Stage 2 Qualification

Applying Health Psychology to Clinical Services, Policy and Practice

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THE FOLLOWING PARTS OF THIS THESIS HAVE BEEN REDACTED FOR DATA PROTECTION REASONS:

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Acknowledgements

Declaration

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Imagination, new and strange

In every age, can turn the year;

Can shift the poles and lightly change

The mood of men, the world's career.

Final verse from the poem 'Imagination'. By John Davidson (1857-1909)

Davidson, J. (2001) 'Imagination', in *Poem for the Day One.* The Natural Death Centre in association with Chatto & Windus.

SECTION A: Preface

Background

The first two years of the doctorate were spent working on a bursary funded placement with NHS Barking and Dagenham under the supervision of a Consultant Clinical Psychologist who ran a Clinical Health Psychology Service. This provided a perfect platform to work in various areas of clinical health, with a primary focus in Cancer. It also provided ample opportunities to complete competency work for the doctorate and learn new skills, such as audit, service evaluation, management strategies, consultancy, and develop as a professional health psychologist applying health psychology principles to research and clinical practice with clients.

The placement provided many opportunities to fulfil doctoral competency requirements such as involvement in three consultancy projects, experience conducting research to a high level, including conducting private consultancy work as a research psychologist. In addition, opportunities to lecture on the Invited Speakers module for the MSc in Health Psychology at City, and after the placement had ended, working as a University lecturer and Module Leader at City University delivering a 10 week elective module in Health Psychology to third year BSc students. Professional development and practice continued in additional roles alongside the doctorate, such as working for a Community Interest Company (CiC) called Read Together facilitating bibliotherapy groups at charities which included Greenwich MIND and Headway East London and working occasionally for Seamless Support Services as a psychologist and consultant. The latter stages of the doctorate involved working as an Honorary Research Fellow at King's College Hospital whilst conducting the doctoral research there.

The following is a brief synopsis detailing the different sections contained in this doctoral portfolio, to show how all the components are inter-related and providing information about topics chosen, the rationales and influences on the field of health psychology.

Section B: Research

The admission of a family member to an ICU can be a distressing experience (Paul & Rattray, 2007) which can have a huge emotional impact on the patients' relatives, who during their time on ICU are at risk of developing psychological symptoms such as high levels of stress and anxiety (Andershed, 2005; Liu and Hutchinson, 2001; Plaka, Boudioni, Fouka and Taket, 2011; Siddiqui, *et al.* 2011; Stayt, 2006; Williams, 2005; Hughes *et al.* 2005), and depression (McAdam, Fontaine, White, Dracup &

Puntillo, 2012). Relatives of critically ill patients are increasingly suffering from symptoms of Post Traumatic Stress Disorder (PTSD) (Hughes, Bryan & Robbins, 2005), from the experience of witnessing their loved one being admitted to the ICU in a critically ill state, often for up to several weeks, whilst also fearing the potential consequences of death, disability or a relapse (Skirrow, Jones, Griffiths and Kaney, 2001). Previous research has shown that effective communication between ICU staff and patients' relatives can help to provide support, reduce stress levels, and improve wellbeing and the ability to make important decisions (Liu and Hutchinson, 2001). Gauntlett and Laws (2008) state that not only are communication skills an integral part of providing good critical care but they are also paramount in the provision of quality end of life care and yet, up to 50% of families of critically ill patients may experience inadequate communication with doctors on the unit. Poor communication between healthcare staff and patients' relatives is one of the major causes of complaints from relatives (Taylor, 2008; Lowson, 2007), so it is important that staff communicate information that is easily accessible and understandable and sufficient enough to aid in decision making, whilst also providing reassurance and clear explanations that relatives will understand (Lowson, 2007).

This research project was a qualitative study and comprised two separate and overlapping studies: Study 1 explored the experiences of individuals who had been relatives of ICU patients, with an emphasis on particular areas of the ICU experience, such as communication with ICU staff, information needs, knowledge and understanding of ICU processes (such as decision making for patients who lack capacity to make their own decisions), coping on the ICU, and the need for psychological support. The study also explored how ICU staff members perceived the same issues in relation to their interaction with patients' relatives. The data obtained in Study 1 also informed the development of an intervention i.e. information booklet and verbal guide in Study 2. Both sets of participants were interviewed about their experiences. Study 2 was the development of the intervention for relatives and friends of intensive care patients admitted to the Medical and Surgical Critical Care Units (CCUs) at King's College Hospital. A focus group was carried out with senior ICU nurses who peer reviewed a first draft of the booklet and this informed the final draft along with the interview data from study 1. The booklet was delivered by nursing staff on the CCUs over a two week pilot, and CCU staff members were interviewed about how they felt the intervention had been received by patients' relatives. Thematic analysis was used to analyse the interviews and focus group data. Findings demonstrated the importance of an information booklet for patients' relatives in helping them to cope with the experience of having a loved one on ICU. The booklet also aided communication between relatives and staff members and provided comprehensive information of

all aspects of the ICU experience and the units, which prepared relatives for what to expect during and after their time there. It also illustrated the effectiveness of an intervention which included written and verbal mediums combined to aid absorption of the information.

Section C: Professional Practice

This section includes case studies for the core and optional competencies.

Unit 1: Generic Professional Supplementary report - This is a reflective report documenting the personal progression of training and experience and ultimately professional development during the DPsych programme.

Unit 3: Consultancy

NICE (2004) determined that if cancer patients and carers of cancer patients are experiencing significant levels of psychological distress, they should be promptly referred to services that provide specialist psychological care, either via local cancer services, mental health services, hospitals, GP practices or hospices. This case study details a large audit undertaken of a hospital based Cancer Psychological Therapies Service, in order to review service provision, the current referral process used by the service, and patient and staff member satisfaction with the service. The aim was to ensure service structure was aligned to meet the needs of the patients, that any necessary improvements were made in line with NICE, and to demonstrate to commissioners the value and demand for psychological work in cancer and palliative care. Two questionnaires were developed, one for current and past patients of the service and one for staff members and these covered aspects such as means and types of referral, appointment times, quantity of provision, waiting times, methods of counselling, resources, benefits of the service and staff education. Recommendations on how to improve the service were made and implemented as a result of the audit findings.

Unit 4: Teaching and Training

This includes two case studies regarding two separate health psychology lectures to different audiences. The first case study describes a lecture developed and delivered to students on the MSc in Health Psychology course at City University about the practicalities of conducting MSc research. It used a primarily didactic approach via a PowerPoint presentation with enough information on the slides to be used as handouts for students to take away and a very interactive question and answer session at the end. The aim of the lecture was to provide relevant information and experience of a process the students were about to embark on and give them a better understanding of it. The

second case study was a lecture developed and delivered for a postgraduate training programme for psychiatrists and GPs with a special interest in psychiatry. The aim of the lecture was to provide an overview of the discipline of Health Psychology and how it could be applied to medicine. The lecture was mostly didactic although interactive discussion was also encouraged in addition to questions and answers. The lecture audiences in both case studies were very receptive and provided positive feedback at the end of each lecture.

Unit 5: Optional competency 5.1 - Implement intervention to change health-related behaviour

This case study describes the clinical practice of providing psychological support to a complex client in the Cancer Psychological Therapies Service. The client was terminally ill and suffering from extreme panic attacks that were adversely affecting his mental and physical well-being. The study details clinical work conducted over a 6 month period which included various therapeutic interventions using techniques from a range of modalities but primarily CBT. It also documents the health psychology theory used in the clinical formulations which evolved over the duration of the case.

Optional competency 5.4 - Provide psychological advice to aid policy decision making for the implementation of psychological services.

This case study documents an extensive piece of private consultancy work for a hospital trust. It involved a large scale audit of a Mental Health Liaison Team (MHLT) based in an Accident + Emergency Department. The audit evaluated many aspects of the MHLT service, such as sources of referrals, presenting conditions of referrals, outcomes of referrals, rates of patient re-attendance, possible therapeutic interventions that could tackle the problem of re-attendance, assessment, treatment of the psychological needs of discharged re-attenders, and patients who did not wait to be seen. In addition the audit aimed to ensure that the service was meeting national standards and that the psychological needs of the MHLT patients were examined to potentially develop the service provision and the role of psychology within it.

Section D: Systematic Review

This section comprises a systematic review of qualitative studies exploring parental beliefs and attitudes towards childhood vaccination and the identification of potential barriers that may impact on vaccination uptake. It was an update of a review by Mills, Jadad, Ross and Wilson (2005). Eight studies were quality assessed by two independent reviewers and seven studies were included in the review. Studies were selected if they used focus groups or semi-structured interviews, were written in the English Language and were published. A content analysis was used to conduct a data synthesis

on the seven selected papers. This identified primary categories which included: Parental and Individual Aspects, Family and Community Aspects, and Services and Systems Aspects, with each primary theme containing generic categories and a number of sub-categories representing a total of 69 barriers and potential barriers to vaccination uptake. The most common barriers reported were related to fear of adverse side-effects, negative experiences, adverse publicity, believing ill children should not be vaccinated, believing doctors did not have their best interests at heart, lack of information, and parental confusion about vaccinations and the immune system. Future research needs to focus on revaluating best practice regarding vaccinations and determining effective interventions to improve uptake.

In summary

This professional portfolio of work reflects the diversity of the discipline of health psychology by the variety of areas addressed by the doctoral competencies, such as coping, stress, communication, informational interventions, health beliefs, public health and clinical health psychology services. It also demonstrates the application of health psychology theory and principles to research, consultancy, teaching and clinical practice.

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New Every Morning

Every day is a fresh beginning,

Listen my soul to the glad refrain.

And, spite of old sorrows

And older sinning,

Troubles forecasted

And possible pain,

Take heart with the day and begin again.

By Susan Coolidge (1835-1905)

Coolidge, S. (2001) 'New Every Morning', in *Poem for the Day One.* The Natural Death Centre in association with Chatto & Windus.

The development of an informational intervention to help critically ill patients' relatives and friends cope with an unplanned ICU admission.

The terms 'relatives' in this report will include: next of kin, spouse and close friend(s) of the patient.

ABSTRACT

Background When a loved one is admitted to intensive care it can be a traumatic experience for the patients' relatives. Poor communication and lack of information from intensive care unit (ICU) staff members can have a negative impact on how relatives cope on an ICU and in the months following the experience. There is a need for interventions to improve these aspects and prepare relatives for what to expect on the ICU using a combination of written and verbal information.

Aims To conduct two separate but overlapping qualitative studies. Study 1: To explore how patients' relatives experience an ICU, their needs during this time, their knowledge and understanding regarding decision making for patients who lack capacity, and their psychological needs on ICU. Study 2: To develop and pilot an intervention for patients' relatives on the Critical Care Units (CCUs) at King's College Hospital (KCH), to help them cope with the experience.

Method and Design In study 1 data was obtained from semi-structured interviews with ten ex-ICU patients' relatives recruited via a national charity, and ten nurses and consultants from the CCUs at KCH. In study 2 data was obtained via a focus group of nine senior nurses, from KCH. Data generated from both studies was used to develop the intervention which comprised an information booklet and verbal guide. The intervention was delivered by nurses to patients' relatives on the Medical and Surgical CCUs for two weeks. Ten CCU staff members were interviewed about how the intervention had been received by patients' relatives. Data was analysed using thematic analysis.

Results Study 1 identified themes related to the importance of good communication with staff, the need for relatives to receive clear and honest information about their loved one, and about the ICU. Findings suggest that relatives lack knowledge and understanding about decision-making for patients who lack capacity and may need to be informed of this process at an early stage preferably in written form. Relatives and staff may also benefit from an ICU based counselling service. The focus group in Study 2 provided feedback on appearance, content and delivery of the booklet which informed the final draft. After the pilot, staff reported positive feedback from relatives and provided encouraging and constructive feedback about the booklet. Findings suggest the booklet has the potential to help patients' relatives cope on the ICU but continued use and testing would better determine its efficacy. Patients' relatives need to feel supported, well informed, and involved on the ICU. Including information about the decision making process in an information booklet may improve relatives' understanding and acceptance of this issue. The booklet should be an adjunct to verbal communication from staff and be one of a range of resources accessible to patients' relatives on the ICU.

Keywords: intensive care; critical illness; patients' relatives; communication; information provision; coping; decision-making; mental capacity; intervention; psychology.

CHAPTER 1: INTRODUCTION

1.1 Review of the literature

While there appears to be some evidence to suggest that relatives are generally satisfied with their experiences of communication and information provision from intensive care staff (Liu and Hutchinson, 2011; Hannich and Wedershoven, 1985; Siddiqui, Sheikh and Kamal, 2011), there is also evidence to the contrary defining the issue of poor communication and information provision between staff and relatives as a common occurrence which continues to be inadequately addressed (Hughes, Bryan and Robbins, 2005; Bloomer, Lee and O'Connor, 2010).

1.1.1 The psychological experience of ICU

"Illness and disability affect whole families, not just individuals" (Royal College of Physicians and the Royal College of Psychiatrists, 2003).

The admission of a family member to an Intensive Care Unit (ICU) can have a significant emotional impact on the patient's relatives, where their own psychological and physical health and well-being may be adversely affected by the trauma of the event and also the support they receive from ICU staff (Kinrade, Jackson and Tomnay, 2009). Due to the often traumatic nature of the ICU environment which can be fast paced and unpredictable, patients' relatives may experience high levels of stress and anxiety (Andershed, 2005; Liu and Hutchinson, 2001; Plaka, Boudioni, Fouka and Taket, 2011; Siddiqui, *et al.* 2011; Stayt, 2006; Williams, 2005; Hughes *et al.* 2005), and depression (McAdam, Fontaine, White, Dracup and Puntillo, 2012). This was demonstrated by Azoulay, Pochard, Chevret *et al.* (2004) who found that when they used the Hospital Anxiety and Depression Scale (HADS) in their study of family members and staff over 78 ICUs that of the 544 family members of critically ill patients who participated in the study, 399 (73%) had experienced anxiety and 192 (35%) had experienced depression. Similar levels of anxiety and depression were identified in a further study conducted over 34 ICUs in France (Azoulay, Pochard, Chevret *et al.* 2001). In addition to symptoms of anxiety and depression, relatives of critically ill patients are increasingly suffering from symptoms of Post Traumatic Stress Disorder (PTSD) (Hughes *et al.* 2005; McAdam *et al.* 2012), from the experience of witnessing their family member being admitted to the ICU in a critically ill state, often for up to several weeks, whilst also fearing the potential consequences of death, disability or a relapse (Skirrow, Jones, Griffiths and Kaney, 2001). The fear of these consequences can also equate to relatives experiencing extreme levels of stress whilst on the ICU (Bond, Draeger, Mandleco and Donnelly, 2003), and according to the Diagnostical and Statistical Manual of Mental Disorders (DSM-IV, 1994), having a family member admitted to ICU qualifies as a 'traumatic stressor' (Hughes *et al.*

2005). In addition, McAdam *et al.* (2012) found that despite patients' relatives' symptoms of PTSD, anxiety and depression decreasing over a 3 month period, a proportion would still remain at a high risk of these psychological symptoms, despite the decline.

Previous research has shown that effective communication between intensive care staff and patients' relatives can help to provide support, reduce stress levels, and improve well-being and the ability to make important decisions (Liu and Hutchinson, 2001). This is a key finding in that both acute and chronic stress can have psychological and physiological effects, which can ultimately impact on an individual's mental and physical health (Ogden, 2007; Morrison and Bennett, 2009; Marks, Murray, Evans *et al.* 2005). It is also possible that if the health of a patient's relative deteriorates, they may be unable to provide adequate support to the critically ill patient, whose health and recovery may then suffer as a result. In addition, Bond *et al.* (2003) found that if relatives did not receive honest information about what was happening to their loved one, this compounded their emotional distress and made it difficult for them to make sense of what they and their loved one was experiencing. Such uncertainty can also have the adverse effect of restricting a relative's ability to understand and interpret a situation (Engstrom and Soderberg, 2007). This could potentially serve to exacerbate relatives' already increased levels of stress and anxiety.

Moreover, honest and accurate information can help relatives to cope with their family member's critical condition, from the moment the family member is admitted and throughout the ICU Pathway (Wahlin, Ek and Idvall, 2009; Bond *et al.* 2003; Dierckx de Casterle, Verhaeghe, Kars *et al.* 2011; Treece, 2007). Good, open communication with relatives and educating the family in the discontinuation of life-saving processes is seen to be crucial if a patient is dying, to prevent confusion, misunderstanding and miscommunication (Parker, 2011). Effective communication can also relieve fears patients' relatives might have of the unknown, in terms of the illness or condition of the patient. If they are properly informed of the patient's progress and expecting a poor prognosis, then the fear of their family member dying might be alleviated (Selwood, 2008). Evidently, having a family member admitted to an intensive care unit can bring various psycho-social issues into play for relatives, in terms of how they feel and are able to cope in this new environment, how they interact with others (particularly staff members), how they perceive the communication they have with staff on the unit, and how they react to and understand information which is provided to them.

Manuel, Solberg and MacDonald (2010) found that the patients' relatives in their study were dissatisfied with several areas of the care of their critically ill family member. These included the lack of opportunity they had as relatives in decision-making regarding care of the patient, the lack of

knowledge of the patient's medical condition and the lack of communication on the part of staff with regard to running diagnostic tests on the patient and the outcomes of these tests. Where relatives lack knowledge regarding the patient's medical condition it is important that staff members communicate information about the condition to the relatives in lay terms which they can understand. Similarly, they need to explain the tests being conducted on the patient and the role of medical equipment surrounding and monitoring the patient's condition, so that relatives understand their function and meaning.

1.1.2 Stress and coping on the ICU

"The 'craft' or art' of good communication is most effectively learnt through experience and reflection" (Pennell and Bryan, 2008, P.27)

The experience of being on an ICU can present many stressors to relatives of critically ill patients, and although a single stressful event may not put excessive strain on individual coping abilities, persistent stressors can (Hughes *et al.* 2005). However, effective communication with patients' relatives and friends and providing much needed and honest information can result in relatives feeling better able to cope with the crisis of having a critically ill loved-one on the ICU, and able to support them, thus playing an essential role that ultimately benefits the patient (Molter, 1979; Evans, Boyd, Malvar *et al.* 2009). How relatives cope with the experience of having a loved one on intensive care will affect how they comprehend the situation, understand information and be able to provide support to the patient. In addition, their cognitive and emotional state will influence how they cope. Coping is seen as being effective when the way in which an individual manages a stressful situation brings them some relief and is ineffective when a person's management of a stressful situation makes the situation more difficult for them to cope with which can be associated with a lack of internal and external resources (Johansson, Hildingh, Wenneberg *et al.* 2006).

Individuals will often adopt an individual coping style to mitigate the effects of a stressor, especially if they have perceived it as harmful. The two most defined coping styles people adopt are 'approach' or 'avoidance' styles (Hickman, Daly, Douglas *et al.* 2010; Ogden, 2007). In terms of the ICU, if a patients' relative uses an approach style of coping, they may find that being proactive and taking direct action, facing the stressor head on, and asking for information, is the best way to mitigate stress and cope with the situation. Conversely, if they use an avoidance style, they might be in denial about what is happening, may try to avoid the stressful situation as much as possible, and find detailed information distressing (Ogden, 2007; Weinman, 1990). However, denial can sometimes be a useful strategy in the short-term, especially when one needs time to process information, such as

bad news and to protect oneself mentally from trauma. It is when this strategy continues, that it can become harmful to the individual.

Similarly, individuals may be categorised as either "monitors" or "blunters" (Weinman, 2007; Hickman *et al.* 2010). 'Monitoring' is likened to the approach style of coping where a relative may actively seek additional and detailed information, often from many sources, to cope with the psychological stress of the situation of having a relative on the ICU. However, if this information is inadequate it may impact on their sense of control and well-being (Hickman *et al.* 2010; Weinman, 2007; Morrison and Bennett, 2009). 'Blunting' is where the relative may actively avoid information or distract themselves from sources of information that they deem in some way threatening. This serves as a protective mechanism because if they are exposed to too much information it can be harmful to their psychological well-being (Hickman *et al.* 2010; Weinman, 2007; Morrison and Bennett, 2009).Various studies have found that monitors are more likely then blunters to interpret ambiguous situations as threatening (Lewis and Ramsey, 1999) and individuals who are blunters may avoid situations where they have to make decisions about their critically ill loved one or meet with medical staff. This behaviour can be prevented by involving them in the decision making process as a shared practice with intensive care staff, so the emphasis is not completely on them to make decisions (Hickman *et al.* 2010). Lewis and Ramsey (1999) state that the differences between monitors and blunters are apparent at both a psychological and a behavioural level, as monitors will suffer greater distress when they are faced with a threat than blunters, but will also have a tendency to experience increased psychological, behavioural and psychophysiological arousal.

However, some relatives will not fit into either category and it is possible that they may demonstrate aspects of both monitoring and blunting. It might be advantageous for ICU staff to be especially aware of what patients' relatives' individual coping styles are and tailor their interactions with them appropriately, especially in terms of communication about the patient and providing information. Again, this may require specific training of staff to accomplish, but could be beneficial to all aspects of communication and information provision pertaining to relatives, and issues of understanding and decision-making on an ICU or CCU. It is important to note that, providing important information to relatives requires staff members to feel confident and knowledgeable enough to communicate that information effectively, thus it is essential that staff members foster good communications skills to interact successfully with relatives (Poles and Bousso, 2011).

1.1.3 Communication between patients' relatives and staff members on the ICU

Communication can be defined as "the imparting or interchange of thoughts, opinions, or information by speech, writing, or signs" (O'Daniel and Rosenstein, 2008, p.1)

Research has predominately focused on the experiences of nursing staff on the ICU, as they spend the most time with the patients and their relatives on the unit (Keenan and Joseph, 2010; Badger, 2005) and therefore have the most intense relationship with them. Their continuous care of patients also means that they are the most available staff members for patients' relatives to communicate with and this can lead to them bearing the brunt of relative dissatisfaction with all aspects of intensive care (Duff, 2006). Problems can arise which may affect the fluency of communication between nursing staff and patients' relatives, and at times even hostile interactions can occur (Hupcey, 1998; Selwood, 2008). These might stem from several reasons, such as the nurse not having enough time to spend with the patients' relatives if they are busy caring for the patient or other patients with greater needs (Hupcey, 1998). In addition, the nurse may misinterpret patients' relatives' questions or regard their involvement with their care of the patient as a criticism (Yagil, Luria, Admi, Moshe-Eilon and Linn, 2010). A study by Badger (2005) found that the main source of frustration for ICU nurses was dealing with the complex emotions expressed by relatives of the patient. Nursing staff have to maintain a difficult balance between working in the best interests of the patient, allowing the relatives to come to terms with end-of-life care, and responding to emotionally laden conversations with them (Taylor, 2007).

Taylor (2007) reports that nurses feel more confident to undertake difficult and emotionally laden communications with relatives if the ethos is talking to and supporting patients and their relatives and where there is an integrated approach to communication skills training this can improve nurses' communication skills. The need to improve nurses' communication skills has led to an increase of communication training modules for nurses, although not all types of training are effective, such as training delivered only through the medium of lectures and theory modalities (Mullan and Kothe, 2010). Mullan and Kothe (2010) conducted a study where they evaluated the relationship between student self rating of their own ability and their satisfaction with a communication skills course. 209 first year nursing students participated in the two week communication skills training module, which combined counselling and communication skills. The module included the following:

1. Formal and informal lectures incorporated with panel interviews
2. Role-play
3. Small group work

4. Interactions with simulated patients

5. Handouts

6. Reflective self-directed learning

The course was assessed by pre and post module questionnaires; a sub-sample of students completed a pre-module questionnaire which assessed self-rated ability and expected satisfaction with the module, and self-related ability was measured for this sub-sample post-module. All students completed post-module questionnaires which assessed satisfaction of the module using quantitative and qualitative methods. Paired samples *t*-tests were performed to determine differences in students' self-rating of ability prior to the module and after it had been completed. They found improvements reported in communication skills on all measures, with an increase in students' confidence levels and competence in being able to communicate effectively after completion of the module. In terms of satisfaction, a regression analysis was performed to determine the relationship between expected and reported satisfaction with the module, and these two measures were significantly correlated, where expectation of satisfaction prior to the module predicted 14% of the variance in actual satisfaction. The quantitative and qualitative data showed that on average, students were satisfied with the module. The results demonstrate the need for communication skills training for nurses to include a variety of teaching methods that include both standard lectures and participatory and reflective learning activities.

In comparison to nurses' experiences of communication with patients' relatives, there is a paucity of research regarding doctors' experiences in communicating with patients' relatives in intensive Care. Doctors (primarily consultants) spend less time with patients and their relatives but have the final responsibility for making decisions relating to the care and treatment of critically ill patients. Working in such a position of power means that it is imperative for doctors to communicate effectively with patients' relatives regarding the patient's condition and why certain treatment options are considered and acted upon, to prevent potential conflict due to relatives' lack of understanding. Gauntlett and Laws (2008) state that not only are communication skills an integral part of providing good critical care but it is also paramount in the provision of quality end-of-life care. However, up to 50% of families of critically ill patients may experience inadequate communication with doctors on an ICU. The lack of or poor communication between healthcare staff and families is one of the major causes of complaints from patients' relatives (Taylor, 2008; Lowson, 2007; Bloomer, Lee and O'Connor, 2010). It is therefore important that staff communicate information that is easily understandable and sufficient enough to aid in decision-making, whilst also providing reassurance and clear explanations that patients' relatives will understand (Lowson, 2007).

Hughes et al (2005) found that relatives often attach more importance to information communicated by a doctor as opposed to a nurse, despite the ICU being a primarily nurse-led environment. Yet relatives reported less satisfaction with doctors' communication and were very satisfied with nurse competence. This may in part be due to relatives forging stronger relationships with nursing staff and weaker ones with doctors who they have much less contact with. Therefore it is critical that doctors are able to foster an efficient style of communication for use in the few interactions they do have with patients' relatives. There is also evidence of sustained improvements in essential communication skills when doctors are given appropriate communication skills training (Nelson, Mercado, Camhi *et al.* 2007).

Since 1993, medical schools have invested heavily in the teaching and assessment of communication skills, and since 2002 healthcare professionals who deliver patient care in the NHS, must be able to communicate competently with patients as a pre-condition of qualification (British Medical Association (BMA) 2004). The GMC present standards for communication skills, which medical graduates must be able to do, such as:

- Communicate clearly, sensitively and effectively with patients, relatives and colleagues
- Awareness of other different methods of communication i.e. sign language
- Communicate effectively with individuals regardless of their social, cultural, racial background or disabilities and be able to communicate with non-English speaking individuals

Graduates should have opportunities to practise:

- Breaking bad news
- Dealing with difficult and violent patients
- Communicating with individuals with mental illness
- Communicating with and treating patients with severe mental or physical disabilities
- Helping vulnerable patients

(BMA, 2004)

However, there is thought to be a lack of follow-up in developing these skills after training and the skills can erode if not maintained by regular practice (BMA, 2004). If communication skills teaching for doctors is to be effective, it should include the following:

- Evidence of current deficiencies in communication, reasons for them, and the consequences for patients and doctors
- An evidence base for the skills needed to overcome these deficiencies
- A demonstration of the skills to be learnt

- An opportunity to practise the skills under controlled and safe conditions

- Constructive feedback on performance and reflection on the reasons for any unconstructive behaviour.

(BMA, 2004)

In addition, medical graduates should be competent in the following areas of interpersonal communication:

- Listening to patients, relatives/carers/partners and other healthcare professionals

- Explaining and providing patients and others with adequate information

- Mediating and negotiating with patients, carers and colleagues

- Handling complaints appropriately

(BMA, 2004)

These requirements in communication skills also reflect those which are needed on the ICU but as the literature suggests are not always being practiced as effectively as they should be. This may indicate the need for repeated refresher training courses in communication skills for doctors and other healthcare professionals, particularly for those who work in a critical care environment.

1.1.4 Potential barriers to effective communication on the ICU – ethical issues

"Mental capacity does not exist if a person is unable to make a decision because of an impairment of, or a disturbance in the functioning of, the mind or brain" (George and Dimond, 2009).

In some countries, such as the United States, family members can act as surrogate decision makers for patients who lack capacity on the ICU (Lind, Lorem, Nortvedt, Hevroy, 2011). This means that they can make important treatment and end-of-life decisions regarding their loved one, rather than the doctors. This can empower patients' relatives and allow them to make decisions which they think will suit their loved one, but it can also prove to be additionally stressful due to the realisation of being responsible for what happens to them (Johnson, Bautista, Hong, Weissfield and White, 2011; Rid and Wendler, 2010). This can be a difficult burden to cope with, especially when it is additional to the already stressful situation of the experience of having a loved one who is critically ill. Having to make such important decisions for a relative has shown to increase the psychological problems experienced by patients' relatives on intensive care (Lautrette, Peigne, Watts *et al.* 2008; Johnson *et al.* 2011). In addition, some relatives may not be aware of their loved one's preferences for such a situation and may have difficulty discriminating between what their loved one's wishes may be and their own interests (Lind *et al.* 2011). However, where shared-decision making is utilised and medical staff and family members make decisions together, this has often proved successful in

that it still upholds the autonomy of the patient without relatives having to make decisions that they may feel unprepared for or do not want the responsibility of making (Lautrette *et al.* 2008).

In the UK, under The Mental Capacity Act (MCA, 2005), if patients lack the mental capacity to make decisions for themselves and have no written will or advanced directive that states how they wish to be treated when critically ill, medical doctors are legally allowed to treat these patients how they see fit, as long as it is in the patient's best interests (Walters, 2009). However, there are many aspects for doctors to consider when a patient lacks capacity, such as whether the patient's lack of capacity is temporary or permanent, evidence of preferences that might have been previously expressed by the patient or the views of those close to the patient who might have insight into the patient's preferences, and what treatment or non-treatment option may be the least restrictive of the patient's future choices (GMC, 2008). Sometimes the doctors' decisions may be contrary to the wishes of patients' relatives, which can cause conflict between patients' relatives and ICU staff, for example, if they disagree with the doctor and were under the impression that as patients' relatives they would have more power over such decision-making processes. Dimond (2008) states that relatives should be informed about how best interests are decreed according to the MCA and the advice given should also include the rationale determining clinicians' opinions. This may denote a need for relatives to be informed about the potential ethical and legal aspects of the intensive care patient pathway at an early stage, to prevent any misunderstandings later on.

When relatives are dissatisfied with communication from staff members on intensive care, further problems with the issue of consent can occur and this can cause crucial relationships between staff and relatives to break down and other issues to arise leading to misunderstanding and frustration for the relatives, and in some cases this can result in medico legal and other implications (Siddiqui *et al.* 2001). Conflict can occur in ethically complex areas, such as Do Not Resuscitate (DNR) decisions and organ donation. The process of consenting to DNR status can cause interpersonal conflict between family members, patients and staff (Jezewski, 1994). Selwood (2008) states that in situations when a patient is beyond resuscitation, in that sustaining their life is impossible, communication is the most crucial method of assisting the patient's relatives to understand that the situation is terminal and unsalvageable in those who may believe there is still hope and that treatment should continue. In the UK medical staff on intensive care must act on behalf of the patient in these cases. This is easier when a patient has an advanced directive or living will, which outlines what they would want in the eventuality of requiring end-of-life care and treatment (Garnett, Vandrevala, Hampson *et al.* 2008). However, most patients do not have an advanced directive or living will unless they felt there was reason to do so, perhaps due to having a chronic

potentially life-threatening condition. Many people will only discuss it if the issue is raised by health care professionals and relatives may only become involved in discussions about this issue in the event that a family member becomes incapacitated (Garnett *et al.* 2008).

Many patients on an ICU are there unexpectedly, due to an accident or sudden life-threatening heath problem. In these cases it is the responsibility of the ICU doctors to ascertain what the patients may have wanted in terms of treatment decisions, by gleaning information from the relatives. However, the ICU doctors are ultimately responsible for deciding what is in the best interests for the patient. This can be extremely difficult for staff members, especially when the patient's family may have different ideas towards treatment decisions. If such differences of opinion arise between clinicians and relatives as to the patient's best interests and these are irreconcilable, an application can be made by the patients' relatives to the Court of Protection for a declaration to be made regarding what the best interests of the patient should be, and in an emergency, this process can happen quite rapidly (Selwood, 2008). However, this process can potentially cause further stress and anxiety to all parties concerned. It can cause distress in relatives if the court rules in favour of the clinician's course of action and can also be distressing for clinicians whose professional and expert views are being questioned.

Similarly, the sensitive issue of organ donation can be another area where good communication and information provision between intensive care staff and patients' relatives is vital. Bein, Kuhr, Kramer *et al.* (2003) conducted a study to assess the personal attitudes, behaviour and psychological involvement of intensive care doctors and nurses, regarding the issues of brain death and organ donation. They found that many of the participants felt they had not had sufficient training to deal with these issues and that care for relatives on intensive care was inadequate. Significantly, 70% of the participants reported they would like to receive special training that focused on brain death, communication with relatives and in managing how to procure donor organs. In addition, Hyde and White (2009) also stress the importance and benefits of communication around the difficult discussion of organ donation, to provide individuals with the confidence and motivation to register and discuss organ donation. This could be a discussion with the relatives or the patient, or even to help the patient feel they can bring up such a subject as part of an advance directive.

Like nurses, doctors' experiences of looking after patients on an ICU can also prove to be very distressing, primarily because doctors often have to deal with complex ethical issues and moral dilemmas (Santiago and Abdool, 2011), in particular, cases where doctors and family members disagree over the benefit of the continuation of aggressive medical interventions (Santiago and Abdool, 2011; Vanderspank-Wright, Fothergill-Bourbonnais, Brajtman *et al.* 2011; Norton, Tilden,

Tolle *et al.* 2003). Cases such as these may be more prevalent in some countries such as the United States, where relatives can act as substitute or surrogate decision-makers. However, conflicts can also occur, when ICU doctors make a decision to end an aggressive treatment because they believe it is in the patient's best interests, but the patient's relatives disagree (Norton *et al.* 2003).

Santiago and Abdool (2011) conducted a study about providing Ethics Debriefing Sessions for ICU staff members. Debriefing sessions can provide a safe forum for staff members to share thoughts and feelings about difficult aspects of their work amongst respectful and supportive colleagues (Santiago and Abdool, 2011). The study was based on a modification of previously established system of debriefing sessions for staff on the medical surgical ICU (MSICU), which had become irregular and was receiving poor attendance. Originally changes were made to improve and formalise the sessions however, monthly attendance numbers had continued to remain low. A focus group of key staff members was facilitated where participants were asked to provide feedback on their experiences and perceptions of the debriefing sessions. Their feedback was implemented in 2010 and involved the meeting location changing to a venue more convenient for nursing staff, the sessions being well advertised in advance and using several different types of media, incentives such as snacks were offered to promote value of staff and encourage attendance, and sessions had an open agenda so staff could choose topics and discuss challenging cases. They were also encouraged to discuss elements they had found emotionally demanding. As a result of the changes, the frequency of sessions increased, which led to a slight increase in the number of attendees. Data obtained from staff who attended these sessions was anecdotal and reported the benefits in terms of improved planning, preparation and implementation of appropriate provision of holistic care for patients' relatives, which had the added value of promoting staff well-being. The sessions also contributed to the collective exploration of alternatives and strategies to address specific concerns about patients and their families prior to family meetings on the ICU. This improved patients' care plans and the consistency of communication with families, and delivery of patient care. Staff interventions such as this may serve to help staff members deal with patients' relatives in a supportive and effective way. It may be advantageous for other critical care units to adopt similar interventions, as this may prove beneficial to staff, relatives and patients.

The asymmetry in the quantity of care delivered to individual patients by doctors and nurses can sometimes create conflict between the two populations of staff, where nurses may disagree with decisions made by the doctor or may be unhappy with how the doctor has communicated with a patient's relatives (Badger, 2005). Sutton (1998) found that relatives viewed the doctor as the purveyor of information and clinical communication, which equalled high status, and the nurse as

purveying sympathy and non-clinical communication, which equalled low status. This appears to massively understate the highly significant role of the ICU nurse. The majority of research involving ICU nurses usually conveys the reality of how paramount their ICU role is to the care of patients and relatives, as they provide 24 hour intensive nursing care on a one-to-one basis, and continuously assess and monitor patients (Duff, 2006). This is in contrast to ICU doctors, who will generally be looking after a number of patients at any one time, so the time they are able to spend with each patient is significantly less than the nurses, and the intensive care consultants, who will effectively be looking after every patient on the unit.

Due to the differences between doctors and nurses in the care of patients and the time spent with their relatives, it is vital that these two sets of important staff members work collaboratively so that they are united in what they say to patients and relatives. When ICU doctors and nurses operate as a team and share the delivery of information and support, research has shown that this better equips them to support the relative, which can have a positive effect, making relatives feel more valued and empowered (Sutton, 1998). However, in terms of ethical and emotional issues that often arise as part of end-of-life decision making, evidence has indicated that the way in which relatives responded to the attitude of the ICU doctor, is a significant factor in whether they agree to a request of organ donation from their loved one (Sutton, 1998). This suggests that a doctor's behaviour and the way in which they communicate with relatives around end-of-life issues may impact on the decision-making and co-operation of relatives.

1.1.5 Communication Styles

"Good communication engenders meaningful and trusting relationships between healthcare professionals and their patients" (British Medical Association, 2004, p.4).

Doctor-patient communication has been a widely researched area (Ley, 1988; Ong, De Haes, Hoos and Lammes, 1995; Ogden, 2007) and is applicable to communication between doctors or other health professionals and patients' relatives. Doctors will adopt certain approaches to the way they communicate with their patients, particularly in their one-to-one consultations with them. Communication styles vary and tend to lie on a continuum from a 'doctor-centred' approach to a 'patient-centred approach' (Marks *et al.* 2005; Morrison and Bennett, 2009; Ogden, 2007). A 'doctor or health professional-centred' approach is often adopted by doctors and other health professionals, who use their authority to dominate their communication with the patient (Marks *et al.* 2005). It is very directive and the patient is a passive recipient who is very much led by the doctor with their expert knowledge and experience, who asks the patient direct questions in order to obtain

important information. This is in contrast to a 'patient-centred' approach, which focuses on the patient. The doctor spends more time listening to the patient, reflecting on what has been expressed through their own knowledge and experience and actively encouraging engagement from the patient who is an active participant (Marks *et al.* 2005; Morrison and Bennett, 2009; Ogden, 2007).

However, these aforementioned approaches may not suit everyone; some people may not fare well with such an acquiescent role where they are directed by the doctor, while others may welcome it. Patients may feel they need someone to listen to them and for that person to show an interest in their welfare, in which case a more patient-centred approach might benefit them. Over time there has been a move to using a combination of these approaches, to a perspective which has been termed the 'interactive dyad' or 'shared-decision making' model. In this model there is a collaborative relationship between the doctor or other health professional and the patient, and decisions regarding health care are shared, particularly in circumstances where a diagnosis has been made to which the doctor can provide information and advice on treatment but the final decision is a joint one (Marks *et al.* 2005; Morrison and Bennett, 2009).

Within ICUs the approach that doctors or nurses use to communicate with patients' relatives may impact on how they react to that communication and how they may benefit from it. Patients' relatives on an ICU may require a combination of approaches depending on what suits them individually: they might want direct, detailed information about their family member, or wish to receive limited information. The need for information is not exclusive to the patients' relatives as ICU staff doctors and nurses often need to glean information from patients' relatives about their loved one and will ask them pertinent questions in order to find out useful details to inform appropriate treatment for the patient. In contrast to the UK and its paternalistic style of decision-making practised by physicians who generally make the ultimate decisions about patient treatment, in North America, White, Braddock, Bereknyei and Curtis (2007) found that higher levels of shared decision making on the ICU was linked to increased satisfaction in patients' relatives. The shared-decision making model allows patients' relatives to have much more input to treatment decisions and is often seen as a preferable approach by critically ill patients and their relatives (White *et al*. 2007).

Potentially this could be a positive way forward in other countries, and in the UK, in that patients relatives will feel more involved in making decisions for their loved one's treatment as opposed to feeling powerless, but will not have to carry the burden of being a surrogate decision maker. The role of a surrogate decision maker may be practised when there is no advanced directive from the patient and if the surrogate has insufficient knowledge about what their loved one might have

wished for in the event they became critically ill, then this may result in the surrogate having to make the decisions based on their own beliefs of what their loved might have wanted (Brudney, 2009). If more and more patients' relatives' desire to be involved in decision-making regarding their critically ill family member, a more collaborative style of communication might be an appropriate approach to take on ICUs and CCUs in the UK. However, there may be a caveat to relatives having more involvement in making decisions for their loved one, in that they could be at risk of developing psychological symptoms such as anxiety, depression and PTSD, particularly if their loved one is a spouse and this could potentially impair their decision making capacity (Lautrette, Peigne, Watts *et al.* 2008).

1.1.6 Health Beliefs

"It is very important to remember that we all bring our own perspectives, beliefs and preconceptions to decision-making" (George and Dimond, 2007, p.74).

Similar to the 'shared-decision' making model of communication between a health professional and a patient (or relative), is Ley's 'Cognitive Hypothesis Model', which sees both the roles of doctor and patient as being important in the consultation. Such as the combination of patient factors in the communication process and health professional factors which include provision of significant information (Ogden, 2007). However, the model does not allow for issues surrounding health beliefs: those of the health professional and the patient. The health beliefs we hold can have a significant impact on how we think, feel and behave (Ogden, 2007). Health professionals are more likely to hold professional health beliefs created through their knowledge and experience of health or medicine. However, in contrast the patient is more likely to hold individual and varied lay beliefs (which may also include differences in culture and religion), that may be very different to those of the health professional (Ogden, 2007). This difference in health beliefs can cause problems in communications about health and treatment and could also apply to the issue of communication between staff and patients' relatives on an ICU. For example, relatives may or may not want certain treatments for their family member due to their religious beliefs (Lautrette *et al.* 2008) or may disagree with decisions made by staff regarding their family member due to personal health beliefs, preferences, and what they think is best for the patient (Lautrette *et al.* 2008; Norton *et al* .2003). In light of this, it is important that ICU staff members are aware of and sensitive to the needs of patients' relatives on the ICU.

1.1.7 Information needs of patients' relatives on the ICU

There may be particular points during the hospitalisation of critically ill patients where relatives' need for information is particularly pertinent. It has been found that the needs of relatives of critically ill patients are greatest during the first 72 hours of the patient being admitted to the ICU, and this period of time was when they required honest information about their loved one and relief from anxiety (Walters, 1995). This indicates that certain types of information required by relatives may require timely provision by intensive care staff members to help relatives come to terms with what is happening with their loved one.

Having access to information about their critically ill loved one and maintaining good relationships with critical care staff are seen as high priorities for relatives of critically ill patients, and it should be a primary responsibility for ICU doctors and nurses to address these needs (Siddiqui *et al.* 2011). Research by Molter (1979) identified the primary needs of patients' relatives who were experiencing the hospitalisation of a critically ill family member in the ICU and how important these needs were when providing total care to the patient. The primary need was the provision of honest and adequate information regarding the patient from staff members, so that the relatives could understand what was happening to their family member, with hope being universally considered as the most important need. Molter's (1979) study also elucidated the importance of meeting needs of patients' relatives as a crucial role in caring for the critically ill patient.

Similarly, Kinrade *et al.* (2009) conducted a study using Molter's Critical Care Family Needs Inventory (CCFNI) to measure, rank and compare needs statements of relatives whose family member has been suddenly admitted to intensive care, and of the intensive care nurses. Relatives were only eligible to partake if their family member had been in the unit for 48 hours. 78% (25 out of 32) of eligible families took part in the study, aged between 34-71 years and including 3 men and 22 women. 69% (33/48) of nurses (full and part-time) took part, and varied in experience from very junior to very senior. Out of the 45 items on the inventory, the most important needs identified by family members and nurses were as follows:

- To have questions answered honestly
- To visit at any time
- To feel that the hospital personnel care about the patient
- To know specific facts concerning the patient's progress
- To know the expected outcome
- To see the patient frequently

- To be assured that the best care possible is being given to the patient
- To be told the truth even if it is distressing
- To have explanations given that are understandable

The need to have questions answered honestly was identified by both family members and nursing staff as the most important need of all (Kinrade *et al.* 2009)

In addition, Zazpe, Margall, Perochena and Asiain (1997) used a modified version of Molter's inventory in a study of 85 relatives of patients admitted to an ICU. Relatives' needs were categorised into four groups including: information, confidence, comfort of the ICU environment, and emotional support. The most frequently identified needs were related to information and confidence, the latter was indicated by 97% of participants who felt that the following six needs were met on the ICU: assurance their loved one was receiving the best possible care, staff cared about their loved one, their questions were answered honestly, they felt accepted by staff, they could talk to the doctor on a daily basis, and have comfortable furniture in the waiting room. There were a number of needs related to information, such as: explanations that were understandable, knowing the prognosis, and knowing what was being done for their loved one. Zazpe *et al.* (1997) concluded that there should be more than one channel of communication used in imparting the types of information desired by relatives.

Similarly, Prachar, Mahanes, Arceneaux *et al.* (2010) revealed that of the top ten needs of relatives of critically ill patients, the most significant were also needs related to information, but also assurance. Moreover, this was reflected in a study of 45 family members and 37 nursing staff members by Kosco and Warren (2000), who used the CCFNI and the Needs Met Inventory (NMI). They found that family members perceived the top ten needs in order of importance in the first 18-24 hours after admission to the ICU. These findings reinforced suggestions from previous research regarding the first 24-72 hours post admission as one of the most sensitive periods for patients' relatives and when they need the most support in terms of information and assurance from staff. Both family members and nursing staff in the study by Kosco and Warren (2000) identically ranked the subscales of assurance, information, and proximity – such as seeing the patient frequently and having facilities close to the waiting room - as most important on the CCFNI. The top six needs ranked as being:

1. To know the prognosis
2. To be assured that the best care possible is being given to the patient
3. To be told about transfer plans while they were being made
4. To be called at home about changes in the patient's condition

5. To receive information about the patient once a day

6. To feel that the hospital personnel care about the patient

(Kosco and Warren, 2000)

Kosco and Warren (2000) stated that when the above needs were met by staff it enabled the family to gain the necessary energy to support their critically ill family member.

Similarly, in terms of the NMI, family members rated the following needs as most important:

1. To know the prognosis

2. To be assured that the best possible care is being given to the patient

3. To know why things are were done for the patient

There were similarities and differences for the nursing staff who ranked the most important needs of relatives as being:

1. To be assured that the best care is being given to the patient

2. To feel that the hospital personnel cared about the patient

3. To see the patient frequently

These findings suggest that relatives and staff members have shared views when it comes to needs being met on the ICU, however as the literature suggests, this does not necessarily equate to these needs being effectively met. This was also demonstrated in the research by Kosco and Warren (2000) where at the end of the CCFNI was an open-ended comments section and one of the additional needs perceived by relatives was "to have better communication between the health care team and the family".

Paul and Rattray (2008) conducted a literature review of the short and long-term impact of critical illness on patients' relatives, and found that communication during the admission period on an ICU affected relatives' perceptions of whether their needs were being met by the unit. This was in terms of receiving adequate explanations about the unit, the equipment being used, the procedures being conducted, and the information provided to them about the condition of their family member who had been admitted. Significantly, previous research by Alvarez and Kirby (2006) and Auerbach, Kiesler, Wartella *et al.* (2005) suggests that when relatives' overall needs were met on the ICU, relatives reported increased satisfaction.

It is also important for patients' relatives to be aware of the fact that if their loved one has been admitted to an ICU or CCU then they are critically ill and this means there is always the possibility that they may not survive. Due to the critical nature of patients on the ICU, staff members often have to deal with end of life issues with patients and their relatives, such as the prospect of

palliation, whether or not to resuscitate, and in some cases expressing the futility rationale to patients' relatives. This is where ICU doctors may predict it would be futile to continue life-sustaining treatments if they are sure these would ultimately prove unsuccessful due to the critical state of the patient (Zier, Burack, Micco, Chipman, Frank and White, 2009). NICE (2011) states that information which is offered to patients who are nearing end of life and their relatives and carers, should include the following:

1. Information regarding treatment and care options, medication and what to expect at each stage of the journey towards end of life
2. Who they can contact at any time of day or night to obtain advice, support or services
3. Practical advice and details of other relevant services such as benefits support
4. Details of relevant local and national self-help and support groups.

However, if people do not wish to be given information they should have their preferences respected (NICE, 2011). In addition, Dreyer and Nortvedt (2007) concluded that the amount and type of information provided by staff members should be filtered to suit the emotional state of the relatives. This may imply that it would be prudent to ask relatives how much information they want to be given and how frankly they want it conveyed, so they have a choice as to how the information is communicated to them.

1.1.8 Methods of information delivery on the ICU – Minimising potential problems

The provision of written information from healthcare professionals to patients has been shown to increase adherence to treatment and advice (Myers and Abraham, 2005; Kenny, Wilson, Purves *et al.* 1998), which implies it also increases understanding and could be applied to the provision of written information to patients' relatives. Written information has proved to be effective in improving ICU patients' relatives' knowledge and understanding, when it is also supported by verbal communication (Azoulay, Pochard, Chevret *et al.* 2002; Kenny *et al.* 1998). For example, in a medical situation where people need to be informed of bad news or need to make important treatment decisions. Often in highly stressed and anxious states, individuals can be unable to fully digest what is said to them by medical professionals, and research suggests that sometimes there is an information overload where people can only absorb so much information at a given time (Ogden, 2007). This has been shown in doctor-patient consultations, where regardless of the doctor explaining the proposed treatment to the patient, they will often not understand and will forget instructions that the doctor gives them, to the extent that patients have been found to forget at least a third of the information provided (Ley, 1979; Myers and Abraham, 2005; Weinman, 1990).

This is also supported by research by Duff (2006) who found that family members found it difficult to absorb large quantities of information, particularly if that information was imparted verbally, and by Hughes *et al.* (2005) who conducted an exploratory study which looked at relatives' overall experiences of the ICU and staff perceptions of these experiences. The primary themes to emerge from the semi-structured interviews were information and communication. Within the first 24-48 hours, they identified that relatives absorbed little information. This is thought to be due to the level of arousal created by the traumatic experience of having a loved one admitted to an ICU and as a result, the ability to process complex information can become difficult. These findings suggest that there may be a need for information to be imparted through additional means, for example a written accompaniment to verbal information, and for important verbal information to be repeated at regular intervals to ensure understanding and comprehension (Hughes *et al.* 2005; Myers and Abraham, 2005).

Hughes *et al*. (2005) also found that dissatisfaction was reported by staff and relatives regarding the dissemination of information. It was found that the amount of information which relatives required from ICU staff differed between individuals; some relatives wanted more information than others (Hughes *et al.* 2005; Dreyer and Nortvedt, 2007). This suggests that information provision may need to be tailored to individual relatives. Hughes *et al.* (2005) concluded that the way in which information is communicated by staff to relatives is crucial and that improvements in the consistency of communication between staff and relatives would reduce relatives' anxiety levels and promote better interactions between staff and relatives. This was also supported by Bond *et al.* (2003) who established that not knowing what is happening to their family member or lack of consistent information, can cause relatives increased anxiety and distress.

In addition, Hughes *et al.* (2005) found that ICU staff in their study advocated best practice in the delivery of information to relatives regarding all aspects of intensive care which included information about the unit, facilities for relatives, details about their family member's condition, and how and when this information should be provided. However, the data obtained from patients' relatives in the study indicated that this transfer of information was not always implemented and that there were often communication problems between staff and patients' relatives, where the relatives often showed a lack of comprehension about what was imparted to them via verbal communication from staff. Rodriguez, Navarrete, Schwaber *et al.* (2008) also found a similar lack of comprehension when it came to relatives' understanding of the basic elements of their family member's care. Further to this, Azoulay, Pochard, Chevret *et al.* (2004) found that 35% (189 of 544 participants over 78 ICUs) of the relatives in their study did not comprehend the diagnosis, prognosis or treatment of their family

member. Comprehension was compared with anxiety and depression to assess the effects of a variety of independent variables such as those mentioned above. On the dependent variable, that was primarily the willingness of the family members to be involved in decision making, they found that those patients' relatives who had lower comprehension and satisfaction were more likely to want to share in decision making related to their critically ill family member.

Bond *et al.* (2003) found that relatives reported inconsistencies in information provided by ICU staff and that five out of the seven participants interviewed in their qualitative study wished that there would be some kind of standard, condensed form of information that could be provided by a single doctor to all of the relatives. This need for consistent information from ICU staff arose from the participants' experiences of receiving conflicting information from doctors, which caused much unnecessary confusion and angst within the family. However, in successfully providing a standard condensed form of information, several elements need to be addressed. Research which has evaluated health care leaflets have indicated that they often require individuals to have a higher reading age to understand them than the average reading age in the UK, which is approximately 9 years (Paul, Hendry and Cabrelli, 2004; Kenny *et al.* 1998). In addition, Butow, Brindle, McConnell *et al.* (1998) found that in their study which explored factors which influenced patient satisfaction and utilisation of information booklets about cancer, that patients made a clear preference for the booklet which had the lowest reading age. Indicating that generally people may prefer medical related information that is easy to read and understand, regardless of reading level (Menghini, 2005). Therefore, readability is an important factor to consider when designing an information leaflet or booklet for patients' relatives who may have differing levels of education and literacy skills.

Another caveat to this finding would be if the style of a leaflet is too simple it may be perceived as patronising and could be less interesting to the reader (Kenny *et al.* 1998), which may impact on the efficacy of the leaflet. Therefore a leaflet for patients' relatives should be easy to understand but should not be over-edited for simplicity, and if it is accompanied with a verbal explanation, should be accessible to all. In terms of readability, Kenny *et al.* (1998) state that all new patient leaflets should have an objective readability score before being peer reviewed by lay people and health professionals, although this can also have draw-backs in terms of fallible measures which are often used in the scoring process. However a peer review of the leaflet is important to evaluate how accurate and effective the content of the leaflet is prior to dissemination.

Research investigating the efficacy of information leaflets or booklets for patients regarding medical conditions or treatments has demonstrated consistent improvements in several areas: patient knowledge, positive changes in mood and even health outcomes (Weinman, 1990), including a

reduction in anxiety (Kenny *et al.* 1998). Research has shown that written information in the form of a family information leaflet (FIL) improves patients' relatives' comprehension of what is happening on the ICU to their loved one and in understanding treatment decisions (Azoulay *et al.* 2002). Yet written material alone, without a verbal explanation and face-to-face communication, can potentially be ineffective as it may be too much for relatives to read and digest if they are tired and stressed (Stricker, Kimberger, Schmidlin, and Zwahlen *et al.* 2009). In addition, Weinman (1990), posits that if communication is poor and if the health professional has not taken into account the patient's beliefs, expectations and concerns, then providing written information might prove ineffective, stating that: "written information is a supplement but not a substitute for good communication between the health professional and the patient" (p.304).

In terms of critically ill patients on Accident and Emergency (A&E) departments who are potentially facing life threatening conditions, Dimond (2008) states that it is helpful if pre-printed information such as leaflets for staff, patients and relatives are available, particularly if they were to contain information regarding aspects of the Mental Capacity Act (MCA, 2005) and the procedures that may be followed in the event that a patient lacks capacity to make their own decisions. Dimond (2008) also recommends that leaflets such as these should be explained verbally to the relatives and friends of the patient, so that they can better understand the law and its practice as applied to the situation. Another potential benefit of using written material in addition to verbal communication of the material is that the relatives can also take the written material away and read it at their leisure, and will also have the information to hand to refer to if necessary.

Lautrette, Darmon, Megarbane *et al.* (2007) conducted a prospective, randomized controlled trial in 22 ICUs in France. They wanted to add a secondary intervention to the current customary use in ICUs of an end-of-life family conference. This is where family members and staff members have the opportunity to discuss the critically ill patient who is dying and where questions can be raised and concerns addressed. Lautrette *et al.* (2007) evaluated the end of life family conference with and without a proactive communication strategy. This consisted of a brochure on bereavement to be provided following the conference, with the hypothesis that this extra intervention would decrease PTSD related symptoms and anxiety and depression in family members, 90 days after the patient's death. The only criterion for this trial was that the patients involved were dying and considered to only have a few days left to live by the doctor in charge. The only exclusions were patients under 18 years of age and patients' relatives who had insufficient knowledge of the French language for the purpose of a telephone interview. From the 132 eligible family members, 126 were enrolled and randomly assigned to the intervention or control group (n=63 per group). In their analysis they

assessed symptoms related to PTSD using the Impact of Event Scale (IES). For the secondary outcome measures of anxiety and depression the Hospital Anxiety and Depression Scale (HADS) was used. The results showed that the addition of the brochure did result in lower levels of anxiety and depression 3 months after the patient's death, with significantly lower HADS scores in the intervention group compared to the control group (P=0.004). 45% of relatives reported clinically significant symptoms of anxiety in the intervention group compared to 67% in the control group (P=0.02) and 29% clinically significant symptoms of depression compared to 56% in the control group (P=0.003). There were also improvements in communication between staff and relatives and consensus on end-of-life decision making. The patients' relatives in the intervention group were more likely to agree with the decisions made my intensive care clinicians and there were high percentages of patients' relatives who reported sufficient time had been spent by staff in providing information and that the information was clear. Fewer patients' relatives in the intervention group reported that they wanted additional information than the relatives in the control group. In addition, the end-of-life family conferences which included the brochure on bereavement resulted in longer meetings which meant that families had more opportunity to speak to staff, express emotions, feel more supported in difficult decision making, and were better able to accept goals of care for the patient. This indicates that patients' relatives need more time to speak with staff members about their family members and having more opportunity to do so helps support them whilst they are on the ICU.

Similarly, Azoulay, Pochard, Chevret *et al.* (2002) conducted a prospective randomised trial over 34 French intensive care units in order to compare comprehension of diagnosis, prognosis, treatment and satisfaction with information provided by an ICU staff member to patients' family representatives. They were either provided with a family information leaflet (FIL) specifically designed for the trial, in addition to standard information, or only received the standard information but not the FIL. "Standard information" included at least one meeting with a doctor every day during the first week of their loved one's admission to the ICU, with information on the diagnosis, prognosis and treatment. Their FIL was four pages which contained the following information:

Page 1 - General information about the unit and the hospital, names and contact details of primary staff on the unit, visiting hours and transportation to the hospital.

Page 2 – A blank space for writing the name of the ICU doctor looking after the patient when the FIL was given to the relatives, and further information about the ICU in terms of why visiting hours are restricted, isolation of patients, and the number of senior and junior doctors on the unit day and night.

Page 3 – Showed a diagram of a typical intensive care room, including the names of all the devices in the room. There was also an invitation to speak to the patient.

Page 4 – Held a glossary of the 12 most commonly used terms on the intensive care unit.

Each page invited relatives to ask ICU staff for additional information or an appointment with the doctor in charge of the patient or unit.

Family representatives were given the FIL upon their first visit to the unit, after which they were also assessed for comprehension, satisfaction, anxiety and depression between the third and fifth day on the unit. These assessments were conducted via interviews with an ICU investigator, a modified version of the CCFNI, and by completing a standardised questionnaire to determine characteristics of the family representatives, followed by completion of the HADS respectively. Comprehension in the two groups was compared, in addition to satisfaction. They found that the FIL improved comprehension and that good comprehension was associated with better satisfaction. Comprehension scores in the FIL group were significantly better than in the control group with 11.5% versus 41% of family representatives with poor satisfaction (P <0.0001). Satisfaction was not significantly associated with provision of the FIL but those family representatives with good comprehension who received the FIL had significantly better satisfaction scores then those who did not receive it. The study confirmed the expected high rates of anxiety and depression in relatives of ICU patients, with 60% (105) relatives suffering from anxiety and 39% (68) suffering from depression. Although there was no significant statistical difference between these parameters, the researchers did find that the FIL improved the 'exchange of information' between relatives and staff which they considered was necessary in fostering positive interactions regarding helping patients' relatives to cope with their distress and allowing them to speak for their loved one if the need arose (Azoulay *et al.* 2002).

In terms of other interventions, Medland and Ferrans (1998) conducted a two-group, pre-test-post-test, quasi-experimental design study to determine whether it would increase patients' relatives' satisfaction with care, more effectively meet their needs for information, and result in them making fewer telephone calls to the ICU. Their study comprised an experimental and a control group with 15 relatives per group. Their intervention consisted of three components: (1) a discussion with a nurse approximately 24 hours after the patient had been admitted (2) an informational pamphlet given at the time of the discussion, and (3) a daily telephone call from the nurse who was caring for the patient that day. In the experimental group they found that the number of telephone calls from patients' relatives was significantly lower than in the control group and satisfaction with care

increased significantly from pre-test to post-test, as did the patients' relatives' perception of how well their information needs were being met.

1.2 Summarising the findings of the literature review

The literature review suggested communication and provision of information is of great importance to patients' relatives in how they experience the ICU and the care of their loved one. That information provided by ICU staff offering knowledge, understanding, and assurance to inform and prepare relatives for what might happen to their loved one could be imperative in helping relatives to cope through what can be a very traumatic experience. It also suggested that relatives of intensive care patients and staff members have benefitted from various interventions that have included some but not all of the following mediums: verbal communication of information (including daily face-to-face discussions on the unit and family conferences, where ample time is given to relatives to support relatives' needs); the repetition of important verbal information; written information that supports what has been verbally communicated; and appropriate training, in terms of delivering communication and information provision, and ethics debriefing for staff to be able to communicate effectively with relatives. Other aspects considered are the language and literacy level of any written information used in an intervention, as levels of literacy will vary amongst patients' relatives and lay terms would need to be used to prevent confusion over medical terminology.

1.3 Rationale

The idea for this research project was triggered by an interest in exploring the decision-making processes on ICU, particularly in relation to patients who lack the mental capacity to make their own decisions, patients' relatives' understanding and knowledge about this area, and how patients' relatives cope with the experience of having a loved one admitted to an ICU. Initially the researcher conducted an initial scoping of the literature about ICU and patients' relatives and engaged in some informal discussions with ICU doctors and consultants, in order to form a clearer picture of what happens on an ICU around these issues. It appeared that patients' relatives could experience high levels of stress and anxiety when their loved one is admitted to ICU and this could be exacerbated if there were concerns related to poor communication between staff members and patients' relatives, lack of comprehensive and timely information provided to patients' relatives, and lack of knowledge and understanding about decision-making regarding patient care and treatment. Research conducted into the domain of intensive care indicated that there was still a paucity of research that had effectively tackled the problems identified.

Regarding the decision making process, as indicated in the literature review, patients on an ICU often lack capacity to make their own decisions, generally because they are in an unconscious state. Where this is the case, ICU medical staff must act on the patient's behalf, and will make decisions about treatment in the patient's best interests (Chronic Disorders of Consciousness (CDoC), 2013) Currently the law does not define the term 'next of kin' (NOK) and there are no legal restrictions on who can or cannot be someone's next of kin. (CDoC, 2013). It is policy in the majority of NHS trusts to ask the patient to nominate a next of kin, but if they are unable to do this, the hospital will endeavour to work out who is the closest person to the patient. However, a next of kin has no legal liabilities, responsibilities or authority and cannot consent to care and treatment on the patient's behalf, but they are identified as the person who staff should consult for guidance and insight into the patient's care and wishes. According to the Mental Capacity Act (MCA, 2005), the Decision Maker should consult with anyone who may be able to offer valuable insight and information as to the patient's wishes, feelings and beliefs, and are engaged in caring for the person or interested in their welfare. This person could include family members, next of kin and anyone else who is identified as being involved in the person's care, treatment and welfare. During informal discussions with critical care staff they described that normal practice in these circumstances would be for the medical staff to utilise patients' relatives to gain insight into the patient's established thoughts, beliefs, behaviour and wishes. This would usually take the form of a dialogue in which the medical staff would attempt to ensure the relatives' understanding and gain their co-operation with the proposed treatment. Critical care staff reported that this could occasionally lead to conflict between patients' relatives and ICU staff, usually due to the patients' relatives being confronted by a traumatic combination of having a loved one who is critically ill; the realisation that their opinions carried less weight than they previously thought; and learning about the risks attached to proposed treatments, which sometimes included end of life decisions.

1.4 Objectives

In light of the findings of the literature review and the informal discussions with critical care staff members, several objectives were formulated that included:

- Investigating the need for an information booklet on the ICU
- Exploring relatives' needs on the ICU and how these could be met appropriately
- To find out whether staff and relatives felt information regarding the decision-making process for patients who lack capacity should be included in a booklet for ICU relatives. This wasn't information that ICU booklets normally contained, so trialling its inclusion would be novel and would add to the field of ICU research.

- Whether an information booklet that tackled all of these issues in combination with verbal support would help relatives to cope with the experience of having a loved one on ICU.

CHAPTER 2: METHODOLOGY

2.1 Research setting

The research was conducted at King's College Hospital (KCH) which is situated in South London and is a tertiary centre for cardio-thoracics, neurological, vascular, colorectal, liver and urological surgery. It is also a tertiary centre for cardiology, a primary PCI (percutaneous coronary intervention) centre and a Hyper Acute Stroke Unit. In addition, KCH is one of the four Major Trauma Centres for London and has one of the busiest A&E Departments in the country (King's College Hospital, 2012).

KCH has four CCUs: Surgical (SCCU), Medical (MCCU), a Liver CCU (which was not included in the research project), and since conducting the research a Neurological CCU has been established. A CCU will normally look after intensive care patients (ICU) and high dependency patients (HDU), including:

- Patients who have had elective surgery
- Emergency patients who have been transferred from the A&E Department (and who may need an operation straight-away)
- Trauma patients who have been involved in some sort of accident or have suffered a heart attack or stroke. These patients will need stabilisation and assessment, and possibly an operation, depending on the severity and nature of their condition.

Level 3 patients (intensive care patients) receive one to one care, with each patient having their own intensive care nurse by the bedside 24 hours a day. Level 2 patients (high dependency patients) receive two to one care (one nurse to two patients). An example of a high dependency patient would be someone who has had a serious operation and needs careful and frequent monitoring that may not be possible to provide on a normal ward. There are 34 beds over the Medical and Surgical CCUs at KCH. A patient's stay on intensive care may vary from hours to weeks to months depending on their condition. Due to some patients only staying for a short time and the sheer number of patients being admitted to the units on a daily basis, the CCUs at KCH maintain greater than 100% capacity. Approximately 1600-1800 patients are admitted to the CCUs at KCH on a yearly basis. These numbers equate to a large proportion of patients' relatives also visiting the unit often on a daily basis to visit loved ones who have been admitted.

2.2 Information for patients' relatives on the CCUs at King's College Hospital prior to project

Before the project began, the CCUs at KCH had been using a basic A4 black and white information sheet which was given to patients' relatives once their loved one had been admitted. However, it only provided basic details about the unit such as visiting times, ward rounds, the different types of staff and what their roles were. Occasionally they would offer the ICUsteps information booklet (ICUsteps, 2010), which is a generic information booklet for patients and relatives on intensive care, created by the national intensive care charity ICUsteps, and as such, was not specific to the CCUs at KCH. ICUsteps was founded in 2005 by ex-patients, their relatives and ICU staff to offer support to patients and their families recovering from critical illness. The charity promotes recognition of the physical and psychological consequences of experiencing critical illness and encourages a wealth of research into these areas. It is also the UK's only support group for people who have been affected by critical illness (ICUsteps, 2014). Significantly, neither the information sheet nor the ICUsteps booklet that the units used provided any information about the potential ethical or legal aspects of decision making that can potentially occur in the critical care pathway. This information was generally provided on an 'as and when' basis by staff when a situation arose that required important decision-making to be made due to the patient lacking capacity to make their own decisions. In addition, the information sheet being used on the CCUs at KCH lacked information regarding the experience of having a family member on the unit and what to expect, and had no specific information pertaining to the psycho-social issues that may be experienced by relatives whilst on the unit.

When the researcher presented the research proposal for this project to members of the critical care team at KCH, they had recently drafted a new information booklet as part of their service development but it had not yet been used. It contained general information about the CCUs and was similar to many ICU information booklets in terms of specific and generic content that patients' relatives might find useful.

2.3 Research Questions

Primary Research Question:

What is the potential of an informational booklet with verbal support, to help relatives and friends to cope with having a loved one on the ICU?

Secondary Research Questions:

- What are the information and communication needs of critically ill patients' relatives and friends on the ICU, particularly if the patient lacks capacity to make their own decisions?

- What would be appropriate content and method of delivery for an intervention such as an information booklet provided to patients' relatives and friends on the ICU?

- How important is psychological support for patients' relatives and friends on the ICU?

2.4 Ethics

This research project was approved by the Research and Ethics Committee of the Department of Psychology, City University London on the 31st of May 2013, and by the R+D Department at King's College Hospital NHS Foundation Trust on the 12th of July 2013. The researcher followed the NHS rules of confidentiality and adhered to the British Psychological Society (BPS) Code of Ethics and Conduct, Performance and Ethics, at all times. Informed consent was obtained from the participants via a participant consent form and accompanied by a Participant Information Sheet providing information about the research project. Participants were informed on the consent form that they were free to withdraw from the research at any time, and if they had any worries, queries or complaints regarding the research or the researcher, they could use the contact details provided on their information sheet to express these concerns.

2.5 Design

A qualitative methodology was used for Studies 1 and 2. Qualitative research can be defined by several aspects, including how it attempts to define and explore how other people make sense of the world and how they experience events within it (Willig, 2001); how it explores individuals' experiences, and extrapolates and interprets identified phenomena; and represents the meaning of a delimited issue or problem (Parker, 1994).

2.6 Research methods

The methods of semi-structured interviews and focus groups were used to conduct the research. Semi-structured interviews are widely used in qualitative research and provide an opportunity for the researcher to listen to participants' accounts and perspectives of personal experiences which are triggered by the researcher asking open-ended questions. The information obtained in the interview can then be used to answer specific research questions (Willig, 2001). The method of a focus group is like a group interview (Willig, 2001; Bender and Ewbank, 1994); the researcher acts as a

moderator and facilitates the group by using an unstructured or semi-structured guide (Byers and Wilcox, 1991), which includes open questions about particular topics, which the participants discuss. This interactive group discussion can provide data which can be used to investigate applied research issues (Bender and Ewbank, 1994) and inform an area of research.

2.7 Health Psychology Model

The research was underpinned by health psychology theory, namely Lazarus's Transactional Model of Stress and Theory of Appraisal (Lazarus, 1966) which proposes that when stress is experienced, this is thought to be a transaction with the individual's external world, where stress is caused by a discrepancy between the perceived demands of a situation and the resources an individual has in order to meet these demands. The model theorises two types of appraisal: primary appraisal is how one views a stimulus or threat and whether it is considered stressful or not, and secondary appraisal is about assessing the resources available for meeting the threat. If the resources are considered to be insufficient this may exacerbate the stressfulness of the situation thus affecting one's ability to cope with it (Lazarus and Launier, 1978; Lazarus and Folkman, 1987; Morrison and Bennett, 2009).

In applying this model to the current research, when first arriving on the ICU after their loved one has been admitted, the patient's relatives' experience of stress may be defined by their primary appraisal of the situation, where they might appraise the event of their loved-one being admitted to the ICU as a significantly stressful event. Their secondary appraisal might be evaluating how effective their strategies for coping with this stressor are. If they felt that their coping strategies were not strong enough, this could be due to lack of internal and external resources. For example, they may view their internal resources as inadequate in helping them to cope with the crisis, and this could be due to a number of reasons, such as the condition of their mental state, their personal beliefs and understanding of what is happening, and their knowledge about how their loved one is being treated. They may view external resources as ineffective due to poor communication, lack of information provision and support from staff members, poor social networks, in terms of having family, friends, or spouse who they feel they can seek support from, and financial difficulties (taking time off work to be with their incapacitated family member, looking after children, etc). The lack of these valuable resources may result in exacerbating their initial stress response, and this could increase or decrease depending on the processes experienced on the ICU. These processes may involve the progress of their family member, how the relatives are coping psychologically, the experience they have of the ICU particularly in terms of communication with staff, information provided by staff about their loved one, and the relationships they forge with staff members.

One the primary aims of Study 2 was to ensure that the intervention would be provided to patients' relatives by the nursing staff, within 24-72 hours of their loved one being admitted to the ICU, which would be when the patients' relatives would most likely be making their 'primary appraisal' i.e. finding out that their loved one has been admitted to ICU and the ramifications of what this might mean. In order to positively influence their 'secondary appraisal' of the situation. In providing the intervention at this sensitive time, it was hoped that the relatives might feel that they did have the resources they needed to cope with this significantly stressful event, thus their secondary appraisal would be improved by the addition of external resources which positively impacted upon their internal resources.

2.8 Procedure

2.8.1 Participants and recruitment

There were two cohorts of research participants:

- Lay Individuals (10)
- ICU Staff Members (23)

Lay Participants

The lay participants were individuals who had been a relative of an ICU patient in the past and were recruited by the researcher via the national charity ICUsteps. Recruitment methods included placing information about the research project along with the researcher's contact details on a webpage on the ICUsteps website and on their online forum *(See Appendix B11 for Recruitment Information on ICUsteps webpage)*. Once potential lay participants had expressed an interest in taking part in the research, they were sent an email asking a few specific questions to ascertain whether they fulfilled the inclusion criteria for taking part in the research. If they did fulfil the criteria, they were asked for their postal address and the researcher posted them a research pack containing the following documents:

- A cover letter of explanation about the research project, contents of the research pack, and how to complete the forms.
- One Participant Information Sheet (PIS)
- Two Participant Consent forms
- One stamped addressed envelope to return one of the two consent forms (once completed and signed).

(See Appendices B1 for Cover Letter, B2 for PIS – Relatives, see B3 for Participant Consent Form).

Research packs for staff contained the same documents as above apart from the PIS which was worded to be specific to staff members. *(Appendix B4 for PIS - Staff members).* Eight out of the ten lay participants were interviewed via telephone and two interviews were conducted by the researcher in a private room at City University. All interviews were digitally recorded.

ICU Staff Members

A total of twenty-three staff members were recruited from the Medical and Surgical CCUs from KCH. *Study 1:* Four consultants and six nurses participated in semi-structured interviews. *Study 2:* Nine senior nurses participated in a focus group to peer review the booklet. Participants interviewed in Study 1 had originally consented to being interviewed in Study 2, however, due to a delay in the pilot starting, four of the original participants were not working over the pilot period, resulting in four new participants being recruited in their stead who had worked during the pilot. Three consultants and seven nurses participated in the semi-structured interviews in Study 2. It was felt that interviewing consultants and nurses would provide different experiences and perspectives regarding relatives on the ICU. Although staff members were recruited primarily using a convenience method, there was a purposive element in that a larger number of nurses than consultants were recruited in both sets of interviews due to nurses' daily contact with patients' relatives and because they would be delivering the intervention during the pilot.

Recruitment process:

- *Focus Group* - Information about the research, in addition to e-copies of the Participant Information Sheet and Participant Consent Form were emailed to staff. *(The PIS was the same as those included in the information packs for the interviews except it was worded for the focus group. See Appendix B5 for PIS – Focus Group).* They were given a Consent Form to complete and sign on the day of the focus group.
- *Interviews* – An email providing information about the research was sent to staff with a verbal guide attached detailing how the nursing staff should deliver the booklet during the pilot and these were forwarded by a member of the CCU administration on behalf of the researcher, to all CCU nurses and consultants at KCH.
- The researcher also visited the CCUs and conversed with CCU staff members, informing them about the project and asking whether they might like to take part. Research packs

were provided to those who expressed interest in participating by hand, post, or they were placed into staff pigeon holes.

2.8.2 Inclusion and Exclusion Criteria

The inclusion and exclusion criteria for all research participants were as follows:

Table B1: Inclusion and Exclusion criteria

INCLUSION CRITERIA	EXCLUSION CRITERIA
Group 1: Lay participants	
• Their loved one had been an unplanned admission to the ICU	• Their loved had been an elective admission
• Their loved one had lacked capacity to make decisions for themselves during their stay on the ICU	• Their loved one had capacity to make their own decisions
• Their loved one had survived their stay on the ICU and was discharged.	• Their loved one had died on the ICU
• The participant is able to give informed consent	• The participant is unable to give informed consent
• The participant is able to read, write and comprehend the English Language.	• The participant is unable to read, write and comprehend the English Language
Group 2: ICU Staff Members	
• Who are qualified nurses and doctors of all grades, and consultants on the ICU at KCH	• Who do not work on the ICU at KCH
• Able to provide informed consent	• Who only visit the ICU at KCH
• Able to read, write and comprehend the English Language.	• Who are unable to give informed consent
	• Who are unable to read, write and comprehend the English Language

2.8.3 Data collection

Sixteen ICU staff participants were interviewed in one of three locations convenient to the participants at KCH. Four staff participants were interviewed over the telephone as this was more convenient for them.

All 33 research participants (Lay and Staff) gave informed consent to take part in the research. Each participant was provided with a participant information sheet to read and keep, and two copies of the participant consent form to read, sign and return one copy to the researcher and keep the other for their records. They were also provided with details on the PIS of who to contact if they had any problems or were unhappy with any part of the project. The majority of the participants asked for a summary of the results of the research project, which was an option on the Participant Consent Form.

This project incorporated two separate but overlapping studies: **Study 1** and **Study 2**.

Study 1 was a qualitative study involving two cohorts:

- Lay individuals who have experienced being a relative of a patient on an ICU
- Band 5 and 6 Nurses, and consultants working on the CCUs at KCH

Study 1 involved two stages:

Stage 1: Semi-structured interviews with ten lay participants *(See Appendix B6 for Relatives Interview Schedule)*

Stage 2: Semi-structured interviews with ten CCU staff members *(See Appendix B7 for Staff Members Interview Schedule (pre-pilot))*

All semi-structured interviews were conducted by the researcher. Study 1 involved an in-depth exploratory study, primarily of:

- How the lay participants experienced having their loved one as a patient on an ICU, what their needs were whilst there, what their understanding was of decision making for patients who lack capacity and their role in the processes involved, and how they had coped with the experience of ICU.
- CCU staff members' perceptions of the same aspects with regard to patients' relatives.

At the end of each interview in Study 1, all participants were also asked about their thoughts on what should be in an information booklet for relatives on the ICU, in order to inform Study 2.

Study 2 was a qualitative study involving one cohort:

- Band 5, 6 and 7 nurses, and consultants on the CCUs at KCH

Study 2 involved six stages:

Stage 1: This stage actually took place prior to Study 1. A first draft of the booklet was developed with some changes in formatting and front cover from the original version, as a result of the findings of the literature review. The following areas were added:

- **Meetings with the Critical Care Team** - Detailing what happens when patients' relatives meet with the critical care team about their loved one and how they should prepare for this.
- **Making decisions** – Detailing the decision making process for patients who lack capacity (including lay information on the law around this issue in the UK). How this issue is handled on the CCUs so that patients' relatives will know what to expect if important decisions need to be made about their loved ones care and treatment, and what their role as a relative would be.
- **Looking after yourself** - Detailing the psychological impact and trauma of having a loved one who is critically ill and how this can affect relatives, and the importance of patients' relatives looking after themselves with advice on how best they can do this.
- **Counselling services** - Detailing what to do if they feel the need for psychological support or counselling services and details for the BACP.
- **When you leave Critical Care** – Detailing when patients leave the CCU, such as being moved to another ward, being discharged from the hospital, and what to expect in terms of care and recovery

An existing sub-section titled: **'After a death'** was extended to include information about bereavement counselling and details of a how to acquire a bereavement counsellor.

Stage two: A focus group of nine senior CCU nurses peer reviewed the first draft. The researcher conducted the focus group as part of a training day for senior ICU nurses at the hospital and was given an hour length slot in the training day programme in which to facilitate the group. *(See Appendix B8 for Focus Group Guide)*

Stage 3: Thematic analysis was employed to analyse the data generated from the focus group. The findings informed the final draft of the booklet along with data obtained from the interviews in Study 1.

Stage 4: The booklet was piloted on the CCUs for a 2 week period and was provided to patients' relatives when they arrived on the CCU for the first time. The nurses delivering the booklet had been instructed by the researcher via a guide, to provide a verbal explanation of the booklet to the relatives by reading them the contents page at the beginning and being available to answer any questions the relatives might have. One hundred booklets were placed on each Medical and Surgical CCU. *(See Appendix B18 for Verbal Guide)*

Stage 5: Once the pilot had ended semi-structured interviews were conducted with six of the same staff members interviewed in Study 1 (who had consented to being interviewed in Study 2), and four newly recruited staff members. *(See Appendix B9 for New Staff Members (PIS) and Appendix B10 for Staff Members Interview Schedule (Post-Pilot))*

Stage 6: The researcher conducted a thematic analysis on the transcripts.

2.9 Data Analysis

The method of Thematic Analysis was used to analyse the data obtained in the research interviews and focus group for this project. This method was based on the model and step by step guide outlined by Braun and Clarke (2006). The researcher deviated slightly from the model in the latter stages of the analysis which are detailed in the table below. This was in relation to the interview data only, where lists of the main themes and sub-themes were created as opposed to the transcript data being organised under the relevant main themes and sub-themes in a separate table. Due to the extensive sets of interview data, this change in the process was felt to be a more effective method of filtering, presenting and locating the data for the final report.

Table B2: Phases of Thematic Analysis taken from Braun and Clarke (2006).

Phase	Description
1. Familiarising yourself with your data	***Transcribing data* – reading and re-reading the data and noting down ideas.** The interviews were transcribed verbatim by a transcription company. The researcher checked each transcript with the recordings to ensure any errors on the part of the transcription company were amended. This also resulted in the researcher

		becoming very familiar with each transcript prior to re-reading them and becoming familiar with the data, and writing down notes.
2.	Generating initial codes	***Coding interesting features** of the data in a systematic fashion across the entire data set and collating data relevant to each code.* The researcher systematically coded every transcript with each code related to extracts of the data so all data sets were coded. Data sets included the following: the focus group as one data set, the pre-pilot interviews represented two data sets (relatives and staff) and the post pilot interviews were one data set. The interview data sets comprised 10 interviews in each set.
3.	Searching for themes	***Collating codes into potential themes** and gathering all data relevant to each potential theme.* The extracts and applied codes of each data set were input to separate tables. All data from the focus group was input to one table and each set of interview data excluding the researcher's primary questions was input to a table each. Next the codes were sorted into potential themes. For the focus group this resulted in another table which presented the main themes and sub-themes identified, with all extracts of data that were coded in relation to them. For the interview data, initial themes were identified per page of the document presenting the tables of extracts and codes created in Step 3 and were listed on a new document, including the page numbers of where the themes were located.
4.	Reviewing themes	***Checking if the themes work** in relation to the coded extracts (Level 1) and the entire data set (Level 2), and generating a thematic map of the analysis.* For the focus group, the researcher checked whether themes worked in relation to the coded extracts and made thematic maps presenting these.
5.	Defining and naming themes	***Ongoing analysis** to refine the specifics of each theme and the overall story the analysis tells, and generating clear definitions and names for each theme.*

	For the interview data, the researcher refined the identified themes ensuring data extracts related to themes formed a coherent pattern and accurately represented the data. Further documents were created which presented the main themes, accompanying sub-themes and page numbers identified from the table of extracts and codes, so relevant information and quotes could be easily located for writing the report of the analysis.
6. Producing the report	***Final opportunity for analysis*. Selection of vivid, compelling extract examples and final analysis of selected extracts; relating back to the research question and literature, and producing a scholarly report of the analysis.** The findings from the analysis were reported in sections related to the main themes and sub-themes defined during the analysis, and included a selection of relevant extracts from the data to evidence the themes. The analysis also determined whether the research questions were answered and if the findings reflected what was found in the literature review.

The thematic analysis approach used both 'theoretical' and 'inductive' methods, with themes identified at a semantic level (i.e. surface level meaning) for information pertaining to the booklet in particular, and in order to ascertain whether the findings supported existing literature and answered the research questions. Where appropriate, the analysis was at a more latent level (i.e. deeper, underlying meaning), in terms of exploring patients' relatives experiences of the ICU (Braun and Clarke, 2006).

2.10 Reflexivity

The researcher attempted to maintain objectivity during the data analysis process by acknowledging that interpretation of the data can be influenced by ones view of the world and the phenomenon in question, because how one interprets subjective data is in itself subjective. To minimise the potential for bias and misinterpretation, a robust method of thematic analysis was used as outlined by Braun and Clarke (2006), which helped to ensure the data was analysed rigorously and in a systematic manner. In addition, samples of coding were reviewed by the academic supervisor.

CHAPTER 3: RESULTS

3.1 STUDY 1: INTERVIEWS WITH LAY PARTICIPANTS

Eight Participants were interviewed on the telephone at the researcher's home and two participants were interviewed in person at City University, London. There were eleven main themes identified from the data and a number of sub-themes within each main theme, except the final theme. Patient's names and names of hospitals are displayed as: [xxx].

Arrival on the ICU

There were a number of reasons why the loved ones of the participants were admitted to the ICU. These included a sudden worsening of a current illness, complications with routine operations, and accident.

Routine to urgent problem: Confusion and uncertainty

Two of the participants' loved ones had come into the hospital for routine operations but there had been unforeseen complications either during or after the operations which resulted in the patient's condition becoming critical, necessitating their admission to an ICU: *"it was all a bit confusing really because, em, it developed very quickly. We thought she'd gone in for gallstones which they'd told us originally, and then within 24 hours, you know, she was having a serious operation."* (LP1) It was difficult for the participants to understand what had happened to their loved one and they were understandably confused as to why they were being called to see their loved on an ICU as opposed to a normal surgical wa*r*d: *"the operation she was meant to have that afternoon was meant ... she was meant to have it, be in recovery and then probably just be on the, um, the card ... the vascular ward for like a couple of days and then home. "* (LP2)

Also knowing that something may have gone badly wrong in their loved one's operation was source of much worry and distress that was further compounded when arriving on the ICU, which a majority of the participants had never experienced before:

> *"she went in for a routine operation, um, and then it ... there was a complication after the operation which is why she was there, so when we got there we didn't know we were going into ICU, we were just told to meet ... um, to come up to the ... like a certain floor, so I had no idea what to expect."* (LP2)

LP8 came into A+E with her son with what they had thought was appendicitis, however, he rapidly went from walking and talking and about to be sent to a ward, to staff not being able to find his blood pressure: *"And at that point he was erm then sent into resus and I was asked to leave the*

room, and then, then all they said to me was, "He's gotta go for some scans, he's gotta be intubated" (LP8)

Even when he had been admitted to the ICU and she saw him the next morning, unconscious and attached to tubes and equipment she still did not realise the seriousness of his condition. However her lack of understanding at the time did result in her being very confident that he would be treated successfully and would make a full recovery:

> *"I, thought this was part of the treatment, you know I had no idea that, that it was probably part of the illness, so yeah, but I was, you know, very confident that they would erm you know everything would be absolutely fine." (LP8)*

This suggests a positive side to lacking knowledge in how critically ill a patient might be, in that she was confident her son would recover and as a result her experience of ICU was a positive one. However, most of the participants wanted to know how serious their loved one's condition was and generally the ICU staff ensured that they were aware of this at an early stage. This may have been useful in preparing them in the event that their loved one's condition became worse and helping them to understand the seriousness of critical illness.

Immediate needs

For participants LP9 and LP10, their immediate needs once they had arrived at the hospital were much the same: they just wanted to get to the unit and find their loved one as quickly as possible. LP9 needed to find out if his wife was still alive, having not seen her since her accident, whilst LP10 just wanted to know where her family were and how her mum was. It seemed imperative that ICU staff members were there to ensure these needs were met so that the participants could get to their loved ones as quickly as possible and by doing so, had a positive effect on their introductory experience of the ICU:

> *"they were really helpful, they, straightaway there was somebody there and they showed me where my family was and it was quite clear where you needed to be ... so yeah it was, it was good ... the doctor came in within probably about half an hour...And spoke to us and was really clear and really helpful and, and really reassuring so that was good." (LP10)*

Admission: Settling in

During the admission process participants mentioned how they had to wait to see their loved one whilst the nurses were settling the patient onto the unit, this would often take much longer than the relatives expected and this added to their existing anxiety. It seemed that some nursing staff did not always inform the relatives exactly how long this process could take: *"they said, you know, this ... this could take some time, but it would have been better if they'd have said, "This might take us up to*

an hour," ... know what I mean? Because like some time ... when somebody's really ill you're kind of pacing a little bit" (LP6)

Initial interactions with staff

Generally initial interactions between relatives and staff members were very positive, supportive and informative for relatives, who felt they were treated well and kept informed about what was happening:

"the staff were very, um ... they were very forthcoming, they were very friendly ... um, even the consultants, you know, told us everything ... anything we wanted to know ... and volunteered information about what was going on as well ... we didn't feel as if we were always chasing our tails."(LP3)

On occasion some relatives met ICU staff prior to arriving on the ICU: *"some of the ICU staff had come down to support the resus team because [xxx] was so poorly ... so we met ICU straight away" (LP6).* LP3 found that as soon she entered the unit to see her daughter, staff members were very good at explaining where everything was located that she and the family might need. Once on the ICU staff members also explained the role of the bedside machinery and about her daughter's condition:

"she had bits coming out of her and bits going into her and all sorts ... um, but they ... they basically just explained top to toe what all the machinery was and also what her injuries were ... and what the implications of those injuries were as well."

Appearance of loved one

Some of the participants mentioned how shocking the appearance of their loved one was, such as swollen faces, lying unconscious, and being attached to all the bedside machinery and equipment. The change in the appearance of four of the participants' loved ones considerably contrasted with how their loved one normally looked:

"everything was swollen and she ... cos she was really well before she went in, so she looked terrible when we saw her ... I thought, "Oh it's horrific to see mum looking like that," but the ICU staff have told us ... like it just takes a while for the swelling to go down" (LP2)

Similarly, for participants LP9 and LP10, their loved one had sustained a brain injury which caused their face to be swollen and almost unrecognisable: *"... there was a tremendous, tremendous amount of swelling ... Got this big fat head ... Looked quite strange."(LP9)*

Reassurance

Generally participants felt reassured by ICU staff members and this seemed very important in helping to ease their anxiety and concern for their loved one and feel confident that everything was being done to help them:

> *"so we met ICU straight away and they started ... even in the lift they were explaining to us what severe shock syndrome meant and ... they would have a dialysis machine on standby and they explained why that was, but they were hopeful that the procedure that had been done in resus would stop [xxx] from having to go on dialysis, so that was really ... really reassuring. "(LP6)*

For the most part, the participants were reassured that their loved one was being cared for appropriately and this seemed to enable them to be more focused in supporting their loved one on the ICU: *"the doctor came in within probably about half an hour ... And spoke to us and was really clear and really helpful and, and really reassuring so that was good."(LP10).* In contrast, a lack of reassurance in this regard resulted in some relatives' anxiety being exacerbated by unnecessary uncertainty, which impinged on how they coped with the experience of ICU. This was demonstrated by LP5 who at one point during her husband's stay on an ICU experienced a significant breakdown in communication with specific ICU staff members and explained how she *"felt very fearful for him".*

Daily life on the ICU

Visiting hours

A majority of the participants mentioned visiting times on the ICU which seemed to vary slightly between different hospitals. A consistent message was that visiting times were fairly rigid and for the most part relatives had to adhere to them: *"I was never allowed in before half past two ... That was probably the hardest part was actually being away because I didn't know what was happening"(LP7)* However, in some cases, it appeared that ICUs could be more lenient about visiting times depending on the how unstable a patient was: *"visiting was only meant to be two till eight I think and they let us come in at ten o'clock in the morning ..." (LP2)*. If necessary, it seemed that some relatives were allowed to stay until late in the evening or even over night if there were worries about a patient's survival, but generally they were encouraged to go home to get some sleep and look after themselves. However, some flexibility in visiting hours made all the difference to relatives who did not wish to leave their loved one:

> *"they were firm on visiting times, but I did really understand that because they've got, you know, a lot of work to do ... um, but they were really good with me if I wanted to stay a bit later of an evening. They were really flexible with that." (LP6)*

Accessing the ICU and waiting to see loved ones

Several participants reported issues with accessing the ICU to see their loved one. Sometimes this was related to there being a door entry system in place. LP1 found this quite annoying: "*cos they would say ring the bell once and don't do anything else and then you would sit there and you'd find out you're sitting there unnecessarily cos they've forgotten you've rung the bell.*" Another issue was when relatives were asked to wait outside the unit or in a visitors' room while ICU staff members were performing their duties. This often caused relatives anxiety, especially if there was something happening with their loved one or they suspected their loved was involved in some way.

For LP1, his worst experience on the ICU was related to this issue: *"they said, "There's going to be a bit of a delay because she's had a heart tremor or something like that which we was a bit anxious about ... And then, em, sort of, we was kept in the waiting room for about an hour and getting more and more worried"*. It transpired that the nurse who had asked them to wait had actually forgotten about them. The length of the delay had convinced them that something serious had happened to their loved one. LP7 reported similar experiences. She would often arrive at the start of visiting hours and be asked to wait in the visitors' room. Sometimes she would be waiting there for up to an hour, but she would only find out the reason for the delay once the staff member came to collect her. She felt she needed some explanation earlier on as to the cause of why the delay was occurring: *"but if somebody could actually come out and tell you that that's what's happening that they're doing something to him then that would've made that wait a bit easier."*

The ICU environment

From the participant's descriptions of ICU, there was a stark difference between ICU and general hospital wards: *"I just think that ICU is a umm different thing, you know sort of a different world"* (LP7). ICU patients were usually situated in one main room (unless placed in a side room, such as the husbands of LP5 and LP6) and each patient had their own assigned nurse looking after them. The patients received 24 hours a day nursing care and were usually attached to many different pieces of equipment monitoring their vital signs and providing medication and nutrition. This meant that the patients looked very different to normal and the equipment they were connected to made various noises and alarms. This created a somewhat alien world that often proved alarming for the relatives, especially at first and this was something else they had to contend with alongside coping with the impact to their daily lives of having a loved one on ICU: *"Yeah, well it's very stressful and very tiring ... And you're spending a lot of time, a lot of hassle getting to the hospital and this business"* (LP1)

In addition to seeing their loved one in a critically ill state, the relatives' distress was often compounded by the realisation that patients do die on the ICU and this was brought home with upsetting clarity to LP1: *"there's other relatives there and then you find out that one of their, their, em, patient in the unit died and that sort of thing, all this, em, all these things are happening and it's quite depressing, really."*

The bedside nurses

From the participant's accounts of their experiences of ICU, the bedside nurses played a very important role, not just in looking after the patients 24 hours a day but looking after the relatives too:

> *"we had a nurse assigned to [xxx] that they called [xxx] and I won't ever forget her, she was absolutely brilliant. She nursed all of us. She looked after [xxx] and she looked after our 3 daughters as well as me and she was wonderful, and…..she explained everything that was happening. And err I wish we could have had her every day … " (LP4)*

Relatives would often forge quite strong relationships with the bedside nurses, particularly if the patient remained on the ICU long-term. In addition to the bedside nurses looking after the patients they also supported and informed the relatives on a daily basis about the progress of their loved one and about any changes in their condition. Part of the bedside nurse's role appeared to be explaining the bedside equipment to relatives and what its function was, and this gave the relatives a better understanding of how it was helping their loved one. Sometimes this explanation took the form of a running commentary:

> *"So what we're doing to your mum now … this is the machine that does this," … the nurses were amazing cos … they literally went through every tube that was going into my mum – what that was doing. What the ventilator did. What … all the … on the, um, monitors what everything beeping meant." (LP2)*

Giving explanations about the bedside equipment seemed to help relieve relatives' anxiety and provide them with reassurance. Moreover, as the bedside nurses had the most contact with the participants than any other ICU staff members, they provided a valuable lifeline to their loved one and an excellent source of support and information.

Ups and downs of a loved one's condition

Participants recounted how unexpectedly their loved one's condition could change on the ICU. Often a loved one would appear to be improving and relatives were hopeful for their recovery, then suddenly their condition would take a downturn and in some cases they would return to being as poorly as they were when they were admitted. LP2 experienced this when she and her sisters were

told her mother had been taken off the ventilator and was sat up in bed. They decided to give her a bit of time to rest before seeing her and told all their family and friends that she was going to be alright. Three hours later when they returned, her mother had experienced problems and had been sedated and put back on the ventilator. This was *"the worst day"* for LP2 who feared her mother would never get better as she had gone *"back to square one and there was then five more days of that"*.

These ups and downs could cause much distress to relatives who seemed to spend much of their time on an emotional rollercoaster; having their hopes raised and then dashed again often more than once.

> *".... he'd really gone downhill again and they'd spent ages with him and wouldn't let us go in the room … I said to them, "You keep saying 'the long haul' and 'we're not round the corner yet', do you mean I can still lose him?" And they said, "Yes, definitely.""* (LP6)

It appears that the shock and uncertainty these ups and downs caused the participants to suffer may have impacted on how they coped with ICU, as sudden unexpected detrimental changes to their loved ones health would invariably provide yet more emotional challenges for them to deal with. Even if the patient was moved to the HDU or a normal ward this did not necessarily mean that they would not experience problems: "*…he had a blip after he'd been in HDU about a week and he went really downhill over a weekend and myself and [xxx] daughter found that really, really difficult"* (LP6)

Staffing issues and turnover

Participants reported varying levels of staffing on the ICU's where their loved ones were patients; a particular observation was that there were very large numbers of staff that changed frequently so participants often saw different faces each day. This surprised the participants who seemed to expect more continuity of staff members:

> *"what I can remember ... is the different number of staff that were involved from day-to-day … You didn't get the same staff there for, you know, more than two days at a time ... new faces turning up virtually every other day sort of thing ... Yes, I think it was to do with their shift patterns ... there was more staff involved than I expected."* (LP1)

LP8 reported how she felt *"extremely lucky"* that it had been a Monday morning when her son was admitted to the ICU, as she feared he would not have had all the appropriate tests and care if it had been over a weekend. This was because she believed staffing numbers would have been low on the ICU, and there were a few weekends on the unit where she said they *"did notice a drop off"* in staff members.

Need for preparation: what to expect

The theme of preparation was identified in several aspects in this study, in terms of preparing relatives for ICU and for seeing their loved ones, and also for later stages on the ICU pathway that involved decision making for loved ones. LP10 felt she would have liked some preparation for what she was going to see on the ICU and this was not just related to seeing her mother as a patient:

"there was a guy that was in with my mum and he'd, I don't know what happened to him but his face was very severely cut ... And, that was really quite gruesome and so on top of being worried about my mum ... you're kind of confronted with these quite horrible images, so I think yeah, maybe a bit of preparation would be nice".

Preparing relatives for ICU seemed particularly important for their initial visit to the unit, especially in terms of how their loved one will appear and what to expect on the ICU. From the participant's accounts it seemed that relatives who were unprepared felt even more overwhelmed and traumatised by what they saw when they arrived and this was not conducive to how those relatives coped with the experience of ICU, as in the case of LP2:

"so you had to walk past like ... that other side of the room, so there's probably ten beds in there and it was basically a lot of people basically dying in front of me ... I've seen grandparents in hospices and all of that ... I've never even been to A&E, you know, like when people are ill. Um, so my first experience was a horrific one and completely overwhelming and I absolutely had a full panic attack" (LP2)

She reported later in the interview that if she ever had to return to an ICU she would still not be fully prepared for it despite her past experience of them, and could not understand how the staff could work there every day.

LP7 wished that ICU staff would have better prepared her for her husband's state while he was on the ICU, because on more than one occasion she had rung the unit in the morning to check how he was and was told he was comfortable and had had a good night. Yet when she arrived a little later his condition had worsened considerably to the point where it looked like he might die, and this caused much unexpected upset and anxiety to her and her family, which she felt could have been avoided:

"they didn't believe he was gonna actually make it and I actually felt that if they'd have, even if they didn't know at the time when I rung up in the morning if they'd have rung me before visiting ... I think I would've been more prepared if I'd have been given a bit more information on that occasion."(LP7)

Family dynamics: systemic issues

Many of the participants' accounts suggested that having a loved one on ICU was a very systemic experience, in that the whole family were affected and friends of the loved one too. Some of the participants recounted how various family members coped with the experience and how this affected the family either adversely in the case of LP2, or positively for a majority of the other participants, in terms of providing much needed strength and support. LP2 had a very upsetting experience which she blamed her sisters for. A few days after her mother had been admitted to the ICU, she received a phone call from her sisters who told her to come in as their mother was half awake, so she had rushed in to see her. Unfortunately they had not thought to prepare her for what she would look like:

> *"so I've got there and I've never seen her like that and it was a really horrible image of my mum and that ... that was the worst, like I just couldn't deal with it, I had to sit outside and I was really sick and I just couldn't bear it"(LP2)*

In addition, one of her sisters did not cope well with the experience of their mother being on the ICU and was still experiencing problems at the time of this study. LP2 felt this sister had ruined things that day because her sister had assumed that as their mother had woken up this meant she would be fine when in actual fact she was still very seriously ill. Her sister's reactions had given LP2 false hopes and the experience was something she still seemed to feel quite angry about:

> *"and then it took for ... the, um, the ward sister to take ... to explain what was going on because my sister just takes any type of ... she's not a positive person, but she takes one positive thing and just dwells on that and spins it if you like, so that ... that's their fault, not the ICU." (LP2)*

Practicalities of having a loved one on ICU

Participants described how having a loved one on ICU impacted on their daily living where as relatives they needed to juggle many aspects of their lives at what was a very traumatic time. While their loved one was lying unconscious on ICU they were trying to spend as much of their time as possible with them, in addition to being in constant contact with friends and family, trying to hold down a job, and looking after their homes. In addition to looking after his house and his business LP9 explained:

> *"you're going backwards and forwards to the, the hospital, you're visiting as much as you can. You're communicating with all the, all the friends and relatives as much as you can about it ... Erm, you know, trying to do a bit of work and ... also, you know, you've got to run a house and ... You know, try and get some rest."(LP9)*

This illustrates some of the difficulties faced by relatives. Everything suddenly needs to revolve around the critically ill person and life becomes an all consuming routine to retain the basic

maintenance of life in order to spend as much time as possible with them. Similarly, LP10 experienced this strange combination of routine and immediacy:

> *"we didn't really do anything for that week we just sat in the room, went to see mum as much as we could … Yeah, it was literally just survival techniques, so you got up in the morning, had breakfast, went in, erm like read the paper … Have lunch there …"(LP10)*

LP10 described the daily routine in terms of surviving the experience of that first significant week after her mother was admitted, where nothing else really mattered; being with her mother was paramount. Yet both LP9 and LP10's accounts show how part of their practical routines involved them looking after themselves too, such as eating regular meals and ensuring they were well rested, which may have also helped them to survive the experience and support their loved one.

General information on ICU

Relatives' information needs

All of the participants had information needs when they first arrived on the ICU and during their loved one's stay on the unit. Unlike the majority of participants, LP1 and LP10 were not always directly informed about their loved ones by ICU staff members as they were not a nominated spokesperson or next of kin. For LP1 his daughter was the primary spokesperson who communicated with ICU staff members. He reported that *"most of the important stuff was dealt with with my daughter … who at the time was quite mature and the most direct relative. So all the important details were given to her."* But occasionally he and his daughter were given information jointly. LP10 had minimal contact with ICU staff members as most information about her mother was directed to her father or on occasion to the family as a whole.

Often the information needs of relatives when they arrived on the ICU were just basic and immediate:

> *"all we wanted to know at that point was how long ... why is she ... why has this happened and why ... how long is she going to be in this state for"(LP2)*

LP2 found that even when the bedside nurse had answered all her questions about the bedside equipment she would continue to ask them over and over, as she felt it helped her to cope with the situation. Her account suggests that this was a way of empowering herself; where she may have asked questions as a way of establishing some level of control to a situation where she felt powerless to help.

Written and verbal information

When LP4 arrived on the ICU she was given information about her husband's condition which was very serious as most of his bodily systems were not functioning properly. She reported that all the information she received form ICU staff was verbal and it would have helped to have been given some written information, which would have helped her daughters, as one was particularly *"averse to hospitals"* and didn't like them at all. This view was echoed by a further participant, as she was barely able to retain any of the information ICU staff imparted to her verbally on the unit:

> *"It's like you've been hit round the head by a couple of bricks and you're … you're on very high adrenalin, you're watching everything, everything …. you don't necessarily remember when you get home and somebody says, "Well Mum what time did…?" "Oh God, I can't remember." (LP5)*

Providing ICU staff with information about the patient

Several of the participants' accounts suggested that the relatives played an important role in providing key information to aid ICU staff in caring appropriately for their loved one:

> *"one or two things that I picked up on and told them though, because he developed gout and I could tell there was something wrong and I managed to illicit from him that he was in great pain with his foot."(LP4)*

LP6 was also able to help staff with treating her partner, when he had appeared to be in quite a lot of pain. Staff asked her if she knew why this was and she was able to tell them that he had *"always suffered with really bad back ache, so I was able to tell them that, so then they prescribed something slightly stronger to help him with back pain".* The experiences of LP4 and LP6 demonstrate how relatives' knowledge of the patient can be a valuable resource to ICU staff. Information they provide to staff about their loved one may be useful if important treatment decisions need to be made and the patient lacks the capacity to be able to provide this information themselves.

Communication on the ICU

Communication between relatives and staff

Good and effective communication with ICU staff members was very important to most of the participants. Relatives needed to feel they could speak freely to staff members, are able to ask them questions, and to feel involved. Rather than simply be told information relatives wanted to feel there was more of a discussion in which they played a part. LP3 found that good communication on ICU was a vital component to the whole experience, and to feel that the staff had the time to reciprocate.

"I think one of the most important things that I've found is just being able to ... to be able to talk to the staff about, um, you know, what's happening ... with your relative, um, yeah, I think that's one of the most ... most important things." (LP3)

Staff communication with patients

Although most of the participants' accounts related instances of their communications with ICU staff members, there were some instances where the ICU staff communicated with the patients too, such as in the case of LP5's husband who spent quite a bit of time conscious and having lucid conversations with his family and his bedside nurse who he was at one point: *"discussing the merits of using butterfly raw plugs on plasterboard walls"* with. Sometimes the bedside nurses would also speak to the patients, even if they were unconscious. LP8 reported how touched she was with how the bedside nurse communicated with her son while he was a patient on the ICU:

"what I did like was that the nurses continually introduced themselves to [xxx] if it was a shift although he couldn't, obviously he couldn't see or hear or, or do anything, and they were talking to him the whole time ... That, for me I found that very very helpful and comforting."(LP8)

Staff language: phrasing

LP6 reported how she found the language ICU staff used, quite difficult to understand; they would use very vague and often metaphorical phrases which sounded like her partner would be there for some time but did not necessarily reflect how serious his condition actually was.

"they said things like 'you're not out of the woods yet', 'you're in for the long haul' and 'you haven't turned the corner yet'. What does that actually mean when somebody's critically ill and I'd have rather they'd have said ... [xxx] could die" (LP6)

LP6 eventually confronted the staff about their phrasing and asked them directly what the situation was with her partner, only to found out that he could actually die. She spoke to the hospital about this language issue and they agreed to look into this. However, this demonstrates the importance of good communication on ICU wards. It suggests that ICU staff members may need to glean early on, how much information relatives wish to receive and how they wish to receive it, so that communications can be tailored appropriately.

Communication breakdown on the ICU

Although all of the participants in this study reported having experienced good communication with ICU staff, it appears that sometimes communications between staff and relatives do not always run smoothly, resulting in serious breakdowns in communication. Such breakdowns were experienced in the case of LP4 and to an even greater extent to LP5. The experience of LP4 was due to ICU staff not letting her know that her husband had been moved to HDU: *"I went to where [xxx] bed was and it*

was empty and I thought he'd died ... And that was just horrible and I was really upset by that ..." (LP4)

LP5 recounted a particularly traumatic experience which involved poor communication related to serious ethical and legal issues. After being told her husband's condition was improving and he would be moving to a ward in a few days, a doctor she had not seen before came and informed her husband that they were not going to ventilate him again and if his heart stopped they would not resuscitate him. Yet her husband had not asked for a DNR order and was awake and perfectly lucid at the time and able to make his own decisions. The consultant sat down with LP5 and her daughter and explained the basis for the decision and also explained this to the husband. Both LP5 and her husband disagreed with the consultant: *"my husband said to him, umm, "Whilst you may be ethically correct you are actually breaking the law of the land.""* (LP5)

After they had left the unit that night LP5 and her family spent the night fearful that her husband's condition might suddenly worsen and he might arrest, and that ICU staff would not resuscitate him: *"came home. This was about midnight. And of course, umm, we'd sat and said, "Well you feel completely powerless, completely powerless." (LP5)*

The following morning there was a different consultant on duty who took over her husband's care and disagreed with his colleague's decision not to ventilate her husband. Later on it was discovered that the original decision not to resuscitate had been based on a misdiagnosis. When the family asked to see her husband's notes, the key pages documenting the incident were missing. They were found but incorrect information had been written in them about what the relatives had been told. Prior to this incident LP5 had had a very positive experience of the unit but this had changed overnight to feeling fearful for her husband's safety. Even after the DNR had been rescinded, she felt so concerned that when she:

> *"went onto the unit if I saw a doctor that I hadn't seen before, usually ... I would go over and say, "Hello, I'm [xxx] [xxx] I'm [xxx] wife. You do understand the DNR's been rescinded, don't you? Would you come over and say hello to him so you can understand what a rational man he is?"*

Ethical issues on the ICU

Decision making: relatives' knowledge and understanding

Participants' knowledge and understanding about the decision-making process for patients on the ICU varied considerably. Some of the participants had little or no knowledge about the process, whereas a couple of the participants had a nursing background and one a background in social work,

so they were au fait with the law around this issue and the rights of patient's relatives. LP3 was a student nurse at the time so was very aware of the laws around decision making:

"Yeah, I know that we can't make decisions, um ... and it used to make me cross when people say, you know, "Oh we had to make the decision to turn their life support off." Or, "We made the decision to do this, that and the other." It's not like, "No, you didn't."

Less informed participants varied in how they viewed the decision making process: when it came to making decisions for her son's treatment LP8 stated that she *"didn't expect to have any rights ... I just thought that they would do the very best for, for him and since I had no medical background or knowledge at all I wasn't, you know I didn't expect to be asked to give any consent".* LP10 stated that she felt reassured that the staff knew what they were doing, but would have been surprised if she had known about her rights in terms of making decisions for a loved one who lacked capacity. If important treatment decisions had been necessary for her mother, she thought it would have been made by *"next of kin, so I would have assumed it would have been my dad."* LP8 was also surprised over the lack of power she had in making decisions for her son: *"I would definitely have thought that having said I, you know I know nothing about it at all, I would definitely have thought that ... I would have had more, you know, input." (LP8)*

Involvement in patient care

There appeared to be some involvement of relatives in their loved one's care and treatment. The partner of LP6 needed to have a temporary pacemaker fitted at one point while he was on the ICU. However, it was at a time when she was away from the unit. ICU staff spoke to her partner who was awake but he was unable to take the information in, so they also spoke to his other family members about it too: *"they did explain to [xxx] two brothers and [xxx] daughter why they needed ... you know, why they needed to do that, so I'd say, yeah, we were ... you know, involved in decision making."*

LP10 described how she experienced a role reversal when her Mother was a patient on the ICU, because she and her family would often feed her. She found this strange and explained that at the time she was only about 24 years old and at that age: *"you're certainly not in the frame of mind where you think you're going to have to look after your parents yet".*

Serious procedures: informed not consulted

Many of the participants reported they were not consulted when ICU staff members wanted to perform serious procedures on their loved ones; they were just informed about what was going to

happen: *"I was told that that's what would happen ... Umm so I, I wasn't really, I was told what they were doing but I wasn't really asked whether to do it, no." (LP7)*

The participants who were informed in this way were not overly concerned, as they trusted that the doctors knew what they were doing. However, not being consulted about serious decisions affecting their loved one, added to relatives' feelings of powerlessness, as highlighted in participants' accounts. In retrospect LP7 felt she should have been involved in a discussion about what the doctors wanted to do with her husband: *"now my husband is alive and everything I'm thinking that actually maybe we should've discussed that rather than him just telling me that's what was gonna happen."(LP7)*

Timely information about decision making issues

LP3 reported that the day after her daughter had been admitted to the ICU, she needed to have a craniotomy (an operation where the head is opened to expose the brain). ICU staff members spoke to her and explained that they would make any decision they thought appropriate and they would not phone her up in the middle of the night to ask permission. LP3 felt that this explanation was provided at an appropriate time:

> *"I think they ... they needed to explain quite early on, um, you know, that they would do X, Y, Z, they wouldn't do, you know, A, B, C. Um, so, yeah, I think they ... they were ... they were quite good with their timings." (LP3)*

LP3 was happy with how her daughter was being treated by ICU staff and their medical decisions, possibly because she was a student nurse, and had a better understanding than most relatives about the way decision making works in a hospital. However, being made aware early on about how decisions will be made and where a relatives stands in the decision making process could better prepare relatives if their loved one's condition becomes unstable and important decisions need to be made.

Honouring patients' treatment wishes

Some of the participants mentioned incidents where they wanted their loved ones' treatment wishes honoured by staff. LP6 was aware that her partner would not want anything that could potentially cause him brain damage and she ensured ICU staff members were aware of this by telling them:

> *"You do whatever you need to do ... but that if anything involves him having any type of brain damage at all, you don't do anything or if the treatment is that risky that it could cause brain damage ... the procedure rather then I want you to speak to me first because [xxx] and I have*

*always had a verbal agreement between ourselves." **...** Um, so ... so, yes, and that was listened to and they reassured me."(LP6)*

Likewise, LP2 recounted how her Mother had specified prior to her operation, that she did not want a tracheostomy. At one point on the ICU it looked like she might need one and LP2 and her family kept saying to staff that: *"She really won't want it."*

Need for written information about decision making

Some of the participants remarked that they would have liked to have written information about the decision making process on ICU. LP10 was not aware of how decisions were made for patients who lacked capacity and had assumed that if serious decisions needed to be made about the treatment of her mother then the doctors would have spoken to her dad and he would have made the decision. She felt that having written information about this issue would be helpful for relatives as long as they were not bombarded by it as soon as they entered the unit, yet still received it at an early stage: *"I didn't really think about it at the time, but yeah, that would, it would have been good around, you know, once we've been there for a couple of days." (LP10)*

LP8 was not provided with information about how the decision making process worked on ICU but stated that if information had been available about this process she would have preferred it to be in written form as opposed to verbal, as she would have worried that her son was either dying or his prognosis was very bleak if the doctor had spoken to her about decision making for patients who lacked capacity. She stated that she would have preferred to have received details in an information leaflet which would have enabled her and her family to read the particulars for themselves and ask questions if required: *"if it had come from the doctor I would imagine that, that you know we're already on the downward slope and that's why they're talking to me about it, whereas if I'd read it in a ... leaflet that's given to everyone" (LP8)*

Medical television programmes

Several of the participants mentioned ICU with reference to television programmes. LP7 mentioned how her only knowledge of ICU prior to her husband being a patient on one was from watching programmes on the television, which she felt were *"nothing like that"*. LP3 stated how *"the view that you get from the telly is, you know ... it's skewed, isn't it?"*. LP2 described how every day on the ICU she thought her mum was going to die, and her thoughts about what might happen were directly influenced by what she had seen on television: *"It's going to come to a point where she's going to be in a coma like you see on the telly and, um, and, you know, she's gonna ... at some point we'll have to choose that horrible like decision of switching off a machine." (LP2).*

It would appear that some of the participants understood that the portrayals of critical decision making on television dramas are often incorrect, whilst others such as LP2 were unaware and her worries about what would happen were perpetuated by skewed portrayals on television. If she had better understood the decision making process for patients who lack capacity in the UK, it may have prevented her feeling burdened by the idea that she might have to turn her mother's life support system off.

Although none of the participants had had loved ones on the ICU at King's College hospital (KCH) because they were recruited from all over the country, KCH was still mentioned in relation to the television programme '24 Hours in A+E' which is filmed there. LP4 waxed lyrical about the programme and the KCH A+E staff remarking how she thought the programme was: *"excellent! I think some of the staff there are absolutely superb."*

Coping on the ICU

Day to day coping

The participants recounted how they coped with having a loved one on the ICU and this tended to vary between participants. LP2 felt she did not cope very well with her mum being on the ICU and found it a very traumatic experience: *"I did a lot of being very physically upset and sitting with the nurses and asking them the same questions over and over again". (LP2)* In contrast, LP5 felt she did cope with the experience of her husband being on the ICU and was so strong that even her children told her it was ridiculous she was coping so well. However, she reported that she could not cope with phone calls at the time. Her sons would attempt to fend these off for her so she did not have to talk to anyone. She had a friend who would relay information to other people about what was happening, but found it very difficult when she received phone messages that two friends left for her in which they wept about her husband:

> *"I haven't seen either of them again because I couldn't … I can't handle them now ... I know that sounds bizarre but it was my way of keeping myself together ... And I actually said to one of them, "I was trying to hold myself together, how much help do you think it was for me getting a weepy phone call?"" (LP5)*

Most difficult aspects to cope with on ICU

Participants found different aspects of the experience of having their loved one on the ICU the most difficult to cope with. On the first night after his wife had been admitted, LP9 left the unit to go home but was unable to sleep due to the distressing images of his wife's accident earlier that day: *"I saw the whole of the accident and err ... You know, with a head injury ... There tends to be quite a bit*

of blood. It, sort of, looks very dramatic."(LP9) In the case LP10 it was right after her mother had been admitted to the ICU that she found most difficult to cope with:

> *"The beginning and just seeing …. it's when you see somebody and they're completely covered in machines and you don't know what any of them are doing... Erm, and I, that first night when we didn't know necessarily if she'd survive that was, pretty horrific."(LP10)*

When she and her family would visit the ICU, and her mother was still unconscious, she found this very hard and also when they brought in items to place round her bed such as pictures and scarves with her mother's perfume on; sensory items that were meant to help her. This was a difficult experience, possibly because it further compounded the seriousness of her mother's condition.

Both LP4 and LP8 found the most difficult aspect to cope with was feeling helpless to do anything for their loved one. LP8 found not having a role was difficult: *"I felt that I had to be there, that I wanted to be there all day. Erm, and yet there was nothing really I could do that I wasn't sort of getting in the way of the machines." (LP8).* LP4 found ringing up her daughters who lived in another part of the country to tell them how poorly their father was, particularly difficult to cope with, and having to tell them that they needed to come and see him:

> *"I found that very hard, erm, particularly when they walked in to the ward and saw how he was. Erm, and I found it very hard leaving him when he was so poorly, I would like to have been there all the time, but that's just not possible." (LP4)*

Psychological needs on the ICU

Need for psychological support and counselling on the ICU

All of the ten participants were in favour of there being some kind of service on the ICU which offered counselling or psychological support for relatives to access. Furthermore, eight participants reported that they would have found such a service beneficial to them personally.

> *"I would've found it very valuable because I was going through hell but I was staying strong for my children and… and if I'd been able to talk to somebody, umm, you know, I'd probably… you know, some relief for me because I was wanting to stay strong for them … " (LP5)*

Neither LP1 nor LP9 felt they required it whilst their loved one was on the ICU but could see the benefit of having it there for other relatives. However, LP9 did feel it would have been useful to him at a later stage:

> *"I think it probably would have been useful to have delivered that, sort of, three or four weeks down the line, where, in [xxx] case, she was in rehab and you could, you know, when, when the ... prognosis was, you know, sort of, far more accurate" (LP9)*

Psychological impact and effects of ICU

Since her recovery, the mother of LP2 had returned several times to the ICU for meetings about her experience as a patient there:

> *"she's been back repeatedly to talk ... because she's had awful traumatising things happen in her head that she's going back to do all these clinical ... not clinical trials, but studies for them into the drugs that she was on and how they dealt with it and all of them, so that they can learn from it"* *(LP2)*

LP2 also suffered with psychological issues after the experience of her mother being a patient on the ICU:

> *"I was then starting to have trouble sleeping and I had a lot of image ... bad imagery and horrendous dreams and stuff. I took myself to the doctor and the doctor said, "I'm gonna refer you to be assessed .... so I went and then got assessed."(LP2)*

Unfortunately, it took four months to receive an appointment, by which time LP2 felt that she no longer required therapeutic support. This suggests the importance of having an easily accessible service based on the ICU for relatives in need of it.

In contrast, LP6 described how she received a form of counselling support from the nurses on the ICU who provided a level of support that she *"would class as very loose counselling."* And that they were very lucky in that there was also psychological input to their follow up appointments at the hospital. The standard process was that within a year after a patient has left the ICU they have three allotted follow up appointments and each one comprised the same staff members: *"one of the main doctors of ITU ... and with them is the main ... a main sister from ITU and it's always the same sister, so it's very consistent ... always the same doctor and with them is always a psychologist."(LP6)*

Support needs, services and networks

For many of the participants, their primary support systems were their families and ICU staff members, particularly the bedside nurses. LP5 explained that *"people desperately need, desperately need support"*

LP7 describes how her family were invaluable in helping her to cope whilst her husband was on the ICU:

> *"my son and daughter and my daughter-in-law were exceptional and without them I really wouldn't have got through it, family support is so important ... Umm because I, I was just in this bubble that I, I wouldn't have eaten, I wouldn't have done anything without them."(LP7)*

Her account highlights the need for support networks and services to be in place for ICU relatives, as not everyone may have family and friends to help them deal with the experience. In the case of LP6, she found attending an ICU support group very beneficial:

"it really did help to talk to other people, either relatives who'd gone through the experience or there were people who'd actually been in ITU themselves and, you know, obviously survived and were there to tell their story "(LP6)

After her husband had been discharged from the ICU, LP5 would have liked to attend a support group with him but when she asked to join one, the nearest ICU support group was too far for her husband to travel to. She also asked at her doctor's surgery whether they could offer some counselling but the choice was either to join a nine month waiting list or pay to see a counsellor privately at the surgery; this made her and her husband feel very unsupported:

"there should be an automatic thing that people have the opportunity of, if they're feeling very frail and very vulnerable, umm, that they can talk it through, they can talk it through with a counsellor ... and they don't have to pay for the privilege"(LP5)

ICU staff encouraged LP2 to be strong in order to be able to support her mother on the ICU and this did give her the strength to get through the experience:

"the sister on the ward kept saying to me was, um, "You have to be strong because when your mum wakes up she's gonna need you to be strong and help her" ... and, you know, that's what kept me going I suppose cos she kept saying that to me every day" (LP2)

Additional experiences and aspects of ICU

Fear of death and/or potential disability

LP2 believed her mother was going to die, which was something she already had an irrational fear about before she became critically ill. So when her mother almost died at one point she really believed that she was not going to survive. In addition, LP9 experienced the fear of his wife potentially dying or being disabled after she had suffered a life threatening head injury: *"It was obviously quite worrying ... As to, you know, one, whether [xxx] would actually survive. And to, what the extent of any long term damage might be." (LP9)*

Patient behaviour on the ICU

A couple of the participants reported how their loved ones behaved strangely or irrationally whilst they were patients on the ICU. LP2 recounted how her mother had woken up and would not take her medicine as she thought the ICU staff members were trying to kill her. The family were called at home and were asked to speak to her. They explained that no-one was trying to kill her and she

must take her medicine so they could come back in and see her; this helped calm her down and she finally acquiesced to the medications.

For LP5, the morning after they had experienced the upsetting episode of a DNR being incorrectly put in place, LP5 who was a retired nurse, went in to see her husband and he had become very agitated: *"at this stage he had five nurses with him trying to calm him down. He was, umm, plucking at the bedclothes which to me is a sign of imminent death, having nursed so many people in my lifetime, and … I couldn't reach him"*. She felt this behaviour was as a result of the stressful events which had taken place the day before when her husband had been informed by the consultant they were not going to resuscitate him if his heart stopped. Being a former nurse, her husband's reactions gave her even more cause for concern and she reported how neither she nor her daughter were able to communicate properly with him at this point which was unusual, further compounding the seriousness of his condition that had only the day before been improving.

Writing a diary

Both LP5 and LP6 reported how important it was to have written a dairy about what happened to their loved one whilst they were on the unit, to help their loved one understand what had happened to them when they were better. In the case of LP6, the ICU had advised her to keep a diary documenting each day and gave her a sheet with headings to start it off. It was felt that this would help fill in gaps in their loved one's memories of ICU, answer questions they might have, and help them cope with the experience and their recovery.

> *"from my experience of going to the support group here people were saying that the ones that have had a diary seem to then have kind of managed the whole sort of … managed the whole situation a little bit better emotionally and everything" (LP6)*

Positive Feedback on ICU staff

Praise for ICU staff

Many of the participants praised staff members on the ICU. LP8 thought that the staff could not have done anything more to help her cope with the experience of having her son on the ICU. She felt they had done everything they could to support her and *"were absolutely fantastic".* She also reported that they appeared to have plenty of time to answer all their questions and were *"very patient with his friends who asked endless questions the whole time."* LP10 also thought very highly of the ICU staff when her Mum was a patient on the ICU, remarking that: *"generally the staff were really great, and they were really reassuring and … they did a really good job".*

Trust in ICU staff

Most of the participants seemed to trust the ICU staff and their medical competence. For example, LP7 was informed by ICU staff that they had put a DNR on her husband, but she respected their expert knowledge and was confident that they were making the right decisions for him because *"I had the opinion that they knew best ... I don't think I would've, or could've really suggested anything better to what they were doing anyway."*

Respectful treatment by staff

Although seven years had passed since his wife had been a patient on ICU, LP9 still remembered how the staff had treated him and his family when they were on the unit. He remembered that they were very communicative and answered all his questions. He also felt that the way staff communicated verbally had been very good and respectful because *"They treated you as adults which was, which was quite refreshing ... You don't get that in other hospital departments I can tell you ... So, yes, so we were treated like, you know, sort of intelligent human beings, adults".*

Transfer, discharge, follow up and recovery

From ICU to HDU

Some of the participants described what happened when their loved one was moved from ICU to HDU and how this made them feel. Initially, LP2 was very unhappy when her Mother was moved to HDU as *"it felt like she'd been downgraded to this place where nobody cared because the difference between ICU and high dependency is amazing"*. Even though LP2 knew that a move from ICU to HDU was not as dramatic as a move to a normal ward and the care is still of a high level, she thought because of the absence of a nurse by her mother's bed watching her 24 hours a day, if something went wrong she was worried it might not be noticed by the nursing staff. These worries were short-lived as her mother was recovering well by this point, but it does reveal how even a relatively minor move from 1-1 care to 2-1 care can be a significant cause for concern to patients' relatives who, in the case of LP2, feared this would adversely affect her mother's recovery, when in fact it was a positive indication that her mother's condition was improving.

Stepping down to a ward

LP6 was not keen on her husband moving from the 1-1 and 2-1 nursing care he had received on ICU and HDU respectively, to the 6-1 care on a general hospital ward:

"when he left HDU that was awful. We just didn't want ... I know it sounds crazy, we'd have been happier for him to continue staying in ICU and HDU …. I think that was because, one we knew how ... how good the care had been". (LP6)

LP6 and her family had developed very good relationships with some of the ICU and HDU nurses who had been looking after her partner, in the same way that LP2 had with the nurses on ICU, so she was very upset to leave them and even begged them to let her husband stay so they could continue looking after him. This level of anxiety about the welfare of her partner conveys how strongly relatives can feel about the safety and well-being of their loved ones and the reassurance they feel when they are being provided with the highest level of care.

In addition, LP6's partner experienced an unpleasant and lengthy transfer to the ward which happened late at night after she had gone home and proved quite frightening for him:

"the ICU department is sort of a long way away from the ward where he was being transferred to, so it was like going in lifts, lots of different corridors and everything, so that was kind of quite scary and then the staff on the ward had no understanding at all of an ... well in my experience of an ITU patient's needs or their relatives' needs" (LP6)

Discharge, follow up services and recovery

Even when a loved one was discharged from the hospital this did not necessarily equate to the participants feeling less concerned about them. When the mother of LP2 was discharged home from the hospital she still felt very concerned for her mother's welfare: *"even when she came home, er, it was really ... that was really hard because I was constantly like "What if something happens in the night? What if something happens in the night? No-one's there to watch" (LP2)*

A number of the participants recounted their experiences related to follow up services and support once their loved had been transferred to a general ward or discharged from the hospital to recover at home. The husband of LP5 experienced no follow up care after he had been transferred to a general ward from the ICU:

"he'd lost two stone in weight and, umm, he was very, very weak and we didn't … There was no follow-up, … there's no follow-up from CCU you're put on a ward which is like the third world … umm, it's do-it-yourself nursing on there, if you don't look after the patient they don't get looked after."

The lack of follow up and support continued when her husband was finally discharged home:

"it took five phone calls to get an appointment for the chest clinic. It took me four phone calls to get a physio out and try to help him walk … he was on a zimmer frame. Umm, incredibly weak. He lost all of the skin from his hands and his feet in great sheets." (LP5)

She felt that a package of follow on care should have been provided for the patients and their relatives as standard procedure and broached the issue with the Critical Care Director and the Matron of the unit. Similarly, LP8 was unimpressed when her son was transferred to a normal hospital ward. She reported it was *"not a good experience"*, and was a stark contrast from receiving 1-1 care on the ICU. She was quite scathing towards the ward staff too as she felt *"some of them I don't think know that you've been in ICU for nine days"*.

The husbands of LP4 and LP6 both remembered the noises of the bedside machines when they were a patient on the ICU and LP4's husband also remembered dreams he had experienced on the unit too. After four months LP6 reported that her husband started to ask questions about the bedside machines on the ICU and they planned to bring these issues up at their next follow up appointment so he could discuss his memories with the ICU staff and obtain a clearer understanding of what happened to him there.

LP8 was very unhappy with how long they had to wait for her son to see the neurosurgeon after he had come out of ICU and was continuing to experience shooting pains down his legs. They were told there was a three to four month wait to see the neurosurgeon which she felt was unreasonable after he had been critically ill: *"Because you can't move forward, you don't know what, what you can and can't do, whether the pains you're experiencing are normal or not normal"*. (LP8)

In terms of recovering from critical illness, according to LP8, physical recovery is only part of the process:

> *"it's like post traumatic stress disorder you can have afterwards and get sort of flashbacks ... And you're not sure whether the things you experienced in the hospital were erm you know true or whether you were hallucinating and all sorts of things"*. (LP8)

Even though a considerable amount of time had passed since her husband was on the ICU, LP6 remarked how she and her husband were still recovering from the experience, and that her husband could still not *"get his head around it"*. LP5's husband reported: *"I just feel like I lost, you know ... seven weeks of my life kind of thing"*.

Benefit of patient returning to ICU post recovery

Several participants mentioned the benefits of patients returning to the ICU once they recovered as it helped to put things *"into context"*. The mother of LP2 had returned several times to have discussions with the nursing staff who had looked after her. LP5's husband had asked staff if he could visit the ICU and *"found that really helpful"*. LP5 felt that part of the follow up process for ICU

patients should be encouraging ex-patients to return to the unit, because *"even if you don't make it for a year, umm, it can be quite healing."*

Suggestions for new information booklet

The participants offered a large number of suggestions as to what they thought the booklet should include and when it should be provided to relatives on the ICU *(See Appendix B13 for Lay Participant Booklet Suggestions).*The most popular suggestions included providing information about how patients will appear, the bedside equipment and its functions, a glossary of ICU terms and explanations, what to expect on the ICU to prepare relatives, lay information regarding the decision making process for patients who lack capacity, contact details of the unit, information on hospital facilities, and to ensure the booklet information was reinforced verbally in case relatives are too distressed to comprehend the written material.

3.2 STUDY 1: INTERVIEWS WITH ICU STAFF MEMBERS AT KCH

Eight Participants were interviewed in person at KCH and two participants were interviewed on the telephone. There were eight main themes identified from the lay participant data and a number of sub-themes within each main theme, except the final theme.

Satisfaction and needs

Improving satisfaction

Participants reported that when speaking to the patients' relatives for the first time they would explain what was happening to their loved one and check that they had understood. Three out of the ten participants also checked that the relatives were satisfied with the information that had been provided and would also encourage the relatives to ask questions. *"Yeah, I usually do check at the end, "Any more questions? Are you…confident? You know are you satisfied?"(SP2a)*. SP5a reported that she did not check satisfaction directly but tended to gauge satisfaction levels from speaking with the relatives and did this by engaging them in *"general conversation around the bed" (SP5a).* Yet she would still ask relatives if they had any questions and if they were happy *"with the care or the experience in general?" (SP5a).* SP1a and SP3a mentioned that they also checked with the bedside nurses whether the relatives were happy or not and would use the bedside nurse as a resource to gather more information about the relatives.

The CCU at KCH uses an intervention they have developed called King's Psychosocial Assessment and Communication Evaluation (KPACE). It provides a means of documenting and improving communications with relatives. SP9a is a Band 6 ICU nurse and a team leader and part of her role is

to audit the KPACE forms and communicate with patients' relatives on a regular basis, talking to them and trying to keep them updated about what is happening with their loved ones. Apparently there are sections in the KPACE forms that are focused on the discussions between ICU staff and relatives; recording what was said and when, due to one of the main complaints from relatives being that there is not enough communication on the CCU. Using the forms they can keep track of how consultants have updated relatives *"so that we don't have one consultant being on one week and then a different one on a different week saying two different things, which can often happen in ITU."* (SP9a).

Relatives' information needs

Six participants provided details about the primary needs of patients' relatives when they first arrived on the unit. There was a consensus that relatives' information needs were *"context dependent"* with each relative having different needs. However, participants also stated that information provision to relatives needed to be simple to understand so as not to overwhelm them and certain information needs were mentioned by more than one of the participants. These included relatives wanting to know about what was happening with their loved one, visiting hours, contact details for the unit, general information about the unit and the hospital. Needs that were mentioned less were relatives wanting to know how long their loved one would be on the unit for, information about support services, wanting to know what would happen if their loved one died, where their loved one's property was, and who was in charge of the unit. SP1a felt that information for relatives needed to be *"verbal and written, yeah. I think the, erm sort of erm appropriately layered verbal information, start simple, introductions, erm explain what intensive care's all about".*

Communication with relatives

Initial interactions

The participants who were nurses tended to have first contact with the relatives when they arrived on the unit, often meeting them at the door of the unit first and then further interactions took place primarily around the bedside. They felt it was important to make relatives feel welcome and comfortable when they arrived on the unit. SP7a stated how they would establish family dynamics and ensure that they were speaking to the next of kin or similar, and then explain what had happened with their loved one and provide an update on their progress, including *"what the doctors are thinking and try and back up really what the doctors are going to say to them later to prepare them" (SP7a).* Not only would the bedside nurse prepare relatives for what the doctor or consultant

might say to them, they would often be present when these discussions took place. SP2a would *"always bring the nurse in and sometimes other people come as well"*.

As consultants, SP2a and SP3a reported that they would always introduce themselves to the relatives first which was seen as very important, and would then establish what the relatives knew so far about the situation before providing any further information because *"you want to pitch it at the right level, you also don't want to condescend. I do tend to put it very much in vernacular speak"* (SP2a). They expressed the importance of tailoring the information provided and delivering it in simple lay terms so that it could be understood, although the right level was sometimes difficult to gauge. SP2a also attempted to use specific non-verbal behaviour to accompany her verbal interactions with relatives: *"I try and look at each one in turn, try and concentrate and of course there's all this, I also try, if possible, to, to be open, so not lean forward, and that, and I'll keep telling myself don't lean forward"*.

SP2a shared that although it was not a good idea to get too emotional around relatives about a patient, she found that expressing one's emotions could be quite helpful sometimes when discussing patient outcomes with relatives, especially if the patient's condition was particularly dire, to say something like *"I am getting a little bit upset about this, it's an awful thing that's happened"*. Perhaps this self-disclosure was effective because it demonstrated to the relatives that she genuinely cared about their loved one.

Family conferences

Participants made references to conducting family conferences with relatives. SP3a reported that her interactions with relatives could be informal around the bed or of a more formal nature such as a family conference *"where we're sitting down in a private room discussing er where we are with their relative's care, erm where we think we're going"*. SP1a also spoke about family conferences with the relatives and described what they entailed, which for the most part was fairly standardised in structure, including introductions, finding out what the relatives know, if they have any questions, and then letting them know exactly what is going on with their loved one. He particularly emphasised the importance of allowing relatives to speak because *"most erm research does show that if you just shut up most of the time then that does a lot of good"*.

Honest communication with relatives

Participants talked about how they communicated with relatives and that a key element of these communications was honesty. SP1a who was a consultant, encouraged the ICU doctors to speak honestly to relatives and this approach could be particularly beneficial if a *"catastrophic event"*

occurred with the patient where a doctor may have been at fault, because he believed that relatives were generally willing to accept doctors' mistakes if *"they just hear it straight"*. Eight participants mentioned the importance of being honest in their communications with relatives, such as nurse participants being open and honest with relatives and ensuring they understood exactly what was going on with their loved one and were confident about asking questions.

Honesty and direct communication were also used by the participants in relation to providing a prognosis for the patient even if that prognosis was bleak, and this included both nursing and medical staff participants. SP2a and SP4a felt that it was important to let relatives know how seriously ill their loved one was to prepare them in case their loved ones' condition deteriorated further or if there was a chance that they were going to die. SP4a felt it was crucial that the staff did not *"try and butter things up, making it sound better. It's about honesty but in a layman's term of language…."* SP4a felt that relatives needed to realise the seriousness of the situation because if the patient then died and the relatives were unprepared *"sometimes that's the biggest shock, when they're like "Oh but I thought they were getting better"."*

SP2a and SP6a felt it was better for the relatives to be given the worst case scenario first than be optimistic about the patient's condition and prognosis: *"I believe that if you give people good expectations and the bad one happens they're a lot more unhappy than if they think their relative has survived ITU against the odds, it's much better that way I think psychologically."* In SP7a's experience relatives *"often get upset if we don't prepare them".*

Conflict and communication

Not all participants had experienced smooth communications with relatives, instances of conflict could also occur. These were generally in the context of disagreements with relatives related to decision-making for a patient's treatment. SP1a found that providing staff *"get the communication right, that doesn't really happen"*. SP2a found that she used to experience confrontations with relatives which were generally related to withdrawal of treatment for their loved one, but now she experienced fewer confrontational incidents. She felt this was due to her communication skills improving over the years. However, her junior colleagues were often involved in confrontations with relatives in much the same way she had been in the past, so there was *"always room for improvement".*

SP2a also reported a recent incident where a relative had complained about one of the nurses on the unit who they had had an upsetting communication with and this had resulted in the relative going to her car and crying. In addition, the relative had been upset again the following day when

she thought the nurse had ignored her on the unit. The relative had the chance to confront the nurse about what happened and the situation was managed appropriately; the nurse had realised he had upset the relative and had been unsure of what to do about it. This incident had caused SP2a to realise how important it is *"to acknowledge patients' relatives on the ward after you've spoken to them. And I try and do that but sometimes you're so busy."*

Communication skills and training

Participants talked about training they had received in communication skills and how these were applied in their work. SP5a felt that communication skills were developed over time on the ICU through consistent experience of communicating with relatives, which also involved the skill of timing information and learning how to answer difficult questions from relatives. SP7a stated how she had struggled with communication when she first started to work on the ICU and that there was little in the way of communication skills training for nurses apart from learning about how to treat patients holistically. She reported only receiving specific communication skills training when she undertook a mentorship course, but the mentorship training was only offered latterly. She was of the opinion that the module should be offered earlier on as it would be very useful to nurses on the ICU because *"You don't know what to say, you don't know when to say it. You don't know whether to touch them or hug them or, you know, it's just really difficult, um, when you start out and some training would help."*

One of the consultant participants was uncertain as to whether ICU nurses received communication skills training but thought they were *"very good at it though." (SP2a)* She also mentioned that the only communication skills training she had undertaken had been about giving bad news to relatives, which she organised and paid for herself as study leave and the level of study allowance available was limited: "*so I pay for nearly all of my training actually"*. *(SP2a)*

Communication between staff members

From the participants' accounts it appeared that the doctors and nurses worked as an effective team on the ICU. Each had their specific roles which would sometimes overlap but in a positive and useful way such as nurses preparing relatives for what the doctor would say to them, and for the most part these roles complemented each other. However, a consultant participant commented that there could occasionally be communication issues between the consultants and nurses, such as a nurse arranging a meeting between the consultant and relatives unnecessarily because *"sometimes they have questions that actually they didn't really necessarily want to speak to me about, they would have been perfectly happy ... to speak to the nurse at the bed space" (SP3a)*. She felt that sometimes

an early dialogue was necessary between the bedside nurse and relatives where the nurse could establish exactly what the relatives want to know and try and answer those questions, as *"sometimes they may not necessarily need to speak to a consultant."(SP3a)*.

SP9a described her role as a team leader which entailed training junior nursing staff in the process of communicating with other members of the nursing team, so that the junior nurses understood what was required of them and expected as part of their role. She also mentioned communication in a more external context in terms of communicating with other departments: *"it's all about the communication aspects between trusts, between doctors, between medical teams"*.

Preparing relatives and providing information

Family spokesperson and conflicting information

Participants emphasised the importance of nominating a spokesperson amongst families because *"you can't have detailed conversations with all the relatives" (SP1a).* The spokesperson can then impart key information to other family members and friends so that staff do not have to repeat information to different people. It was also important that relatives did not receive conflicting information from staff members so steps would be taken to prevent this from happening by ensuring that before speaking to relatives there is:

> *"an inter-professional and multi disciplinary consensus to what you're saying to the relatives, because it's a disaster if they hear obviously little nuance differences is okay but major differences between different multi disciplines or integral professionals is disastrous, particularly where communication is an issue." (SP1a)*

Initial information provision - Nurses

The six nurse participants detailed the information they provided when the relatives first arrived on the CCU, which usually included general information about the unit and information about the condition of the patient. This included being honest about the seriousness of their condition and if the patient might die, in order to prepare relatives for the worst. In addition, they would explain the various equipment and machinery around their bed as *"it's very intimidating" (SP10a)* for relatives to see them, and staff would reassure relatives not to worry about the alarms of the machines: *"I always say to people, "Don't worry about the beeps, it doesn't mean anything's wrong, it just means we need to be aware of something or whatever."(SP6a)* The nurses would make a point of asking the relatives to focus on their loved one rather than the bedside machines because:

> *"relatives get so fixated on the monitors and I explain to them that monitors lie and we know when they're lying and when [there's] interference and things like that, and they get very ...*

anxious ... So I tell them not to look at the monitors and just, I say, "Hold your relative's hand ... and speak to them as normal and let us worry about the numbers side of it" (SP4a)

SP9a added that relatives often want to know about the hierarchy of staff on the unit too, as some relatives feel they should be speaking to a doctor rather than the nurse *"because they don't understand ITU and the ITU way because we're quite nurse led where we're not, in other trusts".*

Initial information provision - Consultants

The consultant participants reported the type of information they gave to relatives initially which demonstrated similarities and differences to the information provided by nursing staff. SP1a would provide relatives with information about the ICU and how it was structured, information about the hospital, links for support services and any ICU literature that was available which was similar to much of the information that nurse participants would provide. Other information provided by consultants generally involved establishing what the relatives already knew about their loved one's condition, expressing the seriousness of the situation and if the patient might die they would also mention this. They would also discuss the patient's prognosis and discuss how they thought the patient's journey might go, *"and an explanation that the recovery ... can be long and complicated, erm ... and unpredictable." (LP8a).* This was not a subject that was usually broached by nursing staff.

In addition, they would also discuss what the plan of action would be for treating the patient and in the case of SP2a she would encourage relatives to ask questions. SP3a related how she would initially prepare relatives for what she was about to say to them before giving them information about their loved one's condition *"because I don't want to wade in with something that, that might be ... potentially life changing information without really having got a feel of where they are before we've started".* She would also try and find out a bit more about the patient from the relatives and what the patient might want in terms of treatment if their condition deteriorates *"Because that's obviously going to really impact on your ongoing dialogue with them over the subsequent days or weeks as well."*

Preparing relatives

It seemed important to the participants to prepare relatives for various aspects of ICU, such as preparing them for seeing their loved one, the ICU environment, potential adverse events such as deterioration or death of their loved one, and difficult discussions that staff may have to have with them around these issues: *"I think the more prepared relatives are I find the better because however hard they find hearing the news or the information I think having it is much more valuable for them than not having it" (SP7a).* Similarly SP2a was of the opinion that it was always a good idea to

prepare relatives if there was the prospect of poor outcomes for their loved one, even if they would find the prognosis very upsetting, because: *"if you prepare them and try and just paint a picture of what life will be like, I think most of them may be quite, quite confrontational to start with and then they go away and discuss it and have a think about it, and come back".* She expressed how important it was that the relatives were aware of how serious the condition of their loved one was and that they could potentially die, or be *"severely handicapped, disabled".* Significantly, when she prepared relatives in this way, they would *"acclimatise to it and, and it makes further discussions easier really."*

Helping relatives to understand ICU

SP9a reported how she helped relatives to understand the nature of ICU *"one of the ways I explain things is we can't heal, we're not healers, we're not god, erm we just provide time and machines that give support to give time for the body to try and heal itself."* She felt this helped relatives to understand the process and depending on how she worded it would result in relatives feeling less angry about the situation. This suggests if relatives have a good understanding of ICU and how their loved one is being treated; it may help them cope with the situation more effectively, as being well informed could lessen anxiety caused by uncertainty.

It appeared that other participants also helped relatives to understand ICU by explaining the daily routine on the unit so the relatives knew what to expect. This included being honest with relatives about the patient's condition, explaining bedside machinery, providing details they may need to know about the unit, and providing information about who relatives can speak to if they are unhappy with the care of their loved one. They would also explain why they would sometimes need relatives to wait outside the unit when they are performing daily tasks on the patient. This was seen as important as relatives could get very worried waiting to see their loved one, so nursing staff would *"just explain to them that, you know … we have to do things and we have to put lines in and do stuff and it's … Yeah, it takes time and I think that's very difficult for them to understand as well that we will get to them as soon as possible, but it's just … it takes time" (SP10a)*

The ICU environment

It seemed quite important to participants that they explain the ICU to relatives in their initial interactions with them, particularly if the relatives had never experienced an ICU before, because of how different it is to a normal hospital ward. One of the first things SP4a reported doing when meeting relatives for the first time on the ICU was to *"explain to them about intensive care, that it's a noisy environment, it can be quite scary and please don't be alarmed and scared by the machine*

noises and what's going on", and SP5a reported that ICU was a *"weird environment"* and *"obviously very emotional"* for relatives. SP10a remarked how *"difficult"* the ICU environment was for relatives, particularly when they were trying to process what had happened to their loved one, which could prove to be problematic when the unit was *"very busy and very noisy"*.

Occasionally even the staff would forget how shocking an environment ICU could be as one participant related how a relative likened the ICU at night to the film 'Alien': *"when the lights are dimmed and monitors are lit up everything's, that sort of thing and you can see all these people lined up and just, I'd never thought about it like that."* (SP4a)

Information mediums and confidentiality

It was felt that having an information leaflet about the unit to offer relatives would be very useful as relatives may be too distressed to retain verbal information because it is *"at a time when their relative's quite sick it is such a muddle anyway, it is, it often comes as a shock so they can't absorb it..." (SP5a).* Although a couple of the nurse participants felt that even if relatives were provided with an information leaflet they may not read it straightaway, as *"they probably sit in the waiting area and read it and stuff probably does go in a little bit, but I think it needs to be simple and to the point" (SP6a).* The majority of the participants mentioned the current leaflet that was specific to the unit and the ICUsteps booklet which they sometimes handed out to relatives. However, the latter was a generic booklet about intensive care for patients and relatives which SP6a felt was a better resource than the information sheet but was not specific to their unit. He was of the opinion that *"if you could combine the two it would be quite better."*

The issue of relatives not understanding patient confidentiality was also mentioned by several of the nurse participants. SP4a and SP7a mentioned this issue in relation to speaking to relatives over the telephone where they are limited as to how much information about the patient they can provide. Relatives find this very difficult and both participants felt it would be very helpful to staff if relatives understood this issue better:

> *"it's so frustrating for them us not telling them anything over the phone because they just want to know which [we] completely understand, especially when they're abroad as well, but they just don't understand all the time why we're saying, "We can't tell you anything." (SP7a)*

SP6a explained how relatives felt entitled to as much information about their loved one as possible, which staff did try to share with them, but this was not always appropriate. He gave the example of relatives trying to read their loved one's medical charts at the end of the bed, and he would have to explain the concept of patient confidentiality in that *"their relative does have a right for them not to know anything really."*

Processing information

It was felt by participants that when providing important information to relatives, they should not be made to feel overwhelmed by it, so it needed to be simple and straightforward to ensure that relatives could absorb it: *"they've got limited erm you know bandwidth basically, particularly ... in a sort of initial period of an emergency unplanned admission"(SP1a).* Timing of information provision was felt to be essential. SP5a felt that a relative whose loved one had just been admitted needed information about what was happening a soon as possible "*so that they're not panicking."*

Supporting relatives on the ICU

Lack of support

The participants gave their opinions about how relatives were supported on the ICU by staff members. SP1a felt that there was not enough support for relatives on the ICU and that *"the overall treatment of relatives is, is appalling. We, we don't do too badly given our, our physical and human resource constraints looking after the patients, but we, we do very badly with relatives."* However, they were taking steps to improve this situation with the use of a satisfaction survey and with the recent development of a new ICU where support of relatives would be improved.

Providing support

As a consultant SP3a found it quite difficult to support relatives in her role due to being so busy, which she saw as a *"major limitation"*. The best she could usually do was to provide the relatives with as much clarity as possible about what was going on and would be very explicit in her language, even if relatives found that upsetting. She felt that the nursing staff forged much more of a relationship with the relatives than she did, thus providing the most support to relatives by virtue of being *"absolutely integral to helping with that because they are at the end of the bed space".* SP4a also mentioned how the bedside nurse provided the majority of support to relatives but there were other staff members who provided support to relatives such as the hospital chaplain and the new palliative care social worker who was *"brilliant ... especially at end of life decisions and supporting the family, and if there's younger children".*

SP7a thought that it would be useful to have a member of staff on the unit who acted as an intermediary between staff and relatives because *"we just don't have time or [an] emergency happens [and] we're running around, so maybe having an intermediary who can sit them down when they feel like they need it".* She felt that health care support workers would make good intermediaries but the few that were currently employed on the units were too busy to provide that

sort of service. They would also need further training to undertake an intermediary role where they would probably need to be explaining to relatives what was happening clinically with the patient.

All of the consultant and the nurse roles appeared to be very busy, with a couple of participants remarking that they wished they could spend more time with relatives but were unable to due to time constraints. SP3a wanted to be able to structure her day so she could meet with relatives more often but was unable to do this: *"I personally would like to be able to have the time to be able to spend it speaking to some of the relatives on a one-to-one, erm you know regarding ... the patient's care, but that's not necessarily always feasible".* When asked why this wasn't achievable, she replied that she needed *"More staff, more time, everything really, yeah".*

It was also seen as important that relatives looked after themselves so they could effectively support their critically ill loved one. SP3a commented on how she would often have to make relatives aware of this and tell them that *"you also look after yourself because if you are here for 96 hours on the trot you're not going to be much use on day five".*

Creating a bond of trust

As a nurse, SP9a remarked how she supports relatives every day but without realising it. It was felt that the key ingredient to supporting relatives was to listen to what the relatives had to say and, for example, if they needed a hug she would provide it. She was aware of the need for there to be boundaries between nurses and relatives, but if she developed a good rapport with relatives they would sometimes ask her questions about herself, such as when she would be working next or on a day off, and she was happy to reply because *"it'll just be giving them a little bit of me back because I've got so much of them".* She reported how relatives needed to feel they had a relationship with the nurses and it was important that the relatives trusted them too, so *"them knowing a little bit about us kind of gives a bond and a bit of trust and it doesn't matter how small it is."*

Decision-making on the ICU

Relatives' understanding about decision-making for incapacitated patients

Eight participants stated that relatives did not understand the decision-making process for incapacitated patients, although SP1a felt that relatives had *"a very wide spectrum of perception and understanding around ... the real legal er process and erm ethics around critical care decision-making",* and although he did not have to explain the process very often there were times when he had to go into detail about it, as occasionally relatives didn't understand the process or disagreed with his course of action for their loved one. For the most part he felt that if you communicated

properly with the relatives there were generally no problems around this issue. However, several of the other participants reported how they regularly spent time explaining decision-making to relatives due to their general lack of knowledge and understanding about the process, and this was regardless of whether communication had been good or not. Moreover, SP9a reported how she explained decision-making to relatives on a *"daily"* basis.

From SP1a's experience what tended to happen was that relatives often felt that the medical staff were asking them to make decisions for their loved one, so he would often have to point out that *"the medical decision-making is being made by the medical team and nursing team, erm but in order to make that decision you're speaking to relatives, to inform, to help inform your opinion".* Three participants also reported that relatives often felt they were being asked to make decisions for their loved one by medical staff: *"I think some people do feel like we're asking them to make a decision about not for resus or to have a tracheostomy or whatever and I've been in with some families where the consultant has said, "We're not asking you, we're asking you for your opinions and what you think they would want".*

In contrast, five participants reported that relatives felt they had the right to make decisions for their loved one *"because they turn round and say, "Well you can't do that without ... our permission" and there are times that it does happen and then I say, "Well actually I can and that is the position".* (SP2a) This could sometimes cause friction between staff and relatives, which in rare cases could lead to legal action: *"we've almost gone to the point with one set of relatives of an injunction. I haven't personally ... but other colleagues have had experience ... of injunctions."(SP2a)*

SP8a remarked that many people did not *"completely appreciate the detail of the law"* involved in decision-making, and this applied to relatives and medical staff, however, he found that if relatives feel involved in the decision-making process then there were usually few misunderstandings. SP7a felt that for the most part relatives did understand the process of decision-making for patients and were happy for the staff to make decisions for their loved ones, but occasionally found that if relatives expressed a very strong opinion about how they wanted their loved one treated *"it's often their opinion rather than ... [what] the patient would have wanted".*

Inclusion of lay information in the new information booklet

The issue of whether there should be a section on lay information about decision-making for incapacitated patients included in the new information booklet was discussed with all the participants. One participant had serious concerns about whether it should be included in the new booklet, because: *"I just unfortunately don't think you can do it in a, erm, protocolised structured*

way, I don't think it's the sort of information that, that is necessary or erm safe really to do that."
(SP1a)

However, all of the other participants felt that it should be included, so that relatives fully understood that their opinions of what their loved one would have wanted will be considered in the decision-making process, but ultimately the doctors will use their extensive medical knowledge to make decisions in the patients' best interests:

> *"cos I think there's always a bit of confusion at the end, and I think yeah I think they can get mixed messages as well from the nurses maybe that involve them so much in ... the care at the bed space and the doctors that come in and just do things, and I think maybe if they knew that ... that the doctors aren't just doing things for the sake of it, but they're doing it for their best interest."*
> *(SP5a).*

Influence of medical television programmes

Sometimes regardless of how many times staff explained the decision making process to relatives they still seemed to be unable to comprehend it, and several staff members observed how the influence of medical television programmes was they felt, partly to blame, because they were often incorrectly portraying the decision making process used in the UK: *"It's all Holby City's fault". (SP9a)* This included the prevalence of American medical television programmes where the decision making process involves the next of kin as surrogate decision makers for loved ones who are incapacitated.

SP6a reported how lucky they were at KCH due to the hospital A+E Department being the focus for the television programme '24 hours in A+E', as many of the relatives had watched the series and were very positive about it, which automatically gave them a positive outlook about the hospital in general:

> *"everybody knows it is a really good TV show and the people have really good experiences, so it's often the thing ... people say that to us specifically. This intensive care, "Oh we're so glad we're here," and things like that which I think is ... Yeah, it is positive for them, it's probably helped them a little bit ..."*

Coping on the ICU

What relatives find most difficult to cope with

Participants gave numerous examples of what they felt relatives found the most difficult aspects of ICU to cope with. SP1a remarked that relatives' coping on the ICU was *"context dependent"* on whether the patient lived or died but the aspects of ICU he felt relatives found most difficult to cope with was dealing with the death of their loved one, bereavement and withdrawal of treatment, particularly the period of time between withdrawal of treatment and the patient dying *"because we*

withdraw or limit treatment in 80% of all the deaths on ITU, so they can find that period quite difficult and that's the one that they often recall." He had also observed that stepping down to a normal hospital ward from ICU and how slow a patient's recovery could be were also difficult aspects for relatives to cope with.

SP6a and SP8a felt that admission of a loved one, particularly if they were an unplanned emergency, was difficult for relatives. SP7a felt that seeing their loved one intubated (tube inserted for breathing) *"or people running around because they're really unstable, I think that's probably the most traumatic and then I would say specific procedures like extubation, tracheostomy".* In addition, when a patient woke up for the first time this could also be distressing for relatives to witness. SP7a also described how relatives could find it very difficult when the unit was really busy, especially if there was an emergency situation and it happened in front of the relatives. Both SP7a and SP8a mentioned when a patient's condition deteriorated and they had to be placed back on the ventilator to help them breathe, that this was particularly hard for relatives if the patient had improved to the point of almost being discharged from the unit. SP8a mentioned a sense of dissonance that relatives may feel when staff member's actions do not appear to be matching what they are saying about the patient, in terms of providing poor outcomes yet escalating treatment: *"because they see us working very, very hard so they, they think oh well there must be hope ... but at the same time we're saying ever bleaker things".*

SP9a mentioned how relatives often found it difficult to understand head injuries on the ICU: *"they think everyone's had a head injury, they don't realise there's different kinds of head injury and ... why have three people left that bed area and my John is still here kind of thing".* SP10a had observed how relatives found it difficult seeing their loved one in the bed, as their appearance can be dramatically different to normal: *"I think they change so much ... their face as well changes so much cos they bring ... some photos in and it's like a completely different person, you see the photo for yourself and it's hard to believe".*

Coping and character

SP10a observed that relatives employ different methods of coping and this could be very dependent on their character, where some relatives are very strong and stoical, others were *"falling to pieces straight away".* She also thought that relatives' coping was influenced by family dynamics, in terms of their position within their family.

Psychology on the ICU

Psychological impact of ICU

Participants made reference to the psychological effects that relatives can experience on the ICU. SP1a emphasised the amount of trauma that relatives can experience whilst their loved one is on the ICU and how important it was to provide effective support to them because the relatives experienced a *"greater life event than the patient"* this was due to the patients mostly being asleep or experiencing periods of delirium which they may have limited memory of, but:

> *"the relatives are aware throughout and we often find in the clinic or when speaking to relatives after the event that it's the next of kin often the husband or wife who has more significant PTSD type symptoms than the patient themselves."*

SP3a commented that being a relative on ICU could be extremely draining, which could in some cases cause depression. However, it was not just what happened to the patient whilst being on the ICU that the relatives had to cope with, it was the psychosocial burden of all the care and support they would need to provide to their loved one once they had been discharged from ICU and returned home. In addition to this was the social burden of the relatives possibly needing to go back to work too, because it's *"not just the patient, it's about the wives, children, parents of these people that actually carry a huge amount of the psychosocial burden."*

Psychological support or counselling service for relatives and staff members

Significantly, all of the participants thought that there should be some kind of counselling or psychological support service accessible to relatives and ICU staff, based on the CCUs. In terms of having the service for relatives, a couple of participants were unsure as to how feasible having a service like that might be, but were still in favour of it: *"I think it would be lovely because it's a great shock to the family ... I think it's very important definitely ... to have that support." (SP10a)*

SP8a reported that he had experienced relatives asking him for such a service before so was also in favour of it being available providing relatives were not automatically referred to it and only accessed it if they wanted to. SP6a thought the service would be useful for relatives who *"don't have any other sort of support network".* SP2a felt "*that would be a good idea. And somebody who's not actually involved directly in the care. And someone they can really talk to about it, would be useful".*

In terms of ICU staff members, again there were a few participants who were unsure how feasible it would be to establish a service or how it would be utilised, but thought *"something should be available." (SP1a).* SP3a thought it was a *"no brainer"* that staff should have the service because the rate of burn out was supposedly higher in ICU staff than any other specialty except perhaps A+E. She

felt that in terms of burn out for ICU nurses there were more triggers around end of life care but it tended to be different for ICU doctors: *"if you look at women under the age of 40 who are physicians in intensive care and some of the literature says there's a 50% burn out rate, so I think that you have to accept that, that possibly erm some form of support or counselling across the board may well be beneficial for that".*

Some of the participants felt that generally ICU staff developed good coping strategies working on the ICU so did not usually require any psychological support, yet staff did try and support each other when they could, but this was not always possible: *"we just don't have much time with the shift we're working, you know, we barely have time to see each other let alone speak, so a bit of venting time is ... really good for us"*. It was thought staff members who were new to working on the CCU would benefit from having a counselling service *"especially if the newer people when you experience something that's completely out of the ordinary or really horrible sometimes, everyone else is used to it and you're not, and, so yeah I think it would be useful". (SP5a)*

In addition, there were occasional patient cases which even the 'veteran' staff members would find upsetting and where some form of counselling was thought to be beneficial, such as when a patient died after they had been on the unit for a long time and staff had become attached to them: *"we had a young 17 year old girl who just had just given birth, who died and she'd been here for a while ... she'd been here for like a month and you got to know her, you got to know her family, they brought the baby down, and, then she died and everyone was absolutely heartbroken." (SP4a)*

Several of the participants mentioned the value of de-briefing sessions when there had been a particularly upsetting case that had impacted on ICU staff, especially those staff members who had been primarily looking after the patient. This had started to happen on the CCUs: *"recently we've had some really difficult cases where what we start doing is debriefing and getting proper sit down sessions, and I've just been debriefing after someone's kind of become unwell or died or transferred out, you know whatever it is it tends to be quite a hideous death in all honesty."(SP9a)* SP7a remarked that there was sometimes a large guided debrief session open to all hospital staff to attend, where they could talk about their difficult experiences and listen to other staff members talk about theirs which had been a very beneficial experience. SP9a mentioned that a counselling service on the ICU could benefit some of the patients too:

> *"because they get used to seeing certain people around, upstairs recently there was kind of three little old guys in a row and then one of them died and disappeared and the other two kind of look at their own mortality".*

Suggestions for new ICU Booklet

Across all accounts many suggestions for the contents of the booklet and its delivery were provided. The most popular suggestions included: useful telephone numbers and contacts, visiting times with an explanation as to why visiting hours were so rigid, glossary of ICU terms, information about being transferred to a general ward, discharge, the decision-making process, warning relatives they may have to wait for a couple of hours while staff settle the patient onto the unit, and a picture of an ICU bed with all the bedside equipment around it to prepare relatives for what to see. *(See Appendix B15 for Staff Booklet Suggestions)*

3.3 STUDY 2: PEER REVIEW FOCUS GROUP OF FIRST DRAFT OF BOOKLET

All participants were senior ICU nurses and included seven females and 2 males. Before proceeding they were given copies of the first draft of the booklet which they were given time to read before the discussion began and were asked about their thoughts concerning communication and written materials for relatives on the ICU and what they found effective. After they had read the booklet the researcher asked the group several open-ended questions related to the booklet content, appearance, structure and delivery. Six primary themes were identified from the group data and a number of sub-themes within each main theme.

Feedback on the first draft of the booklet

Design, structure and content of the booklet

There was a general consensus that the group liked the booklet and were very positive about it. Two Participants commented on the amount of content in the booklet, in that there was *"a lot of information"* (R3) and *"a lot to read"* (R5), but this seemed to be more of an observation then an actual issue. R7 commented that he liked the way the booklet had explained *"what normal is, but it also explains why there will be deviations to the norm"* he felt that this gave relatives an understanding of what to expect and reasons for why they might not be able to visit their loved one during visiting hours, or *"why they may hear conflicting information and what they can do about it"*. R1 thought that the booklet information was *"laid out well"* and liked the size of the paragraphs and R4 thought the typeface of the booklet was friendly and that the way the booklet was structured was simple and straightforward.

There was some uncertainty amongst the participants as to the current front cover of the booklet and what should be on it. The version that the focus group were reviewing had a picture of a feather on the front cover which some participants really liked while others were unsure. R3 questioned the

significance of the feather and suggested that it signified *"if you find a white feather it means an angel has visited"*. R1 suggested it meant *"fragility"* and additionally suggested the picture could be of a sunset, remarking that she liked the booklet and thought it was *"very good".* R2 commented that it *"should be the Kings logo".*

Glossary

It appeared that a glossary of terms was a necessary section to the booklet because the participants discussed how relatives often mis-hear certain terms used by ICU staff and try and reiterate these when talking to the nurses about their loved one:

> *"a family who desperately wanted to be involved and were very concerned about their loved one, and they were trying to talk to you on the same level … or want to kind of assure you that they are at that level and they understand and yet they're using words that are utterly wrong …" (R6)*

R1 remarked how relatives do this because they want to show they understand what is going on but if they have the words written down this may help to prevent them incorrectly pronouncing medical terms or using them in the wrong context. R3 suggested the glossary could be given separately to the booklet after the first day but the other participants disagreed. R1 opined that it was very simple and *"it's lovely, I think it's perfect."* While R8 added that she thought it should be part of the booklet because *"I don't think you can be giving them lots of different information".* There was a general consensus amongst the group that the glossary would help relatives because nursing staff would often tell relatives what was happening with their loved one and about procedures they were conducting such as intubation, so having the glossary in the booklet would mean *"they've got it like later on to go oh maybe that's what they meant." (R6).*

Use of booklet to help relatives

Participants were very positive about how the booklet was written and explained how it would support them in their communications with relatives. R6 commented that *"what I liked about it is that it is quite firm, but yet, erm, quite compassionate, you know, so it, its, kind of some things in here are kind of non-negotiable, but you know, they kind of say it in quite a supportive ... kind of non-confrontational way."* R6 discussed how the booklet would help in relation to explaining decision-making for patients who lacked capacity with relatives, commenting that it *"kind of, er puts the patient first ... As opposed this is about us or ownership over your loved one".* She also thought that the way it was written *"was really good"* and that they could *"use it as a tool to kind of diffuse some of that conflict that can happen in those situations."* Several participants agreed that they would want to take the booklet home with them if they had a loved one on the ICU. R2 mentioned that having the information written down for relatives meant they could *"read it at their own pace and*

take out the bits they want" and it would help them to understand why they have to wait to see their loved one sometimes. Participants were also happy that there was finally an informational resource they could give to relatives again after not having anything for a long time *"so it's good to have something back again, that we can actually give some information for them..." (R8)*

Thoughts on the intervention

Participants were doubtful about how well the intervention could be monitored, and that it might be more a case of trusting the nursing staff to deliver the intervention appropriately, otherwise *"You could be monitoring every conversation then, and you hope it's done with professionalism and good will and you won't be able to do that." (R5).* R3 remarked how even if they give the *"same speech that we've learnt off"*, relatives will be in a state where they may not remember it anyway. Similarly, R1 suggested that perhaps relatives needed something *"very short, and like almost paragraphic"*, initially. R3 remarked that with relatives being at a *"crisis point",* if they were given just three sentences of information "*I still don't think I'd even want to know those three sentences".* R2 was not keen on the units being called the medical and surgical critical care units, because of the connotations he felt were associated with the word 'critical': *"I mean critical means to me that I don't want to leave my relative, I must be with my relative at all times".* However he was more comfortable with the word 'intensive' because that would mean providing intensive care to his patients, which had *"different implications".* This comment was an interesting observation about how relatives might view the meaning of the words for the units, but ultimately superfluous because the units were critical care units comprising ICU and HDU, so not something that could just be changed. However, it suggests that an explanation of the current acronym (CCU) could be necessary to avoid any confusion.

Delivery of intervention

Verbal script – to have or not to have?

The idea of the nursing staff being given a verbal script of what to say when they delivered the booklet was not seen as a viable option and was viewed negatively. If used it was felt that a script had to be very basic. R1 remarked that she would *"actively be offended"* if she had to use a script and R3 agreed with her. R5 commented that relatives were usually very adept at *"seeking out, if they're not happy with the way that they've been given a certain bit of information, they'll wait for that person to go to break and then they'll come and find the other nurse."* R4 felt that they all said basically the same spiel to relatives so in a way they already had their own script. R1 and R2 explained that initially they would go out of the unit to meet relatives and prepare them before

bringing them inside. R5 provided an example sentence about what she might say when if she was to give relatives the booklet: *"this is for you to browse through ... at your leisure and these are the key things, the visiting times ... and please do not hesitate to contact us ...".* The participants comments suggests that rather than a verbal script, giving the nurses a brief guide as to what would be the best way to deliver it in terms of mentioning or pointing out sections they felt were particularly relevant to relatives, would probably suffice.

Initial communications with relatives on ICU

Participants discussed the importance of nominating a spokesperson from patient's families who they can primarily give information to regarding the patient, otherwise:

> *"it can be very frustrating because each time another person arrives you have to say the same thing, it's time consuming and we are not able to spend as much time with each patient ... sometimes this can cause a little friction, and it can cause a lot, and sometimes it can cause more friction because peoples' understanding about what we are saying is completely different."(R2)*

Participants' contributions to the discussion about communicating with relatives suggested it was a significant topic as it was something they were all involved in on a regular basis and they had evidently experienced instances where it had gone wrong: *"Mis-communications can be a complete disaster."(R1)* R1 described the importance of being very clear when speaking to relatives, ensuring they have understood, and that they have all the information they need. Similarly R2 mentioned how the nurses tended to check what the consultants were saying to the relatives, to ensure that they were not saying anything different that might cause confusion. The group discussed how relatives are often unable to process information when they first visit the unit and if they think they are going to lose a loved one *"whatever you say to them or how you communicate, it doesn't compute with them".* R3 was very doubtful that an information booklet would have any impact in the first few hours of relatives arriving on the unit and remarked that *"it's a sad reality that no matter how good the booklet is, it's about the person that gives it and the way they deliver it."* This suggests that the staff members who deliver the booklets may play a key role in their effectiveness.

Participants also mentioned the importance of getting communication right with relatives when they first meet with them because *"if the nurse gets it wrong in those first, in that first half an hour, everything just falls apart like a pack of cards." (R3).* It was felt that if the nurses get the communication right initially they generally experience no other problems with the relatives during the period of time their loved one is a patient. However, R3 also mentioned that *"it doesn't matter how well... you know, you can go out, you will meet people, and, and you say your speech and it goes well and then you can do the exact same a week later and it goes down like um...an absolute*

bombshell". Suggesting that relatives vary, they may have different needs and will respond differently to similar information.

Information provision for relatives

R3 was concerned that as a result of the relatives reading the booklet repetitively, they may start to pick up on certain points and deem them unchangeable which may cause problems, for example if they are not able to immediately see their loved one when the visiting times begin. The discussion returned to relatives' processing of information and when might be the optimal time for them to receive the booklet. R3 remarked that information booklets were *"fantastic when you're at ... day 2, day 3 when you've, when that adrenaline rush has gone and you're actually able, ok I'm having to wait an hour or two I'll sit down and read".* R6 described the initial period of time when the relatives come into see their loved one for the first time as the "*crisis situation"* where she felt that relatives generally just need to know how their loved was, to feel reassured by staff members, and how they can contact the unit. After the initial crisis relatives want to know more information about the unit, such as visiting times. However, R6 commented that if staff know that a patient's death is imminent, visiting times are made flexible to the family and it would *"be inappropriate to give them a leaflet"* at that point.

R2 felt that the booklet was very good and almost *"exhaustive"* in the information it provided. He stated that if he was a relative all he would want to know was who to contact, when could he see his loved one and speak to the doctor. In contrast R7 was adamant that if he were a relative of a patient on ICU the booklet would be beneficial: *"I would want this, so when I went home and got into bed and everything's rushing through my head, I could wake up in the morning with a bit of an idea of how things are going to work."* The idea of the booklet being a *"reference point"* was agreed on by other participants in the group. However R3 had concerns that were related to information booklets that try to ensure relatives have a good experience because they *"promise things we will never be able to, to deliver."* Her worries were due to lack of resources on the units such as the fact that *"Downstairs we've got 18 patients ... they have 2 relatives each; now that's the bare minimum, that's 36 people. You've seen the size of that room ... there isn't 36 chairs in it."* She explained that the reality of the situation was they simply did not have the *"infrastructure"* to support the actual needs of the relatives, or they would be limited as to what they could actually provide.

Conduct on the unit

Being sensitive to other relatives on the unit

The group discussed aspects of relatives' behaviour on the unit and being respectful of the patients and other relatives. Participants discussed whether there should be a paragraph in the booklet that asked relatives to be sensitive to the needs of other relatives on the unit. R4 was worried it might be *"mean"* to do this but that there were instances where "*sometimes there are families that entirely take over, to the point of intimidation".* However, R3 felt that a paragraph would not necessarily change insensitive relatives, and R9 thought that it was not *"a case of being insensitive though, they're in a situation like you say, crisis situation, they're not thinking straight".* She had experienced being a relative of a patient on ICU but because she works on ICU she knew how to behave and act appropriately but other relatives would not.

Respecting patients' dignity

R3 felt that there should be something in the booklet that tackles patient confidentiality issues such as asking relatives to respect that their loved one might not want their relatives to see them:

> *"being washed and rolled or ... being suctioned, you know be cleaned, bowels opening, smells ... it's, to kind of reiterate to them that, we have a job of protecting people's dignity, and that even though you might be a friend or a second cousin three times removed ... that doesn't mean that somebody can just be, their kind of open property".*

R5 mentioned another potential addition regarding this issue which was telephone conversations with relatives because staff could only give limited information about patients over the phone and several other participants agreed.

Relatives staying overnight

Lack of facilities for relatives

Nearly all of the participants had something to contribute to this issue and offered some very useful information for inclusion in the booklet. R5 and R4 usually encouraged relatives to go home. However, R1 suggested the booklet could say that relatives were able to stay at the hospital but there would not be any beds for them, or could explain that there is limited accommodation, which the relatives may have to share with others. R3 stated that *"by putting it in black and white, there are no over-night facilities, you're not actually saying that if somebody was dying that you wouldn't allow them to stay, you are just stating that there is no overnight facilities."*

Several participants offered additional information such as how the nurse in charge usually judged whether relatives could stay overnight and how the booklet could state that relatives can only stay overnight in *"exceptional circumstances" (R1).* R5 and R3 felt that relatives would assume that if they stayed overnight they would have open visiting to their relatives, which would not necessarily be the case. R4 mentioned that *"the hospital is quite a lonely place at night, there's no canteen, there's no food, there's no facilities ...They're actually better off being at home."* Other participants agreed that there was a safety issue with relatives staying overnight and R9 suggested that the section on staying overnight should be moved to the section on relatives looking after themselves, because *"it's part of looking after themselves, encouraging them to have a normal pattern too."*

Importance of locked door and management of relatives

Participants discussed the medical and surgical CCUs, and the issues they currently experienced in managing relatives due to the MCCU being an unlocked unit. The visitor's waiting room was inside the unit so relatives would be constantly coming and going. R5 reported how it often felt they had no control over the unit and relatives could be very demanding which caused the nursing staff some anxiety because *"they're there kind of consuming the time of the nurses who are looking after the patients in the side room because that's directly opposite the relatives' room, so it's kind of impossible for those nurses not to then get caught up in the management of..."* In addition, R6 pointed out that those nurses who were working in that area "*shouldn't really be being pulled away from their duties looking after the relatives".* These comments suggest that perhaps the booklet should include information pertaining to relatives being more aware of nurses' duties in caring for critically ill patients.

In contrast, on the SCCU which is a locked unit and has the visitor's room outside the unit, there were issues with explaining to relatives the reasons why the unit is locked. R9 and R3 agreed that perhaps the booklet should give the reasons as to why it is a locked unit, because sometimes relatives inside would *"let any old Tom, Dick and Harry in, you can have half of Camberwell in there."*

Visiting patients

A few of the participants wanted to change what the booklet said about visiting, because the booklet did not specify the number of relatives allowed per patient bed, just that *"too many visitors at one time can be very tiring for the patients, and that we may have to limit the number of people to the bedside."(R8).* R8 reported that they had experienced quite a few problems related to relatives visiting loved ones, so she felt that the booklet should state clearly that only two relatives were allowed per bed. Occasionally staff would allow more relatives in to see a patient if they were very

unwell but the group felt that this should not be written in the booklet. R5 reported that even with the two people per bed rule there could still be problems because *"if you've got 24 relatives that are two to a bed, then there's no room ... for the rest of the relatives ... Because that's what happened the other day, we had like, about 60 people for 3 people, and the rest of the people were waiting outside."*

Participants pointed out that not only did they sometimes have large numbers of relatives turning up on the unit wanting to see a patient, there might often be people that were not family and who were not necessarily close friends with the patient either: *"you can have somebody's newsagent coming into see them ... you can have ... three wives and two girlfriends, and nobody knows about anybody else, um, you know, as families become more fragmented, it can lead to a lot more."(R3).* However, both R3 and R4 agreed that under the circumstances they had surprisingly *"few problems really" (R4),* especially *"considering the complexities of people's lives" (R3).*

Playing music for ICU patients

R9 suggested adding to the booklet that it if relatives bring in equipment to play music for their loved one to be aware that there would be nowhere to lock it away and that staff members could not be responsible for it, to which R1 agreed. R3 mentioned how she felt some relatives read too much into the concept of playing music for a loved one on ICU because *"you've got people who have never listened to music in their life, and the next thing, someone is bringing in... (laughter) a pair of headphones...and saying well he doesn't really like music but it's written in the book so we'll give it a go..."*

Information external to units

Provision of details about local services (accommodation, transport links, etc)

Several of the participants suggested information to add to the booklet that could help relatives, such as *"a list of local bed and breakfasts" (R8)* and *"a map and um, buses ... Just little things like that or the train" (R1)* and possibly links to *"London website, to get directions" (R7).* R3 mentioned that it was not always appropriate to ask relatives to look up details on the website as many of their patients were quite elderly and relatives sometimes had to come from further afield to visit their loved ones, so may not have the time to look information up online.

Information pertaining to what relatives should expect to see on the unit

Preparing relatives for the ICU

There was some disagreement amongst the participants when R9 suggested that pictures of ICU be included to prepare relatives for what to expect. R1 was unsure whether they could prepare relatives for that which R9 agreed but suggested that *"you can do a snapshot of what an ITU looks like; it's a very alien environment, compared to a ward".* The participants also discussed the very small section in the booklet about patients dying, and whether it should be added to. R3 felt this aspect was quite small, particularly *"for people … who have got such a high risk".* R1 felt that information about death should be kept simple in the booklet *"because you can't replace what we will say to those people, with that, really."* They discussed a bereavement book they have on the units but this was something that would be given separately as it was for relatives whose loved one had died on the ICU. R9 also mentioned the existence of the *"Cicely Saunders Institute"* based at the hospital where relatives could go for support.

3.4 STUDY 2: POST-PILOT INTERVIEWS WITH ICU STAFF MEMBERS

Eight Participants were interviewed in person at KCH and two participants were interviewed on the telephone. There were seven main themes identified from the data and a number of sub-themes within each main theme.

Feedback from relatives about the booklet

Initial reactions

Staff members reported how they had received positive feedback from relatives about the booklet. One participant gave a booklet to a relative whose loved one had been admitted prior to the pilot starting who reported that it was very informative and useful, but felt that it would have been more helpful had he been provided with it from the beginning. SP1b reported how she used to have to give the relatives contact details and information about the CCUs on a piece of paper and had noticed a difference in response between that and handing out the booklet to relatives: *"the fact that they now have a booklet I do think people respond more positively to it, erm, because it has got more information that they need erm and I think that they do appreciate that yeah."*

Improved satisfaction

SP4b and SP10b felt that relatives were more satisfied with their experience of the ICU than before the intervention because the booklet had *"identified a lot of issues that weren't put in the other ones*

and issues that I think probably would make the booklet feel a bit more personal too, certainly it would to my family who are using it as well."(SP4b). SP10b had witnessed relatives using the booklet and commenting on it: *"I've seen people reading through the booklet and erm, both erm … and receiving the booklet and appearing to be grateful for receiving it."* SP3b was uncertain as to whether relatives were more satisfied with their experience of the ICU because of the time of year the pilot was conducted. She had also never asked relatives what they thought of the old information sheet they gave out prior to the new booklet being piloted so was unable to make a comparison. However, the relatives she had spoken to had reported that the booklet information was good and very useful.

Booklet as a supportive informational resource

A professional resource

Three participants stated that the booklet looked professional and was more appropriately structured than the old information sheet which they used to give out to relatives: *"it's all laid out fairly nicely, it's really simplistic and you can see it all and it explains again why things are, which I think was missing from the previous booklet … it's just a bit more in-depth and it looks more professional." (SP5b)*

Sources of information

SP8b felt that critical illness was very difficult to understand for most people. However, he felt that the booklet provided a *"baseline of information"* which was very important in improving relatives' understanding. SP1b reported that the old information sheet they had was an A4 sheet *"which was a bit tatty"* and the nursing staff normally had to find it at the back of a cupboard. She said how when she gave the old information sheet to relatives she always felt *"a bit embarrassed"* by it. But the new booklet had "*got a lot of useful information in it and it's the kind of thing that I … if I was a relative of patient who was admitted to somewhere very strange that I had no experience of I would want all that information"*. She also felt that the booklet would make relatives more confident about the staff member's ability to look after the patients.

Several participants mentioned that they felt that the booklet would provide ample information so that relatives would not feel they needed to search for further information elsewhere, such as the internet:

> *"if you've got no information, normally what people do is run to the internet don't they, and they look at the worst case scenario … at least this gives you something that's actually a lot more factual …." (SP4b)*

SP10b stated how the booklet was a *"very bespoke and local resource"* that relatives may utilise alongside verbal information and the internet. She had seen *"relatives sort of you know sharing and, and talking about it with each other, so it's clearly doing something."* But was unsure as to exactly what that was as yet.

Retention, reinforcement and questions

Several of the participants thought that the booklet would help relatives to retain information imparted to them verbally by ICU staff, because much of what staff members say to relatives was also written in the booklet. SP4b saw the booklet as *"another source of literature to back up the nurse, doctor, whoever's point of when they're talking to them, this is why we do it, there's no ifs or buts around it and you're backed up with a resource."* Some of the participants felt that relatives would continue to ask a similar amount of questions about the ICU as before the booklet, while others felt that relatives would ask fewer questions. SP1b thought that even if they asked the same amount of questions:

> *"the things that we say will be backed up by the book, because often people don't remember things straight away when they're visiting people in ICU because they ask the same questions quite a lot, and I think it's nice for them to have everything written down that they can go back to"*

SP2b was of the opinion that relatives may still ask a lot of questions but they would be less about the ICU and more about *"the patient ... all them nitty gritty little, yeah things".* Similarly, SP4b thought that if relatives are given the booklet they will be more focused on their critically ill loved one because *"if they've got the information there they're gonna be less reluctant to move from the patient and go, "Why? Why?", so that's an improvement from my point of view."* SP10b thought that the booklet had enhanced relatives' knowledge and understanding of the ICU because it is *"a very readable book and so giving them this accessible bit of information ... at least demonstrates that we care about this stuff ... and that we have this resource available."*

SP4b referred to the booklet as a *"third resource"* which would be in addition to the relatives speaking to the doctor and being involved in a family conference with the consultant. The booklet was useful because relatives were not always able to retain verbal information and it was hard to gauge how much each relative would comprehend. SP4b felt that the booklet pulled everything together and that *"reinforcement"* was "*the most important thing".*

Communication and Coping on the ICU

How booklet will help with communication

SP10b felt that generally he was good at communicating with relatives but felt there was always room for improvement and was continually looking at ways he could improve his communication. He thought that the booklet would help to improve communication with relatives on the units *"because this is such a comprehensive booklet, I mean sort of everyone's gonna take it ... every relative is gonna take something ... different out of it."* He also stated that the majority of the content of the booklet would also be reflected in what he would say to relatives *"particularly the front half of it"*. SP2b reported the booklet had not changed the way she communicated with relatives as she still said the same things but she described that when she handed the booklet to the relatives it *"makes sure that you don't forget the some of the stuff that you might need ... to remember you know, it kinda, erm, kind of, I think that probably helps them as well"*. So the booklet helped her by ensuring that she was providing relatives with all the appropriate information but it also helped the relatives because they would often forget important information and the booklet would help them remember it. SP9b was of the opinion that due to the booklet mentioning wills and advance directives, relatives may feel they can broach this area with the staff members, such as the nurses, who were often *"scared to bring up ... the erm subject"* and this *"would improve communication"*.

Helping relatives to cope

Eight participants reported that they thought the booklet would help relatives to cope on the ICU and also upon their discharge. SP3b thought that the booklet would help relatives cope because it was a really informative and concise booklet which was also easy for relatives to carry around with them and stated that it was in lay language so easy to understand. SP4b stated how he thought that the booklet provided factual information, prepared relatives for what to expect and helped them to understand what the staff were doing, which would invariably help relatives to cope as they may think *"right okay so they're doing something about it and they're giving us reasons why" (SP4b)*. SP2b thought that the booklet would be useful for relatives to refer back to when necessary and to give to other members of their family to help them understand the ICU process too, which would be helpful from a nursing perspective. However she realised that the booklet was not a cure-all for the traumatic situation of having a loved one on the ICU, but did think that it was a step in the right direction:

> *"it must make a better, you know things a bit better for them, not that it's ever going to you know make it completely smooth and you know, painless …. I think it's a very good step" (SP2b)*

SP5b did not think it would help relatives to cope but did think it would support relatives because *"it just explains things in a more nicer and easy way for them to understand."* Similarly, SP6 and SP7 also felt that the booklet would support relatives whilst they were on the ICU. SP6 felt that relatives needed to be prepared in different ways, but thought the booklet had covered most aspects, whereas SP7 felt that relatives' coping was more dependent on family and dynamics, but felt that the booklet was useful.

Additional resources

All of the participants except SP4b thought that relatives needed other supportive resources in addition to the booklet. SP4b felt that the need for additional resources for relatives was very individualised and thought that this should be determined on a case-by-case basis. Apart from some relatives possibly needing specific information about certain illnesses or conditions, he could not think of anything other than the booklet that he would give out.

Several participants mentioned types of additional resources, such as the new palliative care social worker on the unit and trying to be more proactive about referring to her for other issues besides end of life and palliative care. The Patient Advice and Liaison Service (PALS) was also mentioned and the importance of support networks such as family and friends of the relatives. SP3b thought that *"from a psychological point of view"* the MacMillan Centre was a useful resource in the booklet that they do not use enough. SP5b was also of the opinion that additional resources were dependent on the individual but generally felt that many relatives needed someone to talk to and this did not necessarily have to be a counsellor. SP10b felt that *"the nurse by the bedside is the single biggest resource in this regard",* and SP8 added that he thought relatives who had a loved one who was a neurological ICU patient should either be given a separate booklet that explained the intricacies of brain injuries or this information could be provided as *"bolt on"* information leaflets or sheets that could be given alongside the booklet.

Psychological support

Encouraging psychological support

SP4b stated that they thought the booklet had encouraged relatives to seek psychological support as he had witnessed this happening: *"the individuals I saw yesterday, yes, erm and there was talk about that and they were pleased that they did".* SP8b expected that the booklet would encourage relatives to seek psychological support, a view supported by SP9b. Other participants were uncertain as to whether the booklet had encouraged relatives to seek psychological support, but either felt that it could do, or was too early to tell, or felt that it was still good to have the booklet as it could

benefit relatives *"Because people might feel a bit bashful, and I'm in hospital why do I feel so rubbish? … Or why do I think I need help, but if it's there as a side-effect if you like, then I think that probably is a helpful thing."(SP1b).*

SP2b thought it was good that that the contact details and information about psychological support and counselling was contained in the booklet *"as some of the nurses didn't know all these places existed as well".* In addition, before the booklet they had normally sent relatives to PALS but that was not always appropriate, but now *"if somebody asks, then you kind [of] know where to, to point them".* Significantly, both SP5b and SP8b thought that having the information in the booklet about possibly needing support and where to get it really highlighted to relatives that it was okay to need psychological support. SP5b was not sure how many relatives would actually seek psychological support but that it was an issue that had not been addressed before that needed highlighting.

Decision-making and preparing relatives

Relatives' understanding of decision making issues on ICU

Similar to the interviews in Study 1, staff members reported relatives' general lack of knowledge and understanding about the decision-making process on the ICU, and how they often had to explain how the process worked to relatives. SP3b felt that relatives' understanding of this issue was dependent on the individual because *"however much information you might give someone they might think that they have the, the ultimate say on what's happening with their relative".* SP6b remarked that relatives usually want to make a decision for their loved one and *"they think that's what we are asking them but we're not ….".* She was unsure that a booklet would be sufficient in providing information to relatives on this issue, but did think the information would be supportive to relatives so it should be included, particularly if they are feeling that *"their wishes, as the relatives, have been overridden"* by the doctors and they would need to know that they cannot make a decision on behalf of their loved one.

Impact of booklet on involvement of relatives in decision-making issues

Eight participants stated that the booklet would help prepare relatives for dealing with decision-making issues on the ICU by primarily informing them about what might happen if decisions needed to be made for their loved one. The majority of participants reported how the booklet had not changed how they approached the issue of decision-making with relatives, but, six participants reported that they thought the booklet would reinforce what ICU staff said to relatives about the decision-making process. SP1b and SP5b felt that the booklet had resulted in relatives being more

informed about the decision-making process. SP5b stated that the booklet acted as an adjunct by backing up what she said to relatives, whilst also providing additional information and knowledge.

SP2b felt that the booklet prepared relatives for the issue of decision-making by being *"quite sincere and it's quite frank"* and encapsulated the reality of the situation by expressing the seriousness of an ICU admission. She felt that the section on decision-making might induce relatives to broach the subject with ICU staff and ask questions about it. Participants' accounts indicated that previously if relatives felt they needed more information about decision-making issues on the ICU "*they would go home and then look things up on the internet, and they don't know what they're reading, the information where it's coming from, erm whereas, this is actually got it there and it's a reliable source." (SP5b)* This suggested that the booklet may provide relatives with enough information to prevent them from seeking it elsewhere. Participants felt that relatives would have more faith in the booklet because it was delivered by staff members as: *"they can believe and understand this more, well, I think they do, because it's coming from us, we're giving it to them" (SP5b)*

SP8b felt that the booklet would be useful before and after discussions about decision making issues with relatives because it *"provides a good contextual background, either before or after the conversation about what's been going on".* He felt strongly that relatives should be involved in the decision-making process on ICU and that the staff members would be *"guiding them"* so it was *"really important to have put something about it in the booklet".*

Understanding and disagreements

Most participants had experienced disagreements between ICU staff and relatives regarding decision-making issues at some point, or where there had been an issue and they had to explain the process in some detail to relatives. SP10b stated that *"when it happens it stands out in my memory and I guess it's on average once or twice a year that this becomes ... an issue."*

As a consultant, SP8b explained that he had witnessed outright confrontations between relatives and staff members in other institutions, which could sometimes *"leave families with a lasting scar".* He thought that it was important that staff work in *"partnership"* with relatives and the referring teams on the ICU, as this could help to avoid any *"significant disagreement",* but this could still be complicated because decisions regarding *"end of life, where to go, escalation of therapy, are all significant events, so by definition, disagreements on these issues are erm, er, are significant".*

Feedback from ICU staff members about booklet

Booklet outcomes: relatives' knowledge and understanding of the ICU

All participants felt that the booklet improved relatives' knowledge and understanding of ICU and it accomplished this in numerous ways, such as: *"the explanation of the machines and explanations of why we have our visiting hours, why we do what we do" (SP1b)*. The booklet was clear, highlighted problematic areas and illustrated the ups and downs of ICU by explaining the nature of critical illness and how quickly it can change, and the difference between ICU and normal wards. Participants liked how the booklet detailed *"the shops and cafes and where to get things" (SP3b)*, whilst also explaining things in *"very good layman's terms" (SP4b).* SP4b was pleased how the booklet addressed issues around discharge of patients, preparing patients to leave the unit, and going from 1-1 care to a normal ward. SP5b really liked the picture of the ICU bedspace and SP8b felt that the booklet helped relatives to understand the ICU because it was so comprehensive in the information it provided. SP9b thought that the booklet helped relatives to understand more about advance directives, which was an issue along with wills that the nurses were sometimes worried about broaching with relatives.

Most effective information in booklet

Six ICU staff members outlined a number of informational points in the booklet that they felt were most effective, such as the process of transferring to a general hospital ward from ICU, the explanation about the visiting hours, and having the photo of the ICU bed with the equipment around it. *(See Appendix B17 for Most Effective Booklet Information)*

Favourable view of booklet

All participants complimented the booklet in general and in some cases specific sections of it. This included positive remarks about the content, appearance and impact of the booklet:

> *"because ... it touches everything you know and it kind of gives a vision of what happens, you know, in the later stages if everything goes well and the patient gets better or if the patient dies, you know, so it kind of covers all, all angles, which I think is great, you know, and because it has to be realistic as well." (SP2b)*

SP4b reported that he thought the booklet was *"a really, really good resource"* and SP8b thought that the booklet was *"excellent"* and that it was *"quite comprehensive"*, whilst SP2b commented that the booklet covered everything and she couldn't think of anything else it should have mentioned, with her final words being: *"Yeah it's an excellent piece of work".*

Booklet appearance

SP3b thought the booklet looked more professional than the information sheet they had used previously because it was in colour and *"not just a piece of paper"* and thought that the format was also improved. SP9b reported that *"even the physical appearance of the booklet rather than a scrap of paper, helps, and like even what it's made out, I know it, it sounds a bit silly but even what it's made out of, it doesn't just get crumpled in your bag ... so you can't even bend it".* SP5b was of the opinion that the booklet *"looks really good and erm I think it does help the relative understand and also for the patients when they go as well, to have a look through and understand why things happen."*

Content concerns and suggestions

Essentially participants were very satisfied with the booklet but there were a few concerns related to booklet content and some participants suggested additions. SP3b was uncertain about the picture of the ICU bedspace, she felt it was useful but was concerned that it might give the *"impression that every patient will have, a kidney machine and you know every patient will be on a ventilator."* She felt this could be rectified by highlighting in the booklet that not all patients would need to be attached to all of the equipment and machinery presented. SP5b felt that some of the terms in the glossary might be unnecessary, such as 'Acidosis' and 'CPAP':

> *"I know we always try talking in layman's terms, erm but I think something like that, that you know 'acidosis', is not really appropriate where your 'speaking valve' is really appropriate ... especially for long term renal patients."* (SP5b)

SP8a reported that *"there are two bits that actually I feel quite strongly about."* These were related to a section which explained to relatives what sort of emotions they might feel on the ICU and not to take anger out on the ICU staff. He agreed with the message but felt it needed rephrasing to better express that staff were there to support them. The second area he felt *"extremely nervous about although it is very popular phraseology"* was related to a description about the best interest of the patient in the section about decision-making where it stated: 'Occasionally the best interest of the patient might not be to survive, if survival means they have no quality of life'. He felt that 'best interest' was a *"very complicated medico-legal term"* and that the sentence needed re-phrasing as it seemed rather *"paternalistic"* and made him feel uncomfortable.

SP9b was concerned that due to the quantity of information in the booklet relatives may end up skim-reading it and thus miss important sections because *"they'll probably look for the key things like the transport and ... especially things like if they read about confidentiality or something like that, that probably might mean absolutely nothing to them."* She also had minor concerns about

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including information related to the death of a patient and organ donation in case it was too much for relatives to cope with, but thought the information was good and phrased correctly.

SP6b made several suggestions such as: not having 'relative and friend' mentioned throughout the booklet but mentioning it at the beginning and then *"henceforth, the patient, your relative or friend will be described as the patient."* She also suggested stating who the unit matron was and mentioning the directors of the CCUs as this could give the unit credibility which *"can only be reassuring for the family"*. In addition, she suggested the booklet could also include the size of the units and the number of doctors and consultants: *"it doesn't say that there are 35 doctors or, you know, 23 consultants."* She thought relatives might be interested to know that it was the third largest CCU in the UK and suggested information could be added about the different CCUs/HDU areas and how patients can be accommodated on all of the CCUs at KCH, regardless of condition.

Booklet delivery and pilot

From the participant's accounts, it seemed that the pilot of the booklet was not long enough to properly evaluate how effective the booklet was with helping relatives to cope on the ICU. The pilot had also been conducted over the Christmas and New Year period, and it had been *"quite emotionally drained upstairs". (SP3b)* SP3b felt that communication with relatives had *"been quite good over the Christmas period"* but was unsure whether this was a result of the booklet or not. SP9a thought that it was not a *"bad time to have done it at all."* Significantly, SP6b related that there had been *"of a lot of end of life decision-making"* over the Christmas period and she had observed that relatives appeared much more receptive than usual in bringing up the subject of organ donation. She was unsure as to whether this was due to the young age of the relatives, whether that generation was more receptive, or if it had been as a result of the booklet, but she reported that it wasn't a topic that was normally broached by the relatives.

Next steps for the booklet

Standard procedure

Eight participants stated that the booklet should definitely be provided to relatives as standard practice on the CCUs:

> *"I think it would be a good thing, I ... genuinely do, I really like it ... I think we are a good unit and I was quite surprised that we didn't have anything like it before and I do think this is really good, so I think they should keep it." (SP1b)*

One participant felt that it could become part of their practice on the units but in order to do so the workforce would need to be completely behind it, which might prove difficult as sometimes 50% of their shifts were being worked by agency staff and they had a high turnover of staff members.

Future of booklet

If the booklet were potentially going to be continued after the pilot had ended some of the participants had ideas as to how this could be accomplished. SP7b felt that the staff needed to improve on giving out the booklets to relatives and this needed to be properly included as part of the KPACE form procedure: *"there's a box there 'has a visitor's leaflet been filled out?' So I've been auditing the KPACE forms and we're not particularly good at filling out the forms let alone giving out the booklets and all of the correspondent part to it, so ... So we need to improve on that, yeah."* SP9b felt that to prevent relatives possibly skim-reading the booklet staff should be educated to point out relevant pages or sections to them and maybe even *"star certain things".* She felt it was the responsibility of the CCU staff to improve the process of delivering the booklets to relatives and *"to help make it, better".*

CHAPTER 4: DISCUSSION

4.1 Summary of findings

In Study 1 this research aimed to explore patients' relatives' experiences of the ICU and those of ICU staff members, to explore their experiences of interacting with relatives and what they felt relatives' needs were on the ICU. In Study 2 the aim was to develop an informational intervention to help relatives to cope with the experience of having a loved one admitted to ICU. The data obtained from participants in Study 1, in terms of their experiences, particularly related to specific areas of ICU and their suggestions as to the contents of the intervention booklet also informed the intervention in Study 2. Both studies helped to answer the research questions posed at the start of the project. The findings of Studies 1 and 2 will be discussed in relation to these original research questions and whether or not they are supported by the current literature.

The potential of an informational booklet with verbal support to help patients' relatives and friends to cope with having a loved one on the ICU.

Study 1

The findings suggest that there was great potential for an information booklet as a supportive intervention for patients' relatives. It was apparent that there are various stages where an

information booklet may be a very useful resource to patients' relatives. Firstly, during the initial stages, such as the admission process of the patient, the need for relatives to be more prepared in understanding critical illness, the strange and often alien environment of an ICU (ICUsteps, 2014), and the appearance of the patient. This was particularly pertinent in terms of a patient being unconscious and attached to bedside machinery and monitoring equipment, in addition to their physical appearance, which participants reported could be significantly different from the norm and an aspect they found very difficult to cope with.

Potentially if the lay participants had been provided with an information booklet in addition to verbal information from nursing staff from the moment they arrived on the unit to see their loved ones this may have helped prepare them for the sights, sounds and experiences on the ICU. Staff members in Study 1 felt it would be useful especially for relatives who may be too distressed to retain large amounts of verbal information, which is a finding widely supported by the current literature (Duff, 2006; Hughes *et al.* 2005; Ogden, 2007; Myers & Abraham, 2005; Weinman, 1990). In reality, there may be no time for relatives to receive a booklet if the patient has already been admitted and the relatives arrive later, as under these circumstances they would probably be taken straight to see them. However, many of the lay participants who arrived around the same time as their loved one to the unit reported that they had to wait up to an hour or even longer to see them whilst they were being settled. Potentially this would be an ideal time in which a member of ICU staff not involved in admitting the patient, could provide an information booklet to relatives which they could read whilst they waited. If this was also accompanied by a verbal explanation from the staff members as to the relevant contents of the booklet and possibly an explanation about what was happening with the patient, this may also aid in the relatives' understanding and comprehension of the information and the circumstances (Duff, 2006; Hughes *et al.* 2005; Myers and Abraham, 2005). The verbal explanation would also be a necessary part of delivering the booklet, particularly if relatives are potentially too distressed to absorb the written material (Stricker *et al.* 2009).

Moreover, there were further stages throughout the participants' experiences which also suggested that an information booklet may be a beneficial addition. Such as, having a lay information section on how the decision-making process for patients who lack the capacity to make their own decisions is handled in the UK. This would be in order to prepare relatives so they understand their rights and those of the patient if such an event transpires. The need for written information about this process was demonstrated by the lack of understanding of this area amongst some of the lay participants and by comments from ICU staff members who reported that the majority of relatives did not

understand the decision-making process. It was also recommended by Dimond (2008), to enhance relatives' understanding of the law and practice of this process.

In addition, the adverse psychological impact of ICU upon patients' relatives was reported by lay participants and staff members, which indicated that relatives could be affected psychologically during several stages of the ICU experience. This included the experience of having a loved one on an ICU, transfer of the patient to a normal hospital ward, and once the patient was discharged from the hospital. These findings suggests it might be beneficial for relatives if they were provided with an information booklet which explains and normalises how they could be affected psychologically by the experience of ICU whilst also providing information about the patient pathway from admission to discharge. It could accomplish this by illustrating the stages that some relatives find particularly difficult to cope with and offering contact details and information of appropriate support services. This finding was reflected in McAdam *et al.* (2012) who determined that relatives of ICU patients who had survived and relatives of patients who had died on the ICU, continued to have a significantly increased risk of symptoms pertaining to PTSD, anxiety and depression, to which they posited that perhaps ICU is simply traumatising to patients' relatives, regardless of the outcome of their loved one.

In terms of coping with the experience of having a loved one on an ICU, the majority of the lay participants appeared to cope relatively well, in some cases developing their own coping strategies and were aware of what helped them to cope and what did not, such as avoiding telephone calls and nominating a close family friend to relay information about the patient to distant family and friends. Many of the lay participants could be classified as "monitors" (Hickman *et al.* 2010; Miller, 1995) in that they wanted to know as much information as possible about everything to do with the care and treatment of their loved one and the ICU, and were as proactive as they felt they could be in the involvement with their loved ones' care and treatment. For these relatives an information booklet might have been welcomed and indeed the proposal of one being developed for patient's relatives on the ICU was actively encouraged by the lay participants and the staff members who were interviewed in Study 1. There did not appear to be any "blunters" amongst the lay participants, namely individuals who tend to find sources of information threatening and stressful so avoid or distract themselves from them (Hickman *et al.* 2010; Miller, 1995), but for relatives who are categorised as such it is possible that an information booklet may be more acceptable than verbal information from staff members as they would only read the book if they wanted to and at their own leisure.

The information and communication needs of critically ill patients' relatives and friends on the ICU (particularly relatives who's loved one lacks the capacity to make their own decisions).

As the literature review suggested, communication and information provision were significant aspects of the ICU experience for patients' relatives and staff members on the ICU. Lay participants' needs for information about their loved one and about the ICU were identified consistently within the participants' accounts. These included their immediate needs from arriving on the unit and wanting to see their loved one as soon as possible, be provided with information as to exactly what had happened to them, and to hear a prognosis, which were similar findings to those of Kinrade *et al.* (2009). These needs were seen as imperative to lay participants and were reflected in the experiences of ICU staff members of what they felt were relatives' immediate needs. These were usually followed by a desire for relatives to know about the bedside equipment and its functions, general information concerning the ICU such as visiting times, location of the visitor's room, where to get food and drink, the location of other facilities such as visitor's toilets, and wanting to be continually updated by ICU staff on their loved one's progress. These needs were also consistent with findings by Kinrade *et al.* (2009) and Kosco & Warren (2000). In addition, it supported Walters (1995), who cited that relatives' information needs were greatest within the first 72 hours of the patient being admitted to an ICU.

In addition, Paul & Rattray (2007) cite that communication during the admission period can influence the perceptions of relatives as to whether their needs are met. Unmet needs suggested a lack of key information provision regarding aspects such as the ICU environment, reasons for procedures, medical equipment, and information pertaining to the patient's condition. Another information need was evident in the accounts of the lay and staff participants in Study 1 and this involved relatives needing to understand why they were often asked to wait in the visitor's room while nursing staff either settled the patient onto the unit or had to perform certain procedures which it was inappropriate for the relatives to be present for. The lay participants mentioned this as being a cause of additional anxiety when they really wanted to see their loved one. This anxiety would be intensified if staff did not tell them how long they would have to wait for or if staff neglected to tell them what was happening straight away. Staff members reported this issue was something relatives found hard to understand.

One of the needs that Kinrade *et al.* (2009) identified in their study was that relatives wanted to be told the truth about their loved one even if it was distressing for them, and this need for relatives to receive information about the patient, whether it was positive or negative, was also cited in a literature review by Linnarsson, Bubini & Perseius (2010). For the most part this was reflected in the

participants' accounts in the current study by the lay participants and by ICU staff, who felt being direct and honest with relatives about what was happening to their loved one was crucial to helping them to understand the seriousness of their loved one's condition and preparing them for what might happen. However, one of the lay participants who had been oblivious to how ill her son had been whilst he was on an ICU, reported that in retrospect she would not have wanted to know how serious his condition was, as not knowing gave her hope that he would survive. This was quite an unusual response compared to other participant accounts. However, Paul & Rattray (2007) commented that hope was a prerequisite for relatives' coping with a loved one's critical illness and suggested that hope could potentially have an empowering effect upon relatives' coping ability. Indeed, the deliverance of hope or being optimistic about a patient's condition was also seen as important by two of the staff members interviewed (a consultant and a nurse) who tended to offer optimistic comments after giving a worst case scenario to relatives. This could indicate that despite the majority of relatives desiring honest information about their loved one's condition (Kinrade *et al.* 2009; Kosco & Warren, 2000), perhaps tempering this information with a sense of hope (if the patient's condition has the potential to improve), may be an effective approach for ICU staff members to employ with relatives to aid in how they cope with the experience of ICU.

Findings also suggested that a key area of information relatives needed to know was regarding the process of decision-making for patients who lack capacity to make their own decisions. Several of the lay participants were not aware of the UK law around this issue or what their role would be in such an event. Similarly, staff members reported that this was an area where relatives had very little knowledge and understanding, which could at times cause friction between staff and relatives when important medical decisions needed to be made for a patient who lacked capacity. Staff members reported that relatives would often think that they were asking them to make the decisions when they were not, or the relatives wanted to make the decisions and could not understand why it was the medical staff members' responsibility. Several relatives reported how they wished they had been provided with information on this area (particularly in written form) earlier on in their ICU experience. These findings were consistent with Dimond (2008) who asserted that it would be helpful if patients' relatives were provided with written information about this process to prepare them in the event that their loved one lacks the capacity to make their own decisions.

In terms of communication needs of relatives, findings revealed the importance of relatives being able to speak to staff members and ask them questions about the patient and the ICU, how and when information was communicated to relatives, and fostering good relationships between relatives and staff members. Both sets of participants mentioned events where there had been

severe breakdowns in communication between relatives and staff members on the ICU, which served to highlight how paramount good communication needs to be between them. The research suggested that relatives were more empowered if they felt informed and involved in their loved one's care and treatment, and having trust in ICU staff members and receiving honest and direct information from them appeared to provide reassurance to relatives. This is also consistent with Kosco & Warren (2000) who identified that one of the most important needs of patients' relatives besides information and seeing the patients frequently, was assurance that the best possible care was being given to their loved one and this was reported by relatives and nursing staff in their study.

The issue of relatives having trust in staff members in Study 1 was highlighted as important for both sets of participants, where staff members realised the need for relatives to trust them and in many cases would forge bonds of trust via daily interactions with relatives around the bedside. The issue of trust was also mentioned in Paul & Rattray (2007) in terms of relatives needing to feel trust in their healthcare provider's ability, and was poignantly felt by one lay participant in particular, in Study 1. She lost her trust in staff members due to a breakdown in communication resulting in her and her family temporarily feeling powerless and having no trust or assurance that select members of staff were providing the best possible care for her husband. The experience also made her hyper-vigilant, causing her to behave as if she was on guard around her husband after the incident, as she feared for his safety. Patients' relatives behaving in this manner on the ICU due to feeling uncomfortable with the nursing staff was also reported in Hupcey (1999).

Findings also highlighted the communication skills of nursing staff and the importance and necessity of ICU nurses in particular receiving specific and comprehensive communication skills training before embarking on employment on an ICU. This was in part due to the often stressful and intensive working environment which could be quite daunting to new and junior nursing staff. The need for nurses receiving effective communication skills training was consistent with the findings of Mullan & Kothe (2010), who determined that a wide range of teaching methods needed to be employed to improve the communication skills of nurses so that they were confident and competent in utilising them effectively.

The majority of the staff members in Study 1 were relatively happy with the way they communicated with relatives but there was a general consensus that there was always room for improvement. In some cases further communication skills training would be welcomed. In addition, consultant and nurse participants reported wanting to spend more time being able to speak to relatives, but were usually thwarted by doing so due to the ICU being so busy. This was in part also reported in Hupcey (1999) whereby if the patients' relatives' loved one was stable, the nurse may need to look after

another unstable patient. This limited the time they could spend with the relatives who did not always understand the shift in the priority of care. Apart from one particular incident, the experiences of relatives' communications with ICU doctors were very positive in Study 1, which did not reflect the inadequate communication experienced by 50% of critically ill relatives reported by Gauntlett & Laws (2008). However it does highlight the need for ICU staff to communicate clear explanations to relatives so that relatives understand the situation and to ensure that information provided is not misconstrued (Lowson, 2007).

The importance of psychological support for patients' relatives and friends on the ICU.

All participants involved in Study 1 thought that providing some form of psychological support or a counselling service on the ICU would be very useful and beneficial to patients' relatives. Several lay participants stated how they would have utilised such a service had it been available to them whilst their loved one was on an ICU. Also highlighted was how important it was to have the service as part of the ICU rather than a separate service in a different location, so it could be readily accessible to relatives when they were most in need of it. There was also a need for psychological support at a later stage after the patient had been discharged from the hospital, as some participants found this period of time very difficult and reported PTSD symptoms, which is consistent with the findings of McAdam *et al* (2012). However, this need for psychological support post patient discharge could potentially be prevented if therapeutic support is received at an earlier stage on the unit to help relatives to cope and could denote a need for psychological follow up of relatives to coincide with the follow up process for patients.

Another significant finding in Study 1 related to this issue was the need for a psychological support or counselling service for ICU staff members. They reported that it could be of benefit, particularly in the form of debriefing sessions where staff members could meet as a group and discuss complex issues and patient cases that they had found difficult to cope with. There were reports of the occasional de-briefing session having already been facilitated for ICU staff members at the hospital, and participants reported that the staff who attended provided positive feedback on them. This finding is supported by Santiago & Abdool (2011) who found that regular debriefing sessions for ICU staff members served to improve the care of patients, communication with patients' relatives, and promoted staff well-being.

Appropriate content and method of delivery of an intervention that includes an information booklet for patients' relatives on the ICU.

Focus Group

Participants provided a wealth of feedback on the proposed intervention which included the first draft of the information booklet, in terms of its appearance, content and delivery. Concerning the booklet's appearance, aspects that seemed particularly important to participants focused on how the booklet was structured, the design, the typeface, and the front cover. Participants were very positive about all of these aspects, especially how the booklet was laid out and the style in which it was written, particularly certain areas that included complex information, such as the section which explained in lay terms, the decision-making process for patients who lack capacity. They felt this was phrased in a firm, but supportive, compassionate and non-confrontational way which they reported was often difficult for them to achieve verbally. It was also felt that the booklet would help diffuse potential conflict between staff members and relatives on the ICU because it clearly put the needs of the patient first. This was an important factor to receive positive feedback about as the readability of an information booklet, particularly medical related information, can influence the satisfaction and utilisation of it by a target audience (Butow *et al.* 1998; Menghini, 2005).

Concerning content, participants were positive about the information already included in the first draft of the booklet, and made a few suggestions for rephrasing or omitting details primarily related to relatives staying overnight at the hospital and number of visitors per bed. They also wrote positive and constructive comments on the copies they were given at the start of the group about these aforementioned points and added suggestions of additional words and explanations to the glossary of terms at the back of the book. Participants discussed other issues about the ICU that were helpful in informing the content of the final draft of the booklet, and covered issues relating to communication and information provision many of which were reinforced by different participants in Study 1. These included how staff communicated with relatives, communication skills of the nursing staff, preparing relatives for the ICU and what to expect, playing music for loved ones, and respecting patient dignity. This suggested that these were key informational ingredients that needed to be added or amended where appropriate in the final draft of the booklet. All of the issues discussed were primarily in relation to the contents of the information booklet and how they felt the booklet would be received and utilised by relatives.

In terms of booklet delivery, the participants reacted quite negatively to the original proposal of having a verbal script of what to say to relatives when delivering the booklet; they were more in

favour of a brief guide as to how to deliver the booklet whilst using their usual tried and tested methods of communicating with relatives. They also felt the intervention could not be monitored during the pilot and there should be more trust in the nursing staff to provide the intervention as instructed. This response is not surprising when the findings from Study 1 and the focus group in Study 2 clearly indicate how important communication is to ICU staff, in particular, the nursing staff who have the most contact with patients relatives (Keenan and Joseph, 2010; Badger, 2005), and thus very established ways of communicating with them.

Study 2 - Initial evaluation of the intervention (after pilot)

Participants provided feedback on the pilot of the intervention and how they felt it was received by relatives. Due to having fairly minimal contact with relatives over the admission process during the pilot period, staff members reported limited feedback from relatives, but what they did report was universally positive. Similarly the feedback from staff members regarding their thoughts on the booklet was also positive but the length of the pilot was highlighted as not being long enough to provide any kind of comprehensive evaluation. Staff members mainly provided feedback on what they thought about the booklet and how they felt it may be utilised by relatives if provision was continued on the CCUs over time.

Findings from this stage of Study 2 provided further answers to the initial research questions answered by Study 1. Feedback from staff members reinforced the need for the information booklet to become standard practice on the units with the aid of verbal support i.e. nursing staff explaining relevant sections to relatives during admission. In addition, the majority of the participants were of the opinion that the booklet would help relatives to cope with having a loved one on the ICU, primarily due to being informative, concise, and written in lay language. The booklet prepared relatives by providing relevant and detailed information about the ICU and about what relatives should expect to see and experience at all primary points of the ICU patient pathway. In addition, it appeared to comprehensively meet the information needs of relatives on the ICU, and these needs could be further supplemented by verbal information from ICU staff members, particularly the bedside nurses. Reported outcomes of the booklet enhancing relatives' knowledge and understanding of all aspects of the ICU is consistent with the findings by Azoulay *et al.* (2002), who found that their family information leaflet significantly improved patients' relatives comprehension and this was associated with improved satisfaction.

The booklet appeared to reinforce verbal information imparted by staff members to relatives, in preparing relatives for events before they encountered them or by reiterating what staff members

had already said to them. Not only was this seen as potentially useful in terms of communications but it also had the propensity to result in relatives asking fewer questions, or at least be more focused on the patient due to having general questions about the unit answered by the booklet. It was also indicated that the booklet may prevent relatives from seeking information from more unreliable sources such as the internet.

The majority of the participants felt that the booklet would prepare relatives for decision-making issues for patients who lack capacity, and only minimal concerns regarding it were expressed by one participant. However, the participant in question had not given the booklet to any relatives and his opinions were regarding the rephrasing of two paragraphs only; one of which was situated in the section of lay information about the decision-making process, rather than material that he thought should be omitted. Although none of the other participants shared his view of what he felt was potentially problematic phraseology, it was still valid and would be worth reviewing in any future updates and evaluations of the booklet.

Findings also added further weight to the importance of having a psychological support or counselling service for relatives and staff members on the ICU, which had been significantly indicated in the findings of Study 1. Although only one participant reported how he had witnessed the booklet actually encouraging relatives to seek psychological support, just having the details in the booklet on how to access services currently available in this regard was considered helpful to relatives and to some staff members who were also unaware of what was available. Moreover it made the idea of seeking psychological support or counselling an acceptable and understandable concept and by having this section in the booklet future relatives would be encouraged to seek necessary support.

4.2 Limitations of the research

Despite the number of booklets delivered to relatives over the two week pilot period, only a small number of staff members who delivered them were interviewed for the project and this will have limited the information obtained on finding out how appropriately they were delivered by the nursing staff and the reporting of relatives' responses to them. In addition, the pilot was not long enough for a thorough evaluation of the booklets to take place. However, this was expected to a certain extent as the project was primarily focused on the development of the intervention rather than the evaluation of it, with any further evaluation considered outside the scope of the project.

Moreover, due to the ethical issues encountered by the researcher prior to the project when the original research proposal was to interview relatives on the units for Studies 1 and 2, this was not

considered ethical due to the relatives being a vulnerable population. Hence why the lay participants involved in Study 1 were all ex-ICU patient relatives recruited from around the country with no relationship to the ICU at Kings College Hospital. This was also the reason why no relatives were directly interviewed about how they felt about the booklet in Study 2, which if they had, could have potentially provided a more powerful and comprehensive evaluation. Instead relatives' responses had to be reported via the staff members who had interacted with them on the CCUs.

In terms of the research methodology being qualitative there is always a risk that due to its subjective and phenomenological approach, data obtained from participants can be open to bias of interpretation by the researcher, a risk of untruthful information from participants, and results that may not be considered applicable to the greater populace. However, steps were taken to reduce these potential limitations by the intensive immersion of the researcher in the data, ensuring samples of coding were checked by an academic supervisor, following rigorous stages of a robust model of thematic analysis, asking participants suitably open questions, and conducting a large number of interviews to ensure enough data was collected to effectively answer the questions which the research project set out to investigate.

4.3 Implications of the research

The research has indentified particular needs of patients' relatives on the ICU and how they appraise and cope with the significant stressor of having a loved one as a patient on the ICU. It has shown how an informational intervention with verbal accompaniment can be an effective resource for relatives on the ICU and have a positive impact on the way they cope with the experience. It demonstrated the potential psychological needs of relatives and the requirement for relatives to be more prepared for the potential eventualities of ICU. In addition, it elucidated the need for information that increases relatives' knowledge and understanding about decision-making issues for patients who lack capacity and where as the patients' relatives they stand in this complex process. It also indicates how this specific information is a vital component in an ICU booklet for patients' relatives and one that before this project was not normally included in ICU information booklets.

4.4 Recommendations

It is recommended that the CCUs on which the booklet was piloted do attempt to further evaluate the booklet, particularly if they wish to use it on a long term basis. They should consider using quantitative approaches, such as a survey method to obtain more concise and objective data directly from the patients' relatives in addition to qualitative approaches. They may also want to adapt it for use over the new units that were being developed during the time this project was taking place and

possibly for different age ranges of relatives e.g. children and adolescents, including a version for ICU patients who may be lucid enough to read it too.

4.5 Concluding remarks

This research project adds a new dimension to the evidence base provided by similar studies that have been conducted prior to it, by offering new insight into the experience of patients' relatives and staff members working on intensive or critical care units. Furthermore, it highlights the needs of relatives regarding communication with staff members and necessary information provision. It identifies the psychological impact of ICU and addresses the needs of relatives whilst on the unit and after their loved one has been discharged. Ultimately the research has developed an intervention to encompass all of these areas through a combination of written and verbal information. The aim being to mitigate the stressful experience of having a loved one admitted to an ICU, by helping patients' relatives to cope and more effectively manage the traumatic circumstances that such a life changing event can bring.

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APPENDIX B1: COVER LETTER TO PARTICIPANTS

████████

███████████

Work Mobile: ████████   Work email: █████████████████

2013

Dear

Thank you for your interest in participating in my research project about helping relatives of critically ill patients to cope on the ICU.

I have enclosed the following documents:

- One copy of the Participant Information Sheet
- Two copies of the Participant Consent Form
- One stamped addressed envelope

Please read the Participant Information Sheet very carefully before you decide to take part and keep it for your records.

If, after reading the Participant Information Sheet, you still wish to participate in the research, please read the enclosed consent form. On page 1 of the consent form there will be 7 statements with a box to the right of each one. If you agree with each of the statements please put your initials in the boxes.

Beneath the statements you will find a further three statements in a row, which asks you whether you wish to receive information about the research findings, please delete the statements as appropriate.

On page 2 of the consent form please write your name, the date and your signature at the top of the page where it states. Beneath this the form will ask you for your name, address and contact numbers, even though I may have these already please put them on the consent form too.

Please keep one copy of the consent form and post the completed and signed copy back to me in the stamped addressed envelope enclosed.

If you decide you would rather not participate after all, that is absolutely fine, just let me know. If you have any questions or queries including about filling in the consent form, please don't hesitate to contact me on the details at the top of this letter.

Kind regards,

APPENDIX B2: PIS - RELATIVES

Participant Information Sheet – Relatives

Title of study: The development of an informational intervention to help critically ill patients' relatives and friends cope with an unplanned ICU admission.

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

There are two parts to this study; part one is about exploring patients' relatives' experiences of intensive care and part two is to develop an intervention to help relatives and friends of patients on the intensive care unit (ICU) at Kings College Hospital (KCH). An 'intervention' is something that is put in place to hopefully improve a situation and help the people involved in that situation. The intervention will be a leaflet designed for patient's relatives on the ICU, which provides information about the ICU and what to expect whilst there, to prepare relatives for the experience. The staff members who provide the leaflet to relatives will also explain what kind of information the leaflet contains and mention certain information in more detail if they think this will benefit the relatives at that time. The leaflet will be provided to patients' relatives on the ICU for a period of two weeks and then ICU staff will be asked about how it was received and if they thought it was successful in helping patients' relatives. It is hoped that patients' relatives and friends will feel they have the resources to cope with the experience of their loved one being admitted to the ICU, by the leaflet providing: useful information about the unit and patient care; improving the ways in which ICU staff and patient's relatives and friends communicate with one-another; and ensuring that patients' relatives and friends feel involved, reassured and supported through what can be a traumatic experience. This research study is to be written up as the researcher's doctoral thesis at City University.

Why have I been invited?

You have been invited to participate in this research project because you fit all of the following inclusion criteria:

- You once had a loved one (spouse, partner, family member) who was a patient on an ICU
- Your loved one had been an unplanned admission to the ICU
- Your loved one had lacked capacity to make decisions for themselves during their stay on the ICU
- Your loved one had survived their stay on the ICU and was discharged.
- You are able to give informed consent
- You are able to read, write and comprehend the English Language.

There will be approximately 9 other ex-patients' relatives in this study with the potential for up to 10 more, and approximately 16-20 ICU staff members, but you will only have contact with the researcher.

Do I have to take part*?*

No. Participation in this study is voluntary and you can choose not to participate in part or all of the study. If you do participate, you can withdraw at any stage or avoid answering questions which are felt to be too personal or intrusive, without being penalised or disadvantaged in any way. It is up to you to decide whether or not to take part.

What will happen if I take part?

The study will last several months but as a participant your involvement will be brief. You would be interviewed once, by the researcher about your experiences of being a patient's relative on an ICU. This would involve various questions related to your experience of the ICU as a patient's relative; these may include your knowledge and understanding of the ICU at the time; any needs you may have had on the ICU, and how you coped with the experience. The interview will be semi-structured, which means that the researcher will ask you a set of open questions. The interview should take approximately 30 minutes and would be recorded using a digital voice recorder.

What do I have to do?

If after reading this sheet you decide you would like to take part in this project, then please read the attached participant consent form very carefully. If you agree with all of the statements on the consent form please initial the boxes and follow the other instructions on the form. Post one copy of the form to the researcher in the stamped addressed envelope provided, keeping the other copy for your own records. If you have any questions about this information sheet or the consent form, please do not hesitate to contact the researcher who can advise you on what to do. Once the researcher has received your consent form, they will contact you to arrange an interview at your convenience. Once you have attended the interview, your participation in the research will be complete. The researcher may send you a summary report of the results of the research if you have chosen that option on the consent form. You will not be required to do anything else for the research project.

What are the possible disadvantages and risks of taking part?

There should be no disadvantages to you if you participate in this study, other than the possibility that you may find talking about your experience of the ICU upsetting as it may bring back painful memories. The severity of this upset may be dependent on a variety of factors, such as how personally involved you were in the experience; the relationship you had with your loved one; the amount of time that has passed since your loved one was on the ICU; what happened to your loved one whilst they were on the ICU; and has happened to them since their discharge from the ICU. The researcher will ensure an accessible and safe location with a private and secure room in which to conduct the interview. There will be access to toilets and refreshments nearby. If you feel upset by the interview, please let the researcher know. If the researcher feels that you need to speak to someone else more qualified to help you, they will refer you appropriately. If you feel you need some additional support after you have taken part in the research, but don't want to speak to the researcher about it, you can contact the ICUsteps charity via the following methods:

- There will be an information page about the research project and a special contact form that you can use on the ICUsteps website. You can find the ICUsteps Website at: http://icusteps.org/.
- Alternatively you can write to the charity's registered address at: ICUsteps, 18 Fortescue Drive, Shenley Church End, Milton Keynes, MK5 6AU.
- Or, you can leave a voicemail message on this number: 0870 471 5238. If you leave a message someone from the charity will get back to you as soon as they can.

What are the possible benefits of taking part?

There is a possibility of finding the interviews a cathartic activity, meaning that you may find talking about the experience therapeutic, especially if you have not spoken about it much before. Another potential benefit may be the knowledge that your participation in the research will help to develop an intervention which could help future patients' relatives and friends to cope with the experience of having a loved one on an ICU.

What will happen when the research study stops?

If by any chance the study is stopped prematurely after you have taken part in it, your data may be kept until the study can begin again. If you decide to withdraw and wish for any data you have provided not be used in the project, we will respect your wishes. If you participate in the study the data you provide in the interview will be used in the development and write up of the research.

Will my taking part in the study be kept confidential?

Yes. Only the researcher will have access to your personal information details and you will be anonymised in the written report of the research, so no-one will know your identity. All information you provide in the interview will be kept confidential and no names of any

participants will be identified. Any personal information you provide such as your name and contact details will only be used to contact you about the research. The researcher will give the digital recordings of the interviews to a transcription company who will transcribe (write down word for word) the interview data so that the researcher can analyse it. The transcription company can also provide a non-disclosure agreement that will protect your anonymity. The interview transcripts will form part of the appendices of the research study report for City University; however the researcher will have given you a pseudonym (a false name) on the transcripts, so you will not be identifiable to anyone from the University. All research data will be kept on an encrypted and password protected USB stick and computer, which only the researcher will have access to. This will ensure confidentiality and protection of your data. Once the study has finished, any data you have given us e.g. in the interview, will be archived and kept securely for up to 5 years and then confidentially destroyed in accordance with NHS policy.

What will happen to the results of the research study?
The information you provide in the interview will be analysed and written up in a final report of the research. It is possible that the research may also be published at some point in one or more peer reviewed psychological and/or medical journals. You can also request access to the full written report or publication of the research once the study has ended, should you wish to *(details about this are on the consent form)*.

What will happen if I don't want to carry on with the study?
If you have started to participate in the study, you are free to withdraw from it at any point, without having to give an explanation as to why. Just let the researcher know that you no longer wish to take part. You will not be penalised or disadvantaged in any way for withdrawing. You can contact the researcher on the details at the end of this information sheet.

What if there is a problem?

If you would like to complain about any aspect of the study, City University London has established a complaints procedure via the Secretary to the University's Psychology Department Ethics Committee. To complain about the study, you need to phone: 0207 0408529. You can then ask to speak to the Secretary to the Psychology Department Ethics Committee and inform them that the name of the project is: "The development of an informational intervention to help critically ill patients' relatives and friends cope with an unplanned ICU admission". You could also write to the Secretary at:

Mrs Carmai Pestell
Secretary to Psychology Department Research and Ethics Committee
School Office A129
Schools of Arts and Social Sciences

City University
Northampton Square
London
EC1V 0HB

Who has reviewed the study?

Comments, concerns or observations procedure: This project has been approved by the Research and Ethics Committee of the Department of Psychology of City University London (project approval number PSYETH (UPTD) 12/13 57).

If you have any comments, concerns or observations about the conduct of the study or your experiences as a participant, please contact the Secretary to the Committee Mrs Carmai Pestell, quoting the above project approval number: Telephone: ███████████████
Email: ███████████████████ Postal Address above.

Further information and contact details

The researcher: Mrs Rosie Freedman. Email address: ████████████████████████
Telephone: ████████████ Researcher's academic supervisor, Dr Alice Simon. Email: ██████████████████████████Telephone: ████████████

Thank you for taking the time to read this information sheet.

CITY UNIVERSITY LONDON   **King's College Hospital** **NHS**
                                   NHS Foundation Trust

PARTICIPANT CONSENT FORM

The development of an informational intervention to help critically ill patients' relatives and friends cope with an unplanned ICU admission.

Name of Researcher/Chief Investigator (CI):   **Mrs Rosie Freedman**

Please initial the following boxes:

1. I confirm that I have read and understood the participant information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I can choose to withdraw at any stage of the project without giving a reason or being penalised or disadvantaged in any way.

3. I understand that all information I provide within the context of the research will be kept confidential and that no information that could lead to the identification of any individual will be disclosed in any reports or publications or to any other party. No identifiable personal data will be published or shared with any organisation.

4. I understand that all research data from this study will need to be kept securely for up to 5 years and then confidentially destroyed as per NHS policy.

5. I agree to the researcher named above recording (with a digital voice recorder) and processing this information about me, and for this information being transcribed by a trusted transcription company, who will provide a non-disclosure agreement if necessary so that my anonymity is protected. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.

6. I am aware that the findings of this research project will be written up as part of a doctoral thesis and could potentially be published at a later date, and that quotes taken from the information I provide in this research may be included in these.

7. I agree to take part in the above study.

Please delete as appropriate:
I would like a summary of the research findings/I would like to access a copy of the full report or publication of the research/I do not wish to receive any information about the research findings or full report.

| _____ | _____ | _____ |
| Name of Participant | Date | Signature |

| _____ | _____ | _____ |
| Name of Person | Date | Signature |

taking consent

Please write your name, address and contact telephone number below, so the researcher can contact you to arrange an interview. Your details will remain confidential and will only be used in the context of contacting you about the research.

Name:

Address:

Telephone number:

Mobile number:

Email address:

Comments, concerns or observations procedure:

This project has been approved by the Research and Ethics Committee of the Department of Psychology of City University London (project approval number PSYETH (UPTD) 12/13 57).

 If you have any comments, concerns or observations about the conduct of the study or your experiences as a participant, please contact the Secretary to the Committee Mrs Carmai Pestell, quoting the above project approval number:

 Telephone: ███████████   Email: ███████████

Postal Address:
Mrs Carmai Pestell
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Thank you for your time.

Participant Information Sheet – ICU Staff Interviews

Title of study: The development of an informational intervention to help critically ill patients' relatives and friends cope with an unplanned ICU admission.

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the project?

There are two parts to this study; part one is about exploring patients' relatives' experiences of intensive care and part two is to develop an intervention to help relatives and friends of patients on the intensive care unit (ICU) at Kings College Hospital (KCH). An 'intervention' is something that is put in place to hopefully improve a situation and help the people involved in that situation. The intervention will be a leaflet designed for patient's relatives on the ICU, which provides information about the ICU and what to expect whilst there, to prepare relatives for the experience. The staff members who provide the leaflet to patients' relatives will also explain what kind of information the leaflet contains and mention certain information in more detail if they think this will benefit the relatives at that time. The leaflet will be provided to patients' relatives on the ICU for a period of two weeks and then ICU staff will be asked about how it was received and if they thought it was successful in helping patients' relatives. It is hoped that patients' relatives and friends will feel they have the resources to cope with the experience of their loved one being admitted to the ICU, by the leaflet providing: useful information about the unit and patient care, improving the ways in which ICU staff and patient's relatives and friends communicate with one-another, and ensuring that patients' relatives and friends feel involved, reassured and supported through what can be a traumatic experience. This research study is to be written up as the researcher's doctoral thesis at City University.

Why have I been invited?

You have been invited to participate in this research project because you fit all of the following inclusion criteria:

- You are a qualified nurse, doctor or consultant working on the ICU at KCH
- You are able to provide informed consent
- You are able to read, write and comprehend the English Language.

Overall there should be approximately 24-30 ICU staff members participating in this study and approximately 8-20 individuals who have had the experience of being a relative of a patient on an ICU.

Do I have to take part*?*
No. Participation in this study is voluntary and you can choose not to participate in part or all of the study. If you do participate, you can withdraw at any stage or avoid answering questions which are felt to be too personal or intrusive, without being penalised or disadvantaged in any way. It is up to you to decide whether or not to take part.

What will happen if I take part?
You would be required to participate in two interviews: one before the leaflet is used on the ICU for 2 weeks, and the other afterwards. In the pre-pilot interview, the researcher will ask questions regarding issues such as communication with patients' relatives; information provision; relatives' knowledge and understanding about certain ICU processes such as decision-making; and about how relatives cope with the experience of having a loved one on ICU. In the post-pilot interview, the researcher will ask you about how the leaflet was received by patients' relatives and whether it has made any positive changes to the areas you were asked about in the pre-pilot interview. The interviews will be semi-structured, which means that although there will be a list of questions the researcher will ask you; these will be quite open and flexible. Each interview should take approximately 30 minutes and would be recorded using a digital voice recorder. The interviews will take place in the research department at Kings College Hospital, by the MCCU.

What do I have to do?
If after reading this sheet you decide you would like to take part in this project, then please read the attached participant consent form very carefully. If you agree with all of the statements on the consent form please initial the boxes and follow the other instructions on the form. Then give one copy of the form to the researcher whilst keeping the other copy for your own records. If you have any questions about this information sheet or the consent form, please do not hesitate to contact the researcher who can advise you on what to do. Once the researcher has received your consent form, they will contact you to arrange a date and time for the interviews at your convenience. Once you have attended both interviews, your participation in the research will be complete. The researcher may send you a summary report of the results of the research if you have chosen that option on the consent form. You will not be required to do anything else for the research project.

What are the possible disadvantages and risks of taking part?
There should be no disadvantages to you if you participate in this study. The interviews will take place close to the ICU. There will be access to toilets and refreshments nearby. If you feel upset by the interview, please let the researcher know. If the researcher feels that you need to speak to someone else more qualified to help you, they will refer you to someone who can.

What are the possible benefits of taking part?
There is the possibility that your participation in the research will help to develop an intervention which will help future patients' relatives and friends to cope with the experience of having a loved one on the ICU. In addition, this may make positive changes on the ICU in your future

communications with patients' relatives. Moreover, by agreeing to take part in the study you will have a chance to provide your expert knowledge and experience to the development and evaluation of the intervention.

What will happen when the research study stops?

If by any chance the study is stopped prematurely after you have taken part in it, your data may be kept until the study can begin again. If you decide to withdraw and wish for any data you have provided not be used in the project, we will respect your wishes. If you participate in the study the data you provide in the interviews will be used in the development and write up of the research.

Will my taking part in the study be kept confidential?

Yes. Only the researcher will have access to your personal information details and you will be anonymised in the written report of the research, so no-one will know your identity. All information you provide in the interviews will be kept confidential and no names of any participants will be identified. Any personal information you provide such as your name and contact details will only be used to contact you about the research. The researcher will give the digital recordings of the interviews to a transcription company who will transcribe (write down word for word) the interview data so that the researcher can analyse it. The transcription company can also provide a non-disclosure agreement that will protect your anonymity. The interview transcripts will form part of the appendices of the research study report for City University; however the researcher will have given you a pseudonym (a false name) on the transcripts, so you will not be identifiable to anyone from the University. All research data will be kept on an encrypted and password protected USB stick and computer, which only the researcher will have access to. This will ensure confidentiality and protection of your data. Once the study has finished, any data you have given us e.g. in the interview, will be archived and kept securely for up to 5 years and then confidentially destroyed in accordance with NHS policy.

What will happen to the results of the research study?

The information you provide in the interviews will be analysed and written up in a final report of the research. It is possible that the research may also be published in one or more peer reviewed psychological and/or medical journals. You can also request access to the full written report or publication of the research once the study has ended, should you wish to *(details about this are on the consent form)*.

What will happen if I don't want to carry on with the study?

Even if you have started to participate in the study, you are free to withdraw from it at any point, without having to give an explanation as to why. Just need to let the researcher know that you no longer wish to take part. You will not be penalised or disadvantaged in any way for withdrawing. You can contact the researcher on the details at the end of this information sheet.

What if there is a problem?

If you would like to complain about any aspect of the study, City University London has established a complaints procedure via the Secretary to the University's Psychology Department Ethics Committee. To complain about the study, you need to phone: 0207 0408529. You can then ask to

speak to the Secretary to the Psychology Department Ethics Committee and inform them that the name of the project is: "The development of an informational intervention to help critically ill patients' relatives and friends cope with an unplanned ICU admission". You could also write to the Secretary at:

Mrs Carmai Pestell

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Who has reviewed the study?

Comments, concerns or observations procedure: This project has been approved by the Research and Ethics Committee of the Department of Psychology of City University London (project approval number PSYETH (UPTD) 12/13 57).

If you have any comments, concerns or observations about the conduct of the study or your experiences as a participant, please contact the Secretary to the Committee Mrs Carmai Pestell, quoting the above project approval number: Telephone: ███–████–████–███ Email: ██████████████████████ Postal Address above.

Further information and contact details

The researcher: Mrs Rosie Freedman. Email address: ████████████████████ Telephone: ████ ████ Researcher's clinical supervisor, Dr Stephanie Strachan. Email: s████████████████████ Telephone: ██████████████

Thank you for taking the time to read this information sheet.

APPENDIX B5: PIS – FOCUS GROUP

CITY UNIVERSITY LONDON

King's College Hospital NHS
NHS Foundation Trust

<u>Participant Information Sheet – Peer Review Focus Group</u>

Title of study: The development of an informational intervention to help critically ill patients' relatives and friends cope with an unplanned ICU admission.

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the project?
There are two parts to this study; part one is about exploring patients' relatives' experiences of intensive care and part two is to develop an intervention to help relatives and friends of patients on the intensive care unit (ICU) at Kings College Hospital (KCH). An 'intervention' is something that is put in place to hopefully improve a situation and help the people involved in that situation. The intervention will be a leaflet designed for patient's relatives on the ICU, which provides information about the ICU and what to expect whilst there, to prepare relatives for the experience. The staff members who provide the leaflet to patients' relatives will also explain what kind of information the leaflet contains and mention certain information in more detail if they think this will benefit the relatives at that time. The leaflet will be provided to patients' relatives on the ICU for a period of two weeks and then ICU staff will be asked about how it was received and if they thought it was successful in helping patients' relatives. It is hoped that patients' relatives and friends will feel they have the resources to cope with the experience of their loved one being admitted to the ICU, by the leaflet providing: useful information about the unit and patient care, improving the ways in which ICU staff and patient's relatives and friends communicate with one-another, and ensuring that patients' relatives and friends feel involved, reassured and supported through what can be a traumatic experience. This research study is to be written up as the researcher's doctoral thesis at City University.

Why have I been invited?
You have been invited to participate in this research project because you fit all of the following inclusion criteria:
- You are a senior nurse working on the ICU at KCH
- You are able to provide informed consent
- You are able to read, write and comprehend the English Language.

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Overall there should be approximately 24-30 ICU staff members participating in this study and approximately 8-20 individuals who have had the experience of being a relative of a patient on an ICU.

Do I have to take part*?*

No. Participation in this study is voluntary and you can choose not to participate in part or all of the study. If you do participate, you can withdraw at any stage or avoid answering questions which are felt to be too personal or intrusive, without being penalised or disadvantaged in any way. It is up to you to decide whether or not to take part.

What will happen if I take part?

You will be required to participate in a focus group facilitated by the researcher, with approximately 9 other fellow senior ICU nurses, in order to peer review the first draft of the leaflet. You will be invited to provide feedback on the current version of the leaflet, and will be asked questions by the facilitator about its content, style, readability, etc, and how it should be delivered to patients' relatives with a verbal explanation i.e. should there be a script for staff to follow and what should be on the script. You will be emailed a copy of the leaflet prior to the focus group. If you are happy to participate in the focus group, please read the leaflet beforehand to save time on the day. The researcher will bring hard copies of the leaflet for each member of the group and pens so that you can make notes on the leaflet as to what you think needs amending, adding or omitting from it, during the group session. The researcher will record the focus group session using a digital voice recorder. The focus group should take approximately one hour. The information you provide in the focus group will help to develop the leaflet. The focus group will take place in the research department at Kings College Hospital, by the MCCU.

What do I have to do?

If after reading this sheet you decide you would like to take part in this project, then please read the attached participant consent form very carefully. If you agree with all of the statements on the consent form please initial the boxes and follow the other instructions on the form. Then give one copy of the form to the researcher whilst keeping the other copy for your own records. If you have any questions about this information sheet or the consent form, please do not hesitate to contact the researcher who can advise you on what to do. Once the researcher has received your consent form, they will contact you about the date and time slot of the focus group which will take place on one of the monthly senior ICU nurse training days at Kings College Hospital. Once you have attended the focus group, your participation in the research will be complete. The researcher may send you a summary report of the results of the research if you have chosen that option on the consent form. You will not be required to do anything else for the research project.

What are the possible disadvantages and risks of taking part?

There should be no disadvantages to you if you participate in this study. The focus group will take place close to the ICU. There will be access to toilets and refreshments nearby. If you feel upset by the focus group, please let the researcher know. If the researcher feels that you need to speak to someone else more qualified to help you, they will refer you to someone who can.

What are the possible benefits of taking part?

There is the possibility that your participation in the research will help to develop an intervention which will help future patients' relatives and friends to cope with the experience of having a loved one on the ICU. In addition, this may make positive changes on the ICU in your future communications with patients' relatives. Moreover, by agreeing to take part in the focus group, you will have a chance to provide your expert knowledge and experience to the development and delivery of the intervention.

What will happen when the research study stops?

If by any chance the study is stopped prematurely after you have taken part in it, your data may be kept until the study can begin again. If you decide to withdraw and wish for any data you have provided not be used in the project, we will respect your wishes. If you participate in the study the data you provide in the focus group will be used in the development and write up of the research.

Will my taking part in the study be kept confidential?

Yes. Only the researcher will have access to your personal information details and you will be anonymised in the written report of the research, so no-one will know your identity. All information you provide in the interview will be kept confidential and no names of any participants will be identified. Any personal information you provide such as your name and contact details will only be used to contact you about the research. Transcripts from the focus group will form part of the appendices of the research study report for City University; however the researcher will have given you a pseudonym (a false name) on the transcripts, so you will not be identifiable to anyone from the University. All research data will be kept on an encrypted and password protected USB stick and computer, which only the researcher will have access to. This will ensure confidentiality and protection of your data. Once the study has finished, any data you have given us e.g. in the interview, will be archived and kept securely for up to 5 years and then confidentially destroyed in accordance with NHS policy.

What will happen to the results of the research study?

The information you provide in the focus group will be analysed and written up in a final report of the research. It is possible that the research may be published at some point in one or more peer reviewed psychological and/or medical journals. You can also request access to the full written report or publication of the research once the study has ended, should you wish to *(details about this are on the consent form)*.

What will happen if I don't want to carry on with the study?

Even if you have started to participate in the study, you are free to withdraw from it at any point, without having to give an explanation as to why. Just let the researcher know that you no longer wish to take part. You will not be penalised or disadvantaged in any way for withdrawing. You can contact the researcher on the details at the end of this information sheet.

What if there is a problem?

If you would like to complain about any aspect of the study, City University London has established a complaints procedure via the Secretary to the University's Psychology Department Ethics

Committee. To complain about the study, you need to phone: 0207 0408529. You can then ask to speak to the Secretary to the Psychology Department Ethics Committee and inform them that the name of the project is: "The development of an informational intervention to help critically ill patients' relatives and friends cope with an unplanned ICU admission". You could also write to the Secretary at:

Mrs Carmai Pestell

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Who has reviewed the study?

Comments, concerns or observations procedure: This project has been approved by the Research and Ethics Committee of the Department of Psychology of City University London (project approval number PSYETH (UPTD) 12/13 57).

If you have any comments, concerns or observations about the conduct of the study or your experiences as a participant, please contact the Secretary to the Committee Mrs Carmai Pestell, quoting the above project approval number: Telephone: ██ ████ ████ ████   Email: ████████████████████   Postal Address above.

Further information and contact details

The researcher: Mrs Rosie Freedman. Email address: █████████████████████████████ Telephone: ████████████. Researcher's clinical supervisor, Dr Stephanie Strachan. Email: ████████████████████████████ Telephone: █████████████

Thank you for taking the time to read this information sheet.

Relatives Interview Schedule

Introductory script:

"Please come in and make yourself comfortable *(I point to participant chair)* and we will start the interview shortly. *(I sit down opposite the participant)*. Thank you very much for coming along today to participate in this research project. As described in the participant information sheet, the aim of the project is to develop an intervention (information leaflet with verbal explanation) for relatives and close friends (this includes spouses and carers) as a resource to help them cope with the experience of having a loved one admitted to the Intensive care Unit (ICU). We hope the intervention will help by improving communication between patients' relatives and friends, and staff members, providing timely and understandable information about the unit and the processes involved with this type of care, and ensuring that patients' relatives and friends receive support where necessary".

"During the interview I will ask you some questions pertaining to various aspects of your experience of the ICU. If you find any of these questions upsetting or you would rather not answer them, please let me know. You are free to withdraw from the interview at any time, or withdraw from the project completely if you wish to. Everything you say to me is in the strictest of confidence and I will ensure your anonymity when I write up the project. Do you still wish to participate in this research project?" *(If yes) "*That's great, thank you". *(If answer is no, "That is fine, thank you for your interest in this project. If you would like to discuss any concerns with me, my supervisor, or my sponsor please feel free to do so" – Provide them with the contact details). "*So, if you feel ready to begin, I will now start the interview". *(Turn on voice recorder)*.

SECTION 1:

"Firstly I am going to ask you a few questions about aspects related to your experience of the unit and ICU staff members".

1. **When your loved one was admitted to the ICU, what was your relationship to them? (i.e. were you their: husband, wife, partner, girlfriend, boyfriend, Mother, Father, brother, sister, son, daughter, granddaughter, grandson, etc)**
2. **Can you tell me about how you experienced the ICU when you first arrived and what your immediate needs were?**
3. **Can you tell me something about what your interactions with staff were like?** *(Methods used to communicate)*
4. **Is there anything that you think staff could have improved upon in their communications with you?**
5. **What sort of information do you recall receiving from staff when you first came onto the unit?** *(Unit and processes)*

6. **What sort of information would have been most useful to you on the unit and when?**

SECTION 2:

"Are you happy for me to continue? I am now going to ask you a few questions about your knowledge and understanding about making decisions for your loved one".

1. **How involved were you in decisions made about the care and treatment of your loved one?** *(What was your role?)*
2. **What did you expect your role and rights would be in relation to determining treatment for your loved one?**
3. **Prior to your loved one being admitted to the ICU, what was your understanding of the law around how decisions are made for patients that cannot make decisions for themselves?**
4. **If your rights were explained to you by staff members, how and when did they do this?**
5. **Did you feel that this explanation was provided at an appropriate time?**

SECTION 3:

"Are you still happy for me to continue? This is the last set of questions. I will now ask you about how you have coped whilst on the ICU"

1. **How do you think you coped with the experience of having a loved one on an ICU?**
2. **Which part of your experience of the ICU was the most difficult to cope with?**
3. **In what ways do you think staff on the ICU could have helped you to cope more effectively?**
4. **What are your thoughts on whether patients' relatives and friends should be offered psychological support or counselling whilst they are on the unit?**
5. **As you know we are planning on developing a leaflet for relatives and friends of intensive care patients, what would you like to see in it?**

"Is there anything else that we have not discussed which you would like to raise?"

"Do you have any questions about the research project?"

"Thank you very much for participating"

APPENDIX B7: STAFF MEMBERS INTERVIEW SCHEDULE (PRE-PILOT)

CITY UNIVERSITY LONDON

King's College Hospital NHS
NHS Foundation Trust

Pre-Pilot Interview Schedule – ICU Staff

Introductory script:

"Please come in and make yourself comfortable *(I point to participant chair)* and we will start the interview shortly. *(I sit down opposite the participant)*. Thank you very much for coming along today to participate in this research project. As described in the participant information sheet, the aim of the project is to develop an intervention (information leaflet with verbal explanation) for relatives and friends (this includes spouses and carers) of ICU patients as a resource to help them cope with the experience of having a significant other admitted to the Intensive care Unit (ICU). We hope the intervention will help by improving communication between patients' relatives and friends, and staff members, providing timely and understandable information about the unit and the processes involved with this type of care, and ensuring that families receive support where necessary".

"During the interview I will ask you some questions pertaining to various aspects of the ICU. If there are any questions you would rather not answer, please let me know. You are free to withdraw from the interview at any time, or withdraw from the project completely if you wish to. Everything you say to me is in the strictest of confidence and I will ensure your anonymity when I write up the project. Do you still wish to participate in this research project?" *(If yes) "*That's great, thank you". *(If answer is no, "That is fine, thank you for your interest in this project. If you would like to discuss any concerns with me, my supervisor, or my sponsor please feel free to do so" – Provide them with contact details). "*So, if you feel ready to begin, I will now start the interview". *(Turn on voice recorder)*.

SECTION 1:

"Firstly I am going to ask you a few questions about issues of communication and information provision on the unit".

1. **What steps do you take to ensure patient's relatives and friends are satisfied with their experience of the unit?**
2. **Can you tell me something about what your interactions with patient's relatives and friends entail?**
3. **Is there anything that you would like to improve about the ways in which you communicate with patient's relatives and friends?**
4. **What sort of information do you provide to patient's relatives and friends when they first come onto the unit?**
5. **What information do you think is most useful to patient's relatives and friends on the unit and when?**

SECTION 2:

"Are you happy for me to continue? I will now ask you some questions about decision-making for the patient".

1. **In what ways do you involve patients' relatives and friends in decisions about the care and treatment of their loved-one?**
2. **To what degree do you think patients' relatives and friends understand the law regarding their role and rights around decision-making for a significant other who lacks capacity?**
3. **How often do you have to explain to patients' relatives and friends what their role and rights are around decision-making if their significant other lacks capacity?**
4. **How do you explain these issues to patient's relatives and friends?**
5. **When do you feel is the most appropriate time to broach such issues and why?**

SECTION 3:

"Are you still happy for me to continue? This is the last set of questions. Finally, I will ask you a few questions about how you feel patients' relatives and friends cope on the unit".

1. **Which parts of the experience of being on the ICU do you think patients' relatives and friends find the most difficult to cope with and why?**
2. **How do you support patients' relatives and friends and help them to cope with the experience of intensive care?**
3. **What are your thoughts on whether patients' relatives and friends should be offered psychological support or counselling whilst they are on the unit?**
4. **What are your thoughts on whether intensive care staff should have access to psychological support and counselling**
5. **As you know we are developing an information leaflet for relatives and friends of intensive care patients, what would you like to see in it?**

Is there anything else that we have not discussed which you would like to raise?

Do you have any questions about the research project?

"Thank you very much for participating"

Peer Review Focus Group: Facilitator Script and Questions
Venue: Kings College Hospital (Seminar Room)
Duration: 1 hour   **Group will be Facilitated by:** Rosie Freedman (CI)
Participants: Senior ICU Nurses

Objectives of Focus Group:

To peer review the proposed intervention (leaflet and method of delivery); help to develop it further prior to the pilot; and to ensure nursing staff are happy to deliver it to patients' relatives and friends.

Opening section - Introduction:

To be read by the facilitator: *"Hello everyone, I hope you are sitting comfortably. My name is Rosie Freedman and I am studying a Professional Doctorate in Health Psychology at City University. As you know I am conducting a research project at Kings which involves developing an intervention to help patients' relatives and friends cope with the experience of having a significant other be an unplanned admission to the ICU."*

"This is obviously a traumatic time for relatives and research shows that they have certain 'needs' which if not met can cause further distress. Needs such as information about what is happening to their significant other and about the ICU, receiving assurance from staff and the importance of good communication with staff on the ICU, in helping them to cope and understand ICU processes."

"The intervention we are developing is in two parts, a written leaflet, accompanied by a verbal explanation. Research shows that having written information alone or just verbal information is ineffective, particularly if the person who is receiving it is in an anxious state, such as a patient or relatives of a patient. But providing both written and verbal information is more effective in helping people to absorb the information and understand it. In the case of this intervention, it would basically mean explaining the content of the leaflet, not word for word but ensuring that relatives understand the different sections and significant information it contains that may help them to cope, for example: how the unit functions, who they can speak to, access to support, and information about ethical areas such as decision-making when a patient lacks capacity. Research indicates that the latter is something that relatives should be educated on as it can prepare them for what might

happen and possibly prevent potential misunderstandings between relatives and ICU staff, for example: the relatives may think they have more power to make decisions for their significant other than they actually have, in terms of doctors having the final say on treatment, and making decisions in the patient's best interests."

So today is about reviewing the intervention so far and helping to develop it further before it is piloted on the ICU."

Question section - Preliminary questions and information:

- Have you all had a chance to read the leaflet and the participant information sheets and consent forms that were emailed to you?
- Are you all happy to take part in this focus group? If so please can you all sign one of these forms. (*I pass out consent forms for signing and participant information sheets if necessary).*
- Are you all happy for me to record this session? (*Turn on recorder*)

"Part of a focus group is having an open discussion about a particular topic and to have some fun whilst doing it! So I want you feel comfortable and relaxed. I would really like you to be as honest as possible as your feedback (positive or negative) is a very important part of developing this project and I really value the expertise and experience that you all bring to the table. Please speak loudly and clearly during this session so the recorder can pick up what you say. Right, if all is ok, I will now ask you some questions:"

Main questions:

1. Before we look at the first draft of the leaflet *(which I will hand out copies of in a moment)*, I would like to ask you all about your thoughts on methods of improving communication and content of written materials for patients' relatives on the ICU...in your experience what do you find effective?
   "Here are copies of the first draft of the leaflet to look at and write on during the session (and pens if you need them). Firstly I am going to ask you about the content, and then about the leaflet's appearance. Then I will ask you a couple of questions regarding the verbal delivery of the leaflet. As you are probably aware, it is likely that nurses will deliver this leaflet to patients' relatives and friends, so we want you to be happy with it and the process by which it is provided. Feel free to write on your copies of the first draft of the leaflet during this session and I will collect them all up at the end. What you say aloud in the session and what you note down on the leaflets will help to develop the second draft of the leaflet."
2. Having read the first draft of the leaflet, what were your opinions of the content?
3. Do you have any suggestions about how the content could be improved or added to?

4. I would be very interested to hear your views on the appearance of the first draft of the leaflet, for example, you first impressions of it and the way it has been structured.
5. If you feel that the structure of the first draft of the leaflet could be improved in any way, what would you like to see changed?
6. As you know, there are two parts to this intervention, the written leaflet and a verbal explanation by staff. What do you think would be the best way of providing the verbal explanation?
7. If having a script to aid your explanation would help you. What do you think should be written on the script?
8. What do you think would be the best method for training staff to deliver a verbal explanation and how might one ensure consistency in delivery? i.e. monitoring
9. How do you feel about delivering both parts of the intervention?
10. What are your thoughts on how this intervention will (or will not) help patients' relatives and friends to cope on the ICU?

(Stop discussion 10 minutes before the end of the session to have time to close).

Closing section – conclusion:

"Thank you for taking part in the focus group and for reviewing this intervention. Is there anything else you would like to add about the intervention?"

"The information you have provided today will help us to further develop the leaflet. In the next stage I will be interviewing patients' relatives and friends and ICU staff. The information they provide will be added to the information from this session and used to create a final draft of the leaflet, which will then be piloted on the ICU for a period of two weeks. After which I will conduct further interviews with ICU staff and patients' relatives and friends who have been involved in the intervention."

"All the information from the focus group and the interviews will be transcribed word for word and I will analyse it using a method called Thematic Analysis. This is a very thorough process which helps to identify themes in the data the meanings of which are then interpreted by the researcher and used to develop the intervention, answer the research questions and evaluate whether the intervention has been successful or not."

"Thank you for your help with this project. Do not hesitate to contact me if you have any concerns or questions." END OF SESSION

APPENDIX B9: PIS – NEW STAFF MEMBERS (POST-PILOT)

CITY UNIVERSITY LONDON

King's College Hospital NHS
NHS Foundation Trust

<u>Participant Information Sheet – ICU Staff Interviews</u>

Title of study: The development of an informational intervention to help critically ill patients' relatives and friends cope with an unplanned ICU admission.

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the project?
There are two parts to this study; part one is about exploring patients' relatives' experiences of intensive care and part two is to develop an intervention to help relatives and friends of patients on the intensive care unit (ICU) at Kings College Hospital (KCH). An 'intervention' is something that is put in place to hopefully improve a situation and help the people involved in that situation. The intervention is a booklet designed for patient's relatives on the ICU, which provides information about the ICU and what to expect whilst there, to prepare relatives for the experience. The staff members who provide the booklet to patients' relatives will also explain what kind of information the booklet contains and mention certain information in more detail if they think this will benefit the relatives at that time. The booklet will be provided to patients' relatives on the ICU for a period of two weeks and then ICU staff will be asked about how it was received and if they thought it was successful in helping patients' relatives. It is hoped that patients' relatives and friends will feel they have the resources to cope with the experience of their loved one being admitted to the ICU, by the booklet providing: useful information about the unit and patient care, improving the ways in which ICU staff and patient's relatives and friends communicate with one-another, and ensuring that patients' relatives and friends feel involved, reassured and supported through what can be a traumatic experience. This research study is to be written up as the researcher's doctoral thesis at City University.

Why have I been invited?
 You have been invited to participate in this research project because you fit all of the following inclusion criteria:
- You are a qualified nurse, doctor or consultant working on the ICU at KCH
- You are able to provide informed consent
- You are able to read, write and comprehend the English Language.

Overall there should be approximately 24-30 ICU staff members participating in this study and approximately 8-20 individuals who have had the experience of being a relative of a patient on an ICU.

Do I have to take part*?*
No. Participation in this study is voluntary and you can choose not to participate in part or all of the study. If you do participate, you can withdraw at any stage or avoid answering questions which are felt to be too personal or intrusive, without being penalised or disadvantaged in any way. It is up to you to decide whether or not to take part.

What will happen if I take part?
You would be required to participate in an interview following the pilot of the new CCU Booklet on the CCUs. The researcher will ask you about how you felt the booklet was received by patients' relatives and whether it has made any positive changes in areas such as: satisfaction, communication, understanding about decision-making for patients who lack capacity, coping, and seeking counselling/psychological support. The interviews will be semi-structured, which means that although there will be a list of questions the researcher will ask you; these will be quite open and flexible. Each interview should take approximately 30 minutes and would be recorded using a digital voice recorder. The interview can take place either by the research office, which is situated on Level 1, Golden Jubilee Wing at Kings College Hospital, below the MCCU and opposite Suite 7, or in a room on the MCCU or SCCU. The interview can also be conducted by telephone, if this is more convenient.

What do I have to do?
If after reading this sheet you decide you would like to take part in this project, then please read the attached participant consent form very carefully. If you agree with all of the statements on the consent form please initial the boxes and follow the other instructions on the form. Then give one copy of the form to the researcher whilst keeping the other copy for your own records. If you have any questions about this information sheet or the consent form, please do not hesitate to contact the researcher who can advise you on what to do. Once the researcher has received your consent form, they will contact you to arrange a date and time for the interviews at your convenience. Once you have attended the interview, your participation in the research will be complete. The researcher may send you a summary report of the results of the research if you have chosen that option on the consent form. You will not be required to do anything else for the research project.

What are the possible disadvantages and risks of taking part?
There should be no disadvantages to you if you participate in this study. The interview will take place close to the ICU. There will be access to toilets and refreshments nearby. If you feel upset by the interview, please let the researcher know. If the researcher feels that you need to speak to someone else more qualified to help you, they will refer you to someone who can.

What are the possible benefits of taking part?
There is the possibility that your participation in the research will help to develop an intervention which will help future patients' relatives and friends to cope with the experience of having a loved one on the ICU. In addition, this may make positive changes on the ICU in your future communications with patients' relatives. Moreover, by agreeing to take part in the study you will

have a chance to provide your expert knowledge and experience to the development and evaluation of the intervention.

What will happen when the research study stops?

If by any chance the study is stopped prematurely after you have taken part in it, your data may be kept until the study can begin again. If you decide to withdraw and wish for any data you have provided not be used in the project, we will respect your wishes. If you participate in the study the data you provide in the interview will be used in the development and write up of the research.

Will my taking part in the study be kept confidential?

Yes. Only the researcher will have access to your personal information details and you will be anonymised in the written report of the research, so no-one will know your identity. All information you provide in the interview will be kept confidential and no names of any participants will be identified. Any personal information you provide such as your name and contact details will only be used to contact you about the research. The researcher will give the digital recording of the interview to a transcription company who will transcribe (write down word for word) the interview data so that the researcher can analyse it. The transcription company can also provide a non-disclosure agreement that will protect your anonymity. The interview transcript will form part of the appendices of the research study report for City University; however the researcher will have given you a pseudonym (a false name) on the transcript, so you will not be identifiable to anyone from the University. All research data will be kept on an encrypted and password protected USB stick and computer, which only the researcher will have access to. This will ensure confidentiality and protection of your data. Once the study has finished, any data you have given us e.g. in the interview, will be archived and kept securely for up to 5 years and then confidentially destroyed in accordance with NHS policy.

What will happen to the results of the research study?

The information you provide in the interview will be analysed and written up in a final report of the research. It is possible that the research may also be published in one or more peer reviewed psychological and/or medical journals. You can also request access to the full written report or publication of the research once the study has ended, should you wish to *(details about this are on the consent form)*.

What will happen if I don't want to carry on with the study?

Even if you have started to participate in the study, you are free to withdraw from it at any point, without having to give an explanation as to why. Just need to let the researcher know that you no longer wish to take part. You will not be penalised or disadvantaged in any way for withdrawing. You can contact the researcher on the details at the end of this information sheet.

What if there is a problem?

If you would like to complain about any aspect of the study, City University London has established a complaints procedure via the Secretary to the University's Psychology Department Ethics Committee. To complain about the study, you need to phone: 0207 0408529. You can then ask to speak to the Secretary to the Psychology Department Ethics Committee and inform them that the

name of the project is: "The development of an informational intervention to help critically ill patients' relatives and friends cope with an unplanned ICU admission". You could also write to the Secretary at:

Mrs Carmai Pestell

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Who has reviewed the study?

Comments, concerns or observations procedure: This project has been approved by the Research and Ethics Committee of the Department of Psychology of City University London (project approval number PSYETH (UPTD) 12/13 57).

If you have any comments, concerns or observations about the conduct of the study or your experiences as a participant, please contact the Secretary to the Committee Mrs Carmai Pestell, quoting the above project approval number: Telephone: ████–████–████–████ Email: ████████████████████████ Postal Address above.

Further information and contact details

The researcher: Mrs Rosie Freedman. Email address: ████████████████████████ Telephone: ████████ Researcher's clinical supervisor, Dr Stephanie Strachan. Email: ████████████████████████ Telephone: ██████████████

Thank you for taking the time to read this information sheet.

APPENDIX B10: STAFF MEMBERS INTERVIEW SCHEDULE (POST-PILOT)

CITY UNIVERSITY LONDON

King's College Hospital NHS
NHS Foundation Trust

Post-Pilot Interview Schedule – ICU Staff

Introductory script:

"Please come in and make yourself comfortable *(I point to participant chair)* and we will start the interview shortly. *(I sit down opposite the participant)*. Thank you very much for coming along today to participate in this research project. As described in the participant information sheet, we have developed and piloted an intervention for patients' relatives and friends (this includes spouses and carers) as a resource to help them cope with the experience of having a significant other admitted to the ICU. We hope the intervention (leaflet and verbal explanation) will help by improving communication between patients' relatives and staff members, providing timely and understandable information about the unit and the processes involved with this type of care, and ensuring that patients' relatives and friends receive support where necessary".

"During the interview I will ask you some questions pertaining to various aspects of the ICU. If there are any questions you would rather not answer, please let me know. You are free to withdraw from the interview at any time, or withdraw from the project completely if you wish to. Everything you say to me is in the strictest of confidence and I will ensure your anonymity when I write up the project. Do you still wish to participate in this research project?" *(If yes)* "That's great, thank you". *(If answer is no, "That is fine, thank you for your interest in this project. If you would like to discuss any concerns with me, my supervisor, or my sponsor please feel free to do so" – Provide them with contact details).* "So, if you feel ready to begin, I will now start the interview". *(Turn on voice recorder)*.

SECTION 1:

"Firstly I am going to ask you a few questions about issues of communication and information provision on the unit".

1. **Do you feel patients' relatives and friends are more satisfied with their experience of the ICU then they were before the intervention was piloted?**
2. **Can you tell me about any improvement in your interactions with patients' relatives and friends as a result of the intervention?**
3. **Which bits of the intervention do you feel were most effective?**
4. **If there were any parts of the intervention that you felt were ineffective, what were they?**
5. **Is there anything that you would like to improve about the ways in which you communicate with patient's relatives and friends?**
6. **In what ways do you think the intervention has helped to improve patients' relatives and friends overall knowledge and understanding of the ICU? (If any).**

"Are you happy for me to continue? I will now ask you some questions about decision-making for the patient".

1. **How do you think the intervention has changed the ways you involve patients' relatives and friends in decision-making about their significant others on the ICU?**
2. **Since the intervention was piloted, to what degree do you think patients' relatives and friends on the ICU understand the law regarding their role and rights around decision-making for patients who lack capacity?**
3. **If you still have to explain to patients' relatives and friends what their role and rights are around decision-making for their significant other who lacks capacity (in addition to what is explained via the intervention), how often do you have to do this?**
4. **In what ways do you think patients' relatives and friends knowing about their role and rights around decision-making for a patient who lacks capacity (via information in leaflet) has been helpful?**

SECTION 3:

"Are you still happy for me to continue? Finally, I will ask you a few questions about how you feel patients' relatives and friends cope on the unit".

1. **How do you think the intervention has helped patients' relatives and friends to cope with the experience of having a significant other be an unplanned admission to the ICU?**
2. **Do you feel that patient's relatives and friends still need resources to help them cope whilst on the ICU?**
3. **Do you feel the intervention has encouraged more patients' relatives and friends to seek psychological support/counselling than before the intervention was piloted?**
4. **Is there anything you feel should be added to the contents and delivery of the intervention?**
5. **What are your thoughts about the intervention possibly becoming standard practice on the unit?**

Is there anything else that we have not discussed which you would like to raise?

Do you have any questions about the research project?

"Thank you very much for participating"

APPENDIX B11: RECRUITMENT INFORMATION ON ICUSTEPS WEBPAGE *(NEXT PAGE)*

icu ste Relatives' experience rese... ✕

Home Support groups Intensive care guide Patients & relatives Professionals
Community About us Contact us
Patient experiences Relatives experiences Research Useful contacts

Relatives' experience research

Hello, my name is Rosie Freedman and I am studying a Professional Doctorate in Health Psychology at City University, London. My research project is in collaboration with Kings College Hospital (KCH), in London, and is split into two separate but overlapping studies.

I would like to interview relatives of ex-ICU patients about their experiences of ICU, to help provide better support for future patients' relatives on ICU.

Study 1 will explore patients' relatives' and ICU staff experiences of ICU, particularly around areas such as communication, information needs, knowledge of ICU processes (such as decision-making for patients who are unable to make their own decisions), coping on the ICU and access to psychological support.

Study 2 is the development of an information leaflet for ICU staff at KCH to provide to patient's relatives on the ICU, and a verbal script for staff to use with the leaflet.

Data from interviews in Study 1 and a focus group with Senior ICU Nurses will help to develop the leaflet, which will be used on the ICU at Kings College Hospital (KCH) for two weeks. This will be followed up with further interviews with the ICU staff from Study 1 as part of a preliminary evaluation of the leaflet.

I am currently looking to recruit participants for Study 1, to interview about their experiences of having had a loved one as a patient on an ICU.

The inclusion criteria for participants are as follows:

- Their loved one must have been an unplanned admission to an ICU
- Their loved one must have lacked capacity to make decisions for themselves at some point during their stay on an ICU
- Their loved one must have survived their stay on an ICU and was discharged.

decision-making for patients who are unable to make their own decisions), coping on the ICU and access to psychological support.

Study 2 is the development of an information leaflet for ICU staff at KCH to provide to patient's relatives on the ICU, and a verbal script for staff to use with the leaflet.

Data from interviews in Study 1 and a focus group with Senior ICU Nurses will help to develop the leaflet, which will be used on the ICU at Kings College Hospital (KCH) for two weeks. This will be followed up with further interviews with the ICU staff from Study 1 as part of a preliminary evaluation of the leaflet.

I am currently looking to recruit participants for Study 1, to interview about their experiences of having had a loved one as a patient on an ICU.

The inclusion criteria for participants are as follows:

- Their loved one must have been an unplanned admission to an ICU
- Their loved one must have lacked capacity to make decisions for themselves at some point during their stay on an ICU
- Their loved one must have survived their stay on an ICU and was discharged.
- The participant must be able to give informed consent
- The participant must be able to read, write and comprehend the English Language.

The term 'relatives' also include adults who are a: Spouse, parent, child, sibling, grandchild, carer, or close friend, of an ex-ICU patient. The research would involve you meeting with me for an interview at City University in London. The interview would last approximately 30 minutes. I will ask you a range of questions about your experience of ICU and the areas mentioned above.

If you would like to take part in this project, please get in touch with me either by emailing me at: ▬▬▬▬▬▬▬▬▬▬ or by giving me a ring on ▬▬▬▬▬▬ Once you have expressed an interest I will send you a Participant Information Sheet with detailed information about the project and what would be required of you, and a Participant Consent form for you to sign.

Your help to improve support for and the experience of ICU for patients' relatives in the future would be much appreciated. Thank you.

APENDIX B12: STUDY 1 - TABLE OF LAY PARTICIPANT GENDER AND RELATIONSHIP TO PATIENT

Lay Participant Number	Gender	Relationship to patient	Patient Gender
LP1	Male	Ex-boyfriend	Female
LP2	Female	Daughter	Female
LP3	Female	Mother	Female
LP4	Female	Wife	Male
LP5	Female	Wife	Male
LP6	Female	Partner	Male
LP7	Female	Wife	Male
LP8	Female	Mother	Male
LP9	Male	Husband	Female
LP10	Female	Daughter	Female

APPENDIX B13: STUDY 1 – LAY PARTICIPANT BOOKLET SUGGESTIONS

Suggestion	Participants
Information about how patient will appear and the bed space appearance and the machines (and medications*) and how these function	1, 2, 3, 4, 6, 7*, 8, 10
Glossary or ICU terminology and functions	3, 4, 6, 7, 8, 9, 10
Explanation of what happens on the ICU to prepare relatives (and medical information*)	2*, 4, 7, 9, 10
Lay information regarding decision making for patients who lack capacity to prepare relatives for process if it arises (only if explained and put into context*)	3, 7, 9, 10*
Information should be written and verbal as it is easy to forget when distressed	3, 4, 6, 9
Contact details for the unit (and when best to ring them*)	1, 5*, 10
Contact details for counselling/psychological support and other support services	2, 5, 9
Information on hospital facilities (where to get a coffee, where to eat, use a mobile phone, etc)	5, 7, 3
Information on how being on ICU can make you feel	1, 5
Description of the effects patients experience after they have been on ICU	6, 8
Keeping a diary for the patient of what happens to them each day they are on the ICU	5, 6
Information on the different staff roles (and uniforms)	7, 10
Pictures for explaining preparatory information (bed space *)	9, 10*
Detailing who relatives can speak to if they have concerns about their loved one's care	5, 6
Someone to help relatives to go through the booklet information with them	2
Encourage relatives to ask staff questions	3
Information on practical issues	5
Information on parking, costs, etc	5
Extol the benefits of patients returning to ICU post discharge as part of follow up and recovery	5
List of useful contacts and local numbers	6

Explaining ICU to children	6
Possibly separate booklets for children of different ages	6
List of other staff that may be encountered on the ICU (physiotherapist, dietician, speech therapist, etc)	6
How difficult it can be when transferred from ICU to a ward	6
How critical illness can affect the body	6
List of nutritious, high protein foods for patient post-ICU (could be separate from booklet)	8
Information on head injuries and the potential ramifications of them	9
General information to be accompanied by individual patient information to help put everything into context	9
Booklet provided early on (after arriving on ICU)	5

APPENDIX B14: STUDY 1 – STAFF PARTICIPANT GENDER AND OCCUPATION

Participant number	Gender	Occupation on ICU
SP1a	Male	Consultant
SP2a	Female	Consultant
SP3a	Female	Consultant
SP4	Female	Nurse
SP5a	Female	Nurse
Sp6a	Male	Nurse
Sp7a	Female	Nurse
Sp8a	Male	Consultant
SP9a	Female	Nurse
SP10a	Female	Nurse

APPENDIX B15: STUDY 1 – STAFF PARTICIPANT BOOKLET SUGGESTIONS

Suggestion	Participants
Needs to be simple	1
Have a geographical description of the CCU	1, 3
Explain the difference between ICU and normal hospital ward	1
Useful telephone numbers and contacts (including PALS* and secular and faith based contacts**)	1, 2, 7*, 8**, 10
Tempo of events of the ICU	1
Frequent reviewing of patients by ICU staff	1
Patient's condition can change more quickly on the ICU	1
Can be difficult for relatives to interpret patient's condition	1
ICU is a complicated environment	1
There may be difference in medical opinion on the ICU	1
Relatives must let ICU staff know about any inconsistencies in medical opinions\information	1
Recovery issues (delirium, etc)	1
Trajectory of recovery process	1
Recovery resources and stepping down process	1
The variety of patients on the ICU	1
Information to support relatives (practical and specific info about ICU*)	2, 10*
Inform relatives about what to expect on the ICU	2
It is natural for relatives to feel a range of emotions, but try not to take these out on the ICU staff	2
Relatives may experience depression	2
ICU staff need relatives to be well to cope with the situation (add support loved one)	2
Let relatives know how difficult it is going to be having a loved one on the ICU	2
Issues such as how different patient will look	2
Explain reasons for visiting times on the units	2, 4, 5, 6, 10
Let relatives know that if their loved one is very unwell open visiting will	2

be permitted	
Ask relatives to check with the nurses before bringing anything in for the patients	2
Importance of relatives role to the patient	2
Encourage relatives to touch their loved one if they are unconscious	2
ICU staff will contact the relatives if their loved one's condition worsens	2
There are two types of patient on the ICU (planned and unplanned admissions)	3
Explain what ICU staff do	3
What types of therapies are offered	3
End of Life Care on the ICU (EOL)	3
Conversation and speaking to a panel (second opinions in decision making, etc)	3
What not to expect	3
What to expect after a couple of days	5
Communication – what relatives can do if they feel they are not being kept in the loop	3
Glossary of ICU terms (lay terminology)	3, 6
General information about daily running of the ICU	4
Explain everything in lay terms	4
Information on discharge from the ICU	4, 6
Information about stepping down to a normal hospital ward	4
Transition from 1-1 care (to 1-6 care*)	4, 6*
The iMobile Team	4
Information on decision making (preparing relatives for it*)	5, 7*
Explain bedside machinery/equipment	5
Patient may be asleep for a few days initially	5
Relatives' rights (decision making)	5
It can take a couple of hours to settle a patient onto the ICU (so relatives will have to wait*)	6, 7*
Staff will come and fetch them when they are ready/finished settling them in or doing procedures	6
Picture of an ICU bed with all the machinery and equipment around it	6, 10

Explain what relatives will see around the bed space	6
How it can be distressing to see the patient if not prepared	6
Explain confidentiality	7
Types of support services that are offered on the units	7
Needs to be written in an empathic way	8
It must recognise cultural and ethnic diversity	8
It must not replace communications with staff	8
It can be an aide memoire for relatives to take away	8
Relatives need to ask the bed side nurse if they want to speak to the doctor	9
Information on where to park at the hospital in an emergency	9
Parking costs	9
Who ICU staff are – colour of uniforms and position	9
How relatives get a sick note for the patient	9
Property issues – where it is kept	9
How the units advocate relatives do not spend too much time there (they need to go home and get some rest)	9
Information on side rooms (and all the paraphernalia needed to go in them)	10
How to seek support from a priest	10
Accommodation – options and where it is located	10
Some local information	10
Encourage relatives to ask staff questions	10
What relatives need to do if they need any documentation (legal, etc)	10
Explain how the CCUs work	10
Explain why relatives may have to wait to see their loved one	10
Nurse could point out to relatives where particular information is located in the booklet	10
Seeing a loved one on the ICU can be shocking	10

APPENDIX B16: STUDY 2 – GENDER AND OCCUPATION OF STAFF PARTICIPANTS

Focus Group – All Senior Nurses

R1	Female
R2	Male
R3	Female
R4	Female
R5	Female
R6	Female
R7	Male
R8	Female
R9	Female
R10	Female

Staff Interviews – Post pilot (* also interviewed in Study 1)

Participant number	Gender	Occupation on ICU
SP1b	Male	Nurse*
Sp2b	Female	Nurse*
Sp3b	Female	Nurse
SP4b	Male	Nurse
SP5b	Female	Nurse*
SP6b	Female	Consultant
SP7b	Female	Nurse*
SP8b	Male	Consultant
SP9b	Female	Nurse*
SP10b	Male	Consultant*

APPENDIX B17: STUDY 2 – MOST EFFECTIVE BOOKLET INFORMATION

Most effective information	Participant number
Stepping down from ICU to a ward/Relocation stress	SP4b and SP10b
Photos of: Bedspace and equipment around it/ICU/coffee shop	SP2b, SP7b and SP10b
Explanation of visiting hours	SP9b and SP10b
Glossary section	SP2b
Accommodation	SP2b
Rehabilitation	SP4b
Spirituality – where to access support	SP4b
Where to get a coffee, sit down, etc	SP4b
Layout of booklet and End of life information	SP7b
What to expect on the unit	SP8b
Typical day on the ICU	SP8b
Discharge from the ICU	SP8b
Transport information	SP9b
Information that nurses provide to relatives	SP9b
Everything being well explained and clear	SP9b
Confidentiality issues	SP9b
Practical information	SP10b
Difference between ICU and a normal ward	SP10b
Getting to the unit	SP10b
How staff work on the unit	SP10b
Orientation	SP10b

APPENDIX 18: VERBAL GUIDE FOR NURSES DELIVERING THE BOOKLET

Two week pilot of CCU Booklet for patients' relatives and friends

Dear CCU Nurses

Over the next two weeks (ending on the 3rd of January), please give each of your patients' families a new CCU booklet when they **first** arrive on the CCU to see their loved one. You will find the booklets next to the main desk on both units. Please **do not** give families any of the old CCU information material like the black and white information sheet or ICUsteps booklet.

You won't have to change the way you normally interact with patients' families or what you generally say to them, but please take a moment to explain the contents of the booklet by just briefly reading aloud the '**Contents'** page at the beginning of the booklet which consists of the section titles which are in blue type and the sub-sections which are in black type. You don't need to go into any other detail about the booklet unless you feel it necessary to do so. But hopefully, discussing what's in the booklet may prompt them to ask you any immediate questions they might have.

 Please suggest that they read through the booklet at their leisure over the next couple of days either when waiting in the visitors' room or when they are at home, and that they bring in the booklet every time they come onto the unit in case they need to refer to it.

Many thanks for your help,

Rosie Freedman - Chief Investigator

The Professional Practice Component of this thesis has been

removed for confidentiality purposes.

It can be consulted by Psychology researchers on application at

the Library of City, University of London.

SECTION D: Systematic Review of Literature

A systematic review of qualitative studies exploring parental beliefs and attitudes toward childhood vaccination and the identification of potential barriers that may impact on vaccination uptake:

An updated review.

ABSTRACT

Background:

Childhood immunisation has been globally effective at reducing vaccine-preventable diseases which are potentially harmful to public health. However, there are still a significant number of parents who decide to opt out of vaccination for their child due to a variety of health beliefs about vaccination and external influences such as negative publicity reported in the media.

Objective:

To systematically review qualitative studies exploring parental attitudes and beliefs towards childhood vaccination in order to identify potential barriers that may impact on vaccination uptake.

Method:

Studies were identified using pre-determined search criteria. Eight electronic databases were searched and a selection of relevant journals were hand-searched. Included studies were peer-reviewed studies published between April 2003 and January 2014. Inclusion of studies in the review was agreed by two independent reviewers. Where any methodological issues were identified, these were discussed between the reviewers. Studies that met the inclusion criteria and were assessed as being of good or excellent quality were synthesised by conducting a conventional, inductive method of content analysis.

Results:

Three primary categories were identified: Parental and Individual Aspects, Family and Community Aspects, and Services and Systems Aspects. The analysis identified sixty-nine barriers and potential barriers to vaccination across the primary categories. The most prevalent barriers to vaccination uptake found across all seven studies were fear and/or experience of adverse side-effects from

vaccines and parents remembering their own or other people's negative experiences of vaccinations. The second most common barrier was parents being aware and/or affected by adverse publicity about vaccines and vaccinations. Barriers which were found in over half of the studies included a belief that ill children should not be vaccinated, that doctors do not have parents and their children's best interests at heart, lack of vaccination information provided by health care professionals, parental confusion, and lack of knowledge about how vaccines and the immune system work together.

Conclusions:

A decade after the previous review was conducted similar barriers to vaccination are still being reported by parents in many developed countries. With recent outbreaks of vaccine-preventable diseases in various countries where vaccinations are provided, this presents a risk to public health now and in the future if these barriers are not effectively tackled and vaccination uptake improved.

Keywords: Qualitative research, systematic review, childhood vaccinations, immunisation, parental attitudes, parental beliefs, barriers.

1. INTRODUCTION

The development of vaccines counts as one of the most significant advances in the history of medicine to date (Jolley and Douglas, 2014). The role of vaccination is multifaceted in providing immunity for individuals and populations by protecting individuals from potentially harmful diseases and reducing rates of morbidity and mortality around the world (Engstrom, 2009; Petousis-Harris, Goodyear-Smith, Godinet and Turner, 2002). In addition, vaccinated individuals are less likely to infect other people (Salisbury, Ramsey, and Noakes, 2006), which reduces the risk of individuals who are not vaccinated being exposed to infectious diseases, and individuals who cannot be vaccinated also benefit from the "herd immunity" that can result from efficacious immunisation programmes (Litmus, 2011; Salisbury *et al.* 2006). Immunisation has proven to be globally effective in the prevention and reduction of a number of once feared and sometimes fatal diseases (Andre, Booy, Bock, Clemens, Datta, John, Lee, Lolekha, Peltola, Ruff, Santosham and Schmitt, 2008; Luthy, Beckstrand, Callister and Cahoon, 2012), including successfully eradicating Small Pox, and eliminating diseases such as Measles from the Americas, and Measles, Mumps and Rubella from Finland (Andre *et al.* 2008). Potentially some vaccine-preventable diseases such as Mumps and Rubella could also be eradicated in the future via the Measles, Mumps and Rubella (MMR) vaccination (Andre *et al.* 2008).

However, there are still a significant percentage of parents who decide to opt out of vaccinating their children for a number of different reasons (Suk and Ruiten, 2013). In recent years there have been large outbreaks of measles across European countries and in New Zealand where the vaccination against the disease has been readily available, (Suk and Ruiten, 2013). This may be the result of negative publicity of potentially damaging side-effects of vaccinations and vaccines such as MMR, which has been incorrectly linked to the development of autism and inflammatory bowel disease if taken as a triple vaccination (Luthy *et al*. 2002; Serpell and Green, 2006; Tickner, Leman and Woodcock, 2006). It is thought that the MMR controversy has fuelled anti-vaccination campaigns and organisations and negatively influenced parental attitudes and beliefs about vaccination, particularly combined vaccines, thus impacting on their decision-making about whether or not to vaccinate their children (Engstrom, 2009; Serpell and Green, 2006; Suk and Ruiten, 2013). However, other factors are thought to be attributable to the decline in uptake, such as: poor service provision, socioeconomic and demographic factors, parental beliefs and attitudes, the attitudes of health professionals and inaccuracies in record keeping (Smailbegovic, Laing and Bedford, 2003).

Evidence suggests that parents' decision-making about childhood vaccination is not explicit; their decisions are guided by their individual beliefs and attitudes towards vaccination, which can be based on various influences including the internet, TV and newspapers, research literature, peers, information from and communication with health professionals and parents' own past experiences and the experiences of others (Serpell and Green, 2006; Suk and Ruiten, 2013; Whyte, Whyte, Cormier and Eccles, 2011). Petousis-Harris *et al.* (2002) explored parental beliefs and perceptions of childhood immunisation and potential barriers to vaccination using focus groups and interviews with parents whose children were fully vaccinated, partially vaccinated, or unvaccinated. They identified six key themes, only one of which was positive in terms of supporting vaccination. The other five included themes that could prove to be potential barriers to vaccination, such as: fear of vaccination, believing vaccination is unnecessary, lack of knowledge about vaccination, negative perceptions of health professionals, and difficulties in accessing vaccinations. However, the researchers used purposive sampling with Maori or New Zealand European participants (Petousis-Harris *et al.* 2002), which could potentially limit its generalisability to other populations.

Similarly, Luthy *et al.* (2012) used a questionnaire with closed multiple choice and open-ended questions to explore the reasons why parents exempt their children from at least one vaccination. They identified five primary categories: perceptions of vaccine harm, health care system issues, concerns about chronic disease, the immune system, and adverse reactions. The most common concerns were related to vaccine safety and links between vaccines and autism and/or overloading

the immune system, all of which may be barriers to vaccination. The study had 801 participants, 287 of them answered the open-ended questions, but a convenience sample of participants was used who were all from the same state in the US, which may limit generalisability of the findings.

Smailbegovic *et al.* (2003) conducted a mixed methods study using questionnaires and interviews with participants who had not fully immunised their children. Similar to the studies by Petousis-Harris *et al.* (2002) and Luthy *et al* (2012), both sets of participants reported concerns regarding vaccine safety and the potential long term effects of vaccines, such as the MMR vaccination being linked to autism. In particular, the ten mothers who were interviewed all expressed major concerns about MMR but not about immunisation in general, unlike participants who had completed the questionnaire, who felt that information received from health professionals was poor and did not meet their needs. The study found the most omitted vaccinations were MMR and Meningococcal C; omission of both being influenced by safety concerns. The issue of safety was also reflected in a systematic review of 47 studies by Tickner *et al.* (2006) who found uptake of vaccination could be motivated by how parents perceived the physical risks associated with it and similar to the study by Smailbegovic *et al.* (2003), found mixed parental views regarding information received from health professionals. Some studies reported parental satisfaction with information, while parental dissatisfaction with information received, particularly in the UK, Australia, and Ireland was considered to be poor, insufficient or unreliable. They reported that lack of information also resulted in missed or delayed Haemophilus influenza type B (Hib) and MMR vaccinations in Italy (Tickner *et al.* 2006). HiB is a bacterium that can cause severe infections particularly in young children under the age of five years and can cause a wide range of invasive diseases, the most prevalent being meningitis (Centers for Disease Control and Prevention (CDC), 2014; The College of Physicians of Philadelphia, 2014).

Tickner *et al.* (2006) suggest that the adverse publicity of the MMR triple vaccine may have influenced parental perceptions of other vaccines, particularly combination vaccinations, where primary immunisation against diseases such as Diphtheria, Tetanus, and Polio by two years of age began declining from 1999 onwards, although not as significantly as the MMR triple vaccine. By this premise, the fact that there are now more combined vaccines than before in terms of the five-in-one vaccine (DTaP/IPV/HiB) which vaccinates children against Polio, Diphtheria, Tetanus, Pertussis, and Hib and that both this and the MMR vaccine require multiple doses to complete the immunisation programme (Tickner *et al.* (2006), parental fears about combined vaccinations could potentially cause further barriers to the uptake of these important immunisations.

Mills, Jadad, Ross and Wilson (2005) conducted a systematic review of qualitative studies exploring parental beliefs and attitudes toward childhood vaccinations and identifying common barriers to vaccination. They felt that qualitative studies may help to elucidate why some parents choose not to vaccinate their children and that by conducting a synthesis of the data from various qualitative studies that examined this issue they could identify barriers across different populations and time periods. The authors hoped that by understanding these barriers, parental concerns about vaccinating their children could be more effectively addressed by heath care providers (HCPs) and policy makers via the development of appropriate strategies to help increase the rates of vaccination (Mills *et al. 2005).*

Mills *et al.* (2005) extracted qualitative data from 15 qualitative studies and identified five themes and a variety of common barriers to childhood vaccination related to:

- Concern of potential harm
- Issues of trust
- Problems with access
- Parental belief of control over child's exposure to pathogens
- Moral or religious reasons

They demonstrated how the synthesis of qualitative data can be a more encompassing and efficient method of providing valuable information, such as supporting policy development in the area of childhood vaccination, as opposed to individual qualitative studies that may be less influential (Mills *et al.* 2005).

1.2 Objectives

To determine the following:

- Whether parental beliefs and attitudes toward childhood vaccination have changed since the original review by Mills *et al.* 2005.
- Whether the barriers to childhood vaccination are the same as identified in Mills *et al.* 2005.
- Whether new barriers to childhood vaccination are identified
- Implications of review findings for practice and further research.

2. METHOD

2.1 Search Strategy

A systematic search of the literature was conducted using the following databases: PsychINFO, CINAHL (Plus with Full Text and Headings), Medline (with Full Text and MeSH), AMED, EMBASE, ERIC, SCOPUS and the Campbell Collaboration. The date range searched was from April 2003 to January 2014: The majority of the databases searched in the review by Mills *et al.* (2005) were searched in this review, except for the Biomedical Reference Collection: Basic and Nursing and Allied Health Collection: Basic, as these proved difficult to access and EMBASE is a comprehensive international biomedical database. In addition the Centre for Reviews and Dissemination (CRD) databases (DARE, NHS EED and HTA) were not searched as these are databases for reviews/systematic reviews rather than single study research papers. However, a scoping search of the CRD site and Cochrane Library was conducted in order to look for systematic reviews which may also be updating the systematic review by Mills *et al. (*2005). There was one systematic review proposal related to this research area registered in PROSPERO International Prospective Register of Systematic Reviews on the CRD site on the 7th of October 2013. However, it was proposing to update a different systematic review by Brown, Kroll, Hudson, Ramsey, Green, Long, Vincent, Fraser, Sevdalis (2010), which reviewed factors underlying parental decisions about combination childhood vaccinations including MMR. Their updated review was to be focused on the factors underlying parental decisions about childhood vaccinations and, unlike this review, would include qualitative and quantitative studies.

The SCOPUS database was also searched as it is the largest database for abstracts and citations of peer-reviewed literature covering a range of fields relevant to this review (Elsevier, 2014). The decision to use only peer-reviewed published studies was an attempt to ensure that the studies reviewed would be of the highest methodological and reporting quality (Rochon, Bero, Bay, Gold, Dergal, Binns, Streiner, Gurwitz, 2002). This may not necessarily guarantee high quality in all cases, but was felt an important measure due to the subjective nature of qualitative research and the plan to present methodologically rigorous research findings in this review. The search was further supplemented by searches on Google and Google Scholar and a selection of relevant Journals were hand-searched *(see Appendix D5 for Additional Information on Searches).*

2.2 Selection of studies

The following search terms were used and ordered in the following 1-6 searches in Table 1:

Table D1 - Search Terms

Search No.	Search Terms
1	Vaccin* OR Immuniz* OR Immunis* OR Innoculat* AND "child health" AND Parent* OR Caregiver* OR "Care giver*"
2	#1 AND Attit* OR percept* OR expectat* OR opinion*
3	#1 AND physician OR GP OR Doctor OR Paeditrician OR "Healthcare Professional" OR Therapist OR Practitioner
4	#2 AND physician OR "General Practitioner" OR Pediatrician OR Doctor OR "Health care professional" OR Therapist
5	#4 AND "Alternative Medicine" OR "Complementary Medicine"
6	#5 AND Qualitative

The following inclusion criteria were used:

Population - The sample included primarily parents (Mother and /or Fathers); caregivers; Physicians; and Complementary and Alternative Medicine (CAM) providers.

Issues addressed - Studies focused on parental beliefs and attitudes towards childhood vaccinations and/or the barriers that parents experience when obtaining vaccinations for their children.

Geography - Studies conducted in developed countries.

Study design - Qualitative studies using either semi-structured interviews and/or focus groups design. Published studies, peer reviewed, and written in the English language.

(See Appendix D2 for Inclusion and Exclusion Criteria)

3. RESULTS

The combined searches yielded 780 abstracts for review, 411 were excluded as duplicates which left 369 abstracts, which were read by the author. 332 abstracts were initially excluded for a variety of reasons, including focusing on specific vaccines, adult vaccination, inappropriate sample population, inappropriate study design or methodology such as structured questionnaires and surveys. A further 19 abstracts were excluded due to similar reasons including one which was unobtainable and another 3 abstracts were excluded as the studies had been conducted in developing countries. This filtering process resulted in 15 studies which were possibly suitable, but with further review 7 of these were rejected (see Fig 1). Eight studies were reviewed and quality assessed by the author and a second reviewer using a Quality Assessment Checklist for Qualitative Research adapted from
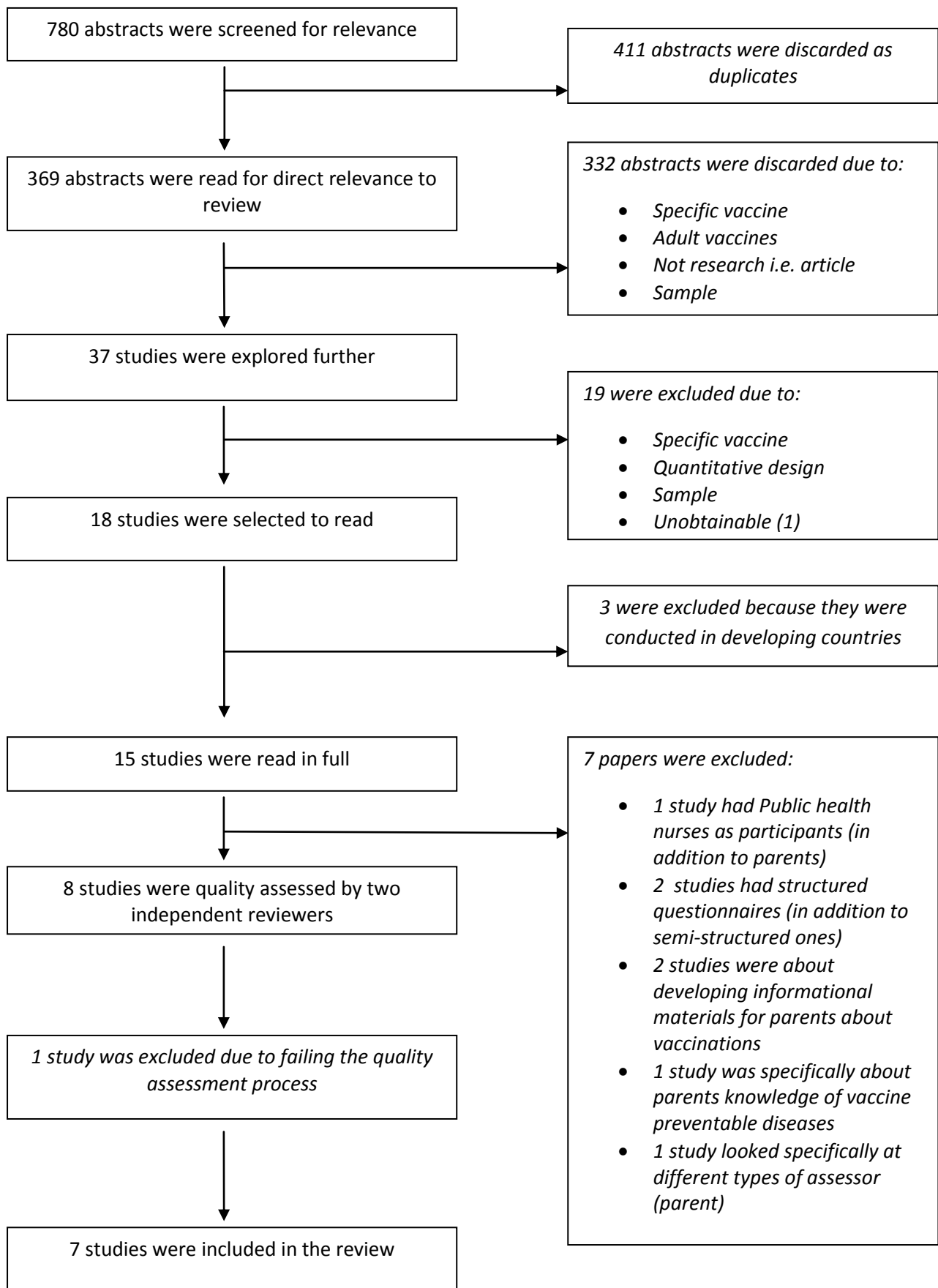
Critical Appraisal Skills Programme (CASP) (2013) *(See Appendix D3).* An adapted data extraction form *(See Appendix D4)* was used to extract the relevant data from each study, which was also checked by the second reviewer. Out of the 8 studies that were quality assessed, one was rejected due to it failing on a number of quality criteria and the remaining 7 studies were selected for the review *(Fig 1).*

The quality assessment checklist included a range of questions over the following nine categories:

- Preliminary Screening
- Research Design
- Sample Recruitment
- Data Collection
- Reflexivity
- Ethical Issues
- Data Analysis
- Research Findings
- Value of the Research

The reviewers quality assessed the studies independently and there were some small differences in the scoring that were discussed and a consensus was reached. The system for scoring the papers consisted of deciding whether the papers answered the quality assessment questions. Each paper was scored one of the following ratings: Yes, Partly, Uncertain, No and N/A (not applicable), to each question. Originally papers were only going to be included in the review if they scored a rating of 'Yes' or 'Partly' with a preference for a majority scoring a rating of 'Yes'. However, two studies which were included in the review scored a rating of 'Uncertain', the question related to how the researcher critically examined their own role, potential bias and influence during the formulation of the research questions, but as both papers scored highly in other related areas they were included. One paper scored a rating of 'No' regarding information on participant recruitment but scored a rating of 'Yes' in explaining why participants were selected and scored a rating of 'Partly' in their discussion around recruitment, which was felt to be sufficient by both reviewers. One paper scored a rating of 'No' to nine of the questions over the following categories of: Data Collection, Reflexivity, Ethical Issues, and Data Analysis, which led to it being excluded from the review by both reviewers.

Figure D1: Flow chart of search and selection of studies

780 abstracts were screened for relevance	→	*411 abstracts were discarded as duplicates*

↓

369 abstracts were read for direct relevance to review	→	*332 abstracts were discarded due to:* • *Specific vaccine* • *Adult vaccines* • *Not research i.e. article* • *Sample*

↓

37 studies were explored further	→	*19 were excluded due to:* • *Specific vaccine* • *Quantitative design* • *Sample* • *Unobtainable (1)*

↓

18 studies were selected to read	→	*3 were excluded because they were conducted in developing countries*

↓

15 studies were read in full	→	*7 papers were excluded:* • *1 study had Public health nurses as participants (in addition to parents)* • *2 studies had structured questionnaires (in addition to semi-structured ones)* • *2 studies were about developing informational materials for parents about vaccinations* • *1 study was specifically about parents knowledge of vaccine preventable diseases* • *1 study looked specifically at different types of assessor (parent)*

↓

8 studies were quality assessed by two independent reviewers

↓

1 study was excluded due to failing the quality assessment process

↓

7 studies were included in the review

3.1 Descriptive Data Synthesis and Tabulation of Participant Characteristics

Characteristics of study methodologies

Three of the selected studies conducted focus groups (Niederhauser and Markowitz, 2007; Hilton, Petticrew and Hunt, 2006; Shui, Kennedy, Wooten, Schwartz, and Gust, 2005) and four conducted in depth semi-structured interviews (Gullion, Henry and Gullion, 2008; Tarrant and Gregory, 2003; Tickner, Leman and Woodcock, 2009; Tarrant and Thomson, 2008). Three of the studies collected demographic data from participants prior to conducting the focus groups (Niederhauser and Markowitz, 2007) and interviews (Tarrant and Gregory 2003; Tickner *et al*. 2009).

Participants were recruited by several different methods of sampling and recruitment including: purposive, snowball, targeted, and convenience sampling. Three studies used purposive sampling (Niederhauser and Markowitz, 2007; Hilton *et al.* 2006; Tarrant and Gregory, 2003). Two studies did not specify a sampling method (Tickner *et al.* 2009; Tarrant and Thomson, 2008). Gullion *et al. (*2008) used snowball and targeted sampling and Shui *et al. (*2005) used convenience sampling. Sample sizes varied between studies but were considered ample numbers for qualitative research by the reviewers in terms of ensuring saturation of data, although only three studies actually mentioned saturation of data (Tarrant and Gregory, 2003; Shui *et al.* 2005; Tarrant and Thomson, 2008).

Two out of the seven studies omitted the duration of the interviews and focus groups (Hilton *et al.* 2006; Gullion *et al.* 2008); the duration of the interviews in the other studies ranged from 60-90 minutes per focus group and 30-90 minutes per semi-structured interview.

Two of the seven studies reported in detail how they had ensured qualitative rigour, in terms of the credibility, transferability, confirmability, and dependability of their research and analysis process (Niederhauser and Markowitz, 2007; Tarrant and Gregory, 2003). However it was evident from the quality assessment of the included studies that all seven had adequately considered these aspects even if they did not report them in such detail. A majority of the studies noted the potentially limited generalisability of their research due to factors such as sampling method, qualitative methodology, sample size, and geographical location. Two studies offered a small financial incentive to participants for taking part (Niederhauser and Markowitz, 2007; Shui *et al.* 2005).

Hilton *et al.* (2006) conducted pilot work prior to the study which helped them to develop a topic guide for the interviews and indicated what the optimal number of participants would be for each group session. Gullion *et al.* (2008) tested their interview questions with two participants prior to the study and as a result made minor adjustments to the questions before using them in their research. Shui *et al.* (2005) developed an interview guide for their focus groups based on The Health

Belief Model and The Theory of Reasoned Action, and Tarrant and Thomson (2008) also used the Health Belief Model in the development of the questions for their semi-structured interviews.

Three types of analytical method were used in the studies: Content Analysis, Thematic Analysis, and Grounded Theory (or principles from it e.g. the constant comparative method (CCM)) and five out of the seven studies used qualitative software programmes to aid in their analysis process such as Atlas - versions 4.1 and 5.0 and NVivo - including version 2.0

Characteristics of study participants

The seven studies in this review included a total of 278 participants: there were three focus group studies (total n = 189 participants) with a sample size mean of 63, and a total of 37 focus groups (mean = 12). There were four semi-structured interview studies (total n = 89 participants) and a total of 87 interviews. In Tickner *et al.* (2009) mothers provided their views for analysis and two fathers contributed to their partners' interviews*.* The studies were conducted in 5 different countries: three in the USA (Gullion *et al.* 2008; Shui *et al.* 2005; Niederhauser and Markowitz, 2007), two in the UK (Tickner *et al.* 2009; Hilton *et al*. 2006), one in Canada (Tarrant and Gregory, 2003) and one in Hong Kong (Tarrant and Thomson, 2008). Participants primarily came from urban areas, however, Tarrant and Gregory (2003) interviewed First Nation mothers from communities in north-western Ontario. Over the seven studies participants ranged in socio-economic background, education, and in their decision-making regarding vaccinating their children. Vaccination decisions included: opting out of all childhood vaccinations (Gullion *et al. 2008);* opting out of certain combined vaccinations such as MMR; obtaining Measles, Mumps and Rubella vaccination as three separate vaccines (Hilton *et al.* 2006); ensuring that their children had all the necessary vaccinations (Shui *et al.*2005; Tickner *et al.* 2009); and in some cases even obtaining additional vaccinations not routinely provided by child health clinics (Tarrant and Thomson*,* 2008).

Table D2 - Participant Characteristics

	Country of Study	Participant relationship to child	Child's immunisation status	Demographics (geographical location)	Reference
Semi-structured interviews					
	USA (North Texas)	Parents	Unvaccinated	Urban	Gullion *et al.* (2008) **Study 3**
	Canada (Ontario)	Mothers	Complete and incomplete	Rural (First Nations)	Tarrant and Gregory (2003) **Study 4**
	UK (Southern England)	Parents (Primarily Mothers)	Complete	Urban	Tickner *et al.* (2009) **Study 6**
	Hong Kong	Parents (Primarily Mothers)	Complete	Urban	Tarrant and Thomson (2008) **Study 7**
Focus groups					
	USA - Hawaii (four different islands)	Parents/Foster parents/Guardians	Incomplete	Wide range	Niederhauser and Markowitz (2007) **Study 1**
	UK (Glasgow)	Parents	Varied (no vaccinations, no MMR, single vaccines, all vaccinations)	Wide range	Hilton *et al.* (2006) **Study 2**
	USA (Atlanta, Georgia)	Mothers	Complete	Urban	Shui *et al.* (2005) **Study 5**

3.2 Data synthesis – Method

A conventional Content Analysis (Hsieh and Shannon, 2005), using an inductive approach (Elo and Kyngas, 2007), was used to conduct a data synthesis on the included studies. A cursory evaluation of the results of the data extracted from the studies resulted in highlighting key words and concepts that seemed important in order to develop an idea of the attitudes, beliefs, and barriers presented

in the studies' results. The next step involved a process of open coding conducted on the results sections of all seven studies and the data was coded for relevant information that emerged. This coded data was then transferred to a coding sheet and organised into an initial hierarchy of categories for each of the seven studies including: primary categories, generic categories, and sub-categories. An initial coding scheme was also developed which tabulated primary and generic categories from the coding sheet. Next was the abstraction process of the categories across all seven studies using a tree diagram method to synthesise them, with each tree diagram illustrating a primary category and their corresponding generic and sub-categories. There were initially four primary categories:

- Parental and Individual Aspects
- Family and Community Aspects
- Services and Systems Aspects
- Specific Barriers (presented in studies 1, 4 and 7)

However, as the majority of the generic and sub-categories under the first three primary categories were evidently potential barriers a table was made to show all of the barriers and potential barriers identified across all seven studies *(Table D3).*

3.3 Data Synthesis – Analysis

There were a total of 69 barriers and potential barriers to vaccination identified across all seven studies. Many barriers identified were not reported as barriers in the studies per se because only studies 1, 4 and 7 actually mentioned barriers specifically in their results. However, these barriers and potential barriers are included in the analysis as they were all reasons why parents reported being worried about vaccinating or why they decided to partially vaccinate or not vaccinate at all. There were 82 barriers (mean=27.33) identified across the three focus group studies (studies 1, 2 and 5) and 57 barriers (mean=14.25) across the four semi-structured interview studies (studies 3, 4, 6 and 7). Study 2 had the most participants (n= 72) but study 1 had the second highest number of participants (n=64) and identified the most barriers out of all of the seven studies (n=44). Study 7 had the lowest number of participants out of all of the studies (n=15) and the lowest number of barriers identified (n=9) and consequently was the most positive study in terms of the participants' attitudes and beliefs towards vaccination.

Table D3 – Barriers and potential barriers identified in all seven studies and presented in their corresponding primary and generic categories

(Shaded boxes represent the barriers identified in the studies)

Potential barriers identified	Semi-structured Interviews (Study No.)				Focus Groups (Study No.)		
	(3)	**(4)**	**(6)**	**(7)**	**(1)**	**(2)**	**(5)**
Sample size, Number (N) =	*N=25*	*N=28*	*N=21*	*N=15*	*N=64*	*N=72*	*N=53*
PARENTAL & INDIVIDUAL ASPECTS							
Parental attitudes, beliefs and fears							
Fear that vaccines can cause immune-overload						▓	
Fear that vaccines can cause immune-vulnerability						▓	
Fear that some children's immunes systems could be prone to long term damage from combined vaccines					▓	▓	
Fear that vaccines may cause long term damage to health					▓	▓	
Concerned about combined vaccines			▓		▓	▓	
Belief that vaccines can cause disease					▓		
Belief that babies are too fragile to cope with vaccinations					▓		
Belief that vaccine-preventable diseases are low risk/manageable			▓		▓		▓
Belief that vaccine-preventable diseases are beneficial to the immune system						▓	
Parents no longer familiar with/lack of knowledge of vaccine-preventable diseases				▓			▓

Belief that there is no long term research into vaccines					■		
Belief that children who are ill should not be vaccinated		■	■		■	■	
Fear/experience of adverse side effects from vaccines	■	■	■	■	■	■	■
Belief that Vaccines/ MMR triple vaccine can cause autism						■	■
Belief that risk of vaccines outweigh benefits	■				■		
Parents remembering their own or other peoples negative experiences	■	■	■		■	■	■
Belief that vaccines are provided at too young an age					■		
Belief that vaccines are ineffective		■					
A preference for alternative medicine					■	■	
Belief that child is too healthy to need vaccinations						■	
Belief that some children's immune systems are not strong enough to cope with general vaccinations					■	■	
Belief that children who get lots of common illnesses have vulnerable immune systems						■	
The MMR triple vaccine could overwhelm fragile immune systems/cause damage						■	
Parental knowledge and understanding							
Parents feeling under-informed and uneducated about vaccinations					■		■
Lack of parental knowledge about vaccines				■			■
Parental research and data collection							

Impact of parent research on decision-making	▓		▓					
Parental organisation and practicalities								
Lack of parental motivation/memory					▓			
Transport issues					▓			
Financial issues					▓			
Lack of health insurance					▓			
Lack of control					▓		▓	
Religious beliefs					▓			
Aware/affected by adverse vaccine publicity	▓	▓	▓				▓	▓
Trauma of the vaccination process (for parent and child)		▓	▓		▓			
Distress of vaccinating pre-schoolers rather than infants			▓					
Child experiences of needle phobia		▓						
Child experiences of pain during vaccination		▓	▓					▓
Experiencing difficulties/embarrassment at child's behaviour during vaccination appointment		▓						
FAMILY & COMMUNITY ASPECTS								
Advice and guidance								
Negative vaccination advice from family				▓				
Parental responsibility								
Parental drug abuse					▓			
Living conditions								
Frequent house moves/transient living conditions					▓			

Beliefs that socio-economic status/environment and care of child influencing morbidity and mortality outcomes of vaccine-preventable diseases				▓			
Parental support							
Lack of family support				▓			
Difficulties in caring for more than one child	▓			▓			
Difficulties in obtaining child care for other children whilst at clinic	▓	▓		▓			
Work commitments getting in the way of vaccination appointments		▓		▓			
Needing to get time off work to take child to be vaccinated	▓	▓	▓				
Disagreements about vaccination with spouse/family				▓			
SERVICES AND SYSTEMS ASPECTS							
Public health services							
Availability of vaccines				▓			▓
Provider's differences of recommendations for shots				▓			
Availability of clinic appointments		▓		▓			
Dissatisfaction with medical practices	▓		▓	▓			
Issues of trust							
Mistrust or distrust of the medical community /HCPs	▓			▓			▓
Perceived bias in information about vaccines	▓						▓
Belief that doctors do not know enough about the immune	▓						

system/vaccinations	▓						
Belief that doctors may be influenced by financial gain	▓			*			▓
Belief that doctors do not have their best interests at heart	▓			*			▓
Belief that vaccine ingredients are harmful/or poor quality					▓		▓
Fear of government conspiracy/experimentation							▓
Communication with HCP's							
Poor communication with HCPs	▓						▓
Negative experiences of interactions with HCPs		▓					
Confusion/lack of knowledge about vaccination schedule			▓		▓		▓
Dissatisfaction with lack of contact with HCPs		▓	▓				
Clinic factors							
Lengthy waiting times at vaccination clinic		▓		▓			
Difficulties in attending clinic with additional children		▓			▓		
Lack of appointment reminders					▓		
Clinic policies					▓		
Information							
Lack of vaccination information provision	▓		▓		▓		▓
Confusion and lack of knowledge about how vaccines and the immune system work together	▓				▓	▓	▓
Number of potential barriers per study	*14*	*16*	*18*	*9*	*44*	*17*	*21*

* Regarding Private Doctors only

4. DISCUSSION

There are similarities and differences between the findings of this review and that of Mills et al. (2005). The majority of the barriers in Mills et al (2005) were identified again in this review such as potential harm and risk of side-effects, the latter being identified in other studies of barriers to vaccination such as Canavati, Plugge, Suwanjatuporn, Sombatrungjaroen and Nosten (2011) which also included: forgetting vaccination appointments and work commitments. In addition, similar results were demonstrated by Stefanoff, Mamelund, Robinson, Netterlid, Tuells, Bersaker, Heijbel, Yarwood (2010) in their survey of parental attitudes to vaccination across five European countries with a minority of "doubters" in all five countries, despite most parents viewing immunisation positively. The most common reason for concern amongst these "doubters" was fear of adverse events resulting from vaccinations, followed by the alleged link between MMR and autism. They also reported concerns regarding disagreement between experts related to the safety of vaccines and poor information about vaccination.

The most common barriers identified in this review were related to fear of adverse side-effects from vaccinations; parents' own and other peoples' negative experiences of vaccinations; adverse publicity about vaccines/vaccinations; believing that children who are ill should not be vaccinated; believing that doctors do not have parents and their children's best interests at heart; lack of information and confusion about how vaccines and the immune system work. However, the latter may adversely influence the other most common barriers because if parents knew more about how vaccines and the immune system functioned, potentially they might not view vaccination so negatively. The second most common barrier in the original review by Mills *et al.* (2005) was concern about vaccines being painful, which was identified to a lesser degree in this review where it was more related to the child experiencing pain rather than concerns about the pain. Likewise, Mills *et al.* (2005) also identified other important barriers concerning perceived efficacy of vaccines, a distrust of the medical community or perception of conspiracy, and a belief that doctors did not understand the adverse effects associated with vaccinations.

Respect and trust in authorities (i.e. the government and medical community) appeared to be a key factor in whether parents chose to vaccinate their children or not. The fact that the barriers of distrust and conspiracy towards the medical community in relation to vaccinations in the original review were identified in this review is of concern. Doctors and other HCPs are the first port of call for parents

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obtaining vaccinations for their children and for informing parents about vaccinations, so trust is paramount: there is already a known association between distrust in health care providers and perceived barriers to vaccination (Smith, Kennedy, Wooten, Gust and Pickering, 2006) and if trust and respect are absent, such as in Gullion *et al.* (2008) Shui *et al.* (2005) and Niederhauser and Markowitz, (2007), then we can continue to expect poor levels of vaccination uptake. In contrast, where there is absolute trust and respect for authorities and the medical community this has shown to result in full adherence of the vaccination programme, as demonstrated in Tarrant and Gregory (2008). The issue of trust was also identified by Jolley and Douglas (2014) who conducted two studies investigating the potential impact that anti-vaccine beliefs and anti-vaccine conspiracy theories could have on the vaccination intentions of parents. They discovered a significant negative relationship between anti-vaccine conspiracy beliefs and vaccination intentions and those participants exposed to information supporting anti-vaccine conspiracy theories were less likely to vaccinate than those in the anti-conspiracy condition or controls. These results were generated by the participants' perceived dangers of vaccines, feelings of powerlessness, disillusionment, and mistrust of authorities. Smith *et al.* (2006) found that there was a strong association between the influence that health care providers have on parents' decisions to vaccinate their children, including among parents who believed vaccinations were unsafe. In addition, if parents are not given enough time to express their concerns and discuss vaccine-related issues, or the trust breaks down due to having their safety concerns dismissed, parents may be more likely to put their trust in alternative practitioners. However, these practitioners may or may not have less favourable perspectives regarding vaccinations and may potentially reinforce parental concerns rather than eradicate them, which could result in discouraging them from vaccinating their children (Smith *et al.*2006; Wright, 2009).

This review revealed that some parents preferred to follow the advice of Andrew Wakefield, the doctor who was infamously struck off the medical register for his now discredited research in which he reported there was a link between the MMR vaccine and the development of autism (Ditum, 2013). Wakefield had advised administering the MMR triple vaccine in three separate vaccines (Hilton *et al.* 2006; Wakefield et al, 1998), and despite his research being retracted from The Lancet journal in which it was originally published, parents still seemed inclined to believe it. There is evidence that giving the MMR vaccination is the best and most effective option; it not only helps to stimulate a greater immune response to generate the antibodies against the diseases, but there is also evidence to suggest that it may be responsible for a reduction in invasive bacterial infections for a 12 week period after MMR

administration, as opposed to 'overloading' the immune system (Miller, Andrews, Waight and Taylor, 2003). In the UK, the separate Measles, Mumps, and Rubella vaccines are not available on the NHS and the single vaccines are not licensed in the UK meaning their quality and safety are not assessed (NHS Choices, 2014). However, single vaccines can be provided through private clinics.

This review has demonstrated additional barriers to Mills et al (2005) related to socio-economic status both in terms of perceived mortality and morbidity from vaccine-preventable diseases and with regards to obtaining vaccinations (Niederhauser and Markowitz, 2007). An association between socio-economic characteristics and immunisation on the recommended schedule was also found in Devkota, Simkhada, van Teijlingen and Rai (2013), where the higher the socio-economic status the higher the adherence to the immunisation schedule. Barriers of parental confusion, lack of knowledge about the vaccination schedule and about vaccinations were found in Mills *et al.* (2005), in this review and in Yousif, Albarraq, Abdallah and Elbur (2013) in which despite 98.4% of parents agreeing that immunisation was important and 91.5% considering that immunisation was more beneficial then harmful, only 41.6% were aware of how important multiple doses of the same vaccine were for the development of immunity. Poor parental knowledge regarding the vaccines that their children received was also identified by Benin, Wisler-Scher, Colson, Shapiro and Holmboe (2006).

This review further echoed Mills *et al.* (2005) by identifying the barrier of parents believing that ill children should not be vaccinated, when in fact it is safe to vaccinate children suffering with minor illnesses with or without fever (Niederhauser and Markowitz, 2007; Tarrant and Gregory, 2003). Tarrant and Gregory (2003) found that some parents were deterred from vaccinating by nurses who did not want to vaccinate children with minor illnesses. Such beliefs were identified in developing countries such as Brazil and Turkey where parents' concerns about vaccinating their children when ill were compounded by HCPs who refused to vaccinate ill children (Figueiredo, Pina, Tonete, de Lima, de Mello, 2011; Topuzoğlu, Ay, Hidiroglu, Gurbuz, 2006). That this barrier has emerged again a decade after the original review, suggests that perhaps HCPs working in public health services and parents, may require further education about this aspect and efficient methods to provide this information need to be determined.

In addition, although this review only comprised studies in developed countries, some developing countries have presented high rates of vaccination uptake, where health services are effective and utilised by parents who realise how important childhood vaccinations are and adhere to immunisation

schedules, such as in Nepal (Devkota *et al.* 2013) and Turkey (Topuzoğlu *et al.* 2006). Factors that motivated parents to vaccinate were also identified in this review, such as parental and social responsibility, which are also reflected in Leask, Chapman, Hawe, Burgess (2006) in which participants frequently described immunisation as a social responsibility and parents who did not vaccinate were considered irresponsible.

Since the previous systematic review by Mills *et al.* (2005) was published, poor adherence to uptake of recommended vaccinations for children is still an area of concern. The studies in this review demonstrate that, although many parents in developed nations may be adhering to vaccination programmes and are aware of the importance of vaccination, there appear to be many barriers that still exist, which are causing parents to be reluctant about vaccinating their children. The studies in the review reported that for the most part detailed information is being provided to parents, so perhaps it is not being provided in a timely enough fashion, or may only explain about the side effects of the vaccines, not about how the vaccines work. Gullion *et al.* (2008) reported that information was being provided to parents but this was often seen as insufficient and there was scant opportunity for discussion about any concerns the parents might have. Parents in some of the studies reviewed believed that combined vaccinations could be damaging and overloading to young, fragile, immune systems as reported in the study by Hilton *et al.* (2006). However, as this review has specified, this is not how vaccines work or how immune systems respond to them. Information about vaccines is readily available on the internet but it may be that parents are not finding it or receiving it from their health care providers. Interestingly, some parents such as those who participated in Gullion *et al.* (2008) who were highly educated, conducted their own research into vaccination due to mistrust of the medical community, yet still chose to opt out of vaccinating their children. However, this may be influenced by the research and information they found and the context within which they understood and processed it; parents may not believe the information they read or are persuaded by inaccurate information about vaccines.

On a positive note, studies such as that conducted by Gust, Kennedy, Wolfe, Sheedy, Nguyen and Campbell (2008); Miller, Verhoef and Cardwell (2008); and Austvoll-Dalgren and Helseth (2010) have made excellent contributions to the type of information parents require about vaccinations and vaccines and the best approaches that HCPs should take to provide this information. Gust *et al.* (2008) successfully created and reviewed tailored immunisation materials for concerned mothers, and Brunson (2013) identified that vaccination interventions must be targeted to parents according to how they

assess vaccination. Studies such as these suggest that changes may need to be made to how the medical profession approach the issue of childhood vaccination with parents if response rates are to improve.

5. CONCLUSIONS

This review has demonstrated a wide range of parental beliefs and attitudes towards childhood vaccinations and how these have the potential to become barriers to obtaining vaccinations. It is pertinent that the most prevalent barriers identified in this review were from studies which were conducted all around the world including the USA (Georgia, Texas and Hawaii), Canada, Hong Kong and Great Britain. There was a variety of populations hailing from urban and rural areas, which included primarily mothers, but also fathers, foster parents and guardians, and ranging in vaccination status of completely vaccinating their children to opting out of vaccinations all together. There are always weaknesses inherent in qualitative research due to its subjective content and methodology, but qualitative research has its strengths too in providing rich and meaningful data that indicates how individuals think, feel, and act about complex issues. In addition, where the results of the studies included in this review may have been limited in their potential generalisability to other populations as single reports, synthesised as they are in this review, the findings become more applicable and carry more weight in detailing the range of parental beliefs and attitudes towards childhood vaccinations and the most significant barriers to vaccination.

The fact that participants reported in 4 out of the 7 studies that they felt doctors did not have their best interests at heart is concerning. Doctors essentially want to help their patients and demonstrate this by encouraging parents to vaccinate their children. Future research in this area may need to focus on revaluating best practice around vaccinations and determining what the most effective interventions might be and whether the goal is improved vaccination rates, parental satisfaction or both and from this can come consideration of how best to achieve these, for example, in providing information. This needs to be as transparent and informative as possible in order to dispel misconceptions and damaging health beliefs, instil parental confidence in vaccines and the medical community and encourage uptake of vaccinations. Tackling these issues is no mean feat, as is evident in the UK, and may be even more of a challenge to address in other countries due to public health service provision in terms of quality, quantity, availability, and cost. However, with evidence of interventions that could prove to be effective tools in encouraging parents to vaccinate their children, such as the tailored information materials by

Gust *et al.* (2008), it may be appropriate for such interventions to become part of future vaccination policy and practice to encourage more parents to vaccinate their children.

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APPENDIX D1: PROTOCOL

Systematic Review Protocol

Review Topic

A systematic review of qualitative studies exploring parental beliefs and attitudes toward childhood vaccination in order to identify common barriers to vaccination.

Background

This is an update of an existing systematic review by: Mills, Jadad, Ross and Wilson (2005) which was published in the Journal of Clinical Epidemiology. They felt that qualitative studies may help to elucidate why some parents choose not vaccinate to their children, and that by conducting a synthesis of the data from various qualitative studies that examined this issue they could identify barriers across different populations and time periods. The authors hoped that by understanding these barriers, parental concerns about vaccinating their children could be more effectively addressed by heath care providers and policy makers, via the development of appropriate strategies to help increase the rates of vaccination (Mills *et al. 2005).*

The authors extracted qualitative data from 15 qualitative studies which explored parental beliefs and attitudes towards childhood vaccination. Using techniques from the method of 'content analysis' they were able to identify a number of themes categorised by the following titles:

- Issues of harm
- Issues of distrust
- Access issues
- Other issues

A variety of common barriers to childhood vaccination were also identified, such as:

- Concern of potential harm *(risk of adverse effects, pain)*
- Issues of trust *(lack of trust or belief that vaccination is necessary, distrust of medical community, perceived conspiracy, belief that target disease for vaccine is not a health threat)*
- Problems with access *(belief that children shouldn't be vaccinated if they have a minor illness, lack of parental knowledge around vaccination schedule)*
- Parental belief of control over child's exposure to pathogens

- Moral or religious reasons

Many of these barriers were identified consistently across the studies included in the review. In addition to the identification of common barriers to childhood vaccination the study not only demonstrated the feasibility of conducting a systematic review of qualitative studies, but of doing this using a content analysis approach. They also illuminated how the synthesis of qualitative data can be a more encompassing and efficient method of providing valuable information, such as supporting policy development in the area of childhood vaccination; as opposed to individual qualitative studies that may only have had a limited influence (Mills *et al.* 2005).

Objectives

The objective of the original systematic review was to determine whether a systematic review of qualitative studies can lead to identification of consistent themes across studies, using barriers toward childhood vaccination as an example. The original review clearly demonstrated that conducting a systematic review of qualitative data was successful and yielded interesting and important results, so this updated review is not necessarily seeking to prove again how efficient a qualitative approach can be, but to further the findings that the original review identified.

This review will seek to determine the following:

- Whether parental beliefs and attitudes toward childhood vaccination have changed since the original review
- Whether the barriers to childhood vaccination are the same as identified in the original review
- Whether new barriers to childhood vaccination are identified

Search Strategy

A systematic search of the literature for English language articles using 8 electronic databases will be conducted looking at papers from April 2003 – January 2014. This date was decided upon due to the previous review which searched for papers up until May 2003. This search may also be supplemented by hand-searching key journals and bibliographies of key articles. In searching the databases, only journal articles/academic papers (preferably peer reviewed), will be searched for in order to obtain applicable research of the highest quality. Only published papers will be included.

Search Terms

The research terms are ordered in the following 1-6 searches:

1. Vaccin* OR Immuniz* OR Immunis* OR Innoculat* AND "child health" AND Parent* OR Caregiver* OR "Care giver*"

2. #1 AND Attit* OR percept* OR expectat* OR opinion*

3. #1 AND physician OR GP OR Doctor OR Paeditrician OR "Healthcare Professional" OR Therapist OR Practitioner

4. #2 AND physician OR "General Practitioner" OR Pediatrician OR Doctor OR "Health care professional" OR Therapist

5. #4 AND "Alternative Medicine" OR "Complementary Medicine"

6. #5 AND Qualitative

Except for the exclusion of MMR and DPT due to the review not focusing on specific vaccines, the individual search terms will be the same as those in the previous review but will not be entered singularly. Instead they will be formatted into appropriate groups of terms and used for each database search; which did not happen in the previous review.

Study Selection Criteria

Participants: Parents (Mother and/or Fathers); Caregivers; Physicians; CAM Providers.

Interventions: Childhood vaccination and information

Outcomes: Parental perceptions, beliefs, attitudes, acceptance, attitude of health-care providers, and decision-making.

Study Design: Qualitative research using semi-structured interviews and/or focus groups.

Please see the 'Inclusion and Exclusion Criteria for Study Selection'

Databases

The databases to be used for this review are as follows:

In combination with EBSCO:
PsychINFO, CINAHL (Plus with Full Text and Headings), Medline (with Full Text, MeSH).

In combination with OvidSP:
AMED and EMBASE

Accessed either via City University Library or Google:
Campbell Collaboration; ERIC; SCOPUS.

Search procedure

A majority of the databases searched in the original review will be searched in this one, except the Biomedical Reference Collection: Basic and Nursing and Allied Health Collection: Basic, as these were more difficult for the researcher to access and were deemed as unnecessary for this review particularly as EMBASE is the most comprehensive international biomedical database. In addition, E-Psyche is no longer available so will be replaced by PsychINFO, as this was considered to be a suitable alternative. The database SCOPUS has also been added to the list as this was thought to potentially add further applicable research to the review. The NRR was an active database when the previous review was conducted but is now an archive storing studies from 2000-2007. It was originally searched for unpublished studies but will not be searched for this review as only published studies will be included.

Study Quality Assessment Checklists and Procedures

A quality assessment checklist has been adapted from '10 questions to help you make sense of qualitative research' (CASP, 2013), and involves assessment of the following areas:

- Initial screening questions
- Research design
- Sample recruitment
- Data collection

- Reflexivity

- Ethical issues

- Data analysis

- Research findings

- Value of the research

Please see the Quality Assessment Checklist.

Data Extraction Strategy

A data extraction form was designed that included the following section headings

- General Information

- Study Characteristics

- Methodological Quality of Study

- Intervention

- Analysis

- Outcomes

APPENDIX D2: INCLUSION AND EXCLUSION CRITERIA

Inclusion and Exclusion Criteria for Study Selection

	Inclusion Criteria	Exclusion Criteria
Population	Parents (Mothers and/or Fathers); Caregivers; Physicians; CAM providers.	Individuals who are not Parents; Caregivers; Physicians or CAM providers.
Issues addressed	Parental beliefs and attitudes towards childhood vaccinations The barriers that parents experience when obtaining vaccinations for their children.	Adult vaccines Specific vaccines (e.g. MMR Vaccine only).
Geography	Studies conducted in a developed or high-income country	Studies conducted in developing nations
Study Design	Qualitative studies: semi-structured interviews and/or focus groups. Published studies. English language articles. Peer Reviewed.	Quantitative studies: Randomised Control Trials (RCTs); Quasi-experimental studies; Controlled observation studies (Cohort studies and Case control studies); Observational studies without a control group; Surveys; Structured Interviews; Case Studies; Expert clinical opinion/Reports; Reviews. Unpublished studies. Non-English Language articles.

APPENDIX D3: QUALITY ASSESSMENT CHECKLIST

Quality Assessment Checklist for Qualitative Research

(Adapted from: Critical Appraisal Skills Programme (CASP), 2013)

Systematic Review Research Papers 1-8

QUESTION	YES	PARTLY	UNCERTAIN	NO	N/A	COMMENTS
Preliminary Screening						
Does the study address parental beliefs and attitudes towards childhood vaccination and/or the barriers they experience when trying to obtain vaccinations for their children?						
Was there a clear statement of the aims of the research?						
Research Design						
Is the research design appropriate to address the aims of the research?						
Sample Recruitment						
Have the researcher (s) explained how the participants were selected?						
Have the researcher(s)						

explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study?					
Is there any discussion around recruitment?					
Data Collection					
Was the data collected in a way that addressed the research issue?					
Was the setting for data collection justified?					
Is it clear what methods were used to collect the data?					
Have the researcher (s) justified the data collection methods chosen?					
Have the researcher (s) discussed saturation of data?					
Reflexivity					
Has the relationship between researcher(s) and participants been adequately considered?					
Have the researcher (s)					

critically examined their own role, potential bias and influence during:						
❖ Formulation of the research questions						
❖ Data collection, including sample recruitment and choice of location.						
If there were any changes to the research design during the study have the researcher(s) considered the implications of these?						
Ethical Issues						
Is there sufficient detail demonstrating that ethical standards were maintained during the study?						
If there were any ethical issues raised by the study, have the researcher (s) discussed them?						
Was ethical approval sought by an ethics committee?						
Data Analysis						
Was the data analysis sufficiently rigorous?						

Is there an in-depth description of the analysis process?						
Is sufficient data presented to support the findings?						
Have the researcher (s) critically examined their own role, potential bias and influence during analysis and selection of data for presentation?						
Research Findings						
Is there a clear statement of the findings?						
Is there adequate discussion of the evidence both for and against the researcher(s) arguments?						
Have the researcher (s) discussed the credibility of their findings?						
Are the findings discussed in relation to the original research question(s)/topic?						
Value of the Research						

Have the researcher (s) discussed the contribution the study makes to existing knowledge or understanding of parental beliefs and attitudes to childhood vaccination and/or the barriers to obtaining childhood vaccination?						
Have the researcher (s) identified new areas where research is necessary?						
Have the researcher(s) discussed whether or how the findings can be transferred to other populations, or consider other ways the research may be used?						

APPENDIX D4: DATA EXTRACTION FORM

Data Extraction Form

GENERAL INFORMATION

Date of Extraction

Study Reference

Author contact details

Identification number in systematic Review:

Notes:

STUDY CHARACTERISTICS

Verification of study eligibility

Type of Intervention

Number and Duration of intervention

Location of intervention

Outcome

METHODOLOGICAL QUALITY OF STUDY

Study Design

Study sample and selection

Mode of delivery

ANALYSIS

Method of analysis used

Type of software used (if any)

Was the method of analysis used appropriate?

Was the analysis performed and interpreted correctly?

RESULTS/OUTCOMES

Results of the research

Overall study quality: **Poor**   **Adequate**   **Good**   **Excellent**

APPENDIX D5: ADDITIONAL INFORMATION ON SEARCHES

List of Journals searched

- Vaccine (Only 2007-2014 was available via the Royal Society of Medicine (RSM))

- Paediatric and Child Health (Only 2007-2014 was available via the RSM)

- Paediatric Annals (2012, Volume 41, Issue 4, in particular)

The journals of: Community Practitioner; Biomed Central Public Health; British Journal of General Practice; Social Science and Medicine; Australia and New Zealand Journal of Public Health; and Public Health Medicine were also hand-searched for key articles. In addition reference lists of a number of key articles were also searched.

Additional information on searches, limiters and filters

Medline, PsychINFO and CINAHL were all searched via the EBSCO host and Medline was searched using MeSH and Headings with CINAHL, which involved use of Explode (EX) and Major Concepts (MC) creating the following headings which were used in all the EBSCO searches and appeared as the following, as a foundation to each search: (MH "Health Services/UT") OR (MM "Community Health Services/UT") OR (MM "Preventive Health Services/UT") OR (MH "Health Education") OR (MH "School Health Services/UT") OR (MM "Immunization Programs+/UT").

Advanced searches were completed on all databases which included special limiters such as: Search modes ('Boolean/Phrase' and 'SmartText Searching' for EBSCO and 'Title/Abstract/Keyword' for SCOPUS and 'All terms - Abstract' for ERIC); peer reviewed; publication year range (April 2003-January 2014); publication types (journal articles, academic journals, research articles); abstract availability; human subjects; English language; and excluding dissertations. In terms of EMBASE, the filter of: 'Clinical Queries' was included with the category of: 'Qualitative - Best balance of sensitivity and specificity' selected from it.

Clinical Queries

Limiting using Clinical Queries restricts retrieval to clinically sound studies; the category selects the best balance i.e. the combination of terms that optimises the trade-off between sensitivity (retrieval of most relevant articles but also off target articles) and specificity (retrieval of fewer relevant articles but also fewer off target articles), as stated on the information tab for this filter on the OvidSP host. Searching

for relevant studies was further narrowed by including applicable Classification and Methodology limiters on the EBSCO host, as shown in Table 2:

Table A - Classification and Methodology limiters on EBSCO

Classification limiters	Health and mental health treatment and prevention
	Childrearing and Child care
	Promotion and maintenance of health and wellness
	Health and mental health services
	Professional personal attitudes and characteristics.
Methodology limiters	Qualitative
	Interview
	Focus Group

On the database ERIC subject filters were selected to narrow the literature search to relevant studies. The following subject filters were selected for searches 2-6 (Search 1 had only yielded 251 results so subject limiters were not used):

Table B - Subject Limiters on ERIC

Search 2	Foreign countries/ Expectation/Interviews/Parent attitudes/Focus groups/ Opinions/ Children/Barriers/Young children/Mothers/Beliefs/Public opinion/ Qualitative Research.
Search 3	Foreign countries/Interviews/Focus groups/Qualitative research/Allied health personnel/ Barriers/Health Promotion/Parent attitudes/Young children/Parents/Immunization programs/Beliefs.
Search 4	Foreign countries/Children/Interviews/Immunization programs/Physicians/Health services/ Parent attitudes/Child health/Young children/Health promotion/ Parents/Prevention/ Mothers/Qualitative research/Barriers/Access to health care.
Search 5	Foreign countries/Physicians/Immunization programs/Interviews/Health services/Child health/Health promotion/Children/Parent attitudes/Prevention/Access to health care/ Mothers/Focus groups/Barriers/Infants/Parents/Child rearing/Qualitative research/Young children/Allied health personnel.
Search 6	Foreign countries/Physicians/Immunization programs/Caregivers/Interviews/Health

	services/Child health/Health promotion/Children/Parent attitudes/Prevention/Access to health care/Mothers/Focus groups/Barriers/Infants/Parents/Child rearing/Qualitative research/Young children/Allied health personnel/Health personnel.

APPENDIX D6 – SYNOPSIS OF KEY STUDY QUALITY CHARACTERISTICS (taken from Data Extraction Forms)

Item	Semi-structured interviews (reference and study no.)				Focus Groups (reference and study no.)		
	Guillion et al. (2008) **(3)**	*Tarrant et al. (2003)* **(4)**	*Tickner et al. (2009)* **(6)**	*Tarrant et al. (2008)* **(7)**	*Niederhauser et al. (2007)* **(1)**	*Hilton et al. (2006)* **(2)**	*Shui et al. (2005)* **(5)**
The research design was appropriate to address the aims of the research	Yes	Yes	Yes	Yes	Yes	Yes	Yes
The study reported gaining ethical approval	Yes	Yes	Yes	Yes	Yes	Yes	Yes
The study explained how participants were selected	Yes	Yes	Yes	No	Yes	Yes	Yes
The study discussed participant recruitment	Yes	Yes	Yes	Partly	Yes	Partly	Partly
Interview questions were predefined	Yes	Yes	Yes *	Yes	N/A	N/A	N/A
Focus group questions were predefined	N/A	N/A	N/A	N/A	Yes	Yes	Yes
The focus groups were overviewed by someone other than the facilitator	N/A	N/A	N/A	N/A	Yes	No	No
Saturation of data was mentioned	No	Yes	Yes	No	No	No	Yes
Data was transcribed (verbatim)	Yes (?)	Yes (v)	Yes (v)	Yes (v)	Yes (v)	Yes (v)	Yes (?)
There was a description of how the research themes were identified	Yes	Yes	Yes	Yes	Yes	Yes	Yes
The research findings were analysed by more than one assessor	Yes	Yes	Yes	Uncertain	Yes	Yes	Yes
The analytical method used was appropriate and rigorous	Yes	Yes	Yes	Yes	Yes	Yes	Yes
There was sufficient data presented to support the findings	Partly	Yes	Yes	Yes	Yes	Yes	Yes

Implications of the research findings were discussed	Yes	Yes	Yes	yes	Yes	Yes	Yes
Study Quality Score **	**Good**	**Excellent**	**Excellent**	**Good**	**Excellent**	**Good**	**Excellent**

*Later interviews included new questions to clarify themes that had emerged in the earlier interviews. NB: Table 2 presents a synopsis of the key characteristics of the studies included in the review, for more detailed assessment of the characteristics please see the Quality Assessment Checklist form template (Appendix 3) used to assess the quality of all the included studies. Originally there were 8 studies 1-8 but number 6 was rejected after the quality assessment, so studies 6 and 7 in Table 3 were studies 7 and 8 on the original assessment checklists.

*** **Overall Study Quality Score Range:** Poor/Adequate/Good/Excellent*

APPENDIX D7: FURTHER DATA SYNTHESIS – DESCRIPTIVE CONTENT ANALYSIS *(and selected representative quotes).*

Parental & Individual Aspects

Parental attitudes, beliefs and fears

Parents in study 2 reported fears that vaccines caused immune-overload and vulnerability. Similarly, parents in studies 1 and 2 feared that some childrens' immune systems could be prone to long term damage from combined vaccines, feared that vaccines could cause long term damage to the future health of children and population, and believed that some childrens' immune systems were not strong enough to cope with vaccinations. Parents in studies 1, 2 and 6 reported concerns about the safety of combined vaccines generally and some participants in study 1 believed that vaccines could cause disease and that babies were too fragile to cope with vaccinations. Some parents in studies 1, 5 and 6 believed that vaccine-preventable diseases were low risk and if children did catch them the diseases would be easy to manage. This tied in with the belief of parents from studies 5 and 7 who were either no longer familiar with vaccine-preventable diseases due to immunisation being so effective or who had little or no knowledge about the diseases. Similarly some parents in study 2 believed that it was beneficial for childrens' immune systems to catch vaccine-preventable diseases in terms of promoting life-long immunity: this presented one end of the spectrum, with parents from study 7 being at the other end, believing that vaccination was necessary to prevent their children catching vaccine-preventable diseases and who were afraid of the consequences to their children's health if they were not vaccinated.

One parent from study 1, who did not vaccinate her children, also believed that there was no long term research into vaccines. Some parents in studies 1, 2, 4 and 6 believed that children who were ill should not be vaccinated, particularly if they suffered with a fever, primarily because they were afraid vaccination would make their child worse and so would delay due vaccinations until their child was better.

"If they're not well I just cancel the appointment, cos I don't think it is worth the risk of causing them long-term problems" (Hilton et al. 2006)

This health belief was sometimes perpetuated by nurses also being reluctant to vaccinate unwell children. Parents from all seven studies reported fear or experience of adverse side effects of vaccination, although on the whole side-effects were mild and temporary.

"My biggest concern was when I started her on the shots that they get when they're 18 months [was that they] can cause autism so actually delayed my daughter [from] getting that shot because was afraid something like that would happen." (Shui et al. 2005)

Similarly parents from all the studies remembered their own or other people's experiences of vaccination - experience being first-hand, second or third-hand and both positive and negative. Negative experiences could prove to be barriers to vaccination whilst positive experiences were more likely to motivate parents to vaccinate their children.

"[I] remember what happened to that child, he had an immunization needle the day before he went into seizures and he died...I heard people say that he had received a needle and that probably was the cause of it." (Tarrant and Gregory, 2003)

Parents in studies 1 and 3 believed that the risks of vaccination outweighed the benefits yet parents in study 7 believed the opposite to be true. Parents in study 1 believed that vaccines were provided to children at too young an age and in studies 1 and 2 there were a couple of reports of a preference for alternative medicine or health care in place of vaccinations. In relation to these beliefs, some parents in study 4 believed vaccines to be ineffective and in study 2 some parents reported that their child was: too healthy to need vaccinations, believed that children who were prone to frequent common illnesses had a vulnerable immune system or believed that the MMR triple vaccine could overwhelm fragile immune systems or cause damage.

Parental knowledge and understanding

Parents in study 1 felt uninformed and confused about vaccinations and what was required of them as a parent in getting their child vaccinated, and parents in study 5 felt under-informed and uneducated about vaccinations to the point where they felt they were not comfortable making decisions about vaccination. Participants in studies 1 and 5 lacked knowledge about the importance of vaccinations, and along with study 7, participants in all three studies lacked knowledge about vaccines in general.

"I do not know much about them because I do not have any experience with immunisations before. The baby gets the immunisation once she is born but I do not know whether they are useful or not."
(Tarrant and Thomson, 2008)

Parental research and data collection

Parents involved in the studies, particularly studies 3 and 6, reported that lack of knowledge encouraged them to conduct their own research to inform their decision making about vaccination. Outcomes of this included feeling more knowledgeable and empowered about the subject and feelings of being on more of an equal footing with health care professionals (HCPs) or knew more about vaccinations than the doctors. How parents processed the information impacted on whether they would vaccinate their children. In study 3, parents were highly educated and used advanced research methods to find information from a large number of sources. However, there was incongruence between the high value they placed on scientific knowledge and their scepticism of the medical community.

"I put faith in, you know, obviously, peer-reviewed medical journals are obviously probably my most favorite source, but then also I take independent doctors that have written articles outside of peer reviewed journals as a good source of information as well." (Gullion et al. 2008)

Parental organisation and practicalities

In study 1, some parents reported a lack of motivation to take children to be vaccinated or forgetting they had an appointment. They also reported problems relating to transport and finances, such as not being able to afford a car or having difficulties using public transport, parking problems and not having health insurance. Religious beliefs were also mentioned as a barrier to vaccination but were not elaborated upon. In studies 1 and 5 some parents reported feeling a lack of control over organisational issues such as getting children to the clinic, work schedules, lack of support (study 1) and lack of information (study 5). In studies 2, 3, 4, 5 and 6 parents reported that they were aware of or were affected by adverse publicity about vaccinations, such as the MMR controversy.

Parents in studies 1, 4 and 6 found the vaccination process to be quite traumatic; this was usually due to the child becoming distressed. In relation to this barrier, parents in study 6 also reported how it was

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more difficult and distressing vaccinating pre-schoolers as opposed to young infants, as older children could more easily vocalise their distress. This issue was also reported in the context of the child experiencing pain during the vaccination process (studies 4, 5 and 6), in addition to needle phobia and experiencing difficulties with or embarrassment at child's behaviour during vaccination appointments in study 4.

"My son...I didn't want to bring him...cause I just didn't like the way they acted every time I brought him here. Like I just didn't like the way he was screaming over nothing...Well, I think it's the needles..." (Tarrant and Gregory, 2003)

Family & Community Aspects

There were fewer barriers in this category than the previous two as the attitudes and beliefs of parents were more positive and thus the generic and sub-categories outlined in the abstraction process were mostly factors that motivated parents to vaccinate their children.

Advice and guidance

Generally parents received positive advice from their families regarding vaccination, particularly from friends and peers, although one parent in study 7 reported receiving anti-immunisation advice from their family. In general the parents in study 7 stated that older family members had very little influence over how they reared their children and advice and guidance about vaccination from them was viewed as outdated, which in Chinese culture is quite unusual; advice from siblings and peers was more influential.

Parental responsibility

Many parents felt obligated to vaccinate their children, as children were viewed as vulnerable to vaccine-preventable diseases so it was the parents' responsibility to protect them: some parents would feel guilty if they did not vaccinate them or were concerned about the consequences if they did not. However, in study 1 it was reported that several family members had to raise children whose parents were abusers of a drug called crystal methamphetamine; one participant remarked:

"Neglect, they don't care with the drugs ....That's why most of these kids don't have all of their shots because their parents are drug addicts." (Niederhauser et al. 2007)

Social responsibility

Some parents in studies 5, 6 and 7 felt the decision to vaccinate their children was forced upon them by societal expectations or they viewed vaccinating their children as a social responsibility that needed to be adhered to in protecting their children from disease and maintaining herd immunity.

Living conditions

Parents in study 1 reported moving house frequently as a barrier to vaccination and expressed beliefs that mortality and morbidity from vaccine-preventable diseases was dependent on environment and care of the child. Parents in study 7 were concerned about the overcrowded living in Hong Kong, where they felt children would be more susceptible to catching communicable diseases, thus providing another motivating factor in ensuring their children were vaccinated.

Parental support

Barriers involved lack of family support (study 1); difficulties in caring for more than one child (studies 1 and 4); difficulties in obtaining child care for other children whilst attending the clinic (studies 1, 4 and 6); work commitments getting in the way of vaccination appointments (studies 1 and 6); parents needing to get time off work to take child to be vaccinated (3, 6 and 7); spousal disagreements about vaccination (study 1).

Cultural differences

There were some marked cultural differences between some of the studies, for example in studies 1, 2, 3 and 5 there was either mistrust, distrust, scepticism or lack of confidence in the authorities, such as the government and medical community. This directly contrasted with study 7 where, as part of Chinese culture, authorities and the public health services they provided were highly respected and trusted, leading to strict adherence to vaccination programmes.

<u>Systems & Services Aspects</u>

Public health services

In studies 1 and 5 parents reported issues of vaccine availability; in study 5 vaccine shortages sent conflicting messages to parents about the importance of vaccinating their children in accordance with the immunisation schedule. Study 1 also reported how differences between provider

recommendations for vaccines could prove to delay scheduled vaccinations. Studies 1, 3 and 6 reported dissatisfaction with medical practices in terms of not being able to get an appointment when needed (study 1) or general dissatisfaction related to their experiences of the vaccination process (studies 3 and 6).

Issues of trust

In terms of trust issues related to the medical community, parents in studies 1, 3 and 5 reported either mistrust or distrust of the medical community in relation to vaccinations for their children. Parents in studies 3 and 5 were particularly sceptical about information and sources of information regarding vaccination - perceiving a certain amount of bias - particularly from the medical community. In study 3 there was the belief that doctors did not know enough about the immune system and vaccines. In studies 3, 5 and 7 parents reported that they felt doctors could be influenced by financial gain (although in study 7 this was only concerned with private doctors, who none of the parents in the study used).

"I don't trust them [doctors]. How do I know [they're not] just telling me this so can get these shots so [they] can get their money." (Shui et al. 2005)

Moreover, parents in studies 1, 3, 5 and 7 did not believe that their doctors had their best interests at heart (directed at private doctors only in study 7). In addition, in study 1 a parent believed vaccine ingredients could be harmful and parents in study 5 reported lack of knowledge of vaccine ingredients and believed that as African-Americans their children would receive lower quality vaccines compared to white children; they also expressed conspiratorial beliefs:

"That [Tuskegee] always sticks in my mind. That you really don't know what's happening and here these people were guinea pigs and just don't want my children to be part of that." (Shui et al. 2005)

Regulations (no barriers)

Parents' vaccination decisions were influenced by social norms and laws, such as a mandatory requirement where all children needed to be vaccinated to attend day-care or school, and parents often felt they had no choice but to vaccinate their children. In study 7 this was a significant motivating factor for parents, due to the importance of education in Chinese culture.

Communication with HCP's

Parents in studies 3 and 5 reported issues of poor communication with HCPs. In terms of study 3, parents felt rushed by their doctors during their vaccination appointments and not provided with enough information. In study 5, poor communication was related to the lack of parental knowledge about immunisation, not having their questions answered by HCPs or not understanding their provider's medical terminology.

"I think healthcare providers are not informing patients and sometimes when you raise too many questions you can see the impatience of doctors not really wanting to answer." (Shui et al. 2005)

Study 4 reported how parental beliefs about vaccination were often influenced by negative interactions with HCPs: some parents had been reprimanded for issues related to childcare, the child's illnesses and frequent visits to the clinic; this resulted in upsetting parents and instilling a sense of inadequacy about how they raised their children. Studies 1, 5 and 6 reported parental confusion or lack of knowledge about the vaccination schedules for their children:

"I remember being very confused about exactly what she was getting and what she needed and when she needed it. It was kind of a guessing game a lot of times." (Niederhauser et al. 2007)

Studies 4 and 6 reported parental dissatisfaction with the lack of contact they had with HCPs: this ranged from parents wishing that nurses listened to them more during clinics (study 4) to lack of contact with the health visitor in particular, which led to parents questioning the importance of pre-school vaccinations (study 6).

Clinic factors

Barriers related to: lengthy waiting times at vaccination clinics (studies 4 and 7), where some parents in study 4 got so upset about how long they had to wait that they left before their scheduled appointment; availability of clinic appointments, when parents could not get appointments when they needed them (study 1 and 5); difficulties in attending the vaccination clinic with additional children to manage (studies 1 and 4); lack of appointment reminders and clinic policies (study 1).

"Imagine. You have three, you're holding the baby, one is getting the shot and then you're chasing the other one around….If you're by yourself it's hard." (Niederhauser et al. 2007)

Information

Studies 1, 3, 5 and 6 reported that parents lacked vaccination information. One parent stated in study 1 that they felt uninformed about the vaccines that their child was meant to receive and when. Parents in study 3 desired more information from their doctors about vaccines and wanted it well in advance of their child being vaccinated so they could digest it and some parents viewed their HCPs as too busy to provide information to them. In study 5 most of the parents reported that they felt under-informed about immunisations and did not know what the benefits and risks were. The parents in study 6 were dissatisfied with the lack of information about pre-school vaccinations:

" . . . if you had a letter explaining to you, and nicely, and treating you as an adult . . . Rather than just a little card saying, 'Your daughter is due for X on X' . . . I guess that that might make you go, 'Oh yeah' and take a bit more interest . . ."