

Patients' decision making processes for uncertain, risky medical decisions.

Submitted by

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## Declaration

This thesis has been submitted for the award of a Doctorate in Clinical Psychology. I declare that this work is my own and has not been submitted to any other institution or for any other qualification or degree.

Danielle Platts

## Structure and Word Count

<b>Literature review</b>	<b>8206</b>
Including references	9549
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## **Abstract**

### **Literature Review**

The systematic literature review critically evaluates and synthesises the available literature on the impact of uncertainty for patients involved in their medical decision making. Studies were identified through electronic database searches. Ten studies were included in the review. A meta-ethnography approach was used to synthesise the qualitative studies which was then considered in line with the quantitative paper. The findings demonstrate that uncertainty is present in the decision making process and the results are outlined under the following themes; 'initial uncertainty and fear', 'an uncertain decision and uncertain information', 'an uncertain choice' and 'coping with uncertainty'. The methodological limitations of the reviewed studies and implications for clinical practice and future research are discussed.

### **Research Report**

The study explored the decision making process for patients who were diagnosed with an unruptured cerebral aneurysm and elected to have neurosurgical clipping. Using semi-structured interviews, 10 participants gave accounts of their decision making processes which were analysed in line with Interpretative Phenomenological Analysis. Results were discussed under the themes of 'the tension between self-determination and responsibility for others', 'relationship with the surgeon and NHS', 'life and death' and 'post-surgical reflections and sense-making'. Participants valued being part of the decision making process, and even when treatment did not have a successful outcome, participants did not regret their choice. The clinical implications of these findings are discussed in addition to recommendations for future research.

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## Section one: Literature Review

The impact of uncertainty for patients involved in shared decision making  
for high risk treatments.

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## **The impact of uncertainty for patients involved in shared decision making for high risk treatments.**

**Objectives.** Medical decisions occur in contexts involving uncertainty, for example, uncertainty is present in the likelihood of potential treatment being successful. How patients manage this uncertainty might influence the possibility of patient satisfaction and reduce the chance of litigation. The aim of this literature review was to integrate and critically evaluate the literature exploring the impact of uncertainty for patients involved in their own risky medical decision making.

**Methods.** A systematic search of the literature was undertaken using the databases Scopus, PsychInfo, PubMed and Web of Science. Quality appraisal of studies was undertaken. Qualitative studies were reviewed using meta-ethnography and then quantitative studies considered in line with the results from the qualitative papers. Ten papers were included, nine of which were qualitative and one was quantitative.

**Results.** Results were discussed under the themes of; ‘initial uncertainty and fear’, ‘an uncertain decision and uncertain knowledge’, ‘an uncertain choice’ and ‘coping with uncertainty’. The literature indicates that uncertainty is involved in more than just weighing up the pros, cons and risks of treatment but uncertainty is also implicated in the medical information and in the patients’ role in the medical decision making. Uncertainty is also present throughout the whole decision making process from diagnosis to post-treatment.

**Conclusions.** Decision making theories do not fully take into account the role of uncertainty within the decision making process.

The most common source of patient dissatisfaction is patients not feeling informed about their medical treatment (World Health Organisation, 2008). A clear trend within health care provision is, therefore, that patients are increasingly being involved in their medical care decisions. It has been shown that patients involved in their own treatment decisions have higher satisfaction and superior clinical outcomes (Lindhiem, Bennett, Trentacosta, & McLear, 2014). One way of involving patients in their treatment decisions is using shared decision making (SDM). SDM is a two way exchange of information between patients and medical professionals where medical professionals provide patients with information about the evidence for diagnostic or treatment options (Charles, Gafni, & Whelan, 1999).

SDM can be effective for reaching treatment decisions with patients, and can improve patient outcomes (Joosten et al., 2008). For males diagnosed with low risk prostate cancer, SDM increased their knowledge, reduced decisional conflict and prepared them to make an informed decision (Myers et al., 2016). Furthermore, it has been argued that SDM not only has benefits for the patient, but also could lead to more cost-effective and safer healthcare services with improved outcomes for patients (Elwyn, Frosch, & Kobrin, 2016). Additionally, SDM also means that patients are playing an active role in their healthcare, therefore, fulfilling requirements for patient-centred care. Patient-centred care is an important initiative for the welfare of patients and the reduction of costs for health services (Francis, 2013).

SDM has been proposed to be based on ‘choice’, ‘option’ and ‘decision’ talk with three stages, consisting of: introducing choice, describing options and then helping patients explore preferences and make decisions based on what

matters to them (Elwyn et al., 2012). For SDM to be beneficial, a patient needs to be provided with all the relevant information, in order to know what matters to them. However, the information provided to patients cannot always be 100% accurate or certain.

### **Role of Certainty in Healthcare Settings.**

Medical decisions often occur in contexts involving uncertainty (Lomas & Lavis, 1996). Thus, decision making is a complicated process, especially for high risk decisions, where the information provided is often not certain. Therefore, patients are involved in making their own medical decisions when they cannot be certain of all the factors involved. Uncertainty within decisions has been defined as ‘multiple possible outcomes whose probabilities are unknown’ (Camerer & Weber, 1992). A critical element of the decision making process is to discuss uncertainties in order to ensure that informed decisions are reached, otherwise the positive aspects of SDM are neglected (Politi, Clark, Ombao, Dizon, & Elwyn, 2011). Uncertainty might lie in some or all of the following; the probability that a patient has the disease or illness, the likelihood of treatment being successful, the risk of treatment side effects and the risk of recurrence of the disease or illness. Uncertainty can be found in scientific evidence, for example survival rates for cancer vary in the literature and survival rates are individual to a certain person (Heesenm Kopke, Solari, Geiger, & Kasper, 2013). Due to ambiguous evidence and each person being a unique case, answers are not known, for example, patients have to decide whether or not to have various treatments for prostate cancer when they are uncertain of their diagnosis and the severity (O’Rourke, 2007). Furthermore, these different available treatments can have effects on

physical, social and psychological quality of life. It is therefore important to explore how uncertainties affect the decision making process.

The Uncertainty in Illness Theory (UIT: Mischel, 1988) and Reconceptualised Uncertainty in Illness Theory (RUIT: Mischel, 1990) acknowledge that uncertainty is involved in diagnosis, treatment, recovery and recurrence of an illness. UIT and RUIT conceptualise uncertainty as a cognitive state where a patient cannot formulate the meaning of an illness. Mischel described three stages of uncertainty, firstly, antecedents of uncertainty which includes all the available information about a decision and support to make the decision. Secondly, appraisal of the uncertainty where patients appraise the decision with emotions such as fear and anxiety due to establishing the consequences of the uncertainty. Finally, coping with the uncertainty, where uncertainty is seen as either positive or negative. If uncertainty is seen as negative, a person might cope by trying to reduce the uncertainty. However, if uncertainty is seen as positive, a person might integrate the uncertainty into their sense of the world and sense of self by accepting the uncertainty if this means that a negative consequence is less likely to be a certainty.

SDM has been considered as a good strategy to use in contexts of uncertainty, by medical professionals providing the best available evidence of the risks and benefits for treatments (Towle & Godolphin, 1999). This decision making strategy is 'shared' as medical professionals pass on their scientific and medical knowledge to the patient, ensuring that the patients understand, then help patients base their decision in the available evidence, which might be uncertain, whilst eliciting their individual preferences. SDM is recommended for decisions involving uncertainty in menopausal health (Legare & Brouillette, 2009).

However, for breast cancer treatment decisions, communication of uncertainties might lead to patients being less satisfied with their treatment decisions (Politi, Clark, Ombai, Dizon, & Elwyn, 2011). Furthermore, it was also found that patients were less dissatisfied with their treatment decisions when they were more involved in the decision making process involving uncertain information, compared to those who were less involved. Politi et al. (2011) highlighted that further research needs to explore the impact of uncertainty for patients involved in their medical decisions, in models such as SDM as patient involvement is important, yet the impact of uncertainty is unclear.

It is important to consider how patients who are involved in shared decision making make decisions in contexts of uncertainty. This is especially relevant for high risk decisions where the consequences are unclear. Therefore, the theoretical background of decision making also needs to be taken into account to see the process of how patients make such decisions.

### **Decision Making Theories**

There are several theories which define decision making processes for medical decisions. The most widely used in the literature include: Rational choice theories, (Homans, 1961), Theory of Planned Behaviour (TPB: Ajzen, 1991), Health Belief Model (HBM: Rosenstock, 1974), Fuzzy Trace Theory (FTT: Reyna, 2008) and Prospect Theory (Kahneman & Tversky, 1979). A distinction has been made between decision theories about how people should make decisions, i.e. normative decision making, and how people actually make decisions under uncertainty, i.e. descriptive decision making (Myers & McCabe, 2005). Rational choice theories (Homans, 1961), which are normative decision theories, presume that rationality is used to decide which option is best to choose

and have worked on the assumption of certainty within information. However, it is now widely known that people do not always make rational decisions, as some normative decision making theories would suggest (Myers & McCabe, 2005).

The Theory of Planned Behaviour (TPB: Ajzen, 1991), was developed because previous research suggested that personality traits or a person's attitude alone were not able to predict behaviours. Therefore, TPB aims to provide more of a descriptive decision theory of how people make decisions. TPB predicts that a person's intention to engage in a behaviour depends on their attitude towards the behaviour, perceived subjective norms about the behaviour and perceived behavioural control. The attitude towards the behaviour is the extent of feelings towards the behaviour, both positive and negative, due to considering potential outcomes of deciding to engage in that behaviour. The perceived subjective norms are the beliefs that the person has about what significant others think about that person deciding to engage in a behaviour. The perceived behavioural control refers to the person's perception about how difficult a behaviour is to do, their perceived control increases when they have more resources and more confidence. However, in decisions there are significant levels of uncertainty for the patient and TPB does not incorporate a specific role for coping with uncertainty. Coping with uncertainty has been suggested as a mediator between both the attitudes towards the decision and perceived subjective norms about the decision and the behavioural intent to engage in the decision (i.e. active or passive) (Malfei, Dunn, Zhang, Hsu, & Holmes, 2012). Additionally, when TPB has been investigated in the context of surgery choices for breast cancer (Sivell et al., 2013), the researchers found that TPB did not take into account a role for anticipated regret although this was found to be a more significant predictor than subjective norms.

Anticipated regret was defined as ‘the regret one anticipates experiencing after engaging in the behaviour, or not engaging in that behaviour’. Anticipated regret is likely to be important due to uncertainties involved in the decisions. Overall, there is mixed evidence surrounding the predictive ability of TPB and literature suggests that TPB does not account for some of the more ‘emotional’ aspects of decision making, such as ‘uncertainty’ and ‘regret’.

The next theory to be considered is the Health Belief Model (HBM: Rosenstock, 1974) which was developed due to a lack of uptake of free health screening and aimed to be a descriptive decision making theory. The HBM suggests that healthcare related decisions are influenced by: perceived severity of the disease or illness, perceived susceptibility of getting the disease or illness, perceived benefits of the potential treatment, perceived barriers or negative aspects of the treatment, cues to action to be ready to take the treatment and self-efficacy (i.e. confidence in the ability to have the treatment). Therefore, the HBM takes into account the wider context in decision making. Research into breast cancer screening has shown some consistencies between health care decisions and the HBM, as greater screening frequency is predicted by perceiving less barriers to screening. However, perceived susceptibility, severity and benefits were not found to be predictors of screening for breast cancer (VanDyke & Shell, 2016). HBM has also been found to be generally applicable to parents’ decisions to vaccinate their children but, perceived severity was not found to be significant (Wu, Lau, Ma, & Lau, 2015). Conversely, when exploring medication adherence, partial support was found for the HBM, with the most relevant factors being perceived severity and attitudes to treatment (Baloush-Kleinman, Levine, Roe, Shnitz, Weizman, & Poyurovsky, 2011).

Research into Human Papillomavirus vaccination decisions suggested that HBM alone did not explain the decision making process, but aspects of TPB, such as perceived subjective norms, needed to be incorporated in order to explain variation between decisions (Krawczyk, Perez, Lau, Holcroft, Amsel, Knauper, & Rosberger, 2012). Furthermore, Sivell, Edwards, Elwyn, and Manstead (2009) conducted a review and found that TPB and HBM together did not account for all variance in decision making and there was an additional role for an emotional component, for example fear, in decision making which is not incorporated fully in either model. Fear is likely to be relevant in high risk decision making, especially in response to coping with uncertainty, as suggested by literature looking into uncertainties in illness (Mischel, 1990).

A further theory that might address some problems with TPB and HBM and provide descriptive decision making theory of how patients actually make decisions is the Fuzzy Trace Theory (FTT: Reyna, 2008) which is based on theories of memory and information processing. FTT is a processing theory whereby people make decisions in terms of their background knowledge. People process dual mental representations; both verbatim representations and gist representations. Verbatim representations are the literal details and gist representations are the subjective interpretations of the meaning of the information. Values are retrieved and applied to the mental representations in the context, e.g. 'I am likely to become ill from this'. Gist representations are meaning based, so differ between individuals and are coloured by emotions, however they are prioritised over verbatim representations of the literal details as they are more stable and less subject to interference. FTT has been applied to vaccination decisions (Reyna, 2008), and has shown that peoples' decisions rely

on where the gist risk lies, for example, if the gist is 'low' risk of contracting a disease but 'high' risk of side effects from the vaccination, the person would likely decide not to have the vaccination even when the risks are uncertain. However, this theory has not been applied to higher risk surgery decisions where high levels of risk are implicated in both choices of the decision. FTT incorporates a role for emotions, stating that they influence perceptions of risk. The theory also acknowledges that context influences decisions, e.g. media campaigns portraying illnesses as high risk.

An alternative view of uncertainty from Prospect Theory (Kahneman & Tversky, 1979), which is descriptive decision theory, weights potential losses more heavily than potential gains in contexts of uncertainty, resulting in people tending to behave in a risk averse manner. This results in people behaving differently in decision making contexts when they have different perspectives on losses and gains. Ackerson and Preston (2009) conducted a systematic review of how women choose whether or not to have cancer screening and found that fears and uncertainty were present for all women, however the sources of fears differ between women. For example, they found that women do not elect to have screening when they fear medical examinations, medical providers, tests and procedures, don't have or seek knowledge and see their current health status as the 'norm'. Conversely, women do elect to have screening when they fear cancer, trust care providers, seek knowledge, understand risks and see routine care as the 'norm'. However, Prospect Theory did not account for all the variation between those who do and do not elect to have screening and further roles were identified for emotions (fear and uncertainty), optimism bias and framing of choices. It has been suggested that theories which focus on 'stress' and 'coping' provide a

framework for decisions regarding genetic screening, e.g. for breast and colorectal cancers, Huntington's disease and Alzheimer's disease, where uncertainties are present (Gooding, Organista, Burack, & Biesecker, 2006). In addition, Gooding et al. (2006) criticise decision making theories for being conflictual, too focused on cognitive aspects of decision making and not including emotional aspects to decision making. Emotional aspects to decision making have been widely cited but have limited implications in the theories, apart from for FTT.

In summary, patients are involved in their medical decision making, in models such as SDM. However, medical decisions are complicated and often have high levels of uncertainty and risk. There cannot always be certainty about diagnoses and the risks and benefits of treatment options for individual patients. Decision making theories and their evidence do not fully acknowledge the role of uncertainty within decision making processes. Therefore, the literature exploring the impact of uncertainty for patients involved in their medical decision making requires review.

This review focuses on the experience of patients involved in their medical decision making. This review aims to integrate and critically evaluate the literature exploring the impact of uncertainty for patients involved in their own risky medical decision making. Further clarity about the patient experience is required to inform medical practitioners and other professionals who support patients throughout these decision making processes.

## Method

An initial search was conducted on 23/6/2015 using the following databases; ‘Web of Science’, ‘Scopus’, ‘Psych Info’ and ‘PubMed’. The search was repeated on 27/01/2016 to check for any new articles. Searches were conducted for the timespan of the databases as there is no definitive date when patients became involved in their medical decisions. Figure 1 outlines the search terms entered into the ‘title, abstract and keyword’ field, which were chosen to capture research which explored patients’ decision making for medical decisions under uncertainty. The term ‘theory’ was included to capture research which reviewed theory in relation to how people make decisions. The inclusion of the term ‘theory’ enabled exploration of how theory acknowledges uncertainty within the different decision making processes explored in the literature. Furthermore, it also enabled research to be captured that critically evaluated how uncertainty was accounted for within the theories. Combinations of these search terms were searched using the Boolean operator ‘AND’ in order to ensure that the greatest number of relevant articles were included. Reference lists and citation lists from the selected papers were also searched by hand in August 2016 to check for any recent papers.

Figure 1  
*Search Terms*

	“Decision”
AND	“Theory”
AND	“Risk”
AND	“Uncertainty”
AND	“Medical” OR “Surgical” OR “Surgery”

As shown in Figure 2, the initial search produced 358 records. A secondary search of the references and citations of these articles provided one further relevant record. One hundred and twelve articles were duplicated across the databases. Ten articles were found to be relevant after screening titles, abstracts and full articles using the inclusion and exclusion criteria outlined below. Of the ten articles which were included, nine were qualitative studies and one was quantitative. Of the nine qualitative papers, six used a Grounded Theory approach (Glasser & Strauss, 1967). A range of patient groups were explored by the literature including: cancer, amniocentesis, genetic screening, hormone replacement therapy and antiepileptic drug treatment.

### **Inclusion/ exclusion criteria**

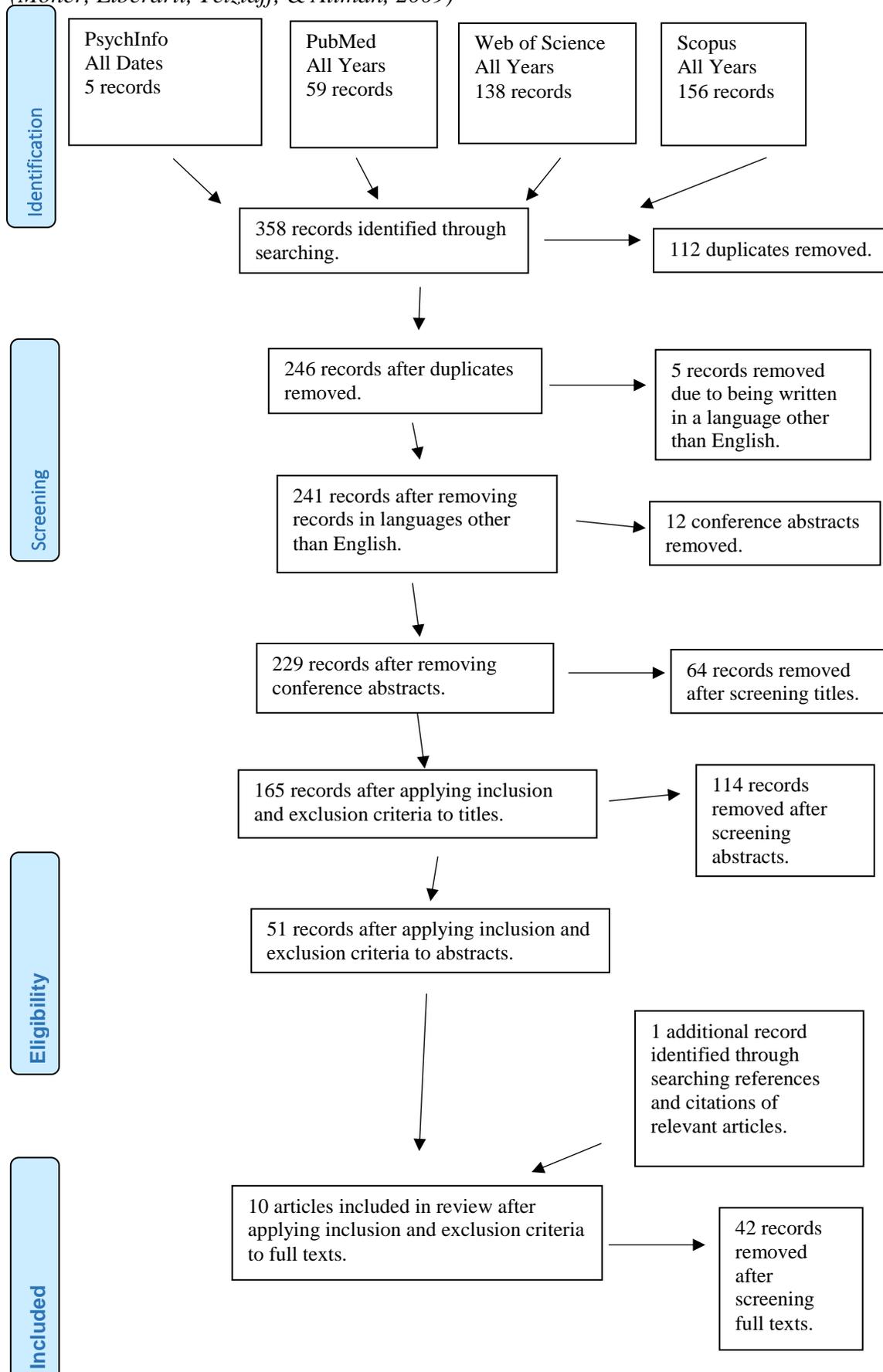
Articles were excluded that were not written in English. Articles were also excluded that were conference abstracts as these did not provide sufficient detail, however thesis submissions were included as they were deemed to have a sufficient level of detail. Articles exploring hypothetical decisions were not included. All included articles explored uncertainty in the decision making process for patients involved in choices regarding risky medical decisions. Articles had to explore the uncertainty of the patient making a decision about treatment or procedures, and not just the uncertainty of the medical professional, making a decision on behalf of a patient.

### **Data synthesis**

The qualitative articles were reviewed using the procedure outlined for meta-ethnography (Noblit & Hare, 1988) due to its systematic approach. The steps to conducting a meta-ethnography are as follows; 1. Getting started, 2. Deciding what is relevant to the initial interest, 3. Reading the studies, 4.

Determining how the studies are related, 5. Translating the studies into one another, 6. Synthesising translations, 7. Expressing the synthesis. Once the qualitative articles had been identified, they were read and re-read to enable familiarisation with the contents. First order constructs (i.e. raw data) and second order constructs (i.e. themes written by the authors) from the papers were then noted. The second order constructs were then compiled in an excel spreadsheet referring back to written notes about the raw data that was detailed in the papers (see Appendix A). The excel spreadsheet was colour coded to show which themes and sub-themes (i.e. second order constructs) from each paper were included in each theme identified by the meta-ethnography. Initially a reciprocal translational synthesis was used where the concepts of the studies were absorbed by one another. Following this, lines of argument syntheses were used to create a story as a whole from the studies, including results from the quantitative study. Throughout the data synthesis, a reflexive diary was kept by the researcher in order to document any thoughts, ideas and emerging themes. This was discussed with research supervisors in order to ensure that themes generated were based in the data from the studies.

Figure 2:  
*Preferred Reporting Items for Systematic reviews and Meta-Analyses Diagram*  
 (Moher, Liberarti, Tetzlaff, & Altman, 2009)



## **Quality assessment**

All included articles were rated using QualSyst (Kmet, Lee, & Cook, 2004). QualSyst is designed to appraise both qualitative and quantitative studies. The quality of the studies was assessed as this impacts on the reliability of the results and the conclusions drawn. It was deemed inappropriate to exclude papers of a poor quality due to the small number of studies. Scores for the quality assessment are displayed in the results table with a higher score indicating a stronger method. Qualitative studies had a total possible score of 20 points from 10 criteria, with a score of 2 meaning that the criteria was met, a score of 1 meaning that the criteria was partially met and a score of 0 meaning that the score was not met. The score was divided by the total possible score to obtain the summary score. Quantitative studies had a total possible score of 28, with 2 meaning that the criteria was met, a score of 1 meaning that the criteria was partially met, a score of 0 meaning that the score was not met and any not-applicable items were removed from the total possible score. The score was then divided by the total possible score to obtain the summary score. A cut-off score of 0.75 is recommended, if excluding papers based on quality ratings.

Limitations highlighted by QualSyst are discussed in more detail throughout the review, whilst outlining the synthesis of the data, as recommended by Dixon-Woods et al. (2007). Four of the papers were rated by an independent researcher, also in their final year of Clinical Psychology Doctoral training and experienced in appraising the quality of papers. There were no points of disagreement.

## Results

Table 1 shows the core methodological details of the studies identified, and the focus of the studies. The validity of the studies is included in this table, represented by the quality rating. Lower quality studies did not report using verification procedures to establish the credibility of the study and did not detail the reflexivity of the account. Better quality studies had a clear objective and context which was connected to a theoretical framework, with an appropriate design, data collection method and data analysis method.

Data synthesis revealed that five of the studies produced stages of decision making processes involving uncertainty using a Grounded Theory approach. The remaining four qualitative studies explored themes related to uncertainty within the decision making processes. The concepts of the studies were absorbed into one another, maintaining a framework of stages of decision making. Following this a story as a whole was created from the studies, including the quantitative study and is outlined in stages of decision making.

Table 1  
*Characteristics of the ten articles included in the review*

<b>Citation</b>	<b>Quality Rating</b>	<b>Patient group</b>	<b>Sample size (% male)</b>	<b>Age range</b>	<b>Country</b>	<b>Methods of gathering data</b>	<b>Analysis</b>	<b>Aims</b>
Bailey et al. (2005)	0.8	Prostate cancer	10 (100%)	64-88	USA	Individual interviews	Content analysis	Explore problems and uncertainties of older men with prostate cancer and the strategies they used to manage these problems and uncertainties after undergoing watchful waiting.
D'Agostino (2014)	0.95	Early stage thyroid cancer	15 patients (7%) 6 significant others (100%)	29-69	USA	Individual and group semi-structured interviews	Grounded Theory	Develop an in-depth understanding of the process by which patients live with a diagnosis of early stage thyroid cancer and make decisions regarding initial treatment options.
Frost et al. (2004)	0.70	Breast cancer genetic screening	15 (0%)	-	USA	Focus groups and individual interviews	Grounded Theory	Determine how high risk patients deal with uncertain clinical results in the arena of breast cancer susceptibility.
Griffiths (1999)	0.75	Hormone Replacement Therapy	17 in interviews (0%) 25 in focus groups (0%)	20-69	UK	Individual interviews and focus groups	Immersion/ Crystallisation analysis	Explore how women approach the decision to take Hormone Replacement Therapy and what influences them and provide an understanding of issues that might be present in a consultation regarding hormone replacement therapy.
Kasper et al. (2008)	0.90	Breast, kidney, tongue and lung cancers	6 (50%)	45-77	Germany	Interviews	Grounded Theory	Survey distinctive qualities of decision-related uncertainty in cancer patients.

Kilinic & Campbell (2008)	0.90	Antiepileptic drug treatment	12 (42%)	15-56	UK	Semi-structured interviews	Phenomenological	Provide an in-depth understanding of withdrawal decisions.
Lam et al. (2005)	0.70	Breast cancer treatment	22 (0%)	23-88	Hong Kong	Semi-structured interviews	Grounded Theory	Explore process of treatment decision making in breast cancer.
Lesser & Rabinowitz (2001)	0.85	Amniocentesis	232 (0%)	18-43	Israel	Structured interviews	Rational Choice Theory applied	Apply rational choice theory to explain women's use of amniocentesis.
Sun et al. (2007)	0.85	Amniocentesis	20 (0%)	Over 35	Taiwan	Interviews and observations	Grounded Theory	Generate a descriptive model for understanding patterns and interpretations concerning women's experiences of amniocentesis in Taiwan.
Weiner et al. (2012)	0.90	Surveillance of an indeterminate pulmonary nodule	22 (14%)	18-89	USA	Focus groups	Grounded Theory	Explore patients responses to detection and evaluation of a pulmonary nodule.

In the review of the literature, uncertainty and ‘not knowing’ were seen as the most difficult and central parts of the decision making process for patients and were the most difficult aspects of the decision making process (Wiener, Gould, Woloshin, Schwartz, & Clark, 2012; Kasper, Geiger, Frieberger, & Schmidt, 2008; Sun, Hsia, & Sheu, 2007). Some participants found uncertainty so difficult, they said they would rather be certain that they had an illness such as cancer, rather than be uncertain. Furthermore, patients were not aware that some tests might end up with uncertain medical conclusions (Frost, Venne, Cunningham, & Gerritsen-McKane, 2004), therefore patients were not always aware that uncertainty could be involved in their decision making processes.

The following sections highlight stages and themes relating to uncertainty identified in the literature. Table 2 shows the organisation of the themes, then each theme will be discussed in turn and illustrated by quotes. By organising the literature into these themes it is hoped that a clearer understanding of the impact of uncertainty throughout the decision making process will be developed. Commonalities in the decision making process were identified, across the different conditions and situations explored by the individual papers.

Table 2

*Themes from analyses of the papers*

<b>Theme</b>	<b>Papers contributing</b>
Initial fear and uncertainty	All except Lesser & Rabinowitz (2001)
An uncertain decision and uncertain knowledge	All
An uncertain choice	All except Frost et al. (2004), Griffiths (1999) and Lesser and Rabinowitz (2001)
Coping with uncertainty	All except Griffiths (1999), Kasper et al. (2008), Kilinic & Campbell (2008) and Sun et al. (2007)

**Initial Uncertainty and Fear**

In the initial stages of decision making, uncertainty was linked to diagnoses, i.e. uncertainties about the patient's current state of health, (Bailey, Wallace, & Mishel, 2005; Kasper et al., 2008; Weiner et al., 2012; Griffiths, 1999). At this stage uncertainty was also linked to prognoses, i.e. uncertainties about what the future course would look like for the patient including future risk and recurrence (Weiner et al., 2012; Kilinic & Campbell, 2008; Kasper et al., 2008; Griffiths, 1999). Uncertainties were noted due to disparities between feeling healthy and yet having an uncertain, but potentially serious diagnosis (Bailey et al., 2005; Lam, Fielding, Chan, Chow, & Orr, 2005):

I have no physical discomfort at all. This is why it's still hard to believe that I have this thing growing in me. (Bailey et al., 2005, p.737)

In addition, it was difficult for patients to understand their health outcomes due to disparities between people leading healthy lifestyles, yet

becoming ill with a life threatening diagnosis (Griffiths, 1999) leading to uncertainties about the success of medications.

At this point in the decision making process, uncertainty was linked to the emotional response of fear (Bailey et al., 2005; Lam et al., 2005; Sun et al., 2008, Wiener et al., 2012):

I felt frightened. I was so scared that I would die...that I would have to suffer. (Lam et al., 2005, p.6)

Fear was categorised as an emotional response to cognitive uncertainty which can cause great distress (Weiner et al., 2012). For example, some patients experienced fear without medical certainty that they had cancer (Weiner et al., 2012):

I've never gotten any definitive answers...and that's scary in itself, not knowing. (Weiner et al., 2012, p.359)

Sun et al. (2008) found that patients feared the uncertainty of their fetus' wellbeing due to the increased risk of abnormalities with the older age of the mother. It was also found that patients had uncertainty linked to fears about the uncertain threat of a diagnosed nodule (Weiner et al., 2012). Uncertainty was, however, concluded to be more than the combination of fear and anxiety for women undergoing amniocentesis (Sun et al., 2008) and the management of uncertainties was central to the decision making process (Kasper et al., 2008). Fear can result in patients becoming emotionally overwhelmed when making decisions, due to uncertainties about the seriousness of diseases and the potential fear of death associated with 'serious' diseases (Lam et al., 2005). Patients

preferred to learn that they had uncertain results when face to face due to the emotional impact of this news (Frost et al., 2004).

Griffiths (1999) found that fear was influenced by previous personal experiences of ill health and experiences of ill health in family members but not previous experiences of treatments. These fears of illness and fears due to the uncertainties of the risks and benefits of medical treatment influenced patients' attitudes towards medications. Fear was found to make patients want to make decisions as quickly as possible, although they were unsure what to decide (Lam et al., 2005). Conversely, D'Agostino (2014) found that those who elect to have surgery had a swift decision making process, although this was not found for patients who elected for an 'active surveillance' treatment approach.

Overall, uncertainties were noted at the initial stage of the decision making process that were linked with fear. This fear made patients want to make a quick decision and fear also influenced their attitudes towards the options within the decision.

### **An Uncertain Decision and Uncertain Knowledge**

Following from patients' initial emotional reactions linked to uncertainty, the next stage of the decision making process was to consider uncertainties within the decisions for treatment. This stage was seen as a 'gamble' due to the many factors which could not be predicted (Lam et al., 2005) or when decisions were only 'worth a try' as there was no way of knowing (Kilinic & Campbell, 2008):

I was quite confused. It's like going to a casino to gamble. It's all dependant on your luck. (Lam et al., 2005, p.6)

OK it's worth, worth a try, I'd like to... (Kilinic & Campbell, 2008, p.509)

It was found that there were many treatment options for prostate cancer with no clarity about the most appropriate treatment (Bailey et al., 2005).

D'Agostino (2014) found that patients who elect to have surgery feel unable to tolerate the uncertainty of an active surveillance treatment approach and therefore gain control of the situation by deciding to take action and physically remove the potential threat through surgery:

Watching could be literally deadly. (D'Agostino, 2014, p.41)

Furthermore, those that did not elect to have surgery felt less threatened by the uncertainty, viewing that they cannot be certain that they have cancer therefore cannot be certain that only a potential threat needs physically removing:

Well to me it means I might and I might not (D'Agostino, 2014, p.44)

Control balanced out the themes of uncertainty and fear for patients considering Hormone Replacement Therapy (HRT) as both fear and uncertainty reduced patient's sense of control, with patients more likely to elect for treatment if the effects and risks are certain, therefore having more control and less uncertainty (Griffiths, 1999). In the methodologically stronger studies, patients expressed uncertainties about the knowledge of medical professionals, whether they had been told everything and reliability of their information (Kilnic & Campbell, 2008; Kasper et al., 2008; Weiner et al., 2012):

I think he is up to date...I hope so at least. (Kasper et al., 2008, p.46)

Griffiths (1999) found that patients generally accept that knowledge is uncertain with the notion that knowledge is continually re-appraised, however this finding is from one of the methodologically weaker studies. Furthermore, in one study patients acknowledged that there was no way of knowing for certain if they would experience side-effects when stopping their medication (Kilinic & Campbell, 2008).

Experiencing relief from the test results was linked to patients' knowledge of the procedure and continued uncertainties they had with amniocentesis (Sun et al., 2008). Supporting this notion, Lesser and Rabinowitz (2001) explored the decision making processes of pregnant Israeli women and found that the participants who elected to have amniocentesis had more knowledge about both the procedure and its associated risks, than those who either did not elect to have amniocentesis or those who were medically indicated to have amniocentesis. Therefore, less uncertainty was linked with more knowledge even though this knowledge could not provide information about the procedures which was certain.

Handing over control to medical professionals to interpret medical information and evidence was also a source of uncertainty (Griffiths, 1999). Sun et al. (2008) identified a stage of decision making which was characterised by gaps in knowledge between the physician and patient, resulting in patients having the misconception that they were having the procedure to increase their chances of delivering a healthy baby. Patients are more likely to choose a treatment if it is framed as the 'standard' by medical professionals, not an 'alternative' treatment (Lam et al., 2005). Patients sought information from other people and from the media (Griffiths, 1999). Information was more trusted when it was provided by a

medical professional, compared to information from the internet, which was more uncertain (D'Agostino, 2014).

Lam, Fielding, Chan, Chow, and Or (2005) recommend that patients have time to digest any information provided to reduce barriers to making the decision. Furthermore, patients who were deciding on treatment for breast cancer were indecisive if they felt solely responsible for the treatment decision and did not have support from a medical professional in their decision (Lam et al., 2005). Patients wanted to receive guidance in addition to information in order to reduce uncertainties (Lam et al., 2005). Patients who trusted their medical professional looked for clues as to the medical professionals' preference for treatment and tended to act in accordance to what they perceived as their preference (Lam et al., 2005). Griffiths (1999) found that for patients to be able to feel happy with their own medical decisions, they had to have trust in the medical professional who was interpreting complex medical information for them. Patients who experienced uncertainty about the necessity of treatment also experienced loss of trust in their medical professional (Lam et al., 2005). In addition, trust in the medical institution, not just the professional, was important with regards to reputation and experience in order to reduce patients' uncertainty (D'Agostino, 2014).

Uncertainty is apparent for 'trustworthiness of the medical professional' and also for the 'patient role in the interactions' for patients deciding upon treatment for breast, kidney, tongue and lung cancer (Kasper et al., 2008). Furthermore, it was found that these uncertainties were less likely to be reported in appointments although this was of high importance to the patients and was recommended to be supported by medical professionals. The authors concluded

that a medical professional who provides all information regarding success and risk as recommended, could still fail to support decision making from the patients' perspective, if other aspects of uncertainty, such as 'trustworthiness of medical professionals' are neglected to be discussed (Kasper et al., 2008).

Griffiths (1999) identified that patients value being able to process information and knowledge with their friends and family, suggesting a link between uncertainty, knowledge and also interpersonal relationships. It was also found to be difficult to share results which were uncertain and patients wanted support from their significant others when in this situation (Frost et al., 2004). Kilinic and Campbell (2008) suggested that GP support was important for patients. Patients also had uncertainties about the reliability of their social relationships in the context of their disease or illness (Kasper et al., 2008). Furthermore, impact of the decision on family members was a more important consideration than impact of the decision on the patient for some patients (Lam et al., 2005). In order to negotiate uncertainties, patients used support from their partners and family members when making their decision (Sun et al., 2008; Lam et al., 2005; Frost et al., 2004). In addition, those who elected to have amniocentesis had more of a consensus with their partners in terms of their decision than those who did not elect to have amniocentesis (Lesser & Rabinowitz, 2001).

Overall, patients were uncertain about the knowledge relating to the decision and were uncertain about their role in the medical decision making relating to medical professionals and family members. However, patients felt that they had more control at this stage of the decision making process. Although they

had control, they wanted support from their significant others and medical professionals due to their uncertainties.

### **An uncertain choice**

Following on from uncertainty in general about the decision, there were also uncertainties involved in the specific choice participants' elected for in their decisions. Patients electing to undergo amniocentesis had concerns about the maternal and foetal safety during the amniocentesis due to a lack of information about the procedure which led to uncertainty, anxiety and fear (Sun et al., 2007). Patients were also uncertain about the appropriateness of their treatment (Bailey et al., 2005).

Uncertainty is not only present throughout the decision making process but has also been found to be present after the choice has been made, for example; for epilepsy medication withdrawal, amniocentesis and breast cancer surgery (Kilinic & Campbell, 2008; Sun et al., 2007; Lam et al., 2005).

Uncertainties post-decision include how patients will cope with their lives after treatment (Kasper et al., 2008) and thinking about what their future lives will look like (Sun et al., 2007). Even when given positive results after amniocentesis (i.e. no identified abnormalities), patients still feared that something was wrong due to beliefs that the test was not 100% accurate (Sun et al., 2007):

...even if the chromosomes and amniotic fluid are normal, it's not a guarantee that nothing is wrong. (Sun et al., 2007, p.2834)

Additionally, research emphasises the need for on-going support following decisions as emotions surrounding uncertainty are still present for patients, even when the decision appears to have been 'successful' (Kilinic &

Campbell, 2008). Patients who elected to have active surveillance saw less threat to their life from the disease than the threat of uncertainty of living without a thyroid due to the surgery, whereas those who elected for surgery could not tolerate the uncertainty of disease progression (D'Agostino, 2014). Wiener et al. (2012) found that some patients progressed to stage of certainty and acceptance of their uncertain growth. This happened once patients felt that they had evidence that their growth was not growing and developing, however not all patients reached this acceptance. There were also some patients who accepted their uncertainty as it meant that there was a potential that there was some chance that they did not have cancer. Bailey et al. (2005) also found that some cancer patients were accepting of uncertainty and able to integrate it into their lives by minimising the threat of cancer and gathering information which backed this viewpoint up. Frost et al. (2004), Griffiths (1999) and Lesser and Rabinowitz (2001) did not explore this aspect of the decision making process and were noted to be the weaker studies methodologically. Overall, uncertainties continued to be present even after the decisions had been made and the choice had been followed through.

### **Coping with uncertainty**

Patients employed the following strategies to cope with uncertainties; vigilance for symptoms, contemplating and controlling risk factors, avoidance, faith, keeping busy, being optimistic, fatalism, medication and social comparison (Wiener et al., 2012; Lam et al., 2005; Bailey et al., 2005):

I didn't let myself think about it. I kept myself very busy. (Lam et al., 2005, p.11)

We attend church, and I certainly have a great deal of faith, and I think anybody in this condition would certainly have prayers on this, and I do... (Bailey et al., 2005, p.739)

Patients sought information as a way to manage uncertainties (Lam et al., 2005; Wiener et al., 2012; D'Agostino, 2014). Patients elected to have amniocentesis as a way to gain control and reduce uncertainty (Lesser & Rabinowitz, 2001) and patients elected for surgery due to the uncertainty of recurrence (Lam et al., 2005). Patients also resolved uncertainty by choosing surgery instead of an active surveillance approach (D'Agostino, 2014). Patients coped with uncertainty by attempting to control all elements of situations, such as perceived risk factors of diet and lifestyle (Weiner et al., 2012). It was argued that the existence of a screening test means that the only way to reduce uncertainty of whether a disease is present or not, and gain control over the uncertainty is to elect to have the screening test to gain control and certainty (Weiner et al., 2012). Not all studies explored the ways that patients coped with their uncertainties (Sun et al., 2007; Kilinic & Campbell, 2008; Griffiths, 1999; Kasper et al., 2008).

## Discussion

The aim of this systematic literature review was to critically appraise the literature exploring the impact of uncertainty for patients who are involved in their own risky medical decision making. As indicated by other research (Ackerson & Preston, 2009), uncertainty is apparent in various diagnoses and treatment decisions. As indicated by the Uncertainty in Illness Theories (Mishel, 1990), uncertainty was also seen to be implicated from the diagnosis stage of illnesses, through to the success of the elected treatments. Implicated in the uncertainty is the information, patients' role in the medical decision related to medical professionals and significant others and choice success. Patients attempt to cope with this uncertainty in a variety of individual ways, some of which are to make the choice which seems most likely to reduce uncertainty. This provides support for the Uncertainty in Illness theories (Mishel, 1990) which takes account of the impact of uncertainty throughout the whole decision making process. In the research, links were made to the Theory of Planned Behaviour (Ajzen, 1991; Kilinic & Campbell, 2008), Fuzzy Trace Theory (Reyna; 2008; D'Agostino, 2014) and Common Sense Model of Health (Rosenstock, 1974; Wiener et al., 2012) in terms of how people make decisions. However, six of the ten included studies used a Grounded Theory approach to analyse their data, due to existing decision making theories not sufficiently accounting for the impact of uncertainty in the decision making process. Therefore, suggesting that consideration of Uncertainty in Illness Theories is a useful guide for patients who are involved in their medical decision making.

## **Limitations**

Although a limitation of this review is inclusion of only English-language studies, these studies originated from a wide range of settings and cultures. Although the papers were from a wide range of different conditions and settings, which could limit commonalities, it is notable that given such divergence, there was relatively little contradiction in the findings. The papers reviewed include participants from America, United Kingdom, China and Sweden, whom all employ different healthcare systems. For some countries, no costs are associated with these medical treatments and investigations at the point of delivery, however in other countries, additional costs and insurances are associated. Although, the studies differ in these contexts it is still possible to compare the decision making processes as in the United Kingdom there are comparable rates of patients not accessing interventions although they are free. In the United States, 18% of women over 18 did not have offered cervical cancer screening and in the United Kingdom, 18% of women also did not have cervical cancer screening (Centers for Disease Control and Prevention, 2007; Cancer research UK, 2007). Although the studies were wide ranging, six of the ten studies used grounded theory approach, enabling their comparison.

It is possible that articles might have been missed due to the narrow search terms and lack of truncation and synonyms. For all studies included, the sample of participants might be biased towards those who are exploring the possibility of undergoing the treatment or intervention, therefore biasing the sample towards those who see medical intervention as less uncertain and those who are more at ease with relinquishing some control to medical professionals. It might be that participants only of a higher educational status participated in these

studies, due to feeling more academically able to discuss the topics, which will have resulted in sample biases. Furthermore, only one person completed the searches and decided whether to include or exclude articles. Again, it would have been beneficial for two people to be involved in this process and seeking the opinion of a third person if the two raters did not agree about the inclusion of a certain paper. There might also be some decisions where uncertainty has a different role, therefore it is important to consider the unique uncertainties of individual decisions.

### **Clinical Implications**

An overall finding of this review was the impact of uncertainty for patients throughout the whole decision making process. In clinical practice, medical professionals should discuss the pros and cons of treatments and procedures, including uncertainties of these, with patients, but also explore other aspects of uncertainty such as their role in the medical decision making and their trust in the medical profession, and impacts on the patients' wider social support. A medical professional who provides all information regarding success and risk as recommended, could still fail to adequately support decision making from the patients' perspective if other aspects of uncertainty, such as enhancing a patients' control, trustworthiness in medical professionals and institutions and emotional responses are neglected to be discussed. These are important considerations when using models such as shared decision making. Patients also require emotional support which continues after the decision has been made. This would empower patients to make decisions and enable them to negotiate uncertainties pertinent to them. There is the possibility that this would improve decision satisfaction for patients and improve patient outcomes. Therefore, medical practitioners should

support the emotional aspects of patients' decision making. This could also inform the development of decision support interventions for medical decisions involving patients.

Through supporting patients' decision making processes, it is likely that patients will have better satisfaction with their treatment course. If patients are more satisfied with their decision making experience, it is likely to have a positive effect on their mental health and wellbeing. This positive impact on mental health and wellbeing could reduce the need for further support or medical treatments.

There is still lots of research needed to look at the role of uncertainty in decision making in medical settings. The relatively small numbers of papers for each medical area, shows that this is a new area of research that is currently expanding. Future research in this area would benefit from more qualitative studies exploring the specific role of uncertainty within decision making, especially for high risk surgery decisions. It might also be useful to specifically compare different cultures and races to explore whether uncertainty holds different cultural and racial connotations. Further quantitative research is also warranted to explore the links between levels of uncertainty and post-decision satisfaction and quality of life. It might also be useful for further research to be conducted into associations between the role of uncertainty within decisions and brain scan results. This might help inform support for surgery decisions relating to brain tumours and brain diseases that have affected parts of the brain implicated in decision making under uncertainty.

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## Appendices

Appendix A – Extract from Metaethnography table of analysis

META-THEMES	THEMES FROM LAM	SUB THEMES LAM	THEMES SUN	NOTES SUN	THEMES WEINER	NOTES WEINER
INITIAL UNCERTAINTY	CAUSAL CONDITIONS	discovery of abnormality subsequent emotional reactions	AMBIVALENCE TO PREGNANCY		COGNITIVE CERTAINTY AND FEAR and COGNITIVE UNCERTAINTY AND FEAR	move through stages fear of death and anxiety re: diagnosis
fear				fear		
UNCERTAIN DECISION (control)	GAMBLE OF TREATMENT CHOICE	indecisiveness	DECISION TO UNDERGO AMNIOCENTESIS		COGNITIVE UNCERTAINTY AND ACCEPTANCE	uncertainty means the re's chance its ok
family and sig others		prioritising personal aims seeking and evaluating information time pressure		discussion with spouses unsure re: meaning of info		
Knowledge						

## Section two: Research Report

A Qualitative Study into the decision making process for patients electing to undergo neurosurgical clipping for an unruptured cerebral aneurysm.

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**A Qualitative Study into the decision making process for patients electing to undergo neurosurgical clipping for an unruptured cerebral aneurysm.**

**Objective.** This study aimed to explore the decision making processes of patients electing to have neurosurgical clipping to treat an unruptured cerebral aneurysm. There has been little previous research into these decision making processes and decision support interventions are generally not grounded in theory. The objective of this study was to contribute to research into decision making processes and explore the processes that are involved in high risk surgical decision making.

**Methods.** Semi-structured interviews were conducted with ten participants who were recruited from a list of those who had had surgery in the past five years. Verbatim transcripts were analysed using Interpretative Phenomenological Analysis.

**Results.** Analysis revealed four superordinate themes that underpin patients' decision making processes; 'the tension between self-determination and responsibility for others', 'relationship with the surgeon and NHS', 'life and death' and 'post-surgical reflections and sense making'.

**Conclusions.** The themes highlight that participants valued being part of the decision making process about their treatment options and even when treatment did not have the desired outcome, participants did not express regret of their treatment choice. It is important to consider the impact of patients' significant others, and interpersonal process with the medical practitioner. The findings could be used to inform development of a tool which could support people when making high risk surgical decisions.

Improvements in medical diagnostics have resulted in patients being diagnosed with medical issues earlier on in the course of illnesses and diseases. Due to advances in medical imaging, patients are now being diagnosed with unruptured aneurysms which have options for treatment. An unruptured aneurysm is described as ‘a bulge in a blood vessel caused by a weakness in the blood vessel wall, usually where it branches’ (National Health Service, 2013). In some instances these unruptured aneurysms can be treated using a coiling procedure which does not require brain surgery as the coil is inserted through the groin. In instances where coiling treatment is not possible, the aneurysm can be left untreated with increasing risk of it rupturing, or can be treated through high risk neurosurgical clipping to prevent the aneurysm rupturing. Leaving the aneurysm untreated leaves the patient with high levels of uncertainty and risk as the aneurysm can rupture at any time, with the risk of rupture increasing year on year. If the aneurysm does rupture, there is a three in five chance of death (National Health Service, 2013). Neurosurgical clipping surgery to treat unruptured aneurysms involves general anaesthetic and open brain surgery, with the surgeon sealing the aneurysm shut with metal clips that remain permanently on the aneurysm. For this procedure, there are risks implicated with the use of general anaesthetic, surgical intervention, and procedures directly involving the brain which could lead to death. There is also a threat to life by leaving the aneurysm untreated, as the aneurysm might rupture which could also lead to death or severe impairments. In a study conducted, out of 4060 patients, there were 1692 who did not have treatment for an unruptured aneurysm, 1917 who had neurosurgical clipping and 451 who had coiling treatment. For patients who did not have their aneurysm treated, it was found that the 5 year rupture rates were between 0 to

50% depending on the size and location of the aneurysm. This was comparable to the risks from surgical intervention (Wiebers et al., 2003). This decision of whether to leave the aneurysm untreated or have neurosurgical clipping involves unpredictability, threat to life and weighing up of risks.

Patients are being involved in their medical care decisions due to recent shifts in the emphasis of healthcare provision (World Health Organisation, 2008). For example, patients are involved in decisions about their cancer treatments (Ambigapathy, Chin Chia, & Ng, 2016), arthritis treatments (Yasser, Gaafrey, Sayed, Palmer, & Ahmed, 2016) and asthma treatments (Cormiers, Legare, Sinard, & Boulet, 2015). Patients involved in their treatment decisions report higher satisfaction and better outcomes (Wilson et al., 2010; Lindhiem, Bennett, Trentacosta, & McLear, 2014). Furthermore, there is evidence that financial costs to healthcare organisations and harm to patients could be prevented if healthcare providers listened more effectively to their patients (Francis, 2013). There is limited research about how to support the decision making process, and therefore, medical practitioners have little available informed literature to draw upon to support patients to make such life changing decisions. Furthermore, current Decision Support Interventions (DSI's) are rarely based on theory (Durand, Stiel, Boivin, & Elwyn, 2007). Being fully informed about treatment is a complicated process because medical professionals also need skills in coaching and counselling in order to support patients to make informed decisions (Foot et al., 2014). Medical professionals are involved in supporting patients' decisions about treatments for their diagnosed unruptured aneurysms.

There is a gap in the research literature into high risk medical decision making. No research into decision making has currently been conducted with

patients who have been diagnosed with an unruptured aneurysm and have elected to have neurosurgical clipping. Currently, there are no DSI's for patients diagnosed with an unruptured aneurysm and existing literature does not explore non-emergency, high risk decision making by these patients. The function of this research is, therefore, to explore, in more detail, the psychological and social processes that underpin patients' decision making, in order to better support medical practitioners in facilitating effective patient decision making. This research might also inform the development of DSI for high risk surgical treatment.

Patients deciding about treatment options for their unruptured aneurysm face high levels of uncertainty when deciding whether to leave the aneurysm untreated or elect for neurosurgical clipping. A recent paper by Platts, Walsh, Isaac and Tooth (in press) reviewed ten studies which explored the impact of uncertainty for patients involved in their medical decision making. They found that uncertainty was implicated in the decision making process from the point of diagnosis, through to treatments being completed and patients recovering from treatment. Uncertainty was linked to fear at the start of the decision making process with patients feeling shocked and overwhelmed. Then uncertainty was linked to control which balanced out the fear to some extent. Uncertainty was also implicated with information and the patients' role in the medical decision relating to medical professionals, then specific uncertainties were highlighted regarding the different choices that could be made. Patients used differing strategies to cope with uncertainty and some decisions were made which would be most likely to resolve uncertainty. As a first step to exploring the decision making processes

where uncertainty and risk as prevalent, appropriate theoretical models need to be considered.

One of the few theoretical models to incorporate uncertainty into the decision making process is Fuzzy Trace Theory (FTT; Reyna, 2008). FTT explores decision making whilst considering how uncertain information is represented by individuals and processed in their decisions, in terms of their background knowledge. FTT is based on theories of both memory and information processing and states that people process dual mental representations; both verbatim representations (i.e. literal details) and gist representations (i.e. subjective interpretation of meaning) in memory. People also apply their values to their mental representations in the context, e.g. 'I am likely to die from this' which someone might value as something which they do not want to experience as they value living a fulfilled and active life. Furthermore, the mental representations are also influenced by emotions, e.g. 'I am likely to die from this and I am scared'. Subjective gist representations are relied upon over and above the verbatim representations because they are meaning based for that individual, yet are more stable and less subject to interference than the verbatim representations. It is argued that specific information does not always have a large impact on decision making, as the gist is relied upon over the verbatim, therefore this theory is considered applicable to uncertain decisions as the gist representation is based on what the information means to that patient.

FTT has been applied to vaccination decisions (Reyna, 2008), and has shown that peoples' decisions rely on where the gist risk, not the specific verbatim risk, lies. In the case of being diagnosed with an unruptured aneurysm, if the gist is 'low' risk of the aneurysm rupturing, but 'moderate' risks from the

neurosurgical clipping surgery, the person would likely decide not to have the surgery. Whereas, if the gist is ‘moderate’ risk of the aneurysm rupturing, but ‘low’ risk of neurosurgical clipping, the person would likely decide to have the surgery. FTT states that emotions influence perceptions of risk, such as fear and anxiety regarding a potential rupture. Furthermore, FTT acknowledges that context influences decisions, e.g. media campaigns for stroke (i.e. a ruptured aneurysm) portraying the high risks of stroke and alerting to the awareness of rapid response to symptoms. D’Agostino (2014) found that FTT was relevant in the decision making processes of patients with early-stage thyroid cancer with patients basing their decisions on their gist representations. However, FTT has not been widely applied to higher risk surgery decisions where high levels of risk are implicated in both choices of the decision. In addition, prior to the development of FTT, the majority of previous literature use a Grounded Theory approach (Glasser & Strauss, 1967) in order to develop theories which account for uncertainty within decisions (Platts, Walsh, Isaac, & Tooth, in press). Therefore, experiential research into high risk decision making is warranted in order to explore the decision making experience, before evaluating the utility of FTT. Processes involved in decision making for high risk surgery, could be explored in greater depth using qualitative methods to understand the processes involved in decision making. Research focusing on patients post-surgery, enables them to reflect on those processes which supported and/or hindered their decision making process to have surgery. This in depth analysis will aim to inform medical practitioners of the processes involved for patients in high risk medical decision making and could lead to development of a DSI in the future. Understanding how

surgical decisions are made will enable practitioners to better support people making these choices.

The main aim of this qualitative study was to explore, post-surgery, the processes that underpin the decision to have neurosurgical clipping for an unruptured cerebral aneurysm. Additionally, the results will be considered in relation to theoretical models of decision making to review the utility of FTT, which in turn might help identify ways of supporting people making these choices and the medical practitioners involved.

## **Methodology**

### **Design**

The study used a qualitative methodology to provide a 'deeper' understanding of the decision making process and experience of participants (Crist & Tanner, 2003) who had elected to have neurosurgical clipping for a diagnosed unruptured cerebral aneurysm. Semi-structured interviews allowed in depth data to be collected to gain insight into peoples' perceptions, understandings and experiences (Ryan, Coughlan, & Cronin, 2009) whilst allowing flexibility and space for participants to talk at length about their experience.

Interpretative Phenomenological Analysis (IPA: Smith, Flowers, & Larkin, 2009) was used to explore the decision making process of those patients, as this approach looked at how people made sense of their experiences. IPA has a critical realist and constructivist epistemological position, that is concerned with human experience 'as it is'. It takes the position that reality can be accessed through social constructions of language, whilst bearing in mind that the 'reality' obtained will depend on the perspective taken. This means researchers engage with a person's relatedness to the world through the meanings that they make and believe that different views of a phenomenon will lead to different insights and conclusions. IPA is phenomenological, as it is concerned with the perceptions of individuals, and interpretative, as the researcher is making sense of data through the lens of their own conceptions and experience. IPA aims to explore experiences of individuals and identify meanings of their thoughts and beliefs through detailed analysis of interviews, looking at the shared and unshared aspects of experience. No studies to date have focussed on this specific decision

making process. The analytic outcomes of IPA will be used to re-evaluate the utility of FTT.

### **Recruitment**

An invitation letter (Appendix A), Information Sheet (Appendix B) and Consent form (Appendix C) were sent by the patients' surgeon to patients who had the treatment between six months to five years ago. Participants were selected in time-period cohorts starting from those who had the treatment six months ago, working towards patients who had the treatment five years ago to ensure consistency of the sample. Participants who replied to the invitation indicating an interest in participation were contacted via telephone to ensure they met the inclusion criteria and a date was arranged to participate in the research. Formal consent was obtained at the start of the interview session when participants had the opportunity to ask any questions they required.

### **Participants**

Participants had had neurosurgical clipping for an unruptured cerebral aneurysm between six months and five years previously. All participants were aged between 18 and 65 and were diagnosed with an unruptured cerebral aneurysm based on a scan and had not previously suffered any haemorrhages, as prior surgical intervention for an aneurysm might have influenced the decision making. Participants were not included who had a ruptured aneurysm as the risk of not treating a ruptured aneurysm is much greater, therefore altering the weighing up of risks in the decision making process. Additionally, patients with a ruptured aneurysm are often too ill to be involved in the decision making process and the decision is made on a best interests basis without their input.

Participants were excluded who were under 18 years of age, not fluent in English, had other major neurological or health problems which impacted on their healthcare or had had surgery more than five years before, as they would have been too far removed from their decision making process.

A sample of ten participants were included in the study in line with the sample size commonly used in IPA (Smith et al., 2009). Twenty nine participants were invited to take part in the study aged between 38 and 77 (mean =  $55.8 \pm 9.53$ ) and ten participants took part in the study aged between 42 to 74 (mean =  $56.3 \pm 9.27$ ). Of the participants invited to take part in the study, 24% were male and 76% were female. Of the participants who took part in the study, 40% were male and 60% were female. Participants invited to take part had their surgery between 11 months and 54 months previously (mean =  $32.7 \pm 12.8$ ) and the sample of participants who took part had their surgery between 11 months and 54 months previously (mean =  $24.4 \pm 15.2$ ). Of the participants who took part in the study, four had unsuccessful outcomes, including three participants suffering a stroke during surgery or the neurosurgical clip coming off the aneurysm straight after surgery for another participant. Therefore, the participants who suffered a stroke were left with some impairments and the participant whose clip came off after surgery, was left with an untreated aneurysm although they elected to have the treatment.

### **Data collection**

One to one semi-structured interviews were conducted by the Trainee Clinical Psychologist (for full interview schedule see Appendix D) at their local hospital or in participants' homes. All interviews were conducted within a four month period. The interview questions are detailed in Figure 1 below.

Figure 1

*Interview schedule*

1. How was your aneurysm found?  
*Prompts: How were you told? What was life like at the time – work, relationships, symptoms? How did you see yourself? Did you talk to other people about it? What happened next?*
2. What was your understanding of the diagnosis when you were making your decision?  
*Prompts: What were you expecting to happen? Who was there? How did you feel about it? What worried you/made you feel that way? How did you cope with that worry/those feelings? Were there any risks that you considered? How did you weigh up these risks?*
3. What did you understand about the pros and cons of treatment?  
*Prompts: What were you expecting to happen? Who was there? How did you feel about it? What worried you? (Were there any other things that worried you?) How did you cope with that worry?*
4. How did you decide to go ahead with the surgery?  
*Prompts: What did you do to decide? What was helpful? What was unhelpful? Could anything have been different? How long did it take to make the decision?*
5. What was important to you when you were deciding whether to have the surgery?  
*Prompts: What information was important? Who did it matter to tell? What did you tell them? What did they think?*
6. How do you usually make important decisions?  
*Prompts: Was there any difference between how you usually make decisions and how you decided to have surgery?*
7. What has happened since you had the surgery?  
*Prompts: What do you think about your decision now? How do you feel now?*
8. What other experiences do you have of healthcare?
9. Is there anything else that you think it might be helpful for me to know?  
*Prompts: What was the interview like? Did anything surprise you?*

After providing informed consent and prior to commencing the interview, participants provided demographic information (see Appendix E). This information included age, gender and time elapsed since surgery. Demographic

information was collated for all people invited to participate in the study, in order to situate the sample of participants who chose to participate.

There was flexibility in the Interview Schedule to allow for interviewees to lead the discussion and talk about issues most important to them. A pilot interview was conducted to familiarise the Trainee with the interview schedule and allow for amendments. The interviews were audio-recorded using an encrypted digital recorder, and lasted from one hour, to 90 minutes. After the interviews were conducted, participants were offered space for reflection on the process of the interview and were made aware of where they could access additional emotional support, if required.

### **Data Analysis**

The data was analysed using techniques consistent with IPA (Smith et al., 2009) to explore how people made sense of their decision making experience. IPA was chosen as it has been used extensively in health psychology research (Larkin & Thompson, 2012) and it fits with the epistemological and ontological assumptions of understanding subjectivity and impacts of the wider context. Three interviews were transcribed by the Trainee and the rest were transcribed by a University approved transcriber (for Confidentiality form and contract see Appendix F).

Transcripts were read and re-read, firstly noting any preconceptions about the data in a reflexive diary. Initial ideas, reactions, key words and points of interest were then written in the left hand margin to initially analyse data on a participant by participant basis. Then, any emerging title themes were noted in the right hand margin, whilst the researcher looked for patterns in the way in which experiences were discussed.

The third stage involved transferring a list of themes onto a separate piece of paper, to start looking for structure amongst the themes. Therefore, the researcher was starting to look for connections between the themes, thereby clustering them together. The transcripts were referred back to during this stage, to ensure that connections were valid. As the list was refined, clusters of themes moved from general to specific and descriptive to interpretative. The researcher produced a table in Excel detailing each higher theme and its subordinate, lower themes, including examples of where each theme could be found in the transcripts (see Appendix G). This process was repeated for each interview transcript.

When all interviews had been analysed, the researcher began comparing the accounts across transcripts. If it was apparent that some themes were not shared between accounts, or they had little evidence, they were not included in the final list of themes. The table of themes was integrated and refined across the interviews until a coherent account of the data was reached. Once the analysis was complete, FTT was re-evaluated in relation to the themes.

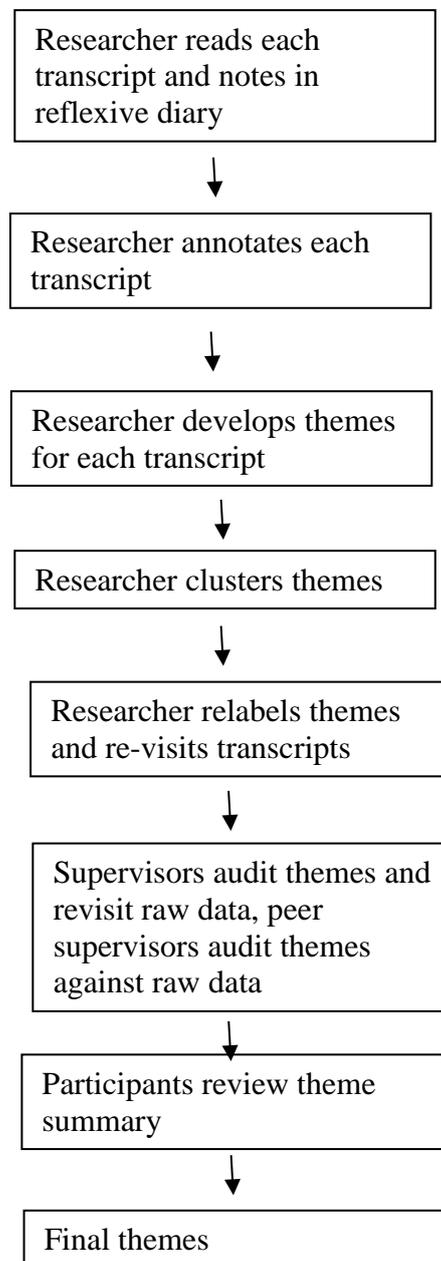
### **Quality Control**

Figure 2 shows the process of analysis and quality control. These procedures are described in more detail as follows. A pilot was conducted with one service user, not included in the final analysis, for the researcher to become familiar with the interview schedule and for opportunity to amend the interview schedule with feedback from the service user. No amendments were deemed to be required following the pilot interview. All themes identified in the analysis were reviewed by the research supervisor to check for coherence and credibility by looking at the themes and supporting quotes. Following on from this, all themes were then checked by supervisors working with the client group to again check

for coherence and credibility. An independent researcher audited a random selection of the themes for three transcripts and the supporting analysis and quotes to ensure that the process was rigorous and transparent (Smith, 2010). Any data received by the independent researcher was anonymised. Extracts and commentary were used to achieve transparency. To facilitate these audits, the researcher completed a table detailing the analysis of the themes, including, superordinate themes and the participants that contributed to the superordinate themes, subthemes and the participants that contributed to the subthemes, cross-references, illustrative quotes and notes (Whittemore, Chase, & Mandle, 2001). The reflexive diary was continually completed during data collection and analysis to acknowledge the intersubjective relationship between the researcher and research topic. The reflexive diary included pre-conceptions, motivations, personal thoughts and reactions, to enable transparency of the process. The reflexive diary was discussed with the research supervisors to ensure all interpretations were grounded in the participants' accounts, instead of in the researcher's assumptions. Three participants reviewed summaries of the themes and stated that they were representative of their experience.

Figure 2

*Flow diagram of analysis and quality control*



### **Ethical Implications**

The researchers endeavoured to conduct all aspects of the research in line with British Psychological Society's (2009) ethical principles of Respect, Competence, Responsibility and Integrity and in accordance with the principles of Good Clinical Practice (GCP). Participants were given the Information Sheet

and had time to ask questions before giving informed consent to take part. Participants were not interviewed whilst making surgery decisions, as this was considered to be a stressful time due to the pressure of the decisions currently being made. Participants were made aware that they did not have to answer every question, could switch off recording equipment and withdraw from the study at any point without any impact on their future healthcare. If participants required further emotional support, they were informed that they could be referred appropriately. Participants were made aware of the boundaries of confidentiality and were informed that confidentiality may be breached if they disclosed information indicating that anyone was at a risk of harm.

To maintain confidentiality, a password protected encrypted digital recorder was used to record the interviews and pseudonyms were used in the write up of the transcripts (see Appendix H). The digital recorder was stored in a locked filing cabinet, to which only the researchers had access. Digital audio files were stored in encrypted files on a memory stick, accessed only by the researcher and transcriber. In addition, effort was made that lengthy quotes or potentially identifiable quotes were not used in the write up of the research to ensure that participants could not be identified. Any personal identifiable information was kept securely in a locked filing cabinet. On completion of the study, transcripts have been stored in a secure locked filing cabinet and the researcher has deleted all stored audio recordings. The research was submitted to the NHS Research Ethics Committee via the Integrated Research Application System (IRAS) and gained a favourable opinion (Appendix I). The research was also submitted to the local NHS Foundation Trust Research and Development office and was given local NHS permission to commence the research.

## **Results**

Participants' accounts of the decision making process covered many aspects of the experience, including diagnosis, understanding the decision, making the decision, having the surgery and recovering from the surgery. All participants discussed the experience for them and for their significant others. Although some participants expressed difficulty recalling specific details of the decision making process, all participants were able to give an account of their experience. The themes described below emerged from participants' accounts of the decision making process. The overall analysis showed four superordinate themes, three of which are divided into separate subordinate themes. Table 1 shows the organisation of the themes, then each theme will be discussed in turn and illustrated by transcript quotes.

Table 1

*Themes from the analyses of transcripts*

<b>Superordinate theme</b>	<b>Subordinate theme</b>	<b>Participants contributing</b>
The tension between self-determination and consequences for others	My decision with only one perceived choice	All
	Taking account of the effect on others	All
	The influence of others in the decision making process	All
Relationship with the surgeon and NHS	Interpersonal skills	All
	Expert skills	All
	Trust and gratitude	All
	Impact of disruptions and cancellations	All except; 4, 7, 10
Risks of life and death	Uncertainty, risks and a gamble of life over death	All
	Vulnerability and the brain	All
	Coping with uncertainty and managing the fear	All
Post-surgical reflections and sense-making		All

**The tension between self-determination and consequences for others.**

The tension between self-determination and consequences for others refers to the tension expressed by participants between having sole control over the decision of whether or not to have surgery and the effect that this would have on their significant others. Participants were aware that whatever decision they made, it would affect their significant others, yet did not feel that it was a decision their significant others could make, although they were affected by it. Furthermore,

participants described that they had a decision, but came to the conclusion that they felt they had only one viable choice. The tension between self-determination and consequences for others is made up of three subordinate themes; *my decision with one perceived choice, taking account of the effect on others in the decision making process* and *the influence of others in the decision making process*.

***My decision with only one perceived choice.*** Participants described going through a decision making process, although they came to the conclusion that they felt they only had one choice they could make. Emphasis was placed on ultimate control of the decision lying with the patient and not with professionals. This appeared to make participants feel more able to accept the surgery decision.

...you still feel sort of in control of what's going to happen. Whereas if you see somebody else or for something else, it's – you go and see them and they say 'right this is what's wrong and what's going to happen, and that's you done. (participant 4 line 361).

I think it's - it's just taking control - being able to have the control of saying if I'm going to go - I don't want to sound morbid or anything - but if I'm going to go, say I died on the operating table, I don't want to be awful or anything, but I'm going to have people round me who will - I'll be at peace won't I, because I'll be asleep, they'll make sure I'm OK. (participant 8 line 344)

Participants described that only they could be the ones that knew how to make the decision, no matter how close they were to other people who were

alongside them throughout the process. Participants had a sense of ownership over their decision.

You've got it, and never mind how close you are, friends and family, you've got it, you're going to have to physically actually do something with it. (participant 5 line 190)

However, whilst participants had control of the decision, they also reflected that there was only one choice they felt they could make.

...that's how I looked at it, I've got no choice, um I had got a choice, where I could have left it, but in my opinion, no, I've got no choice. (participant 2 line 595)

I think that decision for my brain, that – there were no, there were no like thinking..... No, do none of that, it was there and then, put me on the list, I'm having the surgery. (participant 2 line 692)

It was a case of, I needed to have it done. (participant 3 line 202)

***Taking account of the effect on others.*** Participants were aware that although they had the control over the decision whether or not to have surgery, whatever outcome of the decision, their significant others would be affected by the decision and choices made. The effect on others ranged from emotional effects of having a loved one in surgery to financial effects.

Yes it's affected us more than what we - when I say us, it's because we always do everything as a family. (participant 3 line 718)

...but things have changed and I don't think sometimes people realise just – it affects people. It's like when a family gets cancer; it doesn't just affect that person, it affects everybody, doesn't it. (participant 3 line 898)

It's hit my husband harder than probably maybe people might think as well. I mean we've been together over 30 years and I think the thought – I think he's thought 'oh who's going to look after me. (participant 8 line 330)

I class it, I think, as a big operation, because so many things could go wrong, but it's not just you having it done, it's your whole family, because it's not just you that it affects. (participant 4 line 565)

Participants also felt a responsibility to stay well for their family and make a choice that would mean that they could be there for them. Some participants were considering their own desires to be there for their family and other participants were considering a responsibility to protect their family.

I got a lot to live for, you know, my family, my son, I've only got one. (participant 2 line 243)

I've involved them more, because it matters to them, I mean if they lose a Mum, if I'm not around and things. (participant 8 line 567)

Some participants felt that once the decision had been made, the process was more difficult for family than for themselves.

I think my husband was more petrified than I was. (participant 6 line 258)

...like, when they put you to sleep, I think it's always a lot harder for your family than it is for you, because once that needle goes in your vein, you

start counting and you're gone, so time just stands still for you, but for your family, it's hours, isn't it? (participant 4 line 255).

Participants also reflected on how much support they required from their family throughout the decision making process, especially during medical appointments, both emotionally and physically.

I think it's always nice because sometimes it can sweep over you, and sometimes you can still be processing the first detail when he's (surgeon) on to you about the second and on to the third. Another pair of ears and someone who is closely involved in it, then we can go home and discuss what he's said. (participant 5 line 452)

He did a lot, I wouldn't have got this far without him. (participant 6 line 622)

Participants also chose which family members to involve in the decision based on how much they felt it would affect them. This was another aspect of the decision making process where participants assumed control.

We didn't tell them...he doesn't deal with – he can't handle, so he would have been in bits. (participant 3 line 390)

***The influence of others in the decision making process.*** This subordinate theme is an extension of taking account of the effect on others, as participants had described being aware that family members would be affected, and therefore sought the opinions of those family members.

Well, it was going to effect, isn't it, so I mean, my wife's got every right to say – although I'm the one going through the surgery and upset and everything that goes with it. (participant 5 line 884)

It was a big thing asking my wife what did she think, a big thing.  
(participant 10 line 421)

This theme is related to considering the effects of the decision on family members, yet is a separate theme as some people sought reassurance from family members. Whereas, others were seen to be asking opinions of significant others, however not taking these opinions into account in the decision making process, just being reassured about their decision.

...and I'm saying 'do you think I should have this surgery?'" and she's like 'yes' but I'd already made that decision. (participant 2 line 185)

I did ask my wife and I can't really remember what she said, but then again it's my decision. (participant 1 line 278)

It's always nice to have someone there that you can talk to and be reassured by. (participant 4 line 481)

...like they said 'no, whatever your support is, like they supported me. I said I don't want – because it was about putting the family through stress, and worry of it. And like they said, no, look, if you weigh the options, and it's for you, and you feel happy. We're here no matter what. (participant 7 line 279)

...to the family and I said I don't know whether to just leave it and let nature, or like they said 'no whatever your decision is, like they supported me. (participant 7 line 297)

**Relationship with the surgeon and the NHS.** This superordinate theme refers to participants' descriptions of their relationships with both the surgeon, other medical professionals and the medical services. This was on both interpersonal levels and expert levels. The following subordinate themes will be discussed; *interpersonal skills*, *expert skills*, *trust and gratitude* and *disruptions and cancellations*.

***Interpersonal skills.*** Participants all reflected on the appointments with their surgeon and their impressions of them. All participants spoke highly of their surgeons and the interactions they had. Participants described that how appointments were conducted, and how the personal qualities of the professionals, affected their views of the surgeon.

...and there were no like big long words what he was using; everything was very understandable. (participant 4 line 34)

I don't know I think it was more his mannerisms, um, he spoke – like I say, he spoke to us on a normal persons level and um, it weren't, he didn't seem quite so scary. (participant 4 line 43)

I mean he had his desk at the side and I think it's a good idea with his chair there and you were sat on a chair and he had a chair that swivelled on wheels and he would swivel round and sit in front of you and not like you were talking to somebody over a desk cus the desk is like putting a barrier between you before you started. He was just definitely definitely his manner and as I say, he was just wonderful. (participant 9 line 51)

The time taken for appointments and the way that appointments were conducted was also important to participants. Although participants felt that they only had one choice, they valued having the time to be sure of their decision.

It wasn't a two minute consultation, I felt like he'd got all the time in the world for me and he wasn't bothered about the clock. (participant 1 line 245)

I think it was just to doubly make sure that we were going to make the right decision. (participant 4 line 166)

Participants appreciated that their views were taken into consideration during the appointments and valued being seen as a person with valuable contributions.

It was a lot of coaxing and kindness from him and talking to me as a person, rather than just another patient. (participant 9 line 17)

And he doesn't just see you as another patient on his table, he sees you as an individual and he knows that even though it probably is his 700,000<sup>th</sup> time of doing the operation, it's your first. (participant 4 line 565)

Participants also described a desire to connect, on an interpersonal level with the surgeon.

He just made you feel so relaxed, so at ease, like you were having a discussion with your best friend about your health, not like you had a consultant sat opposite you. (participant 9 line 46)

One participant described feeling unable to make a connection with the surgeon although they liked them.

No personality, but I think it's because he has to keep himself aloof from all what happens around him. (participant 5 line 348)

Participants described how other interactions within the hospital setting were also contributory factors to their decision making process. Participants described interactions with secretaries, nurses and other staff and spoke positively of these experiences.

It was a wonderful, wonderful hospital. (participant 9 line 144)

The staff are – they just like made me feel at ease, because I were just frightened to death. (participant 2 line 425)

I think they're a really good hospital and the staff are brilliant. (participant 4 line 682)

...staff were lovely, they on the ward, they were really nice, come and sit and talk to you. (participant 6 line 681)

**Expert skills.** Participants described receiving expert information from the medical professionals involved in their care. It was apparent that this information was important for patients to understand the decision they were making. Participants described that there were expert skills involved in making this specialist information understandable to the patients and the way in which this information was shared.

He did show me scans of my head and he showed me where the problems was. (participant 1 line 244)

...hell of a difference, well its like, is that what I have got in my head, it makes a hell of a difference because when you see something and its pointed out to you and explained right, now this is the bad one, this is the one that I really don't want to mess with, do you know what I mean, it's different like me saying to you, there's a beautiful dress in town, it's like this, it's like that, now if I showed you a picture of it and it scoops at the back and it would really suit you, you would be on my wavelength and think it sounds lovely yes, but if I just described it to you, you would just think oh ok. (participant 9 line 271)

Participants valued the thoroughness of medical professionals and also appreciated the complexity of the tasks they were faced with.

...they were hard to identify, I don't know how they were spotted to start with really. (participant 4 line 149)

Participants were also aware of the reputation of their surgeon. For participants this was the reputation and expert skills that they valued to put trust in them.

...but when you start tinkering about in your brain and cutting chunks out of it, you've got to have someone with a steady hand and someone who doesn't drink. (participant 5 line 328)

I put my trust in (surgeon), I heard good things about how good he was. (participant 10 line 52)

***Trust and gratitude.*** Participants reflected on the trust they placed in the surgeon and team. It was difficult for participants to explain how and why they were able to put so much trust into the medical professionals, however participants described handing over all their control to them.

I don't know what it was, I just thought, these people will put me right.

(participant 8 line 137)

You just put your faith in, your life in their hands really. You just think, well they're going to sort you out, everything is going to be OK.

(participant 6 line 216)

Having trust in the medical professionals also gave participants confidence in their abilities to do a good job.

...(surgeon) just fills you with confidence. (participant 4 line 46)

I just had so much confidence in (surgeon), they could have told me they were taking my head off and putting it back on the other way. (participant 9 line 90)

This trust did not remain at the interpersonal level with the one surgeon, but also extended to the procedures offered by medical professionals.

...and I thought look, it's not like in the olden days, doctors are more advanced and more technology and you know you hear more successful than not successful don't you? (participant 7 line 692)

For some participants this gratitude extended to them expressing feeling lucky to be able to have brain surgery.

Well it's not every day you have the opportunity to have brain surgery is it? (participant 1 line 382)

Well, you can moan and complain about – but ultimately I'm here and these guys at (hospital) are the ones what – they're the reason I'm here, not anything else. (participant 3 line 966)

I felt lucky that it wasn't a stroke or a heart attack. (participant 8 line 87)

I just thought to myself life is for living, there's so many people that don't have that choice, their lives are taken away from them when they can't be helped and I thought, well I've been offered the help here and I just grabbed it. (participant 9 line 196)

Some participants considered how they would feel about their decision when it was not successful. One participant found a way to accept this by putting their trust into another source in this eventuality.

...now if that stopping it doesn't work, and they've tried their hardest to do it, well I've put myself into - well, it's in God's hands then. (participant 8 line 233)

***Disruptions and cancellations.*** This subordinate theme refers to the problems encountered by some participants, which were disruptions to their referrals and/or cancellations of surgery. This represents the negative aspects of the decision making experience that participants could identify with. Participants linked this to a feeling of frustration with the process that was out of their control. Participants described 'building' themselves up for the surgery to find that this had been cancelled which had a huge impact on their wellbeing.

...and then I had to wait another year before open brain, but then they cancelled it, I was right outside the theatre doors, ready to go in, but there was no bed, so I got sent home, so all this anticipation, that was awful.

(participant 6 line 95)

...then I went back in March to have my surgery. So it was that time, from March – from January to March, that I – that weren't good, that one.

(participant 3 line 43)

...and the waiting time is sometimes quite lengthy. And then you get a letter saying it's been postponed and other 6 weeks added to them.

(participant 5 line 92)

Cancellations also affected participants' lives more widely, beyond their wellbeing. Participants described having to make arrangements to go into hospital and cancellations resulted in disruptions to these arrangements.

You're making time and arrangements with your boss because you're having to make cover, and then you're having to go and knock on his door, saying, I'm not going, I'll have to rearrange it, the cover has to be scrapped. (participant 5 line 94)

Participants described a sense of frustration resulting from disruptions in their medical care. This frustration was also linked to worry and anxiety.

They are saying they're large, ready for bursting and yet it seemed to take forever to get them seen to, because you know, waiting for the bed, waiting for this, that and the other, waiting for when I could get in.

(participant 6 line 49)

The waiting game, that's awful. It is, because you just want to get it over and done with. (participant 6 line 268)

Although the majority of participants faced disruptions and cancellations, leading to frustration, they stuck with their decisions to have surgery and did not report re-visiting their choices.

I suppose they would they would have give up and said oh forget it but I thought it come this far, I don't know what made me carry on but I did. (participant 1 line 172)

One participant explained even trying to find another way to have the surgery if possible.

We found out just how good he was, we did have a cancellation, and I did ask my doctor how much it would cost for me to have the surgery private, and he said 'you wouldn't want it, and if you want one of the, if not the best neurosurgeons in the country, you wait'. (participant 5 line 277)

Participants who experienced disruptions could acknowledge the positive impact when disruptions were not present in the process:

And then nearer to the time of me having my operation, because it was pretty quick, weren't it, once they had it all organised. (participant 3 line 243)

**Risks of Life and death.** This theme covers the uncertainty in the decision making process and mostly the uncertainty of life and death. The

following subordinate themes are discussed; *uncertainty, risks and a gamble of life over death, vulnerability and the brain and coping with uncertainty and managing the fear.*

***Uncertainty, risks and a gamble of life over death.*** All participants referred to the risks implicated in their diagnosis and treatment option. It was acknowledged that choosing to have surgery had risks and choosing not to have surgery also had risks.

They said the percentage of coming through it and I could die on the operating table or have a stroke on the operating table. (participant 10 line 22)

All participants eluded to a 'gamble' metaphor to explain that there was uncertainty no matter what choice they made, however they were all making the gamble which seemed to give more chance to keep them alive. Although more chance was given to being kept alive, this did not feel certain and was referred to as a risk.

Well everyone wants to live but you are just playing a roulette wheel.  
(participant 1 line 58)

The risk to not having it seemed worse than the risk to having it because as my daughter put it, you are like a walking time bomb. (participant 9 line 111)

This isn't walking around with a time bomb in my head and the time bomb's saying 'I'm tick, tick, ticking.' I'm having a go at somebody trying to stop the time bomb. (participant 8 line 231)

Participants described the feeling of knowing that an aneurysm was present and untreated as threatening. This was described as an overwhelming presence in their lives.

Personally I couldn't face the death sentence every second of every day, so this surgery became the option that we discussed and chose that we would take the chance. (participant 5 line 257)

Now you know you've got it, you would be concerned that every time that I said goodbye to go to work I wouldn't see her again. Any time I left a friend, any time I walked around a corner, the next person who found me, I'd be on the floor, dead. (participant 5 line 266)

Part of the threat was due to the unpredictable nature of aneurysms meaning that the participants did not know when a symptom might mean something more severe. The possibility of aneurysm rupture was a frightening thought for all participants, which was very overwhelming.

I'm not very good at dealing with the not knowing and I said 'I don't think I can cope with going to bed every night and not knowing if tonight would be my last night and if I have a stroke next week. (participant 4 line 128)

It was like a ticking time bomb, kept thinking 'oh if I get a headache'. (participant 2 line 150)

I get a normal headache, is it the aneurysm, have I lifted too heavier thing at work. (participant 5 line 292)

***Vulnerability and the brain.*** Vulnerability was associated with the threat to life caused by the aneurysm and deciding whether to have the surgery. A factor implicated with vulnerability for participants was linked specifically to the brain. Participants were aware that surgery to any part of the body carried risks, however, they felt less able to comprehend these risks when considering their brain, compared to other parts of their body.

I've had two babies, so I've had pain and stuff, I mean you know, but your head is really precious. (participant 8 line 186)

Near the clockwork of my brain. So, it was quite dangerous and that.  
(participant 6 line 138)

I've got this thing in my head, and if it does something, I'm not going to get to hospital. (participant 3 line 1101)

Consequences on participants' future lives relating specifically about their brain and consequences on their functioning was also mentioned by participants. This was something participants could not predict.

...like you know, is it going to change me, is it going – will I forget my family, because that was the main thing. (participant 7 line 654)

***Coping with uncertainty and managing the fear.*** Participants all described ways of coping with their uncertainty, with coping mechanisms differing between participants. Although coping strategies were individual to participants, all participants made some attempts to manage their uncertainty. For some participants, choosing to have the surgery was one way of minimising the uncertainty.

They can last for a while, but they can also rupture unknown can't they with no warning, and I thought, no if it's gone, it's not there anymore is it.

(participant 7 line 701)

That worry, every time I had a headache, gosh, is it going to you know, and I thought, the only way to do it is to get it done, get it removed.

(participant 7 line 254)

Once the decision was made, but before the surgery, some participants described relief from the uncertainty.

I felt really happy when I got my date through to go and have my operation done, because the fear of not knowing what tomorrow was going to bring was a lot more than the fear of what the operation was going to be. (participant 4 line 334)

Managing the fear after the decision was made was also prevalent. Ways of managing the fear differed between participants with some bottling up all their emotions.

I am a person a bit like that, like to put my head in the sand and pretend it's not happening. (participant 9 line 11)

Other participants described needing them to distance themselves from the decision once it had been made, by cutting off or keeping busy to avoid thinking about it.

You know, don't sit thinking, keep busy. (participant 7 line 405)

One participant needed to know everything that could go wrong, others chose what they did and did not want to know.

It's the actual knowing, and the consequences, it's not the fear of the consequences, it's knowing the consequences, and then if somebody like myself, it's there to be dealt with, ill deal with it and then make a decision about how that's going to be. (participant 5 line 497)

Taking care of themselves was something mentioned by several participants. It seemed that a need to take control of some aspect of recovery that could be controlled was important.

Doctors can only do so much and sometimes it's up to you to help yourself. (participant 1 line 394)

**Post-surgical reflections and sense making.** An important aspect of the whole decision making process was the reflections after the surgery had happened. Participants described reflecting on the decision making process and outcome of surgery as a way of making sense of the experience. For some participants they felt that sense could not be made until after the event as reality was different to their expectations.

If this illness was a book and each page was a part of getting better so you think ah yeah that's that and you get through a lot of pages to get to a chapter, but then when you look back at your first page, you think, was I like that. (participant 1 line 228)

...and really how I expected it, it isn't anything that bad. (participant 7 line 65)

Participants reflected on the outcome of surgery and none of the participants described a sense of regret even when surgery did not have the desired outcome for four of the participants. One participant linked this to a sense of control, they felt happy with the outcome as they had chosen the treatment and were aware that it might not be successful, therefore this was something they were able to accept as part of the process.

I don't regret having it done because for them few months, I went home...I felt cured and at peace and I thought, that's it now, we can get on with living and things. (participant 8 line 601)

It was the right decision definitely. (participant 9 line 255)

I don't regret having it done, because I was really pleased with the outcome and the staff and everything. (participant 7 line 35)

Some participants went on to reflect on a change in perspective on life following their surgery. Participants explained that they felt grateful for smaller things in life which they might have not realised if they had not been faced with such threat to their lives.

I just look out of windows and if it's raining I'm pleased to see it.  
(participant 1 line 236)

We're here and we got this second chance and all that. (participant 3 line 913)

## Discussion

The aim of this study was to explore the decision making processes for participants diagnosed with an unruptured cerebral aneurysm which could be treated through neurosurgical clipping. The decision making process to have this high risk surgery is a previously under-researched area. Ten participants from a surgical intervention group who had been diagnosed with an unruptured cerebral aneurysm engaged in semi-structured interviews, which enabled their accounts of the decision making process to have surgery to be elicited. The following discussion provides a summary of the findings, limitations of the research and a discussion of how the research fits with existing theory.

The analysis of this research highlighted the intrapersonal tension for patients between having control over their decision yet interpersonally affecting others with their choice. Participants had a choice to make which would affect the lives of their significant others, so they felt a duty to involve them in their decision making process, although they had usually already made their choice. This involvement of significant others did also provide reassurance for the participants. Furthermore, patients perceived that although they had control over which choice to make, they perceived that there was only once choice that was viable for them, which was to have the surgery due to considering the risks, threats and uncertainties. The importance of the relationships with medical professionals and the NHS was also highlighted, including how the surgeon shared their expertise with patients whilst maintaining approachability and giving time and space. This theme also included an organisational factor of disruptions to and cancellations of treatment, which resulted in unnecessary frustration and affected participants' lives and wellbeing. A major theme was the uncertainty of

risks relating to life and death, which have to be considered by patients and was eluded to as a 'gamble'. Due to the risks and associated uncertainty, participants felt vulnerable, especially due to the specific risks to their brain. For some participants to manage the uncertainties, they chose to have the surgery. Finally, the analysis highlighted that after the surgery, participants reflected on the process to make sense of this experience, although this was difficult as the experience was not something they felt they could have expected. However, even when surgery did not have the desired outcome, participants did not regret their decision to have the surgery. The limitations of the research are outlined, then the themes are explored in relation to FTT, to reflect on its utility. The contribution of the research to the development of DSI's will also be considered.

### **Limitations**

Before discussing implications of this study, it is important to consider the weaknesses which might impact on the applicability and generalisability of the findings. As it was a retrospective review, cognitive bias has to be considered as participants might have been looking for reasons to justify their decisions that had already been made and could not be changed. In addition, a sample who all made the same decision, without any prior experience of haemorrhage, less than 5 years ago was selected in order to satisfy the analysis. However, this results in a limitation to the study as it means that there was not a diverse sample therefore, conclusions cannot be generalised to wider populations, including those patients who do not elect to have the neurosurgical clipping procedure. Both male and female participants were included in this study, however there was a small sample size of 10.

Another limitation of collecting data by interview is interviewer characteristic, creating a potential bias. Participants were aware that the researcher was a Psychologist which might have made it easier for some participants and harder for other participants to be open in interviews. It was however, considered that all participants spoke openly and honestly without censoring their accounts. This was evidenced by participants being able to discuss negative aspects of their experiences and their ability to reflect on the whole process, without being unwilling to discuss any parts of the decision making process.

#### **The tension between self-determination and consequences for others.**

The subordinate theme of ‘my decision but only one choice’ refers to participants having control over their decision and being aware of the impact their decision will have on their significant others. Participants sought reassurance about their decisions from their families who were also an important source of support for participants. It is important to consider that participants might have sought opinions of those who would agree with their decision and did not consult those who would have provided an alternative opinion. FTT states that context influences decisions, therefore, in terms of the current research, participants took into account their context, i.e. their families when making their decisions. Furthermore, participants also had an awareness that their decision would in turn affect their contexts.

**Relationship with medical professionals and the NHS.**

The subordinate theme of 'trust and gratitude' highlights the trust and confidence that participants had in their surgeons. FTT does not explore an interpersonal role for trust and confidence. Furthermore, the process of shared decision making occurred between the participants and their surgeons and also as a parallel process between participants and their significant others. Participants consulted significant others who reassured them and supported their decisions. This further supports the notion that interpersonal relationships were important in the decision making process.

Even when faced with disruptions and cancellations, participants did not change their mind about their decision which fits with the notion that gist representations are less subject to interference as patients stuck with their decisions. This could be considered that participants had the 'gist' that there was no choice because the risks tipped the balance towards taking the chance on surgical intervention. This was also linked to participants' values and emotional reactions to living with the uncertainty that their aneurysm might rupture.

**Uncertainty of risks of life over death.**

The results showed that negative evaluation of leaving the aneurysm untreated, coupled with positive evaluation about the possible outcome of surgery, resulted in the surgical choice being made. When taking these factors into consideration, participants reflected that the only choice they perceived was to have the surgery. When describing the risks of the aneurysm whether treated or untreated, participants talked about chance and used metaphors such as a 'gamble' to represent the lack of certainty. Uncertainty is a key theme in this

research as many participants chose to have the surgery as a way of managing their uncertainty and therefore, perceived having the surgery as their only viable choice. FTT states that a person's values and emotions are applied to their gist representation, in this case that surgery was the preferable choice due to their fears around the uncertainties of the risks. Participants did not discuss literal details of risk levels (i.e. verbatim representations) in the decision but their descriptions correspond with the idea of gist representations.

### **Post-surgical reflections and sense making**

Participants suggested that the experience was not as they expected it to be when they reflected on it after their surgery. Perhaps this represents that it is an unpredictable situation, which you cannot fully know about or be in control of. However, participants did not regret their choice to have surgery, even when the outcome was not the desired outcome. FTT states that patients apply their values as part of their decision making process, therefore, if patients have made decisions based on their values they would not be likely to regret their decision as it would still fit with the values they hold.

In some circumstances, the concept of post-traumatic growth was also recognised with participants showing positive development from a traumatic experience. For example, although participants acknowledged the adversity of their diagnosis, they could also see a renewed perspective on life, such as appreciating small things they had not previously appreciated. The concept of post-traumatic growth is not explored in FTT.

## **Summary**

There is interesting overlap between the themes in this study and concepts in the FTT. The weighing up of risks by participants was consistent with FTT (Reyna, 2008) as participants had the 'gist' that there was no choice because the risks tipped the balance towards taking the chance on surgical intervention. This gist was influenced by emotions, for example, fear of the aneurysm rupturing, related to the uncertainty of the decision. These gist interpretations were less subject to interference as the majority of the participants suffered disruptions and cancellations but stuck with their decisions. However, FTT does not consider trust and confidence in an interpersonal relationship with the surgeon or the concept of post-traumatic growth. The gist in this study could be considered that participants saw the aneurysm as a threat to life, and a coping strategy was to have surgery as the way to reduce uncertainty and threat. Therefore, surgery was seen as a way to establish more certainty by putting trust and confidence into a surgeon who eliminates threat to life. However, there are themes in this research which are not currently incorporated into FTT, including a relational influence in the decision making process and post-traumatic growth.

## **Clinical Implications**

Participants valued being taken seriously in their role of decision maker, time and space in appointments and did not value cancellations and disruptions to their treatment. Although these points are difficult to achieve in a busy hospital environment, they are important implications for medical professionals and development of DSI's. It is also important to consider that patients dissatisfied with their treatment course, due to having disruptions and cancellations, are likely

to have negative impacts on their wellbeing, mental health and subsequent recovery. If patients have less disruptions and cancellations, they are likely to have better wellbeing and mental health, resulting in higher satisfaction with the treatment outcome and superior treatment outcomes. When considering the development of DSI's it is important to remember how valuable the interpersonal relationship with the surgeon was to participants. It is also important to recognise the impact of the interpersonal relationship on patients' wellbeing, as this is considered a valuable source of emotional support throughout the decision making process.

Further research is required into the role and experience of significant others within the decision making process as all participants discussed the support and involvement of significant others. In the future, longitudinal research to minimise cognitive memory bias would be beneficial. It would be important to use these findings to develop DSI's based on gist meanings so patients are supported to make these decisions and consider risks and uncertainties. Medical professionals also need to be aware of the impact of the way in which they deliver information as this might have consequences on patients' perceptions of risks. The management of uncertainty and emotions around the decision making process is also important for medical professionals to support.

### **Conclusion**

Ten participants shared their decision making experiences to have clipping surgery for an unruptured aneurysm. Themes highlighted that participants valued being a part of the decision making process about their treatment. Much of the literature suggests that shared decision making promotes

improved outcomes and, even when treatment did not have the desired outcome, no participants expressed regretting their treatment choice. This study aimed to extend the evidence base by contributing a richer understanding of the decision making process. Through discussion of the decision making process, it is important to consider patients management of uncertainty and fear and their wider lives, including significant others and consider the interpersonal process between medical professionals and patients.

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## Appendices

Appendix A: Participant invitation letter

Dear \_\_\_\_\_

We are conducting a study investigating the processes involved in the decision to undergo surgery to clip an unruptured cerebral aneurysm. We are hoping that this will inform the development of a tool which could support people making similar decisions in the future. This study is being conducted by Danielle Platts, Trainee Clinical Psychologist. I am enclosing an information sheet about the study. If you would be interested in taking part or finding out more, please complete the reply slip below and return in the stamped addressed envelope enclosed or contact Danielle by leaving a message with Sarah Radgick on 0114 2226649.

**You are under no obligation to take part in this study.**

Thank you for taking time to consider participating in this study.

Yours sincerely

Mr U. Patel  
Consultant Neurovascular Surgeon

**Reply Slip:**

Title of Project: A Qualitative Study into the decision making process for patients electing to undergo neurosurgical clipping for an unruptured cerebral aneurysm.

If you would be interested in receiving more information about the above study and might be interested in participating, please complete the form below and return in the envelope enclosed to register your interest.

Name:..... Contact Telephone  
number:.....

Address:  
.....

.....  
A researcher will contact you by telephone to discuss details about the research.

Thank you for your time.

## Appendix B: Participant Information sheet

### **Participant Information Sheet**

Title of Project: A Qualitative Study into the decision making process for patients who have chosen to undergo neurosurgical clipping for an unruptured cerebral aneurysm.

Name of Researchers: Danielle Platts, Dr Susan Walsh, Dr Claire Isaac and Dr Claire Tooth

You are being invited to take part in a research project exploring the decision making process to have surgery for an unruptured cerebral aneurysm. Before you decide whether you would like to take part it is important you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this. If you choose to take part you will be provided with a copy of this information sheet and your signed consent form.

#### **What is the purpose of this study?**

The purpose of this study is to explore patients' decision making process to have neurosurgical clipping to treat an unruptured cerebral aneurysm. This research aims to explore what helps this decision making process and inform the development of a decision support tool to help patients make this decision in the future.

#### **Who is taking part?**

We are inviting patients to participate in this research, who have had surgery for treatment of an unruptured aneurysm in Sheffield during the past 3 years. We are hoping to recruit approximately 10 people who are willing to be interviewed about their experiences.

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

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form and you can still withdraw at any time without giving your reasons. Any data collected will be destroyed. If you decide that you do not want to take part, this will not affect your future healthcare in any way.

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

If you decide to participate in this research, the researcher will meet you at a Sheffield Hospital, Sheffield University or your house, where you will participate in an interview which will last approximately 60-90 minutes. Travel expenses are available. You will be asked to provide your age, gender and the month and year when you had your surgery. During the interview you will be asked questions about your experience of being diagnosed with an aneurysm and your decision to have the surgery. These questions are designed to allow you to give open answers and respond in-depth with your thoughts. After the interview you can discuss the process with the researcher. Interviews will be audio-recorded and transcribed in line with confidentiality procedures. You will be asked whether you would like to comment on the findings when the interviews have been analysed. This will be entirely your choice.

### **What are the possible benefits of taking part?**

Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will raise awareness of the decision making process for medical practitioners supporting people who are deciding whether or not to have surgery. Some people find talking about their experiences helpful and enjoy the opportunity to voice their opinions. You might also gain a deeper understanding of the process that led to you deciding to have surgery. You will not be provided with any incentives to take part in this research.

### **What are the possible disadvantages of taking part?**

We will be asking you to share thoughts relating to your experience of being diagnosed with an aneurysm and having the surgery. Discussing these experiences might lead you to think about them more, and reflect on your decisions. This might potentially be distressing. However, you do not have to answer any questions unless you choose to, and you can end the interview at any stage without giving your reasons. If required you could also be referred to the Clinical Neuropsychology Service at the Royal Hallamshire Hospital, Sheffield.

### **What happens if something goes wrong?**

If you have any concerns about this research, please contact the researcher who will do their best to answer your questions. If they are unable to respond in an acceptable way or if you wish to make a complaint please contact one of the research supervisors, Dr Susan Walsh on 0114 2226567. If this is not satisfactory, you can also use the normal research complaint procedure at the University by contacting the University's Registrar and Secretary.

### **Will my participation in this research be kept confidential?**

All the information that we collect about you during the course of the research will be kept strictly confidential. Anonymous quotes from your interview might be used in the write up but, you will not be able to be identified in any reports or publications. Your personal identifiable information will be kept separately in a locked and secure location. Prior to completion of the research you will be offered an opportunity to read the results section and request to remove any quotes you believe might lead to your identification. However, if during the study itself we become concerned that you or someone else might be at risk of harm, we would be obliged to inform a professional involved in your care. This is important to ensure you get the support you need.

### **Will I be recorded and how will the recorded media be used?**

The audio-recordings of the interviews in this research will be used only to write transcriptions and to then analyse the interviews. Audio-recordings will be made using an encrypted digital audio recorder, which is password protected. The digital recorder will be stored in a locked filing cabinet to which only the researcher has access. Digital audio files will also be stored in encrypted files on a memory stick, accessed only by the researcher and transcriber. The transcriber will adhere to guidelines regarding confidentiality (you may request a copy of these). Pseudonyms will be used in the transcriptions, of which paper copies will be stored in a locked filing cabinet in the University. After completion of the study, the researcher will delete all stored audio recordings.

### **What will happen to the results of the research project?**

It is the intention of the researchers to publish the results of the research in a scientific, peer reviewed journal. If you would like a summary of the results please let us know.

### **Who has ethically reviewed the project?**

This research has received favourable ethical opinion from the NHS Research Ethics Committee and has been reviewed and approved by Sheffield Teaching Hospitals NHS Foundation Trust Research and Development Office.

### **Who should I contact for further information?**

**Danielle Platts:** Clinical Psychology Unit, Department of Psychology, University of Sheffield, Western Bank, Sheffield, S10 2TN. Email: [dplatts1@sheffield.ac.uk](mailto:dplatts1@sheffield.ac.uk).

Alternatively, you can leave a message with the Research Support Officer at the University of Sheffield on 0114 2226649.

Thank you for agreeing to take part in this research.

## Appendix C: Participant consent form

**Participant Consent Form**

Title of Research Project: A Qualitative Study into the decision making process for patients who have chosen to undergo neurosurgical clipping for an unruptured cerebral aneurysm.

Name of Researchers: Danielle Platts, Dr Susan Walsh, Dr Claire Isaac, Dr Claire Tooth and Mr Umang Patel.

Participant Identification Number for this project: \_\_\_\_\_

**Please Initial boxes:**

1. I confirm that I have read and understand the information sheet dated..... explaining the above research project and I have had the opportunity to ask questions about the project, which have been answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.
3. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.
4. I agree for the data collected to be used in future research.
5. I agree to take part in the above research project.

\_\_\_\_\_  
Name of Participant      Date      Signature

\_\_\_\_\_  
Lead Researcher      Date      Signature

*To be signed and dated in presence of the participant*

## Interview Schedule

I am interested in talking to people who have been told that they have an unruptured cerebral aneurysm and decided to have surgery, in order to gain some understanding of what this experience is like and what it has meant for them and their lives. My role here is to listen to your experiences, however today is not about addressing any difficulties you might be having. If at the end of the interview you would like more information about how to access further support, please let me know.

It is up to you to decide what you choose to tell me. If there are any questions you would prefer not to answer, let me know. Everything you do tell me will be kept confidential. The interview will take between one to one and a half hours, depending on how much you want to share. We can take a break at any point and can discuss the interview once we have finished should you wish. If at any point you want to terminate the interview and withdraw from the study, you can let me know.

10. How was your aneurysm found?

*Prompts: How were you told?*

*What was life like at the time – work, relationships, symptoms.*

*How did you see yourself?*

*Did you talk to other people about it?*

*What happened next?*

11. What was your understanding of the diagnosis when you were making your decision?

*Prompts: What were you expecting to happen?*

*Who was there?*

*How did you feel about it?*

*What worried you/made you feel that way? How did you cope with that worry/those feelings?*

*Were there any risks that you considered?*

*How did you weigh up these risks?*

12. What did you understand about the pros and cons of treatment?

*Prompts: What were you expecting to happen?*

*Who was there?*

*How did you feel about it?*

*What worried you? (Were there any other things that worried you?)*

*How did you cope with that worry?*

13. How did you decide to go ahead with the surgery?

*Prompts: What did you do to decide?*

*What was helpful?*

*What was unhelpful?*

*Could anything have been different?*

*How long did it take to make the decision?*

14. What was important to you when you were deciding whether to have the surgery?

*Prompts: What information was important?*

*Who did it matter to tell?*

*What did you tell them?*

*What did they think?*

15. How do you usually make important decisions?

*Prompts: Was there any difference between how you usually make decisions and how you decided to have surgery?*

16. What has happened since you had the surgery?

*Prompts: What do you think about your decision now?*

*How do you feel now?*

17. What other experiences do you have of healthcare?

18. Is there anything else that you think it might be helpful for me to know?

*Prompts: What was the interview like?*

*Did anything surprise you?*

Do you have any questions you would like to ask?

Thank you for taking the time to participate. Your input is greatly appreciated.

**Debrief:**

1. Was the interview as you expected? Do you have any worries or concerns following the interview?
2. Would you like the opportunity to comment on the findings once the interviews have been analysed?

Appendix E: Demographic Information form

**Demographic Information Form**

Title of Research Project: A Qualitative Study into the decision making process for patients who have chosen to undergo neurosurgical clipping for an unruptured cerebral aneurysm.

Name of Researchers: Danielle Platts, Dr Susan Walsh, Dr Claire Isaac, Dr Claire Tooth and Mr Umang Patel.

Participant Identification Number for this project: \_\_\_\_\_

AGE: .....

GENDER: .....

MONTH AND YEAR OF CLIPPING SURGERY: .....

## Appendix F: Transcribing Confidentiality Form and Guidance Notes

Type of project: Research thesis

Project title \_\_\_\_\_

Researcher's name \_\_\_\_\_

The recording you are transcribing has been collected as part of a research project. Recordings may contain information of a very personal nature, which should be kept confidential and not disclosed to others. Maintaining this confidentiality is of utmost importance to the University.

We would like you to agree:

1. Not to disclose any information you may hear on the recording to others,
2. If transcribing digital recordings – only to accept files provided on an encrypted memory stick
3. To keep the tapes and/or encrypted memory stick in a secure locked place when not in use,
4. When transcribing a recording ensure it cannot be heard by other people,
5. To adhere to the Guidelines for Transcribers (appended to this document) in relation to the use of computers and encrypted digital recorders, and
6. To show your transcription only to the relevant individual who is involved in the research project.
7. If you find that anyone speaking on a recording is known to you, we would like you to stop transcription work on that recording immediately and inform the person who has commissioned the work.

### **Declaration**

I have read the above information, as well as the Guidelines for Transcribers, and I understand that:

1. I will discuss the content of the recording only with the individual involved in the research project
2. If transcribing digital recordings – I will only accept files provided on

an encrypted memory stick

3. I will keep the tapes and/or encrypted memory stick in a secure place when not in use
4. When transcribing a recording I will ensure it cannot be heard by others
5. I will treat the transcription of the recording as confidential information
6. I will adhere to the requirements detailed in the Guidelines for transcribers in relation to transcribing recordings onto a computer and transcribing digital audio files
7. If the person being interviewed on the recordings is known to me I will undertake no further transcription work on the recording

*I agree to act according to the above constraints*

Your name \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_\_

Occasionally, the conversations on recordings can be distressing to hear. If you should find it upsetting, please stop the transcription and raise this with the researcher as soon as possible

## **Introduction**

The course has created the guidelines below for anyone who is involved in transcribing data for staff or trainees in the Clinical Psychology Unit, University of Sheffield.

In addition to adhering to the following guidelines, **transcribers must sign a confidentiality form** prior to beginning any work. If you are unsure about any of the information given below, or for a copy of the confidentiality form, please contact the relevant trainee/member of staff.

When undertaking transcribing, whether from tapes or digital recording, you must:

- Password protect the computer files you are typing **before you type any text** – this can be done easily in Microsoft Word (instructions below)
- Anonymise any personal information contained in the data you are

transcribing as you type e.g. names. Please contact trainee or member of staff who transcribing you are doing if you have any queries about this.

- Delete any files from your computer (including from your 'Trash' folder) once you have submitted your completed transcription.
- Keep the tapes/encrypted memory stick in a secure locked place when not in use.
- If transcribing from a digital recording, you must also adhere to the specific guidance on this (appendix 2 of this document).

### **Instructions for a password protecting files on a PC:**

For Word 1998-2003:

- 1) Open a blank Word document
- 2) Go to Tools on the menu bar and select Options
- 3) Go to the Security tab and insert a password to open the document. You will be asked to re-type this, then please ensure you click ok before closing the Options menu.

For Word 2007:

- 1) Open a blank Word document
- 2) Go to Save As and choose the compatible mode
- 3) Click Tools, then select General Options
- 4) Enter a password to open the document. You will be asked to re-type this, then please ensure you click ok before closing the dialogue box.

### **Instructions for password protecting files on a Mac:**

- 1) Open a blank Word document
- 2) Go to Word on the menu bar and select Preferences
- 3) Click on Security and insert a password to open the document. You will be asked to re-type this, then click ok.

### **Additional Guidance for transcribing from digital recordings**

**Important:** Trainees and staff must provide you with recordings via an encrypted memory stick. Do not accept files via any other means.

**Installing DSS Player Pro software (you only need to do this once)**

In order to transfer audio files to your computer, you will need to have installed the DSS Pro software that comes to the machine. You will only need to do this once, not for each recording.

The procedure is as follows:

On a PC:

1. Insert CD
2. Go to My Computer – select the CD Drive, click on Launcher
3. Install DSS Player Pro programme (NOT the standard DSS Player) – follow the installation instructions as they appear (e.g. agreeing to terms and conditions)
4. You will be asked to provide the License ID number for Windows users- this can be found on the green card in the box.
5. The manual/help instructions for the DSS Player Pro will be automatically downloaded with the programme files.

On a MAC:

1. Insert CD
2. Click on the CD icon – click ‘Setup’
3. Install DSS Player programme (Mac users cannot access the Pro version) – follow the installation instructions as they appear (e.g. agreeing to terms and conditions). Your machine will automatically ask you to restart.
4. Once you have restarted, go to the applications menu and select the DSS Player folder. Click on DSS player and you will be asked to provide the License ID number for Mac OS users, this can be found at the bottom of the green card in the box.
5. The manual/help instructions for the DSS Player Pro will be automatically downloaded with the programme files.

**To listen/download audio files from a memory stick (once DSS player is installed)**

1. Open DSS player programme
2. Plug in encrypted memory stick to USB port
3. Input password to unlock the memory stick
4. In DSS player, click on File/Import Dictation
5. Select the USB memory stick
6. Select the audio file, click ok to upload to DSS file.
7. Exit the memory stick by clicking on ‘lock and exit’ button – hand this back to the trainee, who will delete the audio file for you

(please do not delete yourself)

**To open the audio files in order to transcribe**

1. Locate the folder within DSS pro player
2. Double click on the audio track within this, a pop up window will prompt you for the password. Enter the password given to you by the trainee

**Reminder: ensure you have fully deleted your transcription and the original recordings from your computer once you have passed your transcription to the trainee/member of staff.**

The procedure for deleting files from DSS player is as follows:

- Locate the folder in DSS player where the track is saved within DSS player
- Select the individual files of the audio tracks you wish to delete
- Right click over them and select 'delete'

Appendix G – Extract of transcript analysis with supporting excel table of themes

<p>no regret certainty 255</p>	<p>P – it was the right decision definitely</p>	<p>reflection on process + choice ↳ no regret</p>
<p>256</p>	<p>I – did you have long between making the decision and having the surgery</p>	
<p>quick process 257</p>	<p>P – no no I don't know how long but it was pretty quick</p>	
<p>258</p>	<p>I – what was that bit of time like</p>	
<p>relief 259</p>	<p>P – well it sounds stupid but I was looking forward to it so I thought well that's just one problem with</p>	
<p>260</p>	<p>me that wont be there anymore, you know what I mean. I said █████ explained about the left hand</p>	
<p>danger risk 261</p>	<p>side wasn't so good like I mean iv got one very deep embedded one that they didn't want to mess</p>	<p>risks of life or death</p>
<p>262</p>	<p>about because in case it caused a stroke or thingy but █████ wanted to leave that side alone, but</p>	
<p>263</p>	<p>when I came to see him and I had my leg in straps, well █████ was a bit concerned that █████ although</p>	
<p>symptoms 264</p>	<p>I told him about it umpteen times, the numbness I get in my hand and my foot, that erm █████</p>	
<p>risk 265</p>	<p>seemed to think that it was a mini stroke, not just the fact I had fallen cus I said well I felt like I didn't</p>	<p>risk fear</p>
<p>fear 266</p>	<p>have a foot there, I just went to walk and it had gone and erm █████ was a bit more concerned, that's</p>	
<p>action + support 267</p>	<p>why he was pushing to have these images done of my head to compare them to the ones he took</p>	<p>expert knowledge</p>
<p>268</p>	<p>before so that's what he wanted to do</p>	
<p>269</p>	<p>I – I see and things like being shown those scans, I know theres lots of information, but to see your</p>	
<p>270</p>	<p>scans does that make a difference</p>	
<p>brain can't see it 271</p>	<p>P – hell of a difference, well its like, is that what I have got in my head, it makes a hell of a difference</p>	<p>specific to head</p>
<p>explain 272</p>	<p>because when you see something and its pointed out to you and explained right, now this is the bad</p>	<p>expert skills of surgeon</p>
<p>into 273</p>	<p>one, this is the one that I really don't want to mess with, do you know what I mean, its different like</p>	
<p>visual 274</p>	<p>me saying to you, theres a beautiful dress in town, its like this, its like that, now if I showed you a</p>	
<p>shared understanding 275</p>	<p>picture of it and it scoops at the back and it would really suit you, you would be on my wavelength</p>	<p>shared understanding ↳ sharing knowledge</p>
<p>276</p>	<p>and think it sounds lovely yes, but if I just described it to you you would just think oh ok. You know</p>	
<p>questions 277</p>	<p>what I mean it was like having that information and nothing doesn't matter what questions you</p>	
<p>information help + support 278</p>	<p>asked, if I came out and talked to a nurse, the nurses were exactly the same, so helpful, the</p>	<p>interpersonal skills of all staff</p>

Superordinate theme	Subordinate theme	Quotes
Self-determination vs. responsibility for others	My decision with only one perceived choice	127 - you can walk round as a walking time bomb with aneurysms in your head that can go off at any time or you have your surgery and eliminate it, so that's what I did
		226 - I mean I did ask his opinion, but he said I can't tell you yes to have it done or no not to have it done
		229 - he said it's your choice it's entirely up to you
	Taking account of the effect on others	35 - the children were absolutely devastated well my daughter thinks I was gonna drop down dead 195 - I want to be around to see my grand-daughters get married 219 - I just felt that you know they needed me
	The influence of others	117 - it was important to me because I know I had all their support around me
Relationship with the surgeon and NHS	Interpersonal skills	17 - it was a lot of coaxing and kindness from him and talking to me as a person, rather than just another patient
		46 - he just made you feel so relaxed, so at ease, like you were having a discussion with your best friend about your health, not like you had a consultant sat opposite you
		49 - he had such a warm manner about him
		144 - it was wonderful, a wonderful hospital
	Expert skills	176 - there's not many drs well not in my experience that would get a piece of paper like that and draw your aneurysms for you and draw a sketch of your head
		271 - hell of a difference, well its like, is that what I have got in my head, it makes a hell of a difference because when you see something and its pointed out to you and explained right, now this is the bad one, this is the one that I really don't want to mess with, do you know what I mean, its different like me saying to you, theres a beautiful dress in town, its like this, its like that, now if I showed you a picture of it and it scoops at the back and it would really suit you, you would be on my wavelength and think it sounds lovely yes, but if I just described it to you you would just think oh ok.
	Trust and gratitude	37 - I had a lot of faith and confidence in 38 - ill go through with it cus I had such a good relationship with him 90 - I just had so much confidence in that man, he could have told me he was taking my head off and putting it back on the other way 109 - I had total faith in my surgeon and his team as it were

Appendix H – Security Protocol for the use of digital recorders in the collection of qualitative research data in connection with The University of Sheffield Doctorate in Clinical Psychology Training Programme

This document presents the security protocol to be applied to the collection, handling and storage of qualitative data obtained and processed in relation to conducting research within the Doctorate of Clinical Psychology Training Programme (DClinPsy), University of Sheffield.

**These should be read in conjunction with the ‘instructions for using digital voice recorders’ which are available on MOLE**

### **Overarching principles**

Trainees should be familiar with the University of Sheffield’s Research Ethics Policy, and Note no. 4: Principles of Anonymity, Confidentiality, and Data Protection are particularly relevant here (<http://www.shef.ac.uk/ris/other/gov-ethics>)

Clearly, details of data collection tools/equipment, storage arrangements, and destruction time points should be specified in the research protocol and these aspect of the protocol must have been subject to ethical and governance scrutiny prior to the collection of data. As such the proposed plans for data collection must concur with local requirements of the site where data is being collected. Therefore, trainees are required to liaise with local NHS research governance offices in the preparation of their research protocol, in planning this and other aspects of their proposed research.

In any event, Trainees should ensure that all aspects of data collection and management is in line with The Data Protection Act (see <http://www.ico.gov.uk/>).

Trainees who record interviews with participants are required at all times to apply due diligence to the security of the digital recorder that they use and any field/process notes which they make to accompany an interview. *Such items should be treated as one would treat case notes and only transported between sites with appropriate permissions and should not be left unaccompanied where they might be vulnerable to being lost or stolen.*

### **Minimum requirements**

#### **Equipment and data capture**

1. All equipment must be approved by the research site and relevant research governance office. The department has some equipment that may be loaned but you might need to budget for equipment from the funds available to support your research (if you need to purchase equipment – details must be provided on the costing form within the proposal and you must demonstrate that it is suitable for use at the proposed research site).

2. Encrypted digital recorders are required for use as they provide enhanced security and have a record of being used in the NHS. The department has some DS5000. *These recorders are also likely to be acceptable to NHS sites but it is the trainee's responsibility to check that this is the case.*
3. In the interview itself it is always preferable to ask participants not to name specific people or sites so that the data file will already be anonymous to some degree.
4. Trainees using digital recorders will have the option (and are encouraged to use this) to delete any remaining identifying information present prior to sending recordings for transcription.

### **Transportation**

1. This must be done by a secure mechanism as detailed below.

### **Storage and destruction**

1. It is strongly recommended that anonymous audio files are stored on the trainee's personal space on the University server and labelled with an appropriate code to link them to the original participant and consent form.
2. If they are to be stored on a personal computer or laptop then they should be stored in an encrypted folder and each file password protected.
3. Unless agreement has been explicitly obtained to keep original audio files these should be destroyed following successful completion of the course.
4. Transcripts should be stored following completion of the course as per the site file guidelines.

### **Transcription**

1. If an individual professional transcriber is to be used then they must have signed a confidentiality form (available on MOLE) and be on our approved list. If a company is being used you must provide details in your research proposal of the confidentiality agreement that they have with their transcribers (this information is usually available on company's websites or via email). This information must be retained on the site file.
2. If proposing to use a transcriber you must consult the costing guidelines regarding how to manage payment.

3. Files should always be encrypted and password protected before transportation and on the computer of the transcriber. Pre encrypted audio files should be transported to the transcriber's computer via an encrypted memory stick. These can be borrowed for brief periods from the Unit.
4. Audio files may be uploaded directly to a transcribing company that provides a secure facility/portal (details of this should be contained in the research proposal and is usually clear from providers websites).
5. Once the recordings have been transcribed they are to be saved by the transcriber as password protected word documents and transferred to either a secure memory stick or emailed to your University address. The password should be sent separately or provided by telephone. Internet companies will either send you transcriptions as password protected documents or may require you to log into a secure site (please provide details of this in the protocol).
6. Contracts with transcribers are to stipulate that the transcriber is required to securely erase all data from their computer. Again details on internet companies procedures in relation to disposal of files must be provided in the proposal.

### **Supervision**

1. Typically supervisors and others (as specified in the protocol) will require access to the transcripts. Supervisors may listen to interviews where the audio files have been secured for transportation i.e. are on an encrypted piece of hardware. Only email anonymised password protected transcripts to your supervisor(s)/collaborators.

### **Adherence to this protocol**

1. Any actual or suspected security incidents or breaches of this Protocol are to be reported to the supervisor and to the Director of Research Training at the earliest opportunity.
2. The research tutors and research support officer will periodically audit adherence to this policy.

## Appendix I – Ethical Approval


  
**Health Research Authority**

**NRES Committee East Midlands - Northampton**  
 Royal Standard Place  
 Nottingham  
 NG1 6FS

Telephone: 0115 8839521

29 May 2015

Dr Claire Tooth  
 Consultant Clinical Neuropsychologist  
 Sheffield Teaching Hospitals  
 Department of Neuropsychology, Royal Hallamshire Hospital  
 Glossop Road  
 Sheffield  
 S10 2JF

Dear Dr Tooth

<b>Study title:</b>	<b>A Qualitative Study into the decision making process for patients electing to undergo neurosurgical clipping for an unruptured cerebral aneurysm.</b>
<b>REC reference:</b>	<b>15/EM/0246</b>
<b>Protocol number:</b>	<b>STH18830</b>
<b>IRAS project ID:</b>	<b>173227</b>

Thank you for your email of 28 May 2015. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 22 May 2015

#### Documents received

The documents received were as follows:

Document	Version	Date
Participant consent form	V5	28 May 2015
Participant information sheet (PIS)	V5	28 May 2015

#### Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Interview schedules or topic guides for participants [Interview schedule]	V4	10 March 2015
IRAS Checklist XML [Checklist_14052015]		14 May 2015
Letters of invitation to participant [Invitation letter]	V4	10 March 2015
Non-validated questionnaire [Demographic questionnaire]	V4	10 March 2015

Other [Supervisor cv]	V1	17 March 2015
Other [Email form Sponsor confirming acceptance of signatory]		14 May 2015
Participant consent form	V5	26 May 2015
Participant information sheet (PIS)	V5	26 May 2015
REC Application Form [REC_Form_14052015]		14 May 2015
Referee's report or other scientific critique report [Scientific approval]	V1	17 February 2015
Research protocol or project proposal [Research protocol]	V4	10 March 2015
Summary CV for Chief Investigator (CI) [Chief Investigator cv]	V1	10 March 2015
Summary CV for student [Student cv]	V1	15 March 2015
Summary CV for supervisor (student research) [Supervisor cv]	V1	11 March 2015

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

15/EM/0246	Please quote this number on all correspondence
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Yours sincerely



**Vic Strutt**  
REC Assistant

E-mail: [NRESCcommittee.EastMidlands-Northampton@nhs.net](mailto:NRESCcommittee.EastMidlands-Northampton@nhs.net)

Copy to: *Aimee Card, Sheffield Teaching Hospitals NHS Foundation Trust*  
*Danielle Flatts*

## Appendix J: Signed research contract



Department Of Psychology.  
**Clinical Psychology Unit.**

Doctor of Clinical Psychology (DClin Psy) Programme  
 Clinical supervision training and NHS research training &  
 consultancy.

### **Clinical Psychologist in Training Research Contract (DClin Psy)**

This contract is to be completed by the trainee, academic supervisor(s), clinical supervisor(s) and other significant individuals (including collaborating clinicians and service users) directly involved in the proposed study. All parties should retain a copy for their records and a copy should be included as a permanent part of the site file held by the principal researcher. The initial contract should be attached to the research proposal.

This contract covers the responsibilities of all involved in the undertaking of the proposed project and is open to amendment following the review and agreement of all parties concerned. In any event the contract would normally be reviewed annually until submission of the thesis and then quarterly until successful publication.

Precise details of research responsibilities and requirements should be obtained through consulting the Course Handbook, the University of Sheffield Guidebook for Research Students and Supervisors, and local NHS Research Governance documentation<sup>1</sup>

#### **Researcher Details**

The principal researcher should be indicated by an asterisk and will normally be the academic supervisor as this is required by ethics. However, it should be clear that the trainee holds the primary responsibility for all aspects of the research. Each supervisor's designation should be described in terms of their occupational title and their role in the proposed study (i.e. academic supervisor, clinical supervisor, collaborator etc.). Continue on a separate sheet if necessary.

#### **1. Trainee Details**

Name: Danielle Platts                      Address: Clinical Psychology Unit, Department  
 of Psychology, University of Sheffield, Western Bank, Sheffield, S10 2TH.  
    Telephone: 07900 638099                      Email:  
 dplatts1@sheffield.ac.uk

Date:.....

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<sup>1</sup> This is not an exhaustive list and it is the researchers' responsibility to consult additional documentation relating to local responsibilities/requirements.

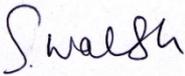
Signature:.....

## 2. Academic Supervisor Details

Name: Dr Susan Walsh                      Address: Clinical Psychology Unit, Department  
of Psychology, University of Sheffield, Western Bank, Sheffield, S10 2TH.  
Telephone: 0114 2226567                      Email:  
susanwalsh@sheffield.ac.uk

Designation: Academic supervisor

Date: 19/12/2014

Signature: 

## 3. NHS/Clinical Liaison Supervisor Details

Name: Dr Claire Isaac                      Address: Royal Hallamshire Hospital, Glossop  
Road, Sheffield  
Telephone: 0114 2713770                      Email: Claire.issac@sth.nhs.uk

Designation: NHS Supervisor

Date: 19/12/2014

Signature: *Claire Isaac*

## 4. Additional Supervisor Details

Name: Dr Claire Tooth                      Address: Clinical Neuropsychology Services,  
Royal Hallamshire Hospital, Glossop Road, Sheffield  
Telephone: 0114 2713770                      Email: claire.tooth@sth.nhs.uk

Designation: NHS Supervisor

Date: 19/12/2014

Signature: 

## ***Key responsibilities of all involved in the project***

### 1. Trainee

**During the course of the research the trainee is responsible for:**

- **The overall development of the research**
- All practical aspects of the study (including recruitment, data management, analysis, budgeting.)
- Arranging and attending regular meetings with supervisors (It is helpful to arrange in advance a set of meetings for each stage of the research)
- Preparing all research documentation (i.e. the research proposal, ethics form, indemnity forms, etc.)
- Submitting accurate expense claim forms.
- Maintaining and updating the site file and this contract
- Ensuring that the academic supervisor has seen and commented upon all drafts or versions of the proposal prior to it being submitted to the research tutors.
- Ensuring that all supervisors and collaborators are kept informed of the progress of the research. It is envisaged that the trainee will prepare and circulate minutes of key research meetings indicating any actions that have been agreed and the date/s of forthcoming meetings. The trainee should ensure that copies of key documents and correspondence are forwarded to all supervisors. The trainee should take responsibility for liaising between supervisors and provide written updates to the research tutors as requested
- Reviewing and updating the research timetable as necessary and planning a research block that enables satisfactory completion of other aspects of the course.
- Ensuring that any documents as required by the course (see course handbook) are submitted to the course administrator in full and on time.
- To ensure that they comply with ethical and professional codes of conduct in carrying out the project including adhering to appropriate personal safety guidelines.
- Ensuring that any data containing personally identifiable information is stored securely.
- Ensuring that any drafts of work that have been agreed to be circulated are provided to supervisors within a sufficient time period to allow a realistic time for review (not usually less than 14 days)

**Additional responsibilities agreed with the supervisors:**

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**Following completion of the research the trainee is responsible for:**

- Ensuring that the site file and other documentation/data as necessary are lodged with the supervisor/course.
- Ensuring that local ethics/NRES and governance instructions relating to the completion of the research project are complied with.
- Ensuring that all supervisor(s) are offered a bound copy of the final thesis and appropriate feedback is provided to the collaborating service and if appropriate participants. The nature of the feedback required by the participating service should be negotiated prior to the trainee completing the course.
- Ensuring that data are stored securely, data files are backed up on computer and access to data for publication has been agreed with supervisors.
- Preparing manuscripts for publication in the target journals identified in the thesis<sup>2</sup>

**Additional responsibilities agreed with the supervisors:**

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**2. Academic Supervisor**

**During the research the academic supervisor is responsible for:**

- Attending regular meetings with the trainee (It may be helpful to arrange in advance a set of meetings for each stage of the research)
- Advising the trainee in developing a psychologically relevant research proposal and ensuring that this complies with the department's/NHS research plan and is likely to lead to research of a publishable standard.
- Advise the trainee in considering ethical and professional concerns that may relate to the project including any relevant personal safety issues.
- Supporting the trainee in the preparation of all necessary research documentation.
- Advising the trainee on developing a realistic timetable and planning a research block that enables satisfactory completion of other aspects of the course.
- Monitoring progress and if necessary advising on the revision of the timetable.
- Advising the trainee in addressing any methodological problems as they arise.
- Reading and commenting on a draft (it may be helpful to discuss the format and number of drafts that will be reviewed).

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<sup>2</sup> Preliminary order of authorship should be indicated in the relevant section of this contract.

**Additional responsibilities agreed with the trainee or other supervisor/s:**

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**Following completion of the research the academic supervisor is responsible for:**

- Advising the trainee in preparing manuscripts for publication in the target journals identified in the thesis
- Ensuring the site file and data is stored in a secure place and is accessible for any future audit process.

**Additional responsibilities agreed with the trainee or other supervisor/s:**

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**3. Clinical supervisor:**

**During the research the clinical supervisor is responsible for:**

- Attending meetings with supervisors as needed (It may be helpful to arrange in advance a set of meetings for each stage of the research)
- Advising the trainee in developing a realistic timetable for the research and monitoring progress and if necessary assisting in revising the timetable.
- Advise the trainee in considering ethical and professional concerns that may relate to the project.
- Supporting the trainee in being aware of and complying with appropriate local R & D procedures.
- Supporting the trainee in accessing participants.

**Additional responsibilities agreed with the trainee or other supervisor/s:**

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**Following completion of the research the clinical supervisor is responsible for:**

- Advising the trainee in preparing manuscripts for publication in the target journals identified in the thesis
- Advising on the nature of the feedback required by the participating service.

**Additional responsibilities agreed with the trainee or other supervisor/s:**

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**4. Additional supervisor:**

**During the research the supervisor is responsible for:**

- Attending regular meetings with supervisors (It may be helpful to arrange in advance a set of meetings for each stage of the research)
- Advising the trainee in developing a realistic timetable for the research and monitoring progress and if necessary assisting in revising the timetable.
- Advise the trainee in considering ethical and professional concerns that may relate to the project.
- Supporting the trainee in being aware of and complying with appropriate local R and D procedures.
- Supporting the trainee in accessing participants.

**Additional responsibilities agreed with the trainee or other supervisor/s:**

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**Following completion of the research the supervisor is responsible for:**

- Advising the trainee in preparing manuscripts for publication in the target journals identified in the thesis
- Advising on the nature of the feedback required by the participating service.

**Additional responsibilities agreed with the trainee or other supervisor/s:**

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***Authorship & dissemination***

Please indicate a working title (or thesis section) for each planned publication and significant presentation/s relating to the thesis. Indicate the rationale for authorship. It is envisaged that the trainee will be the first author on all publications directly arising from the thesis. Additional collaborative publications arising in part from the thesis or data derived from the thesis may have another individual as the first author. It is envisaged that the two primary papers arising from the thesis would normally be submitted by the trainee within 18 months of submission. If this is not the case, the trainee should agree an alternative strategy (e.g. supervisor responsible for publication) with the supervisors concerned.

**1. Proposed title or thesis section (i.e. literature review, empirical study etc.)**

A review of decision making theories applied to elective surgery and treatments.

**Proposed journal / conference presentation / book chapter**

Journal of Neurology and Neurosurgery and Psychiatry, Journal of Health Psychology.

**Proposed order of authorship**

Platts, D., Walsh, S., Isaac, C., & Tooth, C.

**Rationale for authorship (including order)**

Lead researcher, Academic supervisor, NHS Liaison supervisors.

**Proposed submission date:** June 2016

**2. Proposed title or thesis section (i.e. literature review, empirical study etc.)**

A Qualitative Study into the decision making process for patients electing to undergo neurosurgical clipping for an unruptured cerebral aneurysm.

**Proposed journal / conference presentation / book chapter**

Journal of Neurology and Neurosurgery and Psychiatry, Journal of Health Psychology.

**Proposed order of authorship**

Platts, D., Walsh, S., Isaac, C., Tooth, C., & Patel, U.

**Rationale for authorship (including order)**

Lead researcher, Academic supervisor, NHS Liaison supervisors, Consultant.

**Proposed submission date:** June 2016

**3. Proposed title or thesis section (i.e. literature review, empirical study etc.)**

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**Proposed journal / conference presentation / book chapter**

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**Proposed order of authorship**

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**Rationale for authorship (including order)**

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**Proposed submission date**.....

Continue on a separate sheet if necessary.

**Please update this contract at least once a year and at other times as necessary.**