MASTER OF SCIENCE BY RESEARCH

What are the attitudes and perceptions of Doctors to the informed consent process for patients receiving a Percutaneous Endoscopic Gastrostomy (PEG) following a Cerebral Vascular Accident (CVA)?

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By

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Summary

Patients post CVA can often suffer with dysphagia which means that they cannot take diet and fluids orally. These patients may require feed to be provided to them through a percutaneous endoscopic gastrostomy (PEG), in order for this procedure to be completed, doctors must first gain consent from the patient prior to the procedure taking place. In the UK it would appear that there is very little research into the perceptions of doctors around PEG consent post CVA and so I as the researcher identified that research was required to identify the perceptions of doctors around PEG consent post CVA.

This research aims to explore the experiences of gastroenterologists and gerontologists (with experience of CVA) into PEG consent post CVA. A qualitative hermeneutical phenomenological was used in this research. Ten doctors of varied levels of experience were interviewed using unstructured interviews to collect data, each interview was then transcribed and analysed using thematic analysis. Ethical clearance was provided prior to the commencement of the research.

The key findings of the research were displayed in four main themes. The first theme 'task VS process' identified that PEG consent post CVA is a process with several processes rather than a single task or piece of documentation. These processes include consideration of both the needs of the patient and the physical assessment of the patient prior to procedure. Theme two, 'collaborative working' considered the importance of a multidisciplinary approach to PEG consent to ensure specialist assessments and in-depth information was provided to patient, to ensure PEG placement was in their best interests. Theme three 'process of interaction'. In particular the need to ascertain the capacity of the patient as part of the consent process was identified as essential and the difficulties in communicating with both

patients following a CVA and their families about PEG was discussed by the doctors interviewed. Finally, theme four ‘preparation to consent’ outlined that some junior doctors felt afraid to consent patients for a PEG post CVA due to lack of knowledge. Doctors interviewed outlined that they had received little or nil education around PEG consent or clinical nutrition and felt more education from nutrition teams was required.

This research has identified that PEG consent post CVA is in fact a process which requires a multidisciplinary approach to ensure PEG is in the best interests of the patient. Junior doctors require training on how to consent for PEG and clinical nutrition as a whole in order to improve the outcome for the patient.

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Contents

1.0 Introduction 9
2.0 Literature Review 12
2.1 Review of the current National Guidelines 12
2.2 Consent and Autonomy 14
2.3 Review of the research part one. 15
2.4 Review of the research part two 24
3.0 Methodology Introduction 31
3.1 Specific Methodology 32
3.2 Sample 33
3.3 Participant recruitment 34
3.4 Methods 36
3.5 Setting the scene 37
3.6 Interview 38
3.7 Data analysis 40
4.0 Rigour 43
5.0 Ethics 45
6.0 Pilot 49
6.1 Rationale for Pilot 49
6.2 Setting the scene 50
6.3 Participant feedback 51
6.4 Researcher considerations 52
7.0 Results 54
7.1 Theme one ‘Process VS Task’ 55
7.2 Theme two ‘collaborative working’ 66
7.3 Theme three ‘the process of interaction’ 72
7.4 Theme 4 ‘Preparation to Consent’ 83
8.0 Discussion 94
8.1 Participant and other Considerations 94
8.2 Researcher Reflexivity 96
8.3 Discussion around Themes 98
9.0 Conclusion 109
9.1 Dissemination of Findings 109

10.0 References 112
11.0 Appendices 121
11.1 Appendix A 121
11.2 Appendix B 122
11.3 Appendix C 123
11.4 Appendix D 124
11.5 Appendix E 126
11.6 Appendix F 127
11.7 Appendix G 128
11.8 Appendix H 132
11.9 Appendix I 134
11.10 Appendix J 135
11.11 Appendix K 137
11.12 Appendix L 139
11.13 Appendix M 140
11.14 Appendix N 142

1.0 Introduction

The Stroke Association (2012) identify that a stroke (cerebral vascular accident (CVA) can cause swallowing problems in up to forty percent of stroke survivors. This is also discussed from older reports which talk of as many as 40% of patients following a CVA suffering dysphagia (Lagden et al 2007). The Stroke Association (2012) suggest that if the swallow does not improve then a Percutaneous Endoscopic Gastrostomy (PEG) may be required. For patients this is not only a minor operation but an event which will change their lives significantly, they may no longer be able to eat and drink and may be discharged to an environment other than their own home. Pennington (2002) discusses that PEG is not only a procedure, but a major ethical decision for both the medical teams and patients and should not be taken lightly. This would indicate the consent process for this procedure is often not a simple one.

Consent for a procedure is a legal requirement and there should be a framework within hospital trusts on how to complete this. The Department of Health (DOH) (2009) reference guide to consent outlines the method in which consenting for a procedure should be completed for both patients who have and do not have capacity. The DOH provide a guide, but no direct stipulation for individual procedures, which can be cause difficulties for doctors, and experience is required in the speciality of medicine in which the procedure is taking place, in order to consent. VanRosendaal et al (1999) state that consent may not always be fully informed as often information given to decision makers can be limited and incorrect, this could be due to the lack of knowledge.

The reason for undertaking this research is that as a nutrition nurse specialist, I regularly found that doctors had refused to consent patients for PEG with little reason as to why. I was aware of both national and local guidance for consent so wanted to find more information as to how this problem could be resolved. As a result of doctors

refusing to consent, patients often had procedures cancelled and significantly delayed, this often affected the patients discharge and increased anxiety. As a result of this, a research study was commenced into the attitudes and perceptions of doctors to the informed consent process for patients receiving a Percutaneous Endoscopic Gastrostomy (PEG). As the researcher I also recognised the patients that often required a PEG were those who had a suffered a neurological trauma or disorder as discussed by NICE (2008). For this reason the research set about to concentrate on patients who had suffered a CVA, a literature review was then undertaken.

As a Nutrition Nurse specialist with years of experience, I felt that I already had prior assumptions as to what the attitudes and perceptions of the doctors were around PEG consent post CVA. As part of this research I felt it was important to acknowledge these assumptions to allow transparency of the research. The following statements will outline these assumptions:

- The doctors would perceive a PEG placement as just a procedure and not something that would affect patients long term.
- The doctors would have had some training into PEG placement, consent and capacity in both undergraduate and post graduate training. I did not however think this training was adequate as several doctors had stated they did not feel comfortable in completing PEG consent.
- Doctors would accept training around PEG consent from a nurse if it was required.

The results of this research as described later in the text did not reflect my initial assumptions which was of great surprise to me. The results implied that doctors did not perceive PEG insertion as just a procedure and recognised they had little training in

PEG consent. The Doctors also requested nurse training which was an unexpected comment.

2.0 Literature Review

This review will discuss several areas of the literature around the perceptions of medical teams into consent for PEG for patients post CVA. This will include a review of what the current national guidelines (appendix C) say about the subject being researched. Literature relating directly to the topic will then be considered and gaps in the knowledge base outlined. A second part of the review will then discuss literature that relates to certain aspects of the research topic like consent. Finally the structure and process of consent will be identified.

2.1 Review of the current National Guidelines

The National Institute of Clinical Excellence stroke guidelines (NICE 2008) discuss that when symptoms of dysphagia persist a Nasogastric (NG) feeding tube should be placed to provide nutrition and medications. The guidelines go on to say that if a NG tube is not tolerated in stroke patients or contraindicated then a PEG should be placed. ChrLo¨sera et al (2005) define a PEG as an endoscopicaly placed feeding tube which goes through the abdominal wall into the stomach. Mekhail et al (2001) discuss that a PEG can be more comfortable than a NG tube, and is more socially acceptable because it cannot be easily seen. It is also outlined that the risk of aspiration pneumonia may be less in PEG than in an NG. The NICE (2006) guidelines for nutrition outline that if a NG tube is required for two to four weeks then a PEG should be considered as a long term route for nutrition. As a consequence of dysphagia many patients will have a PEG inserted in the weeks following their cerebrovascular accident (CVA). NICE (2008) recognise that being placed nil by mouth as a result of dysphagia can have a large psychological impact on patients. Therefore, it is important that, when a patient does not have capacity, the decision on how to provide nutrition in dysphagic stroke patients is comprehensive.

The European Society of Clinical Nutrition and Metabolism (ESPEN) provide guidance of artificial feeding in Europe and therefore impacts upon the practice in the UK. ESPEN (2005) discuss that dysphagic states (such as things like a stroke) are the most commonly established indication for patients requiring artificial enteral nutrition such as PEG. PEG has been found to be extremely effective in stroke patients with dysphagia and PEG can removed if swallow ability improves. ESPEN (2005) also discuss the importance of considering patients before and after PEG insertion and that ethics are just as important as contraindications as part of the consent process, the patient and family require adequate social support. These guidelines highlight a very difficult process that needs to be individualised. The medical teams must ensure a legally valid informed consent is completed. ESPEN (2005) also discuss that European laws differ greatly from country to country and that this should be considered in the consent process. ESPEN (2005) however does advise that family members should not consent for family members who do not have the ability to consent for themselves, unless this was organised when the patient had capacity.

The General Medical Council (GMC 2008) outline the UK guidelines for gaining informed consent for a procedure; the procedure must be explained, intended benefits and risks outlined, and the options of not having the proposed treatment should be discussed. For consenting a PEG these discussions should be in-depth, with consideration to the psychological impact as well as the physical. GMC (2008) also state that it should always be assumed that the patient has capacity until proven otherwise in concordance with the mental health act (2009). It is often difficult to assess capacity of patients that have suffered a CVA. Often patients who lack capacity have consent forms completed by an individual who is legally is allowed to do so. GMC (2008) discuss that if a medic is completing a consent form when a patient lacks capacity, they should always consider what the family feel the patient's preference

would be if they had capacity. The researcher of the current study feels that this task could be very difficult due to the fact that providing nutrition is a very emotive subject and consent guidelines are not specific to this topic.

2.2 Consent and Autonomy

Quill et al (1996) discuss that informed consent should be an intense collaboration between the patient and the doctor, so the patient can make autonomous choices that are informed by medical facts and the doctor's experience. Beauchamp et al (1986) define medical consent as an individual's autonomous authorisation of a medical intervention. Beauchamp et al (1986) also outline that the law can also affect authorisation and also autonomous consent cannot be complete if it does not meet set laws and institution guidelines (for example age restrictions). Beauchamp et al (2009) discuss five elements of informed consent. These are:

1. Competence
2. Disclosure (information provided)
3. Understanding
4. Voluntariness
5. Consent

Beauchamp et al (2009) also explained the structure that the consent process should take.

1. Threshold elements (pre conditions) should be considered at the start of the process
    1. Competence of the patient
    2. Voluntariness
2. Information elements (detail provided for the patient)
    3. Disclosure (provision of verbal or/and written information)

4. Recommendation by Medic (plan of treatment)
5. Understanding (assessment of understanding of the plan)

3. Consent elements

6. Decision (what plan does the patient favour)
7. Authorisation (of the chosen plan)

Within this structure there are some things that may differ from the previous set structure. These differences could be an informed refusal of the recommended plan. Competence plays a large part in this aspect of the consent process.

Respect for autonomy appears to be the essence of consent and a structured process is essential to informed patient specific consent process.

2.3 Review of the research part one.

The researcher decided in order to collect data around the PEG consent topic, a literature review would be firstly completed.

The initial literature search terms were selected by the use of PICO (Problem, Intervention, Comparison (optional) and Outcome) as discussed by Johnson (2012). The selection of key terms ensures that the research considered is appropriate for the study and the topic question.

P Stroke patients with dysphagia

I Percutaneous endoscopic gastrostomy (PEG)

C NA

O Consent

Words that have the same meaning were also used in order to gather a larger set of results. This was completed by the use of the Boolean operator 'OR' to combine terms with the same meaning (Aveyard 2009). See *Appendix B for details*

The literature review was completed using on-line health databases Medline, Cinahl and Cochrane Library which were accessed through Coventry University.

The time scale of the inclusion of papers was initially ten years. This was extended to January 2001 until Present to ensure the inclusion of already read relevant papers. The last literature search was completed the 1st April 2013.

As the research project is concerned with UK consent laws the exclusion of international research was deemed appropriate. This is due to the lack of comparability within governing guidelines / ethics / law for which are used in the UK and not in other countries.

The literature search was completed using the outlined search terms (*Appendix B)* combined with the results of each term section with all the other columns. The inclusion and exclusion criterion was then applied. See *Appendix A for* details.

When applying the search criteria it was quickly apparent that this search strategy did not provide appropriate literature.

The term ‘dysphagia’ was removed from the search in order to acquire semi appropriate literature. The researcher felt that the inclusion criteria was too narrow and that the term dysphagia should be removed from the research.

The action of narrowing the search did not provide appropriate literature.

As a result of this, the term ‘CVA’ and all similar were removed from the search in order to locate some research applicable to the topic.

This search yielded 68 hits from Cinahl and Medline, of these three met the inclusion criteria, the main reason for exclusion was non UK papers.

- The other reasons for exclusion included, research into the child cohort of patients where the consent process would differ greatly as the parents consent for their child; the child does not consent for themselves.
- Studies where patients that received a PEG for stomach drainage not nutrition were not considered, as the researchers aim was to consider consent in patients undergoing PEG for nutrition.
- Research that considered solely PEG mortality as an outcome was also disregarded as it is not appropriate to the research topic.

It is noted by the author that the three research papers to be reviewed only loosely meet the criteria as they discussed all patients undergoing PEG, not only stroke. These studies were, however, selected to review as they were the most appropriate.

The studies selected to review were:

Brotherton et al (2009)

Skitt et al (2011)

Rahman et al (2012)

The researcher decided not to consider PEG research from other countries as the national guidelines for both consent and PEG insertion differ from other countries as discussed in ESPEN (2005)

To critically appraise Brotherton et al (2009) the critical appraisal tool from Moule et al (2009) for qualitative research was selected. The researcher in this study decided to use this tool as the research to be reviewed is very broad and there is the option of a

broad qualitative or quantitative tool.

The aim of the study was to explore patients and carers perceptions of the appropriateness of information given prior to making the decision to have a PEG placed. The literature outlines that often, individuals undergoing a PEG procedure were not given full information on risk factors and other treatments available. The researchers state that there was a clear need to explore the experiences of those patients who underwent the PEG discussion process to assist with decision making more effectively.

Participants were selected using purposive sampling. The sample was selected from a hospital trust with specific criteria. Aveyard (2009) discusses purposive sample ensures participants are selected suitably. The sample included both patients and carers separately in order to gain a greater understanding. A possible criticism is that the sample selected had been at home for four weeks after discharge and it could be argued that patients may not remember the process. By including newly discharged patients a greater knowledge may be gained from patients. It is also unclear about the patients that were excluded due to communication difficulty. Further research may try to assess the experiences of these patients using communication tools to assess their feelings towards the consent process.

The method of data collection was semi structured interviews with both patients and patient carers. Moule et al (2009) discuss that semi structured interviews are an appropriate method to explore participant experiences and beliefs. The venue of the interview was mainly in patients homes with patients having a choice to complete interviews in a hospital setting. The choice of a hospital setting to interview patients may increase the Hawthorne effect; this is where the variables in the study make participants act in a certain way due to the fact that they are taking parting in research

(Polit et al 2006). Other confounding variable factors could be the fact that patients may have been treated at the hospital they are being interviewed, which may impact upon the way questions are answered. Face-to-face interviews may have led patients not feeling able to be truthful about the experience. This could also be a factor when friends and family were present. For example “would you choose to remove artificial feeding given at present?” This is an emotive question that individuals may feel uncomfortable answering in front of close relations. Another method of data collection could be telephone interviews. Smith (2005) outlines that this method works well with semi structured interviews and negates the possible intrusiveness of face-to-face. This however may mean the richness of field notes would not be available.

The semi structured interviews were thematically analysed in order to code the data. The data was collected using taped recordings and field notes of the interview. The researcher wrote extensive field notes following the interviews which included their thoughts and reactions during the interview. Field notes were not written up during interviews, this indicated some information may have been forgotten. The researcher also assessed their own emotions and reactions to the events, the study did not discuss the reflexivity of the researcher. This may mean that realistic reactions were not captured. The use of another researcher’s observations may have improved transferability of this data.

Ethical approval was obtained prior to commencement of the study and ethical procedures adhered to; patients received information and consent was gained prior to beginning.

Themes from the data were obtained from both carers and patients. Patient themes that arose include medical teams having little time to explain procedures, information being incomplete and/or irrelevant and no discussion regarding the after care of the

PEG. Patients also reported that they were told about the procedure but they did not know who had made the decision and this left them feeling isolated. This information points to a more thorough consent process for patients. Carer themes were that they had adequate information but wanted specifics of PEG care on discharge, if they thought that PEG was not in their families best interests, the medical team told them it was life or death and that there was no other choice when possibly other options were available.

As this research does not outline the capacity of patients at the time of the PEG it is difficult to improve attitudes of patients if the situation is not clear. Another major criticism is that there were no indications of the condition of the patients at the time of PEG insertion. There was no discussion if patients had capacity at the time of PEG insertion of the impact of any other disease process. It may have been more effective to review the medical notes of each participant as well as interviews to consider the specific reactions to each individuals consent process. It may also have been possible to complete individual case studies in order to assess the reality of the situation.

This research identifies a problem with the communication during the consent process for PEG regardless of the situation of the patient. The study suggests the use of a multidisciplinary tool during consent for PEG. This outcome provides evidence that further research is required in this around medical teams perceptions of PEG consent.

Skitt et al (2011) research is primarily quantitative so a quantitative research tool was used from Moule et al (2009) to critique it. The main theme of the research was the implementation of a tool and education to improve the outcome of patients undergoing PEG. This fact is also outlined in the title of the research.

The introduction in this research clearly outlines national outcomes and guidelines as to the reason to complete the research as well as the fact that mortality rates in the

specific trust were high and improvement was required. The introduction also outlines that the research will consider the knowledge of clinicians around PEG indications and complications were to be considered.

The methodology of this study was unclear. It was outlined that quantitative research was being used but the specific methods of data collection were not clearly defined which impacts on the generalizability and validity of the research. The research started with the nutrition nurses at a given trust devising a referral tool for patients requiring a PEG, the nurses also took part in the PEG assessments. The research tool aimed to improve patient outcome. To assess the outcome of the tool implementation the researchers used two methods. The first method was unclear but appeared to be audit, mortality rate was considered, appropriateness of referrals and failed procedures pre and post implementation of the tool. The second method was a questionnaire that was circulated to medical teams around their knowledge of PEG consent following a PEG education session. The style of questionnaire was not clear from the research. The use of percentages in the results and the fact no cause and effect was discussed would suggest a close ended questionnaire. The sample of the doctors completing the questionnaire was not fully defined in the methodology which affects the generalizability of the research. The results did discuss that different levels of doctors were included in the research but to what extent was unclear.

The results from this study showed that the implementation of the tool lead to reduced mortality rates and a reduction in inappropriate referrals. The questionnaires completed by the medical teams were also discussed. Seventy nine per cent of participants filled in the questionnaire, of these there was a poor response to the contraindication question, 77% stated they had read some literature around PEG and 89% now aware of the referral process for PEG.

There are several main strengths of the research. As a result of the interventions put in place there was a significant decrease in patient mortality. The researchers had outlined a clear need for the research within their department prior to the research commencing. The researchers also discussed that there were existing national guidelines that also supported the commencement of the research. The research has highlighted that despite education, medical teams are still not all aware of the contraindications of PEG and often referrals are inappropriate. This fact provides evidence that more education is required for medical teams. This supports the rationale for completing the current research of perceptions of medical teams into the consent process for PEG.

There are some weaknesses in this research. The mortality rates decreased following the implementation of medical team education and the referral pathway implementation. However, it is unclear to what extent each intervention impacted on the medical teams. The nutrition nurse input was also obviously increased at the time of completing this research, but it is unclear to what extent. The researcher of the current piece of research feels that actually the work and presence of the nutrition nurses may have been more influential than the specific education or referral pathway. The use of the quantitative research style meant that no cause and effect was illustrated. This indicates a gap in the research. It is clear that more research is required into the specifics of the perceptions of medical teams. This provides evidence that the current research being completed is required.

Rahman et al (2012) piece of research is a quantitative study so a quantitative research tool by Moule et al (2009) was used to critique it. This research aims to consider the mental incapacity in hospitalised patients undergoing PEG insertion. The title of this study explains what the study topic is, but with no specific indication as to the research direction. The aim of the research was to prospectively determine the

prevalence of mental incapacity in hospitalised patients undergoing a PEG. The introduction outlines that PEG insertion is often far from straight forward because patients often have a limited life expectancy. The abstract also outlines that the decision to PEG is often difficult due to serious underlying disease. This fact provides evidence for this research study as it outlines PEG consent may be difficult. The introduction then summarises that there have been no formal or prospective studies into the capacity of patient having a PEG placed.

The method used to complete this research aimed to interview two groups of individuals to assess capacity prior to procedure commencement. Those who clearly did not have any capacity were left out of the research and for those with questionable capacity, the study was discussed with the family whether they thought their relative should participate in the research. Two groups were assessed, one was patients requiring an upper GI endoscopy and the other group awaiting a PEG insertion. Both groups were interviewed using the MacArthur Competence Assessment tool to assess competence, this is a validated tool which will increase the generalizability of the research.

The results of this study found that 22% of inpatients undergoing upper GI endoscopy did not have capacity to consent, whereas 74% of inpatients awaiting a PEG placement did not have capacity to consent for their procedure. These results suggest that patients undergoing PEG assessment are much more likely to lack capacity.

A major strength of this research is that participants had a diverse range of co-morbidities such as CVA and neurological disorders. This makes the research generalizable to other hospitals in the UK. The research made clear that patients undergoing a PEG insertion are less likely to have capacity, this coupled with the difficult decision to have a PEG also indicates that this could be a difficult scenario for

medical teams. This data provides evidence that more information is required from doctors into their experience of these patient journeys and what can be put in place to provide support during these processes. There are several variables which could have affected the validity of this research. There is no comment on the condition of the patient at the time, for example medications could have affected the patients capacity, a speech and language therapist may also have needed to be called for those with communication difficulties. It would be beneficial to provide more detail into the individual cases. Overall this research provides evidence that PEG consent is often difficult and more research is required.

2.4 Review of the research part two

Due to the lack of specific research into PEG consent in the U.K, the author decided to complete another literature search. This considered the research into the attitudes and perceptions of doctors into the informed consent process. The PICO tool was again used to select relevant search terms (Johnsten 2012).

P= Medical team, medic, Doctor, physician

I=Consent

C=Informed

O= Attitudes and perceptions

The previously discussed inclusion exclusion criteria (*Appendix* A) were then applied to the search. (*S was included to allow for plurals)

- Medline, Cinahl and Cochrane library.
- 2000 -2012 (left 83 hits)
- All research was considered, abstracts to confirm appropriateness

Initial searches showed nil appropriate British research, research found mainly about children which is not appropriate for adult patients.

The author of this research reluctantly decided to consider other countries research around consent. The author recognises that the main themes of non British research may not be transferable to British law but some outcomes may provide insight into the topic. When reading the abstracts one piece of research of the 83 had some relevance (one hit). The reasons for disregarding this research included.

- Some research was too procedure specific, for example cardiac surgery where procedure specific risks were compared for likelihood.
- Country specific laws were too prominent in the research so was not appropriate.

Then it was decided to include knowledge rather than attitudes and perceptions to broaden research scope and assess any related research. One British paper (one hit) was found and two non British studies (two hits).
The term view was then used to replace knowledge. This gave one non British hit (one hit). In total one British study and four non British studies were considered. Of the research selected for further consideration, nil met present inclusion criteria so findings will be considered if elements are appropriate to this research. The focus of this research is qualitative, although survey and quantitative research will be considered.

On closer examination of the five papers it was decided that one non British study had very little appropriateness as it was based totally around oncology and American law. Another study looked solely at patients where the relative gave consent, this does not show any resemblance to U.K law so was not reviewed.

The British studies to be reviewed were:

1.Jamjoom et al (2010)

From this study another study was found to be appropriate to review.

2.Mc Manus et al (2003)

This study had one other sited piece of research about views of consent from patients perspective of consent into emergency theatre which is not appropriate to the current topic.

The non British studies to be reviewed were:

3. Shirazi et al (2005)
4. Larobina et al (2007)

To review the literature the critical appraisal tools for qualitative or quantitative research in Moule et al (2009) were used**.** These research tools were selected to be used as the research to be reviewed has several different design methods**.** As the below studies do not directly discuss PEG and discuss other procedures, only the relevant information from these studies have been discussed.

Jamjoom et al (2010) title outlines that the research wants to consider the attitudes of anaesthetists and surgeons towards informed consent and it states it is an observational study. The abstract of this study did not reflect the title as the study is a quantitative survey rather than an observational study. The background to this study outlined the current British guidelines around informed consent and that was reflected in the study. The background in this study also clearly outlined that there is very little research into doctors attitudes towards consent in the U.K. Studies undertaken in non U.K areas did not reflect U.K laws so were not appropriate to review.

The research was completed using questionnaires, participants were asked to say to what extent they agreed with a statement on a numerical scale. The areas considered were the medics respect for autonomy and the delivery of information and patient

remembering knowledge. It also considered the aims and the complexities of consent for doctors.

Participants were randomly selected and confidentiality principles were adhered to. Sixty eight per cent of participants returned questionnaires which the researchers outlined as low, but accepted this as the demographics of participants was varied. Results were considered using a known statistical package to ensure generalizability.

The results of this study outlined that 79% of the participants thought autonomy was the most important aspect of consent. Some anaesthetists however thought that the process of consent was not important. Surgeons outlined that thorough explanation was also important, anaesthetists did not. Participants also highly rated that age, knowledge and education as being factors as to how much information is provided.

The research concluded that the right to autonomy and an individualised approach are most important in consent, this is in keeping with other research such as Nurumi (1998). The aims of this study were not reflected in the methodology and more depth of information could have been found using a qualitative methodology. In the methods the different rank and sex of participants were discussed, differences in these groups were not discussed in the results. This may have helped to improve specific practice. The researcher in the current piece of research feels although Jamjoom et al (2010) outlines the importance of autonomy and individualisation it also outlined that consent is often different depending on the procedure being proposed, for example specific side effects of procedure specific drugs.

McManus (2003) aimed to consider the variations of practice when consenting for a specific procedure. The background of the study is limited but does outline laws of consent as a basis to the research.

A quantitative survey method was used to gather data. A questionnaire was sent out to general surgeons, they were asked about what information they provided to patients on the possible complications for the procedure they were about to receive. A 54% rate of completion of questionnaires was accepted as being low but in keeping with this type of questionnaire.

Results were cumulated using a recognised statistical method. Results showed a wide variation of practice between medical teams and the possible side effects of surgery discussed during consent. The study did not discuss the demographics of the participants or the fact that patient knowledge may affect information given and results were very simplistic.

They concluded that the practice of consent varied between medical teams. It outlined a clear need for a procedure specific structure for consent and the use of patient information. This research also gave clear indication that further research was required to ascertain the cause and effect of differing practices and perceptions of medical teams into consent. The researcher feels that a more qualitative approach would give more information and this fact provides evidence for the current piece of research to be carried out.

Larobina et al (2007) conducted research in Australia which will not reflect U.K laws and guidelines but themes may have some parallels. The study aimed to find out if informed consent was achievable in cardiac surgery.

The background of this study outlined a clear lack of research into this topic as rationale for the study. The study considered the views of both patients and doctors using a survey methodology. Structured interviews were used to collect data to provide

cause and effect. Of the patient population the majority of patients interviewed knew the risks of their procedure prior to commencement, however when asked what that is (for example what a stroke was) only 40% understood what it meant for them. There was also a significant difference in the knowledge of intended benefits (26% understood a decrease in medication would happen after the procedure). This clearly identifies the patient specific consent should always be completed and information tailored to knowledge.

The interviews with doctors concluded that the amount of information provided differed between each doctor. More important than that it was found that 25% of doctors did not feel they had enough knowledge to consent patients but had still completed the consent process. This study outlines that doctors need a greater knowledge base for consent in complex patients with specific needs.

Shirazi et al (2005) completed research which aimed to assess the ethical knowledge of doctors in Pakistan. The study used survey methodology in the form of questionnaires to complete research. The sample was 120 doctors that were approached, 120 questionnaires were sent back but 19 disregarded as they were illegible. The high respondent rate is questionable as the return rate is unusually high and possibly makes the validity questionable.

Ten questions were on each questionnaire which considered basic knowledge, consent confidentiality and ethical experience. Only ten participants state they had any ethics teaching at university. It was also outlined that only 44% of Doctors had ever read the code of ethics in Pakistan. This is thought to be because Pakistan is a Muslim country so ethics are based around religion and not national ethics. This is a fact that may also

impact upon the U.K as international Doctors are employed in most trusts. Finally only 47% completed informed consent and even then it was not consistent.

This paper is difficult to generalise to a U.K audience due to the cultural differences in the population but it does however indicate that poor education leads to an inadequate consent process.

The research considered in part two only loosely related to the topic being considered in this research as a whole. It was considered largely because the limited research around consent for PEG, so research around the consent process for other procedures was reviewed. In the studies reviewed the majority of results had no relevance to the current research study, there were some elements of the research that did appear to be relevant. It appeared from the research that medical teams knowledge around consent differed greatly as did their education levels. This fact indicates a need for standardisation of training for consent in medical teams. The literature reviewed outlined that a large majority of medical teams did think that patient autonomy was important as well as tailoring the consent process to the education level of the patient. Another theme in the literature reviewed was that teams felt that a procedure specific consent process was required and the use of written information to standardise detail given to patients.

The majority of the research reviewed was quantitative, so gave little information around the cause and effect of the research results. This indicates that there is a gap in the knowledge base around research into consent and the perceptions of teams into this. There is clearly very limited research into PEG consent, highlighting the need for the current research being completed. Further details can be found in the flow chart in appendix L.

3.0 Methodology Introduction

The aim of this study is to gain an insight into the attitudes and perceptions of medical teams around the process of consent for PEG patients post CVA. The study will consider the attitudes and perceptions of specific medical teams within one set National Health Service trust in England of which the researcher is employed. There are currently no set standards or assessment strategies for this type of research in the U.K. or current specific literature relating to this topic. For these reasons qualitative research has been selected so that the attitudes and perceptions of medical team could be uncovered and clarified through the research process.

Pollit at al (2006) outlined that qualitative research will allow flexibility in the research process and for researchers to gain an understanding of the current situation as a whole. The researcher feels that the use of qualitative research is important to gain a true perspective of doctors consenting patients for PEG post stroke.

The 'author' in this research has the philosophical world view of pragmatism. Pragmatism is a practice which is real world practice orientated and is not concerned with empirical observation and measurement as discussed by Cresswell (2009). This world view is important as this study intends to gain insight of the individualism-depth perception of a task. The aim of the study is to gain an insight into the perceptions of medical teams who consent for PEG post CVA, not to assess the rate or amount of an activity completed. Paton (1990) discussed that a pragmatist world view comes from actions, situations and consequences, rather than scientific research. A pragmatic world view will lend itself, more to a qualitative than quantitative as it does not consider scientific or empirical research. This is important because the research wants to look at the phenomena of the PEG consent process post CVA. This supports the use of qualitative methods in this research, as the research aim is to assess perceptions

rather than consider empirical data.

3.1 Specific Methodology

As this study aims to provide a picture of the Medical teams attitudes and perceptions of consent for PEG in patients following a CVA, the design selected for this is phenomenology. Holloway (2005) outlines that the major aim of phenomenology is to generate a description of a phenomenon of an everyday experience, to comprehensively understand its structure. This design is appropriate for the aim of the proposed study as it will provide a way of gaining greater understanding of Medical teams attitudes towards PEG consent, which is an activity they could complete as a possible everyday experience. Cresswell (1998) explains that a phenomenological researcher's aims are to try to understand or explain the sense of participants lived experiences. The use of interpretive phenomenology would allow the researcher to understand the details of medical teams perceptions of PEG consent, therefore allowing future possible improvement of practice.

Hermeneutic phenomenology has been selected in this research as it aims to understand the human experience. Moule et al (2009) outline that hermeneutic phenomenology aims to present a story or picture rather than a specific answer, which allows the reader to gain their own conclusions. One of the aims of this research is to be able to use the information to formulate a support package for doctors completing consent for PEG, so in-depth data is required. Magee (1987) describes hermeneutic phenomenologist's as viewing individuals as coping beings. He also outlines that as beings we are inseparable from the world we live, we exist in an existing world and it is from this world that life begins. This means that as individuals we are moulded by the world we live in and the experiences we are exposed to, so doctors considered will have been moulded by their experience in the world or for the research purposes their experience as a Doctor and an individual gaining consent.

Johnson (2000) outline Heidegger hermeneutic three modes of involvement, this considers a person's involvement in the world. **Ready to hand mode** (stage one) is when a person engages in something without thinking for example driving from one place to another. **Unready to hand mode** (stage two) is when the smooth function of something is interrupted, for example, the car won't start. **Present at hand** (stage three) is where something is viewed with no engagement for example looking at a car without knowing how to drive it. By considering the modes of involvement as a basis for this research, data in the proposed study should explain why actions are completed, the experience and the context in which they have occurred. This links to the overall aim of the research which is assessing the attitudes and perceptions of consent in PEG by medical teams, be it what they are comfortable with (stage one), the areas of possible difficulty (stage two) and the areas of uncertainty (stage 3).

3.2 Sample

Purposive sampling was used to select participants for this study. Moule et al (2009) outlined that purposive sampling is used to collect participants with a certain set of experiences or knowledge. The requirement of the characteristics of participants for this study, were specific to Medical teams in specific specialities, so could not be achieved with another type of sampling. The aim of this study was to consider the attitudes and perceptions of the medical teams into consent for PEG, the researcher has selected the specialist areas of Gastroenterology and Gerontology in which to recruit participants as these are the teams that are likely to have had the lived experience or have been part of the consent process for PEG post CVA. Bowling et al (2005) discuss that within qualitative research the sampling techniques should reflect the aims of the research and should reflect the features of the topic being studied. The specific characteristics of the inclusion criteria are in Appendix F.

All levels of the medical teams will be included in this study, from Junior doctors to consultants. As a consequence of the deficiency of documented research into medical teams' experiences of consent post stroke, the author feels that all team members should be included in the research. Moule et al (2009) also outlines purposive sampling allows the author to use personal knowledge to select relevant participants. This is important as research may suggest a need for education or practice reform so the study results should reflect the specific practice in the trust in which the study is being conducted.

3.3 Participant recruitment

Prior to commencement of the research the study was registered at the specified NHS Trust research and development office. Permission was gained to contact staff prior to the start of the research.

Once participants names were selected they were stored in the Nutrition team data base in a secure and private file. This file is only available to nutrition team members and at the specified trust only legitimate access is allowed in line with the Trust Information Governance policy. All names were anonymised at the end of the study.

In order to recruit participants to the study the following actions were completed.

The secretary of each gastrointestinal and gerontology medicine consultant were contacted via email to arrange a face to face meeting to discuss team members eligible to participate. The secretaries were not informed of the purpose of the names being collected to protect the anonymity of the possible participants. The author also liaised with the medical secretaries to assess the most appropriate time to complete research and gain the highest amount of possible participants. This was completed to assess for the most appropriate time to invite participants during their rotation in either gastroenterology or gerontology so that they meet the participant criteria.

I the researcher decided that prior to recruitment of the participants that I would present my research proposal to the relevant specialities. The researcher felt that if the research was formally outlined at a departmental meeting and the intent of the research discussed then possible participant would gain an idea of the research purpose prior to a formal invite. The researcher felt it was important explain to both the gastroenterology and gerontology participants that the aim of the research was not just to blame and identify poor practice but to gain an understanding of their attitudes and perceptions of PEG consent post CVA. This was due to the fact that some consultants were concerned that this is how the research may be perceived, so reassurance was required.

When the researcher commenced the recruitment of possible participants they were emailed inviting them to participate in the study. Each possible participant will have received a participant information leaflet and two copies of a consent form to sign, one to retain and one to give to the author of the study. This was because not all of the audience spoken to meet the inclusion criteria for the study (appendix A). The invites where distributed via the trust email system which is password protected to prevent any breach of confidentiality.

Following the invitation each participant was given a week to decide whether to participate in the research to ensure participants had time to read the information provided and make an informed decision on whether to participate. Participants were given the contact details of the author to ask any questions. It was also made clear that the interview would be completed when the participants were available, in a busy medical team often time is limited so the researcher must be flexible to the needs of the participants. Oliver (2010) outlines the importance of allowing participants freedom within research to ensure moral rights are upheld. This will be discussed in the ethics section of this study.

During the process twenty five possible participants met the criteria and were eligible to be invited to take part in the research over a five month period. Ten participants chose to take part in the study, five at consultant level and five at a more junior level and five gastroenterologists and five gerontologists. Purposive sampling was used to recruit participants, those who wanted to take part and met the criteria were interviewed. Polit et al (2006) discusses that if the participant group is similar to the target population of the research then this will increase the transferability of the research.

It was noted by the researcher that during the participant recruitment that initially only two participants agreed to take part via email after two weeks of the invitation being sent out. The other eight participants came to speak to me prior to consenting to take part and several stated they would take part but could I email in one month's time when they were less busy and they would take part. Britten (1995) outlined that when considering sampling strategies the flexibility of the researcher in explaining the research, in answering participant questions and giving the participants time is essential to giving the participants assurance of confidentiality. The researcher in this research wanted to make the participants feel relaxed and trust the researcher, so sampling strategies needed to be rigorous and confidential. Britton (1995) discussed that this is important as the researcher can impact how the participants answer questions in qualitative research because of the behaviour of the researcher or how they perceive the researcher.

3.4 Methods

In this research study the data collection method was in-depth interviews. This method was selected as it allows for depth of information into the chosen subject with some control of topics to discuss. Moule et al (2009) explain that the purpose of qualitative interviews is to seek out participants individual experiences or attitudes. Pollit et al (2006) outline that phenomenological research requires in-depth interviews that allow

for depth of data from participants. The use of unstructured interviews has purpose to encourage interviewees to talk freely about a given subject within a certain topic area, this was important as PEG consent post stroke is a large topic. Pollit et al (2006) discusses that the use of unstructured interviews allows a topic to be discussed freely without the structure to restrict their views.

Carpenter et al (2008) discuss that in-depth interviews are the most appropriate method of data collection in interpretive phenomenology. The researcher in this study aims to assess the perception and attitudes of medical teams, as there is limited research into this area and it is unknown what the medical teams attitudes and perceptions to the given topic area, in-depth interviews should be able to uncover the medical teams attitudes and perceptions. Benner (1994) outlines that an interpretive process is important in learning about a clinical situation and understanding how the best clinical judgement is made in uncertain situations. This would suggest that an in-depth interpretive data collection is required to extract the perceptions of medical teams in possibly complex situations.

3.5 Setting the scene

The researcher in this study felt that the interviews should be completed at a time and at a venue chosen by the participant. The researcher felt that because the participant sample was doctors who usually have very little time and could be on call for emergencies, it was important to be flexible. Britten (1995) discussed that by allowing participants to select the venue and timing of the research, the participants feel more comfortable and improve the content of the interview. The researcher in this study made it clear to all possible participants that the research could be completed when they were available. The participant where given two options:

- The research could be completed after work at a venue of their choice.

- The research could be completed during working hours, please provide the dates and times you are available.

The venue of the interview was also discussed, the participants were given the option of choosing the venue themselves or would they like the researcher to organise the venue for them. Moule et al (2009) discuss that the importance of ensuring the participants are in a quiet comfortable environment which allows the participant to relax and therefore engage in the interview. The participants who asked the interviewer to organise the venue were given reassurance that the venue of the interview would be safe and secure to ensure confidentiality was maintained which would also improve participant engagement. A formal invite with the date and venue was then emailed to the participants, in some cases the contact was made through personal pagers to allow for flexibility for work commitments. Johnston et al (2010) out line that a lack of time can be a barrier to recruitment of medical participants into research. Medics often have busy stressful lives, they have little time to complete research so recruitment can be challenging.

3.6 Interview

The researcher in this study had little previous experience in conducting a qualitative in-depth interview, so decided to loosely use an interview protocol that was outlined by Creswell (2009). Creswell (2009) discussed that firstly before the interview starts that the setting should be documented, the date, place, time, level and speciality of the medic being interviewed was documented prior to commencement. This may aid the transferability of the overall research. The researcher in this study firstly began the interview with an ice breaker question about the experience of each participant into the topic. Moule et al (2009) discuss the importance of starting a qualitative interview with a subject related to the overall subject. The use of an initial question in this research should have insured the research was focused on the subject. The question was: *Can*

you tell me about a time when you were involved in the consent process for a PEG insertion, for a patient following them suffering a CVA? Johnson (2000) stated that if participants discuss experience in interviews, true perceptions and attitudes are likely to immerge and be more significant as they will be context specific. This statement supported the researcher's decision to commence the interview with a question about the participants previous experience.

The researcher in the second stage developed some sub-questions that could be asked to improve depth or ask how the research process could be broadened during the research. The research feels these should be used sparingly to ensure information is rich and in-depth and not halted by structure. (Below are the sub questions that were loosely used during the interviews)

- What factors influenced this? (EG, decision or actions completed)
- What things would you differently in the future?
- What improvements could be made?
- What was difficult?
- What other areas should this research explore?

These questions will then be worked into the subtopic being discussed, e.g. what was difficult when you consented that patient for a PEG. This will ensure that the interview has a steady flow to allow depth.

The researcher will then use inquiring questions if required to gain more depth of information. Stage 3 was used to develop probes for the interviewees to allow for elaboration and give depth to answers. The probes where:

- Can you elaborate on that?
- Why do you think that was?

- How did/do you feel about that?
- Can you give an example?

The use of echo probes was also completed in each interview, for example repeating the last thing the participant said or uh hu to encourage. Blumenthal et al (2004) outlined that giving participants time to think and the use of echo probes lets the participants know that you are listening which empowers them within the interview to open up.

The interview protocol also includes the importance of asking the participant if there was anything else, this is to ensure the participant has an opportunity to visit any topics not covered and give more depth to the interview. The final aspect of the protocol outlines the importance of having a closing statement. At the end of each interview the participants were given a closing statement thanking them for their time and stating if they had any queries that they could contact the researcher at any time and to assure them of confidentiality.

Thank you very much for your time, if you have any queries following this interview please let me know. My details are on the participant sheet.

Ritchie et al (2003) discussed the importance of bringing the research to an end with a closing statement gives participants reassurances around confidentiality.

3.7 Data analysis

The method of data analysis selected for this research project is qualitative thematic analysis. Thematic analysis was chosen as it was thought it would allow for the themes within the research data from the medical teams to be revealed. Braun et al (2006) discusses that thematic analysis can be used to report and identify patterns from the data. The research aims to explore the attitudes and perceptions of medical teams into the consent process for PEG post CVA. Bayatzis (1998) discussed that thematic

analysis allows for different aspects of the research topic to be analysed and discovered. The researcher in this research recognises that they have limited experience in qualitative data analysis, choosing thematic analysis allows a simple systematic method of reviewing the data set. The researcher Van Manen (1990) discusses phenomenological thematic analysis completed by stating that looking at data line by line can capture the entire sense of the text. The researcher also felt that by completing the data analysis themselves then all possible themes should be recognised, this is due to the topic knowledge of the researcher.

The structure of thematic analysis chosen is a six step approach by Cresswell (2009).

Step One: Preparation and organisation of data is essential. Firstly interviews where transcribed and field notes completed.

Step Two: Read through all the data to gain an idea of what the research is saying. Decide what is the tone of the research is? The researcher will then record these thoughts on the transcripts.

Step Three: Researcher will begin the detailed analysis which will include a coding process of the data. For a more detailed account see Appendix K.

Step Four: The researcher would then use the codes to construct a description or make links between the codes.

Step Five: Advance the themes uncovered to develop a narrative to convey the findings following the analysis stage.

Step Six: The final step will be an overall interpretation of the meaning of the data and themes. It will also be considered against other literature around the topic.

The researcher in this study will then summarise this process, report findings and make suggestions for future research and practice.

4.0 Rigour

The strategies for rigour where considered prior to completion of the research. The strategies for rigour implemented reflected the criteria for rigour outlined by Lincoln and Guba (1985) including the following four components: credibility, dependability, confirm ability and transferability.

The credibility of the study was increased by asking for a peer review of the plan and initial question in the interview. Prior to the commencement of the study the plans were reviewed by the specific NHS trust nutrition team which includes nutrition nurses, dieticians and speech and language therapists. This use of panel review will help to ensure the study research plan will ensure data is representative of reality, this should increase rigour. Another strategy to ensure the credibility of the study was to ask the participants if they wanted to review their typed transcripts from their individual interviews. This is important to ensure the transcripts reflect what actually happened in the interview, especially from the perspective of the interviewee, this was discussed by Maxwell (1992).This was completed to ask participants to review the truthfulness of the written transcriptions. The researcher chose not to ask participants to review the interpretation of the data but to ask them to check for the content.

I as the researcher of this study have a vast knowledge into the topic of consent for PEG post CVA, the researcher is a nutrition nurse who regularly consents for and places PEGS post CVA. The author will recognise their research bias into this topic and will ensure that they remain as a research tool in data collection and ensure personal views are acknowledged but do not affect the trustworthiness of the data. Bowling et al (2005) outline the reflexivity of the author is important, the author should remain sceptical at all times to ensure the credibility of the research. I as the researcher also recognise that I am a female nurse and accept the bias in which this experience has

given me and how this may impact on the current research.

Dependability in the research will be upheld by thorough documentation of the process of the research throughout the entirety of the study. At each point in the research the researcher will provide rationale for the decisions made. Lincoln and Guba (1985) outlined that an audit trail should be used to ensure the dependability of the research. A full audit trail of the research can be found in appendix D.

The conformability of the research will be upheld by the researcher recognising the processes within the study. For example the thematic analysis of the data will be completed using a standard process from Cresswell (2009), this will ensure analysis of data will be standardised. The interview data will also only be reviewed by one researcher, this means that all data will be viewed from the same stand point therefore results and themes have greater transferability of the findings. All other research strategies and justifications in the research will be outlined in the audit trail found in appendix D.

The research strategies, methods and decision making process should be transparent throughout the entirety of the research to improve the transferability of the research. The researcher in this study wanted the research to be used in practice and to complete further research. The aim of the research was to assess for themes which may reveal a commonality of experience, this could be then transferred to other areas as outlined by Searle (1999).

The research approach of phenomenology will be reflected in all aspects of the research including data collection and analysis. This will ensure consistency between the data collection methods and data analysis in the research. Burns et al (2009) outline congruence in research conduction is essential to ensure the research is transparent and results have transferability.

5.0 Ethics

A literature review was completed prior to the commencement of the research. The author of this research reviewed all literature and noted that research in this area was limited and the available data identified a clear gap in the knowledge into this topic. The limited research into this topic identified a clear need to complete this research, this would suggest it is ethically correct to complete this research. The author will continue to review current literature to ensure there is still a need for this research throughout the duration of the study.

As the study will consider NHS employees at a specific trust, ethical approval was gained from relevant committees prior to commencement of the research as IRAS was not required. The NHS trust selected to complete the research was asked for ethical approval through the Research and Development department. Prior to the commencement of the research the researcher gained written consent from the research and development department was given to complete the research in the specific NHS trust. Ethical approval was also requested from Coventry University Ethics comities as the research participants were NHS staff the author also asked the university if completion of an Integrated Research Application System (IRAS) form needed to be completed, which it was not. The University gave full permission for the research to take place prior to commencement of the study.

Informed consent was gained from all participants prior to commencement of the research. Participants where emailed a consent form and information leaflets at least one week prior to conducting the research. Participants will also be informed that the reasoning for the research is to consider how patient care could be improved as part of the participant information, this will reinforce the information given in the participant leaflet. Oliver (2010) states participants must have the same understanding as the

author prior to engaging in a research study. The participants involved will also be asked if they would consent to the research being published as part of their consent form (Patton 2002).The participant were also offered the opportunity to ask questions about the research and the opportunity which Cresswell (2009) identifies.

Confidentiality was maintained throughout the research process. It is the responsibility of the researcher in a study to protect participants from potential harm, including from wider society by ensuring privacy (Miller et al 2012). In this study all information around identity will be stored in a NHS secure computer folder, annonymised on completion of data collection by calling participants numbers. The information collected will be kept in an encrypted password protected file that will only be accessed by the researcher.

The researcher in this study will maintain confidentiality of the participants, however it was assumed that if the doctors were to discuss something that could cause harm to a patient or that they had caused harm then this information would be reported to the relevant authorities. As a nurse the researcher has a dual responsibility around the research findings and the Nursing Midwifery Council (NMC). NMC code of conduct (2013) outlines you must report concerns in writing if you see problems in the care setting that are putting patients at risk. This was not outlined to participants as the General Medical councils code of conduct (2013) outline this. The code outlines that members have to raise concerns about other members to the council. So if the researcher found that practice being discussed was putting patients at risk then it would have been reported.

Veracity in the research setting refers to comprehensive, precise and objective transmition of information as discussed by Beauchamp et al (2001). The researcher ensured the veracity in the study by ensuring participant information given to participants was always truthful. Beauchamp et al (2001) outlined that veracity in

participant information essential in order to obtain informed consent and trust in participants. Prior to the commencement of the research the possible candidates were given information about the study in the relevant speciality meetings. The researcher felt that if participants were given an accurate account of the reason for the research, then this would improve participants trust and honesty so increasing transferability of the research as outlined by Polit et al (2006).

The aim of the research was to gain in site into the perceptions of PEG consent post CVA and in the longer term produce a guide for medical teams to complete consent for PEG. The aim of this study would be to improve practice and patient care. The researcher aimed for the research to “do well” so there for upholding the principle of beneficence as discussed in Moule et al (2009).

Non malfeasance is the principle of doing no harm or obligation to prevent harm as outlined in Bowling et al (2005), the researcher in this study recognises that the doctor participant may have been worried about the effect on taking part in this research on their career. The researcher felt that in order to ensure participants felt happy with the research that they were offered the chance to review transcripts before analysis. Participants were also told they could stop the interview at any time if they felt they no longer wanted to take part in the research. The researcher in this study did not feel conducting this research required specific psychological support as the aim was to discuss experience of PEG consent, the researcher felt this was a low risk topic in terms of needing psychological support. At the trust the research was completed counselling was available to all employees.

Moule et al (2009) discuss that interviews in research can often be affected by the perceived power levels of interviewer and interviewee. Moule et al (2009) discuss that often the interviewer has a perceived higher power level than the interviewee (EG

Doctor interviewing a patient) this could increase interviewee anxiety. This is not the case in this piece of research as a nurse interviewed Doctors, so the power could be perceived as being with the interviewee, which should make participants feel relaxed. The researcher in this study anxious about interviewing a participant with a perceived higher power level so decided to complete a pilot study.

6.0 Pilot

6.1 Rationale for Pilot

As part of this research study it was decided that a pilot study should be completed prior to completing the actual research interviews. Bryman (2012) discussed that the use of a pilot study will validate the research methods to be used in the real research study.

It was decided that a pilot study should be conducted for several reasons. The overall reason was to improve the transferability of the research with considerations like, preparation of the room environment, to learn how to relax participants and interview technique. The specific reasons as to why the researcher felt it was necessary to complete a pilot study are as follows.

- I as the researcher have limited experience in conducting qualitative research so felt it was important to practice technique and gain feedback. To improve transferability of the final research results.

- I as the researcher felt huge anxiety about interviewing doctors about their practice and appearing unprofessional or lacking in intelligence. The researcher felt by practicing interview technique with a Doctor they could address anxieties and develop strategies to improve this. This would enhance the reflexivity of the researcher.

- I as the researcher felt confident in the subject topic being discussed. The researcher did not however feel confident about gaining the true insight of the participants perceptions through their questions and probing technique. The

researcher wanted to test both the questions and probes to both check for clarity and to ensure topic area was being explored in-depth.

- Finally I as the researcher wanted an evaluation of the interview style from a participant.

6.2 Setting the scene

The pilot participant was selected as they are a consultant level Doctor with experience of research and consent. Due to the limited pool of possible participants for this research study, the pilot participant did not meet the participant criteria for the research but was appropriate for the pilot. By using purposive sampling, I the researcher selected a pilot participant as it was felt that the individual would give feedback which would improve the transferability of the researches outlined by Bryman (2012).

The researcher provided the participant with a participant information sheet and consent forms were completed prior to the interview taking part. The interview was conducted at a time and place chosen by the participant. The participant felt this was appropriate due to the large amount of commitments Doctors have. They also commented having a choice of venue convenient to them was beneficial and meant they did not feel pushed for time. The researcher also noted the relaxation of the participant made the researcher feel at ease. The setup of interview room was in a quiet room with a desk. The participant and researcher sat on adjacent sides of the desk. There were no physical barriers placed between the participant and me as the researcher. This allowed for some eye contact and eliminated the possibility of feeling uncomfortable that a constant face to face environment could bring. This fact was agreed by both the participant and the researcher. The lack of physical barriers also

improved the comfort of both parties. The participant felt comfortable so it was decided this set up could be used in the real interview process.

6.3 Participant feedback

The participant was asked to give feedback on all aspects of the interview process, so we started the discussion by considering the initial question. The participants felt that the initial question in the interview was clear and set the direction of the interview. The participant did go onto say that Junior Doctors may have completed the whole process for PEG consent so I could ask them about their perceptions and what they have been involved in, this would give me larger amount of information into the subject.

To assess my interview skills I asked the participant to comment on the interview style. The participant felt that interview probes used to gather information around the topic being discussed where effective in gaining in-depth information. The participant also stated the interview style used put them at ease when discussing the research topic. The participant outlined that the fact they were being interviewed by someone who understood the topic of the research being understood improved the credibility of the research and that I as the researcher should be more confident.

The participant talked about being flexible around the timing and venue of interviews due to the busy schedules of Doctors. I had already considered this and recognised that getting access to Doctors time could be challenging and it would mean being very flexible.

Finally the participant was satisfied with the interview structure and things I felt may be problematic such as the tape recorder did not cause a problem. The participant did suggest also completing further research into this topic on different specialities, this comment was taken into account.

6.4 Researcher considerations

The completion of this research pilot gave me as the researcher greater confidence as a novice researcher to interview doctors who I regarded as having significantly more power and educational prowess in their field than myself. I had felt there was a power imbalance between me as the researcher and the participants, however this was aided by the pilot as the doctor interviewed pointed out although I am not a doctor I have knowledge on the topic which improved my confidence. During the research I also found it difficult to probe as when the participant was discussing their experience, I found it difficult to probe deeply through fear of making the participant uncomfortable and felt that affected the richness of the data collected. Following a discussion with my Masters supervisor I decided to relook at the methodology I was using to gain greater insight. Large (2008) discusses that in Heidegger's hermeneutics he outlines the world closest to our everyday existence for existence driving a car is simple and familiar to some people, it is only when something different occurs (e.g. a lion roars) that something becomes fearful or different and perhaps may cause an issue. Whilst the doctors interviewed talked simply about the consent process, it was my role as the researcher to probe and not be afraid to find out what happened and why the world that was familiar became more difficult, as by doing this, my research would contain more depth.

On listening to the recording of the pilot interview I noticed that sometimes I talked quickly and sometimes unclearly as well as saying um and er frequently. The completion of a pilot allowed me to review the tape of the interview, I then knew to slow down my speech and speak more clearly, I hoped this would improve the understanding of the participant and the flow of the interview. I also realised that the initial question used worked well so did not change it prior to starting the real

interviews, I did however plan to ask participants their general opinions if they could not think of a specific experience of PEG consent.

7.0 Results

This chapter will discuss the results that have been collected and analysed. The results in this research were in the form of taped interviews that were completed and then transcribed with field notes. Thematic analysis was undertaken to analyse the data collected, the specific methods are described below.

- Taking raw data: Ensure recordings are clear and field notes from each interview were available.
- Organising and preparing: Ensure transcripts and field notes are clearly prepared manuscripts ready for analysis.
- Read through: researcher wanted to immerse themselves in the data.
- Coding the data: The data was given codes which reflected the data content, this was done by hand by the sole researcher.
- Themes and description: Identifying the themes that have emerged from the coding process and a description of them.
- Interpretation: Unfolding the meaning of the major themes and sub themes through the interpretation of the researcher.

During the assessing and coding stage of the research analysis codes were given to the research as per Appendix E. These where then divided in into sub themes and finally major themes. Moule et al (2009) discusses the use of codes reduces the amount of data and allows for larger themes to be uncovered.

Four major themes were identified from the interview transcriptions. The first theme was Process VS Task, A process is a series of actions taken in order to achieve an end point and a task is an activity that needs to be accomplished, so what is PEG consent? In order to legally consent for a procedure, documentation needs to be completed with the benefits and possible risks placed clearly on the consent form. The completion of

this documentation is a task that must be completed prior to the PEG procedure being completed. Theme one will consider if PEG consent following a CVA is in fact a process and not just a task, how do doctors view this and the processes that PEG consent involves.

Theme two is 'collaborative working'. Collaborative working is when a group of individuals work together in a joint intellectual effort. This theme will consider if Doctors perceive a multidisciplinary team (MDT) approach is required as part of the PEG consent post CVA and if so, what teams should be included in this and what are their roles.

Theme three is the 'process of interaction'. An interaction is described as a communication of any sort between two or more people. This theme will consider how Doctors begin communication during the PEG process, who they interact with and the possible barriers they could face.

Theme four is 'preparation to consent'. The words preparation or prepared are the state in which someone has been made ready before hand, they are then in a state of readiness in anticipation of a specific event. This theme will discuss how prepared Doctors are to complete the process of PEG consent post CVA, it will also consider the routes of preparation to consent.

7.1 Theme one 'Process VS Task'

7.1.1 The Signature

If a patient gives consent to a procedure it would usually involve a period of time where they would be asked to sign a consent form, this would then be seen as evidence that they gave consent, in the form of a document. The participants in the research all outlined that consent is not just one period of time but a process. The signing of the

consent form is however the final agreement by the patient that they want that procedure so should still have adequate consideration. The importance of documentation was discussed by several of the doctors that were interviewed, but they still felt that consent was an in-depth process no matter what level of doctor they were and all this should be considered before the final signature. The legal aspect of the final signature was also discussed as an aspect of the final process as outlined below.

"Consent is in fact a process so that although the junior then signs to say they explained it, when the person goes down to have the procedure then the Doctor doing the procedure goes through it again." ***Interview2 page 5***

It is often the assumption that at the time of the consent form being completed by the doctor that all assessments and explanations have been completed, including multidisciplinary communication regarding decisions relayed to the person completing the final documentation part of the consent process. However, this may not always be the case and at the end of the consent process, not all aspects have been relayed to the doctor completing the final paper work as outlined below.

"I suppose the focus is on the immediate, I guess yeah it's not really public in terms of, and I suppose that when you fill in the form it's just filling in the form. But it's not actually explained the long term implications for it. I guess that's because you guess that's been done before but then perhaps it not." ***Interview 7 page 9***

The signature gained from consent, although an important legal aspect, has been discussed as just a short part of a process, and what takes time is the several different elements within the process. This quote identifies consent is actually a clear plan or process which should not be rushed and highlights quality of life as an important consideration in the consent process.

"You should make a clear plan with what the prognosis is and quality of life so that all those issues need to be taken into account, should not be rushed" ***Interview 8 page 6***

Establishing that PEG consent for stroke is a process is important to ensure that thorough care is being completed along all steps in the process and it's not just viewed as a single task of ensuring the final signature is on the legal documentation.

7.1.2 Does the patient need a PEG?

The Doctors discussed that PEG consent is in fact a process and not just a signature on a legal document. Throughout the interviews it was clear during the initial phase of the consent process that the doctors would want to make sure that the patient truly required a PEG. They wanted to ensure that it was not just a quick fix or an unnecessary procedure as illustrated, so thorough consideration would be required as illustrated by the quotes below.

"The main process of consent for PEGs is that whether first of all we have to decide if we need that or not, if they need the PEG then we will have to make sure that the person who is having the PEG needs to know whether or not what involves and why they are having it so that needs to be explained to this person." ***Interview 5 page 1***

"If I am the patients consultant and in most cases I am em I would reassure myself that the patient needed the PEG." ***Interview 1 page 2***

The initial considerations on if the patient requires a PEG would mean consideration of the patients current condition. If a patient has a stroke the ability to swallow can be affected, return or not return so the decision to see if the patient requires a PEG can be a straight forward plan but is often a difficult part of the consent process it is not a clear cut task. This again suggests that the initial phase is an important part of an overall process. The quote below outlines this phase of the consent process post CVA:

"Ok well the initial process the patient comes in presumably a stroke can't swallow and we realise they would benefit from a PEG" ***Interview 6 Page 1***

During the PEG consent process the initial assessment of whether the patient requires a PEG may take time and be patient specific. In theory assessing a stroke patient to see if they require a PEG should be simple but often is more difficult and every patient is different. In some NHS trusts there is a plan which includes assessing what level of risk of aspiration the patient is, this could impact on patient choice as discussed by SIGN (2010). Medical teams may need to be made aware of the variations of swallow assessment and consider that a straight forward question of of whether they can swallow or not is not always the case with stroke patients possibly requiring a PEG. Considering the ability of a patient to swallow or of their swallow to improve is a process within itself, but is also a phase of PEG consent which again outlines that PEG consent is in fact a process as demonstrated by the below quote.

"Well the first thing is to establish that the PEG is appropriate and that its required in someone who's got a CVA and that requires assessing the level of risk that the patient is at " ***Interview 2 page 1***

NICE guidelines for nutrition (2006) support discuss that patients should be left between 2 and 4 four weeks with NG feeding before considering PEG, this would give patients time to see if swallow ability will improve post stroke. This time scale would differ in emergency situations where there was no route for nutrition. The Doctors discussed that PEG consent is a process, it is clear from the guidance from NICE (2006) guidance that PEG consent is a long process and not a quick decision. The below quote suggests that if a patient looses their swallow post stroke it does not mean they need a PEG instantaneously and they need proper assessment throughout the process.

“They need the diagnosis to begin with and once they have been initially been diagnosed with stroke we would not go in straight away and do the PEG procedure um so the patient would be assessed by the speech and language therapist after they had a nurse swallow assessment on the ward. If they had a failed salt assessment then they would be NG feed and you would want to see how they got on with that first whilst you’re evaluating the rest of their co-morbidities.” **Interview 10 page 1.**

This again outlines that PEG consent is a process and not a one off task but a process with several elements that need to be considered before placing a PEG tube.

7.1.3 Co-morbidities and physical fitness

When faced with a patient that has just suffered a CVA, medical teams can find the assessment and the planning process for PEG consent difficult. A CVA is not something that affects everyone the same way and the rehabilitation potential is not always obvious immediately following a stroke. Another phase of the consent process for PEG would be to consider the impact of the CVA which may be difficult for junior Doctors with less experience. A Junior Doctor with experience of stroke was able to discuss this point.

“I guess the trouble with stroke, no one ever had a stroke in the same way, and never will communicate in the same way and have different family. So you can never say this is the way to do it.” Interview 7 Page 7

It’s not only the CVA which affects the assessment part of the PEG consent process but the other aspects of the physical health of the patient. So following the consideration if the patient requires a PEG insertion the next phase of the process would to be to consider other co-morbidities and surgery. The participants discussed that they would speak to gastroenterologists in conjunction with the stroke team in

assessing for risks such as previous abdominal surgery. The quote below from a stoke doctor suggests this.

"They only looked at things like if they had previous abdominal surgery and clotting and things were fine but the main decision was made by the stroke physicians" ***Interview 6 page 2***

The process of PEG consent means that you have to consider the whole picture of the patient, the physical and functional status of the patient. This process is not just a quick task but a process over a period of time, this was discussed by all levels and specialties as demonstrated by the below quotes which are from a gastroenterologist and gerontologist. This suggests it is a view held by all doctors involved in this process.

"Just to give you the whole picture and not just jumping in at point x and saying I am going to get them a PEG or not and look at the whole pathway." ***Interview 10 page 7***

"You have to look at the whole picture and look at the underlying co-morbidities and cognitive states was and take that into account on top of what has happened as a new event. " ***Interview 8 page 2***

As part of the PEG consent process, the doctors outlined the importance of when to establish the patient's previous function regarding ability to take diet and complete activities of daily living when deciding if a patient is appropriate for a PEG to ensure patient specific care underpins the whole process. If a patient lacks the ability to swallow it may be that it is presumed that they will have a PEG, but this is not a clear cut task as it involves looking into the patient's previous function and likely rehabilitation potential which these statements illustrate.

"I tend to look at previous clinic letters to look at what their functioning was like previously. I speak to family members about what degree of decline there has been

over the preceding months and years before they had the stroke to help you to judge. " ***Interview 10 page 7***

"How much is potentially reversible and what the underlying base status was. " ***Interview 8 page 2***

Previous function should be considered as a phase of the PEG consent process including previous diagnosis prior to their CVA. As the patient information is considered as part of the whole picture of the patient, dementia may be considered. It is common that patients who suffer a stroke often have the diagnosis of dementia. This was outlined by Henon et al (1997). As a result of this and the older age of this client group there is a large cohort of patients that have suffered a stroke who also have a diagnosis of dementia, as it is well documented that patients with dementia would not benefit from a PEG due to the level of mortality following the procedure, as discussed below. This junior Doctor felt that this evidence meant that PEG may not be appropriate in dementia patients.

"The only time I have come across it where it never really got that far is for people who had dementia that have had a more severe stroke. I guess the assumption is that there it's not for a PEG full stop. So we never really get as far as to start discussing artificial feeding and that was the only time." ***Interview 7 page 1***

During the PEG consent process, assessment around dementia is important as the documented evidence suggests that people with dementia should not have a peg but this is often a grey area of debate (NICE 2006). Often relatives say their family member is confused therefore the patient is labelled as 'having dementia' so many not be given treatment as a consequence of this label or if a patient has early stage dementia and had previously been functioning independently they also may not be considered for PEG. An important part of assessing for peg consent includes uncovering the true

function and accurate diagnosis prior to any intervention to ascertain an in-depth picture of the patient as explained below.

"Um yeah, a lot of people come in with a diagnosis of their family when they are a bit confused so actually from working on the stroke unit one of the consultants was quite it was quite impressed upon us to find out from the memory clinic and has a formal diagnosis before you can consign them to without artificial feeding." ***Interview 7 page 2***

"You know dementia happens in the old age psychiatrists and they are not very good in communicating that information to us because they keep their own logs, and our dementia nurses are the only ones that have access to them and as a result of which dementia means nothing to me. That might be a erm label that has been attached incorrectly to someone and with someone end stage dementia you need to know erm the level of dementia, who has made the diagnosis, because I have had people saying known dementia which they actually have Parkinson's disease that has been untreated. The person then goes under the label of dementia and then gets deprived of the proper treatment. " ***Interview 5 page 2***

During the consent process the assessment of patients in a situation where dementia has been diagnosed can be difficult. It is often difficult for the doctors to assess because the loss of swallow could be due to the stroke or the dementia. The story below illustrates the difficult circumstances medical teams are put under and may illustrate where a team approach may be required in this process to fully understand the best interests of the patient.

"Ooh actually I have, it was regarding a PEG in a long term dementia patient who I think eventually, I don't know what the answer was um one consultant wanted to it and another didn't and the family where absolutely desperate for it . She was young a fifty

year old with dementia and they wanted her to go into a clinical trial um and it was a really difficult decision to make I think the geriatric team felt she should not have one because her swallowing problems where related to dementia rather than a stroke. If it was a stroke reason then they may have sad yes in the best interest of the patient you would do it but because it was due to the dementia we did not do it. That's a very difficult one." ***Interview 9 page 5***

Considering the physical state and co-morbidities is an important aspect of the PEG consent process and it has been clearly outlined that this aspect of the process cannot just be task orientated. The team involved must be aware of the full picture of the patient prior to making any decisions.

7.1.4 What information do patients require prior to PEG insertion?

With most medical procedures the consent process involves explaining the risks and benefits of the procedure and how the procedure is to be completed as part of the specific procedure process. PEG consent often needs to be much more of an in-depth process as PEG placement can actually have an impact on the rest of the person's life. Patients need to truly understand both the risks and benefits but also the impact on their life, this is done as part of the consent process not just prior to the procedure. This point is illustrated by two gastroenterologists that had firsthand experience of PEG placement.

"Well I mean well as I said initially to make the patient understand why it is being done and to explain the procedure to the patient and also explain the possible complications". ***Interview 1 page 1***

"Um well initially the decision to undertake the PEG the patient to have a PEG from my experience the decision is made quite quickly without any thinking of involving the family of any co-morbidities, sometimes getting the referring team realise that actually

their PEG referral was not appropriate for that particular patient, so that issue. Then actually if the consent has not been done correctly or if the patient does not understand the definite medical decision that has been made by the team, then I find that very difficult as the person putting the PEG in I would not be comfortable to do that." ***Interview 6 page 2***

Whilst the word PEG itself does explain what the procedure is, patients do not understand what a PEG is and there is often the assumption that they do. This should be discussed during the explanation phase of the consent process. As the previous quotes from doctors illustrate, the risks and benefits of the procedure need to be explained, but it is essential that they understand both what the PEG is and how it will impact upon their lives, as highlighted by two gerontologists.

"A PEG does not explain to the patient what it is, so it should be explained more fully" **Interview 8 page 4**

"I think that PEG is more than a straight forward procedure, it's quite invasive, and it changes the way people work, function physiologically as the normal eating process is changed. There is a lot of gratification in the act of eating which I am not sure they will be getting."**Interview 4 page 1**

The explanation of the risks and benefits for PEG is not a tick list task orientated discussion with the patient. There is a clear need to discuss with the patient how a PEG will impact their lives and the specifics of this, for example, how they will receive food and fluids. The route and preparation of medication should also be considered during the assessment process so that a plan can be made prior to discharge with the patient. A PEG can also effect the discharge destination, depending on their needs, the patient should be aware a PEG could affect where they are discharged to. Patients and their family members could be made aware of this, but it's unclear if the medical

teams discuss this during the consent process. Things that impact on daily life could be considered, the below quote is from a very experienced consultant, this suggests one area that needs consideration.

"It would be good if someone looked at the medication they are on and see which bits of medication are easy to administer through a PEG or appropriate to administer through a PEG. " ***Interview 4 page 5***

"Well um as I said the patients that I looked after were able to communicate one way or another so um obviously I had to ask them questions where they could just say yes or nay to me questions. Thankfully I had no problems with that." ***Interview 6 page 2***

The complex consent process requires someone who understands the procedure in order to assess the patient and explain to them what it means for them in the long term and on discharge. Patients are all different so this process cannot be task specific and is a long process which should be completed by people who understand it in-depth. The participants of a senior level that were interviewed appeared to understand this more than the junior Doctors and this is displayed in the quote below.

" The technicalities of the procedure can be explained but also the reasons why we think this is the appropriate treatment and give them an idea of what or how they are going to look after the PEG post procedure and give them and IDEA of what sorts of complications to look out for so that they are fully aware." ***Interview 3 page 3***

" I do believe with something like a PEG the consent has to be taken by someone who truly understands what's going to happen to them" ***interview 4 page 1***

In the current day public health sector, doctors may feel pressurised to complete tasks quickly due to time constraints and there is a lot of pressure to make decisions quickly and persuade a patient to consent quickly. The patient should not be pushed and as

part of a thorough consent process have all of the information provided to them to ensure they make the right decision about their care.

“It’s very easy to be steamrollered into something without a proper insight.”

AND

“The team need to have a good understanding of the procedure benefit but be in a position to make sure the consenter is well informed and has enough insight to make the right decision” ***Interview 4 page 4***

In conclusion the evidence described in this theme suggests that consent is not just a task but a patient specific detailed consent process with several key phases, this conclusion should be illustrated in practice.

7.2 Theme two ‘collaborative working’

7.2.1 MDT communication

The previous theme illustrated that consent for PEG post CVA is a complex and often difficult process, it was also discussed that this process required collaborative working. With the multiple elements to consider throughout consent process for PEG, it is obvious that multiple skill sets will be required to complete this process. There was clear evidence from the Doctors that there was a need for a multidisciplinary (MDT) approach to this process to ensure the best outcome for the patient. The below quote puts this in simple terms by outlining why this process is necessary.

“I think it would be very difficult to make a decision alone, I think other agencies need to be involved, you would not make a decision without discussing it?” ***Interview 4 page 2***

If there is not a collaborative approach to PEG consent then problems can arise once the PEG has been placed and it can be difficult resolve problems later on. If PEG

consent has not been completed properly and the patient was not given all the information prior to the procedure then surely the informed consent would not be valid? Some medical teams may think they are acting in the patients best interests and do not realise until after the procedure that they needed advice, this is outlined below.

"I hope a PEG would never just be put in to get a patient home but that's a hospital you know, then they have been moved on for another agency to look after them, I think that would be a terrible indemnity of the system ***"Interview 4 page 3***

Some senior clinicians who have a lot of experience may be reluctant to listen to junior members of the team or allied health professionals despite the GMC (2013) code of practice outlining a need to ensure skills and knowledge are kept up to date. This is often due to the fact they have been in post longer so feel they know more and do not realise that new changes or developments are being used in practice. A forward thinking senior clinician outlined the importance of MDT working as discussed below.

"Professionals should know themselves and listen to what the juniors are telling them and what other healthcare professionals that this is what they should be doing. So these are some of my experiences."

Interview 5 page 1

An MDT approach is essential to ensure an appropriate plan of care is being given to the patient. Collaborative working ensures the different elements of the consent process are all completed to give the best individualised care. As part of this process effective communication between the different teams is essential, especially with the team who are primarily looking after the patient. This may however need the doctors to have insight and experience to know which colleague to discuss the patient with and realise that discussion with colleagues may improve the patient's consent process. This is identified below

"From my point of view the SALT team sometimes come and review are our patients and they come from a separate thing and they say they are a t very severe risk of aspiration. We are all like where did that come from erm and it really does affect our management of the patient from there on in. Because you know should we feed them should we feed them at risk, has there swallow always been like this, is it slightly worse now because they have come in with a urine or chest infection." ***Interview 6 page 3*** *(note this quote is used twice)*

In the event being described by the doctor, there was obviously a breakdown in communication and a possible misconception of each other's roles. The SALT team may consider that a swallow assessment is just a test and do not realise that Doctors may need support in decision making. Being told a patient is unsafe to eat and drink may make doctors not want to feed the patient but at the same time they may be unsure what they need to. I think this would also explain the concepts in the quote below, as it is clear that in some circumstances SALT and medical teams may need better lines of communication. This again like earlier themes reinforces the need for team working.

"I think the idea of feeding at risk is another thing that I have looked at and many other people have looked at for a long time now but its only recently when the royal college of physicians actually got together and actually produced some guidance that it s actually swayed people away from starvation from speech and language teams." ***Interview 2 Page 3***

During the interviews there were some examples given where medical teams discussed the usefulness of the SALT team in communication with stroke patients when trying to obtain consent or assess capacity, this gives an example of how team collaboration can provide patient centred care. A junior Doctor outlined that the roles of

the SALT, dieticians and nutrition teams are essential in certain aspects of the PEG consent process, by outlining that these aspects of consent are something they would not be able to do. It was not clear if the junior doctor had any understanding of the roles of the MDT in PEG consent at all. The quotes below provide evidence of this.

" If they can't speak its more difficult even I would find that difficult because you have got to find a way of communicating and maybe you would have to do it with let's say the speech and language therapists and they have ways of communicating um and that would be a suitable multidisciplinary thing and even sometimes in those cases we wouldn't be consenting them directly because we were doing it in their best interests but maybe using say indications that they have made by nodding if they understood." ***Interview 9 page 3***

*"Well normally this is something that would be discussed before deciding suitability for a PEG. Not necessarily by me because speech and language would do quite a lot of that and the nutrition team and dieticians would have done there bit of that..so I have never been that involved in that side of things. Unless patients ask directly."****Interview 8 page 3***

7.2.2 The Nutrition team

Research was completed by Joseph-Williams (2014) which outlined patients felt they were not always in charge of their own care but felt it was their consultant who was in charge and they wanted a more collaborative approach to their care. Doctors could feel that they know the patient best so they should be able to make the most appropriate choices for that patient. It has already been outlined that consent is a process with several elements included in it so it would be difficult for any single speciality to manage. A lack of communication could also be the reason as to why medical teams

do not refer to outside agencies as discussed earlier in the theme. This was recognised by one of the senior consultants.

"I think from a personal basis for the most part I have not found it particularly difficult but I can see that some people would and a lot of people would feel uncomfortable if they did not have much experience in this area. Um so that is actually one of the strengths of having a nutrition team and erm you either have a specific interest in it or you don't and that one thing that I have developed over a number of years." ***Interview 2 page 2***

So it has been outlined several times that nutrition teams are required to help and ensure there is a comprehensive process for both before and after PEG for the Patient, providing a specialist service for collaborative working and ensure a comprehensive PEG process. Nutrition team contains several specialists that help aid the process as well as the speech and language therapists. As suggested below:

"Liaising with the dietician and other members of the team to get a more comprehensive approach to nutrition rather than just put something in to get the nutrients in and there should be a comprehensive approach." ***Interview 5 page 2***

Specialist services may be often limited, over stretched and only have 5 day working, the idea of the perfect service could be difficult due to lack of time. This lack of time could mean that communication between teams is difficult and not stream line as patients and their relatives are often getting different information as multiple teams feel they need to keep them informed. It may be that collaborative working is in place but that communication is limited due to resources. This consultant sums this up by outlining more team working could be required and what may be required.

"I guess in an ideal world you would have them, you would talk to the patient perhaps decision has been made they are going for a PEG, you sit down and you explain to

them with the doctors, nurses and nutrition team, this is what it entails, involves and this is what the long term things are. At the end of that conversation you sign a bit of paper. Of course in practice they have a little bit from the nutrition team and they go away, then they have a bit from the consultant, and then someone else comes back with the form to sign a week later when they have an appointment because it is on the day of it and it is not very joined up." ***Interview 7 page 6***

If time is lacking and the nutrition teams have the expertise but not the time or resource maybe they should supply information to aid the medical teams in completing the PEG consent process. It should be concise information that is clear and simple to give junior staff information about PEG consent and what they need to do. At the same time doctors should take some responsibility to use what they do have to read, for example the patient information leaflets, it should be a team approach not just a nutrition team approach as shown below.

"We have got the information booklet, the patient information booklet which highlights what the risks and implications are." ***Interview 10 page 6***

"Well I think you could um I don't know if there guidelines or a short bullet proof leaflet that could be that could accompany ha ha even more paper work any specific PEG forms so if you have a PEG consent form um then they should travel with a four or five bullet point theme just to mind people what the rules are "

AND

"Um and from the point of view of the implementation of that do you think that um the nutrition team could play that role or the nutrition nurses would play a part in that."

Interview 1 page 3

A multidisciplinary team approach is essential to a fluid consent process that we already know from other themes includes several complex phases to ensure the most appropriate care for patients that may need a PEG post CVA.

7.3 Theme three 'the process of interaction'

7.3.1 Capacity

As part of the complex multiphase PEG consent process it was discussed that communication was required between healthcare professionals. This theme will consider communication and what possible complexities this aspect of the process may prove in practice. In order to both communicate and take consent for a procedure the patient must have the capacity to be able to understand information, retain it and relay it (GMC 2008). This is to ensure that the patient can weigh up the information that is being provided and make a decision that is best of them. The PEG consent process according to the Doctors interviewed should have the patient at its route focus and the patient's ability to make that decision should be one of the first things that the medical or multidisciplinary team assess.

*"Like I said the first thing is to look at what the rehabilitation is going to be like and look at the patients capacity and the appropriateness of the procedure um being involved in the whole process as well as the consent suitability for PEG as well just the consent from the patients as well as relatives as well."****Interview 8 page 1***

As part of the consent process for peg, medical teams have to decide by any means if the patients have capacity. A comprehensive assessment may be required…… small chance that the patient does not have capacity then everything is done to ensure this is assessed correctly. The patient is in hospital because they have had a stroke and are unwell, this may mean that their capacity could fluctuate because of things like sepsis or just due to the CVA (Nice 2008), so assessment should be complete at the correct

time. This was discussed by several doctors who argued that the ability to consider a patient's capacity prior to consent as an essential part of the PEG consent process.

"If you don't deem them to have fluctuating capacity or you think they have no capacity to understand the procedure or retain information sort of weigh it up um you would make the decision based on their best interests." **Interview 10 page 2**

AND

"So as I said firstly you need to be sure as to the relative benefits and risks before you can reasonable discuss it with anyone else and er that process ascribing some degree of risk or risk scale does enable that to happen." **Interview 2 Page 2**

The consent of not being able to swallow and eat and drink normally may be a difficult concept to come to terms with and sometimes patients may say no to PEG and choose to eat at risk which could be a difficult choice to make. Taking food orally could result in chocking or severe chest infection which could prove fatal (as discussed in the literature review). Patients who have capacity should understand the choices for treatment they have, think about them and make a thought out choice. This is outlines below:

"We had a patient recently that was refusing a PEG because he had a progressive illness and he didn't want to go down that route. I just think that where patients have got full capacity then it is there decision as long as they are making a fully informed decision." **Interview 8 page 3**

AND

"Do they know do they have an understanding about their swallow um the safety of their swallow, the risk of aspiration and whether or not they are aware of what is

actually going on in terms of, actually do they know they are being NG feed or do they know what their clinical situation is like." **Interview 10 Page 1**

Obtaining consent and assessing capacity can be a difficult task for most doctors prior to a PEG insertion. With patients post CVA it can be especially difficult because patients may have communication problems or lost their capacity as a result of the stroke (as discussed in the literature review). Often medical teams and allied healthcare professionals use all possible means to communicate with patients but sometimes this is not possible and decisions are made in the patients best interest. This could be difficult for the medical teams. This is outlined below:

"Well maybe just like anybody the communication difficulties especially if they had a CVA, the comprehension, patients with expressive dysphasia they don't know if they fully understood it um so in that case they need to speak to the family as well, the family are not the ones that sign the consent form but they should be aware of the risks and benefits because they may be looking after the PEG for the patient when they get home." **Interview 3 Page 2**

AND

"I think my concern in taking consent from people who have had a CVA is that do they have an understanding of the whole process. It is sometimes difficult to do because some people who have had CVA you are not sure that they are receiving information er your not sure it's being processed, and sometimes there responses um may seem logical but in fact they are completely disconnected so that's what the cva or stroke does to the brain it somehow jumbles it up." **Interview 1 page 1**

There could be two schools of thought around the difficulty faced by doctors when assessing capacity and consenting for PEG post CVA. The difficulties medical teams endure have already been discussed. Some doctors feel that it is a difficult task and

that they are ill equipped to assess capacity but interestingly all doctors mentioned the multidisciplinary team during the interview. Other doctors outline that despite the difficulties, patients post CVA experience a good service and process because of the MDT and the fact they are an inpatient for some time and their medical teams know them well. This is compared to other medical specialities other than stroke, which may outline that further consideration may be required into other specialities experience around PEG onset as outlined.

"I find it less difficult in stroke patients than in some other patients and often the teams that are with the patient day in day out they are working with the patient have got a very good understanding of what there recall of information is so its very heavily guided by what the team that are there feel that persons comprehension is and cognitive patterns are and they are not as variable as in certain other conditions." **Interview 8 page 1**

The doctors discussed that as part of the capacity assessment, patients are often assessed several times for capacity if on first assessment the patient does not appear to have capacity. It is possible that a speech and Language team could assist capacity assessments with communication aids, but this should be completed as a team collaboration. It is important that those who complete the capacity assessment know the patient, know what the patient's baseline is and assess mental competence. If this is difficult the consultant may need to be more involved, sometimes saying the patient has not got capacity could be seen as the easy way out. It should not be left to the endoscopist, this again indicates that the consent for PEG is complex.

"So I think clinicians on particularly strokes wards where PEGs are put in a lot should have that knowledge. I don't think the necessarily need to have seen It done but they have to have an understating of what's involved in the process and so on. But far

important that that is understanding the patient and knowing what the current mental competence is."+ "More suitable for a senior clinician." **Interview 4 page 1**

AND

"Sometimes but sometimes it would be more suitable for the team looking after the patients to, but on occasions I have done it, especially when you go to consent and the family are there , then that's the case." **Interview 8 page 2**

Thorough assessment of capacity prior to PEG insertion is an essential aspect of the PEG consent process. It means that the correct decision can be made for the patient during the assessment process. Once the capacity and ability to interact has been assessed then the other aspects of interaction can be considered.

7.3.2 Patient interaction

The communication during the PEG consent process may also complex even if the patient is deemed to have capacity. Communicating with a patient following a CVA can be difficult (NICE 2008), this may be regardless of the topic of conversation which is required. Following a CVA often it is not only the swallow that is affected but the ability to communicate can also be impaired. The stroke Doctors are usually expert on this topic and have a good grasp on the type of deficit the patient has, they also usually are able to then assess capacity and make a plan on how to communicate with the patient as discussed below.

"So what happens when this person stroke is that when you have a stroke and the swallowing and you may also lose your speech at the same time and there are two aspects of losing their speech. One is the expressive aspect which is called expressive dysphasia and the other is the receptive aspect which is called receptive dysphasia so

to initiate the consent process you need to make sure that this person has the capacity to understand." **Interview 5 Page 1**

So the participants discussed communication can be difficult post CVA, but if patients have capacity then health care professionals have the responsibility to ensure the patients voice is heard in whatever form is possible. Doctors feel they have legal responsibility to insure the consent process is valid which is difficult, as discussed below.

"When we do it post stroke the communication is sometimes lacking and there are sometimes other issues so talking to the patient and communicating with them in order for them to get consent makes it quite difficult to get a valid consent from them in terms of communication and things like that when doing it." **Interview 9 Page 1**

Although participants realised the importance of completing the consent process the Doctors discussed that it is difficult to communicate with patients post stroke which may affect the validity of the consent process so Doctors should be aware of support available with specially trained SALT therapy for patients. SALT healthcare professionals help aid interaction between medical teams and patients, by incorporating resources such as word boards to communicate with the patients (NICE 2008). This can be a difficult and lengthy process and is a challenging aspect of PEG consent post stroke that medical teams have to work through. There is a fine balance though and patients can find it difficult if too many people get involved and then the patient feels overwhelmed. The teams in charge should manage this and ensure care is patient specific, as outlined by an experienced gastroenterologist :

"The more people they are bombarded with then they become a bit scared a bit intimidated, so think it's better to have one person that's interacting to them mainly but if you really think it unnecessary but I think less is best." **Interview 3 Page 5**

AND

"The stroke team where I was were very good with aphasic patients that there was alternative ways to communicate and them to communicate with us um so normally we were able to be happy that we were communicating well" + "Um there where word boards and various things they could point out" **Interview 8 Page 1**

The previous quotes illustrate that communication post stroke is difficult which can make interaction difficult between teams and patients. With the ageing population that have a CVA there could also be an increase in patients that also have sight and hearing difficulties that they suffered with often prior to the stroke. It could be thought that a patient with hearing difficulties does not have capacity because they do not respond appropriately. As part of the consent process healthcare professionals must consider any communication deficits patients have and appliances they may need in order to interact, the importance of this was discussed by a senior stroke consultant.

"Obviously there will be issues with some of the older patients as to whether they can see or hear to try to make sure they are in the best position possible to actually be in the best position to have the information explained to them and I am afraid that's not always done very well. Its something that we struggle with, we don't even have on many wards any um audio equipment to facilitate peoples hearing and so I don't know what's happened we used to have ear trumpets at one time, then electronic things that don't work then nothing. So I don't know if something needs to be done." **Interview 2 Page 2**

Even if the patient is able to hear the healthcare professionals there can be other barriers in the interaction between patients and Doctors in the PEG consent process. In a culturally diverse area there are often patients who do not speak English as a first language and an interpreter is required. This can make a challenging process even

more difficult than it was already as interpreters cannot be instantly available and for less common languages difficult to access during the PEG consent process. This is discussed below:

"Certainly can be a problem occasionally but we can usually overcome that within recent years the er translation facilities are to be cut back rather than increased which can also be an issue and of course we are not technically allowed to use relatives or people close to the patient to do that translation." **Interview 2 Page 3**

Interaction with patients around discussing consent for PEG is difficult and needs a degree of team work. This can be made more difficult if the patient is found not to have capacity, so making an already difficult process more complex.

7.3.3 Family interactions

Following an initial communication with the patient and assessment of capacity it may be the case that the patient does not have capacity. If a patient does not have the ability to consent, the decision to place a PEG will be made by the medical team in charge of the patient's care, who would then make the decision in their best interests (GMC 2008). The next of kin would not make consent in place of their relative but in order for the doctors to make a decision in the patient's best interests they would need to interact with the family to assess what they think the patient would have wanted (GMC2008). It may be important to make a decision in the patients best interest, but this can involve the family as they often know the patient well so it may be important to not make the family feel shut out of the process but involve them to make the best decision for the patient. It also may be important to ensure they do not feel totally responsible for the decision but are involved with the process from the beginning as explained below:

"Involving the patient and the family right from the start, that we are concerned with their swallow there was a chance it would get better but if not then this would result in you know, telling them early on in the admission, so telling everyone, so good communication right from the start and saying for the time being and then telling them as things involves definitely crucial." **Interview 6 Page 3**

The Doctors interviewed discussed that during the interactions with family it is essential that healthcare professionals continue to interact with each other so the information given by each member of the team is the same and not conflicting. If one member of the team does not know the answers they should ask another member of the team to assist so the family to get the correct information, this can also improve trust if information given is correct. This is identified below:

"I think it's like anything the more information you have the easier that discussion is to have and if they do not feel comfortable and knew enough than I would have a nurse there, but if I had more information than perhaps I would have that discussion on my own." **Interview 9 Page 2**

AND

"So it's kind of working together and not rushing it" **Interview 10 Page 3**

Interactions with family can be difficult and lengthy processes, it may not just be making sure the family have the information but making sure it is delivered in a dignified and honest way. Three senior consultants outline that these discussions are difficult as PEG is life changing and may not actually be in the best interests of the patient. The Doctors outline that quality of life is sometimes more important than prolonging it. This is very difficult to explain to an emotionally charged family who do not want their relative to die, doctors feel pressured to do everything to keep the patient alive even if it is at the expense of the patients comfort. Below are three statements

that put into perspective the difficult interactions that Doctors face and the fact that PEG consent post CVA is a difficult process.

"Society has lost the ability to accept that death happens and some life is not worth preserving, it should not be we keep people alive at all costs. I think people have accept, I can remember when I was starting general practice defiantly before you were born, going to an 85 year saying she's had a good innings but you cannot do that. They will say your retaining is high you have to go in. Its incredibly interventionalist. I don't think we should be, my mums very old and a bit forgetful and she does not want to be kept alive, if she had a stroke she would not want a PEG. She does not want that and I think it's wrong being kept alive when actually you do not want to be alive." **Interview 4 Page 4**

AND

"*The patient is central theme and family members cos family members are not er there not always altruistic you have to be aware that these patients are often in the evening of their lives and um they have had a stroke which may lead to their death soon so you have to be very careful when you deal with families and you should concentrate on the patient which is what I do."* **Interview 1 Page 3**

AND

"The right thing we as profession and this happens not just at (a specific hospital) but all of the UK, we are very scared to give bad news to people. We are very scared to say that your mother has reached the end stage of Parkinson's, renal disease and your mother or relative is going to die, and whatever we do is just going to prolong their life and not their quality of life necessarily." **Interview 5 Page 3**

These discussions could be difficult and often family have strong views about if the patient is to have a PEG or not and have reasoning for their views. The doctors interviewed discussed families have often been through a lot and are upset and need support and explanation. Some families understand if the team explain the patient is not fit for a PEG they accept the decision, others find this difficult to accept as outlined:

"The views of families and people with particularly strong views one way or the other and obviously and there is also the fitness of the person to undergo the procedure and erm those are all things that we would enclose in the er discussion." **Interview 2 Page 2**

AND

"I think it could I have not seen anything specific to PEG, I think the difference is do the family think their relatives should have everything or where the families think actually oh leave them alone and I think there's sometimes quite a dynamic split in which way these families go so some say I want them to have everything including it or thinking you mothers got heart failure she's got kidney failure you know we are going to really struggle even if we do everything and even then, where others will say she says she's got less problems and she has always said she does not want much intervention let's just let her be. That's, its equal and it's the patient's wishes that you try and take into account when they are doing it cos what is quality of life to them may be different to us." **Interview 9 Page 4**

Families may be desperate to keep a family member alive at all costs and if they feel a PEG could help that happen they will challenge medical teams. If the medical teams feel a PEG will do more harm than good then they will not put the patient through the procedure, there can be sometimes a worry that medical teams will give in to families through fear of litigation or if the family state it's due to religion that they must have the

PEG. Medical teams can find this particularly difficult to communicate as explained below.

*"Um some religions say that life is precious and should be kept at all cases, um but for example when I discuss these issues whether someone should have antibiotics or if someone should have a PEG. We asked these people relatives one say that I want my mum or dad for everything to be done for him or her and the other say that my mum or dad has a good a life I don't want them to suffer." "Thaw shall not kill, no where does it say that you should allow to suffer and keep them alive as long as possible."***Interview 5 Page 4**

It has been already discussed that effective interactions with families can often be difficult. Who would want to tell a family that their family member does not have capacity, cannot swallow and in some circumstances explain that a PEG may not be in the patient's best interests. At the same time Doctors have to manage the different personalities which could involve high level communication skills. A senior consultant outlined as part of further research we should ask families how they would like these interactions to happen to improve the PEG consent process as a whole.

*"Er the other people to talk to are probably the families you could select 2 or 3 families of patients who had strokes who have had PEGs and just interview them as well I think that will be interesting to see what it looks like from their point of view."***Interview 1 Page 5**

7.4 Theme 4 'Preparation to Consent'

7.4.1 Afraid to Consent

It was very clear from the interviews conducted that often junior Doctors do not feel confident to consent a patient for PEG regardless of whether the patient has had a

CVA or not. It was very clear that junior Doctors may be afraid to consent for PEG. It is possible that Doctors feel they should not complete the consent as they cannot complete the procedure, which is not the case as outlined by GMC (2008). Healthcare professionals may expect that most registrar and senior house officer level Doctors would have some knowledge of PEGs and if not would have asked for help during the PEG consent process as outlined below.

"I was due to place a PEG and the patient came down from the ward and they did not have a signed consent form so the endoscopy nurses rang the ward to get a junior doctor to go down and consent the patient and the doctor refused because they said they were not familiar with the procedure themselves they were not allowed to take consent and I think there is a big misconception about this. So I spoke to the junior from endoscopy, I rang them up spoke to them and said no you don't have to actually do the procedure yourself you just have to be aware of the complication and basically explain what happens and that's enough and that they could get that information from the patient information leaflet. um they were still a bit reluctant to actually do it but the problem with doing it very quickly is of course consent is supposed to be a process so I assume that the discussions and the family have already taken place and that they were aware of what was actually going to be carried out. And so in the end they did come down and consent the patient , they came through to the room and did it." **Interview 3 page 1**

A Senior Consultant discussed that it was not appropriate for brand new doctors to complete the consent form as they are unlikely to understand the longer indications of PEG, this also may be due to the fact that the junior Doctors lack confidence during the PEG consent process.

"A house officer on the ward who have never have seen a PEG inserted, doesn't really know what a PEG is and appreciate what the longer term implication of a PEG would be." **Interview 10 page 3**

It has already been discussed that PEG consent post CVA is a process which an MDT approach is required, so no lone junior Doctor should have to consent without support. The earlier statement from interview three does indicate that the consent process may sometimes just rely on a junior Doctor, however it is also possible that the multidisciplinary team make plans without informing the junior Doctors. If this is the case then there could be a need to improve the lines of communication not only with patients and their families but between the Multidisciplinary team. The below statement provides evidence for this:

"The swallowing side of things is purely being looked after by the salt team and the nutrition nurses then, yeah then I could see how the doctors may feel alienated then all of the sudden they have to make a seal of approval in something they have not been involved in." **Interview 6 page 3**

The PEG consent process may not just be about understanding the risks of having a PEG and what it is. It is about the assessment and giving the patient an informed choice, to consider a trial of nasogastric feeding can sometimes be an option given to patients or feeding orally despite being at severe risk of aspiration, rather than PEG. Sometimes senior Doctors and nutrition teams may find this difficult to give these patients the option, so junior Doctors may not be aware of options available other than PEG. The worry is that if Doctors have limited knowledge they could be swayed by fear of legal action and the requests of the patient's family that may not be in the patient's best interests as discussed below.

"Sometimes people drift off and start thinking of things, of families and legal implications and all that but if people can just be trained to think am I doing good for this patient and train people to be oblivious to everything else and concentrate on the patient then they would I think that's where they have the greatest problems." **Interview 1 page 3**

AND

"I think we can never know, I think one has to do a trial of feeding and that's not easy with NG tubes as people don't tolerate them any way." **Interview 2 page 4**

It is possible that if Doctors were given enough information to prepare them to consent the patient for PEG post CVA then the process for patients would be more appropriate and patient centred. It would appear that Doctors need better preparation to consent, especially in complex patients. If the Doctor feels the patient understands or that a decision and plan had been made they would be happy to consent a patient for PEG in uncomplicated cases. This statement illustrates the point:

"He understood the procedure and I was quite happy to consent him coz it was decided by the nutrition team that the consensus was that he needed it and in fact this chap had one before so it was slightly easier as he was less um he knew the procedure and knew the risks already so yeah I was happy to consent him in any standard way I would do with any endoscopy really" **Interview 7 Page 1**

7.4.2 Difficult topic to communicate

As discussed earlier, if a patient does not have capacity to make a decision, then the family would be spoken to in order to make sure the plans are in the best interests of the patient. This could be a difficult subject to communicate and may not be an example of an uncomplicated consent process. Sometimes family members may have

strong opinions on the patient's care and because of the emotive situation they are in can sometimes act irrationally. Doctors can find these family members difficult to communicate with when talking about the possibility of the patient having PEG post CVA. A senior consultant discussed that he heard juniors saying a family were difficult, but indicated it was actually the doctors communication skills that need to improve in a complex situation as explained:

"I believe this was like a conversation we had this morning with the junior doctors saying those relatives are a nightmare, but hold on a minute take a step back and put you in their shoes. The relatives are angry and emotional charged and to add salt to injury you say they are a nightmare. It's your role to explain to them, they are not medically trained that's your role, they may have seen something that has upset them some people's perceptions are very difficult to change but your role is to negotiate with these people." **Interview 5 page 5**

It is clear from the evidence that junior Doctors find it difficult speaking to patients and families about the prospect of not eating orally and having a PEG placed post CVA. Doctors may not have enough experience to be able to communicate these difficult topics with the patients, they may also feel uncomfortable because of own experiences or beliefs as explained below:

*"Because it must be quite unpleasant to have to have that discussion with people that have gone through a life changing illness."***Interview 4 page 2**

*"That's not an easy thing to discuss."***Interview 4 page 2**

AND

"*I don't know if still that would be something I would be comfortable discussing, I don't think I would know enough about it to do it. But I would probably just say this is what*

we are going to do and this is how we are going to do it. The aim of it is to feed them but understandable the risks but also the benefits sometimes, but that's an important conversation to have." **Interview 9 page 3**

It has already been discussed that if consent is being taken from someone who does not have capacity then maybe the consent should be completed by a Doctor with the support of the multidisciplinary team throughout the process. A Doctor alone may have limited experience, so dieticians and nutrition nurses should support junior doctors and give them opportunities to learn and give them confidence. Gastroenterology Doctors can support juniors on the ward and juniors should be a part of meetings even if they are not leading as illustrated below.

"It's a big shock right at the beginning for patient as well as the family I mean the prospect of life with a tube um eventually after a period of time they realise its necessary. As a doctor doing the consent when I was working on the stroke ward er I felt uncomfortable about consenting for a procedure I did not know a lot about." AND "And the consent process as I just said was difficult but I asked the gastroenterologists to give me all the information that I needed and so it was quite straight forward." **Interview 6 Page 1**

AND

"I think it would be a good thing if they sat in on at least one interaction with you and the relatives so they can see what's supposed to be done and then learn from that and there for feel comfortable with them doing that in the future." **Interview 3 page 3**

7.4.3 Educated to gain consent

So it's clear from the previous themes that junior Doctors do not feel confident in gaining consent for PEG post CVA, but it was unclear if this was due to lack of

experience or lack of training. During an interview with a junior doctor, one of the first statements that the Doctor said was that they had never had any training on PEG or how to consent for one that it was just expected. The doctor outlined there was no training at undergraduate level and they felt unprepared to consent for PEG. This junior Doctor was not alone in their feelings as demonstrated below on several occasions.

"We have not had any specific training to do that. When we do it post stroke the communication is sometimes lacking and there are sometimes other issues so talking to the patient and communicating with them in order for them to get consent makes it quite difficult to get a valid consent from them in terms of communication and things like that when doing it." **Interview 9 page 1**

AND

"I don't think we had anything specific to PEG or NG, I think we mostly did OGD or colonoscopy, they where the more common ones that we did and definitely not, I don't think we ever talked about consenting for NG tubes, it was implied." **Interview 9 page 1**

AND

"Because we do not get nutrition training at all at medical school, well at least I did not myself, you know obviously we get the basics of the biochemistry." **Interview 6 page 5**

AND

"I think generally consent is poorly taught... That whole thing is poorly taught then you take that to the more complicated when you have patients that cannot communicate very well and this is not addressed anyway, something you have to learn by experience rather than what someone teaches." **Interview 7 page 4**

The junior and senior doctors also outlined that consent and assessment of capacity as a whole was taught but not with any great depth and that they felt unprepared to consent. It would appear the training had not changed in the time between the junior and senior Doctors training and it was not just PEG consent that Doctors were not given in-depth training on but other aspects of training were also limited.

"So there was, there was house officer training and SHO training but nothing specific to consent taking. They were principles about capacity, assessments, erm and principles about erm validity of consent, but nothing specific to PEGs for example." **Interview 10 page 5**

AND

"I guess with stroke patients and how consenting for PEG is more difficult. I guess just people just take on the responsibilities of consenting for most procedures. Erm but I think any training is better." **Interview 7 page 4**

It was also discussed that the amount of junior doctors that had witnessed a PEG actually being placed is limited, this is concerning as if this is the case then doctors are actually being asked to complete a process of which they have no idea how to complete when they first qualify. This is identified below:

"Making sure that they see one at some point to actually know what happens um particularly with teams that are doing this regularly." **Interview 8 page 5**

"*I think that a lot of juniors have not seen a PEG go in."* **Interview 3 page 2**

So it is clear that official training for PEG consent is very limited, so junior doctors rely on the senior consultant's experience to give them support and guidance when completing the PEG consent process on patients post CVA. The stroke physicians have vast experience on PEG consent due to the fact the loss of swallow function is

common in their patient case load. What is concerning is that if senior Doctors do not have that same experience would they ask the stroke team for their expertise?:

"As a whole the where always there when big decisions needed to be made, I think the consultants are quite well run here." **Interview 7 page 4**

7.4.4 Future preparation

It has been clear that education provided to prepare Doctors to consent for PEG regardless if it is post CVA or not is not sufficient. It has also been clearly discussed that something needs to be done to support medical teams in completing this process. The Doctors interviewed had several ideas as to how things could be improved and did not seem to be concerned about who educated them, this is interesting as nurses would think that Doctors would not want education from nurses. This is discussed below:

"In my mind for what valid consent is it would need to someone who knew about the procedure and was happy to do it to teach us about it about the risks for someone to actually teach us about it for it actually to be a good consent procedure." **Interview 9 page 1**

"Trust wide level at the junior teaching or even in the departmental teaching, I think either of them will work quite well." **Interview 9 page 2**

"I think once you approach them in a friendly way and don't throw your weight around saying I know more than you know, well you will junior doctors will but it's how you do it you know be diplomatic." **Interview 3 page 4**

Several doctors specifically outlined as well as teaching that a written short guide for doctors would also be helpful and prepare them to consent a patient for a PEG. They

even suggested that it should be given to the ward on the appointment sheet from endoscopy as discussed below.

"I think we also need to provide our juniors with a basic consent information leaflet of what they are talking about with these patients." **Interview 5 page 2**

AND

"We do have checklists but actually having them in the notes for the doctors with what the risks are then that might make them feel more comfortable." **Interview 6 page 4**

AND

"*I think maybe it would be quite useful, like the endoscopy prep sheets of a guideline of what you need."* **Interview 9 page 2**

It was also suggested by one of the junior team members that ideas could come from other teams that regularly complete consent for example orthopaedics. The Doctor stated that there could be an online database to provide information to Doctors about the PEG consent process and prepare them to consent.

"Because there are websites for orthopaedics procedures that has all the risks and benefits." **Interview 7 page 5**

A positive aspect of completing this research is that one of the senior consultant's discussed that they were implementing a training plan for junior Doctors and students on endoscopy based procedures.

"Some consultants complaining that there juniors have been asked to complete this consent when they shouldn't be. I think this is because they do not understand what the guidance is. So to get around the issue we have made consent part of the junior doctor induction now." **Interview 3 page 1**

It would appear that the majority Doctors are not prepared to consent for PEG post CVA. They would like help and will accept it from clinical areas other than medical, this would prepare them to complete the consent process in the future.

8.0 Discussion

8.1 Participant and other Considerations

The context in which the data in the research has been collected is an important aspect of the research. Each participant was given the opportunity to select the venue of the interview, also taken into account was that the time slot was appropriate for the Doctor to be interviewed, as the researcher I took in to account that Doctors are busy people. All interviews where completed in a quiet private room and the seating was standardised so that I the researcher had the same view in each interview, this also allowed participants to relax as outlined by Moule et al (2009). Despite being in a quiet private environment nine out of the ten interviews were interrupted by either the Doctors being phoned or contacted via their pager, this disrupted the flow of the interview and several Doctors stated they had forgotten what they wanted to say. If the interview process was completed again the interviews could be organised outside of the working day to try to limit interruptions and lesson the possibility of losing data. Moule et al (2009) outlines that if interviews are completed in someone's own home for example the interviewer will have no control over interruptions, this should be considered but at the same time considering participant comfort. As the researcher I made the decision that the comfort of the participants may make the participants relax which I thought was more important than preventing interruption.

The interview length was between 30 and 45 minutes, this was often due to the fact that the Doctors were busy and would not be able to commit to a longer period. Although in-depth data was collected, it could have been more in-depth if the time was longer, Carpenter et al (2008) discussed in order for interviews to be in-depth they should be approximately 90 minutes. Several of the Doctors interviewed also assumed that they would just have to answer set questions as in the style of (taken out 'a') quantitative research, they found it difficult at first to grasp the concept of an open

interview. As the researcher I feel that as whole Doctors are more used to research like randomised control trials for Medication etc and that the number of participants may be greater than qualitative research. Woolf (2006) discussed that often qualitative research is perceived as “proper” research and quantitative research is more rigorous. As the researcher I now realise the type of research being conducted should have possibly been made clearer in the participant information sheet.

During the interviewing process the initial question asked was “Can you tell me about a time when you were involved in the consent process for a PEG insertion, for a patient, following them suffering a CVA?” Several of the Doctors stated they could not remember a specific time that they had consented for PEG or had limited experience in the area. The Doctors went on to talk around the subject with depth, but only three Doctors told specific stories. As the researcher I felt the Doctors had given in-depth information but may have had concerns with regard to elaborating on the discussion point, for example after the tape was turned off in one case the participant made a few more comments but did not want them documented. Collins et al (2005) discuss that often participants talk in a socially desirable way so do not discuss their true feelings, if the participants in this research are not honest with their experiences or opinions it could affect the transferability of the research.

During the research interviews I felt I had to refocus the research a lot. In at least five of the interviews I felt that the participants were interviewing the researcher and using the interview as a method of improving their nutrition knowledge, which again implies a need for further education for Doctors. Moule et al (2009) discussed the role of the researcher in ensuring the research topic is the focus, this would allow for in-depth information to be revealed. I feel that I managed to do this successfully in order to get valuable and useful data for analysis. The participants asked questions around PEG and what my perspective was. Therefore I felt that I was involved in the discussion

which is allowed in Heidegger research. I felt that it was possible that the participants were using the interview as a forum to learn more about PEG, this may indicate that they had previously had limited teaching.

In the completion of the first two interviews I, as the researcher, felt nervous and felt that the participants used language I did not understand, I did not feel confident to ask them what they meant, so could not probe further. Mason (2002) outlines that the interviewer needs to balance both talking, listening and be responsive to the participant to maintain the flow of the interview. Interviews one and two gave in-depth information but lacked flow of conversation, following review of the recordings it was decided that the next seven interviews would be more confidently delivered; this adjustment in interview technique improved the flow of the further interviews.

8.2 Researcher Reflexivity

Carpenter et al (2008) discusses that reflexivity is a strategy in which the quality of the research is enhanced by the researcher uncovering their prior judgements about the research to improve the research credibility. As the researcher I kept a reflexive account throughout the research process as a research diary, some of the significant prior judgements will now be discussed.

Holloway et al (2001) discuss that within qualitative research interviewers should be aware of their own mind set regarding the research topic. As a Nutrition Nurse interviewer in this research my experience within the topic of PEG consent is very broad and within my experience several perceptions may have developed. The participants in the research were either already aware (due to previous correspondence) or made aware of my experience as the researcher in this topic. Parahoo (2006) discusses that if the researcher is honest about their experience and

knowledge of a topic then this can build trust in the participants which can improve honesty around the topic and the credibility or the research.

As the researcher my preconception was that all the Doctors will have had little formal nutrition training, the junior staff would have little knowledge on the topic and the knowledge of senior consultants would have been gained by experience alone and therefore in most cases able to give greater detail. During the research interviews I as the interviewer probed around these areas if the interviewee discussed them but did not make these views the central focus to allow for participants to freely discuss the impact of their experiences regardless of the level of the Doctor, the importance of this was also discussed by Parahoo (2006).

As the researcher I felt that those interviewed may not have communicated their perceptions and feelings as it tended not to be something they have experience of as they are used to quantitative data collection methods. Calvert et al (1999) suggested that Medics may be more comfortable with scientific research, as qualitative research is more associated with more social based occupations. In order improve the discussion in the qualitative research of the participant experiences, the Doctors were given assurance that research would be completely anonymised and identity kept confidential as well as ensuring the participants were aware that the research aim was to improve patient care. Cresswell (2009) discussed that if participants are assured of confidentiality and that the reason for the completion of the research is made clear this can improve the honesty of discussion in the research. As the researcher I felt that to get rich data and to improve participant trust I would use gentle probes rather than direct questions to assess the impact of participant description of experience. Parohoo (2006) outlined that the researcher must balance the level of probing to ensure meaningful insights are obtained from participants.

8.3 Discussion around Themes

8.3.1 Theme One

Theme one considered that PEG consent was a process rather than one specific event. The Doctor participants all clearly outlined that they felt PEG consent was a process rather than just a document that needs to be completed. Several of the participants also explained that this process takes time and patience to complete. Denis et al (2006) outlined that the decision to PEG is often difficult and that the decision to PEG should not be rushed following a CVA. Having a PEG inserted is a life changing experience and unless required urgently it should not be rushed, this will allow time ensure the PEG is required.

There is an assumption that consent is the completion of the consent paper work prior to the procedure. The GMC (2008) give a structured guide of how to complete consent, however from the current research it would appear that Doctors felt that PEG consent was an in-depth process that should be patient specific. This may suggest that either the GMC (2008) guidance requires updating or a specific guide for PEG consent is required. The participants in this research did not perceive the completion of the PEG consent documentation as the most important part of consent and that actually it was more important to consider the whole process. It is unclear what the Doctor had said to the patient prior to any signature, this could affect the validity of the consent form. So that consent is valid the process of consent for PEG should be documented at every stage of a process not just a onetime document. Mason, J. K. et al (2002) discusses that consent should include every eventuality and that the consent form its self can be ambiguous.

The participants in the research identified that in the initial stages of the consent process it is important to ensure that the patient does require a PEG. Van Rosendaal et al (1997) discussed that when considering if patients required a PEG retrospectively as

many as 33% may not have required a PEG. NICE (2006) also outline that patients should receive a trial of 2-4 weeks nasogastric feeding to ensure that enteral tube feeding is required long term; it should not be rushed into. This statement could be viewed as being ambiguous as guidance is not specific and it would appear from the Doctors interviewed it is a patient specific assessment. Dysphagia is an excepted symptom that occurs as a result of a CVA, this symptom can sometimes be permanent but can often be improved with treatment so a PEG is not always required. NICE (2014) outlines that patients with dysphagia should receive three weekly treatments to improve swallow from SALT while swallow improves. This indicates that time is required before the final decision to PEG to ensure the patient does require a PEG prior to insertion.

The participants in this research discussed that once the decision has been decided that a PEG may be required then the patients fitness for procedure should be considered prior to placing the PEG, to ensure the PEG is appropriate for the patient. It was outlined by participants that assessment of physical fitness to undergo the procedure was required. NCEPOD (National Confidential Enquiry into Patient Out come and Death)(2004) discussed that one in five PEG tubes inserted is futile as the patient was often not fit to undergo the procedure and died within 30 days of the procedure. This provides evidence that it is essential to thoroughly assess patients prior to PEG procedures, to ensure appropriateness, which is supported by the research from Van Rosendaal et al (1997).

Consideration to see if the patient has Dementia prior to PEG insertion was discussed by several of the Doctors that were interviewed. It was discussed that PEG may not be appropriate for patients with the diagnosis of Dementia. Westaby et al (2010) outlines that life expectancy of a patient with dementia following a PEG is limited and so often a PEG may not be of benefit to the patient. Some of the senior Doctors interviewed felt

that although dementia may be a contraindication for PEG, you should consider the patient as a whole and ensure that the patient really has a diagnosis of dementia and also take into account what stage in the disease process the patient is at. Laurila et al (2004) completed research which discussed that older adults admitted to hospital with delirium are often misdiagnosed with dementia, this supports the senior doctors in the research that discussed you should clarify if the patient has a dementia diagnosis. This could improve patient care by preventing miss diagnosis and the wrong course of treatment being given to the patient. The Senior Doctors appeared to have had experience of this in patients post CVA, junior doctors may need more education. In the trust in which this research was completed the dementia nurse specialists had just starting completing dementia training for all levels of Doctor that work in the trust, this illustrates further training may have been required.

As part of the consent process the Doctors discussed that a PEG insertion is not just a simple procedure but one that may change a patient's life. This could affect the information that would be provided to the patient and family during the consent process. The Doctors when being interviewed discussed the importance of explaining the risks and benefits of the procedure. This is supported by the guidance from the GMC (2008) which outlines the importance of thorough explanation of the risks and benefits that could affect the patient. The Doctors interviewed outlined that PEG consent was more detailed and had several things to consider like quality of life, for example the gratification of food and no longer being able to take food orally. The Doctors also suggested those things like medication for discharge should also be discussed and the route of administration to prevent problems on discharge. From a review of the literature it appears there is very little information around quality of life post PEG insertion and the small amount mainly considered life expectancy. Klose et al (2003) completed research into quality of life post PEG, although there was some

consideration into quality of life there was no specific detail and the study mainly considered life expectancy and nutrition received. One study by Brotherton et al (2006) did consider quality of life post PEG, it considered that patients found it difficult not eating at family events and that patients may need more support from healthcare professionals post PEG insertion. The Doctors in the current research outlined PEG consent is not simple during their interviews, as PEG may change a patient's life. With the limited specific research into this area, more investigation may be required in order to consider the best plan of treatment for the patient.

Consenting for PEG post CVA may be complex and it may also take a large amount of time to complete, the Doctors in this research felt that this should be seen as a process rather than a single event. This process may need to be patient specific and consider both the physical appropriateness of PEG but also the patients quality of life post PEG. It would appear to be more than a procedure resulting in a signature on a document. This has implications on doctors time and resources if consent is to be undertaken appropriately as perceived by the participants.

8.3.2 Theme Two

The second theme uncovered from the interview data was the role of the multidisciplinary team in the PEG consent process. The Doctors interviewed felt that because of its complexities the PEG consent process should be completed by the multidisciplinary team. NICE (2006) discuss that nutritional care in hospital should be completed by a Multidisciplinary team including a specialist nurse, dietician and Doctor. NICE (2006) also discuss this team should consider the risks and benefits of enteral procedures and consider their ethical implications particularly how enteral feeding will affect the patient long term. NICE (2006) also discuss the importance of using other teams such as Speech and language therapists (SALT) when assessing patients for enteral feeding, to assess their swallow function. This may illustrate that Doctors may

need further awareness of enteral feeding, if they require a large amount of assistance from the multidisciplinary team, it may be that the assistance is required because the junior Doctor lacks experience not just the complexity of PEG.

During the interview process several of the doctors indicated their dissatisfaction with SALT service in the trust that they work in. They outlined that they felt the speech and language teams did not communicate their plan of care with the Doctors, which is something the Doctors felt they required in order to make a plan of care for the patient to see if swallow would improve and if the patient is likely to need a PEG. The GMC (2013) good practice guide outlines that it is essential that you communicate relevant information clearly especially between different members of the multidisciplinary team to ensure effective patient care. Doctors may feel that SALT should discuss plans of care or results of examinations with the team that are in charge of the patient, in order to improve patient care and make a decision in the patients best interest as to if they require a PEG.

The Doctors that were interview also felt that the Nutrition team were required in the process of PEG consent post CVA, because they had specialist knowledge into PEG consent post stroke. They discussed they felt that they received expert information from the nutrition team in the trust, this support could be particularly useful if the Doctor did not have a specific interest in nutrition support. Although the Doctors felt that the nutrition team were helpful they might not have wanted to say anything derogatory as I the researcher was part of the nutrition team. The BAPEN (2007) document around organisation of nutrition support in hospital, recommend that large hospitals should have a comprehensive nutrition team to organise and enhance nutritional support in hospital. Doctors interviewed felt the nutrition team could provide comprehensive nutrition support for both patients and doctors when assessing for PEG because of their expertise. BAPEN (2013) also discusses that nutrition teams should be involved in

the assessment of the suitability for specific enteral routes of feeding such as PEG. The Nutrition team will have a greater knowledge of feeding options available for example NG or RIG (Radio logically Inserted Gastrostomy) if a PEG is not suitable. The Doctors interviewed appeared to value the support of the nutrition team but felt the nutrition team needed more resources to be able to spend more time on the wards, to support patients and educate Doctors. This is supported by research from Tanswell et al (2007) which suggested that if nutrition teams assess patients for PEG insertion then the mortality post procedure was significantly decreased. This implies the need for nutrition team support in hospitals where PEG assessments are being completed as well as other members of the MDT. Skitt et al's (2011) research outlined the use of a nurse lead assessment tool to assess PEG appropriateness improved the outcome and satisfaction for patients post PEG insertion, which again implies nutrition team support in hospital is required.

8.3.3 Theme Three

The Third theme that emerged from the research was the process of interaction, this included communication with families and patients and the possible barriers that may affect this. The Doctors that were interviewed during this research felt that capacity assessment was one of the important considerations at the beginning of the PEG consent process post CVA. The Mental Health Act (2009) outlines that capacity should always be assumed and that every step should be taken to ensure that a patient has capacity before assuming they do not have capacity. The Doctors interviews also felt that it was important to assume that the patient had capacity even if they appeared to be making a decision against medical advice. The Mental Capacity Act (2009) also agrees that if a patient has capacity it should be their choice “A person is not to be treated as unable to make a decision merely because he makes an unwise decision”. This may suggest that a thorough assessment of capacity is required but if the patient

has capacity and has been given in-depth information about the choices they have around the route of feeding then the final decision should be theirs. Brotherton et al (2009) outlined that often patients that received a PEG were unhappy with the information that they were given, so again this illustrates patients need for in-depth information.

The Doctors also outlined that assessment of capacity post CVA can be complicated, due to communication difficulties. The Doctors interviewed discussed that patients following CVA often suffer with both expressive and receptive dysphasia so communication is often difficult. NICE (2008) discuss that often patients need extensive communication rehabilitation following their CVA, this could make the consent process difficult. During the interviews several of the doctors felt that consent for PEG post CVA was made especially difficult due to the inability to communicate clearly with the patients. Bateman et al (2003) discuss that to obtain valid informed consent post CVA is often impossible due to the inability to communicate.

The Doctors interviewed felt in order to assess capacity post CVA a team approach was required to aid communication but also a team that know the patients personalities well and understanding their communication or interpreting their verbal/non verbal signs. NICE (2008) outlines that communication rehabilitation should be lead by SALT and that part of the SALT team role should be to train and assist other members of the multidisciplinary. The team that know the patient may need to work with the SALT team in order to communicate with the patient in the most appropriate way.

The Doctors interviewed outlined that often older adults have hearing difficulties so sometimes patients are perceived not to have capacity but actually cannot hear health care professionals. This may also be found particularly difficult in patients post CVA as it may be difficult to assess both the patients dysphasia and ability to hear when

consenting fro PEG. Middleton et al (2010) discusses that often it can be difficult to communicate with older adults and that Doctors need specialist training to communicate with and assess older adults with hearing difficulties. This may be any area that requires more investigation in the future.

Several Doctors outlined during their interview that often communication with families during the PEG consent process can be difficult to manage. The Doctors felt that if the patient did not have capacity then the family of the patient should be involved in the PEG consent process. The GMC (2008) guidance for consent discusses that if the patient cannot consent for themselves then they should involve the patients family in the decision to ensure the decision is in the patient's best interest. One Doctor identified that often this is a difficult time for families and that communication with the family should be commenced at the start of the PEG consent process or even when the patient has the CVA. Doctors of all levels and specialities discussed that telling families about PEG post CVA is difficult and several junior doctors felt they would not want to have these conversations around breaking bad news. Friedrechson et al (2006) discussed that often Doctors find it difficult to break bad news through fear of losing control of the situation, be it loosing you your ability to be professional or becoming over emotional in the difficult situations. This may indicate that junior doctors may need support when discussing this topic with families.

The senior Doctors interviewed indicated that sometimes families can try to dictate patient care the patient should be the central concern. The Doctors also worried that other Doctors may be affected by fear of legal action from families and not focus on the best interest of the patient who may require a PEG. The GMC (2008) outlines that medical teams should consider family opinion but also consider the decision should always be in the best interests of the patient.

8.3.4 Theme four

In the other three themes it would appear that there were areas that Doctors may have lacked knowledge. In theme two the Doctors outlined that if they needed assistance they could contact the nutrition team and theme three that without training they would not always feel comfortable discussing PEG insertion with a patients family. When considering these areas I felt that this may indicate a possible need for more support or training for doctors on how to complete the consent process for PEG post CVA and consider what preparation the Doctors would need and to consent for PEG.

During the research several of the Doctors discussed that they did not feel comfortable to consent for PEG and the senior Doctors discussed that PEG procedures may have been cancelled due to Junior Doctors lacking confidence to consent for PEG. All Doctors interviewed stated they had nil or very little formal nutrition or PEG training, and any knowledge they had was learnt from experience which may explain why other Doctors did not feel prepared to consent for PEG. Awad et al (2009) completed research which considered Doctors nutritional knowledge compared with other healthcare disciplines, only 47% of the Doctors were deemed to have an acceptable level of nutrition knowledge. In the Awad et al (2009) research the other healthcare professionals questioned had significantly better knowledge around nutrition than the Doctors questioned. This research may indicate that Doctors knowledge around nutrition may need improvement so it is at a similar level to other health care professionals. The Royal College of Physicians (RCP) (2013) brought guidance for Doctors on nutritional support and discussed that more nutrition training for doctors was required. The plan was to “to review the education/training and provision of expertise in nutrition within universities and the NHS with regard to continuing medical education, inclusion of specialist training curricula and future workforce requirements”(RCP 2013). This guidance includes ten step guides about clinical

nutrition but does not give a specific guide for PEG consent. The RCP (2013) outlined training for Doctors was required but no specific guidance for how training should be completed was outlined or the measure to assess if knowledge had improved. It would appear that a more formal plan for training with both PEG consent and clinical nutrition as a whole is required to improve Doctors knowledge and improve patient care. Following the interview phase of the research it was also decided by the Gastroenterology department that more education was required into PEG consent and that my research had provided evidence that more education was required. Students and junior Doctors would now receive training on PEG insertion, care and where possible they would facilitate Doctors during their training to observe a PEG insertion, this may improve knowledge of PEG consent for patients.

The Junior Doctors in the interview outlined that they would like to receive training around PEG consent and clinical nutrition as whole. They had suggested the use of short information leaflets around PEG consent may aid Doctors during the PEG consent process in the short term, although they also recognised that specialist teaching from nutrition teams was also required. As the interviewer in this research I felt surprised that the Doctors wanted the members of the nutrition team to provide teaching around nutrition and not always Doctors alone. As a member of a nutrition team I was surprised at this information as I felt Doctors may not want to be trained by other healthcare professionals. Howe et al (2000) completed research in which community nurses taught medical students, they found that the students not only learnt about the subject being taught but how to communicate with other healthcare professionals and work as a team. This research suggests that teaching for medical students completed by other health care professionals may improve team work in the Doctor's careers, which may be something to consider in the future. When this was presented at the National Nutrition Nurses Group (NNNG) conference this fact also

resonated with the other nurses in the group which again provides support for the outcome of the research.

9.0 Conclusion

9.1 Dissemination of Findings

This section will summarise all of the major themes from the research process and possible learning points. These learning points will then be considered as to how they could be implemented into practice and what may be required to complete this. From these learning points that have been outlined, areas of possible future research will be discussed. Finally routes of dissemination of findings will be explained and the audience to whom the results will be explained to.

It would appear consent for PEG post CVA is not a just a task or one off question requiring a signature but a multifactor process with several patient specific phases. These included phases such as physical fitness to undergo the procedure and whether the patient requires a PEG placement. This was identified by all participants interviewed but this type of process was not recognised in the literature for consent, suggesting that consent guides may need to be either more in-depth or procedure specific.

The consent process should be completed not just by the Doctors but by a Multidisciplinary team with specific skills to assess patients need for a PEG and give advise around specifics of other options such as NG and support the Doctors. The SALT team are required to aid the Doctors in the assessment of the swallow function of the patient and aid Doctors to communicate with patient post CVA. This however needs to be supported by strong lines of between SALT teams and the Doctors as Part of the informed PEG consent process to provide seamless care for patients. The participants felt that a Nutrition team where an integral part of the multidisciplinary team but felt more input was required from the nutrition teams to support Doctors to consent for

PEG. As the researcher I felt unsure that further education for Doctors may mean that an increased level of confidence so Doctors will not require more nutrition team input.

Communication in the PEG consent process is essential. The assessment of capacity and ability to communicate wishes should be thorough to ensure either the patient makes a decision or that a decision is made in the best interest. The multidisciplinary team should aid the communication process with dysphasia patients especially to ensure any decision is made in the patient's best interest. The participants discussed the importance of communicating with families when patients lack capacity in order to act in the patients best interest, however junior Doctors stated they did feel prepared to discuss PEG consent with families and needed more support and education to do that.

Throughout the research it was outlined that PEG consent post CVA was a complex process, the junior Doctors outlined that this was so complex they did not feel prepared to complete the process. This could be due to the fact that none of the Doctors had any training around PEG as students and limited nutrition training as a whole. They also felt that after qualification knowledge was gained from experience rather than direct teaching. Doctors outlined that they would like not just PEG but Nutrition education and suggested that it should be delivered by Nutrition teams. It was apparent that although the consent process for PEG post CVA was complex, the Doctors outlined that any consent process for PEG may complex and that additional training in several areas was required.

Suggested improvements for Practice:

- Nutrition team lead training on Nutrition for Junior Doctors. See training plan in appendix n.

- Creation of short guide for Doctors around PEG consent to be completed by nutrition teams. This would need to be completed in conjunction with the trust and endoscopy unit it is to be implemented into.
- Creation of a Multidisciplinary team pathway for PEG consent is required. The current consent form for patients who do not have capacity does include a small section for this type of pathway. It is not however comprehensive and also not included in the consent form for patients who do have capacity. This document could be initiated by the nutrition team and then have space for the healthcare professionals to write what their input had been. This would be useful for the Doctor who was completing the final paper work and the endoscopist completing the procedure, so they identify a clear consent pathway.

The findings from this research need to be disseminated to nutrition teams, Gastroenterologists, and Stroke teams. I will employ the following methods to achieve this:

- Present findings to a nutrition nurse conference.
- Prepare and submit findings of research to nutrition Journal.
- Present research to Stroke and Gastroenterology MDT meetings.
- Present to Trust nutrition teams. See plan in appendix m.

Suggested further research:

- Specific research into the experiences of patients and families around the PEG consent process.
- Completion of action research with the implementation of PEG consent training for Doctors.
- Further research into the experiences of Doctors from other specialities into PEG consent.

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11.0 Appendices

11.1 Appendix A

Table to discuss inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
• Papers written in the UK • English language papers • Papers after January 2001 peer reviewed journals. • Papers on adults • Stroke patients (not for part 2)	• Non UK papers • Non English language papers. • Papers before January 2001 • Paediatric papers • Literature which describes the use of gastrostomy for uses other than feeding. • Jejunostomy feeding.
Inclusion criteria (part 2)	Exclusion criteria (part 2)
• Studies which consider consent for medical procedures.	• studies which consider consent for trials not medical procedures.

11.2 Appendix B

Table to discuss search terms

Stroke	Disphasia	PEG	Consent
• Cerebral vascular accident • CVA • Brain haemorrhage	• Speech difficulties. • Disphasic	• Gastrostomy • Percutaneous endoscopic gastrostomy	(only consent selected as it is legal terminology)

11.3 Appendix C

Table to discuss Guidelines considered

Guideline	Topic
General Medical Council, (2008) Consent: Patients and doctors working together.	Consent law
NICE, (2006) Nutrition support in adults.	Guidelines for PEG
NICE, (2008) Stroke	PEG in patients post CVA
Trust specific Guidelines	Specific guidelines

11.4 Appendix D

A Summary of the decisions made through this research process.

In order to allow the assessment of rigour in this research I have included a summary of the reasons behind the decisions made throughout the research. Lincoln and Guba (1985) outline that the decision to include the decision making process can contribute to the assessment of rigour.

Summary of Decisions made	**Area of the research**
As a Nutrition Nurse my interest in this topic is generally what routes of nutrition should be considered and how they should be delivered for those who cannot take diet and fluids purely orally. I often felt that specifically this process was difficult for patients needing artificial nutrition specifically PEG and how Doctors completed the consent for this process. I wondered how Doctors felt this process worked and how this may impact the patients. It was this which made me consider that more research into this areas may be required.	Introduction
As a consequence of my interest I developed a research question in or to review the literature around the topic.	Literature review
The completion of the literature was difficult as research into this area seemed very limited on discussion with other nutrition researchers they agreed that research into this topic was limited. When the research area was widened it was also apparent that research around the consent process was again limited in the UK and international laws differed which made research difficult to relate. The limited research gave grounds to complete my research study. One piece of research did however outline that some patients had been unsatisfied with their consent process, this gave me evidence tocomplete the research. I did consider national guidelines that provided guidance around the topic to balance the limited research base of the topic being researched.	Literature review
My Methodology to choice initially was guided by my apprehension about how the Doctors would feel being interviewed, however after much consideration I did not feel that my initial methodology style would provide depth of information. I decided to use hermeneutical phenomenology for several reasons. • I had asked to consider this style of methodology at university and felt it was a fit for the type of research I wanted to complete. • I wanted to gain insight into the participants perspectives and be provided with great depth of information from experience.	Specific Methodology

• I felt that if I could gain insight into the doctors experience then I could change practice in order to improve patient care.	
The use of unstructured interviews gave me the ability to capture the experience of the Doctors into PEG consent without the restrictions of structure. To ensure the participants discussed issues being researched I used an initial question and prompt to gain insight. I felt nervous as perceived Doctors to have more power than me so used a pilot to aid a strategy to prevent nerves and have confidence to probe the Doctors to gain greater insight.	Specific Methodology
The Sample needed meet a certain criteria in order for them to have the relevant experience in consenting for PEG. For this reason purposive sampling was chosen to select participants.	Sample
In order to collect my data I chose to complete tape recorded interviews. I chose this for two main reason: • I lacked the interview skills and experience to be able to document at the same time as conducting the interview, even though not using a recorder may have made Doctors feel more relaxed. • I wanted to be able to make field notes about the interview as well as my thoughts on the topic to be able to demonstrate rigour.	Data analysis
Thematic analysis was selected to analyse the data. This method was used because I felt I had experience around the topic I wanted to be able to recognise the meaning of the data and immerse myself to truly understand the doctors experience. I also recognised I had limited experience as a qualitative researcher so chose a simple analysis method so emphasis would be the data and not how to use the data analysis tool.	Data analysis

11.5 Appendix E

Research Codes	SUB-Themes	Major Themes
• Is PEG required • Fitness for PEG • Thorough informed consent • Consent process takes time	• The Signature (documentation) • Does the patient Need a PEG • Co-Morbidities and physical fitness • What information do patients require prior to PEG insertion?	Task VS Process
• MDT approach.	• MDT communication • Nutrition teams	Collaborative working
• Capacity • Family communication • Communication with patients	• Capacity • Patient interaction • Family interaction	The process of interaction
• Doctors lack understanding • Doctors can struggle to discuss plans with families. • Limited PEG or consent training. • Ideas for Medical team training.	• Afraid to consent • Difficult topic to communicate • Educated to gain consent • Future preparation	Preparation to consent

11.6 Appendix F

Criteria	Justification
All research in this study is being conducted in one NHS trust, the Medical team members must be employed at the trust at the time of the study.	The study is based on the guidelines and practice for the specified NHS Trust. The participants must be aware of these in order to participate.
Have been in post for at least two weeks.	To familiarise them to trust policies and their current role.
Doctors that as part of their job role will gain consent for patients having a PEG following a CVA. (in the specified trust the teams which complete this are the Gastroenterologists and Gerontologists)	Ensure that doctors have had exposure to the process of PEG consent post CVA.
Only qualified doctors will be recruited to ensure that selected participants do complete consent for patients prior to PEG as part of their job role	Students do not consent for PEG. Doctors can consent regardless of patients capacity, this will give a more rounded view of the topic.

11.7 Appendix G

Participant information Sheet

Participant information sheet

Title of Study: *What are the attitudes and perceptions of Doctors to the informed consent process for patients receiving a Percutaneous Endoscopic Gastrostomy (PEG) following a Cerebral Vascular Accident (CVA)?*

I am inviting you to take part in a research study that is being carried out as part of a Research Masters at Coventry University. Before you decide to take part it is for you to understand why the research is being completed and what the research process will involve. Please read all the information carefully and ask if you have any questions or if you require more information.

- The purpose of this study is to gain an understanding of the thoughts of Doctors into the process of gaining consent in patients who have had a CVA and require a PEG. You have been invited to participate in this study because you are a Doctor who has or is likely to consent a patient post CVA for a PEG.

- It is not essential that you take part in this study.

- If you decide to partake in this study then you will be asked to sign a consent form. If you want to withdraw from the study you are free to do so at any time in the process.

- If you decide you would like to participate in this study, you will be asked to complete an interview.

- The interview can be completed at a location and venue of your choice. The interview will last between 30 to 60 minutes and will be audio taped.

- When the interviews are completed they will be written out as spoken on the audiotape. As a participant you will have the opportunity to ask to review the written interview, to ensure it reflects you true opinions. You will be able to withdraw your information if you are not satisfied with the content of the interview. If you decide you want to withdraw from the study when your interview has been completed then the information you have provided in the study will not be used in the research.

- Once all the interviews are completed the information will be examined and compared to look for common themes.

- The transcripts from the interviews will not have names on them so that your anonymity will be preserved.

- The researcher in this study will be the only person with access to the written interviews and audio tapes. The written interviews will be kept on a password locked computer system. Audiotapes will be kept in a key locked cupboard.

- You will not be paid for participation in this study. If expenses are required for parking then you will be reimbursed.

- Discussing experiences you may have found challenging in your career can be difficult. If you feel unable at any point you are not able to continue at any time then the interview will be terminated. There are not any other expected risks in taking part in this research. As a consequence of taking part in this research, your data may be used to construct tools to aid the consent process for PEG in the future.

Researcher contact details: Elaine Trautner
elaine.trautner@uhcw.nhs.uk
02476 966074

If you decide to participate you will be given a copy of this information sheet and a copy of the consent form that you will have signed in order to take part in this study.

Thank you.

- If you are concerned about your interview being taped please speak to the researcher on the above details with any questions.

11.8 Appendix H

Consent form for the research study on the attitudes and perceptions of Doctors around Consent for Percutaneous Endoscopic Gastrostomy following a stroke.

Please read page one participant information sheet prior to completion of this consent form.

	Please tick and initial.
I confirm that I have read and understood the participant information sheet for the above study and have had the opportunity to ask questions.	☐
I understand that my participation is voluntary and that I am free to withdraw at anytime without giving a reason.	☐
I understand that all the information I provide will be treated in confidence	☐
I understand that I also have the right to change my mind about participating in the study for at least a period of two weeks after the study has concluded.	☐
I agree to be recorded during the interview as part of the research project. (This will be completed by the use of a Dictaphone.)	☐
I agree to take part in the research project	☐

Name of participant:		**Signature of participant:**		**Date:**	
Name of Witness:		**Signature of witness:**		**Date:**	

Name of researcher:		**Signature of researcher:**		**Date:**	

11.9 Appendix I

What are the attitudes and perceptions of Doctors to the informed consent process for patients receiving a Percutaneous Endoscopic Gastrostomy (PEG) following a stroke?

Elaine Trautner CNS Nutrition

BACKGROUND

- Gaining thorough informed consent in stroke patients can often be difficult. Flaherty et al (2008) discuss that as a consequence of a patient's cerebral vascular accident (CVA) they do not always have full capacity to make informed discussions about their care.
- Van Rosendaal et al (1999) state that consent may not always be fully informed as often information given to decision makers can be limited and incorrect..
- Dysphagia, or difficulty swallowing, is a common outcome for patients following a CVA. Evidence reports that as many as 40% of patients following a CVA will suffer with Dysphagia (Langdon et al 2007).
- The National Institute of Clinical Excellence stroke guidelines (NICE 2008) discuss that when symptoms of Dysphagia persist a Nasogastric (NG) feeding tube should be placed to provide nutrition and medications..
- The NICE (2006) guidelines for nutrition outline that if a NG tube is required for two to four weeks then a PEG (percutaneous endoscopic gastrostomy) should be considered as a long term route for nutrition. As a consequence of Dysphagia many patients will have a PEG inserted in the weeks following their CVA.
- Nice (2008) recognise that being placed nil by mouth as a result of Dysphagia can have a large psychological impact on the patients. Therefore, it is important that, when a patient does not have capacity, the decision on how to provide nutrition in Dysphagic stroke patients is comprehensive.
- The General Medical Council (GMC 2008) outline the UK guidelines for gaining informed consent for a procedure; the procedure must be explained, intended benefits and risks outlined, and the options of not having the proposed treatment should be discussed. For consenting a PEG these discussions should be in depth, with consideration to the psychological impact as well as the physical.
- GMC (2008) also state that it should always be assumed that the patient has capacity until proven otherwise in concordance with the mental health act (2005). It is often difficult to assess capacity of patients that have suffered a CVA. Often patients who lack capacity have consent forms completed by an individual who legally is allowed to do so.
- GMC (2008) discuss that if a medic is completing a consent form when a patient lacks capacity, they should always consider the opinions of families of what they feel they patients preference would be if they had capacity.

ETHICS

The NHS trust selected to complete the research was asked for ethical approval through the Research and Development department. Prior to the commencement of the research the researcher gained written consent from the research and development department was given to complete the research in the specific NHS trust. Ethical approval was also requested from Coventry University Ethics comities as the research participants were NHS staff. The University gave full permission for the research to take place prior to commencement of the study.

METHODS

Research Methodology
The study considered the attitudes and perceptions of specific medical teams within a set NHS trust. There are currently no set standards or assessment strategies for this type of research in the U.K. or current literature relating to this topic. For these reasons qualitative research was selected so that the attitudes and perceptions of medical team could be uncovered.

Design
In this research the data collection method was depth interviews. This method was selected as it allows for depth of information into the chosen subject with some control of topics to discuss. Moule et al (2009) explain that the purpose of qualitative phenomenological interviews is to seek out participants individual experiences or attitudes. Ten in depth interviews where completed and recorded with field notes, in a venue and at a time of the participants choosing.

Sample
Purposive sampling was used to select participants for this study. Moule et al (2009) outlined that purposive sampling is used to collect participants with a certain set of experiences or knowledge as part of phenomenological research. The criteria for participants is demonstrated in chart A, the possible candidates where collated by the medical secretaries with the appropriate medical specialities. Possible participants where then provided with information and invited to participate in the research. Ten participants consented to participate, five junior and five senior Doctors, five male and 5 female and five gastroenterologists and five stroke physicians.

Data analysis
Interviews were audio taped and transcribed verbatim by the author of the study.
The data was then reviewed using thematic content analysis. The author then reviewed the transcripts, first for points of interest and then reviewed for emerging themes in the content. This use of data analysis is appropriate as the topic knowledge is limited, so recognition of common themes may indicate if and where reforms are needed in practice.

Criteria for Participants (A)

Criteria	Reason
All research in this study is being conducted in one NHS trust, the Medical team members must be employed at the trust at the time of the study.	The study is based on the guidelines for the specified NHS Trust.
Have sufficient time left in their job rotation to complete the research	Allow time for consent process.
Have been in post for at least two weeks.	To adapt to trust policies.
Medical team members that as part of there job role will gain consent for patients having a PEG following a CVA. (in the specified trust the teams which complete this are the Gastroenterologists and Gerontologists).	Ensure appropriate knowledge.
Only qualified medics will be recruited to ensure that selected participants do complete consent for patients prior to PEG as part of their job role.	Students do not consent for PEG.

CONCLUSION

Consenting a patient for a PEG regardless of whether the patient has had a stroke should be a process not just a tick list or task. The consent process for PEG has several different elements including, assessment of the patient, capacity assessments, communication with the patient and family if the patient does not have capacity. The assessment of capacity and communication can be made difficult by the patients dysphasia post stroke, so it is essential the stroke team, SALT and junior Doctors work together during the process. Consent should be informed and so a specialist nutrition team are required to ensure patients are aware of the options other than PEG and what those options mean long term.

Junior Doctors have little or no formal training on PEG consent or capacity so need assistance from nutrition teams during the PEG consent process. Nutrition teams should communicate with Doctors and not assume that they are aware of the PEG consent process following a stroke. Junior doctors would like more training.

INDICATIONS FOR PRACTICE

- Nutrition teams are required to assist with PEG consent process.
- Nutrition teams to assist Junior doctor nutrition training.
- Quick reference guides to be made by nutrition teams to assist doctors in the PEG consent process.
- Further research is required to consider the perception of patients and families on the PEG consent process.

RESULTS

Themes

Process VS Task:
- The Signature: Consenting for a PEG is not just a paper exercise.
- Does the patient need a PEG: The assessment process is an essential part of the PEG consent process.
- Co morbidities and physical fitness: Doctors should assess for physical fitness and if the patient has a correct dementia diagnosis.

Collaborative Working:
- MDT Communication: Essential to have MDT to cover all Ares of the process. Inclusion of Doctors is essential.
- Nutrition Team: Provide expertise to junior Doctors and need to be part of the PEG consent process.

The Process of Interaction:
- Capacity: Thorough capacity assessment, using SALT to aid communication with patients with speech difficulties.
- Patient Interaction: Understanding expressive dysphasia and receptive dysphasia is essential to initiate the consent process.
- Family interaction: Emotive situations with families with strong opinions, effective communication is essential.

Preparation to Consent:
- Afraid to consent: Some Doctors are afraid to consent patients for PEG, as they lack experience.
- Educated to consent: Doctors receive little or no formal training on PEG consent, consent in general and capacity assessments.
- Difficult topic to communicate: Junior Doctors lack the experience to communicate bad new to patients and families. MDT approach is required.
- Future preparation: Doctors need specific training on PEG consent, this could be completed by nutrition nurses.

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11.10 Appendix J

Ethical acceptance emails

Hospital Ethics

To: Trautner Elaine (RKB) Nutrition Nurse Specialist
Subject: RE: ETHICS

Hi Elaine –

Many thanks coming in to discuss your study with me. I have logged the project on behalf of the Trust and can confirm that we are happy for you to carry out this project within UHCW.

Good luck with your project!

Best wishes,

Ceri

Ceri Jones
Head of Research, Development & Innovation

Research, Development & Innovation Department
First Floor Rotunda (opposite Cardiac)
University Hospitals Coventry & Warwickshire NHS Trust
University Hospital
Clifford Bridge Road
Coventry
CV2 2DX

The following ethics request has been reviewed and set a status of approved. The request has now been passed to the Module Leader, Departmental Ethics Leader or Faculty Leader to finalise.

Ref: P11757

Project Title: What are the attitudes and perceptions of Doctors to the informed consent process for patients receiving a Percutaneous Endoscopic Gastrostomy (PEG) following a Cerebral Vascular Accident (CVA)?

Applicant:	Elaine Trautner
Supervisor:	Jean Astley-Cooper
Module Code:	MOO4MRDC
Module Leader:	

Go to ethics.coventry.ac.uk to view this request in more detail.

THIS MESSAGE HAS BEEN GENERATED AUTOMATICALLY - PLEASE DON'T REPLY TO THIS MESSAGE

11.11 Appendix K

Detailed account of analysis process

Step One: Preparation and organisation of data is essential. Firstly interviews where transcribed and field notes completed.

The tape recordings were typed by myself by hand, this allowed for not only the transcripts to be easily reviewed but also it meant that I could re immerse myself in the literature. The demographics of participants and field notes were also typed to ensure clarity, they where then printed along with the transcripts and stapled together.

Step Two: Read through all the data to gain an idea of what the research is saying. Decide what is the tone of the research is? The researcher will then record these thoughts on the transcripts.

In this stage I read each transcript several times, on the third read through I highlighted sections by hand with highlighter pen that I felt gave insight into the perceptions of the doctor participant. I then made notes in the margin around what I felt the highlighted section was actually saying the perceived topic and concept.

Step Three: Researcher will begin the detailed analysis which will include a coding process of the data.

Once every transcript was reviewed with highlighted sections and comments, the comments were transferred to post it notes with a code relating to information written, I also gave a code so I would remember which transcript the quote and comment had derived from.

Step Four: The researcher would then use the codes to construct a description or make links between the codes.

Once all the post it notes with notes had been compiled they were then reviewed and grouped together in several piles with post its with similar themes and codes. These provisional themes were was decided by whether the codes demonstrated similar views or views around a similar topic. The transcripts were then reviewed with the provisional themes in mind to consider if there was any data with in the transcripts which related to the provisional themes. After the second review of the transcripts more data was extracted and matched with similar themes.

The themes were then read and re read and post it notes were moved to the most appropriate provisional theme where I began to review links between the data. This was

Provisional themes where then grouped together in larger themes. This allowed for depth in the themes by considering several areas within a theme for example when considering preparation to consent theme considered both how the medical teams felt and how this could be improved in the future.

Step Five: Advance the themes uncovered to develop a narrative to convey the findings following the analysis stage.

These themes where linked with quotes that I felt provided evidence for the point in the theme that was being discussed.

Step Six: The final step will be an overall interpretation of the meaning of the data and themes. It will also be considered against other literature around the topic.

11.12 Appendix L

Literature search flow chart

1. The first stage of the literature was a review of UK guidance and around both PEG placement, Stroke or CVA and consent.

2. The initial search strategy was completed using PICO.
P - Stroke and Dysphagia
I - PEG
C - N/A
O – Consent
The necessary Boolean operators were used to ensure the search was comprehensive.

3. On the initial search nil relevant literature was found. Therefore the term 'Dysphagia' was excluded from the search criteria. This was to broaden the search results in order to find the most appropriate literature. This again provided little relevant literature. At this point in the literature search it was decided that 'Stroke' would also not be included, as I the researcher felt that because the research base was limited I needed to widen my search strategy.

4. Following widening the search strategy to consider only the terms 'PEG' and 'Consent', I discovered three appropriate research papers. Due to the specifics of UK guidance and laws I decided not to look at non UK literature. At this point I decided to only consider the research behind consent in the UK in order to have a greater research basis.

5. In order to review the literature behind consent in the UK PICO was used once more with the Boolean operators.
P – Doctor
I - Consent
C - Informed
O – Attitudes or Perceptions

6. Following this search strategy nil British appropriate research papers were found. As the researcher I acknowledge there was little research basis for the topic I had chosen. At this point I decided to consider non UK papers to see if there was any appropriate literature as a basis for my research. Following this I found one appropriate piece of literature for my literature review.

7. Due to the lack of appropriate research available thus far in my literature review I decided to include 'Knowledge', 'Attitudes' and 'Perceptions' in my search strategy. I found three further appropriate pieces of research using this search strategy. This found one UK and two non UK pieces of research that I thought were relevant to the subject topic. At this point I felt I had exhausted the search strategy and it was clear that there was limited research around my topic of PEG consent.

11.13 Appendix M

A brief account of a meeting in which the research results were presented

As the researcher in this study I decided to present my to a group of doctors and allied health professionals from a different trust, using findings the attached presentation. I was only given forty minutes to present my findings so I decided to use twenty five minutes to present my findings and the remaining to discuss them. The aim of the presentation was to educate this group of gastroenterologists and health care professionals but also to assess if my research findings resonated with their beliefs.

Following my presentation I had lots of questions and feedback from the doctors which I will explain in the points below.

1. The doctors agreed that the literature around PEG consent was limited and that UK laws differed from international law. This made the literature review difficult. They did however outline that the research that looked into the training of international doctors could be considered more as there are lots of international doctors coming to the UK. This could be interesting for a future research project.
2. The doctors felt that although the doctors interviewed would have been familiar with PEG consent and would have been able to discuss their experience, they felt I should have included other medical teams such as neuro surgeons.
3. The most overwhelming comments were that none of the doctors in the room had ever had any formal nutrition training apart from at conferences as consultants. The junior doctors outlined that they would like some training around all types of gastrostomy tubes, the consent process for these and the aftercare. Subsequently a few ad-hoc sessions were completed for the junior doctors and I am currently looking into making this more permanent in this specific trust, alongside the nutrition nurses at the trust.
4. Following on from the previous comment one doctor from the team who had been trained in Greece found it unusual that a nurse would do training for a doctor as this does not happen in Greece. Although he accepted this I found it interesting as other international may not be familiar with this and therefore might not accept this.
5. The senior members of the team felt that the problem with the lack of training doctors receive around nutrition was national and senior members outlined that national gastroenterology groups were currently trying to improve this. It was recognised that this was however a large job.
6. Finally the doctors felt communications between doctors and allied healthcare professionals needed to improve to ensure consent was properly informed. This would additionally ensure that all other options for the patient had been exhausted. In particular they again outlined the fact that the speech and language therapists often failed to communicate with the doctors about the swallow function of the patient and whether they thought it would improve.

As the researcher in this study I recognise that this presentation was not in depth, however in a current climate where doctors have little time I felt it was a good opportunity to be given a slot in there breakfast club meeting. I was pleased by the fact that it appeared that my research results resonated with the doctors and they agreed with my findings. I plan in the future to present these findings to some more nutrition teams and also publish the results in order to disseminate the findings.

11.14 Appendix N

Plan of Doctors training

In order to provide artificial nutrition education to medical teams I would like to complete a half day training sessions as part of newly qualified doctors training. I would also like to extend this to medical students on placement and any other doctor that would like to take part. In order to commence this training I would aim gain a place on the regular doctors training by contacting the doctors training facilitators and booking a regular slot on the junior doctors teaching programme.

I think that training for artificial nutrition as a whole rather than just PEG consent is essential to ensure doctors gain understanding of the overall topic. I have outlined a structure of a time table below to illustrate the structure of the training.

Artificial nutrition support study day time table: 0830-12.30

1. **The role of the nutrition team within the trust 0830-0900:** This would me a group presentation by the whole nutrition team including: Nutrition nurse, pharmacist, dietitian, speech and language therapist and doctor (this would emphasise the importance of collaborative working). This presentation would outline the role of each healthcare professional, how to refer and how the multidisciplinary team work together to provide patient care.
2. **The routes of artificial nutrition support 0900-1000:** This would be completed by a nutrition nurse and dietitian and the main aim would be to explain possible routes artificial nutrition and the reason for selection. Each route of artificial would be defined and the method of placement discussed, it would be explained to them why a specific route of artificial should be selected but with consideration around specific patients. Finally the role of artificial nutrition in end of life will be discussed.
3. **Break for coffee 1000-1030:**
4. **The legal aspects of artificial nutrition 1030-1130:** This presentation would be completed by a nutrition nurse and the trust solicitor (the solicitor regularly completes doctor training) This presentation would discuss the legal aspects of consent in relation to artificial nutrition support with specific discussion around patient capacity and the role of best interest meetings. Finally the role of restraint in regards to artificial nutritional will be discussed and the legal documents relating to this.
5. **Groupwork and scenarios 1130-1230:** The scenarios would consider three different areas:
   - **A)** Assessment for artificial nutrition support
   - **B)** Consent for PEG where capacity status is unclear
   - **C)** End of life decision making reguarding nutritional support.

The group would be made into smaller groups with flip charts to discuss the scenarios and discuss what the patient outcome should be with special consideration to the patient

characteristics. The groups would also be feeding back to the group on their thoughts and this would be discussed with the nutrition team members. Questions would also be encouraged at this time.