to the fact that anal screening has been effective and anal cancer rates have not increased despite doubling elsewhere (Jay, 2011).

The only established screening programmes available in the UK are for breast, bowel and cervical cancer screening. According to Cancer Research UK, a screening programme must have a 'good enough' test for it to work (CRUK, 2016), and this test must:

- reliably detect any cancers or abnormal changes that could lead to cancer
- not cause too many false alarms
- be acceptable, so that people will actually take the test
- not be dangerous to health
- be cost-effective.

According to CRUK (2016), if a test doesn't meet the criteria mentioned above, then it is unlikely to be effective for whole population screening, it would not be an effective use of time and money to screen the entire population. This would be harder for the benefits to outweigh the harms of anal cancer screening as this would cause unnecessary worry for those being screened. If good tests are available for rarer cancers, doctors will often offer them to people who have the highest risk of the disease.

In 2012 the UK National Screening Committee (UKNSC) carried out a review for anal cancer screening and concluded that this issue did not meet the criteria for cancer screening programmes (CSP). However, this committee agreed that it was an important issue and the CSP set up an evaluation of utility of HPV testing and liquid based cytology sampling (i.e. Pap smear) for the clinical management of patients at high risk of anal cancer. The high-risk groups were MSM, HIV positive men and women, women who have anal receptive sex, women and men who have had solid organ transplant and this project was set up with GUM and the Lesbian and Gay Foundation in Manchester in the UK (UKNSC, 2013). Results of this study called the Analogy Study, still needs to be published. This study is investigating the feasibility and effectiveness of screening for the precursors of anal cancer in groups who are at increased risk of developing the disease (CRUK, 2016).

One of the largest studies in the UK will be undertaken which is the "Laser Ablation versus Observation to Prevent Anal Cancer" (LOPAC) trial. This trial will be funded by National Institute for Health Research Homerton University Hospital NHS Foundation (HUHFT, 2016). The Homerton Anal Intraepithelial Neoplasia Society (HANS) receives referrals from all over the UK and the aim of this study is to assess whether laser treatment is effective in preventing anal cancer in HIV-positive MSM identified to have high-grade AIN disease (precancer). About 3,500 HIV-positive MSM will be recruited into the trial from four to five HIV units across London and screened for anal precancer. These patients will be followed up every six months with a standard examination, consisting of HRA, DARE and biopsy of persistent or new AIN 2 and/or AIN 3 or other areas suspected of cancer. Recruitment into the study will last 36 months and the total duration of the trial is 72 months. It is unclear whether testing a sample of cells from the anus or other laboratory tests are suitable and is more accurate tool for anal cancer screening. There are many

tests being studied in laboratories, but to establish how good they are, this trial would be able to see how they perform in a 'real-life' setting. Therefore, the aim of the LOPAC study is to find best tests to improve anal cancer screening. It is also hoped this study identifies what lifestyle and health behaviors' may be associated with any anal abnormalities and cancer (HUHFT, 2016).

A US-based multicenter study Anal Cancer HSIL Outcomes Research (ANCHOR) is underway which started in April 2015 and will last for 5 years. This study will help determine whether screening and treatment of HSIL should be the standard of care for people living with HIV and for other groups of people with a high risk for anal cancer. The tissue samples collected in this study will help advance understanding of different HPV strains and their role in causing anal and cervical cancers (The Anchor Study, 2016).

The Study of the Prevention of Anal Cancer (SPANC) in Sydney, Australia, began in September 2010 and concluded in mid-2015. The SPANC study is one of only a small number of cohort studies globally to perform HPV, cytology and HRA screening on all participants over multiple time points as well as performing HPV DNA genotyping. However, follow up of HIV negative and HIV positive homosexual men aged 35 and over will continue to 2018.The findings of this study will contribute to the understanding of the natural history of anal HPV and inform the development of guidelines for implementing anal cancer screening programs in this population (Machalek et al, 2013).

1.9.2 Anal Screening Guidelines

In the absence of any national anal cancer screening guidelines in the UK, the British HIV Association only made recommendations that all major HIV units should develop clinical guidelines for the management of suspected anal cancer and precancer; these HIV units should develop either local clinical expertise, or referral pathways for suspected anal cancer and pre-cancer (BHIVA, 2008). The updated published UK guidelines for the management of sexual and reproductive health (SRH) of people living with HIV infection, produced jointly by BHIVA, BASHH and FFPRHC, includes advice on anal cancer in HIV infection (BHIVA, 2014). These key points and recommendations have not changed the recommendations of BHIVA, BASHH and FFPRHC 2008 guidelines on anal cancer in HIV. Hence this has encouraged some HIV outpatient clinics in the UK to develop anal screening protocols locally once clinicians have undergone the appropriate training for

anal cytology and HRA.

The Association of Coloproctology of Great Britain and Ireland (ACPGBI) Colorectal Disease Position Statement for Management of anal cancer multi-disciplinary team working group has become established in the last 10 years for colorectal cancer, and several sets of Local, National, and International Guidelines have been developed for the management of colorectal cancer (ACPGBI, 2011). In the existing guidelines for colorectal cancer, anal cancer receives only limited coverage because it is a rare tumour. Colorectal surgeons with a large AIN practice where there are many patients living with HIV, may require specific collaborations with their local GUM and HIV clinicians (Scholefield and Nugent, 2011). Further to this position statement in 2011 by Scholefield and Nugent (2011), they seem to think that although there is probably no place for screening for AIN even in high-risk groups, some centres in the United States have started screening for AIN in HIV cohorts using anal cytology. Scholefield et al (2011) states that anal cancer screening is probably only appropriate as part of a trial in high-risk groups in the United Kingdom.

There is a growing concern that anal cancer screening, prevention and early intervention need to be implemented as it is for cervical, breast and prostate cancers (Darragh and Winkler, 2011). In the United States of America, New York State is the only state to develop guidelines for anal cancer screening. The New York State Department of Health AIDS Institute (2018) states that, HIV infection is an independent risk factor for anal neoplasia. Individuals with a history of long cumulative periods of immunosuppression or high viral replication may be at higher risk for developing anal cancer (Guiguet et al, 2009). The New York State guidelines (2018) recommend that at baseline and as part of the annual physical examination for all HIV-infected adults, regardless of age clinicians should enquire about anal symptoms, such as itching, bleeding, diarrhoea, or pain; perform a visual inspection of the perianal region and perform a digital rectal examination. These guidelines also recommend that clinicians should obtain anal cytology at baseline and annually thereafter in the HIV infected populations. Clinicians should refer patients with abnormal anal cytology for high resolution anoscopy and examination with a biopsy of abnormal tissue (The New York State Department of Health AIDS Institute, 2018). Some sexual health clinics in the UK, according to Vera et al, (2013), have adopted anal cancer screening for people living with HIV as stated in the New York State clinical guidelines.

According to the New York State department of Health Aids Institute (2018) HIV guidelines, clinicians should refer women with cervical HSIL; any patient with abnormal anal physical findings such as warts hypopigmentated or hyperpigmentated plaques or lesions; lesions that bleed or lesions of uncertain aetiology for HRA and/or examination with biopsy of abnormal tissue. As part of these guidelines, clinicians should also obtain anal cytology at baseline (first visit to clinic) and annually in the HIV infected populations especially in MSM, any patient with a history of anogenital condylomas and women with abnormal cervical and or vulvar histology (Abramowitz et al, 2007; ; Anderson et al, 2005; Berry et al, 2005; Frisch et al, 2001; Frisch et al, 2000; Frisch et al, 1994). These guidelines also recommend that in communities where there are no clinicians available to perform HRA then patients with abnormal cytology should be referred to a surgeon for evaluation (The New York State Department of Health Aids Institute, 2018).

The European Aids Society (2014) is a not-for-profit organisation, whose mission is to promote excellence in standards of care, research and education in HIV infection and related co-infections, and to actively engage in the formulation of public health policy, with the aim of reducing HIV disease burden across Europe. The aim of the EACS Guidelines is to provide easily accessible recommendations to clinicians centrally involved in the care of HIV-positive persons. These guidelines are to support anal cancer screening in MSM living with HIV. According the EACS guidelines, screening methods should involve a digital anal rectal examination with or without anal cytology. These guidelines are intended to provide the best guide to clinical management while it is recognised that the level of evidence varies, and there is limited evidence from randomised controlled trials on the management of non-infectious co-morbidities in HIV. The current management of anal cancer screening is mainly derived from general medical guidelines and therefore represents the collective consensus opinion from a panel of experts in the field of HIV and range of co-morbidities (EACS, 2012). However, in 2017, recommendations for screening for anal cancer were extended to also include all persons with HPV-associated dysplasia (EACS, 2017).

The European Society for Medical Oncology which is a leading European professional organisation for medical oncology have produced clinical guidelines for screening and prevention of anal cancer and proposed using anal cytology and HRA for high risk

populations, MSM and HIV, women with a history of anal intercourse or other HPV related anogenital malignancies (ESMO, 2015).

Although recommendations exist for anal cancer screening in the UK (BHIVA, 2015), the challenge is certainly the paucity of clinicians with expertise in HRA as this has limited the introduction of screening guidelines for at risk populations (Bower &Newsom-Davis, 2010). Anal cancer is increasing in patients living with HIV. An understanding of the natural history of AIN disease, improvements in the management of AIN and the prudent use of screening programs, the prognosis for anal cancer should continue to improve (Biggar et al, 2005). Smith and Mounzer (2014) agree with the fact that currently, the lack of experienced high resolution anoscopists is a major obstacle for the expansion of AIN screening programs. A study by Patel et al (2014) on global practices of anal cancer screening practices, where data were collected using on line surveys, 82 providers from 80 clinics in Canada, USA, Europe, Asia and Australia took part. This study demonstrated that there is considerable variation in anal cancer screening practices around the world and there does not appear to be any universal consensus on optimal strategies for anal cancer screening, treatment and follow up. In the United States, private insurance and public funds are the two most common methods of payment for anal screening whereas in Canada and other countries public funds are exclusively used for payment. Most clinics in the US, bills are paid by insurance companies or health maintenance organisations, while clinics in other parts of world (i.e. Asia, Europe and Australia) receive funds from hospital budgets (Patel et al, 2014).

These screening programmes have the potential to reduce morbidity but for some individuals screening programmes have the potential to decrease the psychological well-being due to uncertainty associated with screening procedures and results (Barratt et al, 2002; McCaffery & Barratt, 2002; McMaughton-Collins et al, 2004; Shaw et al, 1999; Stewart-Brown & Farmer, 1997). According to Landstra et al (2013), this aspect has not been investigated.

1.9.3 Impact of Publicity about Celebrities in Anal, Breast, and Cervical Cancer Screening

Research has demonstrated that celebrities disclosing their own illness can increase public interest in the specific disease and can change the public's behaviour (Cram et al,

2003). The death of Farrah Fawcett, an American actress in 2009, gave anal cancer a higher profile. She was first diagnosed in 2006 and died at the age of 62 (Ortoski & Kell, 2011). The Farrah Fawcett foundation started in 2007 and has now collaborated with the HPV and Anal Cancer Foundation in helping to create the International Anal Neoplasia Society (IANS, 2013) which is the world's first professional society devoted to prevention and treatment of anal cancer (The Farrah Fawcett Foundation, 2016).

In Australia, the famous singer Kylie Minogue had a breast cancer diagnosis which caused an increase in bookings for mammography. This publicity resulted in a 20-fold increase in news coverage of breast cancer, which emphasised that young women do get breast cancer and that early detection was critical. Screening bookings rose 40% in the 2 weeks of the publicity, with a 101% increase in non-screened women in the eligible age-group of 40-69 years. Six weeks following the publicity, bookings remained more than a third higher in non-screened women (Chapman et al, 2005).

In the UK in 2013, the unprecedented publicity of Angelina Jolie in hereditary breast cancer and her decision to have genetic testing for BRCA1 gene and having under gone risk reducing mastectomy (RRM) and the prelease of NICE guidelines on familial genetic testing in January with final release on 26th June 2013 created a lot of publicity. The 'Angelina effect' which is long lasting and went global appears to have increased referrals to centres for breast screening (Gareth et al, 2014). Jade Goody the reality television celebrity died from cervical cancer on 22nd March 2009. Her illness increased media and public interest in cervical cancer (Metcalfe et al, 2010).

Celebrities disclosing cancer diagnosis in public has influenced peoples' views and interest in cancer screening. Celebrity cancer diagnosis can significantly influence public health behaviour, including the uptake of prevention programmes (Chapman et al, 2005, Twine et al 2006). This study shows that public information, searching behaviour and interest in screening are associated with key events in a high-profile celebrity illness and this suggests a role for the media in influencing public health information seeking (Metcalfe et al, 2010).

1.9.4 Cost-Effectiveness of Anal cancer screening

Anal cancer requires a multidisciplinary team approach with regards to treatment which often requires complex interventions despite it being a rare condition, and these cancer patients have placed a significant burden on the NHS resources (Keeping et al, 2014). Czoski-Murray et al (2010) as cited by the UKNSC (2012) found that screening for anal cancer is very unlikely to be cost-effective and the determinant of this finding was the low observed incidence of anal cancer. The conclusion of this study was supported by research done by Gaisa et al (2011), where they critically reviewed the literature, conducted a comparative analysis and discussed treatment modalities for anal HPV. Findings from the study by Gasia et al (2011) on cost effectiveness were apparent that, screening only for high risk groups i.e. MSM is cost-effective. Lam et al (2011) provides an argument that for HIV infected MSM, anal cancer screening should be initiated with the direct use of HRA as this is the most cost-effective strategy for detecting AIN 2&3. Ong et al (2016) provides an argument that detection of HSIL using anal Pap smears, lack of trained anoscopists for HRA and insufficient evidence that screening reduces anal cancer morbidity or mortality, has led to many conflicting responses for anal Pap and HRA as an intervention to be cost effective.

1.10 Purpose of my Study

The overarching aims and objectives to be addressed in my study is to consider the UKNSC (2012) criterion 15 which states that the benefit from the screening programme should outweigh the physical and psychological harm caused by tests and diagnostic procedures. Under criterion 15, point no 50 concludes that no evidence was identified and therefore there is no update to the conclusions of Czoski-Murray et al. (2010:70): “The screening process does not appear to present any physical harm; however, any psychological effects of anal cytology screening or pap smears have not been evaluated in the studies included in this review.”

The purpose of my study involved the paucity of research undertaken on the psychological aspects of cancer screening as in breast, prostate, cervical, colorectal screening. Clinicians have identified that there are varying practices on anal cancer screening

worldwide, that there are no universal optimal screening strategies for anal screening; there is a lack of clinician training and resources available to set up an HRA service.

My study is designed to produce evidence which could help inform several criteria as identified in the UK NSC (2012) which is necessary to inform decisions about future screening or introduction of routine anal cancer cancer screening programmes. My study is unique in that it includes patients and clinicians to address the research question so decision-makers will be better equipped to design and deliver health services which meet their needs for future development of anal cancer screening programs and guidelines. While addressing patients' and clinicians', either reflecting on their perceptions and experiences of anal cancer screening and health services, or engaging with research itself, I will be able to identify important areas for research and address any gaps needed for future research. My research aims were to explore the perceptions and experiences of patients and clinicians in anal cytology screening and high resolution anoscopy in the UK. The UK NSC (2012) criterion 18 states, "There should be a plan for managing and monitoring the screening programme and an agreed set of quality assurance standards" and point 57 states: "This have not been established for anal cancer although quality assurance guidelines for the screening of other cancers (such as cervical screening) will provide a model for the development of an anal cancer screening program". However, in 2017 the UKNSC reviewed the recommendations on anal cancer screening and states that a national screening program is not recommended as there is not enough evidence and understanding of the condition to be sure a screening programme would deliver sufficient benefit (UKNSC, 2017). The UKNSC (2017) does state that anal cancer remains a rare but important condition, and anal cancer has been removed from the UK NSC's list of topics as this topic is confined to high risk groups. While anal cancer is rare and not recommended for national guidelines at present, my study will provide findings to contribute to the research and evidence needed on the psychological effects on anal cancer screening. My study will also aim to contribute evidence to the advisory groups i.e. BHIVA, BASHH so that consideration for evidence to be included in HIV guidelines for people living with HIV

There are numerous studies on the psychological effects of screening on cervical (Szarewski, 2011), prostate (McNaughton-Collins, 2004), and breast (Brett et al, 2005) cancer. Landstra et al (2012), state that these studies can provide valuable insights into

potential psychological effects of anal cancer screening. The lack of clear guidelines for anal cancer screening or the availability of standardised screening programs, may increase the worry felt by people living with HIV and these authors believe that increasing screening programmes may be accompanied by an increase need or participants to receive some form of psychological support depending on their results and psychological response (Landstra et al, 2013). Although anal cancer can be detected, the British HIV association produced recommendations in the HIV guidelines in the UK in 2008 on sexual and reproductive health of people living with HIV infection, to provide advice on anal cancer in HIV infection. In 2014, BHIVA advocated that all major centres should develop local guidelines for anal screening (BHIVA, 2014). Research is needed on the potential impact screening programs may have on individuals undergoing anal cytology screening and high resolution anoscopy and its impact on future uptake of healthcare.

1.11 Research Aims and Questions

The overall aim of my study is to:

1. Explore the perceptions and experiences of patients and clinicians on anal cancer screening
2. Generate findings to help inform clinical practice for anal screening in sexual health clinics in the UK.

These aims will be achieved by asking the following question: What are the perceptions and experiences of patients and clinicians in anal cytology screening and high resolution anoscopy in the UK?

This chapter has explained how I came to undertake the research on anal cancer screening in the UK. The use of me in my personal account of experiences in anal cancer was necessary to justify why I undertook this study. I used reflexivity to enhance credibility, trustworthiness and transparency is evident in my account which embraces the philosophy of hermeneutic phenomenology. The research aims, and question is made explicit to the research community.

Chapter 2 introduces the review of literature, search methods, studies from varying perspectives around AIN, anal cancer and screening programmes available around the world.

2 Literature Review

A literature review is a process of studying what has already been written on a particular topic and it can serve multiple purposes at different stages of the research and writing process; often it takes place throughout the qualitative research process since the process itself is iterative and new questions and concepts are arise (Creswell, 2009). The process of reviewing the literature requires different kinds of activities and ways of thinking. The activities involve searching and preparation for the review and getting access to sources of information. By understanding ways of thinking, connecting this to how the researcher is engaged in the literature review, and is self-reflective in the process which means that the researcher is engaged in the research process (Baker, 2000). With the help of literature review, the researcher finds a fresh and original research question, identify unknown gaps in the literature or make connections (Shields & Rangarajan, 2013). However, Holloway & Wheeler (2010) suggest some sort of trawl and search for literature should be carried out because an answer to the research question may exist in the public domain. Therefore, when I reviewed the literature, I considered my research question and identified any gaps in the literature to be able to find new research. The role of a literature review in qualitative research depends on the methodology in use, and on the goals of the research itself, and can generally only be determined by consulting available research literature. Literature review can also be used to refer to a section of a research report that describes prior research on the topic (Cresswell, 2009).

I searched a broad range of platforms to identify all relevant information for my study. According to Aveyard (2010), the literature search strategies can be defined as systematic processes followed by the researcher to locate the evidences appropriate to inform the research aims and objectives. For any research to reach firm and relevant conclusions and to inform practice there must be a detailed literature search process. This must detail how data are retrieved, explain the inclusion and exclusion criteria and collate the most relevant data to make firm and relevant judgements. Harvard (2007) states that a well-structured literature search is the most effective and efficient way to locate sound evidence on the subject being researched, that evidence may be found in books, journals, government documents and organisational websites.

This chapter explores the study within current research evidence by:

- Describing the literature search strategy
- Reviewing the literature on the psychological effects of anal screening from participants and clinicians' perspective
- Discussing the findings and relevance of previous studies to present studies
- Demonstrating gaps in the literature

2.1 Inclusion and Exclusion Criteria

Researchers must set inclusion and exclusion criteria for their studies as these facilitate the retrieval of significant literature (Aveyard, 2010). The exclusion criteria for my study were minimal due to the scarcity of publications on this topic. The exclusion criteria for my study were evaluation of treatments for AIN. My study is to explore the perceptions and experiences in anal cytology and high resolution anoscopy i.e. to explore the physical and psychological harm caused by the test (anal Pap smear), and diagnostic procedures (HRA). All studies on patients and clinicians in anal cancer screening were included and reviewed for the following inclusion criteria:

- Screening for anal cancer
- Original research on psychological/psychosocial aspects of anal cancer screening
- English publications from 1997 onwards
- Local, national and international/global publications

The inclusion and exclusion criteria of studies may be defined by factors including population characteristics, health or clinical topic, methods and methodology (i.e. philosophical approach), language, time frame or type of publication. This should be justified for readers to make an assessment about the transferability of the findings to their own setting, as description of the study characteristics and screening and reasons for the excluding studies is needed (Tong et al, 2012). The PEO search strategy method used in my search clearly outlines the characteristics for inclusion criteria. According to Bettany-Saltikov (2012), the PEO methods are used widely in nursing and health research to help manage and break down research questions especially in qualitative.

2.2 The Literature Search Strategy

I used the PEO search strategy where I was able to break down the research question which helped me to identify the key concepts in my research question so that I could develop search terms (discussed below) to describe these concepts and determine my inclusion and exclusion criteria for my study. A researcher should take precautions when applying phrases as it could lead to exclusion of relevant evidences or inclusion of data not necessary to inform the study question (Aveyard, 2010). This acronym PEO is: Population/Problem, Exposure, Outcome and I applied this to my study as follows:

P= Patients living with HIV undergoing anal cancer screening and clinicians undertaking anal cancer screening
E= Anal cancer screening (anal cytology, DARE and HRA)
O= Perceptions and experiences of anal cancer screening

The PEO question for my study: what were the perceptions and experiences of patients and clinicians in anal cytology and high resolution anoscopy? The population is patients living with HIV (i.e. the community affected) and clinicians undertaking anal cancer screening to include anal cytology, DARE and high resolution ansocopy. Exposure was patients undergoing anal cancer screening and clinicians undertaking anal cytology and high resolution anoscopy. The outcomes included the perceptions and experiences of patients and clinicians in anal cancer screening. According to Bettany-Saltikov (2012), the PEO format in qualitative research includes the population and their problems, who are the users, patients or community being affected? What are their symptoms, age, gender etc? Exposure use is for a specific exposure (this term is used loosely) such as “anal cancer” or “anal cancer screening”. Outcomes or themes for example are if you are looking for improvements in pain, responsiveness to treatment, mobility, quality of life, daily living? Usually there will be an element of looking at patient’s experiences

I employed structured search strategies and focused on databases, using specific key words searches as discussed using the PEO format (such as anal cancer screening, AIN, people living with HIV and clinicians undertaking anal screening, psychological effects of anal cancer screening), so that I could yield valid and reliable data from these healthcare databases. Given the nature of my study, the following databases were searched for

relevant studies: British Nursing Index (BNI), PsychInfo, Cumulative Index of Nursing & Allied Health (CINHAL), Embase and Medline. Several databases could be used as sources of retrieving the most relevant evidences to inform studies (Cormack, 201g0). It must be noted that one of the best approaches to ensuring valid and reliable data are retrieved, is the use several data bases (Baker, 2010) and to set inclusion and exclusion criteria as art for ensuring that data included are valid and reliable (Ellis, 2010). These candidate databases I used, covered all aspects of AIN, anal cancer, psychological effects of anal screening. According to Wakefield (2015), the purpose is to present an in-depth examination of the main themes isolated from the data sources accessed, while simultaneously establishing the reliability, credibility and trustworthiness of the sources of information targeted. I did a literature search in two phases. My first literature search run was undertaken in 2011 (Updated October 2017) where I accessed literature from databases such as EMBASE, MEDLINE, BNI, PyschInfo and CINHAL.

The method I used in collection of literature was a computerised database search, snowballing, grey literature search and hand searching. The purpose of my literature review is to investigate the evidence on anal cancer screening and to explore the psychological effects it has on participants. I undertook a comprehensive review of scholarly articles to gain a deep understanding of the psychological impact of anal screening studies like knowledge, attitudes, and willingness to undertake screening, acceptability and evaluation of screening procedure. The purpose of my study involved the paucity of research undertaken on the psychological aspects of cancer screening as in breast, prostate, cervical, colorectal screening.

Another method I used in my literature search was the snowballing approach. Snowballing is defined as a method where the reference list of a paper or the citations is used to identify additional papers. This can also complement searches with a systematic way of looking at where papers are cited and referenced (Wohlin, 2014). Snowballing retrieval of information does not require predetermined search strings but is likely to introduce subjectivity to the process and a researcher bias to studies included (Hagen-Zanker & Mallet, 2013).

Hand searching was also an important and useful process in my literature review strategy. This search is beyond using data bases for searches as it involves a manual page-by-

page examination of the entire contents of a journal issue or conference proceedings to identify all eligible reports of trials. In journals, reports of trials may appear in articles, abstracts, news columns, editorials, letters or other text (Armstrong et al, 2007). By hand searching healthcare journals and conference proceedings is a useful adjunct to searching electronic databases for at least two reasons: (1) not all trial reports are included in electronic bibliographic databases, and (2) even when they are included, they may not contain relevant search terms in the titles or abstracts or be indexed with terms that allow them to be easily identified as trials (Dickersin et al, 1994). To support this argument, a Cochrane Methodology Review has found that a combination of hand searching and electronic searching is necessary for full identification of relevant reports published in journals, even for those that are indexed in MEDLINE (Hopewell 2007a).

To keep up to date with current published literature on AIN I also registered on "ResearchGate", a social networking site for scientists and researchers (OSC, 2015). ResearchGate indexes self-published information on user profiles to suggest members to connect with others who have similar interests (Lin, 2012). However, since this site is designed with academics in mind, it contains many features that allow and encourage its user base to connect and converse around research interests and publications. It also has useful features where this site can recommend relevant articles and other researchers in the same area just based on the research interest that the user has entered (Neal, 2012). I receive regular emails on all published articles from authors, even current publications on AIN which is on the ResearchGate site. I can request articles directly from authors too around AIN from all over the world.

Grey literature (e.g. technical reports, working papers, thesis publications, report literature, government publications, policy documents, fugitive literature, nonconventional literature, unpublished literature, non-traditional publications, electronic publications, online publications, online resources, open access research, and digital documents) other than databases was considered for my research. To locate relevant studies, reviewers can search organisational websites, Google Scholar, thesis databases, specialist journals, and consult with experts (researchers, providers, policy makers) in these fields and librarians

are resourceful, in assisting with searches (Tong et al, 2012). A focus on grey literature can really help increase the breath, relevance, topicality and ultimate utility in literature review (Hagen-Zanker & Mallet, 2013). I explored the literature available on anal cancer screening and Google Scholar was particularly helpful for me in identifying the literature I required for my study. In the UK, NHS regional Research Design Services (RDSs) for the National Institute of Health Research (NIHR) provide a wide range of services for NHS staff in research including support for literature searching (Gerrish & Lacey, 2010). I used most search strategies as the information available in the UK is very limited on anal cancer screening, so I accessed wider search databases, made use of the librarian at my employing trust for literature searches.

There is a need to provide healthcare professionals with reliable evidence in which to base decisions has led to the increasing importance of published reviews (Docherty, 2003). Nurse researchers usually start their research with certain assumptions as they often have the knowledge of the field they wish to explore. Their professional experience and reading of the literature can enhance their research. It generates theoretical sensitivity to concepts and issues that are important for developing a theory. Researchers do not need to be explicit; however, need to uncover their own preconceptions (Holloway & Wheeler, 2010). For my study, literature was revisited after data collection and analysis. This affirms that trustworthiness is demonstrated throughout and that my study findings have come from the data and pre-informed by the literature review process.

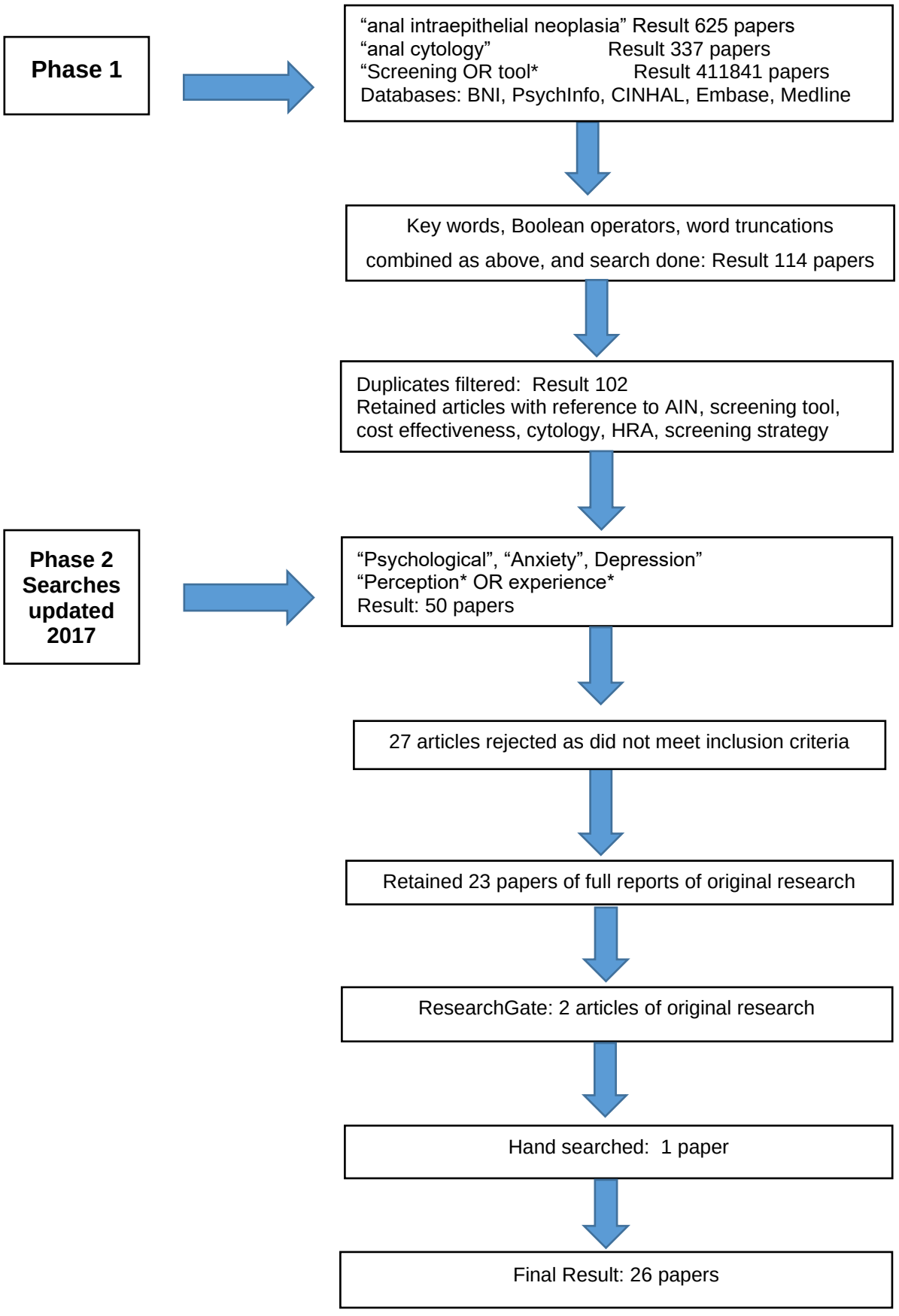
In my first run of searches (Figure 4: Phase 1), I initially I used search phrase “anal intraepithelial”, “ti” (title), “ab” (abstract) on databases EMBASE, MEDLINE, BNI and CINHAL which yielded 625 results. I then searched using search phrase “anal cytology”, “ti”, “ab” using same databases, and this yielded 337 results. I also used synonyms like “screening OR tool* OR strategy, “ti” which produced 411841 results. The Boolean operators “OR” and word truncation symbol (*) like tool* helped me locate data relevant to my study. I then combined the search phrases “anal intraepithelial neoplasia”, anal cytology” and synonyms “screening or tool* to narrow down evidence and came up with 114 results. I combined all the searches and limited it to 1997 to 2016 which produced 102 searches and duplicates were filtered. I used this as the basis of my initial research into the study. I used phrases like ‘anal intraepithelial neoplasia’, ‘anal cytology’ and

‘screening’ or ‘tool’ to make sure that all relevant information I needed met my inclusion and exclusion criteria as this was a broad search relating to my research question. These 102 articles relating to AIN, screening tool, cost effectiveness, cytology, HRA, screening strategy in title were retained.

I did a second run of literature search (Figure 4: phase 2) and included studies of patients and clinicians from 1997 to 2016. I chose this timeframe as the first anal dysplasia clinic was set up 1999 and I searched for literature two years prior so that I did miss out on any prior research on anal cancer screening. CINHAL and Medline databases filtered out any duplicates and 50 results were found using key phrases “psychological”, “Anxiety”, “Depression”, perception* OR experience*.

Of these 23 articles with reference to phrases above, were full reports of original research. 27 articles were rejected as they did not meet the inclusion criteria. I hand searched and found one article while another two articles were sent to me via ResearchGate (Figure 4: total of 26 papers). This chapter focuses on 26 papers arising from the first and second set of searches (phase 1 & phase 2) which were full reports of original research and is discussed in section 2.4. The type of papers I found during the literature review process were 6 cross-sectional, 2 cohort studies, 12 surveys, 2 prospective studies, and 2 evaluations which were quantitative research while, 2 qualitative studies undertook interviews.

Figure 4: Illustration for Literature search strategy



2.3 Literature Review Process

For my literature review, qualitative and quantitative papers were included. According to Aveyard (2010), a very detailed review of literature on the topic and good quality reviews are useful as they summarise all available literature, either quantitative or qualitative. For this review of qualitative and quantitative papers, a combined analysis framework was developed based on the Critical Appraisal Skills Programme (CASP) guidelines (www.casp-uk.net). This appraisal tool enabled a standardised assessment of the 26 selected papers I used to critique the articles (Table 1). According to Hart (1998) and Silverman (2000a), a systematic process for critiquing literature encourages focus and ensures consistency. The points I used to appraise to make this a systemtatic combined framework analysis guided by the CASP appraisal tool for both qualitative and quantitative studies, I included the purpose of the study, methodology, sampling, data collection methods, data analysis, findings, consideration of ethics, limitations of each study, and the value of each research findings.

Table 1: Analysis framework used to review selected papers arising from literature searches, based on CASP guidelines for reviewing qualitative and quantitative studies

Points to consider	Questions to be addressed
Purpose of the study	Was there a clear statement of the aims, goals and rationale clearly stated, its importance and relevance clearly stated?
Methodology	Is the methodology appropriate and seeks to fit with the purpose of the study?
Sample	Was the recruitment strategy appropriate to the aims of research and explains how the participants were selected?
Data collection	Were the data collected in a way that addressed the research issue; is it clear how data were collected (e.g. focus groups, interviews, questionnaires) and how indicate how methods were made explicit i.e. topic guide for example if interviews were conducted?
Data analysis	Was the data analysis sufficiently rigorous and if there is an in-depth description of the analysis?
Findings	Is there clear statement of findings and explicit; if there is adequate discussion of the evidence; if the researcher discussed the credibility of findings
Ethics	Are there enough details on how the research was explained to participants; if issues of confidentiality, consent addressed and if approval has been sought from ethics committee?
Limitations	Are there any limitations of the study and has this been addressed by authors?
Value of the research	Did the researcher discuss the contribution the study makes to the existing knowledge or understanding; if they identify new areas where research is needed or if the researchers have discussed whether or how the findings can be transferred to other populations or consider other ways the research can be used?

2.4 Results of search

Twenty-six papers were reviewed to support the purpose of my study by demonstrating the gaps in evidence currently. The twenty-six studies (Table of literature appraisal-Appendix 2) were summarised describing the diverse psychological domains being investigated.

2.4.1 Characteristics of Included Studies

Of the twenty-six studies, twenty-four studies were quantitative and two studies were qualitative. Most participants in the studies were MSM living with HIV, and of the twenty-six studies, two studies included both HIV infected MSM and HIV uninfected MSM while two studies included women only which did not stipulate if they have HIV infection and were from the general population. Most participants were MSM/bisexual, and some were women. The included studies reported ages between 16-75 years infected with HIV or uninfected with HIV who have undergone anal screening. Characteristics of participants are explained below and in Appendix 2. There is very limited research available on clinicians' perspectives on anal screening and it is important to discuss these limited articles in view of the rationale for my study to add to the body of knowledge.

2.4.2 Quality of Included Studies

The quality of the 26 included studies is critiqued below and in Appendix 2. Qualitative and quantitative designs have a role to play in research as long as the method used is dependent on the question asked. Rolfe (2006) states that we need either to acknowledge that the commonly perceived quantitative and qualitative differences require a range of quality criteria or to recognise that each study is individual and unique. However, quality in qualitative research can be assessed with the same broad concept of validity and relevance used for quantitative research where the research is systematic and has self-conscious design, data collection interpretation which is a basic strategy to enhance rigour (Mays and Pope, 2000). Rigour is enhanced when the sampling method, design, data collection, data analysis and reporting techniques, fit with the overall aims of the study.

2.4.3 Sampling Methods

In quantitative research the representative sample is important because in this way the findings can be extrapolated to the wider population and several factors affect how

representative a sample is i.e. size (Shields & Twycross, 2008). Blankenship et al (2015) recruited participants wanting to be seen in Obstetrics and Gynaecology clinic at an urban university medical centre while Ferris et al (2013) sample comprised of women from the general population, and these 2 studies used convenience sampling. Truesdale and Goldstone (2010) stratified participants into 3 groups according to compliance and follow up recommendations. Consecutive participants were approached for the study by Tinmouth (2011) as they enrolled for the study in Toronto Research for Anal cancer evaluation (TRACE study).

Ten quantitative studies did not identify sampling methods but explained eligibility criteria. Pitts et al (2007) sampled 384 men who attended a large gay community event were approached and invited to participate in a short survey while Fenkl et al (2015) used a sample during an education event as part of a cruise vacation for HIV-infected persons. D'Souza et al (2008) recruited participants from a Multicentre Aids Cohort Study (MACS) in 2005-2006, at their 43rd visit. Reed et al (2010) recruited men who were existing members of the US household maintained by knowledge networks (Menlo Park, CA). Sampling for this study were men who self-identified as gay or bisexual. Similarly, Joshua et al (2015) used a sample from the national panel of US households maintained by Knowledge Networks for sample 1 while sample 2 for this study a sample was drawn from the Harris Interactive LGBT Panel, a subset of the Harris Poll Online Panel (Rochester, NY).

Landstra et al (2012) recruited any HIV infected MSM that attended the HIV clinic during the study. Debnath et al (2015) surveyed 55 women scheduled for anal screening before and after HRA. Likewise, Kaufman et al (2015) identified their sample of 150 women from the EVVA study ((Evaluation of HPV, HIV, and AIN in women) which is a cohort study. Botes et al (2011) included all participants between October 2008-January 2009 and in the study and Hillman et al (2011) included all participants who underwent HRA. Volunteers were recruited among a population of men and women undergoing anal dysplasia screening at a single surgical unit. Moores et al (2015) included all MSM as they registered for health services at an STI testing and treatment clinic in Ottawa. Although some studies clearly state sampling methods, the above studies use purposive sampling. The purposive sampling technique, also called judgment sampling, is the deliberate choice of a participant due to the qualities the participant possesses (Etikan, 2016). The

researcher decides what needs to be known and sets out to find people who can and are willing to provide the information by virtue of knowledge or experience (Bernard, 2006). It is typically used in qualitative research to identify and select the information-rich cases for the most proper utilization of available resources (Patton, 2002). Koskan (2016) used snowball sampling where past participants recommended that friends call the study number and screen for eligibility where participation was voluntary, and no issues identified.

Six quantitative studies with clinicians/providers did not define/state the sampling method instead explained how the samples were recruited into their studies. In the US clinicians and providers are used interchangeably to refer to clinicians that provide a service to patients. Scott et al (2015) stated that 6 providers received in service training on anal cytology procedure and offered anal cytology to all HIV-infected patients seen at the clinic in the hospital as part of routine care, provided the sample. Sowah et al (2015) contacted 47 active HIV providers via email in an academic outpatient HIV clinic to complete an online questionnaire. Fifty medical students and physicians participated in an educational activity and all were given the survey to complete (Ortiz et al, 2013). In the study by Kwong et al (2011) a sample was drawn from the University of Colorado's Infectious Disease Group Practice offering DRE, anal cytology and HRA, while Colon-Lopez used a sample of 104 HIV healthcare professionals in Puerto Rico. Patel et al (2014) sent out over 300 fax and email invitations to 82 providers from 80 clinics in Canada, Europe, Asia and Australia.

In the only qualitative study of Clinicians/Providers, Ong et al (2015) used purposive sampling, where 20 HIV physicians from Infectious Diseases, Immunology, Sexual Health and General Practice in Australia were recruited into the study.

Table 2 below shows an example of how the CASP framework was used to review quantitative and qualitative studies by author, year published, journal, type of study, purpose of studies, sampling methods used, design of the studies, data collection and key findings of the research studies to provide arguments and references to my study. I was able to identify and reveal an evidence gap which proves the need for my study.

Table (2) Example of how CASP framework was used for this study

Author, year published, Journal	Type of study	Purpose	Sample	Design	Data collection	Key Findings
Landstra et al (2012), Psycho-Oncology Journal, Australia	Quantitative	The psychological impact of anal screening cancer screening on HIV Infected men	291 HIV MSM	Prospective Longitudinal survey	Self-reporting questionnaires	There was no evidence that general anxiety, depression or quality of life was significantly affected by the process. Those who had biopsy recommended were more about anal cancer; rated their anal health worse, were less optimistic about their future health than those who did not need further investigations. The group receiving high grade histology results remained worried

2.4.4 Ethical Approval of the Included Studies

All twenty-six studies had ethics approval from their respective countries and states. Research on sensitive topics like HIV/AIDS is very challenging and researchers need to strictly follow ethical procedures and maintenance of anonymity and confidentiality are the key factors for encouraging participants to become involved in such sensitive research (Poudel et al, 2016). Therefore, research ethics is the first and broadest objective to protect human participants, second is to ensure that research is conducted in a way that serves interests of individuals, groups and/or society as a whole, and thirdly the objective is to examine specific research activities and projects for their ethical soundness, i.e. looking at issues such as the management of risk, protection of confidentiality and the process of informed consent (Walton, 2016).

Fifteen studies carried out in the USA sought approval from the Institutional Review Board of their respective states (Davis et al, 2013; D'Souza et al, 2008; Fenkl et al, 2015; Joshua et al, 2015; Reed et al, 2010; Truesdale & Goldstone, 2010;). The study by Ferris et al (2013) was reviewed and approved by The Medical College of Georgia Human Assurance Committee in USA. Three studies carried out in Miami were approved by the University of Miami Human Subjects Institutional Review Board (Blankenship et al, 2015; Blankenship et al, 2015; Koskan et al, 2016). Four Australian studies obtained approval from the Human Research Ethics Committee of their respective hospitals, centers or clinics (Botes et al, 2011, Hillman et al 2011; Landstra et al, 2012; Pitts et al, 2007). Tinmouth et al (2011) obtained approval from the Research Ethics Board at the University Health Network in Toronto, Canada and this study was conducted in accordance with the Declaration of Helsinki while Kaufman et al (2015), Moores et al (2015), Patel et al (2014) obtained approval from Ottawa Public Health's Research Ethics Board.

Six studies of clinicians and providers obtained approval from the Institutional Review Boards in their respective states in the USA (Colon-Lopez et al, 2016; Kwong et al, 2011; Ortiz et al, 2013; Patel et al, 2014; Scott et al, 2015; Sowah et al, 2015). The Australian study obtained approval from the Alfred Health Human Ethics Committee (Ong et al, 2015). These studies have obtained ethical approval from their respective states and countries to protect participants and researchers.

2.4.5 Design Methods and Measures of Included Studies

Studies on Patients

Fourteen quantitative studies used fully tested and validated tools. Validated questionnaires used by Tinmouth et al (2010) in the psychological impact of being screened for anal cancer in HIV-Infected men who have sex with Men in Canada comprised of Impact of Events Scale, Illness Intrusiveness Ratings Scale, Psychological Questionnaire, Hospital Anxiety and Depression Scale and HIV Symptom Index. Other validated questionnaires were an Anal Screening Questionnaire (which was created by modifying the Cervical Screening Questionnaire), Cancer Worry Scale, Distress Thermometer, Medical Outcomes Study Short Form Health Survey (MOS SF-12: is a measure of health-related quality of life that is well validated in Australia) and Depression Anxiety Stress Scale was used in the study of the Psychological impact of anal cancer screening in men with HIV by Landstra et al (2012) in Australia. Blakenship et al (2015) used the visual analogue scale to assess knowledge, acceptability, perceptions, pain, discomfort and embarrassment during HRA among women. Fenkl et al (2015) used the HPV anal cancer knowledge questionnaire (B-HPV/AC KQ) as a validated tool in their study. Kwong et al (2011) used a validated patient satisfaction questionnaire adapted from colon cancer screening. Patel et al (2014) used a web-based survey monkey tool in their study of environmental scan of anal cancer screening practices. Data were analysed statistically and presented in the form of tables, graphs, numbers and percentages. There were 6 cross-sectional studies, two prospective studies, 12 surveys, two evaluation studies, two cohort studies on anal cancer screening.

Anal cancer screening studies produced many variables that were investigated with regards to patients. Ten quantitative studies and one qualitative study assessed knowledge, attitudes and willingness to have anal screening. Two quantitative studies evaluated the screening procedures i.e. anal cytology and HRA (including biopsy). Only two studies produced results on the psychosocial or psychological impact of anal screening (Tinmouth et al, 2010; Landstra et al, 2012).

The only qualitative study used an interview guide of open-ended questions when conducting in-depth interviews which audio were recorded. Demographic information and themes were in a table. This study explored perceptions of anal cancer screening and

behaviours among gay and bisexual men infected with HIV. The broad themes identified were, levels of knowledge, facilitators and barriers experience of anal cancer screening

Studies on Clinicians

Four quantitative studies by clinicians/providers undertook surveys (Kwong et al, 2011; Patel et al, 2014; Ortiz et al, 2013; Sowah et al, 2015), one cross-sectional analysis done by Colon-Lopez et al, 2016), one evaluation study by Scott et al (2015). Validated questionnaires were used in the quantitative studies. Kwong et al (2011) for example used a validated patient satisfaction questionnaire adapted it from colon cancer screening, while the provider used same principles, but descriptive analysis was used. Data were analysed statistically using software for quantitative data analysis. This was presented in counts, percentages, proportions and graphs. Patel et al (2014) for instance exported data from web based surveymonkey (a web-based tool) and undertook descriptive analysis.

One study assessed cancer screening practices worldwide (Patel et al, 2014) to include knowledge of procedure and attitudes towards screening algorithms and provider perceptions. Other studies that assessed the knowledge component of anal cancer screening in providers/healthcare professionals included Ortiz et al (2013) and Colon-Lopez et al (2016). Scott et al (2008) and Sowah et al (2015) described the experiences and perceptions on anal cancer screening. Kwong et al (2011) in their study describes the quality improvement initiatives to increase anal cancer screening in HIV speciality by healthcare professionals in the anal health program.

Ong et al (2015) undertook a qualitative study and used semi-structured in-depth interviews. This study explored the perspectives of HIV physicians on anal cancer and screening in HIV positive MSM.

2.4.6 Findings of Included Studies: Emerging Themes of Anal Cancer Screening

Having reviewed the 26 articles, it was apparent that there were key findings relating to anal cancer screening, which are discussed below, from patients and clinicians/provider's perspective. The main findings I identified in the review from studies of clinicians/providers were knowledge, acceptability, attitudes and willingness to screen for anal cancer; worry about anal cancer screening; sexuality and sexual functioning; the psychological impact of anal cancer screening, evaluation of anal cancer screening procedures; education on anal

cancer screening; barriers to anal cancer screening. Although the results are limited it is not exhaustive. Additional findings may be reflected in my findings on clinicians' experiences and perceptions on anal cancer screening. The following studies assesses the knowledge of anal cancer screening in providers/health care professionals (Ortiz et al, 2013 & Colon-Lopez et al, 2016; Vera et al, 2013), while cancer screening practices reported worldwide by one study by Patel et al (2014) to include knowledge screening algorithms and provider perceptions. Scott et al (2008) and Sowah et al (2015) describe the experiences and perceptions on anal cancer screening. On the other hand, Kwong et al (2011) describes the experience of quality improvement initiative to increase anal cancer screening in the HIV speciality.

2.4.6.1 Knowledge, Acceptability, Attitudes and Willingness to Screen for Anal Cancer

In this section I will discuss studies on anal cancer screening where the main themes from the studies were knowledge, acceptability, attitudes and willingness to screen for anal cancer from patients and clinicians' perspective.

Patients' Perceptions

Most of the studies covered knowledge, acceptability, attitudes and willingness to have screening (Moores et al, 2015; Fenkl et al, 2015; Joshua et al, 2015; Ferris et al, 2013; Reed et al, 2010; Truesdale & Goldstone, 2010; D'Souza et al, 2008 & Pitts et al, 2007; Blakenship et al, 2015; Debnath et al, 2015; Kaufman et al, 2015). While majority of the studies have knowledge, component included on anal cancer, the study on knowledge was first published by Pitts et al in 2007 who found that more than half the sample answered questions incorrectly and awareness of risk factors such as HPV, smoking and anal receptive partner was poor. This was a sample of 384 MSM of which 6% were HIV positive and 47% in a relationship. A paper questionnaire was distributed at a community gay event in Australia which assessed health service use, knowledge, attitudes and beliefs. They also found that higher knowledge on anal screening was found in those with a higher level of education while those who have received a sexual health screen in the past 12 months did not have better knowledge of anal cancer screening. In a recent study by Koskan (2016), exploring the perceptions of anal cancer screening and behaviours among gay and bisexual men infected with HIV, most participants had never heard of anal cancer or had the need to screen unless directly affected by anal cancer. Some

participants confused anal cancer with prostate and colorectal cancer. Those who heard of HPV infection learned this through advertisements for the HPV vaccine and many believed that HPV affected women only. One participant sought medical attention after a year of experiencing hoarseness in his voice. He was diagnosed with condylomas on his vocal chords which were HPV related non-cancerous growths. Although this participant was aware that these growths were warts and HPV caused these warts, he believed that the HPV infection only caused cervical cancer as opposed to other types of cancers.

Fenkl et al (2015) collected data from an educational event as part of a cruise vacation for HIV-Infected MSM where the analysis of this data revealed an overall increase in knowledge in HPV and anal cancer after the event. Participants' who had higher levels of knowledge, or awareness of anal cancer screening, showed more willingness to be screened (D'Souza et al, 2008 & Reed et al, 2010). In the study by Ferris et al (2013) of women's knowledge of HPV, anal cancer and knowledge and attitudes toward the anal Pap test, only 17.6% of women had previously heard of anal Pap test, 48.9% knew nothing, while 38.5% knew only little about anal cancer. While most women (78.6%) knew anal Pap, tests help to prevent cancer, 86.2% knew that anal Pap tests were for people who have anal sex, i.e. men who have sex with men. Lack of knowledge about anal Pap tests, pain, discomfort, costs were the main reason cited in this paper. In the study by Debnath et al (2015), 55 HIV positive women were surveyed, 36% were not familiar with HRA and 64% reported limited knowledge on HRA. This study demonstrated that patients anticipated greater pain and discomfort than they experienced during screening. A survey was undertaken by Blakenship et al (2015) in women from an obstetrics and gynaecology urban university medical centre to understand HPV and level of interest in anal cytology screening. 508 women agreed to participate, 24% had never heard of HPV, 51% were not familiar with anal cytology, 67% acknowledged regular anal cytology screening would be helpful to diagnose early cancer and only 31% affirmed they were interested in anal cytology screening. Of those women that were not interested in anal cytology screening, 48% did not know enough about it and 34% believed it might hurt. Kaufman et al (2015) studied 150 women living with HIV where biannual HPV testing, cervical and anal cytology over 2 years were done. 59 women completed the acceptability questionnaire, 78% (46/59) considered routine anal cancer screening as an absolute necessity. HRA was found to be more painful in 83% (49/59) participants. Moores et al (2015) conducted a survey on 280 MSM and 55% were aware that MSM are more likely to develop anal

cancer compared to the general population. Their source of information was from news media and STI pamphlets while 25% listed their primary care physician or another healthcare provider as their source of anal cancer knowledge. Anal cytology was very acceptable yearly 77% (44/59) and every 2 years by 93% (54/59). DRE was very acceptable yearly by 80% (45/59) and every two years by 93% (53/59). Pain was the main reason for low acceptability.

Most of the studies demonstrated knowledge of risk factors like HPV; smoking and receptive anal intercourse was poor due to lack of awareness of anal cancer. Some studies demonstrated people with higher education level and those who have had anal cancer screening did not have knowledge on anal cancer. Other studies demonstrated in this review, those who have never heard of anal cancer did not have the need to screen unless they had anal cancer. These studies also highlight that participants confused anal cancer with prostate and colorectal cancer and some participants had the perception that HPV affected women only. Those participants who never heard of HPV infection learnt through adverts. Some studies in this review show that MSM were aware that they are more likely to develop anal cancer compared to the general population and their source of information were from news media, STI leaflets, primary care physicians or other healthcare providers. Acceptability for anal cancer screening in some studies indicates that pain was the main reason for low acceptability including the anticipation of pain and discomfort during anal cancer screening.

Clinicians' Perceptions

According to Ortiz et al (2013) the knowledge of medical students and physicians (34 participants) on HPV and anal disease increased only after educational activity of participants while Colon-lopez et al (2016) suggests in their study that in anal cancer the number of years a participant is working with people living with HIV/Aids, the likelihood that this participant would have extensive knowledge increased significantly at least 10% per year. In the study by Vera et al (2013), 73 clinics (62%) responded to survey of which 69 (95%) provide care for HIV infected individuals with regards to knowledge of anal cancer risk factors. 67 (96%) of clinics responded that they were aware of the increased risk of HPV associated anal cancer in HIV-Infected individuals, and particularly HIV-Infected MSM. In relation to the acceptability of anal screening process, clinicians anticipated that patients would experience less pain than reported therefore clinicians need to enhance

patient education, address patients concern regarding the anticipated pain and discomfort associated with HRA procedure (Debnath et al, 2015). These studies concluded that clinician's knowledge only increased after an educational event while other clinicians gained extensive knowledge on anal cancer with working with patients living with HIV for several years. These studies also highlight that acceptability of anal cancer screening will be successful if clinicians enhance patient education on anal cancer screening and anal cancer, address any concerns with regards to discomfort associated with HRA and anticipated pain.

Participants willingness to participate in screening was investigated by five studies only (Joshua et al, 2015; Truesdale & Goldstone, 2010; D'Souza et al, 2008; Reed et al, 2010, Koskan et al, 2016) and being HIV infected was related to being more willing to screen (D'Souza et al, 2008 & Reed et al, 2010). However, Reed et al (2010) mentioned that 83% of men were more willing to screen if it was free and those with higher incomes were also willing to screen than those with lower incomes. MSM with both low and high-grade lesions (LSIL and HSIL) returned for screening after 1 year. This study found that having more sexual partners led to greater return for screening (Truesdale & Goldstone, 2010). Also, factors investigated in this study led to 12 % of MSM not returning for anal Pap smear as it was 'too painful to make it worthwhile' to screen. In the study by Koskan (2016), patients were willing to screen and prevent disease if prompted by a health professional this is often their physician. These studies demonstrate that willingness to screen was related to being HIV positive, those with higher incomes than lower incomes or if screening was free for men, having LSIL and HSIL, multiple sexual partners and those encouraged by a health professional.

2.4.6.2 Worry about Anal Cancer Screening

Participants had a variety of worries related to knowledge of anal cancer and willingness to screen in three studies (D'Souza et al, 2008; Reed et al, 2010; Truesdale & Goldstone, 2010). According to Truesdale & Goldstone (2010), when participants learned that they had HPV, they were upset and worried therefore, three times more likely to have regular follow up than be lost to follow up. When participants perceived a higher likelihood of getting anal cancer or having a worry about anal cancer, they were more willing to have screening. Strong motivators for the regular follow up group reported that if they had physical symptoms, they were 10 times more likely to return for screening after being lost

to follow up as they were worried. Worry about the severity of diagnosis was also a factor and to compliance for screening increased. Participants with HSIL in the regular follow up group were four times likely to return for screening than those with LSIL as being diagnosed with HSIL created worry in these patients (Truesdale & Goldstone, 2010). D'Souza et al (2008) mentioned in their study that HIV infected men who were worried had a greater or higher concern about anal cancer than those with anal warts in last 6 months or ever. When men were concerned about the accuracy of the test, or were embarrassed about asking for a pap test, willingness to have screening was lower (Reed et al, 2010). Conversely, Moores et al (2015) have cited that of the 280 participants that took part in the survey, almost half of the respondents were unaware they were at increased risk of developing anal cancer which partially explains why they do not approach the subject with their primary care physicians. Thus, these studies concluded that participants' who worry about anal cancer is linked to willingness and knowledge to screen mainly when symptoms return, but equally participants that were unaware of the risks of developing anal cancer do not approach their physicians.

Only two studies (Landstra et al, 2012 & Tinmouth et al, 2011) have investigated the psychological impact of anal cancer screening process longitudinally. Both studies have been prospective studies where as the study by Landstra et al (2011) used three time points of screening over a 3-month period and study by Tinmouth et al (2011) used four points over 6 months. In the study by Tinmouth (2011) the swab and HRA was done at the same time and participants had a one timeframe to wait for both results and in contrast the study by Landstra et al (2012) demonstrated a two-stage screening process where results of swabs determined if participants were recalled for HRA. This meant that some participants had to wait and return for results. There was no general impact on psychological health, i.e. depression, anxiety, effects on stress or quality of life (Tinmouth et al, 2011; Landstra et al, 2012). Those with AIN grade 2&3 were no more impacted than others (Tinmouth et al, 2011) but in contrast participants referred for HRA led to higher worry and those with HGAIN or AIN (2&3) continued to be worried (Landstra et al, 2012). Waiting for results to be given has the most negative impact on participants (Tinmouth et al, 2011) while waiting for further investigation by HRA was the time of most impact (Landstra et al, 2012).

Participants who received negative results from the HRA were more optimistic about their future health than those who did not need HRA (Landstra et al, 2012). Tinmouth et al (2011) describes characteristics that were predictive of worry were being younger, living with more HIV symptoms and greater baseline psychological distress. It is evident from both these studies that there is some psychological impact in anal cancer screening with increase worry and concern.

2.4.6.3 Sexuality and Sexual Functioning

Two studies (Truesdale & Goldstone, 2010; Landstra et al, 2012) explored some aspects of sexuality and investigated sexual function or beliefs. Patients who attended for regular follow up were up to two times more likely to agree that if they found out they had HPV it made them feel promiscuous (Truesdale & Goldstone, 2010). Higher levels of sexual activity in this study was associated with improved compliance to screen for anal cancer and this could have resulted from an increased knowledge or a general awareness of sexually transmitted infections and harm reduction that leads to protected sex and a willingness to adhere to provider directed guidelines. The most compelling findings of the study by Truesdale & Goldstone (2010) is that the factors contributing to emotional upset such as severity of diagnosis, physical symptoms and feelings of promiscuity increased compliance for screening.

In the study by Landstra et al (2012) participants who were recalled for further Investigation after anal cancer screening, rated their anal health lower than those who did not need further investigation. This was based on cytology and histology results where three groups were formed i.e. low 'threat group', the 'reassured' or 'false' positive group and the 'high threat' group. The 'low threat' group received negative results or LSIL. The two groups in this study which was the 'reassured' or 'false' positive group required HRA, and where a either a biopsy was not needed or had reassuring histology results which was negative, warts or inflammation. On the hand the 'high threat' group needed HRA and received HGAIN histology results (Landstra et al, 2012). This study shows that anal health was rated worse in the HRA group. These studies demonstrate that sexual function or beliefs were influenced by having HPV and those participants who rated their anal health low participated in anal screening and attended regular follow up.

2.4.6.4 Evaluation of Screening Procedures

Patients Perspective

Evaluation of anal screening procedures was conducted by Botes et al (2011) where 291 HIV positive between October 2008 and January 2009 were recruited into the study. This study directly investigated the acceptability of self-collected swabs. Participants took a self-collected anal cytology sample using a moisten Dacron swab. The findings of the study indicated that 139 (52.9%) of men found it easy to do self-collected swab, 213 (81%) as a highly acceptable procedure, 172 (65.4%) reported no pain and 219 (83.3%) reported no bleeding. A study by Hillman et al (2011) evaluated participants' perspectives on high resolution anoscopy. 105 MSM were given the questionnaire and only 70 participants returned the evaluation forms. 75% of the participants found HRA acceptable while 3.8% needed paracetamol analgesia and 11.4% reported slight bleeding for less than a week. Participants' also indicated the value of effective communication before and during the procedure. The data from this study suggests that most participants found HRA acceptable with a few complications. However, acceptability of HRA was strongly correlated with pain and bleeding during and after the procedure. This Australian study demonstrated that although HRA was an acceptable procedure, new methods to improve participant experience are required (Hillman et al, 2011). A study on tolerability of anal dysplasia screening by Davis et al, (2013) investigated anal HPV infection and HPV related disease in MSM. 296 patients enrolled in this study which was a 2-visit screening study. During the first visit, anal cytology was taken using a swab while HPV testing was taken either with a brush or swab, followed by digital rectal examination and standard anoscopy. At the second visit patients had repeated HPV samples taken with HRA and biopsy taken where indicated. The results of visit 1 showed that standard anoscopy caused most discomfort while at visit 2 less discomfort was reported. Patients who reported that discomfort at visit 1 would prevent them from having the procedures again returned for visit 2. The overall conclusions on screening procedures for anal HPV related disease were well tolerated and did not reduce patient compliance (Davis et al, 2013). These studies evaluated anal cytology and HRA and both procedures were acceptable and tolerable for participants although the Australian study demonstrated initial HRA caused most discomfort and the subsequent HRA caused less discomfort as experienced by participants.

Providers and Clinicians' Perspective

Three studies provided evidence regarding providers' and clinicians' perspective on anal screening procedures. Vera et al (2013) surveyed clinics that offer anal screening and found that only 4 (5%) clinics routinely offered anal screening for HIV positive individuals. However, one of the 4 clinics also screens HIV positive heterosexuals with a history of multi-centric HPV disease as well as HIV negative MSM. While the 4 clinics use DARE and anal cytology for routine screening, only 3 clinics have a dedicated HRA clinic. In the study by Sowah et al (2015) 24 providers responded to the survey and 13 (54.2%) performed anal smear on their patients. Interestingly female providers were 11.7 times more likely to have performed this procedure compared to male providers as gender congruence of physicians and patients especially about intimate procedures and issues may be responsible for this observed difference. This study also highlighted that provider self-rated comfort in performing anal Pap tests were higher for female providers than male providers. Female providers had more years of experience caring for HIV-infected patients in their Urban HIV practice. Majority of the respondents in this study believed that anal cytology screening is important for their practice and recognised the current lack of screening as a gap in care. Patel et al (2014) described the current practices globally on anal cancer screening and just one half of the clinics that responded required patients to have abnormal anal cytology to proceed to HRA. Furthermore, this study mentions that two thirds of clinics offered HPV testing, including treatment for AIN, suggesting a lack of consensus about the best treatment strategy or difference in respondent expertise and access to necessary equipment. These studies provide evidence on the varying practices around the world and the gaps in screening procedures globally.

2.4.6.5 Education of Clinicians and Patients on Anal Cancer Screening

Landstra et al (2012) in their study mentions that it is important to consider the clinical implications of anal screening and given the lack of or low knowledge identified in the studies with MSM's and that of women, therefore, target campaigns should be aimed at the risk factors associated with anal cancer and the need for screening. The most common point for sexual health screening and anal cancer screening are primary during visits to their physicians where they can encourage screening and educational efforts. These physicians should be prepared to counsel patients; be familiar with services in their local communities and explain the pros and cons of screening (D'Souza et al, 2008).

Moores et al (2015) study results across Canada provide evidence for the need of primary care physicians and other healthcare workers working with MSM to discuss anal cancer aetiology, prevention and screening options for this population. Fenkl et al (2015) suggests from their program evaluation that education awareness programs such as “Happy Hiney Health” may be a strategy for encouraging individuals at high risk for anal cancer to discuss screening options with their healthcare providers. Furthermore, these authors believe an important step in developing a comprehensive education and awareness should be targeted to the HIV-Infected MSM and members of the healthcare team play a vital role in the dissemination of research to support initiatives aimed at HPV, anal cancer awareness and the need for cancer screening in all MSM, in particular, the HIV- infected MSM.

In the study by Koskan et al (2016), participants (58 MSM infected with HIV) gave feedback on the best ways to increase awareness among men infected with HIV with regards to the need to screen for anal dysplasia. Participants suggested interpersonal health education methods to increase anal cancer awareness and how a one to one discussion after their interviews about HPV infection and anal cancer was the best way to teach HIV infected men about anal dysplasia screening. Some participants recommended working with HIV/AIDS specialists and case managers to ensure that they discuss anal cancer, with their patients and recommend screening. Other participants recommended a screening check list to use during their primary care visits as this would empower participants with the information, they require to make an informed conversation about screenings they need with their physician. Other recommendations suggested by participants in this study included training local leaders and health care advocates to disseminate information; the creation of print media such as educational brochures, running health education messages in newspapers and magazines for HIV infected population and using posters to increase community awareness about anal cancer; specifically a recommendation was to leave educational brochures in the HIV primary care clinic waiting room as well as examinations rooms for patients to read; posting of informational fliers at bus stops and on buses to reach individuals that use public transport (Koskan et al, 2016). The study by Ferris et al (2013) determined that a clear understanding of the reason for a screening test and targeted population facilitate acceptance and compliance to screening and given the nature of the screening test most women will be willing to have an anal Pap test if recommended by their physician. Patient

education and cooperation as cited in this study, clinical skill and gentle technique can reduce severe discomfort for most individuals. The findings in the study by Blankenship et al (2015), is that medical providers have an opportunity to educate women; regular gynaecologic encounters provide an opportunity for medical providers to capture at risk women and engage in discussions about anal cytology screening when discussing cervical cancer screening and HPV testing.

These studies provide tangible evidence on how important education on anal cancer is and to consider the clinical implications of anal cancer screening, given the lack of or low knowledge identified on anal cancer. These studies also suggest that the point of screening should be with physicians, it is important to target campaigns about risks of anal cancer, that education awareness programs may be a strategy and those members of the healthcare team play a vital role on disseminating research support initiatives.

2.4.6.6 Barriers to Anal Screening of Patients and Clinicians

Scott et al (2008) highlights barriers to incorporating a cancer screening program into routine clinical care. Of the 74 patients who were identified with cytologic evidence of anal dysplasia, only 27 received HRA, and only 9 patients with visible lesions on anoscopy had biopsy. It was even more difficult to ensure adherence to surgical anoscopy and biopsy including follow up. The barriers to surgical intervention in this study included patient centred difficulties such as perceived intolerability of anoscopy procedure, fear of cancer diagnosis, and difficulties with maintaining clinic appointments. Another barrier identified includes substantial physician training and resources needed for anoscopy related activities. Even in a group of physicians who were motivated to do anal screening program in this study, highlights the fact that there are difficulties and time involved in ensuring that everyone is appropriately trained. Ong et al (2015) identified barriers on DARE at 3 levels in routine clinical care. Firstly, systemic barriers included lack of opportunity to undertake DARE, unclear referral pathway, differences in HIV care practices and no financial incentives. Secondly health provider barriers were the lack of evidence, difficulty in discussing DARE with patients and lack of confidence in doing DARE. Thirdly patient factors covered DARE as a procedure that causes discomfort and low anal cancer awareness. The barriers identified by Patel et al (2014) on their worldwide survey demonstrate a considerable variation in cancer screening practices. This survey was sent to 82 providers from 80 clinics in Canada, USA, Europe (UK, Italy, and Spain), Asia, and

Australia and 80 clinics responded to the survey. The findings of this study highlighted that there seems to be no universal consensus on optimal strategies for anal cancer screening, treatment and follow up and this is due to a lack of prospective controlled studies or well-designed observational studies.

The barriers identified in these studies indicate that patients perceived intolerability, pain and fear of a cancer diagnosis as some of the barriers while clinicians' barriers include lack of training and resources for an HRA service and lack of studies and no universal consensus on optimal screening strategies for anal cancer.

2.4.7 Limitations of Included Studies

The included studies have identified limitations in their studies which is summarised in this section. Most of these studies on patients were completed in gay men and only 2 studies (Ferris et al, 2013; Blakenship et al, 2015) included women from the general population. At-risk populations like women with HIV or prior HPV related cervical disease and immunosuppressed transplant recipients were not included (Landstra et al, 2012). This shows that there are studies conducted on gay men, but women need to be more included especially those women with other immunosuppression conditions. Most participants in the study by Pitts et al (2007) were well educated and caucasian and in some studies, most participants had private health insurance which does not reflect the characteristics of MSM or the HIV infected population. Furthermore, participants were voluntary, or convenience samples therefore may have skewed the results towards participants who were more interested, knowledgeable or connected to the gay community (Pitts et al, 2007). Data from the study by Koskan et al (2016) come from a convenience sample of men infected with HIV in primary care clinics who were adherent to antiretroviral therapy and therefore generalisations to other HIV infected individuals should be made with caution. Furthermore, the study interviews were not conducted in the Spanish language and seen as limitation. This indicates that generalising results to HIV infected people is not feasible to individuals not in HIV treatment and the population for the study were Spanish speaking people who did not have their interviews in their spoken language but English instead which shows some bias too. The study by Reed et al (2010) used hypothetical statements which could have failed to anticipate any barriers to screening while D'Souza et al (2011) did not address independently the availability of screening therefore the lower perceived screening availability may not have reflected the actual availability of screening

programs. Finally, these two longitudinal studies used different time points and medical procedures and swab collection which made comparison difficult (D'Souza et al, 2011 & Reed et al, 2010). Most of these studies were done in America except for the longitudinal studies: one in Canada (Tinmouth et al, 2011) and the other 2 studies in Australia (Botes et al, 2011 & Hillman et al, 2011).

In the study by Botes et al (2011) a range of perspectives were investigated e.g. acceptability, ease and potential hurts (i.e. pain and discomfort for example), but the weakness of this study was that a question asking about willingness to repeat the anal cytology swabs was not included. If this study addressed willingness to repeat anal cytology, the authors of this study would have been able to assess if repeat tests were acceptable, less painful, and experience of less discomfort as they would be more prepared for procedure. On the other hand, Hillman et al (2011) used anonymous take home questionnaires to maximise the validity of responses which meant they were unable to investigate the relationship between demographic data and acceptability. Another weakness of this study was the failure to include a question on willingness to undergo repeat HRA. This is to compare acceptability and tolerability of first HRA to subsequent HRA. The study by Davis et al (2013) was that it was confined to a single practice where all procedures were performed by an experienced clinician on the MSM population although this study represented one of the largest sample sizes for tolerability and compliance with anal cancer screening. To validate these findings Davis et al (2013) suggests that data from further follow up and repeated screening on more diverse populations with other clinicians must be collected. This is to encourage clinicians to do more research on other populations like women, immunosuppressed transplant recipients to show how tolerability of anal cancer screening is reflected in other anal cancer screening practices/clinics.

The limitations of studies on clinicians/health care providers/physicians, varies according to the country in which the study was undertaken. This is a unique presentation of limitations as it shows differences in practices in anal screening and will be discussed below. Ong et al (2015) mentions that in the current Australian practice of offering anal cancer screening which is virtually conducted in a research setting. Another limitation meant that the vast majority of physicians interviewed were not participating in any anal cancer screening which influenced the tone of the study with multiple barriers identified.

Similarly, Patel et al (2014) states that the response rate to the study appears low but this is likely to reflect that the recruitment strategy includes a high proportion of persons who did not perform HRA. Scott et al (2008) in their study highlight the fact that even in a group of physicians who are motivated to do anal screening program, there were difficulties and time involved in ensuring that everyone was appropriately trained. Ortiz et al (2013) study's limitation is that the results may have affected by selection bias as 32% of the activity's participants did not answer the survey.

Lastly, four studies discuss the generalisability of their studies and their limitations. This shows how anal screening is different in whichever country or state research is being undertaken. The sampling method in an under sampling of men who see the primary care physician directly for STI screening and oversampling of MSM who are more open about their sexual orientation, show that these results are not generalizable to all MSM (Moores et al, 2015). Thus, limits the ability to determine casual relationships between attitudes, knowledge, interventions and anal cancer. Sowah et al (2015) demonstrates that the study was relatively small as 55.3% of the 47 HIV providers in a large urban academic institution and may not be generalizable to all HIV providers. In this case the suggestion is to include all anal cancer screening practices to be able to generalise results about HIV providers. The results of the study by Colon-Lopez (2016) cannot be generalizable to entire populations of health care professionals working with HIV individuals as this is attributed to knowledge and experience of healthcare professionals working with people living with HIV. Training regarding the pathogenesis of anal cancer is necessary for healthcare professionals, plus the information on the frequency of these services offered to people living with HIV and Aids was not assessed. Although, according to Kwong et al (2011), the provider satisfaction survey was anonymous, the potential for biased responses existed as respondents were colleagues of the primary author and may have felt the need to rate services more favourably. Additionally, some respondents were involved in the overall conception and design of the anal health program so there was a potential for investigator allegiance.

2.4.8 Conclusions from Reviewed Papers

Anal screening does appear to increase health related worry about the procedure but does not have a general impact on mental health. Anal cancer screening is not yet well established therefore there is an opportunity for producing evidence on the psychological

effects of screening which is the rationale or basis for my study. So far, these studies do not suggest acute or significant clinical levels of mental health problems as the result of screening. There were some individuals that experienced some psychological and physical impact but the variation in that individual experience suggests that having worse anal or HIV symptoms, being younger, and worry about anal cancer involved repetitive thoughts to screening and the possibility of having anal cancer. Low willingness to screen was due to factors like poor knowledge of anal cancer, Pap testing and other risk factors like HPV. Clinicians have identified that there are varying practices on anal screening worldwide, that there are no universal optimal screening strategies for anal cancer screening; there is a lack of clinician training and resources available to set up an HRA service.

The next chapter discusses the methodology of my study, an overview of my research approach, stake holder engagement, ethical considerations, sampling process, data collection, reliability, validity and trustworthiness of my study.

3 Methodology

The overall aim of my study is to explore perceptions and experiences of patients and clinicians in anal cancer screening to help inform clinical practice for anal screening in sexual health clinics in the UK. While justifying the methodology for my study I had to examine the philosophical underpinnings in the choice of research methodology for hermeneutic phenomenology. It was important from my point of view to understand the meanings of these realms in the context of the research to be done i.e., epistemology, ontology and methodology and how this fitted into my study. Here again I sought to understand the meanings of these terms before applying it to the research methodology chapter.

3.1 My Research Approach

The goal of my research was to understand the perceptions and experiences of patients and clinicians in anal cancer screening. The focus of my study was on an interpretive meaning and I chose Hermeneutic phenomenology a theory and methodology of interpretation; it is the art of understanding and of making oneself understood as a suitable

approach which is informed by Heidegger. Heidegger developed interpretive phenomenology by extending hermeneutics, the philosophy of interpretation (Reiners, 2012). The interpretive paradigm was viewed suitable for my research because it has potential to generate new understandings based on the premises that reduction is impossible and the acceptance of endless interpretations of each participant's experience. According to Kafle (2011) this is an effort to get beneath the subjective experience and find the genuine objective nature of the things as realized by an individual. I was seeking practical knowledge which according to Ajjawi & Higgs (2007) interactions is embedded in the world of meanings and human beings therefore it was appropriate for me to investigate this phenomenon within the interpretive paradigm. The usefulness of Heidegger's philosophy for nursing research has the potential to provide a framework for investigating the meaning of individual's experiences with in the context of their lives (Johnson, 2000). Heidegger believed that humans are hermeneutic (interpretive) being capable of finding significance and meaning in their own lives and believed context was a central concern (Draucker, 1999). Heideggerian phenomenology is based on the perspective that understanding of individuals cannot occur in isolation of their culture, social context, historical period in which they live (Kumar, 2012; Draucker, 1999; Geanellos, 1998; Orbanic, 1999).

Hermeneutic phenomenology was an appropriate methodology for me to investigate the perceptions and experiences of patients and clinicians in anal cancer screening as it is congruent with the aim of exploring the perceptions and experiences of participants of anal cancer screening. It also allows for an added layer of abstraction and interpretation through my lenses as a researcher taking into account, my professional knowledge and the research objectives set out in my study. Using this interpretive paradigm will enable me to gain a deeper understanding of the perceptions and experiences of participants as a lived experience. Although using this approach may add to the body of knowledge of anal cancer screening, through its reflexive nature it will enable me to engage in my own learning journey towards exploring the perceptions and experiences of patients and clinicians in anal screening to gain a deeper understanding as well as create meaning to the phenomenon I am researching.

Although hermeneutic phenomenology like descriptive phenomenology is concerned with the lived experience (Wilson & Hutchinson, 1991), Laverty (2003) highlights and discusses

the differences with exploration of a lived experience between the philosophers. Husserl focused on understanding of beings or phenomena while Heidegger focussed on 'Dasein' which means the 'mode of human being' or 'the situated meaning of a human in the world' (Laverty, 2003). I used hermeneutic phenomenology to emphasise that individuals cannot abstract or withdraw themselves from various contexts as this influences their choices and meaning of their lived experience. Therefore, Heidegger's phenomenology attempts to address the situatedness of individuals "Dasein" to a broader social, political and cultural context (Campbell, 2001). According to Mackey (2005), our understandings and interpretations reveal the world we live in and are the fundamental features of what Heidegger terms as *Dasein*, our being in the world, therefore our experiences must be addressed through interpretation (hermeneutics).

Furthermore, specifically Johnson (2000) cites that meaning emerges because of the unitary relation between human beings and other things or people which is only possible because of the unique structure of being human. Through this understanding, Heidegger believes a person's history and background is important for understanding the world therefore, described the view that people cannot be made explicit as it is related in cultural, social and historical contexts (Munhall, 1989). Johnson (2000) believes that Heidegger gives a phenomenological researcher a different understanding of how a human being is 'structured', and the origin of the meaning as provided by Husserl's philosophy whereas Heidegger asserts that present things get their meaning out of future purpose. While people living with HIV and clinicians are situated on the assumption of a preunderstanding or as Heidegger called it a "fore-structure of understanding" of an experience or situation (Kumar, 2012). The interpreting of something as something, or the making explicit of something that is understood, is in turn achieved on the basis structure, the structure that Heidegger calls "fore-structure" (Leung, 2011). Fore-structure of understanding consists of all individuals who have come to a situation with practical familiarity or background practices from their own world that makes interpretation possible (fore-having); the sociocultural background gives a point of view from which to make an interpretation (for-sight); and sociocultural background provide a basis for anticipation of what might be found in an investigation (fore-conception). I felt that having fore-structure of understanding as alluded to by Kumar (2012) would give me a clear understanding to reflect on my experience with individuals undergoing anal cancer screening, living with HIV and who have complex needs.

There are apparent distinctions between descriptive phenomenology and hermeneutic phenomenology. In Laverty (2003) phenomenological research is described as descriptive and focuses on the structure of experience, the organisation of principles that give form and meaning to the life world whereas hermeneutic research is interpretive and concentrates on the historical meanings of experience and their developmental as well as the cumulative effects it has on the individual and social levels. In light of these two traditions and descriptions of their philosophical underpinnings I questioned their use in research methodologies by comparing them to see how it fits with my study. The use of a philosophy in methodology requires the ability to be reflective, insightful; sensitive to language and constantly open to experience (van Manen, 1997). When a methodology is used, it needs to follow from and reflect the philosophy chosen throughout the project (Osborne, 1994). In Husserlian philosophy the main features are predominantly descriptive phenomenology where the aim is to describe the 'things in their appearing' (Langdridge, 2007: 86). For Heidegger being-in-the-world is coloured and shaped by our always, already, being in a situation so that the historical and dispositional context of any lived experience is integral to being there, experiencing it (Dreyfus, 1991).

Philosophical concepts like ontology, epistemology, axiology and methodology are considered in my study as it helped me to determine how I undertook my research activities. The ontological perspective of my study focuses on revealing meanings of patients' and clinicians' perceptions and experiences on anal cancer screening rather than developing an abstract theory or arguing a point. The first concept ontology is the form and nature of reality and what can be known about it (Lincoln & Guba, 1995). This in effect is concerned with reality as perceived by the participants in my study. The reality can be external to individuals or produced by the individuals' consciousness (Cohen et al, 2000).

Secondly, epistemology is described as the nature of the relationship between the knower and what can be known; it refers to knowledge and the notion that the research work is supposed to contribute to knowledge itself (Kafle, 2011), while Hartley (2006) explains epistemology as a process through which the researcher makes a knowledge claim. The participants in my study have subjective experiences and insights about anal screening and this will be transformed into knowledge to contribute, to what is known and what can

be known about their experiences and perceptions of anal screening. As a philosophy of knowledge applied to hermeneutic phenomenology the epistemology is grounded on the belief that knowledge is possible through subjective experience and insights (Kafle, 2011).

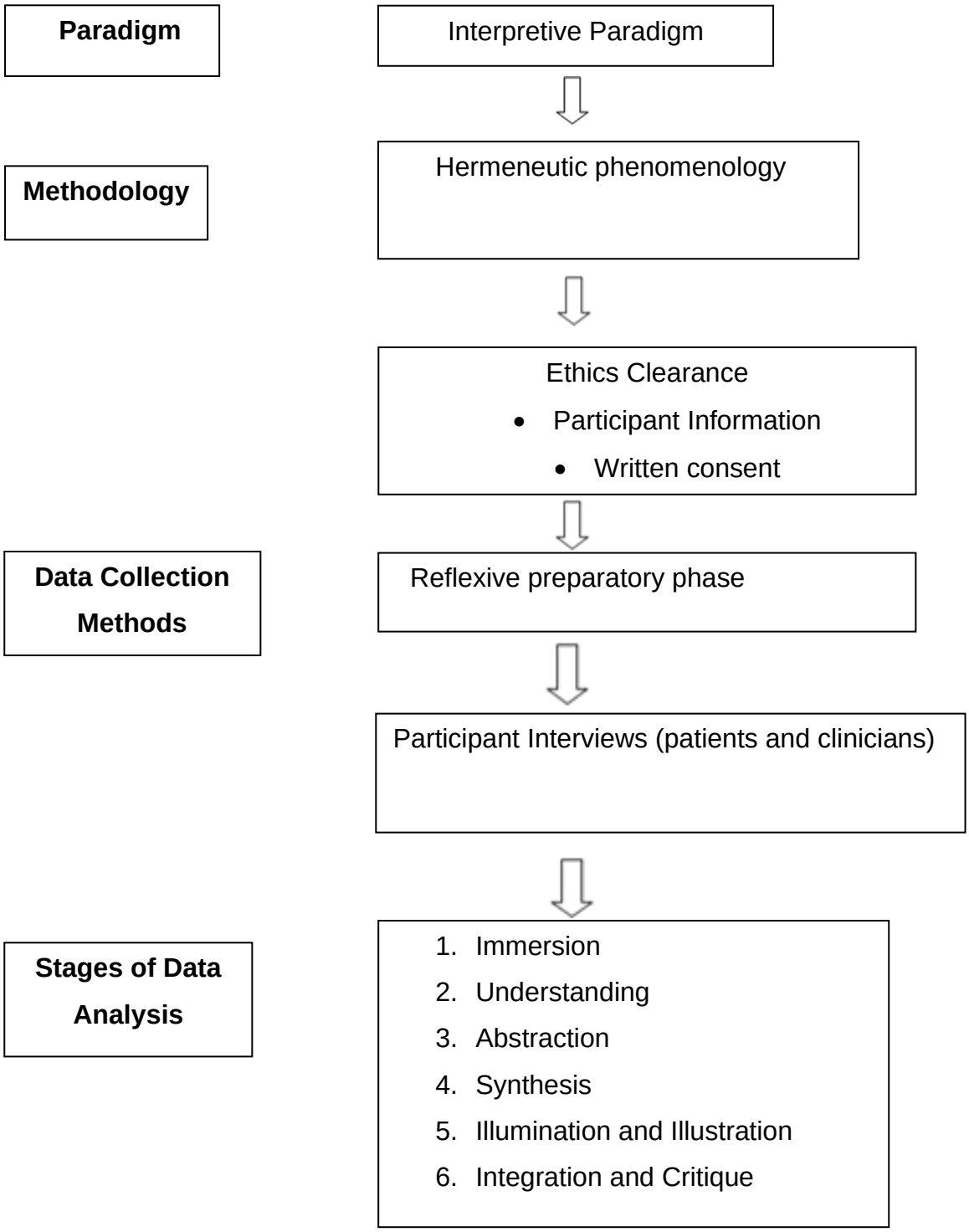
While ontology and epistemology deals with truth, the third concept axiology is about values and ethics (Mingers, 2003). Values in axiology provide the standard for evaluation of epistemological and ontological claims and are also called value theory where the disciplines of ethics, pragmatics and aesthetics are included (Kafle, 2011). In axiology, my values and opinions are considered for generation of knowledge produced in my study. With this connection, hermeneutic phenomenology aligns itself with the idea of practical form of knowledge generation that goes beyond enumeration of mathematical properties. The practical form of knowledge is generated through interviews with participants, eliciting knowledge from their subjective experience of anal cancer screening and interpreting their views and in turn I consider what is known about the truth, consider my values, ethical considerations and opinions I must generate and produce information on anal cancer screening.

The fourth concept methodology is a principle I used to uncover how I was going to gain a better understanding of the perceptions and experiences of patients and clinicians in anal screening which was an engaging process for me. Methodology as a paradigm is about how the inquirer can go about finding whatever they believe can be known which is essential in critiquing and conducting research (Kafle, 2011). In simple terms Carter & Little (2007) mentions that methodology justifies method which in turn produces data and analyses; knowledge is created from data and analysis while epistemology modifies methodology and justifies the knowledge produced.

I have provided a diagrammatic illustration (figure 5) below adapted from Ajjawi and Higgs (2007) for my research approach as I found it helpful in guiding me through the methodology chapter in view of my challenging but interesting journey. Figure 5 provides an overview of the paradigm, methodology, data collection methods and stages of data analysis for my study. The paradigm I use is interpretive, as the aim of my research is to explore and understand participants' perceptions and experiences in anal cancer screening. The methodology I use in my study is hermeneutic phenomenology where ethics clearance was obtained, consent sought from participants and information provided

to participants. Data were collected using a reflexive preparatory phase (consideration of interviewing room and recording equipment, reflexive diary, trigger questions) followed by participant interviews. The stages of data analysis included immersion, understanding, abstraction and synthesis of data. According to Ajjawi & Higgs (2007), the interpretive paradigm fits with the philosophy, methodology and strategies used to gather data and deriving meaning from the data to underpin the quality in interpretive research, rigour (Lincoln & Cuba, 2000) and credibility (Denzin & Lincoln, 2000).

Figure 5: Overview of research approach adopted in this research



(Adapted from Ajjawi & Higgs, 2007)

3.1.1 Key Distinctions in Descriptive Phenomenology and Hermeneutic Phenomenology

Understanding the different types of phenomenology helped me strengthen my research approach. The fundamental features of descriptive phenomenology and hermeneutic phenomenology both emphasise the lived experience. In Husserlian philosophy the main features are predominantly descriptive phenomenology where the aim is to describe the 'things in their appearing' (Langdridge, 2007: 86). Husserl developed descriptive phenomenology, where every day conscious experiences were described while preconceived opinions were set aside or bracketed (Reiners, 2012). Heidegger, who was interested in interpreting and describing human experience, believed that bracketing was not warranted because hermeneutics presumed prior understanding (Reiners, 2012). For Heidegger being-in-the-world is coloured and shaped by our always, already, being in a situation so that the historical and dispositional context of any lived experience is integral to being there, experiencing it (Dreyfus, 1991). Heidegger was concerned with the ontological question of the meaning of being, whereas Husserl's phenomenology addressed the epistemological problem of how we can know and describe human experience (Zahavi, 2003).

However, the methodological issues that I identified were in the apparent distinctions between descriptive phenomenology and hermeneutic phenomenology. To add rigour to my chosen methodology, I have provided an overview of the differences in descriptive and hermeneutic phenomenology to strengthen my chosen methodology, hermeneutic phenomenology. In Laverty (2003) phenomenological research is descriptive and focuses on the structure of experience, the organisation of principles that give form and meaning to the life world whereas hermeneutic research is interpretive and concentrates on the historical meanings of experience and their developmental as well as the cumulative effects it has on the individual and at social levels. In light of these two traditions and descriptions of their philosophical underpinnings, the use of methodology according to van Manen (1997) requires the ability to be reflective, insightful; sensitive to language and constantly open to experience. When a methodology is used it needs to follow from and reflect the philosophy chosen throughout the project to be able to meet the aims of the study (Osborne, 1994). Heidegger (hermeneutic phenomenology) was concerned with the

ontological question of what things are and the meaning of being, whereas Husserl's phenomenology (Descriptive phenomenology) addressed the epistemological problem, of how we can know, and describe human experience (Dahlberg et al, 2008; Reiners, 2012; Zahavi, 2003). In this section I have outlined how Heidegger's structural meaning of 'Dasein', a concept which is an important feature to the interpretations of the clinicians and patients' perceptions and experiences which denotes being-in-the-world and their real lived experience of anal cancer screening.

In the preceding section, descriptive and hermeneutic phenomenology approaches are described in Table 3 below. Both the approaches are useful for guiding inquiries of interest to holistic nursing science (Wojnar & Kristen, 2007). The differences in the descriptive and interpretive approach by Koch (1995), cited by Wojnar & Kristen (2007) provides a summary between the two approaches (Table 3). In descriptive approach the emphasis is on describing universal essences whereas the interpretive approach is about understanding the phenomena in context. Bracketing is a key feature of descriptive phenomenology where the researcher ensures that interpretation is free bias (Dahlberg et al, 2008). In interpretive phenomenology understanding and co creation by the researcher and participants are what makes interpretations meaningful (Lopez, 2004). Those who tend to seek similarities in human experiences, look for patterns, seek universals and aim at finding solutions may be suited to a more descriptive mind set where as those who tend to relish nuances, appreciate differences, embrace ambiguity, and seek uniqueness in a contextualise lived experience may be more given to an interpretive mind set (Wojnar & Kristen, 2007). My study is hermeneutic (interpretive) phenomenology and presents the uniqueness of the perceptions and lived experiences of patients and clinicians in anal cancer screening in sexual health clinics in the UK.

Table 3: Key Distinctions in descriptive (Husserl) and interpretive (Heidegger) phenomenology (Koch, 1995, adapted from Wojnar & Kristen, 2007)

Descriptive Approach	Interpretive Approach
1. The emphasis is on describing universal essences	1. The emphasis is on understanding the phenomena in context
2. Viewing a person as one representative of the world in which he or she lives	2. Viewing a person as self-interpretive being
3. A belief that the consciousness is what humans share	3. A belief that the contexts of culture, practice and language are what humans share
4. Self-reflection and conscious" stripping" of previous knowledge help to present an investigator free description of phenomenon	4. A prereflexive being, researchers actively co-create interpretations of phenomenon
5. Adherence to established scientific rigor ensures description of universal essences or eidetic structures	5. One needs to establish contextual criteria for trust worthiness of co-created interpretations
6. Bracketing ensures that interpretation is free from bias	6. Understanding and co-creation by the researcher and the participants are what make interpretations meaningful

To summarise my approach hermeneutic phenomenology as a methodology, I found it useful for exploring participants' experience of caring, healing and wholeness in relation to their historical, social and political influences that they live in for health and wellness in anal screening. Lastly Kumar (2012) alludes to the fact that hermeneutic phenomenology is grounded in the belief that the researcher and participants come to the investigation with fore-structures of understanding shaped by their respective background, and in the process of interaction and interpretation cogenerate an understanding of the phenomenon being studied.

3.1.2 Why not a different qualitative Method?

The methodological framework I chose for my study was based on many factors.

Hermeneutic phenomenology means that interpretations are all we have and description itself is an interpretive process in order to generate the best ever interpretation of a phenomenon (Kafle, 2011). The focus of my study using this framework is toward illuminating details and trivial aspects within experience that may be taken for granted in our lives, with a goal of creating meaning and achieving a sense of understanding (Wilson & Hutchinson, 1991). In my study, hermeneutic phenomenology was the most fitting approach although it did share similar characteristics with other qualitative methods as it focused on the lived experience, descriptive in nature, being situated in the world (Laverty, 2003). I further explored and explained the rationale for choosing hermeneutic phenomenology over grounded theory. Firstly, there are distinct differences (see table 3 below), as Hermeneutic phenomenology originates from the European philosophy which involves use of thick description and close analysis of lived experience; to understand how meaning is created and through embodied perception (Sokolowski, 2000). On the other hand, grounded theory originates from sociology where it is symbolic of interactions which translate into meaning being negotiated and understood through social interactions and processes (Jeon, 2004). Secondly my choice of hermeneutic phenomenology over grounded theory was that the analysis of data is 'rich thematic description' that provided insight into meaning of a lived experience whereas grounded theory analysis according to Starks & Trinidad (2007) produces an exploratory theory of basic social processes; patterns of analysis are only identified within and between categories which explains 'conceptual thematic descriptions' rather than explanatory theories. Finally, hermeneutic phenomenology provided me with the tools to understand, study participants' perceptions and experiences in my clinical area with the idea that there is no distinction between the individual and experience; that interpreting them as co-constituting without being able to exist without the other (Laverty, 2003).

Table 4: Comparison of Hermeneutic phenomenology and Grounded theory (Adapted from Starks & Trinidad, 2007)

	Hermeneutic Phenomenology	**Grounded Theory**
History	European Philosophy	Sociology
Philosophy	Concerned with life world or human experience as it is lived. Interpretation is primary focus over description. Ontology which is study of being, becoming, existence or reality and their relations.	Develop and exploratory theory of basic social processes
Goal	Creating meaning and achieving a sense of understanding.	"How does the basic social process of (X) happen in the context of (Y environment)?
Sampling	Those who have experienced the phenomenon of interest. Sampling procedure which selects those who have had the experience of interest (purposive sampling)	Those who have experienced the phenomenon under different conditions
Data Collection	Observe participants in the context where the phenomenon is experienced	Observe participants where the basic social process takes place
Interviewing Strategy	Participants describes experience and interview probes for details	Participants describes the experience; the interviewer probes for detail and clarity
Analytical Methods	Identify descriptions of the phenomenon, cluster into discrete categories; taken together, these describe the 'essence' or core commonality and structure of the experience. Views set aside Reflective process	Open, axial, selective coding: Examine concepts across their properties and dimensions; develop an explanatory framework that integrates the concept into core categories Bracket views
Audience	Clinicians, practitioners and others who need to understand the lived experience of the phenomenon of interest	Researchers & practitioners who seek explanatory model upon which to design inventions
Product	A thematic description of the pre-given 'essence and structures of lived experience	Generate theory from the range of the participants' experience.

3.1.3 Limitations of Hermeneutic Phenomenology

As my journey continued in choosing the appropriate methodology for my study I had to recognise, acknowledge and reflect on the limitations of hermeneutic phenomenology. This is a process I needed to address from the start of my study so that any challenges I faced with participants will be addressed as my study progresses. According to Sharkey (2001) hermeneutic phenomenology challenges the researcher to reflect deeply on what it is that the texts of the field have to say. The researcher is called to play with the texts and to get lost in deep conversation with them. The goal of this type of research is not to clone the texts of the field for the reader of the research but to invite the reader to enter the world that the texts would disclose and open up in front of themselves (Kafle, 2013). As with any research methodology there are limitations and hermeneutic phenomenology is suited for answering questions about human issues and concerns which are primarily the "what" and "how" questions (Benner, 1994). My study aims to answer these questions from patients' and clinicians' perspective by exploring their perceptions and experiences of anal cancer screening in their sexual health clinics.

However hermeneutic phenomenology will not help in predicting outcomes of a study but help to gain a better understanding of what the issues and concerns are which may help to anticipate future events, contribute to and add importance in clinical practice or work environment. Predicting outcomes of a research study is usually a goal of empirico-analytical paradigm (quantitative research) (Smith, 2009) and the goal of my qualitative study is to explore perceptions and experiences of participants in anal screening to inform clinical practice. According to the interpretive paradigm, in which my research is situated, meanings are constructed by human beings in unique ways depending on their context and personal frames of reference as they engage within the world they are interpreting (Crotty, 1998). In this type of research findings emerge from the interactions between the researcher and participants as the research progresses (Creswell, 1998).

Hermeneutic phenomenology has many challenges as such an undertaking requires commitment, time and it can be expensive. Not all researchers or participants are willing or even able to take part in this type of research (Benner, 1994). The risks of biases exist in all human sciences therefore the fore-structure of understanding and one's own biases

have to be acknowledged. In this type of study subjectiveness is valued. There is acknowledgement that humans are not capable of total objectivity because they are situated in reality, and constructed by subjective experiences (Ajjawi & Higgs, 2007). There have been some criticisms about interpretive work especially towards the investigator's knowledge and experience; and for not being true to the lived experience of participants (Tripp-Reimer & Cohen, 1987). This is where I chose to use reflexivity to deal with biases and the subjective knowledge, I have on anal cancer screening from the participants' perspective. I kept a reflexive journal to address distortions or preconceptions. It is for this reason that my reflexive journal is where my logs of the interview sensitised me to any prejudices and subjectivities. I also reminded participants at the beginning of the interview of my background and experience in this field of study as it is new to me and my organisation, so it helped with clarification during the interview which I did not find problematic during data collection process.

Finally, in this section I have outlined the philosophy, strategies and the intentions of the interpretive paradigm. The interpretive research paradigm is based on four philosophical concepts of ontology, epistemology, axiology and methodology. My study focussed on the interpretive understanding to access participants' experiences where the important features to the interpretations is a key to generating knowledge from the interpretations of participants. I chose hermeneutic phenomenology as findings will emerge as the research progresses which could be translated into the clinical practice area in sexual health clinics around the UK and inform criteria for screening as set out by the UK NSC.

3.1.4 Insider Researcher

As an insider researcher, I felt that I was in a unique position to study anal cancer screening as an in-depth issue having specialist knowledge on screening. Not only did I have insider knowledge but had easy access to participants and information to enhance that knowledge (patients and clinicians). The insider researcher is one who studies a group to which they belong (Breen, 2007). The insider researcher knows how best to approach people and have a great deal of knowledge which Smyth & Holian (2008) argue that it takes an outsider researcher a long time to acquire and is a disadvantage for the outsider researcher. The three key advantages of being an insider researcher is: a) having a greater understanding of the culture being studied; b) not altering the flow of

social interaction unnaturally; and c) having an established intimacy which promotes the telling and judging of the truth (Bonner & Tolhurst, 2002). I felt that I was confronted with a dual role of being a nurse practitioner and researcher and although I was part of the data collection and analysis process of my study, I had to adhere to ethical principles that apply to research which was addressed by the ethics committee. I had access to sensitive information from participants which was fairly easy to achieve as I am the senior nurse practitioner with access to key gatekeepers. The ability to successfully gain the necessary permissions from the ethical committees and have access to information made my position of an insider researcher sit firmly with the qualitative paradigm. For my study, I made good use of the advantages of collecting the data every day of the week and any time of the day which an outsider researcher might not have achieved. This provided me with the continuity of data collection and this made it possible for me to collect a more detailed, versatile and trustworthy research data.

For insider researchers, the compelling rationale is to make a difference in a work-based situation so that to have an impact at national, regional and local level, even in the organisation you work in, and you would need evidence. While work-based research can provide this evidence to influence policy and decision making, it can also make a difference to individual practice (Eraut, 2004). I chose to use a reflexive approach where I could consciously acknowledge that reflexivity challenged my personal assumptions, clarified individual beliefs and any subjectiveness I faced (Ortlipp, 2008). As an insider researcher, I was going through a learning process; reflection upon current practice, evaluation research work against the university criteria and the adoption of a reflexive approach are crucial aspects of work-based projects (Eraut, 2004).

3.2 Stakeholder's Engagement

I realised through my research journey that stakeholders play an integral part in research projects as they are groups of people that have expert knowledge (Burton et al, 2008). These include individuals, organizations or communities that have a direct interest in the process and outcomes of a project, research or policy endeavor. This stakeholder engagement can be described as an iterative process of actively soliciting the knowledge, experience, judgment and values of individuals which represent a broad range of direct

interests in a particular issue, for the dual purposes of creating a shared understanding; making relevant, transparent and effective decisions (Barber et al, 2012).

It was important to have early and ongoing communication with my employer about my study as the outcomes of this could have an impact on health policy, development of anal screening guidelines and decision making which is supported by Burgha et al (2000) as these authors concluded engagement often emphasise the potential to influence the actions of an organization, project or policy direction. I met with the lead clinician of the sexual health department at the Trust to inform him of my interest in undertaking research with in the outpatient HIV clinic. This clinician undertakes anal screening at my employing trust and supported the idea of my study. I then met with the director of nursing, my manager and human resources from my employing trust to inform them of my study which again was fully supported. The research and development department (R&D) manager met with me on numerous occasions to assist with the ethics approval process and with the necessary R&D forms for the trust. The R&D manager was familiar with the Integrated Research Application System (IRAS) forms needed for approval and assisted me through a period of 8 months to gain ethical approval locally and other site-specific trusts. Once the favourable opinion for my study was given a progress report had to be submitted 12 months later and the annually until the end of my study to the Health Research Authority (HRA). The same annual report is accepted by all R&D departments. However individual sites may also be required to report on initiation, recruitment and completion to the local R&D office (HRA, 2016). Two sites requested an update on my progress which I submitted a year after I started my study. At that point, all clinicians were recruited and interviewed, and no further reports were requested or sent out. These sites involved clinician recruitment. However, my local R&D department requests an annual report as it involved patients.

Finally, I came to a realisation that involving the necessary people or stakeholders in my research process increased transparency. This was important for maintaining scientific integrity and credibility (Stakeholder Guide, 2014). Those stakeholders not involved in all stages of research process can be targeted where they can have most impact like actively inform policy, decisions and for the dissemination of information.

3.3 Ethical Considerations

As I began this chapter I reflected on what ethics and ethical behaviour meant and it seemed straightforward to me as it simply meant not hurting someone. Ethics pertains to 'doing good' and avoiding harm and that the rights of participants are protected. This harm can be reduced by applying the appropriate ethical principles thus the protection of participants in any study is imperative (Orb et al, 2000). In the sections below, I will discuss information to participants, informed consent, confidentiality and anonymity and how I addressed potential distress of participants. My study is conducted in a setting involving the participation of participants in their clinical environment; therefore, it is imperative I am aware of ethical issues that may arise from such interactions. The nature of my study dictated that potential ethical issues needed to be considered from the outset.

People living with HIV and attending a sexual health service to access medical care in an outpatient clinic raises many ethical issues. Given the vulnerable nature of the patient population and potential sensitive nature of my study and how is will affect all participants; I understand that ethical issues will arise as sexual health is private and confidential. Participants often regard any aspects of sexual health to be private and confidential. I had to take care to address ethical issues throughout my study. Parahoo (2006) mentions that while asking embarrassing and sensitive questions can be intrusive for participants and in turn invade their privacy. Screening increases anxiety and worry about cancer and can be detrimental to sexual well-being (Landstra, 2012). I will be addressing how I considered the key ethical issues in my study by ensuring I gained the necessary ethical approval, that participants came to no harm (consideration to psychological harm), informed consent sought, confidentiality maintained and I how I preserved patient anonymity.

Before commencing my study, I made the necessary application for ethical approval from the Research and Ethical Committee (REC) and hospital trust REC committee. The REC is a multidisciplinary, independent body charged with reviewing research involving human participants to ensure their dignity, rights and welfare are protected (ESRC, 2012). I completed an online IRAS application, which is a system for preparing regulatory and governance applications for health and social care. The IRAS application is then considered by the REC committee as studies that involve "more than minimal risk", and therefore require ethical review, may include: studies where the intention is to submit

findings for publication in journals, oral presentations, books, web-pages, and other media, or as part of coursework; studies involving the collection or analysis of data that could be used to identify participants (including email addresses or other contact details); physical contact with participants; any risk of discomfort or inconvenience to participants; any risk of psychological distress to participants or their families for example, require permission to undertake the study (HRA, 2016). I obtained ethical approval from the National Health Authority/ National Research Ethics Service (NRES: 14/LO/0488) (see Appendix 3) and permission to undertake my study is sought from the Research and Development Departments from the participating Trusts with an arrangement to ensure anonymity of participants. This was a rigorous process I undertook to ensure participants were safeguarded by completing the necessary documents for approval to begin my study

3.3.1 Participant Information Sheet

Participant information is an integral part of any research ethical considerations as it provides a comprehensive overview of the processes I intended to use in my study. I prepared patient information sheet (PIS) (see appendix 4) and clinician information sheet (CIS) (see appendix 5) which I will referred to during the presentation in obtaining consent. For the purpose of my study, I included potential risks which could have potentially resulted in psychological harm and the support that was available during interview process. In case of a patient becoming anxious, tearful, distressed or if I perceived actual harm during the interviews, I would have stepped out of the role of a researcher, I stopped the interview, resume the role of a nurse and would have referred the participant to the clinical psychologist (see appendix 6).

However, the basic principles of participant information which I included in my study covered all aspects as set out by HRA (2016). The participant information sheet (appendix 4&5) provided brief and clear information on the essential elements of my study: what the research is about, the condition or treatment under study, the voluntary nature of involvement, what will happen during and after the research has taken place, the participant's responsibilities, the potential risks, inconvenience or restrictions balanced against any possible benefits and the alternatives. It allowed the participant to decide whether the study is of interest to

them and whether they wish to read and discuss it further (HRA, 2016).

3.3.2 Informed Consent

As the participant information sheet is used as the basis for the invitations to take part in my study, informed consent (appendix 7&8) is important to safeguarding human subjects and protecting their right to self-determination therefore participants were given information regarding which enabled them to consent voluntarily and have the power of choice. When I met with the participants, they read and understood the contents of the information sheet. When participants wished to participate in the study, I asked them to give written consent before being interviewed. A signed copy of the consent form was given to the participant and another copy was placed in a folder in the researcher's office cabinet who has sole access to this information only.

I emphasised to the participants that they were not under any obligation to take part in the study. Patients were told that if they decided not to take part in the study that it would not affect the quality of care, they would receive in the HIV outpatient clinic.

3.3.3 Confidentiality and Anonymity

Participants were fully informed about confidentiality, anonymity and its limits in the study. They were also informed that I was the only person involved in the transcription of data. Participants were also made aware of the fact that quotes from the transcripts would be used in my thesis and for a journal article publication and that all identifying information like their names and places would be removed to ensure anonymity. To ensure anonymity for my study pseudonyms were used where participants were given a fictitious name. Participants are named as Patient 1 and 2 and Clinician 1 and 2 etc. to avoid the possibility of pseudonyms being read as real names. Since this study was part of my academic project for a professional doctorate, participants were made aware that my academic supervisors and academic institution would look at my study therefore all transcripts would be anonymised too. As part of the consent process patients were informed that I would have to access to their electronic patient record with their agreement.

One of the dilemmas I experienced in my study was that of power relationship that existed between me and the participants. This power relationship that emerged was researcher-

participant relations. This relationship is complex due to the researchers' and participants conflicting roles (Karnieli, 2009). The participants were patients who I (as a nurse practitioner) have direct involvement in their clinical care and clinicians who are my colleagues in the professional world of sexual health. The unique contribution of researchers and participants to a project make them inseparable parts; participants feel involved because of the examination of their personal experiences while researchers are involved because of their in-depth study of others' experiences (Karnieli et al, 2009).

Identities of participants were protected in all communications and activities during research. The anonymity of participants was protected by giving each participant a code number. I kept a master list of participants' names and their code numbers on a password protected computer in my office with restricted access. Informed consent was filed and locked in a metal filing cabinet in my private office. This is not a shared office. All taped interviews were coded respectively and locked safely with restricted access. Transcripts of data were entered on the NHS computer with code numbers for identification. This was stored on the secure NHS computer, where I have a secure password only. This computer is password protected and encrypted which is in line with the Data Protection Act (1998), Caldecott principals as well as the NHS Trusts organisational policies. No one other than me could access coded information to identify any participants. I was the only person who had access to participants' personal data. Any identifiable data will be destroyed after 3 years and according to archiving procedures in the Trust. According to Sieber (1992) as cited by Kaiser (2009), data collected anonymously i.e. without identifiable information; researchers must collect, analyse and report data without compromising the identity of respondents. Respondents with stigmatising traits or behaviours would be harmed if their identities were revealed as vulnerable populations face negative consequences of identities are revealed (Baez, 2002). As discussed above I have ensured confidentially, and anonymity was maintained as patients living with HIV are a vulnerable group of patients that experience stigma associated with HIV, HPV and AIN.

During various stages of my project i.e. recruitment, data collection, analysis, validity check, it became apparent to me that ethical and methodological dilemmas were related to informed consent, confidentiality, privacy and power and relevance for the study emerged (Shaw, 2003). In recognising this, negotiation of power was important and that there is an ability to change the power balance between researcher and participant. During the initial

stage of recruitment in the research process the control was in my hands, during data collection control and ownership of the data was in the hands of the participant. I mentioned to participants that my role was that of the researcher, using the "researcher hat" and this should not be concern for their medical care in the outpatients' unit after the interview is completed.

The balance of power may be problematic from a research point of view and could potentially influence data analysis (Payne et al, 2007). I addressed this by providing all the information, a private, confidential and comfortable environment which transformed interviews into a dialogue between two people who share an experience. The atmosphere in which interviews took place allowed the participants to willingly cooperate and contribute wholly in the study.

3.3.4 Potential Distress

I acknowledged the risk of taking part in my study could have been potentially distressing for participants therefore; I addressed this by providing all the relevant information prior to an outpatient appointment about what the study would involve in taking part, so that participants could make an informed decision when they returned for their next routine appointment. If participants became distressed during the interview, the interview would have stopped and they would have been referred to the clinical psychologist, a debriefing of interview would have taken place and we would have reflected on the distress. According to Pietkiewicz and Smith (2012), for ethical reasons, and because IPA studies are frequently concerned with significant existential issues, it is crucial that the interviewer monitors how the interview is affecting the participant. Experienced interviewers can easily determine when the participants avoid talking about certain issues, start feeling awkward, ashamed or become very emotional and by using counselling skills may then be useful, and if the interviewer has not developed such competence, he or she should follow specific ethical procedures (e.g., stop the interview and refer the person to a professional in mental care). Even though such situations are rare, the researchers should consider all possible risks. Anal cytology screening and high resolution anoscopy formed part of the medical care provided by the department as best clinical practice therefore patients were offered counselling by the department's clinical psychologist (see Appendix 6) should they have experienced any distress during the interview. There were no potential burdens for patients for example all patient interviews were arranged when they attended for their

routine clinic appointments therefore no extra appointments were needed for interviews. It was not anticipated that clinicians may experience distress but if this did happen then they would have been referred to their occupational health department for counselling or could access the psychologist at my employing Trust. I endeavoured to conduct the interview as sensitively as possible and a debrief session followed each interview which was recorded in my reflexive diary. However, my role as an interviewer was validated further by my work colleague who is a trained psycho sexual therapist, counsellor and HIV clinical nurse specialist within the HIV outpatient clinic where patient interviews were conducted (see Appendix 9-feedback from CNS). The CNS provided a peer review on my interviewing style, assessed the environment and provide me with feedback on the interview session. I invited the Counsellor (HIV Nurse specialist/psycho sexual therapist) to sit in my third interview and to avoid distress to patient. I asked the patient for consent and it was agreed. I also explained the role of the counsellor and that she was just sitting in as an observer on the far side of the interviewing room. I also made it clear to the patient that the counsellor/CNS will not have any influence on the study in anyway or distract our interviews. Apart from mastering active listening and the ability to ask open-ended questions free from hidden presumptions, I had to build rapport and gain trust with each participant. I started each interview with a 'warm-up' discussion which helped to reduce the participant's tension or anxiety and get him or her ready to discuss sensitive or personal issues. These factors helped to alleviate any distress during interviews.

3.3.5 Potentials Risks for Researcher

The potential risks I identified as a researcher were that I was interviewing patients alone and safety was a concern. Therefore, I chose to undertake interviews at the NHS Trust where an interview room was used and accessible to other colleagues or security in case of an emergency. Researchers have the role and responsibility for flagging concerns especially when dealing with vulnerable adults and take action when concerns are identified (Williamson and Burns, 2014). I am experienced in interviewing and regularly deal with vulnerable groups of people, therefore have the expertise to deal with an untoward situation. I have also undergone risk management training and aware of how to assess any risks. According to Williamson and Burns (2014), it is important to care for the health and wellbeing of researchers in the field and the participants in research. I did not anticipate potential risks when clinicians were being interviewed.

3.4 Participant Selection

The aim in sample selection with a hermeneutic phenomenology approach is to choose participants who have lived an experience and are willing to share this with the researcher (De Gagne & Walters, 2010). I chose two sample selections for my study; one which included patients from an NHS Trust that attend HIV outpatient clinic situated within a sexual health service; second sample selection was from multi-site NHS trusts to include clinicians undertaking anal screening in sexual health services from around the UK.

The aim of the sampling process for my study was to make certain that I actively selected the most suitable sample to answer the research question. Any researcher needs to ask him or herself what exactly she or he wants to accomplish, what she or he wants to know and the appropriate sampling strategy will follow (Palys, 2008). It involves the researcher deliberately choosing who to include in the study on the basis that those selected can provide the necessary data (Parahoo, 2006) therefore purposive sampling was appropriate for my study with patients and convience sampling used with clinicians. I employed purposive sampling where I targeted patients that best contributed to my study so I involved these patients who lived with the experience I was researching. I conducted purposive sampling to attract patients who were willing to talk about their experiences. This is a recognised strategy for identifying and accessing a sampling frame which involves criteria that would suit the purpose of the study (Ritchie et al, 2003). This sampling method helped me in optimising the chances of gaining insight into the research question as the patients were the ones with the lived experience of anal cancer cancer screening. There were 40 patients that underwent anal screening which is the total clinic population. Fourteen patients contributed to my study.

Conveince sampling was used with clinicians in my study. According to Etikan et al (2016), it is not possible to include every subject because the population is almost finite and this is the rationale behind using sampling techniques like convenience sampling by most researchers. The main assumption associated with convenience sampling is that the members of the target population are homogeneous i.e. that there would be no difference in the research results obtained. The entire population of 8 clinicians undertaking anal cancer screening in the UK took part in my study. I wrote to them about my study and they

accepted the invitation to take part in my study and all 8 practicing clinicians who offered anal cancer screening in their specialist sexual clinics were included in my study.

Two principles, appropriateness and adequacy guided me in the sampling process. The first principle, appropriateness is derived from the identification and utilisation of the participants who can best inform the research. The second principle of adequacy means that, there will be enough data to develop a full and rich description of the phenomena until no new themes are identified (Morse & Field, 1996). The sample size for my study was determined when data saturation was reached with patients and no new themes emerged from the interviews. Determining adequate sample size in qualitative research is the researcher's judgmental call for the intended study. Purposive sample sizes are often determined based on theoretical saturation (De Gagne & Walters, 2010). The number of participants for a study cannot be determined in advance and recruitment can be stopped when no new descriptions can be found (Sherman & Strang, 2007). Typically, purposive sampling involves samples to enhance understanding of information rich case (Patton, 1990). I therefore, found that purposive sampling was successful as I reviewed the data and analysed this in conjunction with the collection of data.

3.4.1 Inclusion and Exclusion Criteria

The inclusion criteria for patients at an NHS Trust are those that have a diagnosis of HIV, had an anal cytology and undergone high resolution anoscopy, 18 years of age and above, spoke and read English. The inclusion criteria for clinicians are those clinicians who undertake anal cytology screening and high resolution anoscopy in their sexual health clinic. All patients who met the inclusion criteria were purposively selected and interviewed until no new information emerged, however all 8 clinicians that undertook anal cancer screening in sexual health clinics were selected.

Exclusion criteria were patients who never had anal cytology and high resolution anoscopy as part of their medical care at the outpatients' clinic. Patients without mental capacity were not part of this study. Exclusion criteria for clinicians included those clinicians that are not currently involved in the anal cancer screening process within sexual health clinics i.e. anal cytology and HRA.

3.4.2 Patient Selection

To place patient selection in the context of my study, the sample selected were patients living with HIV, attending the HIV outpatient clinic at an NHS hospital Trust only and those patients who have undergone anal screening in the sexual health clinic. I approached patients face to face during their routine HIV outpatient clinic appointments to inform them of the study and they were given the Patient Information Sheet (PIS) with the invitation to take part in the study when they attended for their HIV outpatient clinic appointment (see appendix 4). The PIS contained the purpose, advantages and risks of taking part, information about how the results of the study will be published once complete, confidentiality, who has reviewed the study (i.e. ethical committees) and my contact details if they wished to take part. Patients are followed up every 3 months for routine HIV medical care which coincided with their regular appointments therefore had 3 months to consider whether to take part or not. Patients who were willing agreed to take part in this study were asked if they needed further information and when they were happy with this, I arranged to meet with patients to go through the consent form and interview them at that point. I obtained consent once patients understood the given information about the study. Recruitment of patients were fast and fluid as the PIS was concise to the point, simple to understand and not too lengthy. Patients were excited about the opportunity to take part in the research at their clinic as some of them have been attending this service for many years and wanted to be part of a new development in the HIV service. During recruitment patients were informed that they would not benefit personally from the research but hoped that the findings of this study would guide future research and inform current clinical practice and screening in sexual health clinics in the UK.

The place of interviews was convenient for patients as the interviews were carried out in a counseling room in the outpatient's clinic and patients did not have to make an extra visit or journey for the interview. Scheduling an interview at an amenable time and location is often particularly important to respondents (ELMIR et al, 2011). The room was quiet with comfortable chairs and there were no interruptions. The location I chose to undertake the interviews had a good ambience and I developed this rapport with participants which further contributed to the sound quality, so I could immerse in the data collection process. Participants could relax and at the same time their privacy maintained. It is difficult to hide one's identity from the researcher in face-to-face interviews; however, confidentiality

protections are dependent upon interviewer integrity and data protection methods (Oltmann, 2016). The quality of data collected during interviewing would not be affected in a quiet, confidential environment.

3.4.3 Clinician Selection

Clinicians were informed verbally via telephone, meetings (multidisciplinary team meetings) or when we met at conferences to made them aware of my study. Once ethical approval was obtained clinicians were sent out the Clinician Information Sheet (CIS) via secure NHS email to be able to agree to take part in the study. The CIS (see appendix 5) included an invitation, purpose, advantages, risks, confidentiality, study review and my contact details which was similar to the PIS. Only eight clinicians met the criteria for inclusion in my study and I interviewed all eight clinicians working in sexual health clinics undertaking anal cytology and high resolution anoscopy. I had to travel to different hospital trusts sites to interview clinicians. At the point of my study there were only 8 trained clinicians in total in the UK undertaking anal screening and were considered for my study. Clinicians were informed that their perceptions and experiences on anal cancer screening would contribute to a body of knowledge to inform clinical practice in sexual health clinics in the UK. It must be noted that Smith et al (2009) observed that the typical number of interviews analysed in professional doctorate projects are between four and ten with the emphasis that higher numbers are not indicative of better work.

3.5 Data Collection

Data were collected by in depth interviews that were unstructured. Ritchie and Lewis (2003) explains that in-depth interviews permit the researcher to explore fully all the factors that underpin participant answers, reasons, feelings, opinions and beliefs which provides the explanatory evidence that is an important element of qualitative research. Polit & Hungler (2006) mentions, that the aim is to elucidate respondents' perceptions of the world without imposing ones' "own views", while Hek, Judd and Moule (1998) suggest collecting information by in depth interviews, a theory can be generated. Unstructured interviews can be beneficial to the researcher and will learn more about the topic as the interview progresses (Morse & Field, 1996). Unstructured interviews allowed me to ask open ended questions mainly to explore and build upon responses from the participants. Participants

were able to answer in their own way expressing their perceptions and experiences without feeling restricted by standard questions as in structured interviews.

Patient interviews were conducted at an NHS Trust where an interview room was accessible to other colleagues like the psychologist and security or in case of an emergency both the patient and I would have encountered. Clinician interviews were conducted in their office at each individual trust location which was private and without any disturbance from their colleagues or patients. To avoid any disruptions telephones were put on voice mail to accommodate the interview process. Interviews were conducted face-to-face and recorded using a digital tape recorder. Fain (2004) proposes that the researcher must consider the possibility that participants might be sensitive to the presence of audio equipment therefore ask the participant permission to record. I recorded the interviews and transcribed them verbatim. The participants (patients and clinicians) were interviewed for approximately 60 to 90 minutes to allow for prolonged engagement (average interview was 70 minutes). I asked one question (i.e., "What is your experience in undertaking anal screening in your clinic?") which set the scene for the interview. This is a broad statement, flexible and opened ended to allow the participant to talk freely and openly. This allowed me to explore all aspects of the phenomenon to gain sufficient information for generation of a theory. By using an open and accepting interviewing style is important during interviews (Hallet, 1995). Trigger questions were used to guide the interview for my study just so that I could explore an in-depth idea promptly, the structure of the interview can be loosely guided by a list of questions which is open-ended and flexible (see appendix 10&11). An advantage of trigger questions is the opportunity they provide for rich insight and understanding beyond just mere answers. These questions were discussed with my academic supervisors, peer reviewed and approved by ethics committee.

I chose not to undertake pilot interviews as I am an experienced trained practitioner in interviewing in my role. After each interview, I debriefed with each participant each interview to elicit how they felt and to assess for potential distress and this conversation was not recorded. I kept notes in my reflexive diary of the debriefing session to later reflect on my own. I used these notes to reflect on my interviewing style and following each interview reviewed what trigger questions I could introduce to other interviews to expand on what could be explored further with other participants. By the third interview I

sent interviews to my academic supervisors and we found gaps in research which are not explored in most studies. In keeping with IPA, it shows I am not just duplicating existing research, and that I have a deep understanding of the status of the body of knowledge on the perceptions and experiences of participants in anal cancer screening. Finally, it will mean that I have conducted a research which addresses that gap in the literature in what I could probe further with other participants in view of gathering rich deep experiences for my study. My academic supervisors gave me feedback with the idea of exploring sexual activity and social life with patients. I included one trigger question for the patients (i.e. having been diagnosed with AIN, does this in any way affect your sexual activity or social life?) in the interviews that were to follow. However, I felt that my initial interviews were less informed at times as patients did go off track. One patient started speaking about general health for example, and he started discussing the heart attack he had a few years ago. I have the experience of interviewing therefore I stayed focused during interviews and this has helped me achieve the desired outcomes, and this has helped me improve the quality and depth of interviews with subsequent participants. The data collection process of my study covered the interviewing style I used, data collection procedure, and liaising with my academic supervisors for feedback. My reflexive diary allowed me to reflect on the data I collected.

3.6 Rigour or Trustworthiness

It was important for me to demonstrate rigour and trustworthiness in my study as qualitative research requires that the researcher demonstrates quality in their work which I will discuss in detail below. Reliability and validity are ways of demonstrating rigour of research processes and the trustworthiness of research findings, therefore reliability in qualitative research is thought of as the trustworthiness (Stiles, 1993). Reliability and validity are conceptualized as trustworthiness, rigor and quality in qualitative paradigm and that can be achieved by eliminating bias and increasing the researcher's truthfulness of a proposition about some social phenomenon using triangulation (Bashir et al, 2008). I used different data sources of information by examining evidence from the sources and used it to build a coherent justification for themes, whereas reflexivity according to Bashir et al (2008) is rigorous self scrutiny by the researcher through out the research process and is an important procedure for establishing credibility.

According to Noble and Smith (2015) qualitative researchers aim to design and incorporate methodological strategies to ensure the 'trustworthiness' of the findings. Such strategies included:

1. Accounting for personal biases which may have influenced findings
2. Acknowledging biases in sampling and ongoing critical reflection of methods to ensure sufficient depth and relevance of data collection and analysis
3. Meticulous record keeping, demonstrating a clear decision trail and ensuring interpretations of data are consistent and transparent
4. Establishing a comparison case/seeking out similarities and differences across accounts to ensure different perspectives are represented
5. Including rich and thick verbatim descriptions of participants' accounts to support findings
6. Demonstrating clarity in terms of thought processes during data analysis and subsequent interpretations
7. Engaging with other researchers to reduce research bias
8. Respondent validation: includes inviting participants to comment on the interview transcript and whether the final themes and concepts created adequately reflect the phenomena being investigated
9. Data triangulation, whereby different methods and perspectives help produce a more comprehensive set of findings

In keeping with IPA demonstrating rigour was essential for me so that my research findings would have the integrity to make an impact on practice and health policy. For me validity meant the extent to which the data I collected was plausible, credible and trustworthy; so that it can be defended when challenged. Reliability and validity remain appropriate concepts for attaining rigor in qualitative research. According to Roberts et al (2006), other methods for increasing reliability include ensuring technical accuracy in recording and transcribing, while some suggest that tape-recorded interviews and interview transcripts can help improve reliability. Software programmes can be used to systematically explore basic material, creating a broad agreement amongst researchers about what is being dealt with the quality, rigour and trustworthiness of the research is enhanced (Welsh, 2002). Any biases were reduced by the participant validating the transcripts. The transcripts were given to participants and this in essence means that as a researcher I was able to share any interpretations and theories with participants. They

could check, make amendments and give feedback to me to validate if their accounts were consistent with their experience. It is useful for the participant to provide validation as this can provide researchers with an opportunity to rethink their interpretations (Lincoln & Guba, 1985 as cited by Roberts et al, 2006). Transcripts were also sent to my two academic supervisors for review where they both read the transcripts and provided feedback. We had a meeting and went through the transcripts where we compared their themes and codes to mine. Both my supervisors and I had similar themes and codes which further validated my interpretations and quality of analysis. This process has added rigour to my research where transcripts were validated by participants and my academic supervisors and reliability and validity demonstrated.
Lincoln and Guba (1985) as cited in Noble and Smith (2015) offer alternative criteria for demonstrating rigour within qualitative research namely truth value, consistency and neutrality and applicability.

Truth value recognises that multiple realities exist; the researchers' outline personal experiences and viewpoints that may have resulted in methodological bias; clearly and accurately presents participants' perspectives Noble and Smith (2015). I used a reflective journal to maintained and document any decisions. A colleague who was a pyschothrapist and clinical nurse specialist provided me with a peer review of an interview or debriefing to assist me to uncover any biases, or assumptions, for example, the initial qualitative interviews with patients were focused mainly on anal cancer screening procedure but subsequent interviews took a more holistic approach. The sample of 20 participants willingness to share their experiences in depth and over time enabled clarification of findings as an ongoing process showed representativeness of the findings in relation my study. The audio recorded interviews allowed for repeated revisiting of the data to check emerging themes and remain true to participants' accounts. I used of rich and thick verbatim extracts from participants which assists the reader to make judgements about whether the final themes are true to participants' accounts and the participants were invited to comment on the research themes that emerged from my data.

Consistency relates to the 'trustworthiness' by which the methods have been undertaken and is dependent on the researcher maintaining a 'decision-trail'; that is, the researcher's decisions are clear and transparent. Ultimately an independent researcher should be able to arrive at similar or comparable findings (Noble and Smith, 2015). This was achieved in

my study by having transparent and clear description of the research process from initial outline, through the development of the methods and reporting of findings. In addition to my reflexive diary helped me as I documented challenges and issues which assisted me in maintaining cohesion between the study's aim, design and method.

Neutrality (or confirmability) according to Noble and Smith (2015) is achieved when truth value, consistency and applicability have been addressed. Centres on acknowledging the complexity of prolonged engagement with participants and that the methods undertaken and findings are intrinsically linked to the researchers' philosophical position, experiences and perspectives. These should be accounted for and differentiated from participants' accounts. This was achieved by giving participants the transcripts to comment on the interview transcript and whether the final themes and concepts created adequately reflect their perceptions and experiences on anal cancer screening.

Applicability is the consideration is given to whether findings can be applied to other contexts, settings or groups (Noble and Smith, 2015). The rich detail of context, from the patients managed within the HIV outpatient service, as well as clinicians in sexual health services from around the UK helped facilitate the evaluation of study conclusions and transferability to other sexual health clinics and inform practice, policy and guidelines for anal cancer screening.

3.7 Data Analysis

In keeping with hermeneutic phenomenology methodology, I adopted interpretive phenomenological analysis (IPA) to develop in-depth descriptions of participants' perceptions and experiences of anal cancer screening. IPA seeks to understand in detail how an individual experience a phenomenon from a perspective within a particular context and is concerned with ways in which people make sense of their experience and attach a meaning to life events (Smith et al, 2009). IPA is one such framework which was developed as the techniques used can be further developed into theories, models and explanations that can help understand human experience better (Smith et al, 1999). Reid et al (2005) explains that IPA is an exploration of a lived experience coupled with a subjective and reflective process of interpretation. Reflexivity during the analysis process was important for me as I had to examine my own role within the study. Reflexivity is

viewed as an optional tool which enables the researcher to formally acknowledge his or her interpretive role instead of using this technique to remove bias (Fade, 2004). Any inferences that are drawn from the data are done so cautiously and with awareness of the culture and context within which the study is situated.

The way in which the researcher understands the participant's experience of the phenomenon under study – in this instance learning about transference, and the meanings participants made of this, is influenced by the researcher's engagement with and interpretation of the participant's account. IPA is both phenomenological and interpretive and necessitates researcher reflexivity throughout. Smith et al (1999) stresses the importance of IPA as an attempt to gain an insider perspective of the phenomenon under study whilst acknowledging that the researcher is the primary analytical instrument. I collected, transcribed and interpreted all the data for my study using my experiential knowledge.

I used the hermeneutic circle as a strategy for understanding and interpretation of data in my study. This understanding involved repeated circular movements between the parts and the whole establishing real relationships between reader, text, and context so that reading a sentence involves these repeated circular movements of parts and whole relationships (see Figure 6 below). According to Reiners (2012), interpretative hermeneutics utilizes the hermenuentic circle method of analysis where there is continual review and analysis between the parts and the whole text. I transformed the lived experience of participants into a textual experience by reflection, thinking, reading and writing which occurred in hermeneutic cycles until meanings emerged from the text. This text according to Smith (1997) cited in Ajjawi & Higgs (2007), may be viewed as both the data and product of research. This can also be viewed as a movement between parts of data and whole of data which is an evolving understanding of phenomenon, giving meaning to the other so that understanding is circular and iterative (Bonteko, 1996 cited n Ajjawi & Higgs 2007). Koch (1996) describes the experience of moving dialectically between the parts and the whole. As interpreter, I became part of this circle where I repeatedly moved between interpretations of parts of the text and interpretations of the whole text for an understanding. Through the hermeneutic circle the interpreter attempts to understand "the whole through grasping its parts and comprehending the meaning of the parts divining the whole" (Crotty, 1998: 92). Using the concept and practice of the

hermeneutic circle, the inquirer (researcher) recognizes that the phenomenon or object of comprehension is understood, because its parts are integrated and comprise it. At the same time inquirers recognize how the whole contextualizes each of the parts, seeking to illuminate the phenomenon within its context. The process involves an examination of the parts, examining each component before it is reintegrated into the whole (Bontekoe, 1996).

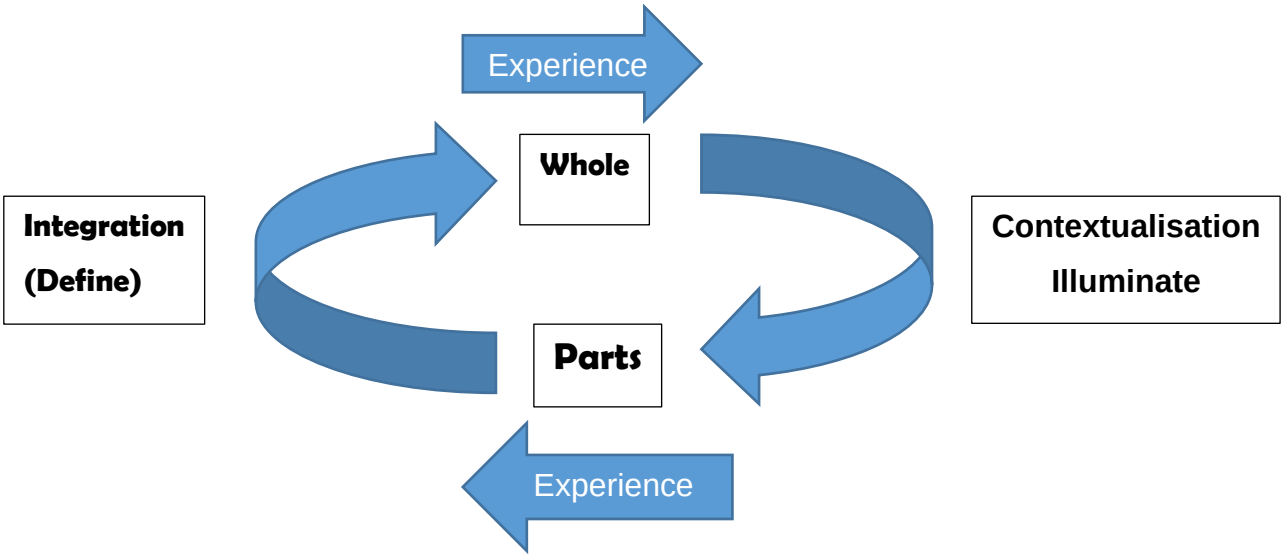


Figure 6: The basic form of the hermeneutic circle (Bontekoe, 1996, p. 4).

I managed to maintain rigour by keeping a reflexive journal as an audit trial, checked and shared interpretations with participants as well as by my rigorous data analysis process. I also shared the detailed description of the research setting (i.e. being open and transparent about the environment and a private interviewing room for example) with participants which maximised research rigour. The purpose of data analysis regardless of type of data, or the underlying research tradition, it is important to organise, provide structure, and elicit meaning from research the data (Polit & Hungler, 2006). Whitehead (2002) states that, some phenomenological researchers advocate a step-by-step set of procedures to aid in the interpretation of phenomenological data. There were six stages in the IPA framework process that I used for my study (see table 5 below) adapted from Ajjawi & Higgs (2007). The six stages of interpretative analysis are immersion, understanding, abstraction, synthesis and theme development, Illumination and illustration of phenomena, and integration and critique. Throughout all stages of the data analysis

process there was ongoing interpretation of the research text and exploration of perceptions and experiences of participants in anal cancer screening depicted in table 4 below.

Table 5: Six stages in Data Analysis (Adapted from Ajjawi & Higgs, 2007)

Stage	Process Used
1. Immersion	• Transcribed data organised into research texts • Constant or Iterative reading of texts • Initial or preliminary interpretation of text to enable coding
2. Understanding	• Identifying first order (participant) constructs • Coding of data using Nvivo software
3. Abstraction	• Identifying second order (researcher) constructs • Grouping second order constructs into sub-themes
4. Synthesis and theme development	• Grouping of sub-themes into themes • Further elaboration of themes • Comparing themes across sub discipline groups
5. Illumination and illustration of phenomena	• Linking literature to themes identified above • Reconstructing interpretations of perceptions and experiences in participants own words
6. Integration and critique	• Critique of themes by researcher and academic supervisors • Reporting final interpretation of research findings

3.7.1 Stage 1: Immersion

Each interview was recorded and manually transcribed verbatim into a Word document. I made notes as the interview progressed where I took note of verbal responses and expressions. I transcribed each interview as I completed a participant interview as I captured what transpired at each interview while I could still remember events of each interview. According to Fade (2004), it is helpful to keep field notes describing verbal and non-verbal communication and this should be inserted in the transcripts while it is still fresh

in the researcher's mind. I took some notes during the interviews to reflect on after each interview. Transcribing took a long time, but it helped me immerse into the data. The notes that I took during interviews were not integrated into my data, instead I used these notes during reflexivity to assess how other interviews could have been improved upon. Besides I took very few notes as I did not want to distract the participants or lose focus during my exploration of experiences and perceptions on anal cancer screening with participants. According to Muswazi and Nhamo (2013) taking notes might distract participants or cause the researcher to miss important aspects of events as well as disrupt the effectiveness of communication between the interviewer and the participant. By interviewing in an open style, I was able to immerse myself as a researcher in the participants' perceptions and experiences related to anal cancer screening with minimal distraction by listening, rephrasing, creating a rapport with participants.

The transcripts were read several times to identify themes for initial interpretation in the data or text (see figure 6 above shows the iterative process I used to understand the data). This was the first step that I undertook in the analytical process to get a sense of the data where I started making notes which described any striking issues to enable me to code. This is where I immersed myself in the transcribed data and manually highlighted with a colour highlighter the examples of these issues on the lines of the transcript and made notes on each transcript which helped me to identify different themes later. I also used NVivo programme to help me speed up the process of manual work of identifying themes which is part of the immersive process. This software indeed helped me reduce several manual tasks I was undertaking as NVivo has a feature to highlight tendencies. Nvivo gives the researcher time to discover tendencies, recognise themes and derive at conclusions. Whilst being immersed in the data I was alert, flexible and positive about the data I collected (Wong, 2008). Any emerging thoughts were documented in the form of memos which was linked to sections in the text. I then moved onto stage 2 of the analysis process.

3.7.2 Stage 2: Understanding

First order constructs were developed from participants when they expressed their experiences and this stage about understanding the individual experiences.

Table 6: **Example of Understanding in stage 2 of data analysis depicting first order constructs developed in my study**

Experience of Participants	**First Order Constructs**
"I'm probably better than most, but even 2 years ago I let an appointment slip and I'm sure it was because of reluctance and then I almost got caught out that they found some cells that they weren't happy about and that that really scared me and put the fear of god in me"-Patient 3	Felt scared for missing screening
"Very anxious, didn't want to walk out of the house even I almost became agoraphobic. My sleep wasn't affected, it was just a very heightened state of being anxious all the time"-Patient 1	Anxious about having anal cancer
"I have had it done previously and I couldn't tolerate the pain, it was awful. I don't look forward to it because it's painful"-Patient 12	Pain during anal screening
"The whole experience of anal exams and whatever, I can't say its ever something that one looks forward to, to dropping your trousers and having someone look up your rectum, – whatever. It's invasive in every sense. It's not invasive physically, it's invasive personally"-Patient 8	Invasion during anal screening

In this stage I identified first order constructs (Table 6) from the participants when they expressed ideas in their own words to capture in detail what the participant was actually saying. My first order constructs were organised into experience and the emotions experienced by participants. Smith and Hesse-Biber (1996) mentions that, Nvivo is mainly an organising tool and this software is designed to carry out administrative tasks of organising data efficiently. Once I transcribed the data, I saved the transcripts in a folder as a Word documents on my computer so that these documents are easily visualised on screen (Appendix 12 & 13). I then uploaded the transcripts onto the Nvivo software programme version 9 (see Appendix 13). By using Nvivo software in data analysis

process in qualitative research adds rigour to the research process (Richards and Richards, 1991). One way in which accuracy could be achieved and rigour of analysis process maintained, is by using the search facility in Nvivo which is seen by the developers as one of the main assets of interrogating data, thus carrying out such search electronically will yield more reliable results than doing it manually simply because it will rule out human error (Welsh, 2002).

The first order constructs refer to participants' ideas expressed in their own words or phrases, which capture the precise detail of what the person is saying. This was checked by giving the transcript to the participants for feedback. My understanding of the first order construct e.g. "felt scared for missing screening" is derived from participants experience ("…that really scared me and put the fear of god in me). Patients were given their transcripts when they returned for follow up outpatient appointment and I emailed the clinicians their interviews via secure email. Patients and clinicians gave me feedback via a telephone me to confirm any changes. Participant feedback is a central aspect of producing findings from interactions between me and the participants as the research progressed (Ajjawi & Higgs, 1997). I intended to validate these transcripts not only to provide rich deeper understanding of their experiences but to allow participants to correct any misinterpretations, clarify information and make any additions if they wished and continue in the research process.

I had to anticipate errors or inconsistencies (e.g. incorrect language, spelling) in the transcripts, which Lapadat (2000) state may be significant and could alter meanings and affect research. The transfer of transcripts to participants allows the researcher to preserve research ethics, empower interviewees by allowing them control of what is written (Mero-Jaffe, 2011). On the other hand, Payne et al (2007) suggests that giving participants transcripts is an act of empowerment and this means that the researcher respects their experience and contribution to research. The responses I received from participants helped me to authenticate what was said in the interview, correct any language and change the balance of power between me and participant. The feedback I received from a telephone call from each participant to verify any changes was that the integrity of transcript was true reflection of interviews and only minor changes like incorrect language and spelling errors had to be made. Researchers also send transcripts to participants to preserve norms of etiquette, individual wellbeing, and freedom of consent,

choice, and principle of justice, decency and equality (Kvale, 1996, cited in Mero-Jaffe, 2001). All of which maintains ethical standards as highlighted in my study. Participants felt respected and their dignity protected by anonymity in transcripts and in my opinion alleviated feelings of embarrassment and threat due the sensitive nature of my study.

3.7.3 Stage 3: Abstraction

In the Abstraction stage second order constructs like fear, anxiety, pain, invasion was developed from first order constructs and grouped into sub-themes.

Table 7: Example of stage 3 of analysis Abstraction where I developed second order constructs to form sub themes

First Order Constructs	Second Order Constructs	Sub-themes
Felt scared missing screening	Fear	Emotional response to anal screening, fear of missing screening
Very anxious, didn't want to walk out of the house even I almost became agoraphobic.	Anxiety	Emotional response to having anal cancer, feeling anxious
Pain during anal screening	Pain	Physical experience of pain during screening
Invasion during anal screening	Invasion	Physical experience of Invasion

Once I coded the first order constructs; I generated second order constructs, e.g. 'Fear' using my knowledge of data and personal knowledge. This was developed from first order constructs like 'felt scared of missing screening' and these were abstractions of the first order constructs. This in effect was where I identified second order constructs (see table 7). The emergent sub themes were listed and organised to form clusters of related themes. Sub-themes were developed from second order constructs like 'fear' and 'anxiety and grouped together to form a sub-theme 'emotional responses'. This process as discussed by Smith et al (2009) of how super ordinate (i.e. putting like with like and developing a new name for the cluster) themes can be identified through abstraction.

Thus, at the end of this stage all the relevant data were grouped under each construct for each subgroup to answer the main research question for my study.

3.7.4 Stage 4: Synthesis and theme development

Sub-themes: Fear and Anxiety for example grouped together to form main themes for example, psychological effects of anal cancer screening. Physical experience of pain and invasion grouped to form a theme-anal screening procedure

Table 8: Example of stage 4 of synthesis in data analysis stage depicting the development of sub-themes into themes

Second order constructs	Sub-themes	Themes
Fear	Emotional response to anal screening, fear of missing screening	Psychological effects of anal cancer screening
Anxiety	Emotional response to having anal cancer, feeling anxious	
Pain	Physical experience of pain during screening	Anal cancer screening procedure
Invasion	Physical experience of Invasion	

In this stage, the second order constructs (e.g. fear or anxiety) were grouped together into a number of smaller broad themes e.g. emotional responses to anal cancer screening (see table 8). These themes were developed from stages one to three of analysis stages and I interrogated the relationship between themes and sub themes by reading and re-reading all the data. I found myself moving backwards and forwards between the literature, research texts and earlier analysis moving from parts to whole following a process as part of the hermeneutic cycle. This was an important part of the analysis process which ensured that I did a thorough analysis of data. This in-depth interpretation of the experiences and perceptions of patients and clinicians in anal cancer screening and its

psychological impact it has on the participants helped me identify meanings that participants could not articulate due to the sensitive nature of the phenomenon being investigated. Some participants found it difficult to express or discuss what they trying to say which required for me to explore and interpret what they actually wanted to say and attach a meaning or interpretation to their experience and perception.

I presented the preliminary findings of themes and sub themes at the International Neoplasia Scientific Meeting (Conference) 2015 in Atlanta, United States to gain feedback on the credibility of the themes and sub-themes (as presented in table 7) to see how these findings could be transferred to clinicians, patients, research community and educators who attended the conference. The preliminary findings of my study showed that patients and clinicians identified that cancer is a worry; the actual procedure is uncomfortable; associated with pain, is acceptable but tolerability was variable. Information available on AIN or anal screening is very limited in the UK and that there are associated psychological effects like anxiety, fear, and embarrassment. I found the research findings presented at the conference helped me refine and further develop a theme which is presented in my findings chapter. The conference feedback provided me with supplementary information into the participants' experiences and reflections which challenged my interpretations when I explored their perceptions and experiences on anal cancer screening. The value of presenting research findings at the IANS conference was to get feedback, but most importantly according to Ajjawi & Higgs (2007) is an opportunity for researchers to reflect on their emerging interpretations in the process of writing and articulating the research process and content. This also challenged my emerging interpretation through an experienced research community abroad which was seen through broad lenses which encourage explanations and arguments which was invaluable to the refinement of my study.

3.7.5 Stage 5: Illuminating and Illustrating the Phenomena

In this stage, I examined the themes and sub-themes from the data and looked for links with the literature. I used the themes and sub themes, looked and interrelationships and constructed participants' experiences and perceptions by quoting their own words (e.g. very anxious, didn't want to walk out of the house even I almost became agoraphobic) to illuminate and highlight key findings from data. I looked further into developing links

between main themes to support theoretical development. In this stage I was able to present the findings with supportive literature as presented in chapter 5 of my study.

3.7.6 Stage 6: Integration and critique

The final stage of data analysis involved critique by my academic supervisors, my work-based lead Physician and feedback from the conference which had an impact and increased my understanding of the phenomenon. Comments received were incorporated into the interpretation and adjustments made accordingly. Verbal feedback via telephone conversation and email communication was sent to me and I included this in my study for example, I presented preliminary findings of my study at the IANS conference in Atlanta, comments received about women and anal cancer screening was the main topic at the conference by most presenters. My study mainly included MSM who were interviewed as AIN was diagnosed mostly in MSM and only one female my study that had been screened and had AIN at my Trust. I therefore had to justify the uptake of women in anal cancer screening in my study although all women were offered anal cytology screening during routine HIV outpatient appointments.

Once the process of Interpretive phenomenological analysis was completed using the six stages of data analysis, I developed 5 main themes and sub-themes as illustrated in table (9) and appendix 14 (nodes/codes). The main themes are presented below:

- Psychological effects of anal screening (Worry, anxiety and fear about anal cancer; Embarrassment, shame, stigma and reassurance)
- Screening procedures (Acceptability and Tolerability of Anal Cancer Screening; Pain, bleeding, and discomfort)
- Education, knowledge and training in anal cancer screening
- Social and sexual activity
- Anal cancer screening guidelines and practices in sexual health clinics in the UK.

Table 9: Stage 6 of data analysis with 5 main Themes and Sub-Themes

Themes	Sub-Themes
1. Psychological effects of anal cancer screening	• Worry • Anxiety • Fear • Embarrassment • Shame • Stigma • Reassurance
2. Anal Screening Procedures	• Acceptability and Tolerability of anal cancer screening • Pain • Bleeding • Discomfort • Invasive
3. Education and Training	• Knowledge and education on anal cancer screening • Training of Clinicians
4. Social and Sexual Activity	• Social life • Sexual activity
5. Guidelines and Practices	• Anal screening guidelines in the UK • Geography of Clinics • Referrals to anoscopy Clinics • Multifocal disease • Evidence based practice • Cost effectiveness • Recommendations for anal screening • Benefits of anal cancer screening

The themes and sub-themes are discussed in chapter 4 and a discussion provided in chapter 5. Some sub-themes are grouped together under main themes as presented in the next two chapters.

4 Findings

The aim of my study is to explore the perceptions and experiences of patients and clinicians in anal cancer screening. Few qualitative studies have examined the perceptions and experiences of patients in anal screening. Clinicians' perceptions and experiences on anal cancer screening were only considered in few studies to date too. Interpretive phenomenological analysis of the unstructured interviews resulted in the following themes: Psychological effects of anal screening, Screening Procedures, Education and Training, Social and sexual activity, Guidelines and Practices. According to Beins (2013), researchers can be in a position to recognise that there may be some psychological processes that manifest in participants depending on culture, race and ethnicity or even socio-economic status. I have included patient demographics to give the reader an understanding of the participants involved in my study.

4.1 Participant demographics

Wyse (2012) describes demographics as characteristics of a population such as race, ethnicity, gender, age, education, profession, occupation, income level, and marital status, which are all typical examples of demographics that are used. My study focuses on anal cancer screening by exploring the perceptions and experiences of participants and through some of these demographic descriptions e.g. MSM, HIV positive patients and clinicians in sexual health clinics in the UK can provide a context for the group of participants considered for my study. According to Polit and Beck (2010), this will allow readers and other researchers to determine to whom these findings can provide a rich, contextualized understanding of some aspect of human experience through the intensive study of particular cases. Furthermore, this inclusion of participant demographics will greatly add to the field's knowledge base and understanding that variations exist among populations (Hammer, 2011). Twenty-two participants in total were purposefully selected from those who volunteered to create the sample for my study. Thirteen patients identified themselves as men who have sex with men living with HIV and one patient identified as a heterosexual female, living with HIV (Table 10). Patients were recruited from one HIV outpatient clinic and were 18 years and older. People living with HIV are a challenging group of and it was not appropriate for me to ask them during interviews about their sexuality or for instance therefore I retrieved this information from the demographic data of

the electronic patient records at the HIV outpatient clinic. The eight clinicians included in my study all work in a sexual health clinic undertaking anal screening. Clinicians were located throughout the United Kingdom of which there were two female doctors, one female nurse practitioner and five male doctors (Table 11). Demographic information of clinicians was obtained during interviews. Data were collected between May and September 2014.

Table 10: Patient demographics: pseudonym name, gender, sexuality & Health status

Patient	Age	Gender	Sexuality	Health Status
Patient 1	44	Male	Homosexual	HIV positive
Patient 2	59	Male	Homosexual	HIV positive
Patient 3	54	Male	Homosexual	HIV positive
Patient 4	29	Male	Homosexual	HIV positive
Patient 5	65	Male	Homosexual	HIV positive
Patient 6	50	Female	Heterosexual	HIV positive
Patient 7	38	Male	Homosexual	HIV positive
Patient 8	51	Male	Homosexual	HIV positive
Patient 9	74	Male	Homosexual	HIV positive
Patient 10	59	Male	Homosexual	HIV positive
Patient 11	40	Male	Homosexual	HIV positive
Patient 12	49	Male	Homosexual	HIV positive
Patient 13	41	Male	Homosexual	HIV positive
Patient 14	48	Male	Homosexual	HIV positive

Table 11: Clinician demographics: Clinician, gender, occupation/profession, specialty and location of clinic

Clinician	Gender	Occupation/Profession	Speciality	Region
Clinician 1	Female	Advanced Nurse Practitioner	HIV/GUM clinic	London
Clinician 2	Female	Gynaecologist/Researcher	HIV/GUM clinic	North East England
Clinician 3	Male	Consultant Physician	HIV/GUM clinic	London
Clinician 4	Male	Consultant Physician	HIV/GUM clinic	London
Clinician 5	Male	Consultant Physician	HIV/GUM clinic	London
Clinician 6	Male	Consultant Physician	HIV/GUM clinic	London
Clinician 7	Female	Consultant Physician	HIV/GUM clinic	London
Clinician 8	Male	Consultant Physician	HIV/GUM clinic	London

The next section of this chapter will include the findings of main themes and sub-themes from patients and clinicians. The above section on demographic information demonstrates the supporting information I provide for my study.

4.2 Psychological Effects of Anal Cancer Screening

In this section I will discuss the main themes and sub themes on how anal cancer screening can provoke emotional responses like, worry, anxiety, fear, embarrassment, shame, stigma and reassurance. Patients and clinicians in my study clearly explains their perceptions and experiences on anal screening where some common themes emerged.

Anal cancer can be viewed as a potentially life-threatening health condition that affects participants who undergo screening for anal cancer.

4.2.1 Worry, Anxiety and Fear about Anal Cancer

There are a variety of worries highlighted in my study relating to anal cancer from patients' perspective. Patients have become worried, anxious and scared even though they received information on the anal cancer screening process. The patients worry is about getting anal cancer. Clinicians worry because of the discrepancies with results of anal cytology and biopsies. They also worry about those patients who go on to get anal cancer inspite of effective treatments as lesions do return in some patients. Fear is what links sets of stimuli to patterns of behaviours and this link in the case of an emotion like fear is much more flexible and the state of this fear can exist prior to and after the eliciting stimuli (Adolphs, 2013). Therefore, fear is a response to a threat which can be real or perceived where having anal cancer diagnosis makes participants frightened. Fear and worry are interrelated as fear causes anxiety and anxiety causes fear which is all related to a life threating disease like anal cancer. These findings demonstrate that the emotions as experienced by participants are real as well as perceived especially in relation to anxiety.

Patients-Worry

"All the information I was given would not have prepared me, you still get worried and anxious and scared because you don't know what is going to happen. So, the information itself does not prepare you. It makes you aware, of maybe what the procedure is going to be, what it's being done for you, but you don't really get prepared in term of relaxing and you know." (Patient 6)

"Yes. I was anxious, well I should because I ... I always try to ... when I got the call, I thought there was an issue, and there was a problem. So, then I panic, oh God why, what was the reason for anoscopy and I went on Google and found the reason for anoscopy and some things came out about anal cancer. I was worried, yeah." (Patient 13)

Patient's perception of worry on cancer or the perceived notion of getting cancer is a far greater worry than having HIV. This is a scary emotional experience for these patients.

"To be honest the thought of progressing to anal cancer probably worries me more than the HIV infection… For me the whole anal cancer thing is scarier, I suppose than the HIV." (Patient 2)

Clearly, patients' family history of cancer contributes to their worry and the realisation that cancer is difficult to treat in the anal area.

"Yes of course I do worry. I mean to be honest I worry about cancer more than HIV because my sister died of cancer and I think first my brother-in-law had ….. I have friends who have got HIV and so once they got cancer …. it's very difficult to fight, that's what I think" (Patient 12)

Clinicians-Worry

Clinicians have also expressed their worry during anal cancer screening. They worry as an anal Pap smear can show dysplasia but during anoscopy procedure no high-grade disease is found even with a targeted biopsy. Another worry is around patients having to return for repeated anoscopies in a short period of time.

"What I can tell you is that it worries me that you can smear somebody and it does show dysplasia and then when you do anoscopy with targeted biopsy you don't pick up the high-grade disease and it worries me because I can't be bringing people back three or four times to do anoscopies in the short period" (Clinician 4)

In clinician's experience, many patients who have undergone treatments for AIN have developed cancers as the lesions are stubborn and keep returning which creates a worry for these clinicians.

"…. even with all these clever treatments, even with excision, laser, and the lesions do stubbornly keep on coming back in some patients. And that's a worry...a number of patients in that category who have gone on to get cancers." (Clinician 6)

Clinicians also believe that patients who have been worried about cancer stopped returning for follow-up appointments as they did not have the courage to do so.

“what I've already kind of said so the psychological impact is there's been a couple who've been worried they've had cancer and stopped having it done because were trying to get the courage to come in and have a screen” (Clinician 2)

Patients have perceived the concept of anxiety differently. These patients that have received results of cytology and biopsies became anxious; described their experience as not wanting to leave the home or just feeling this emotion all the time. This has affected their ability to be part of the screening process. This left the patients feeling helpless or the feeling of being trapped and can result in them avoiding going into to clinic for screening.

Patients-Anxiety

“Emotionally, yes. Very anxious, didn’t want to walk out of the house even I almost became agoraphobic. I didn’t have dreams or nightmares. My sleep wasn’t affected; it was just a very heightened state of being anxious all the time and that was torturous because that actually went on for quite a while” (Patient 1)

“Like I once had a doctor say to me in the early days, when my immune system was failing, his exact words were ‘you don’t have to worry about going blind yet.’ It’s an extraordinary giveaway of what he was trying not to tell me, but the word ‘yet’ summarised everything. It was the fear of the unknown for yourself? So, that created worry and massive amount of anxiety. This would be the same for developing anal cancer” (Patient 3).

Clinicians-Anxiety

In clinicians’ experience, patients overreact to their abnormal cytology result and describe patients experience as the ‘impending sense of doom’ or ‘like death for instance’ which results in a state of anxiety for these patients.

“…patients completely over react so they have a slightly, you know they have some low-grade cytology and they think they're going to die and they're in this huge state of anxiety ahead of having the anoscopy.” (Clinician 3)

Fear can be an unpleasant emotion or even a thought or perception that something is going to happen which is highlighted by patients and clinicians in my study. This can be distressing for patients as it could mean impending danger. Fear is described by patients as “cancer scare” or “scared me and put the fear of god in me” or “it’s like death” while the clinicians fear missing something while doing the procedure. This is a reaction to unpleasant news creates fear of the possibility of patients having anal cancer.

Patients-fear

Patients experienced fear or describe it as ‘cancer scare’ when they hear of cancer due to a personal family experience therefore suggest monitoring for AIN is worthwhile.

“My father had suffered and died of testicular cancer and… I had a cancer scare so it is always good to be monitoring such an area for concern as people may not think it will happen to them, so it is always good to stay ahead of the game.” (Patient 11)

Some patients also explain that not attending follow up screening or the reluctance to screen made them afraid as the results of anal screening meant they had abnormal cells on anal Pap smear. This kept patients in the screening program.

“I’m probably better than most, but even 2 years ago I let an appointment slip and I’m sure it was because of reluctance and then I almost got caught out that they found some cells that they weren’t happy about and that really scared me and put the fear of god in me; I’ll never miss an appointment again.” (Patient 3).

“Maybe scared because as a Doctor I know more than other patients and I know the consequences and everything so it’s a good way of monitoring and preventing?” (Patient 7).

Clinicians-Fear

Clinicians have perceived their experience of patients and being scared as it may be associated with cancer.

“I think that a proportion don’t attend their first appointment because they’re scared. Clearly anything that has cancer associated with it is scary and daunting so I think that

needs to that patients need to be reassured that an abnormal smear doesn't mean they've got a cancer so we try to limit that worry." (Clinician 8)

Clinicians experience fear in most cases especially the fear of missing a diagnosis during anal cancer screening procedures.

"I don't tend to fear of doing the procedure or doing the biopsy or anything like that, but you do have a fear of missing something" (Clinician 2)

The psychological effects of anal cancer screening involved repetitive emotions about the screening process and the possibility of developing anal cancer. Anal cancer screening has generated worry, anxiety and fear in participants which appears to be interrelated as fear and worry causes anxiety, and anxiety causes fear in response to anal cancer and screening.

4.2.2 Embarrassment, Shame, Stigma and Reassurance

Embarrassment, shame, stigma and reassurance are emotions recognised by participants in my study. Patients have constructed and monitored these emotions about their self-image. Whilst these emotions are psychological issues, these emotions can also be social issues too. This is highlighted in emotions like shame and stigma. Embarrassment in the context of my study is clear as patients were self-conscious or felt awkward about anal screening. This can result in loss of dignity and privacy.

Patient Embarrassment

"It just freaks me out a little bit knowing that there is a sort of exposed bit of my body down there and you have faeces rushing past. I'm one of those people that are terribly, terribly fussy and terribly ……." (Patient 2)

"Yes, it is a humiliation, a humiliating procedure really. Yes, it is humiliating, you feel embarrassed, because you have to strip for other people." (Patient 6)
Some patients describe anal examination as an intimate procedure and are concerned if they were dirty in the perianal area.

“Just the fact you have it's a very kind of intimate procedure and I was worried that I would be dirty, so I don't know how I should prepare myself and so …I wanted to ensure that I was clean and there would not be an accident”. (Patient 13)

Clinician-Embarassment

Clinicians mention that patients feel embarrassed about their sexual activity and do not want to be reminded of how they acquired HIV and the possibility of acquiring AIN in the same way as HIV through sexual activity.

“A lot of them fear I think that maybe the way it was acquired it like the HIV by having anal receptive sex and so it's not something they want to be reminded of” (Clinician 2)

Shame as experienced by participants is one of humiliation or distress about how people perceive their AIN or cancer and the assumptions people would make like ‘they had done something to bring on cancer’. This can also be described as an act related to sexual activity that brought on this condition, or shame in the eyes of the community as alluded to by the clinicians’ perspective on women. Patients feel shame with screening for anal cancer, and having AIN, because HIV has been associated with shame and is a taboo subject. This emotion ‘shame in anal cancer screening’ raises many questions about how AIN is acquired.

Patient-Shame

“The whole thing of HIV always comes with …the shame and people are always, even if it’s unspoken, there is always the question of ‘how did you get it? What did you do? or whether you “deserved” it or not’ – all of these issues come up on this.” (Patient 3)

Clinician-Shame

In clinician’s experience, HIV positive women who have had anal receptive intercourse for cultural reasons see this as a shameful act as HIV can be transmitted via anal receptive sex. Therefore, women who acquire HPV through anal sex may have AIN in the anal canal, and this is a subject that’s not spoken about or a taboo.

"Women fear they have acquired the HIV having anal receptive sex and so it's not something they want to be reminded of. So previously culturally they would have anal sex (a) not to get pregnant or (b) also to preserve their virginity and so now they see that as a shameful act because it's possibly how they acquired the HIV there's a lot of onus on anal receptive intercourse and I mean now we know the background and it is a contributory factor, we know HPV driven and I think unfortunately in society anal receptive intercourse isn't spoken about enough" (Clinician 2)

Participants have explained their perception of stigma associated with anal screening on many dimensions like the association of HIV and AIN, people's perception or people in society have strong feelings about sexual behaviours, associating AIN as being a 'gays man's' disease, stigma that HIV positive women experience due to sexual practices as well as self-stigma.

Patient-Stigma

Patients experience stigma and it affects them psychologically as living with HIV is associated with stigma. People label people living with HIV therefore if patients have AIN would be labelled the same way as being HIV positive.

"Psychologically ……, because you know it's a part of my past that I can't ever erase, so you know like HIV in a way I feel it's got a bit of undercurrent to it, a bit of a stigma. I think people assume if you have AIN, that you've been I don't know a dirty slut or whatever." (Patient 1)

Patients experience stigma of having AIN as some of them believe it is related to being gay.

"I was surprised, you know, just wondering what could be going on, about things that can go wrong, you know because most people think like I did, and relate it to gay people. That it would just affect gay men really than the general population" (Patient 6)

Patients have highlighted that stigma exists because of people's perception of HIV and the association with sexual activity. Sexual activity brings out issues of HIV and the

association of HIV with ‘black people’ but at the end of the day this raises the issues of stigma.

“And in fact, even just this week it’s all in the news about the owner of the Los Angeles Laker Sterling making these racist remarks about people of colour, particularly black people, and he raised Magic Johnson’s (the great basketball player) HIV status. I’ll just divert to this because it’s perfect illustration. He criticised him for sleeping around, getting HIV etc etc etc, when in fact the same guy was defending his actions of what he said on tape that was released by a woman that he was associated perhaps sexually, that he was only saying those things because he wanted to get sex out of her. So, the hypocrisy and the irony of his criticism, but what it does also raise is the stigma of HIV.” (Patient 3)

Clinician-Stigma

There is still a lot of stigma experienced by women as perceived by clinicians when screening for anal cancer and it remains a taboo subject which in turn affects their attendance for screening. The main reason for this is that anal receptive sex is not spoken of among women although it is practiced and creates a cultural barrier.

“…t's still a lot of stigma attached to HIV care for these women and I think if it's something that was incorporated in the national programme they would attend… a lot of HIV positive women are all poor smear attenders… they know they are high risk group and I think that the test for them and the association even if it's not spoken when they have receptive sex it's something of a massive stigma for them especially cultural. I think unfortunately in society it's still a taboo subject even though it's something that's being practised regularly” (Clinician 2).

Clinicians experience self-stigma in their practice of anal screening which is attributed to lack of experience in the field of anal screening. Realisation of this stigma has led to learning that stigma can help improve practice through understanding. Clinicians also have perceptions about anal cancer screening and the stigma they have themselves is unacceptable behaviour.

“I didn't realise that maybe I had stigma in my practice because I hadn't had exposure so I think it's been a good learning curve for me. I had stigma about it. I didn't realise I did but personally I thought well it's just not going to be acceptable.” (Clinician 2)

Patients felt reassured knowing that they could be part of a screening programme and found that the treatment offered helps alleviates their fears and doubts about AIN. Being screened for anal cancer provides the comfort of feeling less worried and more confident as they are being monitored and treated. Clinicians feel that patients who are given information regarding anal cancer screening procedures, an explanation of what anal smear results mean and rationale for looking at AIN or high-grade disease provides patients with a degree of reassurance.

Patient-Reassurance

Patients find it reassuring to be part of a screening programme and being able to stay on the programme

“I found it wonderful that the programme was available… I found the fact that I have been able to find a screening programme that I have been able to stay in a great reassurance… I can stay in the screening programme, having already joined it and I find that very reassuring. (Patient 1)

Patients also felt a degree of assurance that they can be offered some treatment for AIN and monitoring.

I think you get reassured because you know that something can be done about it” (Patient 6)

“It was a slight shock but more reassurance that you are covering all aspects that could potentially be life changing or life-threatening situation so for me. It is a bit more inconvenient as I have to keep coming back for other tests but on the flip side I would rather someone be proactive and ensure they monitoring so that it’s one thing that I shouldn’t have to worry about or keep thinking so someone there to say yeah you’ve been here in six months we need to check you every six months just as a precautionary measure so it’s one less thing to worry about so if it’s something like this has to be done so be it.” (Patient 11)

Clinician-Reassurance

Clinicians have reported that by providing information to patients about anoscopy is reassuring.

"We give them an information leaflet about the anoscopy which tells them why they're having it, how to prepare, how not to prepare for it, what to do, what not to do and there's a degree of reassurance …" (Clinician 4)

Some patients who have had AIDS defining illness like Pneumocystis carinii pneumonia, Kaposi's sarcoma, cerebral toxoplasmosis, or tuberculosis for instance, feel it is reassuring to be monitored every three months for AIN.

"Extremely reassuring to be monitored every 3 months, extremely reassuring yes; also, I think because I've had life-threatening illness you know when I have had the AIDS defining illnesses and I thought I was going to die, especially on one occasion, something like this probably isn't as scary…" (Patient 2)

Embarrassment, shame and stigma play an important part in how participants perceive and experience the anal cancer screening process. Reassurance as reported by patients meant they can be part of the screening program offered at the clinic. Clinicians mentioned that by patients just being screed creates less worry, the information they are given about the procedure and rationale for screening creates a degree of reassurance for patients.

4.3 Anal Cancer Screening Procedures

Screening procedures in my study included anal cytology, digital anorectal examination (DARE) and high resolution anoscopy (HRA)which is undertaken by clinicians who have had specialised training in anal cancer screening. The following section will discuss how patients and clinicians experience and perceive anal screening procedures in the UK.

4.3.1 Acceptability and Tolerability of Anal Cancer Screening

Acceptability in the context of my study refers to anal cytology, DARE and HRA as an acceptable screening procedure for patients, while the procedure a patient can endure which is bearable in the time frame in which procedure is undertaken explains their

tolerability. Patients were informed of the anal screening procedures prior to an anoscopy appointment and information leaflets are sent to patients to inform them of AIN, anal cytology and HRA procedure. The reasons for anal cancer screening are also explained in the leaflets as it is best practice in healthcare to inform patients so that they can make an informed choice about their health. Once patients are informed as to why these procedures are performed, they accepted to undergo the screening procedure. Generally, patients felt that the anal cytology, DARE and HRA are acceptable and tolerable. Clinicians on the other hand, felt anal screening procedure for a patient was an acceptable procedure although tolerability was variable.

Patient-Acceptability

Some patients tolerated the HRA procedure and found it acceptable while other patients tolerated the HRA once a numbing sensation was introduced by using an anaesthetic gel.

"My experience in this clinic in terms of screening they are tolerable and acceptable, otherwise I wouldn't come I would find somewhere else" (Patient 3)

"I tolerated it very well" (Patient 10)

"I have had it done previously and I couldn't tolerate the pain, it was awful. That's what put me off having it done again, but this time I was 'numbed up' and it helped me so much." (Patient 4)

Clinician-Acceptability

In clinician's experience in anal screening, when the anoscope is inserted into the anal canal of an MSM who have had anal receptive sex, there is less resistance in the anal canal as the anal tone is not strong therefore are able to tolerate the procedure more than those who have not had anal receptive sex.

"In terms of the anoscopy, there's perhaps less resistance in men who have sex with men which is equivalent of vaginismus of the anus. In gay men who've had receptive anal sex, perhaps there's not such a resistance of the anoscope being inserted, that perhaps the anal tone is not as strong, resistance to scope isn't so strong but those that have had

receptive sex tend to tolerate the procedure much better than those that haven't." (Clinician 8)

Clinicians perceive that women do not tolerate the anoscopy procedure, but have it done and accept it as part of screening as these women want to contribute to evidence.

"*I find it very difficult for them…. You know it's not very tolerable, but they have to accept the fact that it's a screening process… They're excited about that but I think they want to contribute to evidence… it is well accepted from our patient satisfaction surveys that patients have accepted it quite well…. we found it acceptable… a significant number of people found anoscopy, even though it was an invasive procedure, acceptable." (Clinician 7)*

4.3.2 Invasive Procedure

In my study patients and clinicians have experienced and perceived anal screening as an invasive procedure. The anal Pap involves the insertion of a Dacron cotton swab in anal canal for anal cytology. DARE where a finger is inserted into anal canal to palpate any lumps, masses or polyps. HRA is done by introducing the anoscope into anal canal, to visualise any lesions or warts for example and taking a biopsy, where a small piece of tissue is sampled for histology analysis. This can be described as undesirable where objects or instruments are inserted into the body i.e. anus, as part of a medical procedure for anal screening. This also invades the dignity and privacy of patients and is described both by patients and clinicians.

Patient-Invasiveness

Patients have experienced anoscopy invasive in every sense but will undergo anoscopy to protect their health and for their own well-being.

"The whole experience of anal exams and whatever, I can't say it's ever something that one looks forward to, to dropping your trousers and having someone to look up your rectum, your ass, your butt – whatever. It's invasive in every sense. It's always different having a rectal/anal exam from just having blood taken, even in the most invasive procedures and what makes the psychological obstacles go away for me is that I realise and tell myself that I'm doing this for my own wellbeing and my own health. I do that

dialogue with myself that I have to go to this appointment that I have to allow myself to be invaded and examined in order to protect myself." (Patient 3)

"My personal opinion as a user is, I don't like them, for me it is an intrusion. That's why I dislike them. It's going in to my body, I don't like that feeling and I have no control of it." (Patient 4)

Clinician-Invasiveness

Clinicians believe that anoscopy is the gold standard to identify abnormalities in the anal canal and to take biopsies. However, they also believe it is not the most comfortable or dignified procedure.

"it is an invasive test but it's kind of goal standard … it's a good way to identify certain things within the clinic and take biopsies there and it's a goal standard…High resolution anoscopy is definitely an invasive procedure…it's not the most comfortable procedure. It is not the most dignified procedure so there are definitely those issues there." (Clinician 7)

4.3.3 Pain, Bleeding, and Discomfort

Pain was only experienced by patients during anal pap sample collection and during HRA; however, patients perceived pain through the sensation of swab and experienced pain when the anoscope was inserted.

Patient-Pain

There are different reports about how patients experience pain. Patients found that the anal Pap smear was a bit painful but would rather have it done even though they experience some discomfort while the material of the ansocope made the procedure painful for some patients.

"It was a little bit painful but wasn't like something that I would rather have done and have a bit of discomfort" (Patient 13)

"*And that one is painful the metal one, it's called don't know. It's hard and is it plastic? It feels hard anyway. (Patient 6)*

Patients also experienced pain when a biopsy is taken and even after the biopsy was done.

"*When they do the biopsy that can be painful and I'm sure when they taking the sample you can feel quite painful after they've done the biopsy"*
(Patient 14)

It's a really sharp sudden pain for me, but it was over with in two seconds."
(Patient 4)

Clinician-Pain

Clinicians have reported that they are aware of the patients' experience of pain during HRA procedure.

"It can cause a bit of pain; it can cause some marked pain and some patients find it unpleasant." (Clinician 8)

Patient-Bleeding

During HRA examination a biopsy is taken from the anal canal and tissue is sampled for histology to determine the presence of AIN or cancer and graded as such. This can cause bleeding as explained by patients which is minimal and stops after a few days. Clinicians on the hand mention that patients may bleed for a week or two but are fine after some reassurance. Patients do have bleeding after having a biopsy for up to three days in their experience, but bleeding did stop after 48 hours. Patients were worried about the bleeding but were reassured bleeding will stop after 24 or 48 hours.

"The only downside is I know that after the anoscopy, I'm going to be a little bit sore for the next 48 hours, but I think the worse thing is after biopsies when sometimes the bleeding goes on for maybe 2½ days, when you go to the loo or whatever, and it just freaks me a bit to see blood dripping in to the pan erm after going to the loo and blood on the tissue-paper on clean-up of course, but I know that's only going to last for 3 days at the most and sometimes it stops within 24 hours." (Patient 2)

“A small amount of bleeding. No pain. Just a little bit of sensation that things were going on and that’s it.” (Patient 3)

Clinician-Bleeding

Clinicians have experiences with patients who bleed for a week or 2 and these patients just need some reassurance that bleeding will stop. The perception of clinicians is that by reassuring patients that bleeding will stop meant they were fine and attended follow up appointments.

“So here people might bleed for a week or two, there might be one or two that come back to the clinic and need reassurance but they're by and large fine.” (Clinician 4)

The discomfort experienced as described by patients and clinicians is feeling uncomfortable physically during anal screening procedure. Positioning plays an important role during anal screening and clinicians explain how the lithotomy position makes patients vulnerable.

Patient-Discomfort

Patients found the anal Pap smear uncomfortable and describe it as rough but perceive this as potentially life- saving.

“It is only half an hour of your time of discomfort, but it is potentially lifesaving”
“Remember the PAP thing was uncomfortable - it was quite rough”
(Patient 11)

Patients find the anoscopy uncomfortable and find it a horrible procedure while those patients that have never had anal receptive sex or procedure in their anus find it uncomfortable.

“So, the Pap test isn’t an issue, but the anoscopy that I’ve just had and my views on that are basically it is uncomfortable and it’s horrible.” (Patient 4)

“Well it is very uncomfortable, because I have not put in anything inside my anus. So, I am not used to putting anything inside my anus, so it is very uncomfortable.” (Patient 6)

Patients have also experienced discomfort with HRA describing this procedure as ‘very uncomfortable’

“It’s very uncomfortable. It feels like my bowels are about to evacuated. You know, when you put this instrument up somebody, and I don’t know if it’s different for other people, but it feels, it constantly feels like I am about to evacuate my bowels, it is a very uncomfortable feeling. And you …, I don’t know if you have had the procedure but that’s what it feels like, it feels constantly like I’m having a lot of traffic going through my anus. You know, but there is nothing passing. But yeah, it’s uncomfortable.” (Patient 8)

Clinician-Discomfort

In clinicians’ perception of discomfort in patients, find that anoscopy is a foreign procedure for lots of individuals and is not comfortable.
“The procedure itself is foreign to lots of individuals; I mean it’s not necessarily particularly comfortable.” (Clinician 8)

Clinicians mentioned that position of a patient during anoscopy can be uncomfortable for patients.

“I just wish there was a slightly easier way of being able to see inside because I know and especially the women, they find it so uncomfortable. The actual procedure itself is not a very comfortable procedure for a lot of the patients. I think MSM feel vulnerable in lithotomy. I think in America because they do it in left lateral and it feels less vulnerable so that's the first thing that I mean my facilities that way. I've only got facility for lithotomy position” (clinician 2)

I explored with patients how we could minimise discomfort during screening and asked the following question: “What can we do to minimise discomfort?”

“I don’t know. Something to do with positioning may make it easier, I don’t know. Facing forwards rather than lying on your back with your legs up might be an easier way of relaxing your way through it, but I don’t know if that’s feasible from the inspectorial end, or not.” (Patient 5)

Patients have mentioned that they experience pain during anal Pap smear and when a proctoscopy in inserted into anal canal. The sesation of the proctoscope can cause pain and discomfort. Some patients have experienced pain when a biopsy was taken and describe this as a suddent sharp pain which lasts for a few seconds some patient s experience pain even a few days after a biopsy was taken. Clinicians on the other hand allude to the fact that patients who have HRA procedure can cause some pain and some patients have marked pain after procedure and do find this procedure unpleasant. Patients described bleeding after a biopsy is taken can go on for up to 3 days but can stop 24 hours after biopsy is taken and that bleeing is only a small amount. Clinicians believe that patients who bleed for for a week or two after HRA and biopsy need reassurance as bleeding will stop. Although patients found anal Pap smear and HRA procedure uncomfortable, perceive these procedures as "potentially life-saving". Clinicians have mentioned that HRA procedure is foreign to most individuals and the position in which they are examined can be uncomfortable. Patients have suggested that examining them face down (i.e. prone position) during HRA can cause less discomfort for instance.

4.3.4 Anoscopy versus Sigmoidoscopy in Anal Cancer Screening

Clinicians in my study have highlighted that anoscopy is the gold standard for detecting and diagnosing AIN and have explained the superiority to anoscopy versus sigmoidoscopy. Clinicians believe that a sigmoidoscope is inserted too far in to rectum. Clinicians have mentioned that with anoscopy and the use of acetic acid, you would be able to visualise lesions in the lower distal anal canal. Clinicians believe that steady equipment like the anoscope is good especially if examining the rectal anal area.

"Sigmoidoscopy is put too far in and you are interested in 5cm of anal canal …the key of the anoscopy is that you actually apply acetic acid to be able to see the lesions, and you won't be able to do with a sigmoidoscope. it's just a different organ…You are looking at the anal canal you are not looking at rectum, so I think that's just basically case closed." (Clinician 5)

“I think sigmoidoscopy cannot reach the terminal few inches of the anal canal effectively because to steady the equipment is very difficult in that part of the rectal anal area, so you need devices that can be easily applied steadied. (Clinician 6)”

“So, I think that HRA as Palefsky stated is the gold standard.” (Clinician 2)

Generally, patients that have undergone anal cancer screening find it an acceptable and tolerable procedure while clinicians have reported tolerability was variable with patients but acceptable. Patients have reported that anal Pap smear is painful, and they experience some discomfort. Patients also experience pain after a biopsy is taken and clinicians have mentioned that biopsies can cause pain and can be unpleasant for them. Bleeding after a biopsy according to patients persists for up to three days while clinicians reported some patients can bleed up to a week or two but all they need is reassurance. Patients have also experienced discomfort when a Pap smear and anoscope is inserted into anal canal. Clinicians reported that the position in which patients are examined can cause discomfort. Patients and clinicians have reported that anoscopy can be invasive and invades patient’s privacy and dignity. Anoscopy is gold standard for detecting AIN according to clinicians and is superior to sigmoidoscopy.

4.4 Education, Knowledge and Training in Anal cancer screening

In this section, I will discuss the knowledge and education of patients and clinicians with regards to the information around anal cancer screening. Patients have described their knowledge as limited as there is very little information available but the influence of the media, magazines and being an expert patient on health issues has had an impact on educating oneself on anal screening. Clinicians also agree that there is very little information available for both clinicians and patients, that studies are now providing evidence and information like the Study for the Prevention of Anal Cancer (SPANC) study. British HIV Association (BHIVA) and British Association for Sexual Health and HIV (BASHH) have no information available but America has produced information on anal screening. The UK has no information available except information adapted from America, Australia and other and HIV magazines like NAM. There is also little training available for clinicians in the UK with the only accredited course offered in the US.

4.4.1 Education and Knowledge

Patients who started the anal screening programme in some sexual health clinics in the UK had limited information available in the health services but obtained information through other source like they would see it in magazines for instance or through conversations with other HIV positive people.

Patient-information

"I believe I was one of the first patients here to go into the screening programme, so I don't think there was information available ... I'm unaware if there is information available these days" (Patient 1).

"I would see it in HIV positive magazines or in the treatment updates and things like that" (Patient 2)

The first time, well I seem to recall probably about 10 years ago that it was going to the press that anal cancer or problems … I seem to recall seeing that in various or different articles I saw, or through conversation, or whatever, because people with HIV tend to talk to each other." (Patient 3)

Patients also believe that information is important to them especially if they are faced with anal cancer which is a life-threatening disease.

"There needs to be a safety net, but the safety net is information, and honest information, because if they are facing death" (Patient 9)

Patients also mentioned that reading about anal cancer and the influence of the media has encouraged them on educating themselves. Knowledge on areas that impact one's own health like HIV and anal cancer, makes one an expert patient. Patient 1 describes himself as an expert Patient and says:

"So, I think I'm a fairly, expert patient in many ways and I have stayed on top of reading on what's happening in the areas I have interest in, particularly in those areas that might be impacting my own health problems."

Clinician-Information

Clinicians that are undertaking anal cancer screening in the UK do not have much information for the patients and for their practice, and neither is it outlined in any national guidelines in the UK. In this way patients are less informed.

"...the British HIV association for example: there is no information available over there on anal screening or cancer screening … in the States there is a website dedicated where patients can actually get this information about what anal screening is about, where they can get anal …. If you look at BASHH there is absolutely nothing about that" (Clinician 5).

There are only a few anal cancer screening services available in sexual health clinics in the UK and not all patients living with HIV can be screened for anal cancer. This information is not disseminated to people living with HIV.

"There is pretty much very little out there and so I think patients are less informed and in the dark in some ways. Partly because there aren't many services available" (Clinician 6)

"There's not that much information really. We've got a website attached to our project … around the globe you've got the SPANC study, the stuff that's come out of BASHH. There's quite a lot of information … in America... if I googled it as a patient, I don't think the top four or five hits would get you pertinent information as to where we are with anal screening and especially where the UK stands in that mass of information" (Clinician 2)

Clinicians have experienced uncertainty with regards to courses to inform their medical practice but greater uncertainty with what will be available for patients about anal screening.

"I've not seen anything UK wide. I guess from, I mean there's, I believe there's possibly going to be a UK course…. this is going to be the first time in the UK ... may be the information medically wise will be better. I don't know what will be for the patients though" (Clinician 2)

Clinicians have reported that there is very limited information in the National AIDS Manual, and there is a roll for having information leaflets in clinics to prepare patients about AIN, its natural history and the anoscopy procedure.

"There have been features in some of the HIV literature, sort of NAM .... there's a role for having nice quality information leaflets available for patients in all clinics…best thing we can do is to prepare them well with information leaflet ahead of time ... which is about AIN and its natural history … they get a separate piece of paper that tells them about what to expect from the procedure itself" (Clinician 3).

Clinicians have developed information leaflets for patients but have perceived verbal face to face information is important as well.

"There is a patient information leaflet. …. but what has happened at our service is, people get phoned to come to the next appointment... I'm taking more time verbally with patients. That doesn't seem to be a problem actually" (Clinician 4).

4.4.2 Training

Training in essence is about the skill required of clinicians to undertake anal screening. This skill entails the ability to take anal cytology, DARE, perform HRA and take a biopsy from the anal canal for histology assessment. Clinicians have accessed training locally or internationally (e.g. accredited course in the USA). Some clinicians have mentioned that having a gynaecology background has helped them pick up the skill quickly.

Clinicians have trained in America and some clinicians have trained with other experienced clinicians in the UK. Clinicians with a gynaecology background have helped clinicians pick the skill of undertaking HRA quicker.

"I assimilated that procedure from America, came back to the UK and I was trained over about six months or three to six months with …. also, what the doctor taught me in London … he said that evidently my colposcopy background and my laparoscopic background from training to be a gynaecologist had helped me because I picked things up quite quickly." (Clinician 2)

There is no UK based training that's accredited. The only accredited course as mentioned by participants is in America.

"So, I decided to learn about anoscopy as a prelude to setting up a clinical study … so I went to and I spent a week in San Francisco in 1999 learning anoscopy … so you just came back and did it you know that's what I did and of course it was kind of sink or swim" (Clinician 3)

"I was very lucky to go to San Francisco and which is run by the International Anal Neoplasia Society and is an accredited course, two-day course which was involved with a bit of colposcopy as well" (Clinician 1)

Whilst there is no UK based accredited course for ansocopy, trained clinicians provide local training and the vision for the future for clinicians is to set up clinics across England and Wales.

"We've trained people who have started up clinics in Manchester and West London and I am supporting people in North London setting up a clinic …where HRA will be carried out so the gospel is being dispensed and is being promulgated as one of our goals … we are training people, so they can set up HRA clinics in other hospitals across England… there's a need to ripple out into Scotland and …" (Clinician 6).

Clinicians in their experience of undertaking HRA mention the length to time to be proficient at HRA is up to 5 years.

"I can certainly say that it takes a good couple of years to become really proficient at it." (Clinician 3)

"It can take up to five years to be a completely brilliant trained up anoscopist...I'm going to you know trundle on gently for five years".
(Clinician 2)

Some clinicians that have been undertaking anal screening still do not consider themselves as an expert.

"I've been doing anoscopy for a few years only. I still do not consider myself an expert. I am not going to be any sort of expert until I've had minimum five or ten years of training…." (Clinician 7)

Clinicians mention that there is published data to show that training to be an anoscopist can take a few years to acquire skills.

"There are published data out there showing that people learn over a period of years in terms of acquiring these skills" (Clinician 6)

Both patients and clinicians have reported that there is very limited information on anal cancer screening in the UK. The media, HIV magazines and being an expert patient has helped patients to gain knowledge and educate themselves on anal cancer. Clinicians believe that there is a role to develop information leaflets for patients and highlighted that information inadequate even in the National AIDS manual, but there is also value in provided information face to face. Clinicians have trained locally with other experienced clinicians undertaking HRA. Some clinicians have undertaken an accredited course in San Francisco and have reported that it can take up to five years to be fully trained in HRA.

4.5 Social and Sexual Activity

Patients who have had anal screening and have diagnosed with warts or AIN have experienced varied changes to their social and sexual activity. I asked the following question: Having been diagnosed with AIN, does this in any way affect your sexual activity or social life? The responses are varied as some patients' experience no change in sexual activity while as other patients stopped having sex and socialising.

"In answer to the last question, it hasn't affected my social life but it has affected my sexual activity. I used to regularly have receptive anal sex (Albeit only ever with a condom) but after being diagnosed and treated for AIN I no longer do this. Mainly because the treatment makes me sore and I'm afraid of damaging myself." (Patient 2)

Patients having a diagnosis of AIN increased their protection in sex.

“No not really there was no difference with sexual activity, I was just extra careful. I used condoms. My social life was not affected.” (Patient 5)

However, some patients associate sexual activity with warts and cancer. Some patients experience anoreceptive sex as painful while others perceive anal cancer to be self-inflicted by engaging in sexual activity. Some patient’s social life was affected and stopped dating.

“*No when I had the wart, I did not have any sex, because I think it can be contagious. I stopped dating and I did not have a regular partner. Also, I was working and studying so I had no time for socialising. I am very nervous to have receptive anal sex because it hurts.” (Patient 13)*

“It’s like smoking cigarettes; you get lung cancer and die. If you engaged in sexual activity, then you get genital warts and get cancer so it’s kind of like self-inflicted, no I don’t have sex” (Patient 14).

Sexual activity was only mildly affected by patients having warts or diagnosis of AIN, but, remarkably, some patients reported not having sexual intercourse and stopped socialising. Interestingly some patients associated anal cancer as a self-inflicted behaviour caused by sexual activity. The diagnosis of AIN or warts made patients aware that using condoms for sexual activity is important and some patients who had treatment for AIN or warts reported they stopped having sex as it was painful.

4.6 Anal Cancer Screening Guidelines and Practices in the UK

This section will discuss the key findings of my study on guidelines and anal cancer screening practices in the UK.

4.6.1 Guidelines

Guidelines are important to guide clinical decisions. Clinical guidelines recommendations on how healthcare professionals should care for people with specific conditions. They can cover any aspect of a condition and may include recommendations about providing information and advice, prevention, diagnosis, treatment and longer-term management (NICE, 2015). A clinical guideline, clinical protocol or clinical practice guideline is a

document with the aim of guiding decisions and criteria regarding diagnosis, management and treatment in specific areas of healthcare (IOM, 2011).

Patients-Guidelines

Patients are aware that there are established cervical screening guidelines and a cervical screening programme for women in the UK. Patients believe there should be a national anal cancer screening programme for high risk men in the UK as it is for women.

"… Women are routinely screened for cancer of the cervix and it's the same HPV strain that puts them at risk. If they have a national screening programme for women why not have a national screening programme for high risk men." (Patient 2)

"Women have the right in a way to have had their programme and I think the fact that it has been rolled out across the country, we are talking about reducing the age at which that screening programme starts so we can catch a few more people. I think that screening programme has already been shown to be worthwhile." (Patient 1)

Clinician-Guidelines

Clinicians have knowledge that there are no national guidelines in the UK on anal cancer screening but they are aware of the guidelines in the USA for people living with HIV.

"There are no national guidelines as to who to screen is a setback. Anal cancer screening is not recommended in any national guidelines… In the United States, particularly in New York, they recommended anal cytology screening of HIV positive individuals, in gay men and those with some other criteria… NICE have not recommended it. BHIVA have not recommended it." (Clinician 8)

Clinicians see patients with multi focal disease as there is no gold standard for treatment or guidelines and manage this within their clinics. This is a disease process which involves the perianal skin, the anal canal including the anal canal transitional zone and there is a strong clinical association with cervical (CIN), vulval (VIN) intraepithelial neoplasia (Scholefield et al, 2011).

"If there are multi-centric, multifocal lesions, if there are more sort of proximal lesions, perianal lesions; it is about how to best manage it as there are no gold standards, there are no national guidelines." (Clinician 6)

Clinicians therefore suggest a way forward with screening or reason for screening in the absence of guideline is to develop techniques for anal cancer screening and that there should be robust evidence to develop guidelines. Most clinicians have developed anal cancer screening guidelines, training and competencies for their sexual health clinics based on the colposcopy guidelines in the absence of national anal cancer screening guidelines in the UK.

"there are no guidelines in the UK and the … we're screening with cytology, HPV and anoscopy is to see whether we can develop a screening technique without using anoscopy if you have evidence, that's robust then I think it would be very easy, it would be much easier to formulate guidelines, form a consensus." (Clinician 7)

"…my thought was that anoscopy was very similar to colposcopy, so I managed to get hold of the national training guidelines for colposcopy nursing in the UK and did my own guidelines and my own workbook and based that all around what the UK colposcopy guidelines are, and I used that as a template really" (Clinician 1)

4.6.2 Anal Cancer Screening Practices in Sexual Health Clinics in the UK

Anal cancer screening is unevenly distributed geographically across the UK, which is presented in the preceding section. Anal cancer screening is offered mainly in the London region and patients as well as clinicians have reported that this is not offered throughout the UK.

Patients-Anal cancer screening practices in UK

Patients are well informed that anal cancer screening is mostly offered in the London region and not all patients can access screening due to lack of specialists, treatment centres and equipment

"… I'm thinking of all the people around the country that aren't able to get it and maybe are at risk." (Patient 11)

"I would like to see it rolled out over the whole of the UK really…HIV specialists in provincial HIV treatment centres…don't have any facilities at their hospital to check. They must realise that in London...people with HIV are being screened … Most provincial treatment centres just do not offer this. I think it was London, Manchester and maybe Edinburgh was the only medical centres that were doing this …." (Patient 2)

Clinicians-Anal cancer screening practices in the UK

Clinicians see patients from all over the country as not many sexual health clinics offer anal screening and patients do not want anyone to know of their HIV status.

"I have patients who attend Manchester sexual health who live as far as nearly on the border of Scotland who come to Manchester because they don't want anyone to know about their HIV status."
(Clinician 2)

4.6.3 Relationships with Health Care Professionals

It is important for clinicians to work in partnership with patients and share with them the information they will need to make decisions about their care. According to Cumming and Noble (2010), patients may experience stress about their conditions therefore it is important to treat a patient's physical ailments as well as his or her emotional needs. Patients have mentioned the most fundamental principles of healthcare professionals (clinicians) like trust, compassion, being sensitive, supportive, and professional are important to them.

"I trust the doctor totally and I know what they're doing and as long as you keep up with your appointments and they monitor what is happening down there then I am absolutely fine with what the doctor is doing to me because I totally put my trust in doctor." (Patient 12)

"Very nice! They very compassionate, very caring …But here they are more professional, they counsel they give and offer one to one bespoke service …. Medical staff and patients and here one feel more spoiled. …the fact that the medical staffs here treat you as valued." (Patient 11)

Patients perceive healthcare professionals as being sensitive toward them and were caring plus supportive during their anal cancer screening appointments.

“I think everybody is being very sensitive” (Patient 9)

“It was part of a very caring package and care was being given by a set of very caring people in the clinic who were very supportive, I felt, in all manner of ways” (Patient 5)

“They help me and sometimes its Psychological help. Because of course, people with HIV they have many psychological problems, because they need to accept that they have HIV. And they help even when they call you with your first name, its Personal. Here they call by name and its more like warmth, its warm, it’s more polite.” (Patient 7).

4.6.4 Multidisciplinary Team Approach in anal cancer screening

A multidisciplinary team (MDT) approach is essential for the management of anal cancer screening. Clinicians have suggested MDT centres for instance, teams should consist of clinicians, surgeons, histopathologists, cytopathologists, gynaecologists, HIV consultants and administrative person to coordinate the anal cancer screening pathway for patients.

Clinicians believe that there should be MDT centres which is attached to a tertiary referral centre across the regions in the UK.

“I think possibly the way forward of this being managed is that you would have these MDT centres attached to a tertiary referral centre with a gynae/oncology and a colorectal specialist maybe… you've got Brighton near London but maybe London, Birmingham, Manchester, somewhere in Scotland and you've then got a spread up and down country that patients can access.” (Clinician 2)

According to clinicians who participated in my study mentioned that MDT teams should consist of histopathologists, cytopathologists, surgeons, gynaecologists, HIV consultant and an administrative person.

"The whole team who is involved in this, so we have the histopathologist, cytopathologist who is involved with reading specifically anal smears. We have the surgeons as… part of the colorectal surgery network…a gynaecologist, HIV consultant, an admin person …." (Clinician 5)

4.6.5 Referrals into Anoscopy Clinics in the UK

Patients at the outpatient's clinic were mainly informed about anal screening by the nurses at the NHS trust. Some patients read about AIN screening and treatment clinical trials in AIDs magazine and self-refer for anal cancer screening. Clinicians see patients from all over the country and from other clinician referrals while most patients self-refer for screening.

Patient-Referrals

Patients are informed of anal smear by their clinicians which are part of their routine HIV outpatient clinic visit.

"The nurses, they said it has become routine now. So, they are offering the other smear, the normal smear, and then they offer you this one as well… but it has become routine now. (Patient 6)

Some patients were aware of anal cancer screening through AIDS update dedicated for people living with HIV and entered a treatment clinical trial many years ago.

"I probably became aware of the importance of doing that sort of screening from reading the AIDS update which had some interesting articles about AIN. Well I suppose there's a debate about whether how you split it to have a screening as opposed as to treatment and that kind of treatment with clinical trials." (Patient 14)

Clinician referrals

Clinicians receive referrals for screening from all over the UK and it is evident that patients attend for anal cancer screening from other regions.

“I also see a lot of people from all over the country, certainly from and predominantly from different parts of London but I get referrals from people come to see me from quite far.” (Clinician 3)

One clinic which is a tertiary referral centre is long established and sees patients from all over the UK, clinicians from other hospitals or by doctors from their own sexual health clinic.

“The service … is long established and we get referrals from all over UK …. this is a tertiary referral clinic, so all our patients are referred by other clinicians from other hospitals or internally by other doctors and so therefore we offer all cytology and HRA.” (Clinician 6)

Patients also self-refer or get referred by their HIV clinician
“They’re self-referred or referred from their regular doctor and they may or may not have been symptomatic with warts. They may have a previous history of warts or may not have a previous history of warts and so we will see them. (Clinician 7)

4.6.6 Multifocal Disease in Anal Cancer Screening Sexual Health Clinics

In the presence of multi focal disease in patients, anal screening is offered in one sexual clinic in the UK. Clinicians have reported seeing patients with multifocal disease in their clinics.

“We also see women who’ve got a history of vulval cancer or vulval disease, vulval HPV or VIN.” (Clinician 7)
However, only one tertiary referral centre sees patients with multifocal disease and treats these patients.

Obviously, women with cervical CIN, they might have a cervical lesion and quite likely to have an anal lesion. I ask them about previous PAIN, CIN, and AIN and if they say that they've had something I will ask them when it was treated and where they're up to with their smears and things, that's also my gynaecology background. I've had two or three

women - perianal wise I assess it and I biopsy it and some of the ... well one cancer that I found they also had a suspicious lesion perianally. Two years ago, we teamed up with Cancer networks in London and we now have an arrangement whereby all patients with multifocal anal genital neoplasia in women are referred to for assessment with HRA and offered treatment. So, the treatment spans over anal canal disease, perianal disease, vulval disease, vaginal disease and except for cervical disease." (Clinician 6)

4.6.7 Evidence-Base for Anal Cancer Screening in the UK

Evidence can help support patient care once a diagnosis is made. Evidence-based practice can generate questions about treatment, diagnostic tests, aetiology and prognosis about AIN disease. Patients suggest more evidence is needed for prevention of progression of AIN or psychologically. Clinicians are being proactive in doing a trial to contribute to evidence in the UK while there are many studies produced in Europe.

Patients-Evidence-base for anal cancer screening in the UK

Patients believe more evidence is needed in the NHS on anal cancer screening as the sexual health clinics are part of the NHS.

"I think the NHS needs evidence and once we have more evidence that it's worthwhile, whether preventing progression or if it's worthwhile in psychological terms, those are maybe two end points that could be explored." (Patient 1)

Clinician-Evidence base for anal cancer screening in the UK

Clinicians believe that the LOPAC trial to be undertaken in the UK will to contribute to evidence.

We're going to do a big research soon called 'LOPAC' trial which stands for laser ablation versus observation for prevention of anal cancer and that is to answer precisely the point. Is treatment going to stop cancer development in patients with high grade disease and one of the problems of screening is that the screening agenda has been hampered by the lack of evidence in terms of treatment and in terms of prevention of cancer so we try to think we have to provide some data to support that." (Clinician 6)

Clinicians have also mentioned that the US and Europe are contributing to evidence by producing lots of studies while the UK haven't done much to date in terms of studies to contribute to the evidence.

"The States and Europe are producing a lot of studies, but we haven't done much here." (Clinician 2)

4.6.8 Prevention and Funding of Anal Cancer Screening

Patients' perception on anal cancer screening is that they feel it is better to prevent disease than treat disease. Clinicians state that anal cancer is increasing especially in the HIV positive MSM and that it would be cost effective to screen these high-risk groups instead of a screening programme targeted at everyone. In the UK screening is considered and funded by clinical commissioning groups but these decisions are likely to have capped funding according to the clinicians.

Patients-Prevention and funding for anal cancer screening

Patients believe that it cheaper to prevent disease than treat someone with the disease. Patients mention screening will help prevent a person from becoming ill and it will be cheaper to screen than treat illness.

"So, I think it's becoming clearer when you look at costs based on the burden of ill health care, if you can prevent things happening in the first place you might actually save a bit to actually do it, but it's often cheaper overall than having someone become ill than whatever it is you are screening for."
(Patient 1)

"Yes, prevention is better than cure no matter what way we explore it. That seems to be proven from personal reassurance, reduction of anxiety and then
from the health care provider view we have less burden of illness regarding costs and other things. Whichever way we think of it I think it's personally a winner." (Patient 2)

"If it is something that could kill me, I would prefer to know about it beforehand rather than afterwards. Early prevention seems to be a good thing really." (Patient 5)

Patients want to do their best to prevent a problem and name a celebrity who ended up having cervical cancer as she did not follow up her appointment, which meant she did not take responsibility for her own health and the hospital did not follow-up on her too.

"I just want to do my best to prevent a problem, rather than solve a problem, but my understanding is that the small percentage of the population thinks that way. A large part of the population waits until a problem happens. It seems to me that if a clinic can get people to think along the lines of preventing a problem rather than waiting for it to happen, so it's like for example, what's her name, Jade Goody, who died from cervical cancer, well I think 2 things happened. I think she didn't follow-up on an appointment and I also think that the hospital didn't follow up on her, so it was a double failure. It was a failure for her to take responsibility for herself and it was a failure of the clinic to follow up efficiently and aggressively." (Patient 3)

Clinicians-Prevention and funding for anal cancer screening in the UK

Clinicians believe that it will be cost effective to screen people living with HIV for anal cancer.

"Anal cancer is increasing in MSM HIV patients and in that particular group of patients the rates are extremely high. So, it might not be cost effective as a national programme for everyone to have anal cancer screening and I would agree with that because it's not cost effective but for a particular group of patients such as HIV positive patients, I think it is cost effective." (Clinician 5)

Clinicians have stated that anoscopy does not have a financial incentive as currently they are being paid by a locally agreed tariff and with the restructure of the NHS; Clinical Commissioning Groups will be agreeing a financial cap. Clinicians believe anoscopy should be based on clinical benefits and see if costs can be reduced so more patients are seen.

"There was a not necessarily financial incentive but we were paid recently per patient seen in anoscopy with a locally agreed tariff...we were seeing with the restructure of the NHS and move to Clinical Commissioning Group… hence that may potentially limit the number of patients that we should be screening and seeing in anoscopy who I think it should be

done on clinical benefit, not on financial capping and… to see if there is any way we can reduce costs unnecessary costs so we can see potentially more patients." (Clinician 8)

4.6.9 Recommendations for Anal Screening in the UK

Patients suggested screening to be rolled out throughout the UK as they recognise anal screening is limited to the London region mostly. Clinicians have mentioned anal screening is a new field and this should be part of the London cancer care pathways and anal cancer group.

Patient-Recommendations

Patients have recommended that anal cancer screening should be rolled out across the UK especially within their health area, and where they attend for their HIV outpatient appointments.

"I would like to see it rolled out over the whole of the UK really, so that in all HIV treatment centres wherever they could send you somewhere within their health area anyway that could do what we are doing here." (Patient 2)

Patients have mentioned that a TV celebrity star had anal cancer many years ago and died. The impact of her messages about anal cancer and its complications has been widely documented and reached people.

"I would recommend it, but I would also say, 'look I'm sure you don't want to do this, but you probably should'. So like back like, I don't know how many years ago, a famous actress died of anal cancer and she made a documentary about its 'Farah Fawcett' and she documented it and I admire her bravery, not only for the cancer but also about a cancer that has other issues associated with it, it's not like a skin melanoma." (Patient 3)

Clinician-Recommendations

Clinicians are aware anal screening is a new field which is changing quite rapidly. They will be able to shape management, protocols, develop national guidelines for anoscopy as data is being published. Clinicians would like to share this experience with other clinicians around the world which is a positive step to preventing anal cancers.

"It's a new field…you're working in a field that I think is changing quite quickly. New data is being published…by doing anoscopy, being able to shape management, protocol, develop national guidelines…share your experience with other clinicians around the world… will be shown to be a positive step in preventing anal cancers." (Clinician 8)

Clinicians in the North East of London have introduced anoscopy and management of AIN as part of a cancer care pathway. They hope to pass this on to other cancer networks.

"Well we have now introduced high resolution anoscopy and management of AIN-3 as part of the cancer pathway so in terms of London cancer networks, anal cancer pathway is very much part of what we do now…This is for north east London at the moment, but we will want this to be emulated in other networks and London cancer pathway for London…for other parts of the country too in future I hope." (Clinician 6)

Clinicians suggested an anal cancer group where data are pooled together to build a business case for commissioners to consider funding.

"We need to sort of have an anoscopy anal cancer group and centralise all that data and say that this is what has been found collectively and then build a business case …. convince commissioners that this is a worthwhile service to commission. (Clinician 7)

4.6.10 Benefits of Anal Screening Practices in the UK

Patients perceive the benefits of anal screening valuable as they are being screened and treated to prevent further progression of AIN and at the same time feel in control of their health. Patients also felt that they would have peace of mind as they are monitored for cancer. Clinicians feel that screening does pick up early disease and they can offer surveillance and health promotion. Clinicians believe that they are being proactive by providing preventative medicine.

Patients-Benefits of anal cancer screening in the UK

Patients mentioned that a screening programme will be worthwhile if they are screened and treated to prevent disease progression and people will feel in control and in charge of

their health if they are in a cancer screening program which offers monitoring and surveillance of AIN.

"I would hope the screening programme will show its worthwhile both that if you are screened and treated it will help prevent further progression, but also that while people are in it they do feel more in control and in charge of their own health." (Patient 1)

The benefit of anal screening is that patients will have peace of mind that someone (as in clinicians), are aware of cancer risk by screening.

"The benefit is the peace of mind that somebody is keeping aware of the cancer risk." (Patient 11)

Clinicians-Benefits of anal cancer screening in the UK

According to clinicians, the advantages of anal cancer screening are that disease is picked up early and surveillance offered with health promotion.

"So, I think the advantages are that it does pick up early disease and, if anything, you can at least offer surveillance. You can offer some health promotion." (Clinician 7)

Clinicians also believe that offering preventative measures by offering anal cancer screening is being proactive.

"I think we're being proactive versus reactive so offering preventative medicine." (Clinician 8)

Patients have reported that women have a national cervical screening program and believe that the UK should have the same guidelines for anal cancer screening for high risk men. Clinicians have reported that there are no national guidelines for anal cancer screening in the UK for people living with HIV. Anal cancer screening practices vary across the UK and accessibility and availability of screening centres are limited to the London region mainly. Some contributing factors for this are lack of specialists in HRA, treatment centres and equipment. Patients have mentioned that they trust their clinician;

they are sensitive, supportive and compassionate. Clinicians have suggested MDT centres attached to tertiary referral centres across the UK. Patients are informed about anal cancer screening by nurses at the outpatient clinic while, some patients have read about anal cancer screening in AIDS magazines and entered clinical trials. Clinicians receive referrals from other clinicians from around the UK or patients self-refer in screening centres. Only one tertiary centre offers screening and treatment for multifocal disease. Patients believe that evidence is needed for the prevention and progression of AIN and for psychological aspects too. Clinicians have stated that the UK will be starting a clinical trial (LOPAC trial) to contribute to evidence needed for anal cancer screening, however the US and Europe are contributing to evidence needed e.g. the natural history of AIN.

Patients believe that it is better to prevent disease by screening than treat disease and clinicians have suggested that high-risk groups should be targeted for anal cancer screening. Funding for anal cancer screening in sexual health clinics is approved by clinical commissioning groups and there is a cap on how many patients can be screened. Patients suggested that anal cancer screening should be rolled out throughout UK as accessibility and availability of screening centres are currently limited. Clinicians have reported that anal cancer screening is a new field in the UK and that it should be part of the London cancer care pathways and anal cancer group. Patients reported that the benefits of anal cancer screening will be worthwhile if they are screened and treated to prevent progression of AIN so that they can feel in control of their health. Clinicians have stated that anal cancer screening does pick up early disease and they can offer surveillance and health promotion to patients at risk of AIN and anal cancer.

5 Implications for practice

The purpose of this study was to a) explore the perceptions and experiences of patients, and clinicians on anal cancer screening and b) generate findings to help inform clinical practice for anal screening in sexual health clinics in the UK. This was guided by asking the following question: what are the perceptions and experiences of patients and clinicians in anal cytology screening and high resolution anoscopy in the UK?

This is the first study in the UK to provide a detailed exploration of the perceptions and experiences of both patients and clinicians in anal cancer screening. The UK National Screening Program (UKNSC, 2012) Criterion 15 states that 'the benefit from the screening programme should outweigh the physical and psychological harm caused by the test, diagnostic procedures and treatment'. No evidence was identified and therefore there is no update to the conclusions of the literature review done by Czoski-Murray et al (2010). The literature review states that the screening process does not appear to present any physical harm; however, any psychological effects of anal cytology screening or pap smears have not been evaluated in the studies included in this review. Studies by Landstra et al (2013) and Tinmouth (2011) have researched the psychological aspects of anal cancer screening since the review by Czoski-Murray et al (2010). A recent study by Russo (2018) aimed to investigate gay, bisexual and MSM's experience, understanding and emotional response to screening techniques for anal cancer to determine how best to minimise psychological distress in future programs. My study sets to explore the perceptions and experiences of patients and clinicians in both anal cytology screening and high resolution anoscopy in patients living with HIV undergoing screening and clinicians undertaking anal cancer screening in sexual health clinics. My study provides insights into the psychological aspects of anal cancer screening, perceptions and experiences during anal screening procedures, knowledge and education on anal cancer screening, guidelines and practices across sexual health clinics in the UK.

This section will discuss my findings under the main themes identified in my study as follows:

- Psychological effects of anal screening
- Anal Cancer Screening Procedures
- Education, knowledge and Training

- Social and sexual activity
- Guidelines and Practices

5.1 Psychological Effects of Anal Screening

The psychological effects of anal cancer screening are not widely researched. Emotional responses worry, anxiety, fear, embarrassment, shame, stigma and reassurance are presented in my study. Although some authors according to Vrinten et al (2017) suggest that 'cancer fear' and 'cancer worry' are conceptually different as these distinctions are poorly understood. For example, 'cancer' may be associated with perceptions of treatment, incapacitation, and death, and these could be considered separate fears relating to cancer. I will discuss how worry, anxiety and fear of anal cancer are linked or interrelated emotional responses. Distinguishing between the various worries, that cancer can evoke According to Murphy et al (2018), may help inform efforts to allay undue worries in those people who are deterred by these worries, and from engaging with cancer prevention, and early detection. In my study both patients and clinicians highlighted how these emotional responses has psychological effects on them such as worry, fear, and anxiety for instance, particularly in response to anal cancer screening available in sexual health clinics in the UK. Balasooriya-Smeekens (2015) mentions how fear of 'getting cancer' may facilitate cancer screening participation to, obtain reassurance, while fear about cancer treatments may be a barrier to screening to avoid being diagnosed. Below I will present each emotional response and discuss how these emotions are related to worry about anal cancer screening.

Patients' perception of worry on anal cancer or the perceived notion of getting cancer is a far greater than having HIV. HIV is less of a worry today for people living with HIV as they live longer with highly active antiretroviral therapy (HAART) and less people are progressing to AIDS (Dandapani et al, 2010). However, because of an ageing HIV population and the advent of HAART for people living HIV, non-AIDS defining cancers such as anal cancer is on the rise (Oette et al, 2016). Patients who have had a family history of cancer have contributed to their worry and the realisation that cancer is difficult to treat in the anal area. The anatomy of the anal canal makes it difficult to treat disease and there is no optimal treatment available. According to Dyson and Draganov (2009) little is known about the aetiology, prognosis, and optimal treatment for squamous cell carcinoma of the anal canal. While Palefsky (2012) mentions that the anal canal has

uneven topography; obscuring lesions due to haemorrhoids, folds, stool or mucus; or lesions being located at the base of folds and anal glands, therefore is a challenging area to examine and treat. Patients in my study have identified these factors and are willing to have anal screening purely because developing anal cancer is their worry. Patients have perceived this worry as a scary emotional experience and therefore had anal cancer screening. This is similar to the findings in the study by Truesdale and Goldstone (2010), they mention that patients who have had greater worry about anal cancer or higher perceived likelihood of getting anal cancer were willing to have anal cancer screening.

Clinicians in my study worry for several reasons. This is attributed to the discrepancy between anal cytology and targeted biopsy results. Clinicians have reported that an anal pap smear can show dysplasia yet when biopsies are done there is no evidence of high-grade disease which correlated with the study done by Bean et al (2010). These authors explained that the sensitivity and specificity of a single anal-rectal cytology specimen is comparable with that of a single cervical cytology test, but cytological interpretations do not always correlate with lesion severity. Clearly the differences in anal pap results and targeted biopsy results create a worry for the clinicians as they feel they may be missing some disease or HSIL therefore HRA is repeated. Clinicians reported that bringing patients back for repeated anoscopies can create greater worry in these patients although they have treatment interventions in place for treating AIN. In other words, in some patients' high-grade lesions in the anal canal do not respond to the treatments available. Another worry that clinicians have reported is that they have had patients who subsequently had anal cancer although there are treatments like laser ablation available to treat high-grade AIN. According to Goldstone et al (2005 and 2007), screening and treatment modalities are highly efficacious but repeat treatments are often required due to HSIL's relatively high recurrence rate and this is due to high grade lesion persistence. Clinicians mention that stubborn lesions keep coming back and these patients go on to develop anal cancer.

Truesdale and Goldstone (2010) suggests the need for multiple treatments to fully eradicate disease highlights the critical need for follow up and screening in patients with HSIL. Clinicians have reported that patients stopped coming in for anal cancer screening as they worry about of having anal cancer. This meant that clinicians provided support to patients during their routine HIV outpatient appointments; call them on their mobile or home phone and talk to them to alleviate any fears and worries about anal cancer. This

can be time consuming for the clinician as there is a time constraint for each consultation with a patient. Providing this kind of support is not always feasible therefore clinicians reassured patients by giving them information leaflets on AIN and anal cancer to be able to better understand anal cancer screening and their results at home in their own time. Landstra et al (2013) show in the results of their study that specific worry about anal cancer increases throughout the medical process and suggest that receiving some threatening information and then reassuring information may produce greater optimism for screening than never receiving threatening information. Similarly, Truesdale and Goldstone (2010) in their study mentions that the severity of diagnosis was related to more compliance with screening. My study highlights that patients with a diagnosis of AIN perceive this diagnosis to be anal cancer which affected them psychologically which in turn affected their follow up screening. Patients will return for anal screening with the appropriate information relating to their disease and face to face discussions with their clinician.

Anal screening has led to patients experiencing anxiety of some degree. Patients have described their feelings of anxiety as they think they may have anal cancer and according to Wardle et al (2003) patients most anxious are those with a perceived risk of anal cancer. Some patients have reported that they felt anxious all the time while others did not want to leave their home and almost became agoraphobic. Although patients in my study have been given patient information leaflets on anal cancer screening and explanation of results before and after anal cancer screening, patients experienced anxiety about not understanding the result. Patients who had been told they had a low-grade dysplasia result, felt that they had anal cancer. In a recent study by Russo et al (2017), abnormal screening results affected participants' sense of well-being and were associated with anxiety and concern about developing anal cancer. This anxiety has also been demonstrated in studies like breast and cervical screening where anxiety increases with abnormal results from screening (Brett et al, 2005, Swarewski, 2011). Patients in my study came back to the clinic for follow up appointments for results of their tests and at this point clinicians have reported that a face to face consultation with patients has helped alleviate some anxiety about their screening results. In the study by Brett et al (2005) on breast screening women do not appear anxious after being given a clear mammogram results and were placed on normal recall for breast screening, but women who have had further investigations following routine mammogram experienced significant anxiety in the

short term and possibly in the long term. Conversely, Nelson et al (2009) in their review of literature on breast cancer screening studies have shown conflicting results about anxiety where women had persistent anxiety despite eventual negative results and some women showed only transient anxiety. These studies highlight anxiety as experienced in most cancer screening, that education and understanding results is key to reducing anxiety for patients. This emotion of anxiety in my study is attributed to the lack of understanding results in anal cancer screening.

Clinicians in my study alluded to the fact that patients receiving news of their cytology puts them in a state of anxiety while some patients felt anxious all the time after receiving a positive result which is different to the opinions presented in the study by Landstra et al (2013). Landstra et al (2013) provides an argument, although the possibility has not been investigated that HIV-infected populations may differ from other groups, in that they are familiar with regular medical testing for their HIV, may therefore not be upset by waiting for test results or receiving 'bad news'. However, studies in breast and prostate screening have shown increased anxiety with worry where this anxiety is associated with increased medical follow up and patients go for repeated follow appointments to clinics, or where patients are encouraged to do self-examinations and information seeking from the internet (Brett et al, 2005; McNaughton et al, 2004; Hay et al, 2005). My study show that anxiety exists with anal cancer screening and related to results patients receive after screening.

Another emotional response in my study is fear. Some patients have reported that their family members have died of cancer (e.g. testicular cancer for instance) and this made them afraid therefore stayed in the anal screening program at the clinic. Clearly there is a parallel between family history and the perceived risk for these patients as they are aware that they have a great chance of developing cancer. According Bobridge et al (2014), in colorectal cancer screening, the cancer risk perception and screening decision making have been shown to influence future screening intentions and uptake. Hay et al (2005) concluded that cancer worry increases the likelihood of patients screening for cancer but fear of positive results or the test itself may deter screening. Fear of knowing about anal cancer or to have a diagnosis of anal dysplasia encouraged patients to come in for screening in my study. These patients fear getting anal cancer. On the contrary, the study by Koskan et al (2016) demonstrated that fear is a barrier to anal screening where the fear

of knowing about having anal cancer and confront the diagnosis served as a barrier to screening.

Clinicians believe patients are scared if find anything associated with cancer and felt that a proportion of the patients do not attend first anal screening appointments because find this experience scary and daunting. A similar finding to my study was from Scott et al (2008) where their study highlighted that barriers to screening for patients were fear of a cancer diagnosis and difficulties of these patients with maintaining clinic appointments. However, clinicians in my study believe reassuring patients that an abnormal screen does not mean they have cancer can limit that worry. Wilkinson et al (2000) mention that they provided patients with written information about what an abnormal Pap smear meant, and this led to less anxiety and fewer patients think they have cancer. Some clinicians also felt they are afraid of missing a diagnosis or a lesion during HRA, but they are not afraid of performing HRA or taking a biopsy. This is because clinicians are aware that other lesions or metachronous lesions may be present in the anal canal and a high possibility of missing that lesion. These metachronous lesions present during first HRA examination or according to Brambilla et al (2013) it occurs within the first three years after the primary lesion is identified. Truesdale and Goldstone (2010) have demonstrated in their study the development of metachronous lesions is a great driver for recurrence rates of HSIL following treatment. The other factors may be due to the anatomy of the anal canal and multiple folds that may obstruct or make visualisation of lesions possible and clinicians are afraid that they may miss a lesion. Palefsky (2012) mention that HRA can be challenging which includes uneven topography of anal canal, obscuring of lesions due to haemorrhoids, folds, stool or mucus or lesions being located at the base of folds and anal glands when examining the anal canal.

In my study embarrassment is highlighted as an emotional response to anal cancer screening. Patients have reported they felt embarrassed, that it is ‘bizarre’ or mention “freaks” them out to know a part of their body is exposed and faeces may come past or bowels about evacuate during HRA. Some patients felt that HRA is an intimate procedure and were worried about being dirty. Patients felt the need to be clean and prepare for the procedure. In relation to anal screening Ong et al (2015) highlighted that patients were worried about not being clean for the examination in their study. This too is strongly evident in my study and responses to embarrassment of anal examination when being

screened. Women in cervical screening often described their embarrassment using terms like ‘unclean’ and ‘dirty’ (Szarewski, 2011). To overcome this embarrassment Ong et al (2015) suggests one strategy to increase digital anorectal examination (DARE) for instance, is allow patients time to prepare physically and psychologically for the examination, while Ferris et al (2013) suggests that embarrassment can also be minimised by empathetic discussions before the procedure. Landstra et al (2012) in their study states that anal cancer screening is similar to other cancer screening like prostate and cervical cancer screening; both are associated with private parts of the body and are related to sexuality. The examination is embarrassing for patients because it is a body part that is connected to sex and to something private. According to Sörensdotter & Siwe (2016) genitals are perceived as a special body part connected to sexuality and intimacy and they discuss how gender, cultural norms and sexuality affect examinations. In cervical screening women identified barriers to screening due to embarrassment with regards to the examination which affected attendance to screening (Szarewski, 2011). However, the study by Waller et al (2009) endorsed the most frequent barrier to cervical screening remains as embarrassment for those intending to go when due for a test. Longabaugh (2017) who is a patient and author had active bleeding into the toilet; the itching became unbearable, and she eventually consulted with her physician, although she felt awkward and embarrassed. This was due to her being self-conscious with her physician and the nature of the examination which is intimate involving private body parts. My study highlights how many factors can contribute to embarrassment in anal screening i.e. not being clean, feeling exposed, being symptomatic which can be barriers to screening. However, patients in my study were not deterred from anal cancer screening and stayed in the screening program inspite of feeling embarrassed. Clinicians have reported that patients were embarrassed and afraid of having AIN, as this disease is acquired in the same way as HIV (i.e. sexual practices like anoreceptive sex for example), and their patients did not want to be reminded of it. The association of AIN and HIV meant that in clinicians experience their patients were embarrassed with sexual activity and the link with anoreceptive sex. These findings are similar to the study by Martin and Bower (2103), who states that aside from smoking, one of the independent risk factors for developing AIN or anal squamous intraepithelial lesions is a history of anal intercourse.

Shame is another emotional response in my study. Patients have reported that while HIV comes with stigma, the shame they experience with the diagnosis of AIN is like having

HIV. Patients feel ashamed because of the questions that arise about their sexual practices. The issues that arose in my study for these patients are about how they acquired AIN and questioned themselves about what they did to acquire this diagnosis other than having a positive diagnosis for HIV. Datta et al (2017) mention that staff should be sensitive to men's fears about being judged negatively especially those not used to being open about their sexuality and sexual practices. Clinicians have reported that HIV-positive women who have had anal receptive sex for cultural reasons for instance, see this as a shameful act. Clinicians who offer anal screening to women in their clinics have mentioned that women feel ashamed of their diagnosis of AIN. Women feel ashamed as their understanding of acquiring AIN is low regarding anal cancer risks; therefore, the onus of acquiring AIN is on receptive anal intercourse and the association with HPV. The only heterosexual female in my study felt ashamed and associated anal disease with men who have sex with men, and could not believe she had HSIL after screening, as she never had anoreceptive sex in her life. According to Kojic et al (2011), many women fail to recognise that anal HPV infection can develop irrespective of anal sexual practices. While clinicians are aware that women are not interested in screening or feel that they are not risk, therefore decline anal cancer screening, they need to understand that they are still at risk due to the association of cervical HPV and progressive neoplasia in the anal canal. This is reported in a study by Turner et al (2015) that anal HPV may be associated with cervical HPV due to the anatomical proximity of the anus and genital tract, permitting tracking and infection between both sites; autoinoculation of genital HPV into the perianus and anal canal during front to back wiping, after urination and/or defecation. Other factors like insertion of fingers or sex toys into the anal canal can also result in anal HPV infection in women who do not have receptive anal intercourse (Blankenship et al, 2016). A study on women's knowledge and attitudes towards anal pap testing demonstrated that other than anal sex, the risk factors of anal cancer were poorly recognised by these women (Ferris et al, 2013).

Stigma is an emotional response experienced both by patients and clinicians in my study. The perception of stigma patients highlighted is that HIV has related stigma and so they have a notion that AIN will have the same stigma attached to it as HIV. Bucher (2015) states that the stigma surrounding anal cancer is similar to that of HIV where both who have these diseases are open to judgemental assumptions about their sexual activity, self-respect, even morality by others. This is clearly an assumption of societal stigma where

the idea of promiscuity is identified; unprotected sexual activity and spread of sexually transmitted infections are reported by patients in my study. Interestingly this is discussed in a study by Newman et al (2008) where the participants stated that the health risks associated with unprotected receptive anal intercourse have been evident since early in the HIV epidemic and is openly discussed in the gay community. This study concludes unprotected anal intercourse is not socially acceptable in the gay community due to its implication in spreading HIV infection, syphilis and other diseases. Patients in my study have reported that this stigma is affixed to them as person by society just because they have a chronic condition HIV which is related to sexual activity (receptive anal sex, multiple partners, and people from ethnic minority groups which include gay men or being promiscuous). The most compelling findings of the study by Truesdale & Goldstone (2010) identified factors contributing to stigma associated with emotional upsets were feelings of promiscuity, severity of diagnosis, and physical symptoms. Salati and Kadi (2012) states that promiscuous sexual behaviour increases the risk of HPV and HIV infection thereby increasing the risk of anal cancer; that receptive anal intercourse also increases the risk of anal cancer in men and women. In cervical screening, Asian women who were offered the HPV vaccine for example cited that HPV is sex-related with the possibility of increasing promiscuity (Marlow et al, 2009). Patients have mentioned that it is taboo to discuss anoreceptive sex and it is associated with men who have sex with men. Longabaugh (2017) mentions from her personal perspective as a patient who was diagnosed with anal cancer, that there is a stigma attached to anal cancer, and the stigma can be paralysing where the isolation is notable. She also describes anal cancer as an overwhelming, stigmatised and discriminatory (‘squeamish’) type of diagnosis where patients can and often relegated to silence. In a study by Goldman et al (2009) with regards to colorectal screening and risks, almost all participants who cited sex as implicated in colorectal cancer referred to anal sex, usually between men, but sometimes between men and women; many participants who believed in sex-related causes, used words that demonstrated their discomfort in discussing the topic and this was particularly true among women who believed that colorectal cancer risk was greatest with homosexual behaviour.

Clinicians have highlighted self-stigma in their practice of anal screening in my study due to lack of experience in anal screening in the UK. Clinicians are aware of the stereotypes that describe a stigmatised group like those living with HIV and at risk of anal cancers to

experience this self-stigma. These clinicians who internalise these negative beliefs can have low self-esteem and can adversely affect the ability to perform anal cancer screening or their ability to undertake HRA. Corrigan et al (2009) mentions that because people have self-stigma, they suffer from low self-esteem and low self-efficacy and avoid using evidence-based practices to achieve their goals. Clinicians in my study did not have low self-esteem but discuss low self-efficacy as they lack experience in HRA and anal cancer screening, as it is still new in the UK but rely on evidence for anal cancer screening from countries with established anal cancer screening guidelines and practices. Clinicians in my study have realised that self-stigma is not acceptable behaviour as professionals and has led them to improve their practice through understanding sexual practices, the need for training, the need to screen high-risk groups of people and evidence produced by other countries like the US. Therefore, clinicians have mentioned that they are aware they can seek help from the wider community (other practicing clinicians, International Neoplasia Society or cancer networks) who undertake or perform anal screening. This can help alleviate feelings of inadequacy and provide an effective anal screening service to people living with HIV in their clinics. Bucher (2015) states that there is the IANS professional body devoted to the prevention and treatment of AIN and anal cancer; its mission is to provide a forum for individuals with a broad spectrum of backgrounds, viewpoints and geographic origins, an exchange of ideas and dissemination of knowledge regarding the pathogenesis, diagnosis, treatment and prevention of anal neoplasia. Clinicians undertaking anal screening in the UK are aware of IANS where most clinicians are members and can access up to date information and support from this scientific society. Whilst IANS provides a forum for clinicians on AIN, this is a dedicated site for learning, conferences, publications and webinars where clinicians can present difficult cases or challenges in their practice. Within this IANS has a link to the HPV organisation to support patients with HPV related cancers, information leaflets, mentors and buddies and clinicians can refer patients to or clinicians to use a reference when seeing patients. In the UK the cancer network and web page provide information on anal cancers (CRUK, 2016).

Another emotional response is reassurance. Patients felt reassured to be part of a screening program and this is available to them at their HIV outpatient clinic. They also felt reassured that treatment is available for AIN. This finding is similar to prostate cancer screening where screening may have some reassurance value for men, and that added reassurance afforded by screening (Scott et al, 2002). Clinicians on the other hand give

information leaflets to their patients on anoscopy which informs them on how to prepare for the procedure which creates a degree of reassurance for them. Landstra et al (2013) mentions that a person's knowledge about screening can influence their psychological response to screening which is highlighted by clinicians, where information provided to patients gives them a degree of reassurance. My findings concur with the findings of Colon-Lopez et al (2016) that developing comprehensive cancer screening programs for people living with HIV to achieve earlier diagnosis and promptly initiate treatment.

The emotional responses presented above highlights worry, anxiety and fear are interrelated. Patients worry they may have cancer, worry about cancer results in anxiety and worry about anal cancer makes them fearful. These emotions are real or perceived and are all related to anal cancer. Embarrassment makes patients self-conscious about screening as they have to expose private and intimate body parts for examination during HRA. Patients have highlighted that feel humiliated as there is a connection with HIV, AIN and sexual activity. Some participants felt that having anoreceptive sex is a shameful act and like HIV, this is a taboo subject. Stigma was experienced both by patients and clinicians. Patients experienced societal stigma due being HIV-positive, being gay and having anoreceptive sex. Clinicians experience self-stigma because of lack of training in HRA in the UK. Patients felt reassured to be part of an anal cancer screening program in their sexual health clinics, that treatment was available to treat AIN. Clinicians believe that information given to patients create a degree of reassurance as knowledge can influence their psychological response to anal cancer screening

5.2 Anal Cancer Screening Procedures

Anal screening procedures in my study included anal cytology, DARE, HRA and anal canal biopsies. Patients and clinicians have discussed and expressed their experiences and perceptions on acceptability and tolerability, pain during HRA, bleeding after biopsy, discomfort and anal screening as an invasive procedure.

Most patients found anal screening acceptable however tolerability in my study was variable in terms of their experiences and perceptions**.** However, clinicians' have reported that women who have anal screening find it an acceptable procedure but did not tolerate it well while men who have sex with men accept and tolerate screening well. The reasons for women not tolerating the anoscopy procedure is due to anal tone and women who do

not have anal-receptive sex find it difficult when the anoscope is inserted into the anal canal, but these women want to contribute to evidence needed in the UK. This is supported by some studies as discussed in the preceding discussions.

Blankenship et al (2016) explains that a significant factor influencing anal cytology acceptability was high levels of familiarity and belief in the utility of anal cytology in detecting anal intraepithelial neoplasia. Botes et al (2011) suggests that participants who take self-collected anal swabs, 81% of men reported this procedure as highly acceptable. Acceptability of screening is also associated with pain, discomfort and embarrassment. Davis et al (2013) in their study of tolerability of anal dysplasia screening demonstrated that screening procedures for HGAIN are generally well tolerated by patients with minimal to no discomfort; no single screening procedure caused enough discomfort to decrease patient compliance with anal screening. My study highlights that HRA was very well tolerated although it is by far the most complicated procedure performed. Moreover, clinicians taking a biopsy did not add to perceived discomfort for these patients, as the biopsies were performed within the anal canal and above dentate line or pectinate line (i.e. is a line that divides the upper two thirds and lower third of the anal canal), where there is no pain sensation and is carried out by an experienced clinician. Data produced by Hillman et al (2011) on participants' perspective of high resolution anoscopy found most participants found HRA acceptable, with a few complications as acceptability was strongly correlated with pain and bleeding during and after the procedure.

Clinicians have reported that tolerability of anal cancer screening was variable for patients. This tolerability is due to some patients who have receptive anal sex, and due to reduced anal tone where internal and external sphincter muscle is more relaxed, it is easier to tolerate the anoscope. Women don't find anal screening very tolerable mainly because the anal tone is tight. Clinicians have described in their experience of undertaking anal screening is different for men who have sex with men and women. On the other hand, clinicians have explained that although women do not tolerate anoscopy procedure, they accept it is a screening process and are excited about contributing to evidence needed in their clinics. These surveys are included in the study by Vera et al (2014) undertaken in the UK. My study does highlight that clinicians found when they undertook patient satisfaction surveys at their clinics, that several patients found anoscopy acceptable although invasive procedure. Some other reasons as alluded to by Davis et al (2013) for

tolerability of screening procedures may be the result of anoscopy performed after non-lubricated cytology and HPV sampling followed by DARE which have progressively irritated the anal canal and perianal skin.

Patients have reported that anal exams are invasive in every sense; it is not something they look forward to where they must undress, and a clinician must examine their rectum. Newman et al (2008) mentioned in their study that men have poor knowledge about their perianal genital area and the apprehension of having an anal pap meant that this would publicise a body part that is so private, that the anus is a body part that is never discussed, seldom seen and neglected. Several participants in the study by Newman et al (2008) also equate the intra-anal space to a women's vagina which is unseen, unknown and present. My study has highlighted that anal examinations (includes anal Pap smear, DARE and HRA) where patients must undress, and an intimate examination of the anal canal is done, is invasive as reported by patients. Clinicians on the other hand explain that anoscopy is invasive in every sense, is not most dignified but is a 'gold standard' for screening. The study by Koskan et al (2016) have reported that men who have sex with men found that anal pap smears not overly invasive or painful but described how the test was mildly uncomfortable. One of the strengths of my study explored invasiveness with both patients and clinicians experience in anal screening procedures.

Patients in my study have experienced pain during anal pap collection, insertion of anoscope, and when biopsy taken. Patients' that have anticipated experiencing pain prior to HRA procedure, did actually experience pain during HRA. Clinicians have also noted that patients have marked pain when biopsies are taken for instance, and these patients can find it unpleasant during HRA. In breast screening, pain, is associated with menstrual cycle, anxiety and anticipation of pain during mammography (Armstrong et al, 2007). In my study pain is perceived and experienced during HRA and correlates with this study only in relation to the anticipation of pain. Nelson et al (2009) describes patient negative experiences such as pain during procedures, anxiety and other psychological responses are common. These experiences seem to be transient and do not adversely influence future screening. The study by Davies et al (2010) suggest HRA which is by far the most complicated procedure performed, it was well tolerated and the fact that the biopsy did not add to perceived discomfort, meant that all biopsies were performed within the anal canal and above the dentate line where there is no pain sensation.

Patients may experience or can have bleeding during HRA guided biopsies. Patients have reported bleeding for up to 3 days and it worries them when they see blood in the toilet pan or tissue paper. But they have the knowledge and understanding that the bleeding will stop. Bleeding can occur after a biopsy is taken from the anal canal as a small piece of tissue is cut out measuring about 3mm for histological sampling to detect AIN. Clinicians have seen patients bleed for a week or two after having a biopsy sample taken during HRA and have not experienced any adverse events but all they needed was reassurance. In the study by Botes et al (2011), 17% of participants reported some level of bleeding after screening procedures (i.e. HRA guided biopsy); while Hillman et al (2011) reported only 11.4% of participants have slight bleeding for less than a week. In my study, there were no significant reports of prolonged bleeding and patients were aware they could to seek help with the clinicians if bleeding persisted.

Patients have experienced discomfort with anal cytology, where a Dacron cotton swab is used to obtain an anal Pap sample and patients have described this procedure as 'rough' and uncomfortable. It is clear, that the feeling or sensation of the swab inserted into the anal canal for cytology sample collection caused discomfort for patients in my study. In the study by Davies et al (2013) the higher mean discomfort was experienced by participants when the sample was collected with an HPV brush, followed by an HPV swab, and then anal cytology swab where the perceived sensation between first swab and second brush was reported as increased discomfort. In my study patients have described their experience in HRA procedures as uncomfortable while clinicians perceive screening procedure as foreign to most patients, and women find this procedure very uncomfortable. According to the study by Davies et al (2013), HRA was found to have the highest negative rating where patients have cited this is a procedure that will keep them from returning to be screened and it appears that discomfort increases as more procedures are performed in succession therefore, proposed future research to try and diminish discomfort further with a goal of keeping even fewer patients objecting to the procedures. Although screening my study included anal cytology, followed by DARE, HRA and biopsy, none of the patients stopped screening due to discomfort as it was well tolerated.

The position in which a patient is examined is important during HRA procedures are highlighted in my study. Patients suggested a positional change for their comfort 'like facing forwards' (prone position) for instance. Hillman et al (2011) suggested that new

methods to improve participant experience are required although they have demonstrated HRA to be an acceptable procedure. My study concluded that discomfort has taken into consideration that some patients prefer a change in position to minimise their discomfort. The most important aspect of examining a patient during HRA is the position in which a patient lies on the examination couch. Clinicians in my study examine patients in the left lateral or lithotomy position. A study done in the UK by De-Masi et al (2018) reported that patients are examined in the outpatient (office) setting in the dorsal lithotomy position with an adjustable bed. A commonly used position for HRA is the left lateral position, the position I examine patients in, but lithotomy and prone positions have been cited in some studies. In the left lateral and prone positions, the patient should be as close to the bottom edge of the table as possible to facilitate focusing the colposcope. Normally, during HRA the patient is in the left lateral position, in the foetal position, with the buttocks at the edge of the table (Albuquerque, 2015). The prone position is used if an overhead colposcope is available which means patients bend forward over the table (Watt, 2005). All patients in my study are examined in the left lateral position as I use a colposcope which is mobile with wheels to adjust positioning and focusing for HRA procedures. Clinicians should consider the equipment they have to examine patients and patient's choice. Sometimes, the type of colposcope a clinician use may only allow them to examine a patient in the left/right lateral position as it is a mobile colposcope, whereas other clinicians may have an overhead colposcopes which they can use to examine patients in a prone position.

Clinicians in my study have compared high resolution anoscopy to sigmoidoscopy and mentioned that lesions are better located in the anal canal using the colposcope during HRA. HRA is very different from flexible sigmoidoscopy and cannot adequately examine the anal canal for the problems being detected by HRA. Patients must have anaesthetic for a sigmoidoscopy procedure whereas in HRA only local anaesthetic can be used. Clinicians have reported that a sigmoidoscope is inserted too far into rectum and they are interested only in 5cm of the anal canal. The sigmoidoscope does not allow for visualisation of the distal anal canal. Anoscopy allows them to apply acetic acid into anal canal to see lesions, whereas this cannot be done with the sigmoidoscope. They also mention that steady equipment is needed, like the anoscope, which is easily applied and steadied in anal canal. Clinicians have highlighted the superiority of HRA to detect AIN as it is best visualised with an anoscope rather than the sigmoidoscope. Alonso-Coello and Castillego (2003) in their study stated that the most accurate method for examining the

anal canal and distal rectum is anoscopy since it detects more lesions in the anorectal region than does a flexible sigmoidoscopy and visualisation are best achieved with the anoscope. Two prospective studies by Kelly et al (1986) and Korkis & McDougall (1995) found that anoscopy detects a higher percentage (99% versus 78%) of lesions in the anorectal region than does flexible sigmoidoscopy as it is a procedure for evaluating rectal disease. It is however very reassuring, that my study concurs with other studies (Jay, 2017; Alberquerque, 2015; Palefsky, 2012; Gimenez, 2011) to recognise that anoscopy is a gold standard in detecting anal canal disease or AIN. Gosens et al (2017) reiterates that high-resolution anoscopy is the gold standard for screening. Newman et al (2008) mentions that most experts suggest direct visualization of the anal canal by using a bright light and external magnifier called a colposcope, which is a better way to locate areas for biopsy. The standard for AIN detection is high-resolution anoscopy in combination with biopsies and histopathological analysis of suspect lesions De Vries (2015).

My study can conclude that screening procedures for the diagnosis of AIN including anal Pap smear, HRA/anoscopy and biopsy are acceptable while tolerability is variable due to factors like anal tone and anal receptive intercourse. There is a degree of discomfort, bleeding and pain but this is not a major issue which seem to be transient and do not adversely affect patients. However, it must be noted that anal screening is an invasive procedure which is not highlighted in many studies. The gold standard in anal screening is high resolution anoscopy as reported by clinicians.

5.3 Education, Knowledge and Training in Anal Screening

It is vitally important that the necessary information is available for patients and clinicians, so they are knowledgeable on anal cancer and screening. Training that clinicians receive to be able to undertake or perform HRA warrants good knowledge and education to be able to deliver a robust screening program for people living with HIV. It is important to note that the limited information available in the UK on anal cancer screening, knowledge and education are identified in my study. Most the knowledge that patients and clinicians acquired was through magazines, the press and articles on anal cancer screening.

Patients have highlighted that there very little information available on anal cancer screening except in HIV magazines or in treatment updates. Patients have also

mentioned that knowledge and information were mainly given to them by their clinicians (see appendix 15). Landstra et al (2012) states that raising awareness may increase concern and there is a perceived vulnerability of participants, therefore it is vital to increase motivation to have anal screening because education is particularly important for high-risk groups. Patients in my study have reported that they take care of their own health have self-knowledge and do their own research on anal cancer and screening. They also feel that the influence of the media plays an important role in educating one's self. Some patients perceive 'being in charge' of their own health and having knowledge of HIV and anal cancer means that they are the 'expert patient'. Patients also reported that information on anal cancer is important especially if faced with a life-threatening disease as that information is a 'safety net' and they having different needs in terms of knowledge and education on anal cancer screening. Some patients believe that they are expert patients as they are well read or do research while others feel information provided to them is a safety net. According to Bower and Gilbody (2005) different support may be needed by different people therefore where possible it would be helpful to have a variety of support options available such as written information, support staff available by phone or email, patient support groups or have access to a psychologist or social worker. In view of the limited information available to patients, access to written information in the form of leaflets with links to websites about anal cancer and screening, access support by phone or email if they wished to contact clinicians and the availability of a psychologist for counselling is useful for them. Newman et al (2008) highlighted that the participants in their study offered a variety of suggestions like advertising in a wide variety of venues would increase HPV infection and anal cancer screening; pamphlets in the doctors' offices; and in healthcare settings using posters, outreach workers, media and press Longabaugh (2017) acknowledges that the quandary or perplexity for patients with rare cancers are the lack of resources, which reinforces the challenges patients experience with information, and education in my study. Furthermore, it is important to note patients faced with cancers like breast, cervical, and prostate cancer for instance, resources are easily available unlike anal cancer, and there is very little information. According to Longabaugh (2017), education, support groups, websites, study availability and resources to help for breast, cervical prostate even colorectal cancers are readily available. Currently anal cancer is not widely advertised in healthcare settings except in clinics offering anal cancer screening in the UK. For example, clinicians undertaking anal cancer screening inform patients face to face, give them information leaflets, refer to screening centres via clinicians' and in

patients' case, they inform their friends and colleagues about anal cancer screening. BASHH and BHIVA don't have information on anal cancer screening but in the USA, there is a dedicated website available for patients (https://www.analcancerfoundation.org/). Clinicians have also highlighted that patients are not informed due to the lack of screening services available in the UK. Individual clinics have developed their own patient information leaflets

The results of my study demonstrate that education, knowledge and information on anal cancer screening is limited to the media, press, magazines and those clinicians offering screening at their sexual health clinics in the UK. Vera et al (2014) completed a national survey in the UK and concluded that the increasing risk of HPV-associated anal cancers in high risk groups, (i.e. those with HIV infection). A study by Colon-Lopez et al (2016) highlights that healthcare professionals (clinicians) that were interviewed in their study, reported that they were not aware of any resources or programs providing anal cancer prevention services for people living with HIV. Longabaugh (2017) suggests that it is imperative for the medical community to be educated on anal cancer screening and prevention and those immunisations for HPV are key to reducing the incidence of anal cancer for future generations. My study also demonstrates that HRA is a skill that takes a long time to acquire and clinicians have mentioned that it is a steep learning curve. Palefsky (2012) states that a long learning curve is typically required before becoming fully competent in this technique of HRA while, Richel et al (2014) mentions that HRA is a complicated procedure which should never be underestimated as it requires extensive training and experience. Even though there is a small group of clinicians in the UK who are motivated to undertake anal screening, there are difficulties as the only accredited HRA course is through IANS in the US (IANS, 2016), although the UK held its first course in 2014 (HUHFT, 2014) and Europe 2016 (anoscopycourse.eu, 2016).

5.4 Social and Sexual Activity

Most patients have reported that having AIN has not affected their social life but has affected their sexual activity, mainly because treatment makes them sore. Some patients have reported their social life was not affected and that sexual activity did not change as they used condoms. It is evident that some patients adopted safe sex practices, like using a condom to resume normal sexual activity for reasons of companionship or even to

satisfy their sexual desires. This is vital for patients to improve quality of life and for patients' sexual health well-being. According to Koole et al (2007), assessing health related quality of life in addition to sexual functioning is important because sexual well-being is a crucial part of overall quality of life. Other patients reported having anal warts stopped them from dating as they are aware that having HPV are contagious from skin to skin contact or can be passed on through sexual activity. Some patients have mentioned that they did not have time for socialising as they were busy studying or working. This is a form of escapism where patients would rather be busy with work or study to avoid sexual activity with the effort of not dealing with a stressor like HPV which is linked to anal cancer. Some patients associated sexual activity with AIN and smoking with lung cancer for instance and describe this as self-inflicted behaviour. The reference to self-inflicted behaviour means if patients have unprotected sexual intercourse then they will be more likely acquire sexual infections including HPV and eventually get anal cancer. Sexual risk behaviours and engaging in sexual intercourse with multiple concurrent (or lifetime) partners, have been shown to be associated with an increased risk of acquiring genital HPV infection thus, likely explaining the association of these behaviours with cancer risk (D'Souza, 2008). According to Brown et al (2009), despite diverging theoretical perspectives, a common thread across theories is that self-inflicted injury is related to severe emotion which emphasizes the importance of self-invalidation and shame in the development and maintenance of self-inflicted injury and this is to escape or avoid aversive emotions. This could also be linked to patients living with HIV and the inability to cope in healthy ways with psychological pain of then having unprotected sex and getting HPV which then leads to anal cancer. Patients in my study have highlighted that sexual activity, sexual practices and sexually transmitted diseases are risk factors for acquiring anal intraepithelial neoplasia which are associated with anal cancers. Goldstone et al (2011) states that the risk factors for new or persistent anal HPV infections include anal intercourse, having multiple sexual partners, and smoking. Uronis and Bendell (2007) mention the association between anal cancer and sexual practices including anoreceptive intercourse and MSM is clear, but the association between anal cancer and HIV infection has been difficult to separate from cofounders as HIV positive patients are more likely to be infected with HPV and often with more than one subtype of HPV. Similarly, according to Szwareski (2011) shock, embarrassment and shame were common responses in cervical screening with women using terms like 'unclean', 'dirty', 'cheap' and 'nasty' to describe how they felt about their HPV result, affected their attitudes towards sex and

relationships. Patients in my study are aware of the risks of HPV, being HIV positive and sexual activity are factors that may contribute to acquiring AIN through having unprotected sexual activity.

5.5 Guidelines and Practices

This section will report on the perceptions of patients and clinicians on anal cancer guidelines and practices in the UK. It must be acknowledged there are no guidelines available in the UK for anal cancer screening while BASHH and BHIVA are not committed to anal cancer cancer screening. National population screening programmes are implemented in the NHS on the advice of the UK National Screening Committee (UK NSC, 2013), which makes independent, evidence-based recommendations to ministers in the four UK countries.

Patients believe that there should be a national screening programme for high risk men as they are aware a national screening programme for cervical cancer screening exists. Clinicians have reported that there are no guidelines available for anal screening in the UK and they rely on local protocols and best practice, especially for multicentric/multifocal disease. The Institute of Medicine Committee on Standards for Developing Trustworthy Clinical Practice Guidelines (IOM, 2011) in the US define clinical practice guidelines as statements that include recommendations intended to optimise patient care that are informed by a systematic review of evidence and assessments of the benefits and harms of alternative care options. The Association of Coloproctology of Great Britain and Ireland Colorectal Disease published a position statement by Scholefield et al (2010) on guidelines for the management of AIN but screening recommendations are still very unclear in the UK. IANS has published international guidelines and practice standards on the detection of anal precursors in 2016 for clinicians around the world who undertake anal cancer screening. Clinicians in the UK use these guidelines and practice standard to guide their practice and develop standards for their own sexual health clinics. The New York State Department of Health Aids Institute is one of the only few health departments' worldwide recommending anal cytology screening for HIV positive MSM (The New York State Department of Health Aids Institute, 2018).

Nearly all anal cancer guidelines avoid any direct recommendations regarding routine screening as there are no clinical trials or data on anal screening available. According to

Leeds & Fang (2016) large randomised clinical control trials are necessary to demonstrate the increasing consensus among practitioners that anal cancer screening offers a cost-effective, prevalence lowering of anal cancers and interventions for screening in high-risk groups. These authors further suggest that the SPANC and ANCHOR studies will be helpful in determining whether routine screening to build the evidence for a population wide recommendation on anal cancer screening. The study results from SPANC which will published in later 2018 will contribute to understanding of the natural history of anal HPV and inform the possible development of guidelines for implementing anal cancer screening programs in this population (Machalek, 2013). The purpose of the ANCHOR study, which started in 2015 is an 8-year study, is to determine whether treating anal HSIL is effective in reducing the incidence of anal cancer in HIV-infected men and women (anchorstudy.org, 2018).

Patients in my study have reported that people who are living with HIV and at risk of anal cancer cannot access screening because most of screening is offered in London region and not in other parts of the country. Patients have also stated that they are aware that specialists in provincial HIV treatment centres do not have the facilities to undertake anal cancer screening. These patients have identified centres in London, Manchester and possibly Edinburgh are screening people living with HIV. Clinicians have mentioned patients that attend Manchester sexual health clinic live as far away as Scotland and come for anal cancer screening to Manchester as they do not want anyone to know their HIV status. This can also be related to the stigma people have about HIV, so these patients are migratory and seek medical care for their HIV in other parts of the country or regions. According to the StigmaSurveyUK (2015) the reason for this could be attributed to a considerable number of people in the UK still hold stigmatising attitudes towards those living with HIV. Anal cancer screening is offered to patients living with HIV mainly in the London regions while one clinic offers anal screening on North East England. According to Baylis et al (2017), almost half of all people who receive treatment for HIV in the UK do so in London. The rate for new HIV diagnosis in the capital is more than three times higher than any other area; the population with HIV is more diverse than anywhere else in the country; and there are more people living into older age with HIV in London than anywhere else in England. The trends in epidemiology and behaviour are often seen first in London, as are the clinical and wider responses to those trends. Patients have suggested that they would like to see anal cancer screening rolled out across the UK. A national survey

completed by Vera et al (2014) stated that despite the increasing risk of HPV-associated anal cancer in high-risk groups such as those living with HIV, only a minority of sexual health clinics are offering anal cancer screening in the UK. Clinicians have reported that they see patients from different parts of London and they are referred from other clinicians in the UK due to the limited number of sexual health clinics offering anal cancer screening.

The face of HIV as a chronic disease has changed as a result of advances in HIV treatment in the last three decades but a new set of HIV-associated complications have emerged, resulting in a novel chronic disease that for many will span several decades of life. Treatment does not fully restore immune health therefore, several inflammation-associated and/or immunodeficiency complications such as cardiovascular disease and cancer are increasing (Deeks et al, 2013). Despite all the complications associated with HIV, effective treatments mean that increasing numbers of people with HIV now have normal life expectancy. Baylis et al (2017) reported that we are seeing rapid increases in the overall the number of older people living for long periods with HIV, alongside co-morbidities such as hepatitis and mental health needs, plus health and care needs associated with ageing including cancers which is non-AIDS defining illness. As the result of HIV being a long-term chronic illness, patients form long term relationships with their clinicians as they will have been seeing the same clinicians for many years. Patients have reported that they trust their clinician, as long as they are being monitored and therefore put full trust in them. Patients also describe their clinicians as compassionate and professional as they offer counselling as well as a bespoke service for anal screening and have described medical staff treat patients a being ‘valued’, and they feel ‘spoilt.’ Patients also believe their clinicians are sensitive, caring and very supportive during anal cancer screening. Datta et al (2017) mentions that the personal qualities of clinic staff were key features of services, and participants of this study wanted staff to be friendly, professional, discreet, knowledgeable and most of all not to be seen to judge their sexual lifestyles. Griffin (2006) reported whilst it is evident that having a positive relationship with a care professional and that holistic care is provided, the development of such relationships implies a long-term caring context for these patients. Patients can benefit from the development of such relationship’s patients can also benefit from anal cancer screening through these relationships with the professional especially with the institutional and economic pressures of today.

Clinicians think the way forward to managing high grade disease and AIN is through multidisciplinary team centres (MDT) that are attached to tertiary referral centres like London, Birmingham, Manchester, and Scotland so that there is a spread across each region in the UK. Clinicians have also reported that there is only one tertiary centre in the UK. This service in the London region is well established for many years and patients are referred to this service by clinicians from other hospitals or from within the tertiary clinic where HRA and cytology is offered as part of the screening. Clinicians have suggested MDT centres with gynaecology, oncology, colorectal specialists, histopathologist, cytopathologists, and surgeons who are part of colorectal teams as well as an administrative person attached to tertiary referral centres. These recommendations are in line with Renehan and O'Dwyer (2011) who suggest that within the United Kingdom, each cancer network, or two adjoining networks if population numbers are small, should establish a network anal cancer MDT, which meets regularly and to include a team of colorectal surgeons, clinical oncologists, radiologists and pathologist, supported by a dedicated MDT coordinator, advanced nurse specialist and data manager. Multidisciplinary teams should improve coordination, communication, and decision making between health-care team members and patients, and hopefully produce more positive outcomes (Flessig et al, 2006). According to Scholefield & Nugent (2011), multi-disciplinary team working has become established in the last 10 years for colorectal cancer, and several sets of local, national, and international Guidelines have been developed for the management of colorectal cancer in the UK. In the existing colorectal guidelines these authors explain that lymphomas and sarcomas of the anus are even less common but have increased in incidence in recent years, particularly among patients with HIV. It is reassuring to note that increasingly, surveillance programmes for patients with AIN disease occur in parallel with the anal cancer MDT and detect early invasive carcinomas (Scholefield et al, 2011).

Only one clinic in the London region sees patients with multifocal disease which is a tertiary centre as there are parallels between AIN, CIN, VIN intraepithelial neoplasia (Scholefield, 2011). This tertiary centre has established MDT's and links with the cancer networks for that region. Clinicians have reported that women with a history of vulval cancer or vulval disease, vulval HPV or VIN are offered anal cancer screening as they are aware there is a risk of developing anal intraepithelial neoplasia. While Scholefield et al (2011) mentions a strong correlation with etiological factors in AIN, CIN, VIN, and any

perianal disease. My study highlights that patients with multifocal genital neoplasia are offered HRA assessment and treatment. Grulich et al (2012) states that the risk of anal cancer is increased in immunosuppression, including those living with HIV and in women with a history of HPV associated genital precancerous lesions. This is significant with the only clinic in the UK that offers anal screening including HRA to those patients with multifocal disease within a sexual health clinic. It is interesting to note that Palefsky et al (2001) found in their study that HPV infection may act as a reservoir or source of anal HPV infection and studies have shown that those who have high-grade lesions in the cervix or vulva are more likely to develop anal lesions. Hillman et al (2015) mentions that rates of anal cancer are generally higher in women than in men as women with a history of cervical, vaginal and vulval HPV related disease are at a higher risk of anal cancer.

Patients believe that the NHS need more evidence as there is a lack of data like natural history of AIN, for anal cancer screening programs as it worthwhile for the prevention of anal cancer. Clinicians are going to start trials like the LOPAC which is going to be the biggest trial in the UK and this will contribute to evidence needed for anal cancer screening. In the meanwhile, trials in the US, Australia and Europe are producing studies to contribute to the evidence needed. Salit et al (2010) in their study mention that the implementation of anal screening is hampered by the lack of data from randomised controlled trials and it is highlighted in my study by patients and clinicians that more evidence is needed. Leeds and Fang (2016) mentions that the SPANC and ANCHOR studies will be helpful in determining whether routine screening through to a cancer diagnosis will ultimately be necessary to build evidence for a population wide recommendation (i.e. HIV negative and HIV positive people to include men and women at risk of HPV-related AIN). According to the data in my study, the current practice in the in most sexual health clinics are to screen high risk people (like MSM, patients with multifocal disease) and people living with HIV. According to Sackett et al (2000) because evidence-based practice is a continuing process, it is a dynamic integration of ever evolving clinical expertise and external evidence in day to day practice. The SPANC and ANCHOR studies will be helpful in determining whether routine screening through to a cancer diagnosis will ultimately be necessary to build the evidence for a population-wide recommendation (Leeds & Fang, 2016). These two studies are important to contribution of evidence-based practice for anal screening.

Patients in my study have believe that it will be ‘cheaper’ to prevent disease like screen for AIN than treat illness (i.e. cancer) especially in terms of costs based on ill health, hospitalisation and treatment for cancer. Patients are aware that in the early days of HIV, many patients have been hospitalised with AIDS defining illness which was in their perception a financial burden on the NHS as testing for HIV and prevention services were not widely available in the 1980’s. Clinicians on the other hand recognise anal cancer is increasing in the MSM living with HIV and agree that it is not cost effective to have a national screening program for everyone i.e. the general population but will be cost-effective for people living with HIV. Clinicians reported that picking up early disease is being proactive in anal cancer screening to detect AIN rather than being reactive to patients who go on to develop anal cancer. According to Goldie et al (2000), anal cancer screening programs in the MSM population are considered to be cost-effective. With the restructure of the NHS and funding for services agreed by Clinical Commissioning groups, there is going to be a cap on funding thus limiting the number of patients seen in anoscopy services for anal cancer screening. Yet clinicians believe that anoscopy would be performed for clinical benefit see how they can reduce unnecessary costs and see more patients for anal screening, instead of capping or limiting on the number of patients screened in their clinics due to funding. Lam et al (2011) in their study summarised that with HIV infected MSM and where resources permit that anal cancer screening should be initiated with HRA, is the most cost-effective strategy for detecting AIN 2/3. While MSM falls under the category of high-risk groups, it is evident that all high-risk groups would benefit from anal cancer screening in detecting high grade AIN. The CRUK (2016) states that it is most cost effective to screen people whose doctors think are at higher risk especially with an uncommon illness. Conversely, Czoski-Murray et al. (2010) concluded that in the reference case cost-effectiveness model, screening for anal cancer is very unlikely to be cost-effective and a key determinant of this finding was the low observed incidence of anal cancer in the UK population. According to Ong et al (2016), the cost effectiveness of regular anal examinations in HIV clinics to screen for anal cancer in HIV positive MSM would improve if there was a reduction of extra costs associated with investigations carried out by specialist referrals. This can be done by upskilling HIV physicians to manage common anal conditions and only referring lesions suspicious for anal cancer. A study by Fox et al (2005) mentioned that screening patients for AIN has significant cost implications and this has deterred any clinician in the UK from setting up a true screening programme.

Patients recommended that they would like to see anal cancer screening rolled out throughout the UK. Clinicians suggest anal cancer screening should be part of the cancer care pathways or anal cancer groups. Cancer care pathways, groups and networks can influence national agenda on cancer screening and these are normally within a geographical area or region. In this way data would be centralised to a database and it is evident the only one tertiary centre in the London region is part of the cancer care pathway. It is hoped that this would be rolled out to other parts of the UK. Patients feel that a screening program will show it is worthwhile if people were screened and treated to prevent progression to high grade disease. Patients also believe that people will be in control and in charge of their own health if they are part of a screening program and patients will attend for regular follow up appointments for anal screening, and they will be more aware if they detect any lumps by self-examination or even highlight to their clinicians when they have any symptoms like anal itching or bleeding for instance. The benefit of anal screening according clinicians will mean that patients will have a peace of mind that someone is monitoring them or aware of cancer risks. Reed et al (2010) noted in their study that although gay and bisexual men have notably high rates of cancer, it is promising that the potential benefits of anal cancer screening are comparable to the observed benefits of cervical screening for women as highlighted in the study by Goldie et al (2000). However, the research to date in the UK indicates that the benefits of screening to survival rates are not yet fully understood (NSC UK, 2012). Clinicians reported the advantage of anal cancer screening is that disease is picked up earlier and surveillance is offered with health promotion, that offering 'preventative medicine' is important (i.e. clinicians to focus on ways to prevent disease or illness before they develop in a patient's body). Fox et al (2005), give three reasons as to why a screening program might be beneficial as reported by clinicians in my study. Firstly, patients with high grade AIN would be made aware of a potential risk of anal carcinoma and might be more likely to report an anal lump at an earlier more treatable stage; secondly, careful follow up would detect some early anal carcinomas at a treatable stage; thirdly a cohort is needed to develop effective treatments (Fox et al, 2005). Piketty et al (2003) suggests that it would be advisable to screen all HIV positive patients as there are unconfirmed reports that heterosexual male injecting drug users have a high prevalence of AIN.

My study highlights that there are no anal cancer screening programs available in the UK. Anal screening practices are different in most clinics and screening offered mainly in

London with only one tertiary referral centre offering screening and treatment for patient with multifocal disease. Patients and clinicians have alluded to the fact that preventing anal cancer by screening is cheaper or cost effective rather than treating patients who go on to develop anal cancer. Patients feel that being part of anal cancer screening means they are in charge of their health while clinicians believe patients will have peace of mindwhen a clinician is monitoring cancer risks.

5.6 Summary of Implications for Practice

The findings from my study explored the perceptions and experiences of clinicians and patients in anal cytology and high resolution anoscopy in sexual health clinics in the UK. Anal cancer screening did not have adverse effects on mental health of participants and none of the participants needed a psychologist or a referral to a mental health unit. However, the emotional responses like worry, anxiety and fear had some psychological consequences where patients did not attend for follow-up appointments for instance due to cancer worry. With worry being highlighted by participants, this was alleviated by clinicians giving patients information leaflets, web links, informing patients on patient support groups and clinicians gave information face to face during clinic appointments. Landstra et al (2012) suggested a variety of support options such as written information, staff available by phone or email, support groups or access to a psychologist or social worker. Educational campaigns will be beneficial; however, this must be accompanied by policy changes in the UK to ensure that it is cost effective and widely available to people living with HIV.

In addition, where patients were at risk of emotional distress during the anal cancer screening process, clinicians provided patients with additional support like counselling if required, especially those with worry about anal cancer. The consequences of these emotional responses in my study were minimal. Therefore, anal cancer screening can be part of patients' routine HIV outpatient care. However, further exploration is needed in women living with HIV and anal cancer screening in the UK, and the exploration of patients' perceptions and experiences on anal cancer screening in other sexual health clinics around the UK.

Whilst there is a lot of uncertainty around anal cancer screening in the absence of guidelines and what populations to include in screening, Salit et al (2015) state that there

is uncertainty about which at-risk population to include and there are differing views in the cost effectiveness of screening and screening methods. However, according to Uronis and Bendell (2007) the use of Pap smear in high risk patients may lead to an earlier diagnosis with dysplasia, whose development of anal cancer and anal cancers that do develop may be treated at an earlier stage. Patients seen in gynaecology or sexual and reproductive services in the UK with a diagnosis of CIN or at-risk patients, clinicians can advise and inform these patients on anal cancer screening as this is an opportunity to screen these patients for AIN. Patients attending these services can be given information about AIN and anal cancer screening to educate them on screening. Blankenship et al (2015) alludes to the fact that regular gynaecological encounters represent an opportunity for medical providers/clinicians to capture at-risk women and engage them in discussions about anal cancer screening.

Another important factor is the availability of clinicians that are knowledgeable and skilled in HRA, biopsies and follow up on results. The UK has very few clinicians providing anal cancer screening to people living with HIV although the study by Vera et al (2014) mention that more clinicians are looking train to undertake anoscopy and offer anal cancer screening. According to Salit et al (2015) detecting high grade anal canal is limited by the availability of experienced anoscopists as there are only 80 documented HRA clinics worldwide. The geographical spread of clinics offering anal cancer screening is mainly in the London region, therefore regional centres should be considered throughout the UK.

5.7 Limitations of My Study

Patients in my study were recruited from a small NHS healthcare Trust, and were people living with HIV, is what makes this group of people a homogenous group. This may limit the transferability of results to other individuals not living with HIV e.g. HIV negative MSM. Clinicians were only limited to 8 practising anal screening in the UK at the time of my study but more clinicians have trained since (this data is not available yet), therefore it will be important include or target those clinicians in future studies to help inform and develop a screening program to reflect a comprehensive view on anal screening.

5.8 Future Recommendations

Future studies need to explore societal stigma experienced by patients in anal cancer while the self-stigma clinicians experience in their practice is a new finding in anal cancer screening as highlighted in my study. There should be some ownership from our UK regulatory bodies like the UKNSC, BHIVA, BASH, and NICE to recognise that anal cancer, especially in high-risk groups, is increasing and it is urgent we have programs to prevent anal cancer. These bodies should consider anal cancer screening in high risk groups and indicate this in their guidelines, but also recognise there is lack of evidence and screening guidelines in the UK. They should call on clinicians and centres, as well as patients, to see how they can adopt evidence-based approach to anal cancer screening in the UK. There are many studies from Europe, US and Australia that can inform the UK on future screening, but it must also be noted that the incidence of squamous cell carcinoma of the anus is greater in patients with HIV (Uronis & Bendell, 2007). Clinicians undertaking anal cancer screening in the UK should produce data; work with cancer networks in the UK to provide robust evidence for screening and for the development of cancer screening guidelines.

5.9 Conclusions

My study is first to report qualitative data from both patients and clinicians in the UK on perceptions and experiences on anal cancer screening. Although the emotional responses have been identified and common, my study highlighted what other studies have endorsed and more in terms of the psychological effects of anal screening. My study also covered aspects of physical experiences of anal screening procedures, future screening for people living with HIV, discrepancies and differences in screening practices in sexual health clinics and only few centres offering anal screening in the UK.

My findings support previous publications in that there are no major psychological effects of anal cancer screening with the greatest emotional response being ‘worry’ on anal cancer. However other emotional responses like anxiety, fear, embarrassment, shame and stigma were highlighted without severe psychological consequences. With regards to stigma, there is the association with sexual practices and HIV and the notion that AIN is associated with sexual practices. This is societal stigma where the attachment of

association is promiscuity, unprotected sexual activity and spread of sexual infections, with the main perception that anal disease is associated with men who have sex with men. Clinicians have experienced self-stigma in their practice due to lack of experience and internalise these as negative beliefs. Patients also feel reassured that they can be part of a screening program where treatment is available, plus patients feel reassured when they were given information leaflets in AIN and anal cancer screening. As far as screening procedures are concerned, my study shows that anal screening is acceptable, but tolerability varies according to sexual practices. Patients who have receptive anal intercourse, their anal tone are relaxed therefore able to tolerate anoscope during HRA while those patients who do not have anoreceptive sex are not able to tolerate the anoscope. Some patients have experienced pain and bleeding after a biopsy is taken. Compliance to anal screening did not decrease due to discomfort. My study demonstrated patients would rather experience a few minutes of discomfort to know their diagnosis. Patients and clinicians have mentioned that anoscopy as a procedure is invasive in every sense i.e. patients must undress and expose themselves, an intimate part of the body is examined, which is the anal canal and this not a dignified procedure for patients. Anoscopy is superior to sigmoidoscopy in detecting anal canal lesions. HRA is a gold standard procedure for detecting high grade disease.

All anal cancer guidelines avoid direct recommendations regarding screening and since no guidelines are available in the UK, clinicians undertaking anal cancer screening rely on local protocols. Anal cancer screening is offered mainly in the London region, while one clinic offers anal screening in the North East of England. MDT's should consist of gynaecologists, oncology, colorectal specialist, histopathologists, cytopathologists, surgeons and administrative person. A recommendation is that cancer networks should establish an anal cancer MDT.

Patients usually self-refer to existing anal cancer screening or clinicians inform patients during their HIV outpatient appointment. Some clinics see patients from all over the UK due to limited anal cancer screening services available in the UK. Only one tertiary referral centre in London region see patients with multifocal disease. The UK needs more evidence to determine if anal cancer screening is worthwhile for prevention of anal cancers but screening people with HIV or high-risk people, i.e. HIV-negative MSM, are important, while clinical trials are in progress, in an attempt to support screening. In the UK funding is

approved by CCG's. HRA is the most cost-effective strategy in detecting High grade disease. Lastly, these findings can now inform the UKNSC on the on criterion 15 as the screening program does outweigh psychological harm caused by tests and diagnostic procedures. The screening process does not present any physical harm to any patients. My results provide a better understanding of the emotional responses during anal cancer screening process. Anal cancer screening should be accompanied by education around anal cancer, screening process and what the test results mean. Collaboration with other departments like gynaecology is important to target women with CIN and screen them for AIN. As anal cancer screening is not yet established in the UK, there is an opportunity to set up a consistent and evidence-based approach to anal cancer screening to support guidelines.

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Appendix 1: Bethesda Classification for Anal Dysplasia

Table 1: Comparison of Cytological and Histological Classification of Anal Dysplasia

Bethesda Classification (cytology)	Anal Intraepithelial Neoplasia (AIN) (histology)	WHO Terminology (cytology)
• ASC-US • ASC-H	Atypia	–
LSIL	AIN I	Mild dysplasia
HSIL	• AIN II • AIN III • CIS	• Moderate dysplasia • Severe dysplasia • Carcinoma *in situ*
Cancer	Cancer	Cancer

ASC-US, atypical squamous cells of undetermined significance; ASC-H, atypical squamous cells (HSIL cannot be excluded); LSIL, low-grade squamous intraepithelial lesion; HSIL, high-grade squamous intraepithelial lesion; AIN, anal intraepithelial neoplasia; CIS, carcinoma *in situ*

Appendix 1

Anal Cytology (Anal Pap Test)		Anal Histology (Anal Biopsy)	
Term	**Definition**	**Term**	**Definition**
■ **ASCUS***	Atypical Squamous Cells Undetermined Significance		
■ **ASCH***	Atypical Squamous Cells suspicious for HSIL		
■ **ASIL**	Atypical Squamous Intraepithelial Lesion	■ **AIN**	Anal Intraepithelial Neoplasia
□ **LSIL**	Low-grade Squamous Intraepithelial Lesion	□ AIN 1	mild dysplasia
□ **HSIL**	High-grade Squamous Intraepithelial Lesion	□ AIN 2	moderate dysplasia
		□ AIN 3	severe dysplasia/carcinoma in situ
■ **SCC**	Squamous Cell Carcinoma	■ **Invasive Anal Carcinoma**	

Appendix 2: Table of Literature Appraisal

Author, year published, Journal	Type of study	Purpose	Sample	Design	Data collection	Key Findings
Landstra et al (2012), Psycho-Oncology Journal, Australia	Quantitative	The psychological impact of anal screening cancer screening on HIV Infected men	291 HIV MSM	Prospective Longitudinal survey	Self-reporting questionnaires	There was no evidence that general anxiety, depression or quality of life was significantly affected by the process. Those who had biopsy recommended were more about anal cancer; rated their anal health worse, were less optimistic about their future health than those who did not need further investigations. The group receiving high grade histology results remained worried
Tinmouth et al, (2010), Diseases of the Colon and Rectum, Canada	Quantitative	The psychological Impact of Being Screened for Anal Cancer in HIV-Infected MSM	104 HIV MSM	Prospective Cohort Study	Questionnaires	Anal cancer is not associated with greater adverse psychological impact in most men who have sex with men. Younger patients, those with more HIV related symptoms had greater baseline psychological distress, are at risk for increased psychological distress during screening.

Table 2 Characteristics, purpose, sample, design, data collection methods and findings
MSM= men who have sex with men, HIV= Human immunosuppressive Virus, HSIL= High grade squamous epithelial neoplasia

Author, year published, Journal	Type of Study	Purpose	Sample	Design	Data Collection	Key Findings
Reed et al (2010), American Journal of Public Health, USA	Quantitative	Gay and bisexual men's willingness to receive anal Papanicolaou testing	306 (236 gay, 70 bisexual)	Cross-sectional study	National Survey	Anal cancer screening was highly acceptable to gay and bisexual men, although cost was a major barrier. Efforts to reduce anal cancer disparities should target beliefs about anal cancer and barriers to anal Papanicolaou testing in this population
Truesdale & Goldstone (2010, International Journal of Aids, USA	Quantitative	The fear factor: drivers and barriers to follow-up screening for human papillomavirus-related anal cancer in MSM	195 MSM	Cross-sectional study	Questionnaire	Positive predictors for screening compliance include an upsetting experience during the HPV diagnosis, physical symptoms driving the initial visit and HSIL. Engaging patients in a firm, salient approach may facilitate follow-up compliance

Table 2 Characteristics, purpose, sample, design, data collection methods and findings
MSM= men who have sex with men, HIV= Human immunosuppressive Virus, HSIL= High grade squamous epithelial neoplasia

Author, year published, Journal	Type of Study	Purpose	Sample	Design	Data Collection	Key Findings
D' Souza et al (2008), USA	Quantitative	Anal cancer screening behaviours and intention of men who have sex with men	901 HIV infected men 1016 HIV uninfected men	Cross-sectional Analysis	Interview-administered and audio computer assisted self-interview	This study demonstrates a low rate of anal cancer screening and intention to screen among MSM. There are higher rates in HIV patients; in locations where perceived availability of screening was greater. MSM rely on primary care physicians for anal health care. Training and information needs to be targeted to this group
Pitts et al (2007), Journal of Sexually Transmitted diseases, USA	Quantitative	What do gay men know about human papilloma virus? Australian gay men's knowledge and experience of anal cancer screening and human papilloma virus	384 MSM	Cross-sectional study	Questionnaire	The test for anal dysplasia is still largely unknown among Australian gay men and they currently have poor sense of personal susceptibility to the disease. Health education strategies are suggested to improve this situation

Table 2 Characteristics, purpose, sample, design, data collection methods and findings
MSM= men who have sex with men, HIV= Human immunosuppressive Virus, HSIL= High grade squamous epithelial neoplasia

Author, year published, Journal	Type of Study	Purpose	Sample	Design	Data Collection	Key Findings
Ferris et al (2013), Journal of Lower Genital Tract Diseases, USA	Quantitative	Women's Knowledge and Attitudes Toward Anal Pap Testing	370 women	Pre-intervention Survey	Questionnaire	Although most women had limited knowledge about anal cancer and anal Pap tests and few recognized known risk factors for anal cancer, women were receptive to screening. Further implementation of anal Pap testing for women may be improved by understanding women's limited knowledge
Blakenship et al, (2015), Journal of Lower Genital Tract Disease, USA	Quantitative	Knowledge and Acceptability of Anal Cytology among Women	400 women	Survey	Questionnaire	Medical providers should improve counselling about anal cytology screening among at-risk women, to familiarise then with the procedure, describe its role in detecting AIN, and address expectations around pain to increase it acceptability

Table 2 Characteristics, purpose, sample, design, data collection methods and findings
MSM= men who have sex with men, HIV= Human immunosuppressive Virus, HSIL= High grade squamous epithelial neoplasia

Author, year published, Journal	Type of Study	Purpose	Sample	Design	Data Collection	Key Findings
Koskan et al, (2016), Journal of the Moffit Cancer Centre, USA	Qualitative	Exploring the Perceptions of Anal Cancer Screening and Behaviours Among Gay and Bisexual Men Infected with HIV	58 MSM infected with HIV	open-ended questions	In-depth Interviews	Future intervention work to focus on ensuring that health care professionals, among HIV/primary care specialists, promote screening for anal dysplasia. Intervention methods use a community-based approach to raise awareness about the need to screen MSM for anal cancer, infected with HIV
Botes et al, 2011, Sexual Health, Australia	Quantitative	Participants perspectives on self-collected anal cytology swabs	291 MSM HIV positive	Cross sectional study	Questionnaire	Evaluation of self-collected anal swabs for screening. 53% rated the swab easy to collect and 81% reported as highly acceptable

Table 2 Characteristics, purpose, sample, design, data collection methods and findings
MSM= men who have sex with men, HIV= Human immunosuppressive Virus, HSIL= High grade squamous epithelial neoplasia

Author, year published, Journal	Type of study	Purpose	Sample	Design	Data collection	Key Findings
Hillman et al, 2011, Sexual Health, Australia	Quantitative	Participants' perspective of high resolution anoscopy	105 HIV positive MSM	Evaluation	Questionnaire	This study suggests that most participants found HRA acceptable with a few complications. However, acceptability was strongly correlated with pain and bleeding during and after the procedure. Participants also indicated the value of effective communication before and after the procedure. This study demonstrated that HRA is an acceptable procedure but new methods to improve participant experience are required.

Table 2 Characteristics, purpose, sample, design, data collection methods and findings
MSM= men who have sex with men, HIV= Human immunosuppressive Virus, HSIL= High grade squamous epithelial neoplasia

Author, year published, Journal	Type of study	Purpose	Sample	Design	Data collection	Key Findings
Joshua et al, 2015, Journal of Lower Genital Tract Disease, USA	Quantitative	Gay and Bisexual Men's Willingness to Use a Self-Collected Anal Cancer Screening Test	Sample 1: 306 Sample 2: 428	Cross-sectional study	Survey	Majority of gay and bisexual men were willing to self-administer an anal cancer screening test at home. If anal pap tests are shown to be an effective means of reducing incidence and mortality from invasive anal cancer, allowing men the option of home testing could improve screening uptake. This study identified 3npotentially modifiable factors associated with willingness to use self-test and potential concerns men have with using a self-test that could be targeted in future public health campaigns to increase screening rates

Table 2 Characteristics, purpose, sample, design, data collection methods and findings
MSM= men who have sex with men, HIV= Human immunosuppressive Virus, HSIL= High grade squamous epithelial neoplasia

Author, year published, Journal	Type of study	Purpose	Sample	Design	Data collection	Key Findings
Moores et al, 2015, The Canadian Journal of Human Sexuality, Canada	Quantitative	Anal cancer screening, attitudes, and experiences among men who have sex with men in Ottawa, Ontario	280 MSM	Cross-sectional study	Survey	This study indicates that a substantial percentage of MSM are not aware of their increase anal cancer risk nor of options for screening and prevention. Further research to explore these knowledge gaps and determine the best way to increase awareness among MSM. This study also highlights the need for more discussion between MSM and their primate care physicians to ensure MSM are aware of their risk and of available screening and prevention options recognising the limited evidence base for anal cancer screening.

Table 2 Characteristics, purpose, sample, design, data collection methods and findings
MSM= men who have sex with men, HIV= Human immunosuppressive Virus, HSIL= High grade squamous epithelial neoplasia

Author, year published, Journal	Type of study	Purpose	Sample	Design	Data collection	Key Findings
Davis et al, 2013 Journal of Lower Genital Tract Disease, USA	Quantitative	Tolerability of Anal Dysplasia Screening	296 MSM (45% HIV MSM, 37% undergoing first time screening	Prospective Study	Questionnaire	Screening procedures for anal HPV related disease were well tolerated, and no single procedure or HPV sampling device reduced patient Compliance
Fenkl et al, 2015, Journal of the Association of Nurses in Aids Care, USA	Quantitative	Evaluation of an HPV/Anal Cancer Screening Awareness program for HIV-Infected Men Who Have Sex with Men	94 HIV-infected MSM	Evaluation	Questionnaire	The most prevalent of all STI's is HPV an under investigated precursor of anal cancer in men. This evaluation program was important step in developing a comprehensive education and awareness program targeted to HIV infected MSM. Members of the healthcare team play a vital role in the dissemination of research to support initiatives aimed at HPV, anal cancer awareness and the need for anal cancer screening for all MSM particularly the HIV-Infected MSM

Table 2 Characteristics, purpose, sample, design, data collection methods and findings
MSM= men who have sex with men, HIV= Human immunosuppressive Virus, HSIL= High grade squamous epithelial neoplasia

Author, year published, Journal	Type of study	Purpose	Sample	Design	Data collection	Key Findings
Kaufman et al, 2015), Sexual Health, Canada	Quantitative	Acceptability of anal cancer screening in women living with HIV: results from the EVVA study	150 Women Living with HIV	Cohort study	Questionnaire	Most participating WLHIV considered screening necessary and very acceptable. Pain management can be improved and potential adverse psychological effects of screening should be explored.
Debnath, et al (2105), Sexual Health, USA	Quantitative	Pain, discomfort, and embarrassment during high-resolution anoscopy among women: a potential barrier to care?	55 HIV positive Women Providers at Urban Medical Centre	Survey	Questionnaire	This study demonstrated that patients anticipated greater pain and discomfort than was actually experienced. In contrast, providers anticipated that patients would experience less pain than reported. Consequently, providers need to enhance patient education and address patient concerns regarding anticipated pain and discomfort associated with the HRA procedure.

Table 2 Characteristics, purpose, sample, design, data collection methods and findings
MSM= men who have sex with men, HIV= Human immunosuppressive Virus, HSIL= High grade squamous epithelial neoplasia, Papanicolaou=Pap, WLHIV-Women living with HIV

Author, year published, Journal	Type of study	Purpose	Sample	Design	Data collection	Key Findings
Sowah et al, 2015, Journal of the International Association of Providers of Aids Care, USA	Quantitative	Anal Cancer Screening in an Urban HIV Clinic: Provider Perceptions and Practice	26 Providers in an academic outpatient HIV practice	Survey	Questionnaire	This study was to determine the acceptability and perceptions of providers on anal Papanicolaou tests where one third of the providers received screening requests from patients. Female providers had higher levels self-rated comfort with anal Pap tests compared to male providers. This survey revealed that not all providers are comfortable with performing anal cancer screening for their patients.
Scott et al, 2008, American Journal of Sexually Transmitted Diseases, USA	Quantitative	Routine Anal Cytology Screening for Anal Squamous Intraepithelial Lesions in an Urban HIV clinic	6 providers at HIV clinic	Evaluation	Chart Review	This study demonstrates that providers are able to incorporate anal screening as part of routine HIV care in an urban clinic with diverse HIV risk factors. Screening is a feasible tool regardless of gender and HIV risk factors

Table 2 Characteristics, purpose, sample, design, data collection methods and findings
MSM= men who have sex with men, HIV= Human immunosuppressive Virus, HSIL= High grade squamous epithelial neoplasia, Papanicolaou=Pap

Author, year published, Journal	Type of study	Purpose	Sample	Design	Data collection	Key Findings
Ong et al, 2015, BioMed Central Public Health, Australia	Qualitative	Why are we not screening for anal cancer routinely-HIV physicians' perspectives on anal cancer and its screening in HIV-positive men who have sex with men: A qualitative study	20 HIV physicians	Semi structured interviews	In-depth telephone interviews	The best method for anal cancer screening is an area of uncertainty for the Australians HIV physicians. Most of the physicians interviewed were not participating in anal cancer screening therefore influenced the tone of the study and multiple barriers were identified. While HIV physicians remain ambivalent regarding the most effective way to screen for anal cancer, more research is needed to address the physicians concern before anal screening can be implemented into routine HIV care.

Table 2 Characteristics, purpose, sample, design, data collection methods and findings
MSM= men who have sex with men, HIV= Human immunosuppressive Virus, HSIL= High grade squamous epithelial neoplasia, Papanicolaou=Pap

Author, year published, Journal	Type of study	Purpose	Sample	Design	Data collection	Key Findings
Ortiz et al, 2013, Puerto Rico Health Sciences Journal, Puerto Rico	Quantitative	Recognising and Treating Anal cancer: Training Medical Students and Physicians in Puerto Rico	34 medical students and physicians	Survey	Educational activity of demographic survey and a pre and post-test on anal cancer	The educational activity increased participants' knowledge of and cancer, most of the participants were interested in future and in collaborating in a clinical trial. This study evidences the lack of knowledge among medical students, residents and faculty members and the need for training in anal cancer. Most participants did not know that are national screening guidelines for anal cancer
Patel et al, 2014, Cancer Medicine	Quantitative	Environmental scan of anal cancer screening practices: Worldwide survey results	82 providers from 80 Clinics who were health care professionals	Survey	Online Survey via fax or email	This study has demonstrated considerable variation in anal cancer screening practice. There is no universal consensus on optimal strategies for anal cancer screening, treatment and follow up

Table 2 Characteristics, purpose, sample, design, data collection methods and findings
MSM= men who have sex with men, HIV= Human immunosuppressive Virus, HSIL= High grade squamous epithelial neoplasia, Papanicolaou=Pap

Author, year published, Journal	Type of study	Purpose	Sample	Design	Data collection	Key Findings
Kwong et al, 2011, Aids Patient Care	Quantitative	Improving Anal Cancer Screening in Ambulatory HIV Clinic's Experience from a Quality Improvement Initiative	62 HIV patients Providers: 89% clinicians in the Infectious Disease Group Practice	Survey	Patients completed voluntary self-administered questionnaire Providers completed anonymous on-line survey	However, the dedicated program addressed one of the perceived barriers to screening, which was an infrastructure for treating patients found to have abnormal cytology or physical exam findings. By addressing a major clinician-perceived organizational barrier, the anal health program provided more opportunities for clinicians to discuss anal cancer screening, perform their own exams, and/or refer patients for a focused examination. This combination of factors resulted in an overall increase in the number of patients screened in the clinic.

Table 2 Characteristics, purpose, sample, design, data collection methods and findings

MSM= men who have sex with men, HIV= Human immunosuppressive Virus, HSIL= High grade squamous epithelial neoplasia, Papanicolaou=Pap

Author, year published, Journal	Type of study	Purpose	Sample	Design	Data collection	Key Findings
Colon-Lopez et al, 2016, Puerto Rico Health Sciences Journal, Puerto Rico	Quantitative	Measuring Knowledge of Cancer Screening and Prevention Strategies in HIV Healthcare Professionals	104 Healthcare Professionals	Cross-Sectional Analysis	Face to face interviews, telephone interviews, administered a survey	For anal cancer in particular, as the number of years a given participant had been working with people living with HIV/AIDS increased, the likelihood that this participant would have extensive knowledge of anal cancer screening significantly increased (10% year). Health education interventions, tailored to healthcare professionals who recently finished their formal education should be developed in HPV-related cancers. Such training would improve cancer prevention and control efforts, thereby benefitting the HIV population in Puerto Rico.

Table 2 Characteristics, purpose, sample, design, data collection methods and findings

MSM= men who have sex with men, HIV= Human immunosuppressive Virus, HSIL= High grade squamous epithelial neoplasia, Papanicolaou=Pap

Author, year published, Journal	Type of study	Purpose	Sample	Design	Data collection	Key Findings
Vera et al, 2013, HIV Medicine, United Kingdom	Quantitative	Anal cancer screening in the United Kingdom: A national survey on the perception and practices among sexual health clinics	116 sexual health clinics from England, Wales, Scotland and Northern Ireland	Web based Survey	Questionnaire	Awareness of risk factors and screening methods for HPV associated anal cancer among a sample of Sexual Health clinics in the UK is high. Only a minority of Sexual Health Clinics are offering anal cancer screening at present despite the increasing risk of HPV associated anal cancer in high risk groups such as those with HIV infection. Although more clinics are planning to offer anal screening in the future
Blankenship et al, 2015, Sexual Health, USA	Quantitative	Medical students' perception of the acceptability of anal cytology screening among women	308 Medical students	Survey	Questionnaire	Future medical providers must improve their understanding of HPV and women's expectations regarding anal cytology screening to effectively educate patients and increase acceptance of anal cytology screening

Table 2 Characteristics, purpose, sample, design, data collection methods and findings

MSM= men who have sex with men, HIV= Human immunosuppressive Virus, HSIL= High grade squamous epithelial neoplasia, Papanicolaou=Pap

Appendix 3: NRES

Content removed on data protection grounds

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Evidence of insurance or indemnity - Zurich Municipal		19 September 2013
Investigator CV - Mrs Anosha Ramsammy	11	03 March 2014
Letter from Sponsor - Bucks New University		26 February 2014
Other: Academic Supervisor CV: Dr. Gulen Addis	10	03 March 2014
Other: Academic Supervisor CV: Keiran Henderson	13	03 March 2014
Other: Supervision Record	12	03 March 2014
Other: Draft Project Plan	8	03 March 2014
Other: Changes to previous REC Application	9	03 March 2014
Other: NRESCommittee London-Harrow Unfavourable Opinion Letter (13/LO/1550)		18 October 2013
Participant Consent Form: Clinician consent	4.1	15 April 2014
Participant Consent Form: Patient consent	5.1	15 April 2014
Participant Information Sheet: information sheet for patients	3.1	15 April 2014
Participant Information Sheet: Information sheet for clinicians	2.1	15 April 2014
Protocol	1.1	15 April 2014
Questionnaire: Guiding Questions for Patients	6	03 March 2014
Questionnaire: Guiding Questions for Clinicians	7	03 March 2014
REC application	143859/574621/1/23	05 March 2014
Response to Request for Further Information		15 April 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

14/LO/0488	**Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely
pp

Dr John Keen
Chair

Email:NRESCommittee.London-Brent@nhs.net

Enclosures: "After ethical review – guidance for researchers" *SL-AR2*

Copy to: *David Sines, Buckinghamshire New University*
Mr Simon Lewis, Ealing Hospital NHS Trust

Appendix 4: Information Sheet for Patients

To explore the perceptions and experiences of patients and clinicians in anal cytology screening and High Resolution Anoscopy

- **Invitation**

You are being invited to take part in the research project of Anal screening in your sexual health clinic. Before you decide it is important for you to understand why the research is being done and what it would involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

- **What is the purpose of the study?**

  The study aims to explore the perceptions and experiences of patients who had anal cytology screening and high resolution anoscopy at your HIV outpatient clinic, which could inform clinical practice and guidelines for anal screening in the UK. It can also assist in the development of more effective practice to all sexual clinics in the UK.

- **What will happen to me if I take part?**

  You will be asked to participate in a tape-recorded interview. This is a one-to-one face-to-face interview in an environment in which you should feel comfortable without any disturbances. The interview will be at the outpatient clinic interviewing room. The interviews would last at least 60-90 minutes. We will maintain confidentiality and anonymity

throughout the interview without mentioning names and disclosing your person. You will be shown the transcribed data once completed for your viewing.

- **What are the advantages and risks of taking part in this study?**

  The benefits of this research are to explore your perceptions and experiences in anal screening and high resolution anoscopy in the UK which could inform clinical practice. If you become distressed at any point a clinical psychologist has agreed to see you at any point during the research process. Details provided below in the Contact details.

- **Do I have to take part?**

  It is up to you to decide whether or not to take part. If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

- **What will happen to the results of the study?**

  The results of the study will be used to provide an insight into anal screening. It can also assist in the development of more effective practice and inform national, local guidelines as well as protocols for sexual clinics in the UK. Currently this study is for a Professional Doctorate and the investigator may consider this study for publication at a later date or presented at a scientific conference.

- **Will the identity part of this study be confidential?**

  Your identity as a participant will be protected in all communications and activities during research. Anonymity as participants will be protected by giving each participant a code number.

- **Who is organising the study?**

  The researcher is organising the research study in conjunction with the learning institution, the employing trust and the supervisors. There are not costs involved and no rewards offered.

- **Who has reviewed this study?**

  This study has been reviewed by the National Research and Ethics Service. Management permission has sought from the Trust and relevant approval received from the NHS Trust

- **Contact for further information**

  If you would like any further information, please contact any one of the lead research Co-ordinators listed below:

Content removed on data protection grounds

Appendix 5 Information Sheet for Clinicians

To explore the perceptions and experiences of patients and clinicians in anal cytology screening and High Resolution Anoscopy.

- **Invitation**

You are being invited to take part in the research project of Anal screening in your sexual health clinic. Before you decide it is important for you to understand why the research is being done and what it would involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

- **What is the purpose of the study?**

  The study aims to explore the perceptions' and experiences of clinicians undertaking anal cytology screening and high resolution anoscopy in sexual health clinics in the UK, experiences which could inform clinical practice and guidelines for anal screening and high resolution anoscopy in the UK. It can also assist in the development of more effective practice to all sexual clinics in the UK.

- **What is involved in participating?**

  You will be asked to participate in a tape-recorded interview. This is a one-to-one face-to-face interview in an environment in which you should feel comfortable without any disturbances. The interview can be your own choice like your office or the conference room at your

institution. The interviews would last at least 60-90 minutes. We will maintain confidentiality and anonymity throughout the interview without mentioning names and disclosing your person. You will be shown the transcribed data once completed for your viewing.

- **What are the possible advantages and risks of taking part?**

  The benefits of this research are to explore your perceptions' and experiences of anal screening which could help inform clinical practice. If you become distressed at any point a clinical psychologist has agreed to see you at any point during the research process. Details provided below in the Contact details.

- **Do I have to take part?**

  It is up to you to decide whether or not to take part. If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

- **What will happen to the results of the study?**

  The results of the study will be used to provide an insight into anal screening in the UK. Currently this study is for a Professional Doctorate and the investigator may consider this study for publication at a later date or presented at a scientific conference.

- **Will my taking part in the study be confidential?**

  Your identity as a participant will be protected in all communications and activities during research. Anonymity as participants will be protected by giving each participant a code number. All taped interviews will be coded respectively and locked safely. Transcripts of data will be entered in the computer with code numbers for identification.

- **Who is organising this study?**

  The researcher is organising the research study in conjunction with the learning institution, the employing trust and the supervisors. There are not costs involved and no rewards offered.

- **Who has reviewed this study?**
  This study has been reviewed by the National Research and Ethics Service. Management permission has sought from the Trust and relevant approval received from the NHS Trust

- **Contact for further information**

  If you would like any further information, please contact any one of the lead research Co-ordinators listed below:

Content removed on data protection grounds

Appendix 6: Clinical Psychologist

Content removed on data protection grounds

Appendix 7: Patient Consent Form

To explore the perceptions and experiences of patients and clinicians in anal cytology screening and High Resolution Anoscopy

Please tick the appropriate boxes

I have read and understood the project information sheet
……. ☐

I have been given the opportunity to ask questions about the project
……. ☐

I agree to take part in the project. This is a questionnaire which is confidential and anonymous
……. ☐

I understand that my taking part is voluntary; I can withdraw from the study at any time and I will not be asked questions about why I no longer want to take part
……. ☐

I understand my personal details such as phone number or address will not be revealed to people outside of this project
……. ☐

I understand that my words may be quoted in publications, reports, web pages, and other research outputs but my name will not be used unless I requested it above
……. ☐

I agree this study forms part a Professional Doctorate study and all interviews will be kept in a locked drawer and stored onto a data base which is secure, and passcode locked at the institution where the researcher is employed. All questionnaires and computer data will be in line with Data Protection.

…… ☐

I understand that other researchers may use my words in publications, reports, web pages and other research

…… ☐

I agree to assign the copyright I hold in any materials related to this project to Anosha Ramsammy (Principal Researcher)

…… ☐

On this basis I am happy to participate in the study for the Professional Doctorate study

Name of Participant ……

Signature…… Date…….

Name of Researcher……...

Signature…… Date…….

One copy to be kept by the participant, one to be kept by the researcher

Appendix 8: Clinician Consent Form

To explore the perceptions and experiences of patients and clinicians in anal cytology screening and High Resolution Anoscopy

Please tick the appropriate boxes

I have read and understood the project information sheet
……. ☐

I have been given the opportunity to ask questions about the project
…… ☐

I agree to take part in the project. Taking part in the project will include an audio tape interview lasting between 60-90 minutes
…… ☐

I understand that my taking part is voluntary; I can withdraw from the study at any time and I will not be asked questions about why I no longer want to take part
…… ☐

I understand my personal details such as phone number or address will not be revealed to people outside of this project
…… ☐

I understand that my words may be quoted in publications, reports, web pages, and other research outputs but my name will not be used unless I requested it above

…… ☐

I agree this study forms part a Professional Doctorate study and all interviews will be audio taped and kept in a locked drawer at the institution where the researcher is employed. All transcripts will be transcribed by the researcher and stored on the computer with codes and keeping in line with Data Protection

…… ☐

I understand that other researchers may use my words in publications, reports, web pages and other research

…… ☐

I agree to assign the copyright I hold in any materials related to this project to Anosha Ramsammy (Principal Researcher)

…… ☐

On this basis I am happy to participate in the study for the Professional Doctorate study

Name of Participant ……

Signature…… Date…….

Name of Researcher……...

Signature…… Date…….

One copy to be kept by the participant, one to be kept by the researcher

Appendix 9: Peer Review

Content removed on data protection grounds

Appendix 10: Patient Trigger Questions

Examples of guiding questions that may be used for the unstructured interview with Patients:

1. Tell me about your experience of anal cytology screening and high resolution anoscopy in your clinic?
2. Tell me about information you were given on anal screening in your clinic?
3. How did you feel when your doctor or nurse offered anal screening?

Appendix 11: Clinician Trigger Questions

Examples of guiding questions that may be used for the unstructured interview with clinicians:

1. Tell me about your current experience of anal cytology screening and high resolution anoscopy in your clinic?

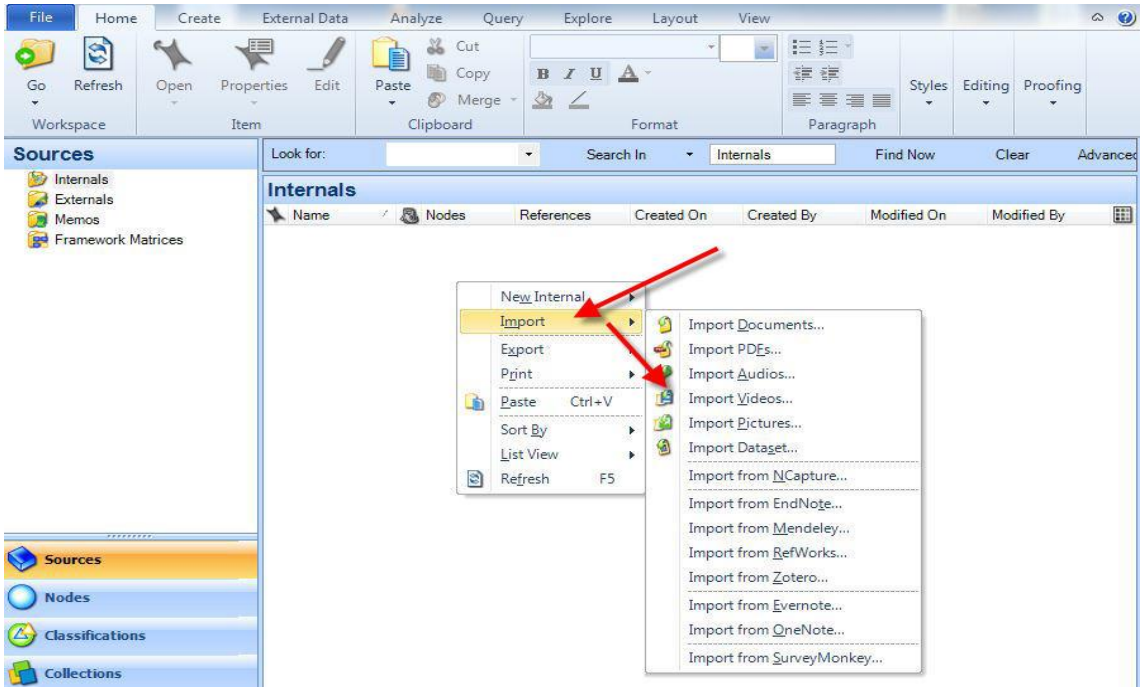
2. What are the advantages and disadvantages of offering this service in your clinic?

3. Explain the training you had to undertake anal screening?

4. How do feel about extending this role to other clinicians, e.g. nurses?

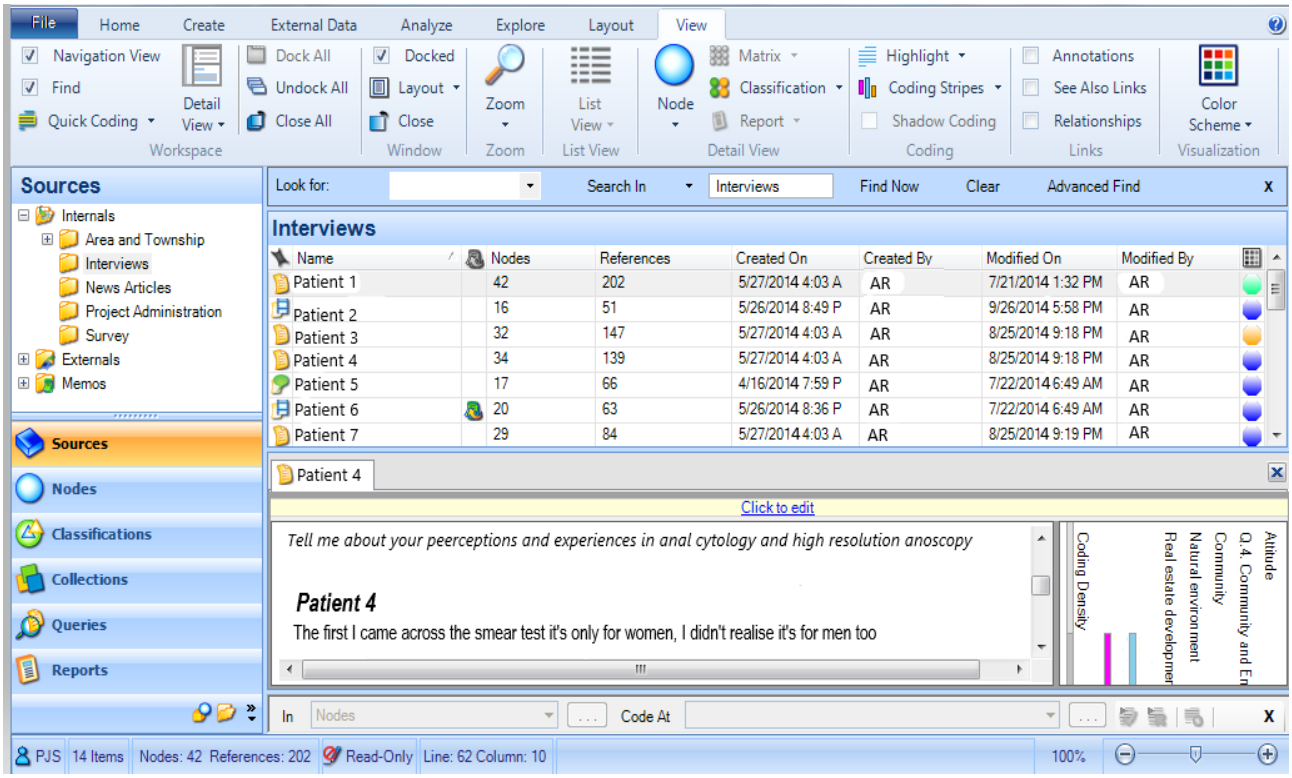
5. How do you feel about the information available on anal screening?

Appendix 12: Screenshot of Nvivo



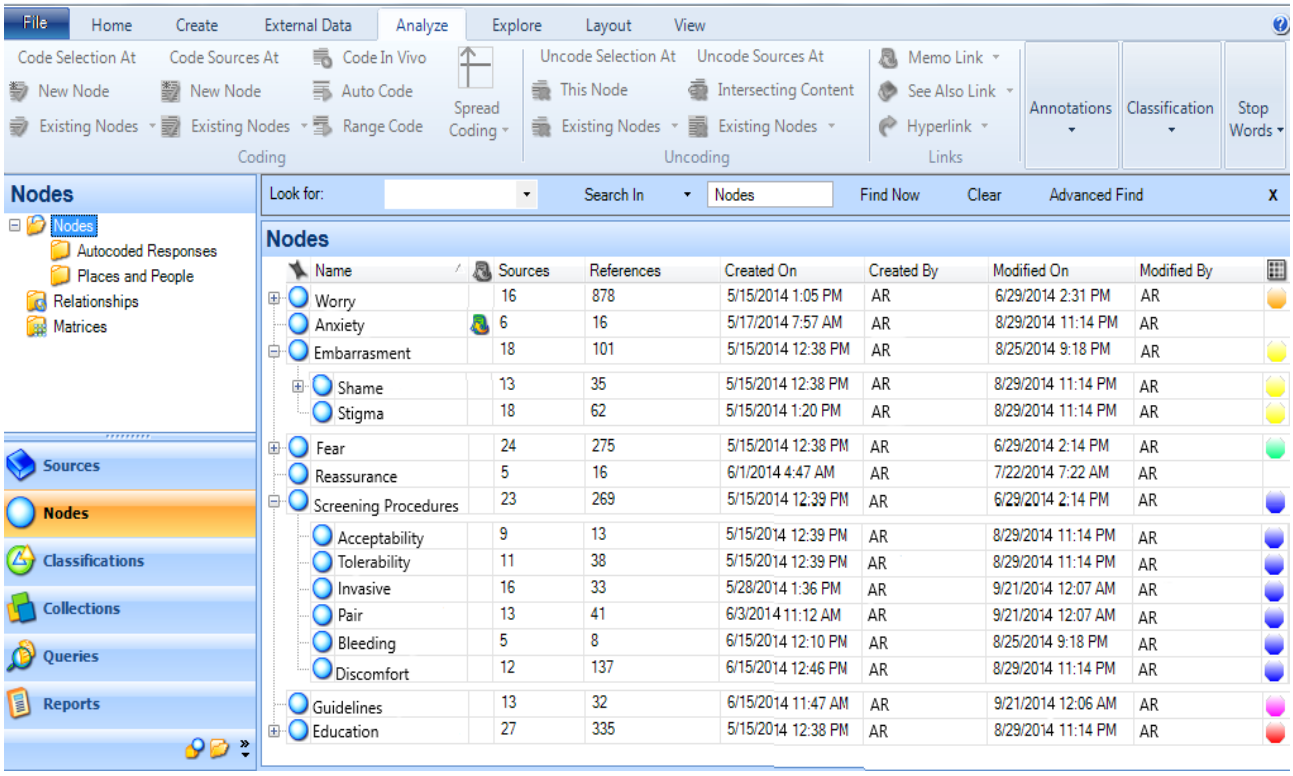
Appendix 13: Screen shot of How I imported transcripts from word to Nvivo (v.9). Importing Documents to Nvivo see red arrows with options to choose where documents are saved on your computer

Appendix 13: Screenshots of Interview Scripts



Appendix 14: Screenshot example of interview transcripts uploaded onto Nvivo (v.9)

Appendix 14: Nodes/Codes



Appendix 15: Nodes the term used by NVivo (v.9) to represent a code, theme, or idea. The data in my study is referred to as codes but stored under nodes in Nvivo program.

Appendix 15: Patient Information Leaflet

ANOSCOPY CLINIC

Information for patients

WHAT CAN YOU EXPECT TO HAPPEN AT THE ANOSCOPY CLINIC?

The main aim of the 'Anoscopy clinic' is to monitor anal dysplasia (see next page).

A doctor/Nurse will perform the anoscopy
You will be asked to lie on your left side and an anal smear test will be taken at the start of the procedure. It is important that your anus is clean for this. Please avoid very vigorous or repeated washing before the procedure.

Anaesthetic gel will be applied and then a small telescope (proctoscope) will be inserted into the anus to enable the lining to be examined with a magnifying microscope.

The surface of the anal canal may be gently examined to feel for any lumps.

If any abnormalities are seen, then a tiny piece of tissue will be removed for analysis (biopsy). This is not painful but may cause temporary mild discomfort.

The doctor will discuss what treatment and follow up (if any) that you may require.

WHAT IS ANAL DYSPLASIA OR AIN?

Anal dysplasia (AIN) is a slight thickening of the lining of the anus which is usually only detected by taking an anal smear test or from a tiny tissue sample (biopsy) using magnified vision (anoscopy).

Anal dysplasia is caused by a long-standing infection with a virus called 'Human Papilloma Virus' or 'HPV'.

There are **two** 'grades' of AIN.

The first type is known as **low grade AIN.** It is extremely common, especially in people with HIV infection and is often associated with anal warts. The association between low grade AIN and anal cancer is weak and so it can therefore be monitored safely with yearly anal smear tests.

The second type is known **as high grade AIN.** It carries a small risk of developing into anal cancer. For this reason, it is advisable that the condition is carefully monitored.

If you have AIN, whether it is low grade or high grade, you are encouraged to practise regular self-examination of the anus with a finger. Your doctor or specialist nurse can instruct you how to do this.