

**University of Greenwich
School of Education**

Doctorate of Education (EdD)

**“Organ and Tissue donation: an evaluation of health care
professionals’ knowledge and training and implications for
education”**

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Doctoral Thesis

A thesis submitted in partial fulfilment of the requirements of the
University of Greenwich for the Doctorate in Education (EdD)

DECLARATION

"I certify that this work has not been accepted in substance for any degree, and is not concurrently being submitted for any degree other than that of Doctorate in Education (EdD) being studied at the University of Greenwich. I also declare that this work is the result of my own investigations except where otherwise identified by references and that I have not plagiarised another's work.

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Abstract

The United Kingdom (UK) has one of the highest transplant waiting lists in Europe, with currently 7,000 people in the UK waiting for a transplant with many people dying before an organ becomes available (NHSBT 2013). An organ or tissue transplant has been proven to be an effective life enhancing treatment for end-stage organ or tissue failure (Collins 2005). The Department of Health (DH) in 2008 recommended that all health care professionals who had potential involvement in donor patients should receive regular education and training. This study provides an original contribution to knowledge as no research has been undertaken since to evaluate whether these recommendations have been implemented and whether any relationship exists between education and its influence towards health care professionals perceived attitude, confidence, knowledge and decision making within three different health professions working within critical care areas within the NHS.

This post-positive mixed methods methodology study utilised a self-completion questionnaire distributed to doctors, nurses and operating department practitioners (ODPs) n=3000 working in Intensive Care, Emergency Departments and Operating Theatres within 18 hospitals and focus group interviews involving 8 nurses from 3 hospitals within England. The questionnaire response rate was 1180; quantitative data was analysed using the Statistical Package for Social Sciences (SPSS).

The results revealed that only 23.7% of the sample were given pre-registration donation education and only 56.2% stated they received education as part of post-registration continuing professional development (CPD). Data established knowledge deficits relating to contraindications for solid organ and tissue donation, ability to discuss brain stem death to relatives and differences in clinical management between circulatory and non-circulatory donation approaches. Results found a direct relationship that CPD education improves attitude and participation in donation care amongst health professionals. Data established that there was no bias towards attitude or education provision if the participant worked within a transplant centre versus a non-transplant centre. The study found that there was a direct relationship between the more experienced and senior the practitioner was the more knowledge and confidence they had towards donation. Doctors consistently demonstrated more knowledge and perceived confidence relating to donation issues compared to nurses or ODPs. ODPs consistently demonstrated less knowledge and confidence when compared to doctors and nurses and were less likely to be provided with donation education. Practitioners working within intensive care were significantly more likely to have received donation CPD. The majority of education delivered to health care professionals (HCP) is informally by Specialist Nurses for Organ Donation. The study was underpinned by the theoretical perspectives of Eraut and Dreyfus relating to professional learning and development.

This study provides a contemporary assessment of HCPs' attitude, knowledge and education provision relating to donation establishing that mandatory training as advocated by the DH (2008) and NICE (2011) has not been implemented into frontline practice. The study concluded that HCPs have knowledge deficits relating to organ and tissue donation with education opportunities being limited. The results found a recurring theme that the more experience the HCP has the more knowledge and confidence they have relating to donation. The results will be used to inform and recommend future pre-registration and post registration education and learning strategies relating to donation care.

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Abbreviations

A&E	Accident & Emergency
ANOVA	Analysis of Variance
BERA	British Educational Research Association
BTS	British Transplant Society
BSD	Brain Stem Death
CPD	Continuing Professional Development
DH	Department of Health
DTC	Donor Transplant Co-ordinator
DBD	Donation following Brain Stem Death
DCD	Donation following Circulatory Death
ED	Emergency Department
HCP	Health Care Professional
ICU/ITU	Intensive Care Unit
IRAS	Integrated Research Application System
NHS	National Health Service
NHSBT	National Health Service Blood & Transplant
NICE	National Institute for Health & Clinical Excellence
NIHR	National Institute for Health Research
ODP	Operating Department Practitioner
ODR	Organ Donor Register
OT	Operating Theatres
PIS	Participant Information Sheet
REC	Research Ethics Committee
RDC	Research Degrees Committee
RN	Registered Nurse
R&D	Research & Development
SNOD	Specialist Nurse in Organ Donation
SPSS	Statistical Package for Social Sciences
UK	United Kingdom

Definitions of Terms:

Brain stem dead/death: is when a person has received catastrophic brain injury often following a head injury or bleed in the brain which results in permanent damage to the brain stem. The brain stem is responsible for maintaining conscious level, breathing, blood pressure, swallowing and when the brain stem is damaged these basic functions of life are lost. There is no potential for gaining consciousness and a ventilator is keeping the patient breathing and heart beating. A set of brain stem death tests undertaken by two senior doctors can confirm that brain stem death has occurred and the patient is then legally dead.

Critical care: A specialist branch of health care concerned with managing the most critically ill patients within hospital. These patients require multi-organ life-support treatment involving mechanical ventilation (life support machine).

Doctor: Registered with the General Medical Council (GMC) and has undertaken the necessary academic education to be a medical doctor.

Donation after brain stem death (DBD): Refers to the retrieval of organs and or tissues for the purposes of transplantation following brain stem death neurological criteria being confirmed. These patients have been confirmed brain stem dead but their breathing and heart control is being sustained by a ventilator.

Donation after cardiac death (DCD): Refers to the retrieval of organs and or tissues for the purposes of transplantation after death that is confirmed using “traditional” cardio-respiratory criteria. The pathway refers exclusively to “controlled” DCD that is donation which follows cardiac death that is the result of withdrawal or non-escalation of cardio-respiratory support that are considered to be no longer in a patient’s best interests (previously referred to as non-heart beating organ donation).

Organ donor: a patient who has donated their organs for transplantation purposes after death.

Emergency department (ED): also known as an accident and emergency department (A&E) is a medical facility specialising in acute care of patients who present without prior appointment.

General Medical Council (GMC): refers to the statutory professional obligatory register of doctors within the UK. All doctors have to be registered with the GMC in order to legally practice as a doctor.

Intensive care (ICU/ITU): often referred to as critical care.

Nursing and Midwifery Council (NMC): refers to the statutory professional obligatory register of nurses within the UK. All nurses have to be registered with the NMC in order to legally practice as a registered nurse.

Operating department practitioner (ODP): refers to a health care professional that has undergone professional education that is involved with the overall planning and delivery of a patient’s perioperative care in surgical theatres. ODPs are regulated by the UK’s Health and Care Professions Council (HCPC).

Operating theatres: a surgical area within a hospital that operations and solid organ donation and transplantation take place.

Organ donor register (ODR): refers to the NHS organ donation register which is a national confidential database holding the details of people who have registered their intent to donate their organs when they die.

Recipient: a patient who has received an organ transplant from a donor.

Registered nurse (RN): Registered with the nursing and midwifery council (NMC) and has undertaken the necessary academic education to be a registered nurse.

Solid organ donation: This is the retrieval of solid organs from a recipient for the purposes of transplantation. This is normally following donation after brain stem death (DBD) or cardiac death (DCD). Organs retrieved for the purposes of life saving transplantation include; heart, lungs, liver, kidneys, pancreas, small bowel.

Tissue donation: refers to the retrieval of tissue such as corneas, skin, bone, tendon, cartilage, heart valves. Most people who die can donate tissues. Unlike solid organs, it may be possible to donate tissue up to 48 hours after a person has died. Solid organ donation is often referred to life-saving where as tissue donation is referred to life enhancing (for instance a corneal donation will not save life but may restore someone's eye sight).

Transplant recipient: a patient who has received a life-saving or enhancing organ or tissue following transplantation from a donor.

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Chapter 1 - Introduction

1.1) Introduction

In the United Kingdom (UK) and other western countries, transplantation surgery using a variety of human organs and tissues has become an established treatment for a number of end-stage diseases (NICE 2011). Improvements in transplant immunology, enhanced surgical techniques, and better immunosuppressive agents has resulted in improved transplantation clinical outcomes (Roels *et al* 2010). Such developments have made transplantation one of the great medical success stories of the past three decades (NICE 2011). However, the UK transplant waiting list continues to increase year on year with demand for life-saving transplants being at an all-time high with 1000 people a year dying in the UK whilst waiting for a transplant which equates to three people a day (NHSBT 2012 and NICE 2011). Currently there is a national shortage of organs and tissues available for transplantation with waiting lists outstripping supply (NHSBT 2013 and NICE 2011). The UK has one of the highest transplant waiting lists in Europe, with currently 7,000 people in the UK waiting for a transplant with the figure rising by around 5% per year (NHSBT 2013 and NICE 2011).

Most organ donors come from patients being managed in critical care areas such as Intensive Care (ICU), Emergency Departments (ED) and Operating Theatres (OT). As a consequence it is essential that health care professionals recognise, manage and identify potential organ and tissue donors in these clinical areas. In 2008, the Department of Health (DH) recommended that all health care staff who had potential involvement in the care of donor patients should receive appropriate education and training. Since the publication of these guidelines no research has taken place to evaluate whether the recommendations have been implemented or whether there is any link between the impact of education on staffs' confidence and knowledge in managing these complex patients within the National Health Service (NHS).

This study aims to evaluate the impact on key staff of organ and tissue donation education and training on both pre-registration and post registration level; and to identify the degree to which this knowledge is subsequently applied to clinical practice by health care professionals. Of particular interest is whether there is an impact on staff knowledge and their perceived confidence in clinical practice when managing a potential organ donor patient. It is anticipated that these findings will contribute to an understanding of the impact that education and training has on health care professionals' perceived knowledge, attitude and practice towards organ and tissue donation.

This multi-hospital site study is restricted to a number of acute NHS hospitals within England and involves doctors, nurses and ODPs working in ICU, ED and OT as key health care staff responsible for donor patients in specialist hospital clinical environments.

1.2) Professional context of researcher's role

The author has been employed as an ICU Clinical Nurse Educator within an NHS Trust over the past 6 years. This involves creating an active learning environment within the ICU for health students and post-registration health care professionals. The role involves both bedside clinical coaching in addition to theoretical classroom teaching using a variety of learning and teaching strategies. The post involves planning, implementing and evaluating all the educational requirements for health care professionals employed within the ICU. A significant part of the role involves the identification and development of policies which provide guidance for staff to apply the principles of evidence-based practice to their management of critically ill patients. An important aspect of the role is as a member on the NHS Trust's organ donation committee which aims to develop initiatives and policies to enhance the number of organ donors available within the Trust in order to reduce the transplant waiting list. This has led to the writing and implementation of policies and guidelines that have enhanced the organ donation process within the author's workplace.

This professional involvement in the field of donation has enabled the author to represent the nursing profession on the national organ donation committee which has resulted in the production of the National Institute for Health and Clinical Excellence (NICE) guidelines for organ donation (NICE 2011).

1.3) Justification for the study

There is a national shortage of organs and tissues available for transplantation (NHSBT 2012 and NICE 2011). It is vital therefore that health professionals recognise, manage and identify potential organ and tissue donors and have the skills and confidence to approach their families for consent. The author's professional and clinical experience as a critical care nurse for seventeen years has reaffirmed that the donation process is often poorly undertaken or sometimes ignored. Further, the author's experience in clinical practice suggests that health care staff have limited knowledge concerning the donation process and limited access to education enabling them to gain this information. One reason for this may be due to inadequate exposure to this subject in pre-registration education. Discussions with many health care staff reveals a lack of awareness that the majority of patients who die could, as a minimum, donate at least one tissue such as corneas which would provide a transplant recipient with the gift of sight. This appears to suggest that health staff lack knowledge and understanding of these issues which has been attributed to suboptimal education and training on donation issues in pre and post registration training.

This concern has provided the starting point and an interest in researching this topic. The UK has one of the highest transplant waiting lists in Europe and three people a day dying whilst waiting for a transplant. The author's view is that education and training of health professionals is paramount to identifying more potential donors in order to reduce the

transplant waiting list (DH 2008; NICE 2011) and forms the basis of the research undertaken.

1.4) Original contribution to knowledge

This study provides an original contribution to knowledge as there is no multi-site study in the UK that specifically investigates three different groups of health care professionals in terms of their perceived knowledge, education and attitudes towards donation. An examination of the literature has shown that where research papers exist, the studies were predominantly undertaken outside of the UK and involve pre-registration medical or nursing students rather than registered practitioners who are responsible for the decision making processes involved in managing donor patients (Cantwell and Clifford 2000; Akgun *et al* 2003; Bogh *et al* 2003; Roels *et al* 2010 and Melo *et al* 2011). In addition there are no studies that make comparisons of donation knowledge and attitudes between three different health care professions using a mixed methods research design. Further originality relates to the application of the theories of professional learning by Eraut (1994; 2000 and 2003) and Dreyfus (1980) to health. The study will also provide a contemporary assessment of the education and training provided to HCPs since the DH (2008) recommendations stating that all HCPs potentially involved in donor management should have regular donation training. There has been no study since these DH (2008) recommendations were published that has assessed and evaluated the implementation of these training recommendations. It is for these reasons that it is anticipated that this thesis will make an original contribution to knowledge in the field of healthcare education and practice.

1.5) Theoretical positioning of the study

The theoretical underpinning of this thesis is provided by Michael Eraut (1994; 2000 and 2003) whose work has focused on the development of professional knowledge and

learning amongst professions and the evolution of concepts of “professionalism”. Although his research has focused upon a number of professions, frequent reference is made as to how health care professionals develop and learn both through learning and teaching in their academic institution and in the experience gained within their workplace. Eraut examines two interacting themes, on one hand the nature of professional knowledge, competence and expertise while on the other, the development of these through professional education. He examines how professionals initially obtain their professional knowledge through both formal and non-formal environments predominantly at pre-registration level and how professional development progresses through their career through situational and workplace learning (Eraut 1994 and 2007).

In addition to Eraut’s theories of professional knowledge and competence, the Dreyfus (1980) model of skill acquisition will be applied to this study. This model provides a five stage continuum commencing with level 1 (novice) and progressing to level 5 (expert) articulating how individuals acquire skills through formal theory and practice (Appendix 1). Dreyfus and Eraut both have theories relating to situational learning involving tacit knowledge development with emphasis placed on learning from work based practice. Baume and Kahn (2004) confirm that Eraut has conducted the most comprehensive evaluation of professional knowledge and learning and this, with its relevance and significance to health care professionals support the application of Eraut to the research undertaken.

1.6) Research questions

Three research questions and four subsidiary questions frame the study presented:

RQ1: What is the relationship between the knowledge and attitude of registered nurses, doctors and operating department practitioners (ODP) working in ICU, ED and OT to organ and tissue donation?

Subsidiary questions:

- 1b. What is the knowledge base of registered nurses, doctors and ODPs working in intensive care, emergency departments and operating theatres towards organ and tissue donation?
- 1c. What is the attitude of these acute health care professionals towards organ and tissue donation?

RQ2: How does the education received by these groups determine the decision making and management of the organ donation process?

Subsidiary questions:

- 2b. What is the nature and extent of pre-registration education received by these professions in relation to organ and tissue donation?
- 2c. What is the nature and extent of the post registration education received by these professions as part of their CPD in relation to organ and tissue donation?

RQ3: What are the implications for education and training for health care professionals in general?

Chapter 2 - Literature Review

2.1) Search strategy

The following search databases were accessed: Blackwell Synergy, CINAHL, Medline, Swetswise, British Nursing Index, National Electronic Library for Health, Athens, NHS Evidence and Google Scholar. The following search words were used: *'organ donation'*; *'organ transplantation'*; *'tissue donation'*; *'attitudes and organ donation'*; *'training organ donation'*; *'education organ donation'*; *'perceptions organ donation'* and *'knowledge organ donation'*; *'Eraut'*; *'Dreyfus model of skill acquisition'* and *'Eraut education training and competence'*. In addition to these search terms, the descriptor of *ICU, ITU, A&E and critical care* were also used to focus the literature review. Once selected articles were obtained, the references from each article were evaluated for their relevance and their origin identified. Although a time frame of ten years was initially set to ensure access to the most current literature, it was apparent that seminal pieces of UK literature, limited as it was, predated this. On the basis of this the time frame was increased to 15 years. Due to the complexity of translating papers, only literature written in English was reviewed. However, the vast majority of papers found were published in English. The search found a number of articles that originated from a number of different countries and professional journals. When the literature was obtained, it was systematically critiqued against Rees (2003) framework for evaluating research evidence (Appendix 2) as this provided a model enabling the identification of the strengths and limitations of papers. The literature search yielded a number of both quantitative and qualitative studies, the majority of which used surveys or interviews as part of their research design.

2.2) Structure:

The literature will review the attitudes, education, training and knowledge of HCPs towards organ and tissue donation presenting this as five themes comprising of:

i. UK, European and International attitudes of HCPs towards organ donation.

This is to enable discussion of cultural and social differences between the UK population beliefs compared to those of other countries.

ii. Relationship between attitude, knowledge and participation in donation.

This aims to explore whether there is a relationship between the extent of HCPs' knowledge of donation and their attitude towards donation. The literature will be evaluated to investigate whether HCPs who have a positive attitude and good knowledge of organ donation are more likely to participate in the care of a donor patient.

iii. Donation knowledge, education and training for Health Care Professionals.

This theme will examine whether current knowledge, education and training towards donation for HCPs is effective and whether there are knowledge deficits in either students or registered health professionals' understanding of theory and practice relating to donation.

iv. Government policy and professional organisations documentation relating to education and training on organ donation.

Documents from the Department of Health and other relevant professional organisations which inform the NHS relating to organ and tissue donation will be reviewed. This will include current recommendations for education and learning relating to donation from the government and other influential organisations.

v. Professional learning and education.

The literature will explore how health care professionals learn both in the academic context as well as through workplace learning and relate this to Eraut and Dreyfus theoretical theories of how professionals acquire both explicit and tacit knowledge.

2.3) Overview of the literature

There has been extensive literature concerning HCPs' attitudes towards donation and how this relates to education experienced on the subject. However these findings are predominantly based on European and International research rather than research originating from the UK (Ingram *et al* 2002; Akgun *et al* 2003; Kim *et al* 2004 and Kim *et al* 2006). Although there is international literature relating to the importance of donation education within health care professionals' pre-registration curricula (Kim, Fisher and Elliott 2006; Cantwell and Clifford 2000; Jones-Riffell and Stroeckle 1998 and Whisenant and Woodring 2012), there is limited contemporary research that specifically evaluates registered HCPs' knowledge and education using non-convenience sampling multi-site methodology within the UK. There appears to be no literature analysing and comparing three different HCPs knowledge, education and attitude towards organ and tissue donation from ICU, ED and OT within the UK using a mixed methods design which supports the claim for originality of this study.

2.4.1) European and International attitudes of HCPs towards organ donation

Kim *et al's* (2004) exploratory study of nine health professionals comprising transplant surgeons; donor transplant co-ordinators and transplantation nurses working in three hospitals in South Korea, found that attitudes to donation was ambivalent; there was a lack of fundamental knowledge surrounding brain death and the organ donation process and expressed difficulty in accepting brain stem death as true death. This seems surprising as they were practitioners directly involved in donation and transplantation. The basis of this

attitude was determined mainly because of an expressed difficulty in accepting brain stem death as true death.

A similar ambivalent attitude was identified in a study of 292 pre-registration nursing students in a South Korean nursing college (Kim *et al* 2006). Several interesting findings emerged: including that 29% of respondents did not consider donation a valuable option for bereaved families, and 67% feared that brain death could be misdiagnosed and would violate patients' rights. However, despite such a negative attitude and perception of donation, more than 70% of the students expressed their own willingness to donate, but only 50% would consent to donate their families' organs. On evaluating these two studies caution is needed in terms of generalising from these studies as both were undertaken by the same researchers (Kim *et al* 2004 and Kim *et al* 2006) and although it is not stated it is likely that the samples were drawn from the same population which may account for the similar attitudes found. A negative attitude was also seen in the survey by Gross *et al* (2000) involving 199 staff in one Swiss hospital who found that their sample overall had a negative attitude towards donation, similar to that found in Swiss public donation surveys.

A German study investigated HCPs' attitudes towards donation compared to those of the general public (Radunz *et al* 2010). They initially surveyed 242 staff and found that 55% carried a donor card. They implemented an awareness campaign and educational programme towards donation for both the public and staff within the hospital and re-surveyed staff to find that from the 151 returned questionnaires the number of staff carrying donor cards increased from 55% to 66% and general public carrying a donor card increased from 35% to 48%. They concluded that an awareness programme relating to donation improved both the public and health care professionals' attitude in carrying a donor card.

An earlier German paper by Weber *et al* (1999) found that physicians and nurses were overwhelmingly supportive towards donation. They found that physicians were more willing to donate and carry a donor card compared to nurses. However, both these studies were biased towards one demographic area in Germany and again this might not be applicable to the UK population of HCPs and the public. As with the majority of surveys it could be argued that the sample that volunteered and took time to complete the questionnaires were either positively or negatively biased towards the subject and therefore influence its findings, this would not provide wide representation of staff and public attitude to donation (Parahoo 2006).

Conesa *et al* (2005) conducted a Spanish survey involving 58 doctors and 51 nurses which demonstrated a positive attitude towards donation. A further larger Spanish survey by Rios *et al* (2006) replicated a positive attitude towards donation with 92% of doctors (n=171) supporting the benefits of organ donation. These results from the Spanish studies are not surprising as Spain has the highest number of organ donors in Europe and in contrast to the UK has a relatively low transplant waiting list (NICE 2011). The DH (2008) and NICE (2011) have scrutinised the Spanish model of donation which has higher donation rates compared to the UK which they attribute to differences in cultural, social and political origins between the countries. They also found differences in health and safety laws; donation practices, and financial expenses for potential donation families which may all contribute to increasing donor numbers in Spain.

Roels *et al* (2010) undertook a large (n=19,537) multi-site study involving eleven different countries but which excluded the UK. Roels *et al* (2010) examined critical care nurses' and doctors' attitudes; confidence and educational needs and then correlated this to each country's specific donation rates. This study found that nursing staff had a significantly lower positive attitudes compared to those of medical staff and that there were variations

in positive attitudes towards donation across the eleven countries. The most positive attitudes of nursing and medical staff were found in Finland (93.6%) and Belgium (93.2%) with the lowest being in Israel (71.8%) and Japan (54.8%). This shows the disparity of HCPs' attitudes towards donation across different countries. The overall average was 91.3% of the total sample in support of organ donation with 81.2% overall stating they would personally donate their organs (Roels *et al* 2010).

2.4.2) UK attitudes of HCPs towards organ donation

It is evident in the literature that there are numerous studies that have been undertaken outside of the UK analysing HCPs' attitude towards donation (Gross *et al* 2000; Kim *et al* 2004; Conesa *et al* 2005; Kim *et al* 2006 and Roels *et al* 2010). These studies indicate that there are variations in attitude and support for donation across the world. A cautious approach needs to be taken when making comparisons between overseas studies evaluating HCPs' attitudes towards donation which may not be applicable to the UK HCP workforce. This could be attributed to several reasons, but is often associated with differences in sociocultural beliefs, types of health care system and the reluctance of the British to talk about the inevitability of death (Roels *et al* 2010; NICE 2011 and Collins 2012). This range of differences found in overseas research in the attitude of HCPs towards donation may make it difficult to draw generalisations.

The largest survey undertaken in the UK analysing nurses' attitudes, knowledge and behaviour towards organ donation was carried out over 13 years ago (Sque *et al* 2000). This research is still perceived as seminal, primarily as this is the largest study within the last 15 years and is still regularly referred to in UK donation literature. Sque *et al* (2000) distributed (n=2465) postal questionnaires to nurses in order to assess their personal attitudes, knowledge and behaviour relating to donation, and achieved a 54% (n=1333) response rate. It was evident that 78% of the sample agreed that donation was positive

with 10% clearly opposed to donation and the other 12% were unsure. The sample comprised of registered nurses recruited from across a number of clinical areas including ICU and OT, however, curiously, the sample also included nurses (n=283) from general wards. It could be argued that as organ donation does not routinely take place from general ward areas but only in critical care, bias was introduced in that the sample were being surveyed about interventions that they would not see on wards. The concern is that this might have had an influence on the overall results since 21% of ward staff were included from outside of critical care and so would not be directly involved in organ donation care. Sque *et al* (2000) acknowledges that ICU nurses had the most positive attitude towards donation with general ward nurses having the lowest attitude towards donation. This therefore supports the argument that ward staff may have a more negative attitude towards donation probably due to their lack of direct involvement in donation procedures.

A UK survey study by Cantwell and Clifford (2000) compared pre-registration nursing and medical students' attitudes towards organ donation. Their convenience sample of one hundred students from a single university found that 98.6% of students favoured donation and that nursing students were more willing to commit to personally donating organs and signing donor cards compared to medical students. Although the study demonstrated that health students had a positive attitude towards donation, the limitations of the methodology meant that the findings could not be extrapolated to all health care students in the UK. This study could be criticised for using a single site convenience sample which might not be seen as representative of the general population of nursing and medical students.

A later and larger UK survey study by Davies *et al* (2002) involving 290 registered doctors and nurses in addition to 3rd year medical and nursing students, found that 40.7% carried a donor card. They reported that 97% of the sample agreed in principle with donation with

only 47% either carrying a donor card or registered on the organ donor register (ODR). Davies *et al* (2002) found no statistical difference in attitude between their sample that had cared for transplant patients and those who had not. Interestingly it could be expected that staff working with transplant patients would see the benefits of donation, however it is acknowledged that this group would also witness at first hand the negative aspects of transplantation such as organ rejection in comparison to HCPs not working with transplant patients. The study found no statistical difference between the level of commitment to donation between the medical and nursing cohorts. Despite this study being one of the few undertaken within the UK, it has a number of limitations to its methodology. The sample was recruited by distributing a questionnaire to HCPs attending a lecture within a London teaching hospital. The sample was not randomised and was restricted to a single education institution. Davies *et al* (2002) had 100% response rate for their questionnaires which is unusual in research data collection, an aspect not acknowledged in the paper.

The UK study carried out by Kent (2002) (n=776) explored the psychosocial factors that influenced nurses' willingness to discuss donation intentions with relatives of potential organ and tissue donors. The study reported a moderately strong positive attitude towards donation and transplantation and that nurses found it difficult to discuss donation issues. It emerged that their willingness to raise the issue of donation was influenced by personal attributes and socio-historical factors as well as their knowledge of the donation process (Kent 2002). This study was restricted to nurses' working in district general hospitals within two geographical regions within the UK and was undertaken prior to the implementation of the DH (2008) and NICE (2011) organ donation recommendations and so must be seen within that time context.

A UK convenience survey by Collins (2005) found that their sample of registered nurses working in a district general ICU (n=31) also held mixed views on attitudes towards

donation. This convenience sample taken from one ICU, found that eight nurses (26%) strongly agreed with donation with ten (32%) agreed with eight (26%) being unsure and five (16%) disagreeing with organ donation. The study found that the major reason why nurses held a negative opinion towards donation was that organs could be rejected causing heartache to the transplant recipient and their families. This was an insightful perception, as this was a non-transplant hospital and so the sample would not regularly be exposed to patients undergoing transplantation and would not be witnessing organ rejection at this study site.

To put this into context with the overall public attitude, the last national survey undertaken in 2003 by UK Transplant found that 90% of the public support organ donation (NICE 2011). Currently, there are nearly 17 million people registered on the NHS ODR but the UK donation rate remains poor, with 38% of families refusing consent for organ donation when approached by a HCP (NHSBT 2013). This appears to suggest that the public is positive towards organ donation when asked in a survey however when actually approached in traumatic hospital circumstances the public are less likely to give consent for donation.

UK studies of HCP attitudes towards organ donation by Sque *et al* (2000); Davies *et al* (2002); Kent (2002) and Collins (2005) found a mixed attitude of HCPs towards organ donation. The UK literature shows that despite HCPs having a generally positive attitude, they may not necessarily be on the ODR or have personal willingness to donate. However, the research of Cantwell and Clifford (2000) found that pre-registration students had a more favourable attitude towards organ donation. The UK research surveying HCP attitude is limited in sample size and recruitment sites, apart from the studies of Sque *et al* (2000) and Kent (2002). Additionally all the studies reviewed were dated in that they predate the DH (2008) and NICE (2011) guidance on education programmes in donation.

An additional point is that the studies reviewed were also undertaken prior to the requirement of higher education institutions implementing multi-professional education into schools of health and medicine. All these factors may produce differences in attitudes if they were replicated currently, hence this study will provide a contemporary assessment of HCPs attitude towards donation which will provide a current contribution to original knowledge.

2.4.3) Summary between European and International and UK HCPs attitudes towards donation

From reviewing the literature, the following key points have emerged between European and International research and UK Research relating to HCPs attitude towards donation:

1. There appears to be a mixed attitude towards donation both within the UK and globally (Gross *et al* 2000; Kent 2002; Kim *et al* 2004; Collins 2005; Kim *et al* 2006 and Roels *et al* 2010);
2. German studies found that HCPs had a positive attitude towards donation (Weber *et al* 1999 and Radunz *et al* 2010) with Roels *et al* (2010) finding large variations in positive attitude towards donation across eleven countries;
3. Kim *et al* (2006) South Korean study found that 70% of their HCP sample would donate organs and Rios *et al* (2006) Spanish sample stated that 92% support donation. However these were small, single site studies so do not represent the majority of their countries HCPs, but do provide a valuable insight;
4. Roels *et al* (2010) large multiple country study found 91.3% of their overall HCP sample had a positive attitude towards donation with 81.2% stating they would donate their own organs;
5. Sque *et al* (2000) multi-site UK study (n=1333) found that 78% of nurses found donation positive with 10% clearly opposed. Cantwell and Clifford (2000) found that 98.6% of their student HCP sample favoured donation and Davies (2002) stating

- that 97% supported donation. Kent (2002) found that their sample had moderately positive attitudes towards donation. However apart from Sque *et al* (2000) and Kent (2002), these studies were single site and involved small sample sizes which involved predominantly students rather than registered HCPs;
6. Due to cultural, social and political differences between countries, the attitude and practice of donation varies between countries which makes comparisons difficult to the UK (Roels *et al* 2010). Also the UK is unique with the National Health Service (NHS) which makes it difficult to draw conclusions against other countries who adopt hugely different models of health delivery which may have an impact upon staff attitudes and practices (NICE 2011).

2.5) Relationship between attitude and knowledge

Ingram *et al* (2002) found in their survey that there was a direct correlation between nurses' (n=69) knowledge and their holding a more positive attitude towards donation. They confirmed a direct correlation between increased knowledge and previous experience for determinants that influenced nurses' attitudes positively towards donation. The research by Duke *et al* (1998) further supports the relationship between a HCP with an increased knowledge having more positive attitude towards donation. This study surveyed 152 nurses in three rural hospitals in Australia focusing upon the relationship between staff knowledge and attitude towards donation. Duke *et al* (1998) concurred with Ingram *et al* (2002) and Roels *et al* (2010) research that the more knowledge the practitioner had on donation the more positive their attitude was and the more likely they were to participate in donor management.

This also concurs with a large international study (n=19,537) by Roels *et al* (2010) evaluating whether there was a relationship between countries donation rates and critical care staffs' attitudes, confidence and educational needs. This questionnaire study

involving quantitative statistical analysis from a large sample of doctors and nurses found a direct relationship which showed that countries whose staff had sufficient knowledge and confidence in donation had higher donation rates. Roels *et al* (2010) established in their sample involving eleven different countries that there is a direct link that education and knowledge enhances staffs' attitude which impacts positively on donation rates. This study excluded the UK in its sample.

Ozdogan *et al* (2001) found that 87.7% of their sample of nurses working in three general and two midwifery hospitals in Turkey had a positive attitude towards donation. However, despite this positive attitude only 34.4% stated that they would talk to relatives about donation and approach families for consent. Their questionnaire found that only 10.8% stated they knew donation law. Ozdogan *et al* (2001) concluded that there was a direct correlation between staff who had been provided with education and good knowledge, and whether they asked relatives for donation consent and actively participated in the donation process. Another Turkish study by Akgun *et al* (2003) involving doctors and nurses (n=1184) in five hospitals found that 44.2% of the sample was willing to donate their own organs with doctors more willing to donate than nurses. They found the doctors had significantly better knowledge about organ donation compared to the nurses. Their survey revealed that lack of knowledge had a negative impact on HCPs' attitudes towards donation and that education and training programmes in Turkey were vital to prepare HCPs to identify and manage donor patients.

A multi-site survey by Bogh and Madsen (2005) involving 689 doctors and nurses in fifteen hospitals in Denmark found similar results in that doctors (95%) were more positive towards organ donation as compared to nurses (81%). The survey found that despite the majority of staff being positive about donation that only 54% of the sample had sufficient knowledge about donation. The researchers found that there was a lack of knowledge and

experience in their large sample size with further education and training required for staff on how to identify donors and supporting families through the donation process.

A recent comparison intervention trial by Whisenant and Woodring (2012) involving nursing students (n=184) from a single school of nursing within America aimed to compare the impact of education on attitude of students towards donation. This research involved a convenience sample that were all given a pre-test questionnaire to assess their attitude towards donation and then they were randomised into two separate groups. The intervention group (n=101) were given one hours education relating to donation and the control group (n=83) were not, two weeks after the pre-test and 1 week after the education intervention both groups were retested on their attitude towards donation. Statistical analysis between the intervention and control groups found that students' knowledge increased by 40% as well as attitude increasing by 8.5% in the education intervention group. Whisenant and Woodring (2012) support the use of education interventions that increase knowledge and attitude of nursing students and they established a direct link between how education increases knowledge which has a positive influence on enhancing students' attitude towards donation and advocate pre-registration donation education. This study does have some limitations relating to convenience sampling techniques and involving a single site within America, the study also has limited details on how the randomisation process took place between the two groups. It could also be argued that these results would be expected and would not be surprising following an education programme that knowledge should increase and attitudes maybe influenced and could be applied to numerous subjects not just solely relating to organ donation.

From reviewing the literature, there appears to be evidence of a term defined as "support hypocrisy" where the HCP states that they support donation but when asked if they personally or a family member would consent to donation they are reluctant (Pugliese

2001 and Chernenko *et al* 2005). This suggests that from a professional perspective, they feel that transplantation is positive in terms of witnessing this in clinical practice, but when correlating this to the HCP personal circumstances, they are less likely to give their own or family donation consent. This is demonstrated in a number of studies which have found this phenomenon. Chernenko *et al*'s (2005) survey involving one hundred and thirty five HCPs in five hospitals in Canada found that 98% supported donation in general but only 84% would consent for a family member for donation. With similar results from an Italian study by Pugliese (2001) involving (n=1576) HCPs who found 91% of the sample support organ donation but only 79% support family donation. From this it appears that HCPs are generally supportive of donation but a significant reduction in support occurs when the issue becomes more personal. There also appears to be a direct relationship between the more knowledge that a HCP has on donation, the more positive their attitude.

2.6) Relationship between attitude, knowledge and participation in donation

There is evidence to support the relationship between attitude and HCP motivation and participation in donation. Previous UK studies by Kiberd (1998); Randhawa (1998); Cantwell and Clifford (2000); Kent (2002) and Collins (2005), all suggest in their samples the existence of a direct relationship between HCPs who had a positive attitude towards donation and who had more confidence in the donation process being more likely to care for a donor patient. This is further supported by Roels *et al* (2010) large International study establishing a confirmed link between if a HCP demonstrates a positive attitude and good confidence levels they are more likely to participate in donation care and notably more likely to have successful conversion of a potential donor into an actual donor.

Sque *et al*'s (2000) large UK survey study found that knowledge about donation positively affected nurses' views of the process of donation and were more likely to commit to donation personally and participate in the donation process. Similar findings emerge from

Erdogan *et al* (2002) who examined the relationship of doctors' knowledge and participation in donation. They found that the main reason why doctors avoid donation or fail to obtain relative consent for donation was that they had deficits in knowledge and training. This study, which interviewed 308 physicians concluded that physicians who were provided with staff support, had higher levels of knowledge having been effectively educated on donation; were associated with more participation in caring for donors and this consequently influenced the organ donation rate.

The role of training was further endorsed by a recent study by Lin *et al* (2010) who found that within their sample of 12 nurses within three different ICUs in Taiwan that attitude towards donation was increased following an education lecture on donation. They found this lecture produced a marked increase in knowledge and attitude and were more likely to identify and manage a donor patient. The literature suggests that there is a positive relationship between attitude and education and HCP participating in managing a potential organ donor patient.

An intense educational programme as advocated by Manyalich *et al* (2010) has been shown to enhance Spanish health care students' knowledge about donation and stimulate a positive attitude towards donation. Manyalich *et al* (2010) assessed medical and nursing students' knowledge prior to undertaking a 45 hour course on donation and transplantation and then re-surveyed students following its completion. They found that confidence, knowledge and attitude all increased that subsequently improved donation rates by staff having more confidence in donation management. They conclude that effective training for health care students in the donation process will enhance medical education and helps improve donation rates (Manyalich *et al* 2010). This concurs with a similar Spanish survey study by Lopez-Montesinos *et al* (2010) who found that attitude and confidence in the donation process improved in 3rd year nursing students following a course on donation.

Spain is seen as a world leader in donation as they have the lowest transplant waiting list in Europe. From the Manyalich *et al* (2010) and Lopez-Montesinos *et al* (2010) studies, it is evident that health students in Spain have extensive education at pre-registration level on donation which has a positive impact upon the future HCP participation in the donation process which they state improves donation rates.

2.7) Donation knowledge, education and training of HCPs

This section of the literature review will aim to determine what knowledge and education that HCPs have been provided on organ donation and how this impacts upon their perceived confidence and practice.

Many studies emphasise the importance of ongoing education related to organ donation for health care professionals (Kim *et al* 2006; Cantwell and Clifford 2000; Jones-Riffell and Stroeckle 1998). The evidence appears to suggest that there is a direct relationship between staff who have received education and training on donation and improvements in confidence, attitude and management of donation patients in clinical practice (Kim *et al* 2006; Collins 2005 and Roels *et al* 2010). The majority of the recent literature relating to health care professional knowledge, education and attitudes towards organ donation has been undertaken outside of the UK.

The large scale UK study by Sque *et al* (2000) concluded that there was direct relationship between nurses' education and knowledge and how this enhances confidence and participation in the donation process. From reviewing the literature there does appear to be a common theme that education and training is an important determinant in increasing HCP confidence and knowledge when managing the donation process. However there is limited current research available particularly from the UK which evaluates HCP knowledge and training towards organ donation.

Kiberd (1998) used a convenience sample taken from an academic institution in Canada to compare knowledge and attitude between 1st year and 4th year nursing degree students using a confidential questionnaire. It was concluded that the nursing curriculum did not include sufficient theory to educate students of the role of the nurse in organ donation. They advocated a review of strategies within the nursing curriculum to ensure that nurses were prepared for organ donation upon registration (Kiberd 1998). A similar study by Jones-Riffell and Stoeckle (1998) reported comparable findings in their results in an American school of nursing. This study explored knowledge and attitude towards donation in 28 degree nursing students using a questionnaire. This convenience sampling study found that students lacked knowledge and recommended that educational institutions should teach donation identification and management as part of initial pre-registration nursing programmes. This study could be criticised for being small scale involving only 28 students from a single academic institution which it could be argued does not represent the numerous schools of nursing within America and caution needs to be given not to generalise from these results.

Randhawa (1998) reviewed education practices within nursing curricula in the UK and has criticised the lack of knowledge and depth of training in donation within the nursing profession. His recommendation was that all critical care nurses should have access to education and training programmes that focus upon identification and donor management including approaching family for consent and communication with grieving relatives. This training programme should include presentations, role play situations and discussions based upon past experiences of organ requests. Although Randhawa (1998) provided an outline of an education programme he did not provide any research data that actually analysed nurses existing knowledge and training on donation and its impact upon their practice. Randhawa (1998) does support the argument that effective education needs to

be provided as it appeared at the time of the publication it was not common practice in nursing curricula according to his review of the evidence.

Kent (2002) surveyed registered nurses (n=776) from two different health regions within the UK with the aim of evaluating the psychosocial factors that influence nurses' involvement with organ and tissue donation. This study found that nurses had knowledge deficits relating to donation inclusion criteria and contraindications for donation. Kent (2002) found that negative attitudes of nurses appear to exert an inhibitory effect on approaching families for donation. Interestingly, this study revealed that the influence of knowledge on the perceived ability of nurses to approach families for donation was not statistically significant. This was despite the sample stating that education was a major obstacle to why participants were reluctant to discuss the options of donation with relatives. Kent (2002) suggest that it might be the knowledge acquisition that nurses' gain through societal awareness from media campaigns and past clinical experimental experience that influences their ability to discuss donation, rather than any formal education programme. It should be recognised that this study was undertaken prior to NICE (2011) and DH (2008) recommending that all potential donor patients be referred early to the SNOD who are now based within hospitals so that a collaborative approach for discussing donation can be undertaken, rather than nurses taking personal responsibility for seeking for consent.

Similarly, Dutra *et al* (2004) surveyed medical students (n=779) from a university in Brazil to investigate the students' knowledge relating to donation and transplantation. They found that the majority of their single site sample had a positive attitude towards donation (69.2%) but their level of knowledge about organs available for transplantation, the concepts of BSD and Brazilian transplantation law was low. Dutra *et al* (2004) found that only 1.7% of their sample said that they knew Brazilian transplantation law. The

researchers state that only a few medical schools in Brazil have included the subject of donation in their curriculum. This study concluded that greater emphasis needs to be given to providing organ donation education in medical schools to improve the knowledge of future HCPs about transplantation issues (Dutra *et al* 2004).

Collins (2005) surveyed 31 UK nurses in an adult general ICU in an aim to assess nurses' knowledge and educational needs towards organ and tissue donation. The questionnaire aimed to evaluate staffs' existing knowledge and deficits in organ and tissue donation. This limited study involving a convenience sample taken from one ITU found that the sample lacked confidence in approaching relatives for donation consent and had knowledge deficits in brain stem death and donor criteria. Only 35% (n=11) of the sample stated that they were adequately educationally prepared to nurse the organ donor patient with 39% (n=12) saying they were not prepared for the role whilst 10% (n=3) were unsure. When asked whether they felt they had enough knowledge to explain brain stem death (BSD) to a bereaved relative, only 61% (n=19) said they could do so with 26% (n=8) believed they could not effectively do so and 13% (n=4) unsure. Collins (2005) also found that 42% of the sample were not fully aware of the criteria that certified a patient BSD. There were also knowledge deficits in staff identifying contraindications to donation. The study found that 90% of the sample agreed that a training programme on donation would enhance their knowledge and confidence in managing the donation process. A common theme in this survey was that the more experienced the nurse, the more knowledge and confidence the nurse had relating to donation. This study highlights that nurses had perceived knowledge and confidence deficits when managing and communicating during the donation process which may have an impact upon their clinical practice but due to limited sampling techniques generalisations across the UK cannot be established.

This concurs with another UK paper by Elding and Scholes (2005) who undertook an audit within a single NHS Trust to assess baseline knowledge and confidence in organ and tissue donation. This audit found that many HCPs working in this Trust were unaware that donation could be considered. The results from 100 questionnaires found that many respondents lacked knowledge and confidence to be able to identify and discuss options of donation with families. This further supports the fact that UK HCPs lack knowledge and confidence towards organ donation. This paper could be criticised because the baseline audit was not an empirical research study and used data from only one NHS hospital, so questioning the generalisability of the findings to all UK HCPs.

European studies have found similar issues with knowledge deficits in-relation to donation and also advocate education and training programmes for health care professionals. Mekahli *et al* (2009) undertook a survey of 1st year French medical students which evaluated their level of knowledge and attitude as well as their gaps about organ donation. They found good knowledge levels regarding donation in a sample (n=571) of medical students but also identified some knowledge gaps that could be improved. They recommended a greater emphasis on providing education regarding transplantation in medical schools to improve the knowledge of future health professionals.

This issue of knowledge deficits in nursing and medical pre-registration students relating to donation and transplantation is further supported by numerous overseas studies which all use convenience sampling surveys of students from single site University Institutions. A number of studies (Bardell *et al* 2003 in Canada; Goz *et al* 2006 in Turkey; Essman *et al* 2006 in America; Martinez *et al* 2009 in Spain and Zampieron *et al* 2010 in Italy) have examined health care students' knowledge relating to donation within University institutions and found that students lacked theory and understanding of the donation process. They draw similar conclusions in that health institutions need to review

curriculums and emphasise the importance of organ transplantation and include donation in curricula. They acknowledge that education on this subject needs to start at pre-registration to enable future HCPs to acquire knowledge and understanding of the significance of donation as part of end of life care. These studies recognise that part of the solution to the chronic shortage of organs may be addressed by embedding the topic within students' initial training.

A recent mixed methods methodology study (n=309) involving surveys and interviews by Demir (2011) concluded that there were knowledge deficits in 309 doctors and nurses working in dialysis and transplant centres in Turkey. They found that 59.7% of staff lacked confidence in donation and a general lack of essential knowledge of family-related issues and communication relating to donation. Demir (2011) supports the argument that HCPs lack essential knowledge in donation and they advocate targeting HCPs with educational programmes which they believe is crucial to increase the number of HCPs who can act as positive role models which may have an impact upon the general public embracing donation as being a consideration for end of life care.

Lopez-Montesinos *et al* (2010) analysed attitudes and training of 3rd year Spanish nursing students concluding that attitudes towards donation were favourable but increased significantly following a training programme. They found that students prior to the training course had knowledge deficits relating to donation. They concluded that where the sample had a more positive attitude towards donation which was increased by the education programme, they were more likely to participate in the identification and care of donor patients. This study also concurs with Topbas *et al* (2011) who surveyed HCPs to assess their knowledge before and after implementing a training seminar relating to donation and transplantation. Prior to the seminar, HCPs stated that they often did not take part in the donation process as they lacked information about donation. Following the

training seminar, HCPs demonstrated more knowledge relating to the subject and it generated a more positive attitude towards managing a donor patient. This methodology could be criticised as it would be expected that if you had surveyed delegates immediately after a training sessions that their knowledge and attitude would increase. For the study to gain more credibility, the researchers should have re-surveyed the delegates at a later date to see how long the positive attitude remained and whether delegates could recall the knowledge learned at the seminar. Like other studies reviewed, Topbas *et al* (2011) advocated the need for constant effective education to enhance knowledge of HCPs.

An Indian survey study by Mishra *et al* (2004) involving doctors, nurses and medical students (n=181) in a Delhi hospital found that only 25% stated they had adequate knowledge about donation, with 51% said they knew the legal implications of donation and concerns raised about approaching families for consent. They found that the overall level of knowledge was poor, which Mishra *et al* (2004) suggest has a negative influence in donor identification. However, 72% of the sample stated that the single most important tool to improve donation was education and training programmes being made available to HCPs. This view is also found in the Rachmani (1999) multi-site Israeli survey evaluating 59 physicians' and 93 nurses' knowledge towards BSD. This study found the knowledge of BSD among the subjects to be low. Further, the general knowledge of BSD was similar between physicians and nurses; however, the subjects recruited from transplantation units had more knowledge and positive attitude towards donation compared to staff who worked in non-transplant hospitals. Rachmani (1999) like other authors, emphasise the importance of integrating BSD and donation training into professional education curricula.

Comparable results were found by the survey carried out by Bogh and Madsen (2005) involving 689 doctors and nurses from 15 hospitals in Denmark. They found a significant lack of experience in organ donation with only 54% of respondents stating they had

sufficient knowledge to explain BSD to relatives. They concluded that there was a considerable need for more education and training, especially on how to identify potential donors as well as communication and support of donor relatives.

Kim *et al* (2006) used a convenience sample to survey 292 undergraduate nursing students in a South Korean college to evaluate their knowledge and attitudes towards organ donation. They found a lack of knowledge regarding diagnostic tests relating to BSD. Kim *et al* (2006) concluded that the study identified that an effective education and training programme for nursing students in Korea was necessary, as at the time of the study there was no specific programme for nursing students.

A recent multi-site survey involving 572 registered ICU nurses from 28 Norwegian hospitals investigated nurses' perceptions of their professional competence in the organ donation process, provides further emphasis on the significance of education (Meyer *et al* 2012). This study found that few ICU nurses had extensive experience of or competence and training in organ donation. They found that where a nurse had experience of actual donor acquisition that they had a more heightened perception of their professional competence in the donor process. This study confirmed that both actual skill acquisition and educational input was an important component to enhancing the nurses' professional competence in donation. Meyer *et al* (2012) also concur that training by experienced educators and a culture that encourages discussion about aspects of the donor process can develop nurses' professional competence.

Another Scandinavian study also supports the argument that registered ICU nurses' have limitations in knowledge and understanding of donation (Floden *et al* 2011). This multi-site study involved 702 ICU nurses taken from a number of ICUs in Sweden using a questionnaire design to assess their knowledge and attitude towards donation. They

found that nurses lacked knowledge in relation to brain stem death, legislation and interaction with relatives and recommended that training was provided to address issues in lack of knowledge and confidence (Floden *et al* 2011).

Similar findings were established in Jelinek *et al* (2012) Australian survey study involving doctors and nurses (n=811) working in EDs. They found that generally their sample was positive towards donation but approximately 25% of their sample had received no education relating to donation. Jelinek (2012) established a relationship between the more positive the attitude towards donation the more likely they were to participate in donation and retrieval related tasks. This study supports the benefits that education and training relating to donation can have on creating a more positive attitude towards donation and influencing HCPs participation in donation management. Jelinek *et al* (2012) identified that more education was required by ED HCPs and this was essential to support staff to identify and manage organ donors within the ED. This study could be criticised as the response rate of 20.4% to the online questionnaire was very low where as Edwards *et al* (2002) explain that an average questionnaire response rate of 32% was expected from surveys involving clinical practitioners. As with all questionnaires a major limitation of their methodology is that the practitioners that reply are normally very positive about the subject matter and this is what motivates them to respond (Creswell 2009 and Peat 2002). It could be argued that with Jelinek *et al* (2012) below average response rate that their sample may have consisted of participants who were biased towards donation and that this may not represent the entire population of ED HCPs knowledge and attitudes. However, this is a known limitation of questionnaire and survey research and these limitations need to be interpreted when analysing the results as is in the case of the author's research study.

A Portuguese study carried out by Melo *et al* (2011) also supports the argument that HCPs have knowledge deficits relating to donation. The group surveyed doctors and nurses (n=495) working in emergency departments using a questionnaire to assess their knowledge and behavior towards organ donation. They found that 78% of the sample had received organ donation training as part of CPD however a further 62% stated they wanted further education on the subject. Melo *et al* (2011) found that their sample lacked knowledge relating to brain stem death and the organ donation process and there was no difference between doctors or nurses knowledge relating to donation. Their study found that those who had received education were more likely to get donation questions correct in the questionnaire which established a link between if a HCP had received donation education this created improvements in knowledge recall. Melo *et al* (2011) like previous researchers also support the implementation of donation education for all HCPs in order to enhance knowledge of the donation process.

From reviewing the literature, deficits in knowledge of HCPs relating to organ donation and transplantation appears as a recurring theme. The literature found that education and training programmes in pre-registration curriculums was essential to enhance and develop future HCPs knowledge which would enhance their attitude and confidence in donation. It was also apparent that continuing professional development for registered HCPs was essential to maintain current theory and practice relating to donation.

2.8) UK Government and organisation documents relating to education and training on organ donation

The UK Department of Health (DH) set up the Organ Donation Task Force which aimed to set future national DH policy and recommendations for enhancing donation in the UK. The DH Organ Donation Task Force (2008) published its recommendations for the future 5 year plan and beyond for donation and transplantation in the UK. The DH (2008) stated

that donation should be seen as usual end of life care for patients in the UK and that education would play a significant part in achieving this philosophy. The DH (2008:16) states that;

“all clinical staff likely to be involved in the treatment of potential organ donors should receive mandatory training in the principles of donation. There should also be regular update training”.

This is further endorsed by the recent publication of the National Institute for Health Care and Clinical Excellence (NICE) clinical guideline for organ donation (NICE 2011). NICE (2011) state that HCPs involved in identifying, referring and managing a potential donor should have specific knowledge and competencies within the donation process. NICE informs the NHS on best practice and hospitals should implement these recommendations into their routine policies. National policy set by both the DH and NICE advocates that HCPs should be provided with education and training relating to donation in order for health professionals to have essential knowledge and competencies in managing the donor patient and their bereaved relatives. It is clear that both the DH and NICE support the implementation of education and training for HCPs potentially involved in donation which should also include regular updates. An objective of this study is to investigate whether these recommendations of education and training for all HCPs working within critical care have been implemented to front line staff.

In relation to donation and the professional regulatory bodies, the General Medical Council (GMC) state that doctors have to consider the option of organ donation in end of life decisions and that it should be routine taking into account patient preferences and decisions (GMC 2010). Unfortunately, the Nursing and Midwifery Council (NMC) has not been so decisive in providing clear guidance for nurses. However, the doctors' regulatory body provides explicit guidance to its practitioners that donation should be seen as part of

routine end of life care. It is anticipated that in the future, guidance from the NMC will make explicit reference to this and maintain parity with its partner the GMC.

2.8.1) Professional Learning

In order to become a registered practitioner in medicine, nursing or operating department practice the pre-registration student must undertake an approved higher education programme which has been accredited with the profession's governing body in order to legally practice within the discipline (GMC 2009; NMC 2010 and HCPC 2012). To become a registered practitioner within these professions students must achieve the acquired theoretical and practical assessment in order to safeguard the public and meet the roles required for the profession (GMC 2009; NMC 2010 and HCPC 2012).

Traditionally the study of medicine has required a period of academic study within a University for a number of decades and this has become an established norm (GMC 2009). Only approved universities which met the requirements from the GMC can offer programmes of higher education study which lead to professional registration for an individual to practice medicine (GMC 2009). Compared to medicine, the study of nursing within higher education institutions is relatively new and operating department practice even newer (Burke 2006 and HCPC 2012). Previous to 1995, nurses' education was provided by schools of nursing in large hospitals since when all pre-registration nursing has been provided within higher education institutions (Burke 2006). Similarly the move of ODP education into academic institutions has only occurred within the last decade and like nursing before it, is now gaining the academic credibility of being a profession that requires the rigour of a higher education qualification (HCPC 2012).

In reviewing these professionals education, it is apparent that there is a commonality in standards for professional preparation between the three which relates to how learning

occurs in what Eraut (1994 and 2000) would define as comprising both formal and informal learning. All three professions have numerous assessments of theoretical knowledge relating to their profession normally undertaken within the formal academic setting and also practical assessment within the workplace (GMC 2009; NMC 2010 and HCPC 2012). Both these components of learning have equal standing and influence in enabling pre-registration health professionals to achieve the professional rigour, theory and skills necessary to enter their chosen profession (GMC 2009; NMC 2010 and HCPC 2012). Higher education institutions aim to provide the necessary theory which the student, through workplace facilitation, applies to clinical practice. This is known as applying professional theory to practice which is a key component to health professional learning and development which is necessary to produce skilled and competent HCPs (Frankel 2009).

Michael Eraut (1994; 2000; 2003 and 2007) has provided pivotal theories on how professionals transfer knowledge between education and practice settings. Eraut (2000) discusses how this process is facilitated and the problems associated with knowledge transfer between the formal classroom and the hospital environment. His proposal is that workplace learning is often underestimated. This, he proposes is where professionals can gain new knowledge and competence through observation, reflection, social interaction between colleagues and tacit knowledge development which all provide acquisition of professional learning and competence. The literature also supports that learning does not stop on the qualification of the health professional and that professional learning and expertise is on-going (Scholes 2006; NMC 2002 and RCN 2007). Pre-registration education prepares the practitioner for safe practice at the point of entry to the register but due to the increasing complexities of health care it is essential that the registered practitioner continues with life-long learning within their profession in order to gain specialist knowledge and practice to meet the changing demands of health care (NMC

2002; Eraut 2000 and 2007). The three professions have mandatory requirements that continuing professional development (CPD) is essential for developing and maintaining professional knowledge and competence which can involve both formal and informal learning activities (Eraut 1994; 2000 and RCN 2007). All three professions are required to maintain CPD as part of their on-going registration with their professional governing body and are required to show evidence of this being achieved to continue to practice on the professions register (GMC 2012; NMC 2011 and HCPC 2012).

Eraut (2000; 2006 and 2010) argues that a number of professions develop expertise in knowledge and skills comprising of intuitive decision making, in which not only pattern recognition but also rapid responses to developing situations are based on tacit knowledge. Eraut (2000) states that tacit knowledge is often referred to knowledge which we know but cannot tell, with professionals relying on knowledge relating to explicit knowledge and tacit 'knowing how'. Eraut (2006) proposes that there are three types of tacit knowledge that professionals develop within the workplace relating to;

1. Situational understanding based primarily on previous experiences and remaining mainly tacit;
2. Standard, routinised procedures are developed for coping with the demands of work. These may have begun as explicit procedural knowledge and become automatised and increasingly tacit'
3. Intuitive decision making based upon tacit knowledge.

These theories relating to situational workplace learning and tacit knowledge development could be applied to the context of how HCPs gain knowledge and competence relating to organ and tissue donation through situational workplace exposure.

From reviewing Eraut's theories of professional knowledge and competence, comparisons can be made to Dreyfus and Dreyfus (1980) model of skills acquisition. The Dreyfus (1980) model provides a five stage continuum starting from level 1 (novice) to level 5 (expert), describing how students acquire skills through formal theory and practice (Appendix 1). The Dreyfus model (1980 and 1986) relates to the concepts of Eraut's theories, as the model relates to situational learning involving tacit knowledge development with emphasis placed on learning from experience in the workplace. The Dreyfus (1980) model proposes that novices require frameworks, guidelines, instruction and supervision to structure their work compared to experts who due to repeated situational exposure internalise these frameworks which become second nature and are integrated into the practitioners' tacit and initiative knowledge. The Dreyfus model was adapted by Patricia Benner who applied it to the professional development for the nurses (Benner 1984). Benner (1984) proposes that nurses develop expertise in nursing skills and patient care over time through both education and a multitude of experiences which informs their intuition and decision making. Benner's (1984) adapted model provides specific examples for how nurses build on previous experiences and refine their practice and move along a continuum from novice to expert. There are criticisms of Benner's (1984) and subsequently to Dreyfus (1980) original theories in that the models do not provide analysis on the way the knowledge is processed, filtered and synthesised to form a nursing diagnosis and intervention (Scholes 2006 and Gobet and Chassy 2008).

The decision was taken to use Dreyfus' (1980) original five stage model of skill acquisition rather than Benner's (1984) adapted work, as Dreyfus' (1980) concepts underpinned Benner's adaption. A further consideration was that Benner (1984 and 2001) applied her model solely to nursing and did not include other professions such as medicine or operating department practice, whereas Dreyfus' (1980) original concepts can be applied generically across different professions (Pena 2010).

2.9) Summary of literature review

The following key points emerged from the review of literature in relation to HCPs' attitudes towards donation:

There appears to be a mixed attitude towards organ donation amongst HCPs. This is evident with some studies demonstrating negative attitudes whilst others showing a positive attitude of HCPs towards donation (Gross *et al* 2000; Kim *et al* 2004; Conesa *et al* 2005 and Kim *et al* 2006). This mixed attitude appears to vary between countries and this attitude appears to be influenced by different social and cultural beliefs (Sque *et al* 2000; Kent 2002; NICE 2011 and Collins 2012). The literature found that there is a direct relationship between the more knowledge and experience the HCP has and the more likely they were to hold a positive attitude towards donation (Dukes *et al* 1998; Ozdag *et al* 2001; Ingram *et al* 2002; Akgun *et al* 2003 and Whisenant and Woodring 2012).

There was a relationship between HCPs who had a lack of knowledge producing a more negative impact towards HCPs' attitudes towards donation (Akgun *et al* 2003 and Whisenant and Woodring 2012). When comparing willingness to donate and attitude towards donation amongst doctors and nurses, doctors demonstrated a more positive attitude compared to nurses towards donation (Akgun *et al* 2003 and Bogh and Madsen 2005). There existed no literature analysing or comparing three different health care professions such as nurses, doctors or ODPs. There was no study analysing ODPs' attitudes. The literature (Pugliese 2001 and Chernenko *et al* 2005) appears to suggest the term "support hypocrisy", whereby a HCP states they support donation but when asked if they personally or family member would consent to donation, they are reluctant. This suggests that HCPs when asked to relate donation to their personal circumstances, revealed that they were not so positive about donation.

Within the UK, there has been no study focusing upon a multi-site sample for over a decade since Sque *et al* 2000 and Kent 2002. Both their samples included only nurses and did not allow comparison with other HCPs such as doctors or ODPs. Sque *et al* (2000) found that 78% agreed with donation, which demonstrated a lower positivity towards donation compared to overseas studies which generally were more positive. Kent (2002) found knowledge deficits relating to donation and that personal negative attitudes, socio-historical factors and past clinical experience all influenced if nurses' initiated donation discussions with families. Single site studies involving convenience sampling techniques involving nursing and medical staff were limited within the UK. These studies found a mixed view of HCP attitudes towards organ donation (Cantwell and Clifford 2000; Davies *et al* 2002 and Collins 2005). It is evident that the more knowledge the practitioner has on donation the more positive their attitude is and the more likely they were to participate in donor management (Kiberd *et al* 1998; Sque *et al* 2000 and Erdogan *et al* 2002).

HCPs provided with education, staff support and had higher levels of knowledge are associated with more participation in caring for donors and have more confidence with donor and relative management (Sque *et al* 2000; Collins 2005; Kim *et al* 2006 and Lin *et al* 2010). Studies found that both pre-registration and post registration HCPs' lacked knowledge and understanding of BSD and the donation process. This was found in both UK and overseas studies (Bardell *et al* 2003; Collins 2005; Goz *et al* 2006; Zampieron *et al* 2010; Melo *et al* 2011 and Meyer *et al* 2012). However, UK studies analysing knowledge deficits were outdated and were undertaken prior to NICE (2011) and DH (2008) donation recommendations (Cantwell and Clifford 2000; Sque *et al* 2000; Kent 2002 and Collins 2005). It was considered that education institutions should include donation training into pre-registration curricula and that continuing professional development is provided for registered practitioners in donation and transplantation (Collins 2005; Mekahli *et al* 2009; Lopez-Montensinos *et al* 2010; Demir 2011 and Floden *et al* 2011). Both the DH (2008) and NICE (2011) recommend that HCPs

potentially involved in donation have mandatory training and updates in donation. Eraut (1994 and 2000) states that HCPs learn both within formal classroom higher education settings and within the workplace and gain professional learning and knowledge by gaining situational exposure within the workplace and by developing tacit knowledge from experimental learning.

Chapter 3 – Methodology

3.1) Research design

This chapter examines the methodology used for this study including discussion of the research paradigm, the design, sample, data collection methods and ethical considerations.

Weaver and Olson (2006) describe paradigms as patterns of beliefs and practices that regulate and inform research inquiry within a discipline, by providing a framework and process through which investigation is accomplished and essential in focusing the theoretical approach of a research study (Cohen *et al* 2007 and Creswell 2009).

The post-positivist paradigm that underpins this study allows for mixed method approaches to data collection and analysis. Post-positivist research is characterised as a modified version of positivism (Guba 1990). The post-positivist paradigm still advocates objectivity but accepts that society is imperfect and that absolutes are difficult to establish (Burgess *et al* 2006 and Crossan 2010). Whereas, pure positivists aim to discover truth through objectivity and verification in the belief that scientific methods used to investigate the physical world can be used to investigate aspects of the social world (Guba 1990 and Crossan 2010). However, a limitation of positivism according to Kleynhaus and Cahill (1991) is that the paradigm ignores the possibility that humans actively construct their social world and knowledge. A further counter argument of pure positivism is that the perceptions of value-free observations are impossible as observations based upon perception, a function of prior knowledge and experience is ignored (Playle 1995 and Parahoo 2006).

Post-positivism developed in the 1960s, takes into account the limitations of positivism and assumes that there are many ways of knowing aside from using the scientific model (McGregor and Murname 2010). Rather than testing hypothesis with a positivist stance, post-positivist scholars attempt to understand and interpret why people operate in a manner that they do or try to reveal power relationships and influences within their research (Kim 2003 and McGregor and Murname 2010). The post-positivist paradigm assumes that research should not be value free and unbiased but value-laden which may be subjective or inter-subjective (McGregor and Murname 2010). This study aimed to compare relationships between HCPs and whether education and experiential experience influence how people or professions operate when managing the donation process. It is proposed that this is aligned to post-positivism.

According to Tashakkori and Teddlie (2003) and Clark (2002), post-positivist research designs can draw on a mix of data collection methods traditionally such as interviews or observations and then interpreted into a post-positivist paradigm. Tashakkori and Teddlie (2003) explain that often post-positivist research incorporates methods used within the constructivist paradigm which involve qualitative approaches to data collection. Many post-positivists are also constructivists who believe that we as individuals construct our view of the world based on our perceptions of it (Cohen *et al* 2007). This study evaluated the perceptions of HCPs in terms of their attitude, knowledge and previous education relating to organ and tissue donation. This, it is proposed falls within constructivism (Tashakkori and Teddlie 2003). The information gathered for the purpose of this study demonstrates the use of a mixed methods approach, using both quantitative and qualitative data collection techniques. The use of the questionnaire allowed the measurement of variables such as whether donation knowledge was provided and how many hours this constituted and provides opportunity to compare and establish relationships between variables (Creswell 2009). In addition the sample size allowed for statistical analysis to identify and

compare relationships and correlations between variables (Creswell 2009). Whilst the qualitative approach using focus group interviews will enable staff to express, interpret their views and perceptions and reflect on donation training as well as being given the opportunity to generate solutions to enhancing donation knowledge. These discussions and viewpoints would not be measurable within a quantitative data collection tool such as a questionnaire focusing on a purely positivist approach (Cohen *et al* 2007 and Creswell and Plano Clark 2011).

The research design of this study sets out to gather data in order to answer the research questions using both quantitative and qualitative data collection methods. The author proposes that the use of a mixed methods research design using both quantitative questionnaires with statistical analysis and qualitative focus group interviews will be the most effective data gathering instruments for this investigation. The research was conducted using the philosophical approach of the post-positivist paradigm (Peat 2002; Parahoo 2006 and Creswell and Plano Clark 2011).

3.2) Research questions

In order to address the research questions and to ensure that focus is maintained to achieve answers to each question, three research questions and four subsidiary questions frame the study presented:

RQ1: What is the relationship between the knowledge and attitude of registered nurses, doctors and ODPs working in ICU, ED and OT to organ and tissue donation?

Subsidiary questions:

1b. What is the knowledge base of registered nurses, doctors and ODPs working in ICU, ED and OT towards organ and tissue donation?

1c. What is the attitude of these acute health care professionals towards organ and tissue donation?

RQ2: How does the education received by these groups determine the decision making and management of the organ donation process?

Subsidiary questions:

2b. What is the nature and extent of pre -registration education received by these professions in relation to organ and tissue donation?

2c. What is the nature and extent of the post registration education received by these professions as part of their CPD in relation to organ and tissue donation?

RQ3: What are the implications for education and training for health care professionals in general?

Data from both questionnaires and focus group interviews were used to answer these research questions.

The research was carried out in three stages:

- Pilot Study
- Phase 1: Questionnaires – involving 1180 health care professionals taken from eighteen hospital sites.
- Phase 2: Focus group interview- involving eight nurses from three hospital sites.

3.3) Description of the sample

The population for this study included three different registered health care professional groups: doctors, nurses and operating department practitioners (ODP) from eighteen hospitals ICU, ED and OT departments. The population only included these critical care areas specifically because this is where potential or actual brain stem death or organ donor patients requiring specialist complex care are managed (NICE 2011). The population was chosen as hospitals were approached to take part in the investigation by having the study registered on the National Institute for Health Research (NIHR) portfolio

(appendix 3). Having the study registered on the NIHR portfolio provided the author with named research co-ordinators within a number of hospitals in England. This enabled the author to obtain assistance in both gaining local relevant research and development (R&D) approval and a named person who would confidentially distribute the anonymous questionnaire in their relevant hospital.

The author sought to measure attitude and education and correlate relationships in the population of three HCP groups working within critical care areas. Therefore it was essential that a representative sample was available to ensure that the measurements and variables could be generalised to the population. The sample size needed to be large enough to allow statistical analysis as well as include sampling taken from a number of hospital sites within England, thereby reducing the likelihood of bias and influence on the sample and ensure more rigour in generalisations to be made. In total 3800 practitioners working in critical care from the eighteen sites were deemed eligible to take part in the study and all 3800 practitioners were anonymously sent the questionnaire. In total 1180 completed questionnaires were returned from participants across the population (31.05%).

Eighteen hospitals within England were approached and questionnaires sent to all the nurses, doctors and ODPs working within the inclusion critical care environments. These hospitals were selected from the London and Home Counties NIHR portfolio enabling the author easy access in travelling to sites. The response rate of the number of questionnaires returned would determine the sample size but needed to be large enough to represent three different professions; offer broad representation of different grades and professional experience and reflect the bias and influences that might be found in particular hospitals. The sample included only qualified and registered practitioners who mainly worked in ICU, ED and OT. From all three professions the sample included staff with a variety of professional experience and academic qualifications which ranged from

being 'newly qualified' to 'very experienced' with higher levels of academic degrees. The sample included both transplant and non-transplant hospitals as it could be hypothesised that staff working in a transplant hospital would be more positively biased compared to staff that did not.

3.4) Pilot study

A pilot or feasibility study is where the logistics and design of an experiment can be tested prior to starting a larger study in order to improve the quality and rigour of the main study (Gerrish and Lacey 2010). The questionnaire was sent to seventeen of the researcher's work colleagues within the ICU with a response rate of 82% (n=14). The questionnaires were analysed with Statistical Package for Social Sciences (SPSS) version 20. As expected the sample was not significant enough to gain statistical analysis via SPSS but tested the data set for the statistical package. The pilot study showed that staff were willing to complete questionnaires on this subject matter and that the questionnaire was clear and easy to complete. The questionnaire did have some minor refinements in relation to layout and sequencing of questions following evaluation of the pilot study. This was undertaken as some of the questions were missed and from discussions it was apparent that the layout needed to follow a more logical format. The pilot study also confirmed the fact that a mixed methods approach was essential in order to ensure that the focus group interviews provided qualitative responses in order to triangulate both data collection methods to provide findings to answer the research questions. Following completing the pilot study, the author in discussion with academic supervisors and Trusts R&D department, evaluated the design and structure of the study. This enabled the author to refine the study where appropriate and ensure that the data collection methods and methodology for the larger study was suitable for a large multi-site study.

3.5) Questionnaires

In this post-positivist mixed methods study, quantitative and qualitative data collection techniques in the form of questionnaires and focus group interviews were used. The advantage of using questionnaires is that they provided an opportunity to survey a large population of people across a variety of sites in order to identify a number of facts and opinions from specific groups of respondents and are relatively cheap to distribute (Denscombe 2003). A further advantage and of relevance to this investigation is that questionnaires could be anonymous. Due to the sensitive nature of the subject in addition to asking staff to potentially disclose their knowledge deficits, a questionnaire was seen as providing an ideal method for maintaining anonymity for answering the research questions in this study. This argument is supported by Thom (2007) who explains that by using confidential questionnaires, participants are less likely to have respondent bias and are more likely to be truthful as they are aware that the information they provide is anonymous.

The questionnaire included both open and closed questions (Appendix 4). The closed questions asked the practitioner to either answer: yes, /no/unsure, or to rank their perceived knowledge or attitude using a Likert scale with 0 equating to strongly disagreeing and 10 strongly agreeing. The 0-10 Likert scale was chosen as this is the scale recommended by Pallant (2007) when using SPSS. The closed questions enable quantitative measurement of staffs' perceived knowledge and training and where given options to select when answering the questions which help to ensure that irrelevant or redundant information was not collected. The questionnaire also included demographical information relating to profession, age, gender and years of experience and qualifications that would allow the author to undertake comparisons and analysis across the sample (Gerrish and Lacey 2010). A single open question was placed at the end of the questionnaire that allowed participants to record any strategies they felt could be used to enhance donation education and training providing an opportunity for the participant to

communicate to the researcher in their own words (Opdenakker 2006). However, the use of open-ended questions were restricted as these were perceived as limiting comparisons between respondents and to undertake statistical analysis across a number of questionnaires in this case 1180 replies (Boynton and Greenhalgh 2004).

The questionnaire was specifically designed for this study as no pre-existing questionnaire met the needs of this study. The questionnaire was initially evaluated by academic supervisors and fellow students on the thesis programme. Peer review feedback was also obtained from research colleagues in health and education within the University, NHS Trust's R & D department and the NHS Research Ethics Committee. The questionnaire was initially piloted with five clinical practice staff who provided constructive feedback on the questionnaire design prior to the formal pilot study. Following this feedback, the questionnaire was then revised and adapted following the evaluation and pilot study. The questionnaire was printed onto magnolia coloured paper in the aim to make the questionnaire distinctive as this would allow the respondent to distinguish the questionnaire from other paperwork that needs to be completed. Boynton and Greenhalgh (2004) explain that this makes the questionnaire more likely to be noticed and returned. When developing the questionnaire, the author was very conscious that the questionnaire was being sent to staff working in very busy clinical areas and wanted to employ strategies that would maximise staff completion and response rate. Edwards *et al* (2002) advocated a number of strategies to enhance response rates which were utilised by the author which are summarised in this chapter.

In addition to the questionnaire, an introduction letter (Appendix 5) and a participant information sheet (PIS) (Appendix 6) which outlined the aims and rationale for the study, were included to ensure respondents were fully aware of the nature of the research. This was dictated by NHS Research Ethics Committee to ensure that the staff member had

sufficient information to make an informed decision if they wanted to participate in the study. The survey pack also included a completed self-addressed envelope, which allowed the respondent to send back the questionnaire confidentially and without the respondent taking more time to write a reply envelope, factors which it was anticipated would help increase response rates.

As a questionnaire can be considered an intrusion into the life of the respondent, mainly in terms of the time taken to complete the questionnaire and sensitivity of the questions, it was important to ensure that the respondents were not coerced into completing the questionnaire and that the HCP had the informed choice of either replying or not (Peat 2002). The PIS explained that the staff member did not have to complete the questionnaire and that in doing so, no repercussions would occur. The questionnaire was anonymous and the respondent had the option of providing an e-mail address if they wanted to take part in the focus group interviews. The PIS explained that this e-mail address would be kept confidential and would only be used for the purposes of the research investigation and would not be shared with anyone else.

A survey pack was made up consisting of the questionnaire, introduction letter, PIS and a self-address envelope. The granting of NIHR approval enabled the author to access a number of hospitals' research nurses. The author then gave the relevant hospitals research nurse the required number of survey packs which they then distributed in their respective clinical areas via staff pigeon holes. In order to maximise response rates, two weeks after the questionnaires had been distributed a general reminder letter was sent out to all staff (Appendix 7). As responses were anonymous the author was not aware of who had responded to the questionnaire and the reminder letter was sent out blindly to all staff that had initially been sent a questionnaire.

The author did consider using an electronic questionnaire which could be e-mailed to staff concerned. However, it was felt that this would compromise the staff members' anonymity to the response to the questionnaire. Additionally the NHS Research Ethics Committee would have not given consent to the author being made aware of staff e-mail addresses as this would have breached NHS Trusts information governance procedures. Despite being time consuming, a paper questionnaire survey was felt to be the most effective method rather than using an electronic survey.

The questionnaire was distributed via the hospitals' research nurse once the hospital had granted R&D permission to participate in the research. These were sent out to staff over a 5 month period as not all NHS hospital site permission was granted at the same time. This also helped with the immense photocopying and packing of survey envelopes that was required. The NIHR research network provided funding for the photocopying and also provided some administrator assistance with packing the envelopes for the survey. The questionnaires were returned to the author in pre-printed self reply envelope.

3.6) Data Analysis for questionnaires

The quantitative data from the questionnaires were entered onto a Microsoft Excel spreadsheet and then imported into the SPSS package version 20 for statistical analysis. The data was inputted by the author and checked for errors and was then validated by a statistician and the Trusts R&D department. The Trusts R&D department proved valuable in confirmation and assistance on inputting the data as they regularly deal with statistical packages involving patient surveys and clinical trials that pre-dominantly involve large amounts of positivist quantitative data. The author had regular discussions with a statistician in the planning and results stages of the research. The author undertook the initial statistical tests using SPSS referring to Pallant (2007) SPSS handbook. Once completed, the findings were then checked and validated by the statistician. Throughout

the process of data analysis, the author undertook all the initial data inputting and completion of statistical tests which were then verified by the statistician to ensure validity of the findings. The author also coded the qualitative data from the open questions in the questionnaire into recurring themes.

Following advice from the Trust statistician, the author was advised to undertake non-parametric tests as these are more appropriate when data is measured in nominal (categorical) and ordinal (Likert ranked) scales as was the case with this study (Pallant 2007 and Ramasawmy 2012). Parametric tests make assumptions about the distribution of the population being equal and with similar sample sizes (Pallant 2007). Whereas non-parametric tests, whilst being less sensitive than parametric tests in detecting differences between groups, are more effective when testing different sample sizes between groups which was the case with this study (Pallant 2007 and Ramasawmy 2012). The statistician also advised that due to the significantly smaller sample size of ODPs (n=81) it was not always possible to undertake statistical tests involving comparisons and correlations with ODPs due to the difference in the professions sample size compared to doctors (n=313) and nurses (n=786). However, due to the larger sample sizes gained of the doctors and nurses, these samples could be statistically correlated against one another.

Non parametric statistical tests included Chi-square analysis which allowed relationships to be established between independent and dependent categorical variables in determining relationships between groups. Cross tabulations were used as these provide a summary of categorical data within a table that establishes any interrelation between two variables (Ramasawmy 2012). When establishing comparisons between groups, one-way between-groups analysis of variance (ANOVA) was used to explore relationships between one categorical independent variable (e.g. health profession) to one continuous dependent variable (e.g. perceived knowledge of contraindications to tissue donation) (Pallant 2007).

Ramasawmy (2012) explains that ANOVA is a statistical test that allows comparisons to be made between groups and to determine whether relationships are apparent. Statistical tests were measured against the probability value or p value, which when interpreting the p value for a test, states that if the value is less than 0.05 then the statistical test is significant, and where the value is above 0.05 the result is not deemed as significant (Pallant 2007 and Ramasawmy 2012).

It was recommended to undertake correlations looking at exploring relationships with variables using Spearman's product-moment correlation coefficient. This statistical test was chosen as it shows how strongly two variables are associated with each other (Pallant 2007). Spearman's rho correlation test was used as it can identify relationships between variables and is commonly used in health and psychological research which involves data collection using a ranked Likert scale which was the case in this study (Pallant 2007). In determining the strength of the relationship when using Spearman's test, the value needed to be compared to the correlation coefficient. This can range from -1.00 to 1.00 and indicates the strength of the relationship between the two variables (Pallant 2007). A correlation of 0 indicates no relationship where as a value of 1.0 or -1.0 indicates perfect correlation (Pallant 2007).

The strength of the relationship between correlation coefficient between two variables can be defined as being either: small, medium or large and is set out in Table 3.1.

Table 3.1: Correlation coefficient for determining strength of relationships between variables

Small	$r = .10$ to $.29$	$r = -.10$ to $-.29$
Medium	$r = .30$ to $.49$	$r = -.30$ to $-.49$
Large	$r = .50$ to 1.0	$r = -.50$ to -1.0

Pallant (2007) explains that the negative sign refers only to the direction of the relationship and how the question was asked and not the strength, therefore the strength of the

correlation of $r = .5$ or $r = -.5$ is the same in large correlation, but just in a different direction. When assessing if a correlation is established in this study, the correlation coefficient will be evaluated against this criteria. The statistical analysis will also present the standard deviation (SD) which measures the spread and variability in distribution of the results (Rumsey 2010) and the mean average scores within the groups which will allow comparisons of mean scores. These statistical correlations were chosen as they provided the most effective method of establishing relationships between education, training and attitude towards organ donation in order to establish answers to the research questions.

3.7) Focus group interviews

It is acknowledged that in using a mixed methods methodology, the questionnaire would provide predominantly quantitative data but the additional use of focus group interviews would provide qualitative data that the questionnaires would not be able to capture and so support triangulation (Polit *et al* 2001 and Tashakkori and Teddlie 2003). It was decided to use focus group interviews in conjunction with questionnaires in the methodology as the chosen interview questions to elicit information about attitudes, opinions, perspectives and enhancements to donation education which could not be gained from a questionnaire only. This according to Burgess *et al* (2006) allows the participants the opportunity to convey their own perspectives and emotions to others within a dialogue.

The focus group interviews would provide the opportunity to explore emergent key themes that had surfaced through the questionnaires and consider staffs' opinions and attitudes in order to answer the research questions in this study. The focus groups would also provide the opportunity to explore potential solutions regarding how donation education and training might be enhanced, how future training strategies could be delivered through generating discussions whilst reflecting upon the groups' experiences of donation and previous learning on the subject.

The focus groups comprised a self-selected group who provided e-mail addresses on their questionnaires, who were contacted and invited to attend the interview. All potential interviewees were sent an invitation to participate in a focus group letter (Appendix 8) and also a focus group participant information sheet (Appendix 9). This allowed the HCP to make an informed decision as to whether they wanted to participate in the interviews. All staff who attended, signed a consent form and were made aware that the interviews would be recorded and transcribed (Appendix 10). They were made aware that the interviews would remain confidential and anonymous and that they were allowed to leave the interview at any point with no repercussions in line with NHS Ethical and British Educational Research Association (BERA) guidance (DH 2001; DH 2011 and BERA 2011).

Focus group interviews were selected as a qualitative data collection method having the advantage of providing extensive data within a short time period in addition to enabling the author to observe group dynamics and interaction between participants (Burgess *et al* 2006). As the group would consist of three different HCPs, the author wanted to observe the interactions and comparisons between the professions which could potentially generate different opinions and discussions within the group. These multi-professional discussions would not be evident if individual interviewing strategies were used. Prior to undertaking the focus group interviews, the author prepared an interview schedule to provide a plan and focus for the discussions (Appendix 11). Open-ended questions were included which would allow the interviewer to probe into participants' knowledge and provide the opportunity for the group to discuss their opinions and ideas in relation to how donation education could be enhanced (Sim 1998).

It is acknowledged that there are disadvantages to focus groups as some members may dominate the interview and hence discourage others from expressing views (Smithson 2000). The author was very aware of this and made sure that all participants had equal contribution in an attempt to avoid this. Smithson (2000) also states that recording and then transcribing data after the focus group can be problematic due to the transcriber being unaware of the individual who was talking. In an attempt to reduce this limitation all the participants at the start of the interview were given a number and profession title (e.g. nurse 1, nurse 2 etc) and this was put on an identity badge for them to display. It would be made clear that whenever an individual was to talk they need to state their profession and number so that transcribing of discussions could then be correlated to the individual and their health profession but done anonymously.

3.8) Data collection from focus group interviews

All participants who had provided their e-mail address on the questionnaire were invited by e-mail to attend for a focus group interview. A number of apologies were received and in total 8 practitioners participated in the focus group interviews. This consisted of only nurses and despite doctors and ODPs providing e-mail addresses and being contacted none of them attended. The 8 nurses consisted of broad range of practitioners in terms of experience and seniority ranging from band 5 to 8a. The nurses consisted of representation from staff who worked in ED and ICU and consisted of staff working on three hospital sites. Despite e-mails sent to all three professions inviting them to attend, it was only nurses who were recruited on the day and therefore the concept of having a multi-professional focus group was not achieved but the decision was made to continue the interviews but with acknowledgement that the qualitative discussions were biased towards the nursing profession.

3.9) The use of focus group Interviews in this study

Attention was given to where the interview was held in terms of arrangement of venue, seating, how the author dressed and the strategy used to ensure equity amongst group members. The author wanted to ensure that group members were relaxed in order to encourage more discussion and opinions on the questions. All participants were given a PIS and explained the purposes of the research (Appendix 9). All members signed a focus group participation consent form which referred to confidentiality and anonymity issues. This was within the template advocated and approved by the NHS REC (Appendix 10).

The author had an outline of questions to ask the group to ensure structure and purpose was maintained (Appendix 11). There were a number of techniques chosen to facilitate the natural course of the conversation which included the use of open questions. This involved using questions such as “What do you think”, “What about”, “Supposing” as advocated by Cohen *et al* 2007 (Appendix 12).

The author was also aware of the importance of active listening which showed the participant that close attention was being given to what they said and also would allow the author to keep the participant focused upon the subject (Fern 2001 and Cohen *et al* 2007). The participants were reminded at the start of the interviews that conversations were being audio recorded for which written consent had been obtained. Due to the audio recordings not being able to identify the person talking, the author made all participants state their profession and allocated number when they entered into a discussion for the benefit of the audio recording in the aim to make it easier for the transcribing of the discussions. A medical secretary was used to transcribe the audio discussions electronically. The author and the secretary frequently met in person to ensure that during the transcribing process the transcripts accurately reflected the discussion verbatim. The author read the transcripts during the transcribing process to ensure that there were no discrepancies

between the transcripts and audio discussions. The medical secretary was familiar with the medical jargon and terminology used within the discussions and was bound by a confidentiality agreement.

The use of the qualitative focus groups provided the author with a wealth of rich verbal data which related to HCPs emotions, opinions and verbal perceptions which would have not be captured by using only a questionnaire approach. This mixed methods data collection approach provided far more meaningful data in order to address the research questions in the study.

3.10) Data Analysis for the focus group interview

The author analysed the audio tapes and transcripts searching for common themes and concepts. Cohen *et al* (2007) suggests that interview data are organised into manageable amounts and texts are labelled or coded and then stored by these codes. The study followed this protocol, analysing the discussions for themes and concepts from the interviews. This was achieved by the author highlighting key issues in the data which was coded which Charmaz (2002) refers to as open coding when qualitative data is initially analysed. The qualitative data was then processed by axial coding which involves grouping key issues together to make themes which could be applied to answering the research questions (Charmaz 2002). The approaches advocated by Burnard (1991); Appleton (1995) and Charmaz (2002) in using a category system that enables the text to be analysed in a systematic approach by grouping themes into codes was undertaken to analyse the qualitative data in this study. This was carried out by analysing the transcripts and highlighting key discussions relating to the research questions which were then colour coded according to the theme of the research question. The author also set out to apply the emergent themes arising from the interviews to Eraut's (2000) and Dreyfus' (1980) perspectives on how professionals develop knowledge and competence and their

relationship to the work place. The coding of data provided a method for cross referencing both the focus group data and also to the questionnaire data.

3.11) Managing potential bias in the research

To reduce the bias, the limitations of the sample group have been addressed. Researcher bias was reduced because the sample was taken from a number of hospitals which meant that the majority of the questionnaires returned were unknown to the author who as a consequence had no influence on the sample.

The selection criteria for the sample were: being employed as an ODP, RN or doctor working within ICU, ED and OT within one of the eighteen NHS hospitals who had received NHS R&D approval to participate in the study. Therefore all staff in these areas were selected and sent a questionnaire so there was no sample selection bias. These staff and selected clinical areas were chosen as this is where organ donation takes place within acute hospitals. This would also reduce the bias of gender, experience and seniority of all staff employed in these areas as they were all invited to participate in the study. Despite every participant who provided an e-mail address being invited to attend a focus group interview which included representation from all three professions, only nurses attended the interviews. It is acknowledged that the focus group interviews therefore were biased towards nurses despite the author's attempts to ensure representation of all three professions at the interview. This provides bias towards the nursing profession when interpreting the focus group interviews and responses which may not be applicable to the two other professions included in the questionnaire sample.

It was important that all the research participants were treated as independent and with respect so that they were protected from exploitation. This ensures that participants are not selected based on a desire to prove a specific research objective (Peat 2002; Cohen *et*

a/ 2007 and Creswell 2009) This was not the case with the questionnaires being sent out to all HCPs using a multi-site approach which meant the author could not unintentionally bias the recruitment selection. The hospital sites included a number of hospitals involving transplant and non-transplant centres which reduced any specific local bias that may be evident on a specific hospital site.

When undertaking the focus group interviews, steps were taken to ensure that the author avoided becoming focused upon one viewpoint when observing participants as this could endanger the impartiality of the research (Kitzinger 1995). The author was very conscious of this and attempted to adopt neutral and unbiased responses throughout the discussions and interactions.

When the questionnaires were distributed, the invitation letter (Appendix 5) stated that participants had 6 weeks to complete and return the survey. It was imperative that staff had enough time to complete the questionnaire and did not have procedural bias placed upon them to complete in a short turn around period.

It was important to be aware that a limitation of surveys is that participants who tend to complete the questionnaire are biased if the questionnaire is related to a subject matter they are interested in which may provide a positive bias (Thom 2007). Alternatively, where a participant held a very negative view on the subject matter, it was recognised that this might also promote a response rate resulting in more negative bias. With organ donation being a very sensitive and emotive topic, there will have been both positive and negative responses due to these influences. It is proposed that bias was negated through the use of a large multi-site sample and questionnaires providing the most effective data collection tool for anonymously surveying a large number of staff.

Throughout the study, the author stressed that all responses would be anonymous and confidential unless they decided to provide an e-mail address to participate in the focus group interviews. The author did not want staff to feel that they were being judged or that any possible deficits in their perceived knowledge would be made known to their colleagues or managers. If this was not explicit, staff would feel very aware of their answers and would be biased towards providing answers that they would want their managers or colleagues to see so that they would protect themselves from any potential repercussions. This would have provided a major source of bias in the research had not the questionnaire and focus groups been anonymous and confidential.

3.12) Assuring validity and reliability

Validity is an important key to effective research. According to Cohen *et al* (2007) the definition of validity has taken many forms, with earlier versions based upon the view that a particular instrument measures what it proposes to measure. More recently with qualitative data validity might be addressed through honesty, depth, richness and scope of the data achieved and the objectivity of the researcher (Cohen *et al* 2007 and Creswell 2009). In quantitative data, validity might be improved through careful sampling, appropriate instrumentation and appropriate statistical treatments of the data (Creswell 2009).

The questionnaire validity as a method to measure the research questions was evaluated by peer review feedback from clinical staff, fellow thesis students and academic supervisors, NHS REC, Trust R&D, and was also tested in the pilot study. Although the questionnaire had not previously been published or used in a research study before, the development of the questionnaire went through a rigorous validation process. When developing the questionnaire, published literature relating to questionnaire development and analysis using SPSS was cross-referenced to provide maximum benefits of using this

data collection tool. The testing of the reliability of the scales used in the questionnaire was measured by Cronbach's alpha coefficient which indicates internal consistency of questionnaire scales (Pallant 2007). The reliability of a scale can vary depending on the sample with which it is used. DeVillis (2003) explains that ideally the Cronbach alpha coefficient should be above .7 but values above .8 are preferable. Cronbach alpha coefficient values for this studies questionnaire were above 8.02 which suggested good internal consistency reliability of the scale used within this sample (Pallant 2007 and DeVillis 2003).

The quantitative data was statistically analysed with supervision from the Trust's R&D department and a statistician who provided quality assurance relating to the validity and reliability of the statistical analysis.

The focus group interviews were undertaken using an interview schedule which had been reviewed by the NHS REC. The author was aware that there was a potential of interview bias in that the participants may be unintentionally asked questions which may support the viewpoints of the author. Silverman (1993) and Creswell and Plano Clark (2011) suggest that reliability of interviews can be enhanced by careful piloting of schedules; effective coding of responses and the use of open questions to allow the respondent to reply in their unique way of looking at the world. Where possible the author tried to remain aware of this using the interview schedule as a method to reduce potential bias.

Reliability is also another important factor in research that needs to be considered when undertaking any investigation. This relates to precision and accuracy of the research and that if the study was to be replicated elsewhere by others under similar conditions it should lead to same or similar outcomes (Burgess *et al* 2006).

The HCPs involved in this sample involved doctors, nurses and ODPs working within critical care areas that were likely to identify and manage potential organ donors. This was significant as the results would be very biased if the sample included health professionals working outside of these clinical areas because they would not be exposed to donor patients and would therefore be unlikely to have training or experiences of managing donor patients. It was made explicit in the research protocol that questionnaires would only be distributed to HCPs working in these areas. This was similar to nursing, medical and ODP students who would only undertake a short placement within these clinical areas and the remit of the research question was to evaluate registered practitioners knowledge and training, therefore they were excluded. The reliability of this was assured by the question asking the sample to identify their registered profession and the length of time that they had been a registered HCP. All questionnaires not including this information were excluded from the data analysis.

The sampling involved a number of different hospitals within England which involved transplant; non-transplant centres; neurological; trauma and general hospitals. This would allow for a mixture of staff working in different clinical specialty hospitals rather than biasing transplant hospitals which might produce more positive outcomes compared to non-transplant hospitals. It was considered that the inclusion of a variety of hospitals in different geographical locations would minimise hospitals and geographical bias that may influenced the reliability of the results. However, as previously discussed the focus group interviews were biased to the nursing profession despite e-mail invites sent to participants from all three professions involved in the questionnaires. Therefore, caution needs to be made when interpreting the interviews as they may not be directly applicable to the two other professions involved in this study.

It is documented that a study can be biased by respondents of questionnaires being influenced in replying to a survey if they have a bias (either positively or negatively) to the subject of the questionnaire (Peat 2002 and Parahoo 2006). This would be the case in this study as it could be argued that the replies would be from staff who had a positive bias towards donation and therefore might have more knowledge on the subject, or equally, the reverse with staff being more negative. However, as already discussed in terms of surveying a large number of the NHS health professional workforce this potential bias is acknowledged.

This potential bias could also be applied to staff attending the focus group interviews as they pre-dominantly had very strong views towards donation. This again would be biased as it could be argued that as the sample included busy clinical practitioners only the participants who were confident and positive towards donation took part as this involved additional time out of the practitioners busy work schedule to take part in the interviews.

3.13) Ethical considerations

Ethical considerations are fundamental to the research undertaken, from the initial planning and design of the study, the data collection process and the way in which the data is handled, analysed and presented. Bassey (1999) argues that there are three main ethical values that researchers need to acknowledge in their design and practice; respect for democracy; respect for truth and respect for persons. These three values were seen as critical by the author in underpinning the research undertaken. DH (2011) states that all participants in research have the right to expect protection from physical harm, psychological, social, legal and economic harm at all times during an investigation. This study had ethical issues surrounding anonymity, confidentiality and informed consent that needed to be assured. The research proposal was agreed and supported by the study University Research Degrees Committee who acknowledged that NHS REC was also

necessary (Appendix 13). Under NHS constitution all research undertaken within the NHS involving either patients or staff that takes place on NHS property requires a comprehensive research and ethical evaluation by an NHS REC. In order to do this investigation, the researcher had to apply and gain approval from the NHS REC.

3.14) Gaining NHS Research Ethical Committee approval

The journey of gaining NHS REC approval was a long one taking approximately 10 months involving extensive applications via the electronic Integrated Research Application System (IRAS) and then the author having to be present at two REC panel meetings. The IRAS and REC is a rigorous process as they evaluate both the ethical and research design of the study. NHS REC approval provides a valuable safeguard for researchers and their participants alike and ensures that the rigor of the methodology has been extensively evaluated (DH 2011). The author was required to attend two RECs in order to present assurance that the research was using NHS National Research Ethics templates to ensure that the PIS, consent forms and confidentiality issues were being maintained as per NHS ethics regulations as the initial documentation did not adhere to NHS research templates and needed to be amended into these templates. REC approval provides reassurance to patients and other volunteer participants that the study is ethically credible, thereby maintaining confidence in the integrity of the researcher and the research process (DH 2011) (Appendix 14 - NREC 11/10/1098). In addition to gaining the study University Research Degree Committee and NHS REC approval, senior executive workplace approval for the study was also given by the NHS Trusts director of nursing (appendix 15).

3.15) Gaining NHS site R&D approval

Once NHS REC approval had been gained, then approval by each individual hospital was sought through an application to their R&D Board/Panel which was designed to ensure that research complied with the specific hospital research governance requirements. This

was time consuming as R&D for each hospital NHS Trust was required with some hospitals having a backlog of applications with some sites taking up to three months to obtain approval. At the same time NIHR approval was given for the research to become a portfolio registered study which provided the credibility of the study being registered with the NHS Comprehensive Research Network (Appendix 3). This allowed access to the research nurses on the chosen hospital sites to distribute the questionnaires on the author's behalf. This process took approximately three months to complete.

3.16) Informed consent

Throughout the research, it was made clear via the invitation letters and PIS that all participants who were sent the questionnaire had the right not to participate and complete the questionnaire without ramifications and this right was respected. All participants were made aware of the aims and benefits of the research by the PIS to enable them to make an informed decision whether to complete the questionnaire without any experience of coercion. It was agreed by NHS REC that informed consent was given if the participant had completed and returned the questionnaire to the author. As all the questionnaires were anonymous unless an email address was voluntary provided, it was made explicit in the PIS that once a participant had returned a questionnaire they could not retract the questionnaire as it could not be identified to be removed from the study.

Within the questionnaire staff were invited to take part in a focus group interview and where the participant wanted to do so, they were asked to provide an e-mail address. It was made clear in the PIS that the e-mail address would be used solely for the purpose of the research study and would not be shared with anyone else apart from the author. The author then emailed the HCP asking them to take part in a focus group interview. The focus group PIS was e-mailed with the invitation letter to attend for an interview

(Appendices 8 and 9). Staff were reminded that despite their initial interest to attend a focus group they did not have to commit to this and the PIS allowed an informed decision to be made relating to their final involvement. Focus group consent forms were signed by participants before the start of the interview indicating that they had given informed consent and were reminded that they were free to leave the interview at any point without any consequences (Appendix 10). There was no issue on the ability to consent or the participant losing their capacity as all staff were registered practitioners and were able to make an informed decision to participate in the research. Participants were advised how the data would be stored, used and accessed including details of how confidentiality will be maintained. This was explained in the PIS and had been approved by the NHS REC.

3.17) Ensuring anonymity and confidentiality

In order to ensure anonymity of the questionnaires names or hospital sites were not required unless respondents provided an e-mail address as an expression of interest to take part in the focus group interviews. This was to both maintain ethical principles but also to reduce the risk of any respondent bias should the HCP have any concern that the survey could be linked back to them. Within the PIS, it explained that all e-mail addresses would be used solely for research purposes and would not be disclosed to any other parties. All e-mail communication was undertaken via NHS.net which is a secured electronic system and was blinded so that e-mail users could not visualise other participants email addresses in the study. The consent form for the focus group explained the significance of maintaining confidentiality of the discussions that took place within the interviews. All HCPs who participated in the interviews were also registered HCPs with a governing body which all have codes of practice that has stipulations about maintaining confidentiality which they apply to their daily working practice (GMC 2006; NMC 2008 and HCPC 2012).The author was also conscious that within the thesis itself that no individual or NHS organisation could be identified thereby maintaining anonymity.

Chapter 4: Results and Discussion

4.1) Structure

The results of both the quantitative and qualitative data will be presented together to allow integration of both data collection methods in order to effectively analyse and discuss the findings in terms of answering the relevant research questions. As this study uses a mixed method approach, the quantitative statistical results will be presented with the qualitative interview data that will embrace triangulation of research when presenting the findings (Tashakkori and Teddlie 2003). The findings from both the questionnaires and the focus group interviews will be discussed in the context of relevant contemporary literature, so deepening the analysis and commentary in the thesis. This will allow the results to be presented in a logical format but also provide the opportunity to effectively allow discussion and argument against existing trends, models and relationships with previous published literature within the discussion.

The study found a number of emergent themes and trends from triangulating both the quantitative and qualitative data when evaluating HCPs knowledge, education and attitude relating to organ and tissue donation. It was apparent that the more experienced and educated the HCP was the more knowledge they had gained from situational exposure and tacit knowledge development relating to donation. Doctors have more knowledge, education and confidence relating to donation compared to nurses or ODPs.

Qualitative data coding identified the following emergent five themes arising from the focus group interviews and qualitative questionnaire feedback relating to how education and training could be enhanced and developed for HCPs. These five themes relating to implications for education and training related to:

- Mandatory training on donation
- E-learning
- Post registration CPD provision
- Pre-registration education
- Nationally accredited training course

Throughout the results and discussion chapter these themes will be analysed and related to contemporary literature and theoretical perspectives. The results section will highlight pertinent findings in bold text to identify significant findings established from the data.

4.2) Questionnaire response rates

A total of 3800 questionnaires were sent to doctors, nurses and ODPs working within critical care areas of eighteen acute hospitals within England. The overall response rate from practitioners was 31.05% (n=1180). Edwards *et al* (2002) states that an average response rate of 32% is expected in samples from clinical environments, therefore this study correlates to the average clinical response rate. The individual hospital response rates varied between 16% and 48%. The sample comprised 66.6% (n=786) registered nurses, 26.5% doctors (n=313) and 6.9% (n=81) ODPs. The difference in health care professions response rates would be due to nurses being the higher number of staff employed in critical care, then doctors and with ODPs being the minority employed of these professions. This reflects the proportions of the staff working in those areas (DH 2000). The sample included 465 (39.8%) HCPs who work in a tertiary referral transplant hospital and 702 (60.1%) working in a non-transplant hospital with 12 people not answering the question. The age range of the sample was from 21 to 71 years old, with a mean age of 39 years.

4.3) Demographics of questionnaire sample

The sample comprised of 71.9% (n=849) females reflecting a predominantly female profession of nursing (n=680/786), a characteristic shared with the 71.9% of ODPs (n=58/81). In contrast to the majority of doctors being male (64.5% n=202/313). The doctors had a slightly higher mean age at 40.54 years compared to the nurses (38.73 years) and ODPs (38.72 years). This small difference in mean years between professions was not significantly different (p=0.696). The minimum age of the sample for nurses and ODPs was 21 years compared to 24 years for doctors. This would be attributed to the fact that nurses and ODPs pre-registration education takes 3 years to complete and that of doctors' being more than 5 years. Table 4.1 shows that the mean time a registered nurse had practiced was 14.48 years, with the range being between 0 meaning less than 1 year to 51 years of service. The doctors' mean was slightly higher at 15.53 years (ranging from 0-40 years) and ODPs mean length of qualification being 9.95 years with a range of 0-34 years.

Table 4.1: Questionnaire sample details

Health Care Profession	Sex		Total	Age	Age range	Years of being a registered practitioner	Range of years being registered practitioner
	Male	Female		Mean in Years	Years min & max	Mean in years	Years min & max
Registered Nurse	106 13.5%	680 86.5%	786 66.6%	38.73	21-71	14.48	0 - 50yrs
Doctor	202 64.5%	111 35.5%	313 26.5%	40.54	24-65	15.53	0 - 40yrs
ODP	23 28.4%	58 71.6%	81 6.8%	38.72	21-60	9.95	0 - 34yrs
Total numbers n= 1180	331	849	1180	39.19	39.19	14.46	14.46
Total %	28.1%	71.9%	100%				

The questionnaire was used to gain an understanding of whether the health care professional had undertaken their initial pre-registration within the UK, Europe or internationally, in recognition that the UK is a multi-cultural society and that health care staff reflect this (table 4.2).

Table 4.2: Breakdown of where the health care professional undertook their initial pre-registration training

		Where did you undertake your initial pre-registration training?			Total
		United Kingdom	Europe	International	
Health Care Profession	Registered Nurse	546 (70.2%)	42 (7.7%)	190 (24%)	778
	Doctor	198 (64.2%)	32 (10.3%)	78 (25.3%)	308
	ODP	78 (97.5%)	1 (1.3%)	1 (1.3%)	80
Total (n=1166)		822 (70.4%)	75 (6.4%)	269 (23%)	1166

It was apparent within the sample that a large proportion of doctors and nurses had undertaken their initial training outside of the UK and then travelled or moved abroad to practice in the UK. As expected this was not apparent within the ODP group as this profession has grown and expanded within the last 20 years and is now a pre-dominantly UK health profession as in other countries nurses frequently carry out the role of the ODP in the operating theatre.

The sample consisted of a variety of bands of nursing and ODP staff ranging from the most junior to the most senior. Band 4-5 represents a junior nurse or ODP who is at staff nurse level. Band 6 represents a junior sister/charge nurse or senior ODP, a band 7 senior sister/charge nurse, band 8a matron or clinical lead and 8b being a senior nurse manager or consultant nurse (table 4.3).

Table 4.3: Banding and seniority of the RN and ODP in the sample

Health Care Professional	What is your current band & seniority as an RN or ODP?							Total
	band 4	band 5	band 6	band 7	band 8a	band 8b	other band	
RN	4	401	220	137	15	4	1	782
%	0.5%	51.2%	28.1%	17.5%	1.9%	0.5%	0.1%	100%
ODP	0	45	32	3	1	0	0	81
%		55.5%	39.5%	3.7%	1.2%			100%
Total numbers (n=863)	4	446	253	140	16	4	1	863
%	0.4%	51.6%	29.3%	16.2%	1.8%	0.4%	0.1%	100%

The questionnaire sample also consisted of a variety of different levels of doctors ranging from the most junior to the most senior (table 4.4).

Table 4.4: Seniority and doctors' job title within the sample

	Frequency	% of doctors	
Level of seniority of doctor within sample	F1 doctor	9	2.9
	F2 doctor	3	1.0
	Senior House Officer	41	13.3
	Registrar	38	12.3
	Senior Registrar	32	10.4
	Staff Grade	35	11.4
	Consultant	150	48.7
	Total (n=308)	308	100.0

The F1 doctor corresponds to foundation year which is the most junior doctor who has just qualified from medical school up to consultant which is the most senior doctor in the profession.

4.4) Focus group interview response rates

In total 97 questionnaire participants indicated that they were willing to take part in a focus group interview, this comprised 73 nurses, 18 doctors and 6 ODPs. All participants who provided an e-mail address were contacted via NHS.net which is a secure NHS e-mail service. All participants were sent a focus group invite letter (Appendix 8) and participant information sheet (Appendix 9). Participants were e-mailed 6 weeks prior to the date of the focus group so that it enabled time for them to plan the interview into their working schedule. After the initial invitation a further reminder e-mail was sent two weeks later and then 1 week before the interview taking place. A number of participants replied back with apologies and some automatic e-mail replies stating the e-mail address was no longer in operation. The focus group took place in a meeting room on NHS Trust premises which was private and provided no disruptions. On the day of the focus group interview, the sample consisted of 8 nurses and the author, with the interview lasting for approximately one hour and 10 minutes. All those who attended signed a consent form and were reminded of the importance of confidentiality and anonymity. All participants were reminded that the interviews were going to be recorded for the purposes of the research only and consent was given. All staff were given an allocated number e.g. nurse 1 and were asked to quote their number prior to talking for transcription purposes. The discussions were led by the author using an interview schedule.

4.5) Demographics of focus group interview sample

The focus group sample consisted of 8 registered nurses from three different hospital sites. The sample consisted of a variety of experience and seniority ranging from newly qualified band 5 nurses to an 8a matron. The sample consisted of 7 nurses working in ICU and one nurse working in ED. All participants were female apart from one male, as with the questionnaire sample this was probably due to nursing being a pre-dominantly female profession and is representative of the gender balance in nursing. Despite e-mails being sent to doctors and ODPs unfortunately on the day only nurses attended the interviews despite participants being invited from the two other professions.

4.6) Analysis of research questions

RQ1: What is the relationship between the knowledge and attitude of RNs, doctors and ODPs working in ICU, ED and OT to organ and tissue donation?

4.7) RQ1 Overview of findings

Data established that staff feedback following a donation taking place which detailed the beneficial effects that the retrieved organs had made to other people's lives, improved HCPs' attitudes towards donation. Education programmes involving the direct input and views of relatives or transplant patients provide HCPs with a personal insight into the benefits of donation and can enhance future behaviour and participation of HCPs in donation. Statistical analysis revealed that HCPs provided with pre-registration education relating to donation made no difference to their perceived attitude towards donation. The results revealed that HCPs who have received CPD education have a more positive attitude towards donation and perceive that donation produces more patient benefits compared to those practitioners who have received no donation CPD.

4.8) RQ1 Results

The questionnaires and the focus group interviews revealed a direct relationship between knowledge and attitude of staff towards donation. The focus group interviews established

that nurses believed that there was a direct relationship between knowledge and a positive attitude towards donation.

“I think education can take on a favourable attitude on organ donation..... you may not have an opinion either way so I think more education will help your attitude become more favourable towards donation” (Nurse 8).

From interpreting this data, it was apparent that education was essential in order for a HCP to produce a viewpoint towards donation, whether positive or negative.

An example was given by a nurse relating to how an education study event had a direct influence on enhancing her attitude towards organ and tissue donation. The nurse attended a bereavement study day when she was newly qualified which included aspects relating to donation in the curriculum which she felt positively influenced her attitude towards donation. The study event included a talk from a relative who provided a reflective verbal account of her experiences when she lost her loved one in hospital and how she had not been approached for organ donation. The nurse stated,

“When I was a junior nurse we had a talk from a relative and she said she had not been approached about organ donation, she felt actually cheated that she hadn't been approached..... That changed my whole attitude because I never thought of it that way..... Somebody had denied her that right and didn't mention [donation] at the time. this made me think and feel that I always should say something to relatives however difficult that is so for me that was a good example of how training and education changed my attitude” (Nurse 8).

This provides a personal insight into how a nurse was provided with a learning opportunity which provoked deep personal reflection that involved promoting a more positive attitude towards donation which then had an impact upon the practitioner's participation in donation care. This change in attitude appears to be heavily influenced upon the relative's discussions on how they felt “cheated” by not having the option of donation discussed with them, this appears to have provided inspiration and acceptance by the nurse. The interviewees all concurred that the impact of having bereaved relatives who have been

involved in donation and transplant patients being able to discuss their experiences of the process at study events made a large impact, enhancing HCPs attitude and participation in donation care. Following analysis of the interview data, it was apparent that education programmes involving discussion from relatives or transplant patients really provided a personal insight into the benefits that donation could bring at a time of tragedy and whether a HCP should or should not allow relatives the option to consider donation. This idea is discussed by Randhawa (1998) and Elding and Scholes (2005) who propose that education programmes that use exploration and analysis of feelings that encompasses reflection of the advantages of donation, may prove more effective than a didactic lecture. This appears to support the findings in this study in the case of the nurse who enhanced her attitude to donation following witnessing discussions from relatives involved in the donation process.

A further finding of how nurses remained positive towards donation was by being given feedback after staff had facilitated a donation. This feedback is normally in the form of a personal letter from transplant services to the HCP that formally thanks staff members concerned and provides a summary of how the organs retrieved have benefited other individuals. This was highlighted by nurse 8 who stated;

“I find it really pleasing that you get feedback about what has happened [this is a letter sent to the staff involved in the donation on how the organs have benefited other patients]. It’s a really good thing..... that encourages you to be involved because it’s nice to get feedback about what’s happened a thank you..... It makes it all worthwhile. It encourages you to do that behaviour again” (Nurse 8).

There was agreement by the focus group sample that this feedback facilitates a more positive attitude towards donation and makes the process all seem worthwhile when you hear that despite the practitioner being involved in end of life care that other people have had their lives saved by the donation taking place. The focus group clearly identified the

significance of staff feedback following a donation taking place which embraces a more positive attitude and encourages practitioners to repeat the donation process again.

4.9) Relationship between pre-registration knowledge and attitude of HCP towards donation

The quantitative data (Figure 4.1) revealed no relationship between staff who had received pre-registration donation education before becoming a registered HCP in producing a more positive perception towards organ donation (Spearman correlation test $\rho=-.21$, $n=1167$, $p=0.475$).

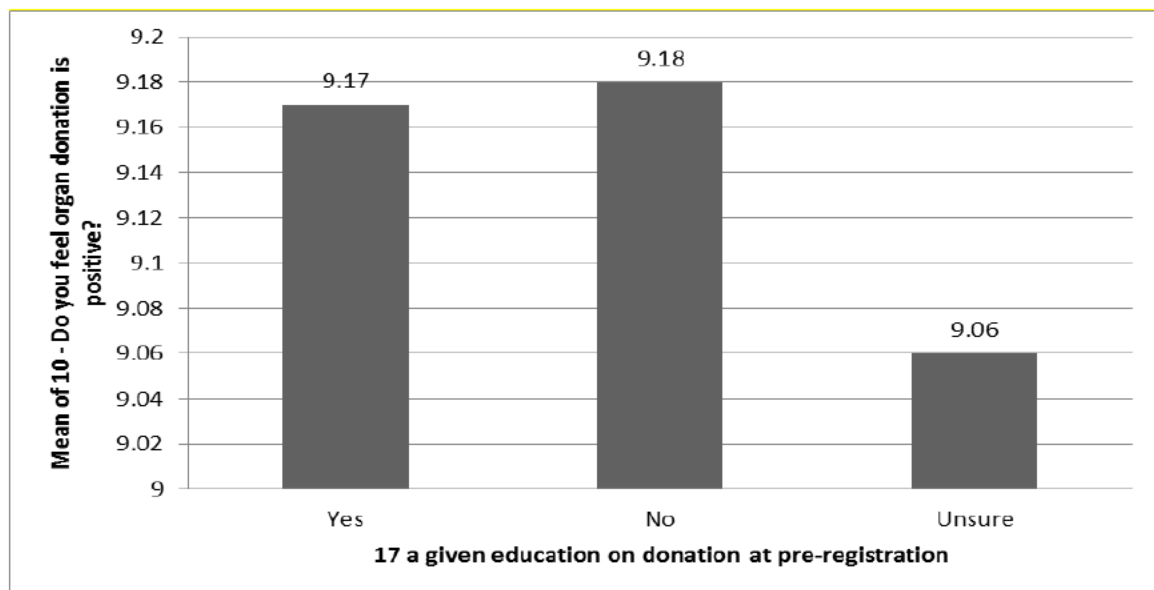


Fig. 4.1: Lack of statistical difference between staff who are more positive towards donation and whether they have received pre-registration training on donation ($p=0.475$ $n=1167$)

The results are in contrast to a recent study by Whisenant and Woodring (2012) who found that donation education improved student nurses knowledge and attitude towards donation compared to those students who were not given any education on the subject. Despite this study and Whisenant and Woodring (2012) finding contradicting results, caution needs to be taken when interpreting their results due to differences in methodological approaches. Whisenant and Woodring (2012) compared two nursing

student groups in an American school of nursing with one group having a one hour donation education intervention and the other not. In contrast, this study consisted of registered HCPs who were reflecting back on their pre-registration education in determining whether they perceived this had an impact upon donation. However, with limited studies available this does inform discussion on the impact of student nurse education influencing attitude towards donation.

Previous studies by Kiberd *et al* (1998); Sque *et al* (2000); Erdogan *et al* (2002) and Roels *et al* (2010) found that there is a direct relationship between knowledge and attitude in that the more knowledge the practitioner has on donation the more positive their attitude is and the more likely they are to participate in donor management. However, this has not been evaluated against determining the influence of pre or post registration education, as this study has established. This study wanted to identify whether pre-registration or post registration CPD education had any influence in terms of developing a positive attitude of HCPs towards donation. **The data established no statistical difference (p=0.475) between the three HCPs who had received pre-registration training and if this influenced a positive attitude towards donation.**

Despite pre-registration education making no difference on HCPs' attitudes towards donation, this does not necessarily mean that HCPs should not be provided with donation education before registration. If organ and tissue donation are to be viewed as part of routine end of life care options as advocated by DH (2008); GMC (2010) and NICE (2011) it is therefore imperative that education and training is provided prior to qualification of HCPs. The aim of pre-registration education is to prepare the HCP to practice autonomously and be accountable for their decision making. Caring for patients in their final hours before and after death is a fundamental role of any HCP and part of that requires staff to give the option of donation to patients and bereaved relatives. Otherwise,

it could be argued that if this is not covered within pre-registration education it is presented as not being essential and will mean that donation will never be viewed by HCPs as part of end of life care. This was expressed within the focus group interviews as they believed that pre-registration education provides an initial awareness of donation which could enhance future attitude towards donation.

“Pre-registration students should definitely be given donation and transplantation education. It almost demeans the subject if it is not covered in your nurse training.....When I was a student I was involved with my mentor witnessing a donation..... I did not understand how many people can benefit from one donor. I spoke to the SNOD and they gave me teaching on the unit. This made me very positive towards donation and changed my viewpoint..... Education at pre-registration focusing upon the benefits of donation would be very productive and increase students' attitudes.....” (Nurse 3)

Despite the statistical analysis finding no correlation between pre-registration education enhancing attitude, the focus group data provided specific evidence on how nurse 3 believed her attitude towards donation was positively enhanced. The consensus within the focus groups was that pre-registration education played a vital role in raising awareness of donation in order to demonstrate the benefits of transplantation, enhancing more positive attitudes towards donation. This education, the focus group sample believed would provide the initial foundation knowledge that could then be developed through future learning and experience. There was a clear theme within the discussions that pre-registration was important and should not be under-estimated in terms of embracing a culture of donation being routine for end of life care. The focus group stated that none of the sample had received pre-registration education relating to donation and this only occurred when they had become registered nurses.

This argument is supported by studies that suggest pre-registration health care students' have knowledge deficits relating to donation and that education and training of these students is paramount (Whisenant and Woodring 2012; Zampieron *et al* 2010; Martinez-

Alarcon *et al* 2009; Mekahli *et al* 2009; Goz *et al* 2006 and Cantwell and Clifford 2000). Therefore, this study's quantitative results have found that education given to students at a pre-registration level does not enhance professional attitude towards donation upon qualification. However, qualitative discussions support pre-registration education in that this will hopefully provide the notion that donation is to be viewed as routine and not unusual in end of life care. This education can provide the foundation which can be further developed when the HCP qualifies and can be readdressed in CPD learning programmes and situational exposure in the clinical setting as proposed by Erauts (1994 and 2000) concepts of professional learning.

4.10) Relationship between post-registration CPD knowledge and attitude of HCP towards donation

The data revealed a strong significant statistical correlation if a staff member had post registration CPD and having a positive perception towards organ donation (Pearson correlation, $\rho = -0.73$, $n=1167$, $p=0.014$). Statistical analysis found no difference between the three professions ($p = >0.66$) and which hospital department they worked in ($p=0.334$) in relation to CPD influencing perception towards donation (Figure 4.2).

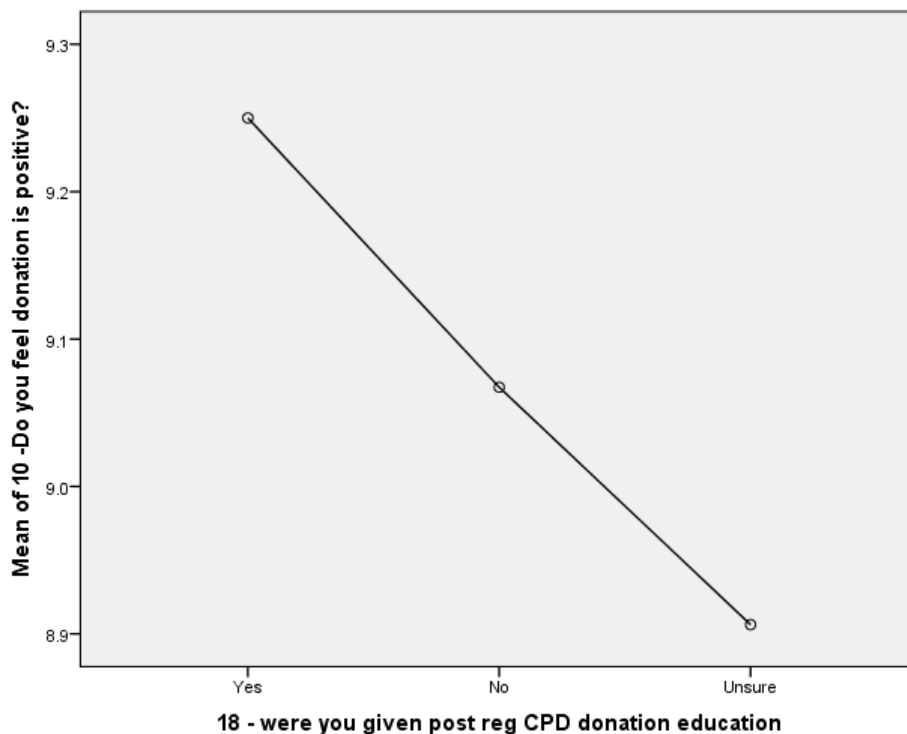


Fig. 4.2: Influence of CPD education on HCPs attitude towards donation (rho=-0.73, p=0.014, n=1167)

The data established that post-registration CPD education directly influences whether a HCP views donation as being a positive. These statistical findings also concur with the focus group interview, which found that post-registration CPD education directly influenced whether a HCP viewed donation as being positive.

“Education and training is so important..... I did not really know much about this [donation] until I started in ITU. The education [CPD] given to me really opened up my viewpoint towards donation and I did not know how many people benefit from one donor..... The education given to me by the SNOD really improved my perception of donation and I went straight home after my training to join the organ donation register. This training made such a difference to my outlook to donation” (Nurse 7)

The focus group discussions confirmed that all participants perceived that CPD education plays a vital role in developing knowledge that influences positive attitude towards donation. Both the quantitative and qualitative findings from this study concurs with previous overseas studies by Dukes *et al* (1998); Ozdag *et al* (2001); Ingram *et al* (2002); Akgun *et al* (2003) and Roels *et al* (2010) that show a relationship between education and

attitude, in that the more education and knowledge provided to the HCP particularly after qualification produces a more positive attitude towards donation. This confirms the findings established in this study demonstrating this is apparent across the three professions within the sample. The findings found no predominance to a particular profession or hospital department but regardless of profession or department, it is evident that if HCPs are provided with CPD education this influences a more positive attitude towards donation.

The results from this study are of relevance to policy makers as they suggest that in order to create a more positive attitude towards donation, registered HCPs should be targeted, and that education they receive as part of CPD should not be under-estimated in terms of its potential to influence positive attitude towards donation. This emphasis on education as instrumental in creating a more positive attitude is significant as it supports earlier studies that show that where a HCP believes that donation is positive and beneficial, they are more likely to participate in donor management (Sque *et al* 2000; Kim *et al* 2006; Lin *et al* 2010 and Rios *et al* 2010). It was not the purpose of this study to try and replicate these publications but to examine the potential impact that education and training may have on attitudes towards donation. Therefore since this study suggests that CPD education does produce more positive attitudes towards donation compared to those HCPs who have received no CPD, it could be argued that if all HCP's were provided with mandatory CPD education that this could influence positive attitudes towards donation. This could be extrapolated (Sque *et al* 2000; Kim *et al* 2006; Lin *et al* 2010 and Rios *et al* 2010) suggesting that an increase in numbers of staff participating in donor management would have an impact on the reduction of the transplant waiting list.

4.11) Research Question 1b

RQ1b: What is the knowledge base of RNs, doctors and ODPs working in ICU, ED and OT towards organ and tissue donation?

4.12) RQ1b Overview of findings

The data established knowledge deficits relating to contraindications to solid organ and tissue donation, BSD and differences in DBD and DCD clinical management. The results found that participants are infrequently involved in tissue donation despite the majority of patients who die being able to donate at least one tissue. Both quantitative and qualitative data revealed that HCP's who were provided with CPD education were more likely to participate in tissue donation and approach families for consent compared to those who had received no CPD. There were deficits in HCPs confidence with explaining BSD to relatives however correlation was established that education enhances knowledge and confidence of explaining BSD to bereaved relatives. Doctors consistently had more knowledge relating to aspects of donation and were more confident in explaining BSD to relatives compared to nurses and ODPs. There was a continuing theme that the more senior and experienced the doctor or nurse then the more knowledge and confidence they had relating to donation.

4.13) HCPs knowledge of absolute contraindications to donation

A statistical significant difference (p=0.02) was established between the three professions knowledge of absolute contraindications to donation but it was evident that the overall majority of the sample were either unsure (45.6% n=527) or were not aware of the contraindications (30.5% n=352). The results indicate that doctors were statistically more likely to be aware of the absolute contraindications to solid organ donation, with consultants 44.5% (n=65) stating they were aware of contraindications, 14.4% (n=21) were not aware and 41.1% (n=60) were unsure (table 4.5).

Table 4.5: Cross tabulation between HCPs and their awareness of the absolute contraindications for solid organ donation

			aware of absolute contraindications			Total
			Yes	No	Unsure	
Health Care Profession	Registered Nurse	Count	144	258	367	769
		% within Health Care Profession	18.7%	33.6%	47.7%	100.0%
	Doctor	Count	127	46	134	307
		% within Health Care Profession	41.4%	15.0%	43.6%	100.0%
	ODP	Count	5	48	26	79
		% within Health Care Profession	6.3%	60.8%	32.9%	100.0%
Total n=1155		Count	276	352	527	1155
		% within Health Care Profession	23.9%	30.5%	45.6%	100.0%

Data revealed only 23.9% (n=276) of participants stated that they were aware of the absolute contraindications to solid organ donation. This identifies that HCPs are not aware which patients specifically are contraindicated for solid organ donation. However, during recent years NHS Blood and Transplant (2011) has been encouraging universal referral of all patients who may be potential donors regardless of possible contraindications so that the transplant team can decide whether they are appropriate for donation in order to ensure every eligible donor becoming an actual donor where appropriate. Absolute contraindications include any cancer spread outside the affected organ within 3 years of donation, HIV disease and Creutzfeldt-Jakob disease (CJD) (NHSBT 2012).

This deficit in HCP's knowledge of contraindications determined in this study was also evident in a prospective study by Ploeg *et al* (2003) who analysed medical forms (n=4,877) on people dying in eleven hospitals in the Netherlands. They found that only 5% of physicians got a 100% score on criteria for contraindications for donation. They concluded that physicians lacked knowledge concerning medical criteria and

contraindications for donation. However, on evaluating Ploeg *et al* (2003) methodology it is unclear how they can assess a HCP knowledge and understanding of contraindications when referring to patients' medical notes following patients' deaths. It is unclear how Ploeg *et al* (2003) could determine that physicians lacked knowledge on contraindications when they did not ask physicians directly and data were drawn from retrospective medical notes. In contrast to this study where the HCP was asked via a questionnaire if they were aware of contraindications to donation and to state exactly what they were. However, there does appear to be a trend in the literature despite Ploeg *et al* (2003) using different methodology and this study finding that only 23.9% of HCPs or one in four are aware of the absolute contraindications to organ donation.

Kent (2002) UK study found similar trends in registered nurses having knowledge deficits relating to identifying the contraindications for donation. Kent (2002) found that only 8% of the sample correctly identified all the exclusion criteria for donation concluding that knowledge deficits relating to donation contraindications were apparent in the sample (n=776). Collins' (2005) small scale (n=31) survey involving only nurses' within one non-transplant ICU also found that nurses were not fully aware of contraindications to donation with 61% (n=19) of the nurses stating that meningitis was an absolute contraindication, whereas meningitis is not a listed contraindication (NHSBT 2011). Collins' (2005) findings support this study in that there appear to be knowledge deficits in identifying the absolute contraindications to organ donation. The significance of HCPs not being aware of the contraindications of donation may not be so influential on donor identification if the hospital has effective policies in place that any patient who is BSD or who has a planned withdrawal of treatment, is automatically referred to the SNOD. This universal referral of all patients believed to be BSD or having a planned withdrawal of treatment is now being advocated by NICE (2011) and NHS Blood and Transplant (2012). Therefore, from an education and training perspective, curriculum planning should be focused on the

importance of referring all potential BSD patients or planned withdrawal of treatment patients early to the SNOD rather than dismissing a potential donor at a referring hospital. This would account for the reason why NICE (2011) in their education recommendations do not stipulate that consultants are to have knowledge of absolute contra-indications to donation. However, it is evident that overseas education programmes on donation in Spain (Lopez-Montesinos *et al* 2010) and in Australia, do include contraindications for donation in their curriculum (ADAPT 2012).

4.14) HCPs knowledge of tissue donation

Having determined that participants' knowledge of absolute contraindications to solid organ donation was insufficient, further analysis revealed a poor understanding of the contraindications specifically for tissue donation.

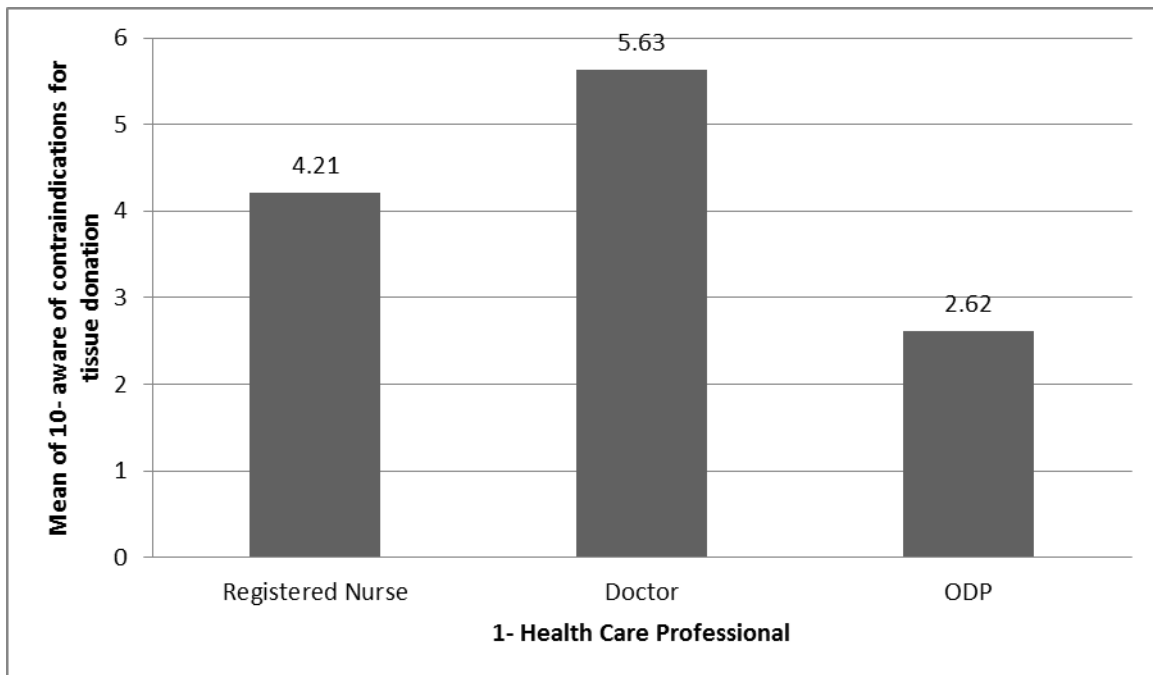


Fig. 4.3: Breakdown between HCP and whether they are aware of the contraindications to tissue donation.

Analysis revealed (Figure 4.3) a statistical difference that doctors (M=5.63, SD=2.803, n=303) are more aware of the contraindications for tissue donation compared to nurses (M=4.21, SD=2.841, n=763) and ODPs (M=2.62, SD=2.280, n=76. ANOVA test p=0.004). The overall mean score was 4.48 (Likert 0-10, SD= 2.905, n=1142) across the three professions which demonstrates participants are not aware of the contraindications for tissue donation. The focus group clearly identified that there was a common theme that tissue donation infrequently occurs and there were lots of missed opportunities which was due to poor awareness and limited education on the subject.

“There is a distinct lack of education and awareness on tissue donation.....
Increasing awareness of referral..... Many staff are just not aware of
the options for tissue donation and there are missed opportunities” (Nurse 7).

Data from both questionnaires and focus group established that HCPs are not aware of tissue donation as an option due to poor awareness of contraindications and the referral process.

A positive correlation was established between experience and seniority of the doctor or nurse influenced awareness of the contraindications to tissue donation (Spearman correlation- doctors, rho=+0.195, p=0.01 n=299 and nurses, rho=+0.68, p=0.01 n=837). Due to the smaller sample size of ODPs statistical correlation was not possible. This is also confirmed by qualitative data as the focus group revealed the importance of liaising with more experienced senior colleagues if they wanted further advice or assistance with managing a potential donor. The focus group commented on the value of not only theoretical education but also situational exposure of nursing the donor patient which could only be achieved through clinical practice exposure.

“Junior staff should be involved in the process but should be led by a senior nurse that has experienced maybe some of it before [donation].....so that they can support junior staff and identify more potential donor patients..... and refer earlier to SNOD due to their previous experiences of donation” (Nurse 2).

This relationship between the more experience the HCP has and its correlation to increased knowledge can be applied to Eraut's (1994; 2000; 2007 and 2010) theoretical perspectives on how professionals learn and gain competence in the workplace. Eraut (2000) argues that professional knowledge evident in health care professions has a large tacit and situational learning dimension. Eraut (2007) discusses that professional work deals with complex situations that require the use of situational learning from previous experiences that have been encountered where the practitioner has gained tacit knowledge and intuitive decision making which can then be applied to further developing situations. Eraut's (2000 and 2007) theories of HCPs professional knowledge and competence development could be applied to this finding because HCPs develop knowledge and competence from other people in the workplace through sharing and exchanging knowledge and also understanding and reflecting upon new situations through informal social learning. Therefore, Eraut's (1994; 2000; 2007 and 2010) theories of professional learning could relate to the more situational exposure a practitioner has to donation within critical care practice, the more knowledge they will construct from experience, social interaction and reflection. In the context of this study there is a direct relationship between the more senior the doctor or nurse and them being more aware of the contraindications for tissue donation, directly illustrating Eraut's theoretical perspective of how professionals learn from on-going life and work experiences. This was an emerging and consistent theme that was evident throughout the results of this study in that workplace experience of the HCP is a major contributing factor for participants to gain knowledge and confidence when caring for organ donors within critical care.

Despite there being positive correlation between seniority of practitioner and perceived knowledge of contraindications to tissue donation, the overall mean for all three professions of 4.48 revealed that HCPs lack knowledge of the contraindications for tissue

donation. Anecdotally in clinical practice the author had observed HCPs state that they will not be approaching a bereaved family because the patient who has died had poor eye sight or was elderly which the HCP believed was a contraindication for corneal tissue donation. This statistical data found that HCPs have knowledge deficits relating to the contraindications for tissue donation which supports the author's anecdotal observations from clinical practice. NHSBT (2012) state that nearly anyone can be considered for tissue donation, however there is no donor age limit for skin, cornea, or bone donation but there are some medical contraindications, although poor eye sight is not one of them. The findings in this study also endorse Kent's (2002) earlier UK research that identified that the sample of nurses' (n=776) lacked knowledge and awareness of the contraindications for tissue donation.

Tissue donation is not seen as life-saving compared to solid organ donation but is viewed as life-enhancing as corneal donation can restore sight and skin donation can aid skin burn recovery (NHSBT 2012a). NHSBT (2012) which is responsible for all donation within the UK, state that there is a shortage each year of approximately five hundred available corneas for transplantation and the number of requests to NHSBT cannot be met due to increasing demand. From reviewing the literature, the DH and NICE strategies focus upon enhancing donation in solid organs as this is where donation is life saving and has significant burden on the societies medical and financial dependency (NICE 2011 and DH 2008). This is also observed from the authors anecdotal observations where emphasis is placed on solid organ donation due to this reason rather than on tissue donation. However, NHSBT (2012) acknowledge that the majority of people who die are eligible to donate at least one tissue which is also supported by the Pont *et al* (2003) Spanish study who reviewed deaths in a university hospital and found missed opportunities for potential tissue donors. This would suggest that it is now time for NICE, DH and NHSBT to produce

strategies which also focus upon increasing tissue donation uptake rather than solely focusing upon solid organ.

The results established that 15.6% (n=180) of participants had not been involved in any tissue donation management with a further 25.4% (n=300) being involved in just one tissue donor. The data found that 80.3% of practitioners had been involved in the management of a tissue donor on five or less occasions. Despite there being a national shortage of tissues available for donation the overwhelming majority of HCPs are infrequently involved in tissue donation despite the evidence supporting that the majority of patients who die can at least donate one tissue (NHSBT 2012). Although the mean time of post-registration practicing experience of participants is 14.46 years and 80.3% of the sample being involved in 5 or less tissue donations, this does not reflect the large number of dying patients that these HCPs would have cared for in their careers. This is further supported from the focus group data which revealed that staff infrequently participate in tissue donation:

“from a ward perspective there are always many opportunities [for tissue donation] but are always missed..... this is due to lack of awareness of tissue donation” (Nurse 2).

The focus group discussed that tissue donation infrequently occurs with the sample stating that they were not aware of this being an option until they were provided with training on the subject or they started a job in ICU.

The results show that HCPs infrequently identify and manage tissue donation as reflected in the literature by Pont *et al* (2003); Collins (2005); Gumbley and Pearson (2006) and Sharp (2009) that opportunities for tissue donation are infrequently missed as part of end of life care.

Table 4.6: Number of tissue donors the sample has been involved in managing during their registration career.

	Number within sample	Percent %	Valid Percent	Cumulative Percent
0	180	15.3	15.6	15.6
1	300	25.4	26.0	41.7
2	134	11.4	11.6	53.3
3	139	11.8	12.1	65.4
4	76	6.4	6.6	72.0
5	96	8.1	8.3	80.3
6	83	7.0	7.2	87.5
7	95	8.1	8.2	95.7
8	2	.2	.2	95.9
9	1	.1	.1	96.0
10	14	1.2	1.2	97.2
11	5	.4	.4	97.7
12	5	.4	.4	98.1
15	3	.3	.3	98.4
20	6	.5	.5	98.9
25	1	.1	.1	99.0
30	1	.1	.1	99.0
40	1	.1	.1	99.1
50	3	.3	.3	99.4
100	5	.4	.4	99.8
150	1	.1	.1	99.9
200	1	.1	.1	100.0
Total	1152	97.6	100.0	
Missing System	28	2.4		
Total	1180	100.0		n=1152

Table 4.6 demonstrates that tissue donation is not embedded into routine end of life care seven though a mean career time of registration of 14.46 years, would suggest that the HCP would have the opportunity to participate in numerous end of life care situations. The results revealed that HCPs infrequently manage tissue donors despite there being patients on the tissue transplant waiting list who are missing out on donors and a life enhancing transplant (NHSBT 2012). This is despite the GMC (2010) stating in their professional

guidance that doctors providing end of life care should be prepared to explore patients' and relatives' views relating to organ and tissue donation in order to determine whether donation was a possibility. This statement from the GMC (2010) as well as documents from the DH (2008) and NICE (2011) indicates that organ and tissue donation should be seen as a routine option as part of end of life care. This involves the HCP routinely considering any contraindications and options for tissue donation and where the views of the patient are not known then the HCP should be initiating discussions with the next of kin with consultation with tissue services.

It is widely accepted that when approaching families for solid organ donation that a collaborative approach is used which involves the consultant, bedside nurse and SNOD as advocated by NICE (2011) however there is no recommendation specifically for tissue donation. This is carried out differently from solid organs due to the nature of the limited number of organs that become available and the complexity of the organ retrieval process. Often it is expected that the bedside nurse or doctor will approach the family for tissue donation consent but often without a SNOD being present. The HCP needs to first identify whether the dead patient is potentially eligible for tissue donation with no contraindications being present and then approach the family for consent and then make a telephone referral to tissue donation services. Gumbley and Pearson (2006) state that nurses are ideally placed to advocate the team approach to tissue donation as they explain that nurses are approachable to families since their role actively encourages the formation of close relationships with patients and their relatives. This approachability, Gumbley and Pearson (2006) argue, puts nurses in a key position to discuss tissue donation with relatives.

Despite GMC (2010), NICE (2011) and DH (2008) recommendations stating that organ and tissue donation should be viewed as part of routine end of life care, the findings from

this study have determined this is not the case. This argument is confirmed by the findings that 80.3% of participants have only been involved in 5 or less tissue donors in their career which does not represent the notion that donation should be seen as part of routine end of life care.

An earlier small scale convenience sample involving nurses (n=31) by Collins (2005) within one UK ICU found similar deficits in knowledge relating to tissue donation. Collins (2005) found that the sample had deficits in knowledge in identifying which tissues could be donated and found that 40% were unaware of the contraindications for tissue donation. They also found that nurses in the sample infrequently approached families for tissue donation and did not routinely offer this option to bereaved families. This study's findings supports previous research by Collins (2005) in establishing that tissue donation is infrequently offered to bereaved families within critical care as HCPs do not routinely participate in tissue donation. However, this study provides a more rigorous assessment of the situation across eighteen hospitals and uses a large sample size which compares across three HCPs that are involved in end of life care.

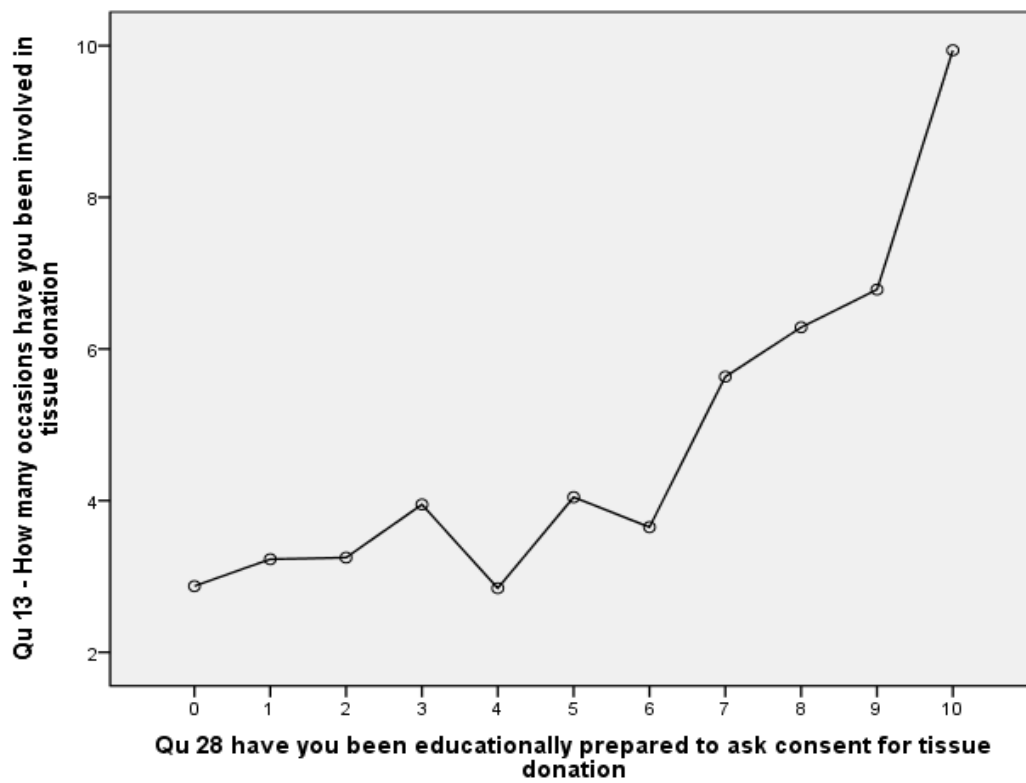
An argument why tissue donation may not be embedded into routine end of life care maybe explained by limited awareness compared to solid organ donation which is viewed as being life-saving compared to tissue donation which is viewed as life enhancing. Having reviewed the literature available from professional bodies and government organisations such as the DH and NICE, there appears to be superficial national advice relating specifically to tissue donation. NICE (2011) guidelines specifically excluded tissue donation in its terms of reference and so did the 2008 DH organ donation task force. There are no NICE guidelines specifically focusing upon tissue donation unlike solid organ donation and likewise no DH task force focusing upon tissue donation. The author concurs with Gumbley and Pearson (2006) that tissue donation appears to have less

profile compared to solid organ donation with no national advice or guidelines from the DH or NICE. The GMC (2010) has provided professional advice to doctors relating to establishing donation as part of end of life care however there is no specific advice for nurses from their professional regulatory body the Nursing & Midwifery Council (NMC). In order to maintain parity between both professional bodies to ensure that donation is seen as routine for end of life care, the NMC needs to follow its partner organisation to ensure that nurses have similar guidance that will enable tissue donation to be embraced by the nursing profession.

4.15) Relationship between education and the HCP involvement in tissue donation

The results found statistical difference (ANOVA $p=0.001$, $n=1122$) that the more educationally prepared the HCP is, the more likely they are to participate in tissue donation (Figure 4.4). There was no difference between health profession with an overall medium correlation established between increased education and involvement in donation (Spearman correlation $\rho +0.421$ $p=0.001$ $n=1122$).

With the corneal waiting list not meeting the supply of patients on the transplant waiting list, HCPs need to be provided with education and training programmes that will enable them to be aware of how to identify and approach families which will enhance the HCPs confidence when managing tissue donation. This will then have an impact upon the number of occasions that a HCP is involved in tissue donation and may influence the number of corneal grafts and other tissues available and reduce the transplant waiting list.



Interestingly, this study has contradicted the results of Kent's (2002) research exploring the psychosocial factors influencing nurses' involvement with organ and tissue donation in nurses (n=776). Kent (2002) found no statistical influence of knowledge on perceived ability to discuss donation to relatives in their sample of nurses working on critical care, medical and surgical wards. Kent (2002) opposes the findings in this study; however this may be due to differences in Kent (2002) sample population which only included nurses in district general hospitals and from ward environments as well as the study being undertaken over a decade ago. However Kent (2002) study found knowledge deficits in their sample and discusses that past experience and more societal awareness of certain donation issues as highlighted by the media may have more of an influential effect than specialist education input.

In contrast, studies by Sque *et al* (2000); Collins (2005); Kim *et al* (2006); Roels *et al* (2010) and Lin *et al* (2010) support the findings in this study and contradict Kent (2002) research in that HCPs who received more education were more likely to participate in donation and care of relatives. When evaluating these studies, it needs to be recognised that Kim *et al* (2006); Lin *et al* (2010) and Roels *et al* (2010) were overseas studies and were undertaken using a different methodological design compared to this study. UK studies by Collins (2005) were limited to just 31 nurses using convenience sampling techniques and Sque *et al* (2000) study was involving nurses from the wards outside of critical care environments who may not regularly be exposed to donation and were undertaken prior to the DH (2008) advocating mandatory donation training. However, the results revealed from this study do correlate to previous literature despite using different methodology and sampling in that the more education that HCP receives the more likely they are to be involved in the tissue donation process. Therefore, a theme occurring in this study is that education plays a significant part in influencing HCPs decision making in approaching and undertaking tissue donation management in the clinical environment.

Gumbley and Pearson (2006) argue that for tissue donation and transplants to increase, that education and raised awareness of tissue donation is essential. This theme was also revealed in this study's focus group where there was universal agreement that the reason why tissue donation is not occurring is due to lack of awareness and education relating to tissue donation as HCPs are not aware of the options of tissue donation. An example of this was highlighted by a nurse discussing that tissue donation was missed as a direct result of lack of training of HCPs:

“there are loads of wards who have never had training at all..... we've failed to pick up tissue donation time and time again” (Nurse 7).

The findings have shown that education and training has a direct influence on whether a HCP approaches a family for tissue donation consent and without effective education the last wishes of patients may be denied as well as the negative impact it has on the tissue transplant waiting list.

4.16) HCPs knowledge of brain stem death

The findings revealed an overall mean score of 5.91 (SD=3.364) that established health care professionals lack perceived knowledge and confidence in effectively explaining BSD to relatives (Figure 4.5).

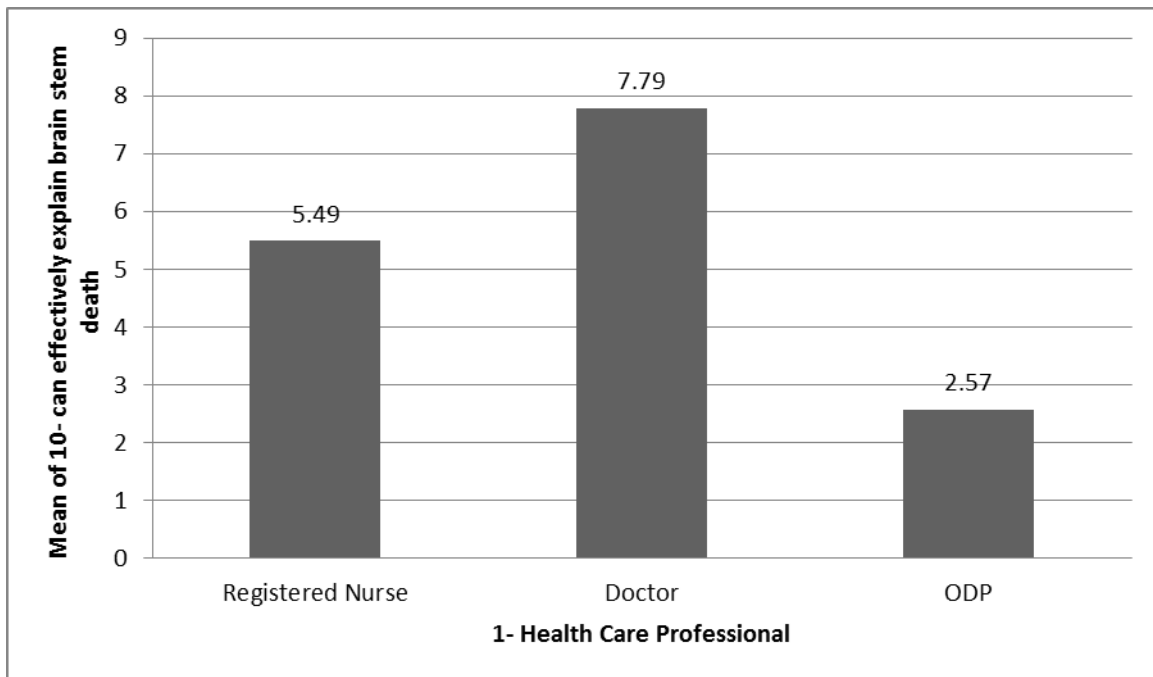


Fig. 4.5: Breakdown of HCP and their perception of how effectively they can explain brain stem death to a relative

The data found that doctors (M=7.79, SD=2.618, n=313) perceived they could explain brain stem death more effectively than nurses (nurses M=5.49, SD=3.301, n=786) or ODPs (M=2.57, SD=2.526, n=81; ANOVA between groups test $p < 0.001$) Correlation established the more senior the doctor or nurse the more effectively they believed they could explain BSD (doctors, $\rho = .226$, $p = 0.00$, $n = 308$ and nurses, $\rho = .420$, $p = 0.00$,

n=735 Spearman's correlation). This result demonstrates that the level of experience and seniority influences staffs' perception and confidence on how effectively they believe they can explain BSD to a relative. The smaller sample size of ODPs meant that statistical correlation was not possible.

The overall mean score of 5.49 for whether a HCP feels they can effectively explain BSD to a relative indicates a deficit in HCPs knowledge and confidence in explaining BSD. This knowledge deficit in understanding and explaining BSD has been found in similar studies that have used different methodological approaches compared to this study but also support the findings. Rachmani (1999) Israeli study found that doctors (n=59) and nurses (n=93) had a low understanding of BSD however their study found similar differences in confidence and knowledge of BSD in both doctors and nurses. This study involving an English sample of HCPs found that doctors were statistically more confident in explaining BSD to a relative compared to nurses and ODPs. This lack of knowledge and understanding of BSD is also supported in earlier overseas research by Bogh and Madsen (2005); Kim *et al* (2006) and Melo *et al* (2011).

It needs to be acknowledged that when dealing with a potential donor patient, NICE (2011) advise the early involvement of the SNOD who will assist in expert discussions with the family concerning the diagnosis of death and donation. However, NICE (2011) do state that all HCPs need to be aware of the diagnosis of BSD and how to communicate this effectively to relatives. There is clear evidence that in order to maximise the chances of obtaining donation consent from a family, the concept of BSD (NICE 2011) needs to be effectively explained. Due to the traumatic circumstances involved, this process of explanation may need to be repeated a number of times for families to fully understand and accept the concept of BSD. It is clear that all HCPs need to have the underlying knowledge and confidence to effectively explain BSD to relatives to enable them to make

informed decisions about donation. However, the literature shows that if relatives have not been effectively explained BSD they are less likely to give consent and valuable organs maybe lost which could have be used for life saving transplants (NICE 2011).

The results support the literature in that HCPs perceive that they do not have the knowledge and confidence to explain BSD to relatives (Bogh and Madsen 2005; Kim *et al* 2006 and Melo *et al* 2011). An emerging and recurrent theme in this study is the influence of the level of experience the HCP has in terms of ability the staff member has to explain BSD to relatives. This again relates to Eraut's (1998; 2000; 2003 and 2007) theories of situational learning and the development of professional expertise. This recurring theme between the relationship between experience of the HCP and their knowledge and understanding of donation can also be related to Dreyfus' model of skill acquisition (Dreyfus and Dreyfus 1980 and 1986). The Dreyfus (1980) model emphasises the relationship between perception and decision making rather than routinised actions. They define skills as an integrative overarching approach to professional action, which incorporates theory, routines, situational learning and decision making whilst maintaining "skilled behaviour" (Dreyfus 1980). This situational development of tacit knowledge from Dreyfus (1980) five stage model of skill acquisition ranging from novice to expert provides a theoretical perspective to this study's findings.

The theme emerging from the data already established within this study shows that the more experience the HCP has within critical care, the more knowledge, participation and confidence they have towards donation. It could be argued that the development of medical and nursing expertise requires both the use of formal theoretical learning but also the exposure of situational learning to develop intuition and tacit knowledge which can be combined together to develop professional expertise and decision making (Eraut 2000). Therefore, it appears that theoretical teaching on donation is essential but so too is

situational exposure of managing the organ donation process with the two forms of learning involving theoretical and practical knowledge acquisition, both informing each other. There is no debate that dealing with recently bereaved relatives as well as the organ donation process, is one of the most complex and stressful situations for a HCP to manage. Using Dreyfus and Dreyfus (1980 and 1986) and Eraut's (2000) theories of situational learning, critical reflection and intuitive tacit understanding of past experiences as well as learned theory provides HCPs with a continuum of skill acquisition ranging from novice to expert. Relating Dreyfus (1980) model of skill acquisition to this study, it appears that the F1 junior doctors and band 4 and 5 nurses and ODPs are at a novice level 1 stage of skill acquisition compared to senior nurses and consultants who have developed situational exposure along their careers which has allowed them to gain skill acquisition along this continuum to perhaps reaching level 4 or 5 at a proficient or expert level.

The data further revealed a correlation between explaining BSD to a relative and the influence of whether a HCP had received donation CPD. **There is a significant statistical relationship at the $p < 0.001$ level that if the HCP received CPD education they felt more effective at explaining BSD to relatives (mean score for yes $M=6.95$, $SD=3.019$, $n=632$, no $M=4.46$, $SD=3.272$, $n=416$ and unsure $M=4.67$, $SD=3.317$ $n=60$). This shows that education is an influencing factor upon confidence and knowledge when communicating to relatives at a time of distress (Figure 4.6).**

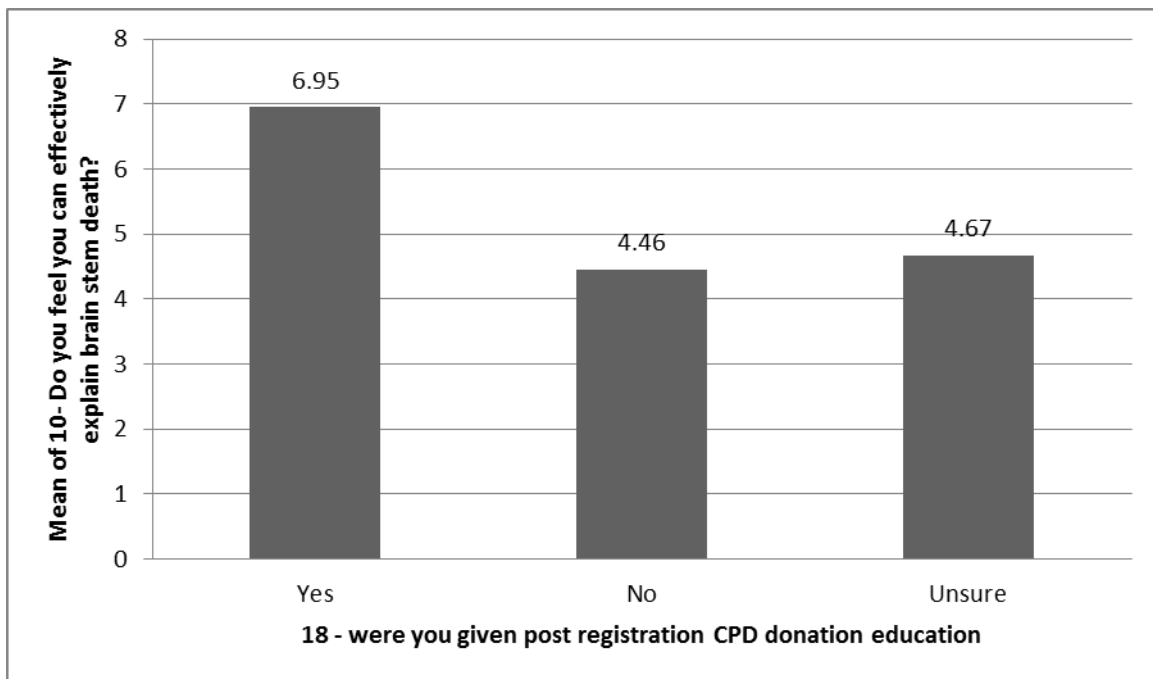


Fig. 4.6: Relationship between whether a HCP had received CPD donation education and their perception of whether they believed they could more effectively explain BSD to a relative ($p < 0.001$).

This concurs with previous results that found the more educationally prepared the HCP is, the more likely they are to participate in tissue donation. These findings support the argument that education plays a pivotal role in improving knowledge and confidence when communicating with bereaved relatives regarding donation. The theme emerging in this study is there are overall deficits in HCPs' knowledge relating to donation but education significantly influences understanding and confidence with donation issues. The results reveal that if a HCP has not received education they are less likely to participate in tissue donation and cannot effectively explain BSD to a relative. Therefore, education plays an influencing factor on developing knowledge of HCPs to enable them to identify and manage the donation process which concurs with Melo *et al* (2011) Portuguese research. This argument is further strengthened by Spanish studies by Manyalich *et al* (2010) and Lopez-Montesinos *et al* (2010) who found that after implementing an education programme for nurses that their perceived knowledge and confidence improved. These findings have identified a clear correlation that education and training enhances HCPs'

knowledge, understanding and confidence when managing and communicating in the donation process and supports these Spanish studies. This also concurs with studies by Roels *et al* (2010) and Melo *et al* (2011) who found similar knowledge deficits as revealed in this study results and that those professionals who had received donation education were more positive towards donation, had more understanding of donation theory and were more likely to participate in donation care. This study has established these links which do correlate to other research undertaken outside of the UK.

4.17) HCP's knowledge and education on the differences in management of DBD and DCD donation

The sample were asked (using a Likert scale of 0 -10, 10 being the most positive) to assess their level of knowledge relating to the differences in clinical management of a DBD and a DCD donor patient. Comparisons between different hospital departments and professions were then compared to the survey question (see Figure 4.7).

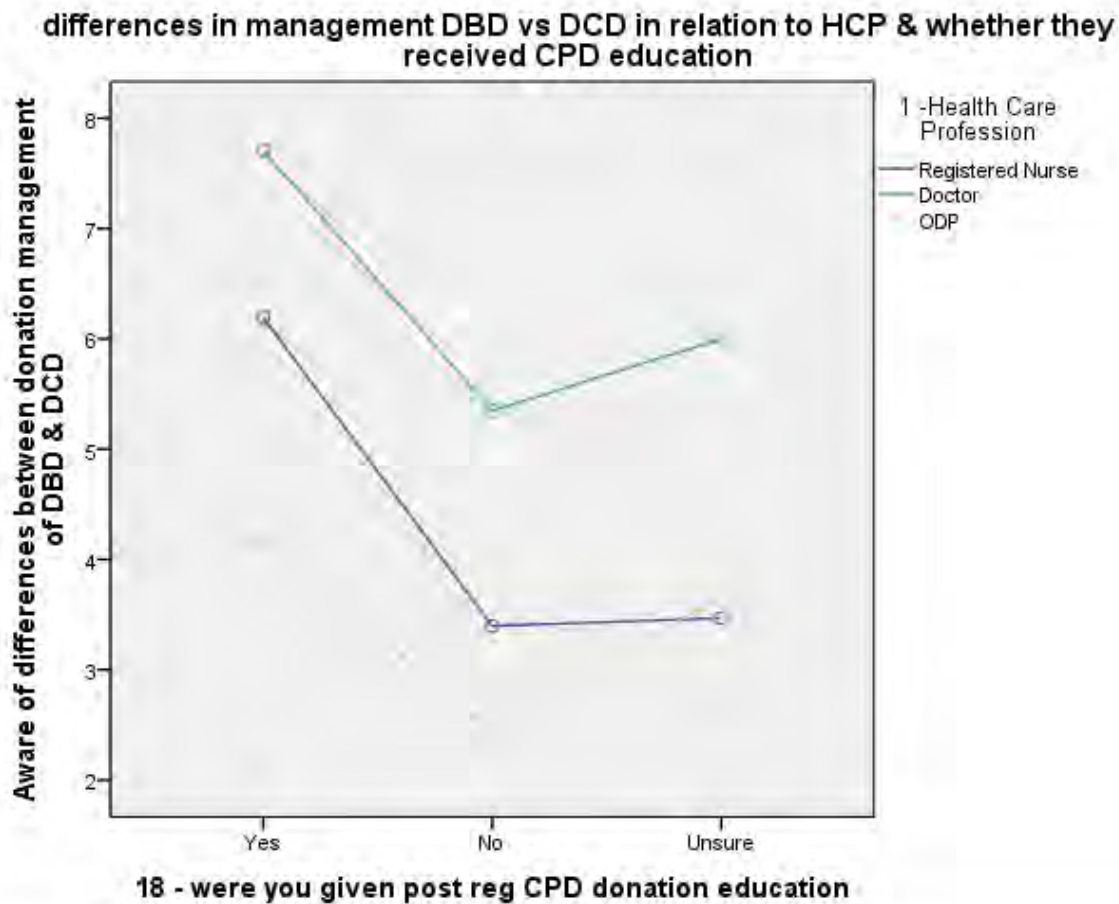


Fig. 4.7: Breakdown of HCP analysing if CPD education influenced HCPs knowledge on the differences in management between DBD and DCD donation.

This study found that CPD education increases HCPs knowledge of the differences in clinical management between donation following DBD and donation following DCD (Figure 4.7). Statistical difference (ANOVA test $p < 0.001$) found that doctors ($M=6.89$, $SD=3.346$, $n=307$) are more aware of the differences in DBD and DCD clinical management compared to nurses ($M=5.01$, $SD=3.346$, $n=768$) and then ODPs ($M=2.93$, $SD=2.668$, $n=75$). The overall mean score was 5.38 across the three health professions which identifies that HCPs lack knowledge and understanding between the two donation retrieval techniques. A direct correlation was established between the more senior the doctor or nurse the more effective they were aware of knowing the differences in

management between a DBD versus a DCD donor (Spearman's correlation test). This was more significant with doctors ($\rho=.362$, $p=0.00$, $n=307$) establishing a medium correlation compared to nurses ($\rho=.194$, $p=0.00$, $n=768$) revealing a small correlation, this again demonstrates that the level of experience and seniority influences staffs awareness of the differences in management between DBD versus DCD. Due to the smaller sample size of ODPs statistical correlation was not possible. This reaffirms the theoretical theories of Eraut (2000) and Dreyfus and Dreyfus (1980 and 1986) on how HCPs gain professional knowledge and competence from situational exposure within the workplace.

A further theme developing is that doctors appear to have more knowledge relating to donation compared to nurses and ODPs. This was established by the results revealing that doctors achieved consistently higher Likert means than the other two professions which demonstrates that doctors have more knowledge of the contraindications to tissue and organ donation, knowledge of BSD and the differences between DCD and DBD donation. In relating this study theme to contemporary literature there is variation in donation knowledge amongst doctors and nurses. Roels *et al* (2010) large international study found that doctors had more knowledge in aspects of donation compared to nurses and this was further supported by Akgun *et al* (2003) Turkish study. However, Melo *et al* (2011) large multi-site questionnaire study contradicted this and found that there was no difference in donation knowledge between doctors and nurses in their sample. The results from this study concur with Roels *et al* (2010) and Akgun *et al* (2003) overseas findings that doctors demonstrate more knowledge relating to donation compared to nurses. No study was found that correlated the experience and seniority of the health profession to knowledge acquisition as revealed in this study's results and which compared knowledge against ODPs an aspect which contributes to the originality to this study.

4.18) Research question 1c

RQ1c: What is the attitude of these acute health care professionals towards organ and tissue donation?

4.19) RQ1c Overview of findings

The findings established that participants had an overall positive attitude towards donation perceiving that organ donation provides benefits to patient outcomes. Statistical analysis revealed no difference in attitude between the three professions. Correlations were established that the more senior the doctor the more likely they are to have a positive attitude towards donation. This was not evident with nurses, as no correlation was found between seniority of nurses influencing the attitude of the practitioner. Results revealed no statistical difference in attitude if the HCP worked in a transplant or non-transplant hospital. Quantitative data found that 78.2% (n=910) of participants would recommend a family member to join the organ donation register (ODR) where as 17.1% (n=199) were unsure and 4.6% (n=54) would not recommend this. No statistical difference was found between the three health professions.

RQ1c- Results

4.20) Health care professionals perceived attitude towards donation:

The survey assessed the samples attitude towards donation by asking the HCP from a Likert scale of 0 -10 (10 being the most positive) to assess whether they felt organ donation is positive and produces benefits to patient outcomes (Figure 4.8). This then allowed the author to compare attitude across three professions and the different critical care departments involved in the sample in order to determine if any themes were evident.

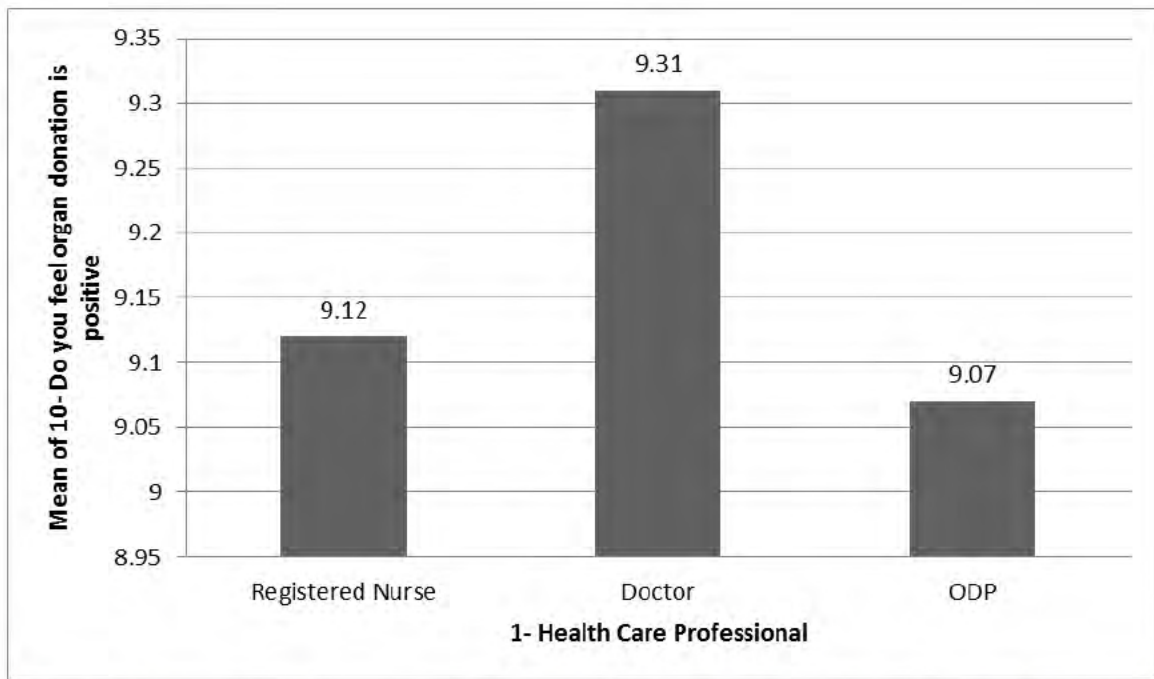


Fig. 4.8: Comparison between HCP and the perception on whether organ donation is positive and produces benefits to patient outcomes

Table 4.7: Breakdown of HCP on whether they feel organ donation is positive and produces benefits to patient outcomes.

Do you feel organ donation is positive & produce benefits to outcomes?

	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
					Registered Nurse	777		
Doctor	311	9.31	1.265	.072	9.16	9.45	3	10
ODP	81	9.07	1.603	.178	8.72	9.43	1	10
Total n=1169	1169	9.16	1.459	.043	9.08	9.25	0	10

An ANOVA test revealed that doctors were marginally more positive in attitude towards donation, with a mean score of 9.31 (SD=1.265, n=311), with nurses having a mean score of 9.12 (SD=1.513, n=777) and ODPs a mean of 9.07 (SD=1.459, n=81, table 4.7). However, this was not statistically significant (p=0.093) with no correlation between the three health professions. The focus group established that the sample had a positive attitude towards donation but this sample was biased to only nurses.

Despite the results finding a marginally more supportive attitude towards donation from the medical profession this was not statistically significant. This finding was in opposition to those presented by Demir *et al* (2011) who found that their sample (n=309) was supportive of donation but this was statistically more significant with doctors compared to nurses. With 95% of doctors and 81% of nurses declaring that donation was positive. Bogh and Madsen (2005) survey (n=689) involving doctors and nurses in Denmark found similar results in that doctors were more positive towards donation compared to nurses. Akgun *et al* (2003) concurred that doctors were more positive towards donation as compared to nurses. The results of this study failed to establish a significant difference in attitude in HCPs which oppose previous overseas research by Demir *et al* (2011), Bogh and Madsen (2005) and Akgun *et al* (2003) that found doctors were more positive towards donation compared to nurses.

A previous study by Cantwell and Clifford (2000) of English nursing and medical students' attitudes towards organ donation found the opposite, that nursing students were more positive towards donation and transplantation compared to medical students. However, this involved pre-registration students from a single university who had not gained situational experience and were not registered practitioners. This makes it difficult to extrapolate these findings directly to this study due to the differences in sampling techniques. From analysing the literature there appears to be no study comparing three HCPs attitude, education and knowledge towards organ donation. Therefore, this study has assured that generally HCPs believe that donation is positive and provides benefits to patient outcomes with no statistical difference between the three health professions that are involved in donation within this English sample. Studies from other countries have found a more favourable outcome in doctors compared to nurses but did not compare three separate health professions.

A direct correlation suggesting that the more senior the doctor the more positive they were towards donation, illustrates Eraut's (2000) and Dreyfus' (1980) model of skill acquisition and development of tacit and situational learning with clinical exposure to donation which appears to generate a more positive attitude towards donation (Spearman's test finding correlation $\rho=+0.24$, $n=308$, $p=0.030$). With the most junior doctor F1 having a mean positive score of 8.89 ($n=9$, $SD=1.537$) increasing across the continuum with consultants having a mean score of 9.45 ($n=150$, $SD=1.078$). This establishes a beneficial result in terms of clinical leadership, as consultants are the most senior doctors in a clinical team and are ultimately responsible for medical decision making. The data found that the consultants' mean positive attitude score was 9.45. This is an important aspect since this study found that consultants hold the most positive attitude towards donation and are influential since they take the lead in relation to junior doctors' education and decision-making. This will potentially influence the views of donation amongst the clinical team and provide a culture of role modelling "tomorrows" doctors that donation is positive. However, there was no statistical correlation when comparing this to nurses (Spearman's test, $\rho=+0.038$, $n=777$, $p=0.268$). This correlation shows no relationship between the more senior the nurse is the more positive they are towards organ donation.

This study also evaluated whether there was a difference in attitude if the HCP worked in a transplant hospital compared to a non-transplant hospital. Collins (2005) suggests a limitation of their study is that it was a convenience sample taken from one hospital and if the sample involved nurses from a transplant centre this may have produced a more favourable attitude towards donation as these staff see the benefits of transplantation compared to non-transplant centres. Alternatively it could be argued that HCPs working in transplant hospitals would also see the negative effects of transplantation rejection compared to those who do not work in a transplant centre. Due to this debate the author compared attitude of HCPs working in both transplant ($n=458$) and non-transplant

hospitals (n=699) using an ANOVA test. **The results revealed no statistical difference between the two groups (p=0.804) with staff working in a transplant hospital having a mean score of 9.18 (SD=1.368) and staff not working in a transplant centre mean score of 9.16 (SD=1.508). This provides an original contribution to knowledge as there appears to be no research that investigates these relationships within the UK and the result can answer the limitation that was highlighted in Collins (2005) convenience sample.**

The focus group revealed the potential impact that a HCPs personal attitude and beliefs may have on the donation process. Discussion took place relating to how a HCPs attitude and personal beliefs towards donation may have an impact upon a HCPs participation in communicating to bereaved families and the involvement in the donation process. This involved one nurse stating,

“You might be personally for it or against it but is it OK to decide whether to enforce that view on the relatives of the patient involved?” (Nurse 7).

Reviewing the focus group and questionnaires found there was no direct evidence that a HCP was imposing their views onto potential relatives however, there is published literature and the results from this study, that find that if a HCP is more positive towards donation they are more likely to participate in donation care, therefore producing a direct link between attitude and decision making in relation to donation (Ingram *et al*, 2002; Akgun *et al*, 2003 and Roels *et al* 2010). There was universal acceptance within the focus group that personal beliefs of the HCP should not interfere with clinical management of a potential donor and communicating to relatives. HCPs are bound by professional regulations which state they should be non-judgemental in their care and respect the beliefs and viewpoints of patients in their care (GMC 2006; NMC 2008 and HCPC 2012). This viewpoint was made by the group, that professionals were bound by this code and

regardless of the practitioners personal beliefs they should be providing the opportunity for donation.

One nurse commented,

“I think you should put your personal beliefs aside..... donation has got to be the families choice so I think personal beliefs [of the HCP] should be pushed to one side” (Nurse 7).

The philosophy of what the patient would have wanted with regards to donation is pivotal and by asking the family, these wishes would hopefully become apparent. The sample agreed that despite some HCPs finding it difficult to accept that they may not personally want to be a donor, it was not for the HCP to avoid participating in donation care as ultimately it's about the patients' and relatives' choice and not that of the practitioner.

4.21) Relationship between HCP and the organ donor register

Data revealed that 78.2% (n=910) of respondents would recommend a family member to join the ODR, with 4.6% (n=54) stating they would not recommend a family member to join and 17.1% (n=199) being unsure (table 4.8). A Chi-square test revealed no statistical difference between the three HCPs ($p \Rightarrow 0.152$).

Table 4.8: Cross tabulation of the relationship between HCP and whether they would recommend to a family member or friend to join the organ donor register (ODR)

			11. Recommend family member to join ODR			Total
			Yes	No	Unsure	
Health Care Profession	Registered Nurse	Count	595	32	147	774
		% within -Health Care Profession	76.9%	4.1%	19.0%	100.0%
	Doctor	Count	250	17	41	308
		% within -Health Care Profession	81.2%	5.5%	13.3%	100.0%
	ODP	Count	65	5	11	81
		% within -Health Care Profession	80.2%	6.2%	13.6%	100.0%
Total n=1163		Count	910	54	199	1163
		% within -Health Care Profession	78.2%	4.6%	17.1%	100.0%

The literature found diverse attitudes and willingness on behalf of HCPs' beliefs or that of recommending a family member to be a potential donor. This could be due to studies being undertaken in different countries which all have their own cultures, beliefs and different health care systems which would all have an impact upon influencing the HCPs attitude towards this. Demir *et al* (2011) found that 90% of their sample (n=309) supported transplantation and an impressive 77% of the sample had an organ donor card with doctors being more positive and showing intention for donation. This corresponds similarly to the results in this study with 78.2% recommending a family member to join the ODR with donation intention.

An earlier Turkish study by Goz *et al* (2006) involving pre-registration medical and nursing students (n=651) found that 65.5% were willing to donate an organ with 25.5% unsure and 9% not willing with no differences between the nursing and medical students. In relation to

this study with results finding that 78.2% would recommend joining the ODR it appears that the sample in Goz *et al* (2006) were less favourable towards donation compared to the participants in this study. Goz *et al* (2006) sample involved pre-registration students so this did not involve them gaining situational experience in donation as advocated by Eraut (2000) and Dreyfus (1980 and 1986) theories which may account for the lower positivity to donate organs compared to Demir *et al* (2011) and this study's post registration sample.

Findings from this study found no difference between HCP in whether they would recommend a family member to join the ODR or not, however previous overseas research oppose this result. Bogh and Madsen (2005) who found that 70% of doctors compared to 45% of Danish nurses in their sample (n=689) would donate their organs. Akgun *et al* (2003) Turkish study concurs that doctors were statistically more likely to show willingness to donate their organs compared to nurses. This concurs with Bogh and Madson (2005) and Akgun *et al* (2003) studies finding that nurses were less likely to show willingness to donate organs and were more negative to donation compared to doctors. However, the statistical results in this study revealed no difference between the three health professions in terms of them recommending a relative to join the ODR and personal attitude towards donation which is in opposition to these overseas studies.

The difference in overseas culture and health care systems makes it difficult to draw comparisons between this study's results revealing attitudes towards joining or recommending being on the ODR however it does provide an interesting comparison. Within the UK, no research has been found analysing attitude towards donation comparing three HCPs, this is one concept of how this research provides originality. An early study by Cantwell and Clifford (2000) focusing upon nursing and medical students in one university found that nursing students were more positive towards donation compared to

medical students. They concluded that student nurses were significantly more positive compared to medical students and were more likely to show willingness to donate their organs. In contrast to this study's results establishing no statistical difference in both attitude towards donation or willingness to recommend donation amongst the three professions.

Sque *et al's* (2000) survey of UK nurses assessing their attitudes towards donation found similar results established in this study. Sque *et al* (2000) found that 78% of nurses were positive towards donation with only 10% being opposed (n=1333). Sque *et al's* (2000) study involved nurses sampled from staff working in the ward environment where they would not be exposed to solid organ donation, it is evident that Sque *et al* (2000) supports this study in terms of nurses' displaying positive personal attitude and willingness to join the ODR.

This similar positive attitude towards donation was found in Davies *et al's* (2002) sample of doctors and nurses which also included 3rd year medical and nursing students in that 40.7% (n=118) had registered on the ODR with 97% (n=281) of the sample (n=290) agreeing with donation. They also found that there was no difference between attitude towards donation within both professions and their students. Despite differences in methodology and sampling it appears that the results found in this study support previous research undertaken in the UK over a decade ago that found that HCPs had a positive approach to donation but found no statistical difference between the three HCPs in terms of their willingness to recommend a family member to join the ODR or their personal attitude.

4.22) Research question 2

Research Question 2: How does the education received by the groups determine the decision making and management of the organ donation process:

4.23) RQ2 Overview of findings

The focus group data revealed that nurses are more likely to change their behaviour and discuss tissue donation options routinely following a study event that has involved relatives discussing the benefits they have gained from giving donation consent. The focus group established deficits in knowledge relating to tissue donation due to limited education and training opportunities with lack of awareness found to be the main obstacle to why tissue donation does not occur as part of routine end of life care. Quantitative results found a direct relationship between practitioners who had been given donation education perceived they were more effective at explaining brain stem death to relatives compared those with no donation education. Statistical analysis shows that HCPs who had been given donation education were more likely to participate in tissue donation and approach families for consent compared to those who had received no education ($p=0.001$, $n=1122$).

RQ2 Results

4.24) Education received and its impact on decision making and management of the donation process

Evidence from the focus group established that education is significant in nurses' decision making and management of the donation process. As previously highlighted in RQ1, nurse 8 stated how her involvement in donation changed following undertaking a study day whereby a bereaved relative discussed their experience of feeling "cheated" by not being approached for donation. Nurse 8 explained that by attending this study event and reflecting upon the discussions from the relatives and transplant patients that this made the nurse challenge their practice which now involves her discussing tissue donation options routinely with bereaved relatives. Nurse 8 revealed that this change in practice

was influenced directly by the education received on this study event. This relationship between education and decision making within the clinical context concurs with Sque *et al* (2000); Collins (2005); Kim *et al* (2006); Roels *et al* (2010) and Lin *et al* (2010) who found that HCPs provided with education, staff support and had higher levels of knowledge are associated with more participation in caring for donors and have more confidence with donor and relative management. This also concurs with the quantitative findings from this study which found that practitioners who had been given donation education were more likely to participate in tissue donation and approach families for consent compared to those who had received no education ($p=0.001$, $n=1122$). The quantitative results also established a direct relationship between practitioners who had been given donation education perceived they were more effective at explaining brain stem death to relatives compared those with no donation education ($p=0.001$). Therefore, quantitative data concurs with the qualitative data in this study that education informs decision-making of practitioners within the donation process.

The significance of how education influences decision making in donation is further established by discussions from nurse 2 and nurse 3 who stated that prior to having education they did not participate in donation care as they were simply just unaware.

“I received no education previouslya year and half I worked on the wards and there was not one person referred [for donation]..... this was due to lack of education and awareness” (Nurse 3).

There was universal agreement within the focus group that education was pivotal to raising confidence and knowledge of HCPs to enable them to use appropriate decision making to identify, refer and manage a tissue donor patient. The sample was in agreement that there were especially deficits in knowledge relating to tissue donation due to limited education and training opportunities and this was the main obstacle to why tissue donation does not occur as part of routine end of life care.

When the sample was asked the reasons why tissue donation is not frequently being undertaken as part of end of life care, the data revealed that;

“No awareness due to lack of education..... there needs to be training to ward managers who lead their teams as well as all staff” (Nurse 6).

The focus groups established that education and training was lacking particularly with tissue donation with participants stating this was the reason why it has not been adopted into routine decision-making for approaching bereaved families at the time of a patient's death. This also concurs with the quantitative results from this study that established a direct link showing that the more education that a HCP receives relating to donation, the more tissue donation the practitioner will participate in. This supports the literature that found the more knowledge the practitioner has on donation the more positive their attitude is and the more likely they were to participate in donation decision making and management (Kiberd *et al* 1998; Sque *et al* 2000; Erdogan *et al* 2002 and Roels *et al* 2010).

4.25) RQ2b: What is the nature and extent of pre-registration education received by these professions in relation to organ and tissue donation?

4.26) RQ2b Overview of findings

The results revealed that 61% (n=712) of participants had received no donation training as a pre-registration student, 15.5% (n=178) unsure and 23.7% (n=277) had received training as a student. There was no statistical difference between doctors and nurses receiving pre-registration donation education. The results established that pre-registration education should give an awareness of donation especially tissue donation to establish the culture of this being routine for end of life decision making.

Findings from participants who had received pre-registration education as a student, showed that this was delivered using a variety of teaching methods including seminars, problem-based learning and personal reading with the most common teaching method involving a lecture in 51.7% of the sample. Of the participants who had received pre-registration education, 62.5% (n=190) could not recall how many hours were dedicated to donation training where as a further 29.9% (n=91) stating donation training consisted of 1-2 hours. The results found that only limited time was allocated to donation during pre-registration. The data revealed that HCPs perceived that pre-registration education did not effectively prepare them for managing and identifying both organ and tissue donors. Statistically doctors perceived their pre-registration education prepared them more effectively to manage organ and tissue donors compared to nurses or ODPs. Focus group findings established that none of the sample had been provided with donation education as a student. However, the group highlighted the importance of having an awareness of donation issues especially tissue donation which could allow further development of knowledge as part of CPD but would allow the notion of donation being viewed as part of usual end of life care for students.

4.27) RQ2b Results

Data found that 61% (n=712) had received no donation education in their pre-registration programme with a further 15.3% (n=178) stating they were unsure and 23.7% (n=277) who had received pre-registration education (table 4.9). This was also evident in the focus group as none of the eight nurses had received any pre-registration education relating to donation. On statistical analysis there was no difference between doctors and nurses showing equal distribution amongst these professions who had received training to those who had not. The sample for ODPs was too small to correlate between the doctors and nurses.

Table 4.9: Cross tabulation of health care professionals who received education in organ and tissue donation within initial pre-registration training.

			Were you given education on donation in pre-reg training?			Total
			Yes	No	Unsure	
Registered Nurse	Count		188	469	121	778
	% within Health Care Profession		24.2%	60.3%	15.6%	100.0%
Health Care Profession Doctor	Count		71	186	52	309
	% within Health Care Profession		23.0%	60.2%	16.8%	100.0%
ODP	Count		18	57	5	80
	% within Health Care Profession		22.5%	71.2%	6.2%	100.0%
Total (n=1167)	Count		277	712	178	1167
	% within Health Care Profession		23.7%	61.0%	15.3%	100.0%

The results revealed that the majority of HCPs received no education relating to donation at a pre-registration level. With a significant number of patients who die being eligible for tissue donation and with the transplant waiting list not keeping up with demand, it seems no wonder why bereaved relatives and patients are not being given the option of donation if no awareness of this is delivered in pre-registration curriculums. From reviewing the literature, there appears to be no study evaluating quantitatively the numbers of HCPs who have undertaken any donation training at a pre-registration level further supporting the originality of this study.

The focus group revealed a mixed viewpoint on the impact of pre-registration training in relation to donation. It was evident that some of the sample believed that pre-registration education was important where another nurse declared that education at this stage of their career would not have personally helped them. This created diversity and debate amongst the sample, however it was established that education at pre-registration level

needed to focus on promoting donation and transplantation awareness predominantly on tissue donation as this is applicable to a large proportion of patients that die.

One nurse agreed that;

“pre-registration students need to have an awareness as part of palliative care and the care of the dying” (Nurse 2).

There were discussions that the level of knowledge required at pre-registration did not need to be as in-depth compared to that required by registered HCPs working in critical care areas which would be expected as this knowledge could be developed as part of CPD upon qualification. The sample were all biased to nurses and if there were doctors or ODPs within the focus group then this may have provided different discussions on what they perceived they required in terms of level of knowledge and education at pre-registration.

One nurse commented that;

“pre-registration training wouldn't have helped me to approach [for tissue donation] but may have helped me to identify patients.....and then make a referral to someone more senior” (Nurse 2).

A similar statement was endorsed by nurse 6. This data suggests that pre-registration would not provide all the education necessary to prepare a practitioner to undertake donation but would provide an initial awareness which could be further developed. The concepts of Eraut (2006) could be applied to how pre-registration students develop tacit knowledge within the workplace. In relation to Eraut's (2006) theories of tacit knowledge development, pre-registration students would need to be provided with initial education on donation which could be provided within a formal education setting but it would be with situational learning through witnessing more experienced practitioners undertaking the role of identifying and approaching tissue donors, that experiential knowledge of undertaking this role would be developed. These opportunities of observing experienced staff doing this role would support underlying education awareness and provide previous situational

learning that the student can reflect upon through tacit knowledge development (Eraut 2006).

The results support the view that pre-registration students need to be provided with an awareness of donation that is seen as part of the culture whereby tissue donation in particular is part of routine end of life care. This supports earlier work by Zampieron *et al* (2010); Martinez-Alarcon *et al* (2009); Mekahli *et al* (2009); Goz *et al* (2006); Cantwell and Clifford (2000) and Randhawa (1998) who found knowledge deficits in their student samples and all recommend that pre-registration students should be provided with donation education on their university curricula. This study found that 61% of the sample received no pre-registration education on donation. Initial student health professional education provides the building blocks for the students professional journey and by having donation included in the curriculum will provide the ideology to future healthcare professionals that donation is routine for end of life care and is not viewed as occasional option. The message of raising awareness of the option of donation needs to be embraced by students otherwise embedding a culture of donation for end of life care will never be fully adopted and the transplant waiting list for organs and tissues will continue to outstrip supply.

4.28) Pre-registration education delivery methods and allocated time in curriculum

Those HCPs who had received pre-registration education were asked to identify how this education was delivered to them. The most common method of delivery was the use of a lecture in 51.7% (n=223). There was a variety of teaching methods involving the more formal such as a lecture to personal reading and problem based learning (table 4.10). There was no statistical difference when comparing the three health professions to which teaching delivering method was used. Unfortunately, no qualitative analysis of pre-

registration teaching methods could be evaluated from the interviews as none of the eight nurses present received any donation education as a student.

Table 4.10: Teaching strategy used to deliver pre-registration education relating to donation

How was education delivered	Number of HCPs who received pre-registration education	% of HCP who received pre-registration education
University Lecture	223	51.7%
Seminar	46	10.6%
Group work	25	5.8%
Directed study	16	3.7%
Personal reading	43	9.9%
Problem Based Learning (PBL)	12	2.7%
Cannot remember	66	15.3%

All HCPs who stated they were provided with pre-registration education were asked to quantify how many hours had been allocated in their initial education to donation (table 4.11). The results found that 62.5% (n=190) could not remember how many hours had been allocated however the majority of the sample 29.9% (n=91) was provided between one to two hours of education relating to donation. There was no statistical difference between the three HCPs in terms of how many hours were allocated for education.

Table 4.11: Number of hours of pre-registration education allocated to donation

How many hours of pre-registration education was allocated to donation	Number of HCPs who received pre-registration education	% of HCP who received pre-registration education
Cannot remember	190	62.5%
Less than 1 hour	4	1.3%
1 – 2 hours	91	29.9%
2 – 4 hours	9	2.9%
4 – 6 hours	5	1.6%
6 – 8 hours	3	0.9%
8 – 10 hours	2	0.6%

n= 304 however n=127 stated they received pre-registration education but did not answer n=127

Despite the focus group revealing that none of the participants had been provided with pre-registration education, the group were asked how many hours of donation education should be allocated within a pre-registration curriculum.

“This should be a morning or afternoon.....for 3 hours” (Nurse 8).

When analysing the interviews there was a clear theme with strong emphasis from participants within the group that pre-registration should provide the initial foundations of education relating to the subject and that this should be on going during the HCPs career. As stated by nurse 2.

“you need continuous support and training throughout your nursing career” (Nurse 2).

These discussions on how initial student donation education can provide fundamental knowledge which can be nurtured and built upon during the HCPs professional career is supported by Eraut's (2000 and 2004) notions of professional learning. This relates to acknowledging that HCPs are on a professional continuum or journey of gaining competence in developing skills and expertise through acquiring various types of knowledge acquired from workplace and formal learning and implementing this into practice during their career pathway (Eraut 2004). This continuum of gaining informal and formal learning is also developed through the acquisition of tacit knowledge from situational learning which combined together provides professional learning and competence for health care professionals (Eraut, 1994; 2000 and 2004) Therefore, as nurse 2 stated this could be interpreted that initial education as a student is essential but on going emphasis on donation education needs to be facilitated through learning and clinical application of this knowledge in the workplace environment as part of continuing professional development as encouraged by Eraut (2004).

There appears to be no UK multi-site investigation surveying registered HCPs on the delivery of donation education they received if any, as a student and making comparisons across three health care professions. There is some overseas literature which does allow some limited comparisons between what health care students may receive in donation education before professional registration. Essman and Thornton (2006) compared 1st year and 2nd year medical students' donor education uptake in an American medical school (n=537). They found that 22% (n=106) had received donation coursework, 19% (n=92) had read articles on donation, 8% (n=37) had cared for patients who received transplants and 15% (n=71) had participated in the care of a dying patient and their family. Their research fails to elaborate on what is defined as donation coursework and provides no details of teaching delivery or the number of hours this involved. Essman and Thornton (2006) acknowledge that their sample was provided with limited donor education and recommends all students receive education on the subject.

Two Spanish studies, from the nation that has the lowest number of patients on a transplant waiting list in Europe and which is viewed as a leading country in donation, provides evidence of education programmes that they provide for pre-registration students. Manyalich *et al* (2010) describes the PIERDUB project that aims to produce a validated university credited course which provides education for medical and health science students in the donation process and they are planning to establish the course across universities in Spain. Manyalich *et al* (2010) states that the course involves forty five hours of study but they do not provide details on any teaching strategies used to deliver the course content. A further study by Lopez-Montesinos *et al* (2010) looked at the impact of an established donation course had on 3rd year nursing students' knowledge and attitude towards donation. They compared knowledge and attitude before and after the 32 hour course was delivered to students. Lopez-Montesinos *et al* (2010) found that attitude and knowledge of their pre-registration students increased considerably following

re-surveying students following completion of the course. This course consisted of thirty two hours of study and involves a comprehensive curriculum involving criteria for donation, identification of donors, BSD, clinical management as well as communication with family members and bereavement. Lopez-Montesinos *et al* (2010) provides detailed explanations of the curriculum and hours involved but also like Manyalich *et al* (2010) provide no details of learning and teaching strategies used and assessment methods. This current study found that there appears to be no established course within England which offers such comprehensive education programmes for both pre and post registration students compared to Spain or Australia.

It appears that Spain appreciates the significance of providing pre-registration healthcare students with a comprehensive donation education programme which can embed theoretical knowledge and awareness of donation which will allow confidence for future health professionals to participate in donation and provide the final wishes of their patients and also increase the availability of transplants. This strong focus on education which is evident in Spain could be one factor that makes donation a “norm” in the Spanish healthcare system and provides Spain with the lowest transplant waiting list in Europe. This study found that the majority (61%) of HCPs received no pre-registration donation education and those that did mainly consisted of below two hours of time. The UK could make strides in addressing the transplant waiting list which involves three people dying a day whilst waiting for a life-saving transplant by policymakers evaluating health care curriculums to include teaching on aspects of donation that increases awareness of donation issues.

Despite this study finding that HCPs appear to have limited pre-registration education relating to donation, it needs to be acknowledged that the average length of registration of the sample was 14.46 years since qualification. Due to this time lapse, pre-registration

education may have evolved to include donation education especially following DH (2008) and NICE (2011) documentation. The author would recommend a further study be undertaken evaluating a number of medical and nursing schools within the UK in order to determine exactly what donation education is currently provided in higher education curricula.

4.29) Comparison to show whether pre-registration education prepared HCPs to identify and manage tissue donors

Participants who stated that they received pre-registration education were asked whether this prepared them to identify and manage tissue donors.

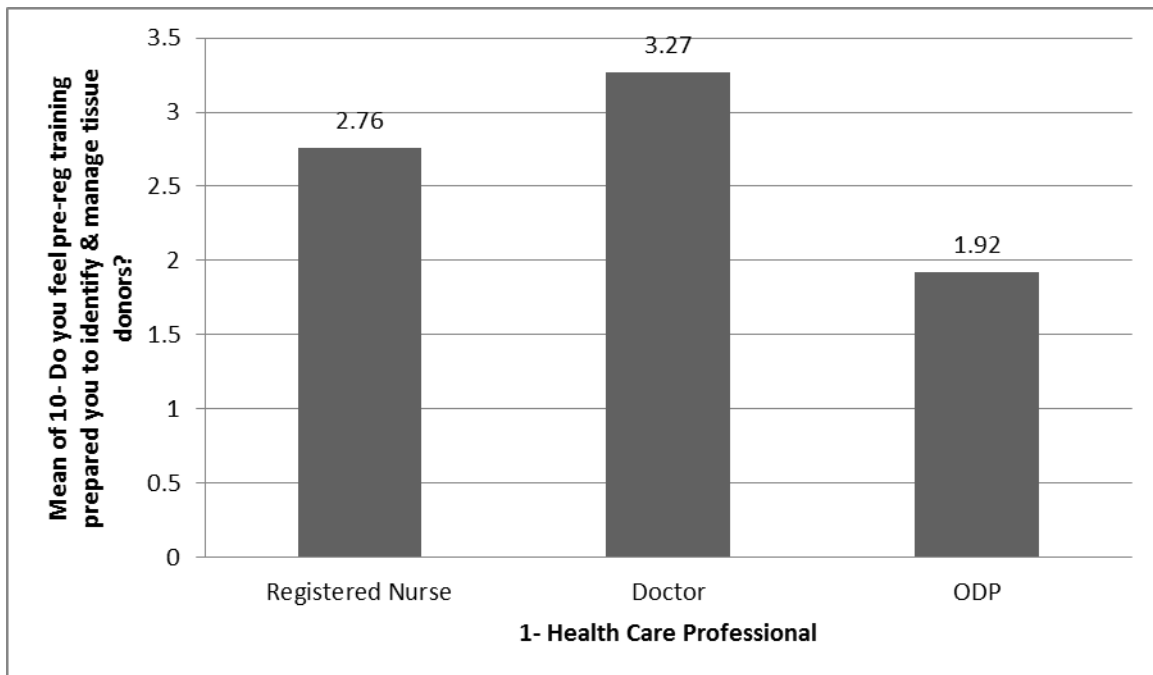


Fig. 4.9: Comparing HCP to mean Likert score (0-10) of whether pre-registration education prepared staff to identify and manage tissues donors as part of end of life care.

An ANOVA test revealed a statistical difference ($p=0.031$) that doctors ($M=3.27$, $SD=2.677$, $n=71$) perceive their initial pre-registration education compared to nurses ($M=2.76$, $SD=2.463$, $n=188$) and ODPs ($M=1.92$, $SD=2.002$, $n=18$) was more effective in identifying and managing potential tissue donors (Figure 4.9). However, with the

mean score between all three professions being extremely low at 2.84 (SD=2.517) this suggests that HCPs believe that they were not effectively educated at a pre-registration level for identifying and managing potential tissue donors as part of routine end of life care.

This confirms the previous argument that with the majority of patients who die being eligible to donate at least one of their tissues and that tissue donation is relatively unheard of in comparison to solid organ donation (Gumbley and Pearson 2006). This result suggests that HCPs feel that they have not been given enough education to provide the option of tissue donation for bereaved relatives. This also relates to the previous findings that show 80.3% of the sample have been involved in 5 or less tissue donors in their career, showing that HCPs are infrequently involved in tissue donation. The study also found correlation between those HCPs who perceived that they had been educationally prepared to manage a tissue donor that they were more likely to be involved in approaching bereaved families for tissue consent. Therefore with this finding showing that HCPs believe that their pre-registration education did not prepare them for managing a tissue donor, if this education was enhanced and delivered using a similar comprehensive curriculum as advocated in Spain by Manyalich *et al* (2010) and Lopez-Montesinos *et al* (2010) this would suggest that more HCPs would be involved in tissue donation that would increase the numbers of tissues available for transplantation.

4.30) Comparison to show whether pre-registration education prepared HCPs to identify and manage solid organ donor patients

Participants stating they received pre-registration education were asked whether this prepared them to identify and manage solid organ donor patients. This correlation would

determine if pre-registration influenced staff confidence, knowledge and decision making when managing solid organ donation.

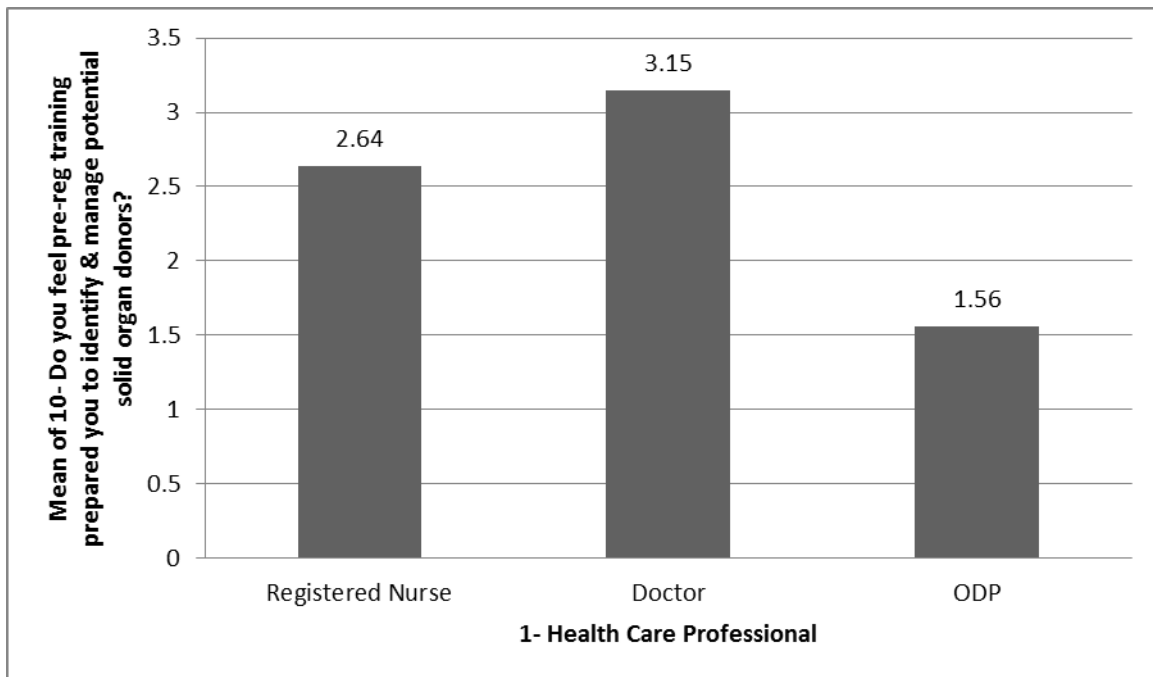


Fig. 4.10: Comparing HCP to mean Likert score (0-10) of whether pre-registration education prepared staff to identify and manage potential organ donors.

A statistical difference was established between ($p < 0.001$) doctors ($M = 3.15$, $SD = 2.693$, $n = 71$) perception of their initial pre-registration education compared with nurses ($M = 2.64$, $SD = 2.390$, $n = 188$) and ODPs ($M = 1.56$, $SD = 1.685$, $n = 18$) was more effective in identifying and managing potential solid organ donors (Figure 4.10). The results revealed low mean scores between all three professions with the overall mean of 2.71 ($SD = 2.468$) finding that HCPs strongly perceived that they were not effectively educated at a pre-registration level for identifying and managing solid organ donors. These results also concur with tissue donation in finding that pre-registration education did not prepare the HCP to identify and manage tissue and solid organ donors. The results found that pre-registration education was viewed more negatively to prepare HCPs for solid organ donation ($M = 2.71$ versus $M = 2.84$) compared to tissue donation, however this was only a marginal difference.

The results established that pre-registration education did not provide enough educational opportunities to develop health professionals, this supports previous studies undertaken that have shown that students lack knowledge and confidence in donation. Overseas studies using different methodological approaches to this study by Zampieron *et al* (2010); Kim *et al* (2006); Essman and Thornton (2006) and Goz *et al* (2006) all concur with this study that pre-registration training does not provide the building blocks of knowledge to prepare the practitioner to provide the options of tissue or organ donation as part of end of life care. These results support previous overseas research that education programmes within schools of medicine and health need to be reviewed in order to ensure that a curriculum can provide knowledge and confidence for new HCPs relating to donation care.

4.31) Research question 2c

Research question RQ2c: What is the nature and extent of post registration education received by these professions as part of their CPD in relation to organ and tissue donation?

4.32) RQ2c Overview of findings

The results revealed that overall 56.2% (n=638) of practitioners had received donation CPD compared with 38.2% (n=434) who had received no donation CPD and a further (n=64) 5.6% stating they were unsure. Statistical evaluation found that ODPs were significantly less likely to be provided with donation CPD compared to doctors or nurses. The data established that the delivery of CPD education can be sporadic with no formal national accredited learning course being provided. The results revealed that HCPs working in ITU were more likely to have received donation CPD compared to staff working in ED or OT. CPD was most likely to be delivered by the SNOD in the workplace rather than within a formal university environment. Participants were not provided with regular updates and that 44.1% of the sample had received less than two hours CPD training during their registered careers. Correlations showed that practitioners

who received CPD education perceived they were more effective at identifying and managing organ donors. Data revealed that participants perceived that post registration CPD did not effectively prepare them to identify and manage solid organ donors. Correlation found the more senior the doctor or nurse, the more positive they were that CPD education prepared them to manage solid organ donors. Qualitative data established that nurses need not only education to gain initial theory relating to donation but also workplace exposure and situational experience within the clinical environment.

4.33) RQ2c Results

In comparison to pre-registration, it was evident both within the quantitative and qualitative data analysis that HCPs are more likely to have received education on donation upon qualifying and then working in critical care. The focus group data found that all eight of the nurses had received CPD donation education. The quantitative sample revealed that 56.2% (n=638) had received donation CPD compared to 38.2% (n=434) who had received no CPD, with a further (n=64) 5.6% stating they were unsure. Doctors were more likely to have received CPD (63.2%) compared to nurses (56.8%) but this was not statistically significant. It was clearly identified that ODPs were less likely to be given donation CPD (23.1% n=18) compared to doctors and nurses. Relating these findings to Melo *et al* (2011) survey that found that 78% of their sample (n=495) of doctors and nurses working in different EDs in Portugal had received CPD education relating to donation. Interestingly, 62% of their sample stated that they felt they needed more training relating to donation education. However Melo *et al* (2011) suggest that HCPs in Portugal appear to have more CPD opportunities relating to donation compared to the sample involved in this study.

The focus groups provided an interesting contrast to the statistical results as one nurse perceived that doctors get very minimal education relating to donation compared to nurses. The focus group revealed that one nurse stated;

“I believe that doctors get very minimal education on tissue and organ donation” (Nurse 6).

However, the statistical data revealed that doctors received more CPD education compared to nurses despite this nurse’s perception that doctors were provided with minimal education. Despite this it could be argued that with 36.7% of doctors receiving no CPD education that the nurse still has a case to state that she feels that doctors need more CPD education; however it appears that this is evident across all three professions involved in this study and not just restricted to doctors.

The quantitative data established that ODPs were not provided with donation CPD upon qualification as there was no increase in the numbers of ODPs who received CPD education compared to pre-registration education. This was evident as 22.5% (n=17) of the ODP sample surveyed stated they were given pre-registration education on donation but a comparable figure of 23.1% (n=18) was found when ODPs were asked if they had received any education on donation as part of CPD following qualification. This shows that ODPs are not offered education on donation as part of their CPD despite working in an environment where donation retrievals take place and assisting on occasions with anaesthetics and surgical procedures involved in organ retrieval. There has been no research found that evaluates ODPs organ donation education which means that this cannot be evaluated against contemporary literature due to the originality of the findings.

Table 4.12: Cross tabulation of whether health care professional has received any post registration CPD education towards organ donation

			were you given post reg CPD donation education			Total
			Yes	No	Unsure	
Health Care Profession	Registered Nurse	Count	431	279	49	759
		% within Health Care Profession	56.8%	36.8%	6.5%	100.0%
	Doctor	Count	189	98	12	299
		% within Health Care Profession	63.2%	32.8%	4.0%	100.0%
	ODP	Count	18	57	3	78
		% within Health Care Profession	23.1%	73.1%	3.8%	100.0%
Total	Count	638	434	64	1136	
	% within Health Care Profession	56.2%	38.2%	5.6%	100.0%	

The results revealed that only 56.2% of participants received CPD education on donation (table 4.12). Organ donation is not a daily occurrence within critical care areas and therefore highlights further the importance of providing on-going education to raise awareness amongst staff. Ensuring regular training as part of CPD for critical care staff would also support the notion from the DH (2008), GMC (2010) and NICE (2011) that donation should be seen as usual rather than unusual in end of life care. Despite the DH (2008:16) recommending that,

“all clinical staff likely to be involved in the treatment of potential organ donors should receive mandatory training in the principles of donation. There should also be regular update training”

Only 56.2% of participants working within critical care were provided with CPD and there was no evidence of regular update training as endorsed by the DH (2008) and NICE (2011). This is concerning as the results have highlighted the significant link that

education plays by increasing staff confidence and knowledge in explaining BSD to relatives, differences between DCD and DBD management and increasing staff involvement in tissue donation. There is also confirmed links from Akgun *et al* (2003); Roels *et al* (2010) and Melo *et al* (2011) that endorse this in that education influences health professionals' participation in donation management and can increase the number of potential donors becoming available. It is proposed that provision of mandatory yearly training on donation for all clinical staff as indicated by the findings from this study, would have positive effects on the availability of organs and tissues available for transplantation.

The focus group data revealed that all participants had received CPD education whereas none of them had received pre-registration education. Participants agreed that all HCPs working within critical care should receive CPD donation education and this should be refreshed regularly to maintain awareness of the subject. It was identified that the delivery of donation CPD was very infrequent and was not formalised and all the group agreed that in order to enhance the number of organs being available it should be mandatory and given more priority. The focus group discussed how resources are limited within hospitals and that being released for education was not seen as a priority due to the immense workload that staff were being put under and that time was not being given for staff to attend non-mandatory training.

One nurse commented;

“[CPD donation education] is very adhoc..... Is not on the mandatory programme” (Nurse 8).

This provides further evidence that the DH (2008) recommendations concerning mandatory donation training are not being delivered to front-line staff. This study has clearly established that HCPs are not being provided with regular CPD training despite DH

recommendations to do so. This deficit in providing on-going CPD to HCPs may be one reason why the UK has one of the highest transplant waiting lists in Europe.

4.34) Relationship between clinical department and whether HCP received CPD donation education

With the results finding that only 56.2% of the sample had undertaken donation CPD, a statistical breakdown was performed to determine whether there was any particular clinical department who were more likely to have received donation CPD.

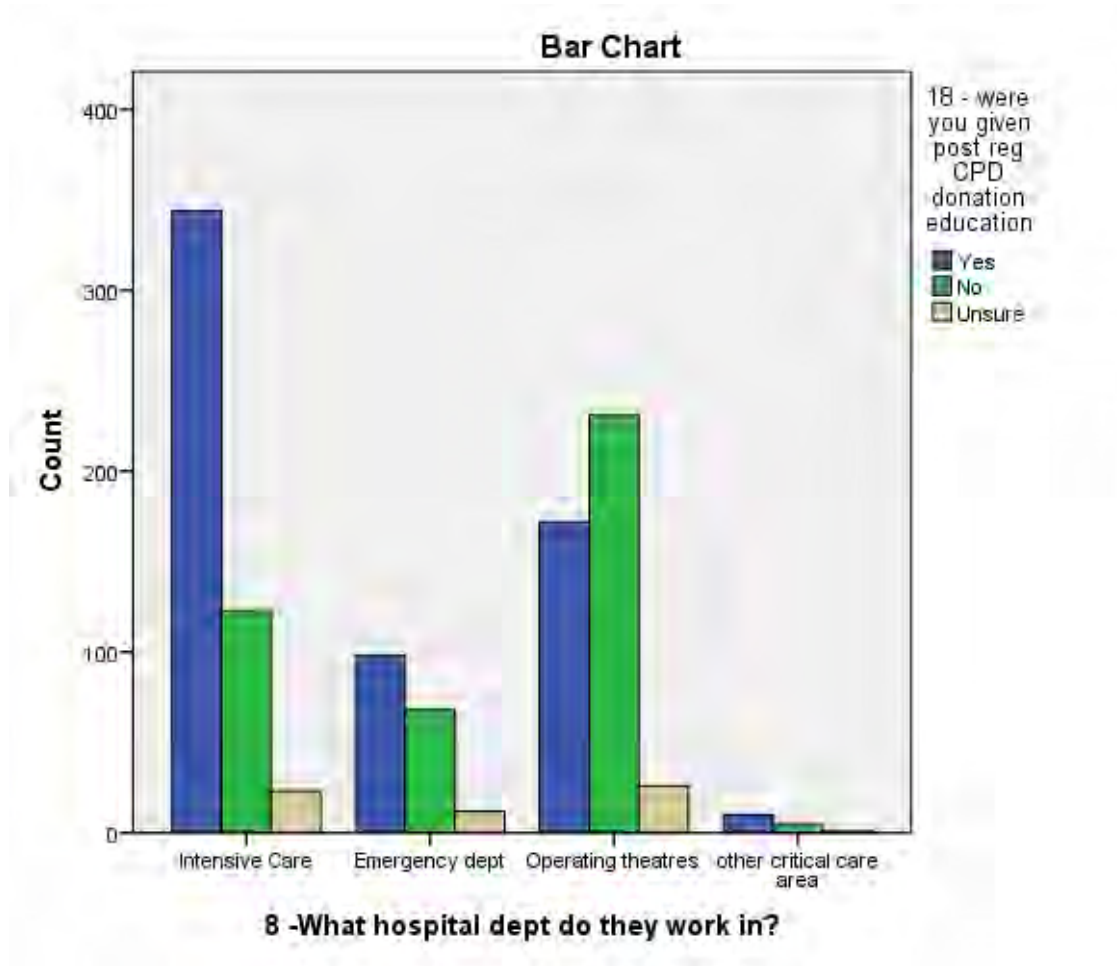


Fig. 4.11: Breakdown of clinical department and whether health care professional has received post registration CPD donation education

The results found that it was statistically significant ($p < 0.001$) if staff worked within ICU they were more likely to have received donation CPD compared to ED and OT.

The results revealed that 70.2% (n=344) of ICU staff had received CPD with 25.1% (n=123) having received no CPD and 4.7 % (n=23) being unsure. With ED staff 55.1% (n=98) had received CPD with 38.2% (n=68) had no CPD and 6.7% (n=12) unsure compared to theatres who had 40.2% (n=172) had CPD, 53.8% (n=231) had no CPD and 6.1% (n=26) unsure (Figure 4.11). All these clinical areas have the potential involvement to treat donor patients and they should be receiving CPD as stated by the DH (2008) and NICE (2011). The results established that with 55.1% of ED staff in this study having received no donation CPD this falls well below the numbers of ED practitioners in Melo *et al* (2011) research finding 78% of Portuguese ED doctors and nurses had received donation CPD. This suggests that English ED HCPs are less likely to receive donation CPD compared to Portuguese ED HCPs. This further suggests that UK HCPs receive less donation education compared to other countries (Roels *et al* 2010; Manyalich *et al* 2010 and Lopez-Montesinos *et al* 2010).

This statistical data is also supported by qualitative discussions that identified that donation is often seen only as an occurrence within ICU rather than also being possible within ED. This is despite tissue donation being an option with any potential death within a hospital or community setting. One participant commented:

“donation seems to be in a little bubble on an ICU..... but potentially every death could be a potential donor whether its cataracts [tissue donation].....education needs to be given ” (Nurse 2).

This qualitative data confirms statistical results that donation education seems to be concentrated to staff within ICU with limited focus to other clinical areas where this can occur. Whilst it is important that ICU HCPs are provided with the necessary CPD it is also imperative that all clinical areas likely to be involved in potential solid or tissue donation receive education and training to support them with this role.

The statistical results revealed that ED and theatre staff required emphasis on training with focus group discussions revealing that ICU appears to be the focus point within a hospital as to where donation takes place. This is often the case as the majority of solid organ donors come from ICU departments but there is also an increasing number of patients who can donate from EDs (NICE 2011). The results found that within all departments, staff had limited CPD with no evidence to suggest that staff received frequent update training as advocated by the DH (2008). The frequency of this updated education is not defined by the DH (2008) but as with other mandatory training for instance, health and safety and infection prevention control, this is provided on a yearly basis. The study highlights that there was no mechanism within the eighteen hospitals involved in the study to ensure that regular update training was provided to staff as advocated by the DH (2008).

4.35) Post-registration CPD education delivery methods and allocated time given for CPD

The study aimed to identify exactly what CPD learning approach was used to deliver donation education as part of HCPs' CPD. The results found the most common method of delivering donation CPD was by the SNOD giving teaching within the department (30.2%), then 24.6% having informal in-house training, 18% attending a formal donation study day, 16.5% through personal reading and then 9.8% through formal post-registration university education. This also concurred within the focus group as participants revealed that their CPD education was delivered by a SNOD either in the workplace or via a study event.

There was no statistical difference when comparing the three health professions to which CPD learning method was used. The results established that the majority of CPD education is provided by what Eraut (2000 and 2004) describes as informal learning in the workplace rather than within formal classroom settings such as universities. This informal learning involves the SNOD in the workplace and may take the form of learning in

response to recent or current situations relating to donation and perhaps during a quiet period in the clinical environment on a spontaneous opportunity rather than in a formal classroom where time has been set aside for teaching (Eraut 2004).

This was also supported by the focus group as nurse 1 stated that;

“targeting sessions using the SNOD in critical care environment as it embeds knowledge” (Nurse 1).

The results identified that the SNOD within the workplace environment is a valuable resource to providing informal learning opportunities which facilitates knowledge and situational learning as advocated by the concepts of Eraut (1994; 2000 and 2004) notions of professional learning and tacit knowledge development.

The results revealed 16.5% of CPD involved staff undertaking personal reading about donation which provides another informal learning opportunity as proposed by Eraut (2004). The findings show that there was the opportunity for more formal learning strategies involving allocated study days (18%), university education (9.8%) and conferences (0.9%). The results demonstrate that HCPs obtain limited CPD donation education (9.8%) within a formal higher education setting as part of on-going post registration CPD (table 4.13).

Table 4.13: Continuing professional development (CPD) education delivery type as part of post registration donation training.

How was CPD education delivered?	Number of HCPs who have received CPD education	% of overall CPD
Teaching from Specialist Nurse for Organ Donation (SNOD) within department	327	30.2%
Informal in-house training	267	24.6%
Formal organ donation study day	195	18%
Personal reading	179	16.5%
Post registration university education	107	9.8%
Attendance at Conference	4	0.9%
e-learning/online training	2	0.2%

The results revealed that participants who had received post registration CPD may have undertaken more than one CPD education type. For example, some staff had attended a formal study day and then further supported this learning by undertaking personal reading. Therefore, some participants had ticked more than one CPD education strategy on their questionnaire.

The results found that there was no national course or education programme available for donation and that CPD education was run in house and pre-dominantly led by hospital SNOD. This was evident in the questionnaire results and within the focus group data.

“There doesn’t seem to be any definite programme [relating to donation]” (Nurse 8).

The results found no formal education accredited curriculum for HCPs as defined by Eraut’s (1994; 2000 and 2004) concepts of formal learning through classroom delivery within a standardised curriculum with measurable learning outcomes which are academically assessed. This is in contrast to other countries such as Australia who

provide HCPs with a nationally accredited course focusing upon donation called the ADAPT course which has clearly defined learning outcomes and is delivered in hospitals throughout Australia, this is also occurs in Spain (ADAPT 2012 and Lopez-Montesinos *et al* 2010).

Following analysis of the CPD education delivery methods used in providing post-registration donor education, the study wanted to determine how many hours HCPs spent undertaking donation CPD (table 4.14). All HCPs who stated they were provided with post-registration CPD were asked to quantify how many hours they had undertaken. Data found that 24.4% (n=125) could not remember how many hours they had undertaken, with 12.5% (n=64) having spent less than one hour on the topic with the highest number (31.6% n=162) of HCPs undertaking between one to two hours and only 1.2% (n=6) spending more than ten hours of time. There was no statistical difference between the professions in terms of how many hours were allocated for education.

Table 4.14: Number of hours of CPD education undertaken by health care professionals relating to donation

How many hours of CPD education was allocated to donation	Number of HCPs who have undertaken CPD education	% of HCP who received CPD education
Cannot remember	125	24.4%
Less than 1 hour	64	12.5%
1 – 2 hours	162	31.6%
2 – 5 hours	97	18.9%
5- 10 hours	58	11.3%
More than 10 hours	6	1.2%

The findings revealed that participants were not provided with regular updates as stated by the DH (2008). With the average career of the practitioner being 14.46 years, it seems astounding that 44.1% of the sample had received less than two hours donation CPD

during an average career span of over 14 years. The results established that HCPs working in critical care are provided with minimal donation CPD which involves no regular update training, in comparison to other countries such as Spain and Australia that provide a more formal and standardised CPD education approach with providing a nationally recognised course. If the UK wants to enhance donation education and embrace this as part of routine critical care updates, a standardised course and learning programme should be developed to provide compliance to DH (2008) and NICE (2011) recommendations.

4.36) Relationship between CPD education and HCP being prepared to identify and manage solid organ donors

The results found that of those practitioners in the sample who had undertaken CPD education, those participants believed that this education had not effectively prepared them to identify and manage solid organ donors (Figure 4.12).

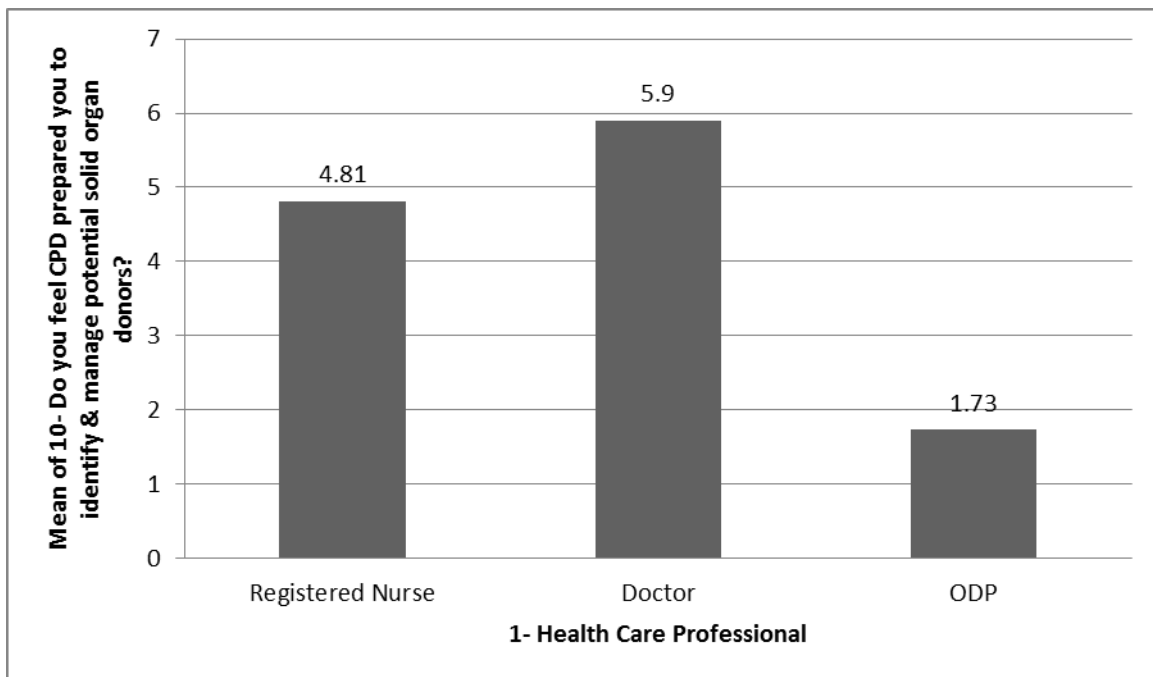


Fig. 4.12: Comparing HCP to mean Likert score (0-10) of asking whether the education given in post-registration CPD has adequately prepared them to identify and manage potential solid organ donors.

Results revealed that the overall mean score was 4.92 (ANOVA test SD= 3.228 Likert scale 0-10) across the three health professions finding that post registration CPD had not

effectively prepared practitioners to identify and manage solid organ donors. Direct correlation established the more senior the doctor or nurse the more positive they were that the CPD provided prepared them to manage solid organ donors. This positive correlation between the two variables (doctors, $\rho=+0.270$, $p=0.01$, $n=260$ and nurses, $\rho=+0.193$, $p=0.01$, $n=642$, Spearman's test) reveals that experience and seniority influences whether the HCP perceives that CPD education has prepared them to identify and manage organ donors. Due to the smaller sample size of ODPs statistical correlation was not possible. This theme was also evident in the focus group in terms of situational exposure to donation and experience.

Data revealed a statistical difference ($p=0.003$), in mean scores between the groups. The mean score for doctors ($M=5.90$, $SD=3.158$, $n=260$), nurses ($M=4.81$, $SD=3.158$, $n=642$) and ODPs ($M=1.73$, $SD=1.863$, $n=56$). This established that doctors perceive their CPD education compared to nurses and ODPs was more effective than the other two professions in identifying and managing potential solid organs within acute hospital environments.

These findings agree with Collins' (2005) small single site study involving nurses ($n=31$) in that 39% ($n=12$) were not educationally prepared to nurse a multi-organ donor patient. Meyer *et al* (2011) and Roels *et al* (2010) also support this study's findings in that health professionals may not be provided with effective post-registration education to manage organ donor patients within ICU. These studies did not compare different health professions or clinical environments and were undertaken using different methodological approaches involving samples from outside the UK compared to this study. These studies also did not analyse the relationship between the experience and seniority of the professional towards their CPD and did not evaluate how the CPD education was delivered (Collins 2005; Roels *et al* and Meyer *et al* 2011). This study's results relating to

CPD delivery and its influence on participants perceived effectiveness of managing donor patients provides new evidence that further education strategies need to be provided to ensure that all critical care practitioners have sufficient knowledge and CPD relating to donation. This is pivotal as the results revealed that there is a direct relationship between the more educationally prepared a HCP feels, the more likely they are to participate in the care of donor patients.

There was universal agreement within the focus group that education was vital but nothing could replace gaining hands on experience with managing a donor patient. This was supported by a number of comments from the group which can be applied to the concepts of Eraut's (1994 and 2000) and Dreyfus (1980 and 1986) continuum of learning through situational exposure, reflection and acquisition of tacit knowledge which can be applied to on-going decision making when caring for donor patients.

The focus group findings clearly identified the significance of experience in developing situational learning relating to donation by the sample stating:

“education is good but.....nothing prepares you for it rather than experience” (Nurse 6).

“junior staff.....lack experience and might have had the education but without the build of experience overtime” (Nurse 7).

“donation should be led by a senior nurse that has the experience” (Nurse 2).

“experienced nurses is really key to educating more junior staff..... It embeds everything that you might have done before” (Nurse 4).

This qualitative data reveal that nurses need not only education to gain initial theory relating to donation but also workplace exposure and experience to donation in the practical sense. This supports Dreyfus (1980) novice to expert model where by the more exposure the practitioner has relating to donation the more the practitioner will develop tacit knowledge and intuition which provides skilled behaviour from acquiring interpretation

and decision-making by learning from previous donor patients that the practitioner has managed (Eraut 1994; 2000 and 2007) .

Table 4.15: Cross tabulation looking at the relationship between HCP working in a transplant hospital and whether they have received post registration CPD donation education

		were you given post registration CPD donation education			Total
		Yes	No	Unsure	
Do you work in a transplant hospital?	Yes	Count 259	Count 170	Count 24	Count 453
	% within - Do you work in a transplant hospital?	57.2%	37.5%	5.3%	100.0%
Do you work in a transplant hospital?	No	Count 376	Count 257	Count 40	Count 673
	% within - Do you work in a transplant hospital?	55.9%	38.2%	5.9%	100.0%
Total	Count	635	427	64	1126
	% within - Do you work in a transplant hospital?	56.4%	37.9%	5.7%	100.0%

A Chi-square test established that 57.2% (n=259) of HCPs employed in a transplant centre received donation CPD compared to 55.9% (n=376) for a non-transplant hospital (table 4.15). Finding no statistical difference (p=0.856, with no correlation) if a HCP works in a transplant hospital that they are more likely to receive donation CPD compared to a non-transplant hospital. Therefore the common anecdotal perception that if a HCP works in a transplant hospital they are more likely to receive donation CPD was not established. From reviewing the literature there appears to be no UK research that compares CPD education between transplant and non-transplant hospitals making this an original contribution to knowledge. This means that policy makers should not just assume that if a HCP works in a transplant hospital that CPD education is embraced in the culture of the workplace. The findings support that CPD education strategies should be made available to all HCPs regardless of a hospital being a transplant or a non-transplant centre.

4.37) Research Question 3

RQ 3:

What are the implications for education and training for health care professionals in general?

4.38) Overview of findings

Qualitative data collection approaches found that regular mandatory training for HCPs working in critical care was essential for raising awareness and knowledge of practitioners relating to donation. The use of e-learning as a method of updating HCPs relating to donation was viewed as being negative as this did not provide the option of discussion, interaction and reflection amongst peers. Data analysis revealed that post-registration CPD was essential for staff working in critical care and that this should be delivered by the SNOD. That pre-registration education should provide fundamental knowledge relating to donation which can facilitate embedding donation options as being part of usual end of life care. The use of a standardised DVD with facilitator and student discussion could provide awareness to health care students providing an initial introduction to the benefits of donation and the options available in end of life care. The data found that donation training is sporadic with no nationally accredited course available for HCPs.

4.39) RQ3 Results

This research question aimed to investigate solutions that could be provided to enhance education delivery that could have an impact upon education and training for HCPs relating to donation. The questionnaire had a qualitative comment box that allowed the HCP to provide any discussion on how future education and training could be developed. Through using a mixed method approach of analysing and interpreting data from both the qualitative section of the questionnaire and the focus group there were identifiable themes established in the data. These themes aimed to address the research question in terms of

what health professionals perceived were the implications for education and training of HCPs relating to donation. The data focused upon five themes emerging from the qualitative data which revealed implications and enhancements for education and training. The five emerging themes were coded from the questionnaires qualitative comments and from the focus group interviews.

These five themes relating to implications for education and training related to:

- Mandatory training on donation
- E-learning
- Post registration CPD provision
- Pre-registration education
- Nationally accredited training course

4.40) Mandatory training

The questionnaire qualitative data revealed that 84 (out of 1180 or 7.1%) participants perceived that if mandatory regular update training on donation was provided that this would enhance future education and training relating to donation. Many staff commented upon how they were already provided with yearly compulsory training for other subjects such as health and safety which at times they found difficult to see the relevance to their working practice and believed that mandatory training on donation would be more pertinent than other compulsory updates. This supports Mythen and Gidman (2011) who state that mandatory training is an integral part of learning in the public health sector in order to maintain internal and legislative compliance. NHS Trusts set their own mandatory training to achieve this but Mythen and Gidman (2011) explain that this provides an educational challenge as staff have no choice on this learning and are often unmotivated to learn. Mandatory training is often dictated to health care staff due to necessary legislative and financial objectives and is delivered didactically, which often contradicts the

theories of adult learning (Mythen and Gidman 2011). With this in mind, this is the most likely reason that the group commented that existing mandatory training is not well received and is often difficult to apply to clinical practice.

Staff members commented upon how donation was not a daily occurrence and by having a yearly update on donation it would raise staff awareness and allow it to be in practitioners' minds when potential donors were admitted. The study results established that only 56.2% of HCPs had received CPD education and that there was no evidence that regular updates were being provided to practitioners despite the DH (2008) recommending this. Currently there is no legislative requirement for critical care HCPs to undertake regular mandatory training relating to donation unlike infection control. The DH (2008) recommended this but there are no legislative endorsements which mean that hospitals do not have to enforce this and can choose to ignore this, which appears to be evident from the findings in this study. Hospitals are under immense pressure to reduce costs and providing study leave away from busy clinical areas is a privilege, therefore NHS Trusts are only providing necessary mandatory training in order to achieve legal requirements (Mythen and Gidman 2011). The literature argues that mandatory training provides minimal emphasis upon continuing professional development for the learner but focuses more upon how hospitals can show legal compliance to NHS governing bodies (Mythen and Gidman 2011). This notion appears to be supported by the qualitative data with one questionnaire participant stating that;

“we have so much irrelevant mandatory training where I find it difficult to see the relevance to patient care but donation training should be mandatory as it is so relevant to patients..... It will constantly re-vitalise awareness of donation and keep it in the front of our minds” (Questionnaire participant 737).

This theme was apparent in a number of questionnaire responses as well as within the focus group interviews. This was evident with the group stating that training needs to be

mandatory in order to provide a continued awareness amongst staff in order to identify and manage potential donors.

“training needs to be mandatory.....it will keep continued awareness of the subject [donation] (Nurse 3).

Both data collection methods from the focus group and the questionnaire open question revealed that donation education should be given more emphasis and priority within the workplace and that HCPs should be provided with mandatory training on a regular basis. If the DH (2008) recommendations are to be embraced into practice then legislative stipulations need to be required so that hospitals ensure that funds and prioritisation is given to donation in line with other mandatory training such as infection control.

4.41) E-learning

The questionnaire established that 16 participants (out of 1180 or 1.3%) suggested in the qualitative section on the questionnaire that e-learning should be made available as is the case for other subjects that currently have compulsory update training for health professionals. However, an alternative argument was that seven participants stated that e-learning was not conducive as this did not provide effective learning delivery as donation should be discussed within a team and e-learning did not provide this opportunity. The analysis of the data revealed that some participants were very disillusioned with e-learning with one participant commenting:

“We need education..... but this should not be provided by e-learning, we have so much e-learning to do and it does not help me” (Questionnaire participant 212).

This negative perception relating to e-learning was also apparent in the focus group interviews with all eight participants stating that e-learning should not be used as a learning and teaching strategy for donation. When analysing the focus group data which were similar to the questionnaire responses, the group spoke with immense passion and

intensity that e-learning has no role to play in donation education. These discussions involved changes in voice tone and disapproving body language which created universal agreement that e-learning was not a positive learning initiative within the clinical workplace. The universal condemnation of e-learning by the group produced statements based upon past experiences;

“e-learning is very superficial.....does not allow any discussions or interactions and it’s a chore” (Nurse 6).

The viewpoint within the group was that e-learning did not provide a medium to allow discussion and opportunities to ask questions or discuss reflections upon previous situations relating to donation that the HCP has participated in. Discussion established that e-learning is not undertaken in a conducive learning environment as it is difficult for health care staff to effectively absorb the learning and knowledge whilst working in busy clinical areas. This negative viewpoint of the group towards e-learning can be summarised by the following statement:

“There is so much e-learning.....its just a tick box exercise, its often done in busy clinical environments with lots of distractions. I learn nothing as I have 10 things in my head for what I need to do for patients and don’t absorb learning. I get no study time if I do it out of work..... If I could go to the library and not worry about clinical pressures I would learn more” (Nurse 4).

The group acknowledged that no time was being given for HCPs to be relieved from busy clinical environments and they were expected to complete numerous e-learning modules whilst they were working within clinical environments. From analysing the discussions it appeared that e-learning had been forced upon clinical staff without any planning and consideration in the need of creating a conducive learning environment whilst staff undertake their e-learning with some clinical areas facing additional pressure because of having limited computers for access. This argument is also validated by Roe *et al* (2010) who states that e-learning should enhance face-to-face teaching and workshop learning but not replace it. Unfortunately the data from the focus group and questionnaire supports

that e-learning is replacing direct contact teaching and with Ruiz *et al* (2006) explaining that e-learning can generate significant cost savings compared to traditional teacher led sessions. In the current financial climate of reducing expenditure it appears that NHS Trusts are increasingly using e-learning with the hope of reducing costs however, despite the advantages of e-learning the impact of learning on health care professionals within clinical practice needs to be effectively evaluated.

The contemporary literature has established many advantages and disadvantages to e-learning but there does appear to be limited research appraising the actual benefit of doing e-learning in busy clinical environments which has many distractions which would impede knowledge acquisition (Roe *et al* 2010). Ruiz *et al* (2006) explains that e-learning has many advantages which includes increased accessibility of information for learners, increases participants computer skills, ease in updating content to ensure its current and relevant, personalised instruction, ease of distribution which involves standardised content which ensures all participants are taught the same theory and an assessment which provide an objective measure to determine if learning has taken place. However, as argued by Roe *et al* (2010) the majority of the literature published on evaluating the impact of e-learning has been published in higher education, government and corporate environments and not busy clinical settings with frequent distractions and where health care professionals are managing unwell patients where they cannot divert from this care as it may have a disastrous effect on patient care. Therefore, these potential benefits of a learner undertaking e-learning in a health care environment cannot not be easily extrapolated to a complex clinical context. It appears that more research needs to be undertaken evaluating the impact of e-learning in the clinical setting but it is not for this study to address this research deficit.

The published literature relating to the limitations of e-learning support some of the sample's argument that e-learning would not be appropriate for donation training as it does not allow discussion and reflection with an educator or senior practitioner relating to past experiences of donation which the sample stated would help to consolidate previous learning. This corresponds to Roe *et al* (2010) and Young Hee *et al* (2008) who explain that e-learning has limitations as it fails to provide opportunities for learner discussion, interaction and feedback which in certain learning activities are essential. In relation to the study findings it was established that participants concurred with the published literature in terms of discussion being an essential component to donation learning. The use of a blended approach to learning as advocated by (Roe *et al* 2010; Young Hee *et al* 2008 and Ruiz *et al* 2006) where by e-learning opportunities can be provided but also facilitated with an educator to promote discussion, interaction, application to practice and reflection would provide more effective education and learning strategies for donation than e-learning alone.

4.42) Post registration CPD provision

There was a theme established in that some questionnaire participants who had attended a study event which involved bereaved relatives and transplant recipients talking about their personal circumstances relating to donation. 33 participants stated how the involvement of relatives and transplant recipients presenting in education courses was very emotive and showed the benefits that donation can provide both to bereaved relatives and those who have received a lifesaving transplant. This provided a medium for practitioners to challenge their practice relating to donation and to witness first hand from patients and relatives the benefits that HCPs actions can do by participating in donor management within the clinical environment.

One questionnaire participant stated;

“The most beneficial thing in my career relating to donation was hearing a bereaved mother stating how she took so much relief and comfort knowing that her tragic sons’ loss had helped other people to survive..... All donor education should involve discussion from relatives in this situation as it made it so worthwhile and my attitude change considerably..... I now know the benefits of donation..... I am routinely involved in donation....” (Questionnaire participant 988).

This example highlights how education programmes need to incorporate discussions from relatives and transplant recipients as the data revealed that this provided an effective learning strategy for HCPs to see for first-hand the benefits of donation and transplants. This notion is supported by Randhawa (1998); Collins (2005) and Elding and Scholes (2005) who state that education and training should be encouraged to discuss, share and reflect upon cases that involve bereaved families and transplant recipients reflecting upon their situation and involvement in donation. This can be very emotional for all parties concerned but does provide the opportunity for HCPs to visualise directly the positive impact that donation can have on both the bereaved and patients who have received a life-saving transplant. The results from the qualitative data support the involvement of relatives and transplant patients in education programmes that can positively influence a change in a practitioner’s attitude and involvement in donation.

The questionnaire qualitative feedback also found a recurring theme that post registration university curriculums within critical care need to incorporate education relating to donation as this was often not provided (n=23). This was something that was not specifically highlighted from the focus group interviews as the sample stated that they believed the best professional to deliver donation education was the SNOD. They stated that SNODs need to be involved in both workplace and formal post registration CPD programmes which involves them as specialists being invited into higher education institutions to deliver education relating to donation.

One nurse commented that:

“The SNOD is really beneficial..... they need to have a visible presence in every hospital to deliver education and advice at present they are scarce” (Nurse 5).

The sample found that the SNOD was a valuable resource that needed to have a visible presence to influence decision making and education within a hospital.

4.43) Pre-registration education

The qualitative data also established a further theme with 41 questionnaire participants stating that more emphasis on donation and transplantation should be included on pre-registration curriculums. Data from the questionnaire and focus group established that if fundamental knowledge was provided at pre-registration particularly with emphasis on tissue donation that it will embed a culture on tomorrow's health professionals that donation should be seen as part of routine end of life care-planning. One participant summarised this by stating,

“I received no education as a student..... it sort of sees donation and transplantation as being not important if you get no teaching on it as a student..... All students should be taught the underlying principles especially cataracts [tissue donation] as so many people who die can donate this but its not covered so it will never be seen as routine” (Questionnaire participant 613).

The data revealed the significance of starting with initial education of students to try to embrace the culture that donation should be viewed as usual and not unusual as advocated by the DH (2008). This was also reinforced from the focus group interviews that established pre-registration education should focus upon awareness of donation. The findings from both qualitative data collection methods suggest that if education was provided at a pre-registration level then HCPs may establish donation as part of usual end of life care.

The focus group sample was asked how they believed that education could be most effectively delivered at a pre-registration level. Discussions took place that the emphasis should be placed on donation and transplantation awareness that was not too much in-depth as the entire sample agreed that this would potentially have a negative effect on their knowledge and confidence by potentially alarming them on a role that they would not be autonomously involved in as a student. As one nurse commented that;

“they [pre-registration students] should have an awareness they should not go into too much detail..... as this may effect confidence as a student they would not do this on their own” (Nurse 6).

Discussions led on how the teaching should be delivered within a pre-registration programme, this involved the focus group collectively and decisively stating that all students should be taught the benefits of donation and transplantation and how teaching strategies need to promote discussion and be interactive in delivery. The theme of having a transplant recipient attending a seminar to discuss the benefits from their perspective was again supported. However, the practicalities of this in terms of planning and gaining consistency with standardisation across all pre-registration education programmes was identified as being in-practical in achieving this.

One nurse discussed the concept of developing a video which could be developed by NHSBT in conjunction with higher education institutions which would provide a standardised DVD that could be used across a number of pre-registration health programmes within the UK. The content of the video could include discussion by bereaved relatives who gave consent to organ donation as well as transplant recipients who could both reflect upon their experiences about the benefits of donation. This DVD could include theory relating to the management of organ and tissue donors and have some role play on patient situations and communication strategies that could be used to support and approach families for tissue donation.

“pre-registration students should have standardised DVD which they view and then have discussion following this..... a video where they interview lots of different people and then could be used in pre-registration.....with discussion afterwards and everybody would get the same kind of thing” (Nurse 4). This idea was universally agreed within the group as an excellent concept of how a standardised approach to organ and tissue donation could be provided to student health professionals. The group discussed that the DVD could provide the introduction but also there should be some discussion points from the video which could allow interaction and reflection. These discussion points should be led by the students but also a discussion schedule with appropriate feedback answers from NHSBT in relation to donation best practice so that it can be used as a guide for the lecturer facilitating the seminar. The group were very enthusiastic about this notion and they believed that if this concept was implemented and was mandatory for pre-registration students it would have a positive impact upon embedding donation as part of usual end of life care practice. This standardised approach would ensure that all HCPs will have initial donation foundation knowledge which could be further developed through future learning and experimental experience as part of CPD as advocated by Eraut (1994 and 2000) theories of professional learning. This would also provide an education delivery strategy to address the deficit that only 23.7% of questionnaire participants had received pre-registration donation education.

4.44) Nationally accredited course

The qualitative questionnaire data found that twelve practitioners commented that there should be a nationally recognised post registration CPD donation course. Participants commented that this should be developed on the similar terms of the UK Resuscitation Council (2010) Advanced Life Support course which is a standardised course delivered throughout the UK involving a variety of teaching strategies which when completed means that the same learning outcomes have been achieved regardless of where the course was undertaken. One questionnaire participant replied by stating:

“There is no national course in donation..... if you are lucky to get any education on donation it may be adhoc..... there needs to be standardisation with providing an accredited course”(Questionnaire participant 992).

This statement also supports focus group findings:

“formal education training programme..... with regular follow up” (Nurse 1).

The qualitative data revealed that there was no formal accredited education curriculum for donation, and that HCPs believed that a course was required to provide standardisation across the UK in relation to donation training. The literature shows that other countries such as Australia and Spain have nationally accredited courses focusing upon donation with nationally delivered learning outcomes and teaching strategies (ADAPT 2012 and Lopez-Montesinos *et al* 2010). The focus group and questionnaire findings established that a nationally accredited donation course would provide more standardisation to training and curriculum which would have influence on future learning for HCPs which would aim to enhance donation management within the UK.

4.45) Overview of findings applied to Eraut and Dreyfus theoretical perspectives

This study was informed by theoretical perspectives on how professionals develop professional knowledge and competence using Eraut's (1994; 1998; 2000; and 2007) theories of learning from situational practice exposure using both informal and formal learning strategies. This also related to the Dreyfus and Dreyfus (1980) model of skill acquisition where initial background education is further supported by an experimental continuum model involving situational exposure, reflection and practical development along a 5 stage continuum starting at novice and ending at expert. Eraut (1994) argues that professional development is part of the concept of competence and should be interpreted as an ideology of continually developing skills and expertise. This involves the notion that professional competence involves acquiring numerous types of knowledge

through informal and formal learning and implementing this knowledge in an appropriate method in the workplace.

It was apparent that these theoretical perspectives could be applied to this study. The findings found a recurring theme that the more experience and senior the practitioner was the more knowledge, participation and awareness they had of aspects relating to donation. This follows theories of situational learning in the workplace relating to the more exposure of relevant situations that has allowed critical reflection of decision making and the development of tacit knowledge, the more knowledge and awareness of donation the HCP has (Eraut 1994; 2000 and Dreyfus 1980 and 1986). Therefore, the more situational exposure the HCP has within their workplace managing organ donor patients, the more they develop their knowledge and skills through application of workplace learning and critical reflection from tacit learning from previous organ donors they have clinically managed. This follows Dreyfus (1980) model of novice to expert in skill acquisition as the most junior nurse and doctor could be applied to the novice level of the model with the most senior doctor or nurse being at the advanced level of the model.

The results found that the majority of CPD education was provided through informal work-based learning with SNODs undertaking workplace learning rather than formal learning in a classroom setting such as provided by higher education institutions (Eraut 2000 and 2010). The results established that, despite limited formal education being provided at both pre and post registration level, informal work-based learning has made a significant impact on HCP knowledge and participation in donation and despite this study finding deficits in knowledge and education, this would have been far worse if informal workplace learning was not being provided to health professionals. This supports the notions by Eraut (2000 and 2010) that often informal workplace learning is often under-estimated within education and that professional knowledge and competence is very dependent upon

these informal learning opportunities which appears to be evident with HCPs when developing knowledge and competence in managing the donation process.

4.46) Summary of results and discussions

RQ1: What is the relationship between the knowledge and attitude of RN, doctors and ODP working in ICU, ED and OT to organ and tissue donation?

1. There was no statistical difference between HCP who had received pre-registration donation training and those who did not in influencing positive attitude towards donation. There was no statistical difference between the three health care professions;
2. There was a large statistical difference that if a staff member was provided with post registration CPD this then leads to the HCP perceiving organ donation as being more positive and to participate more in donor care. There was no statistical difference between the three professions and also which hospital department they worked in. This concurred with focus group interviews which revealed that education produces a more favourable perception to donation;
3. If HCPs were provided with mandatory CPD education this would influence HCPs positive attitude towards donation which might have an impact upon influencing staff to participate more in donation care;
4. Qualitative data established that education programmes involving discussion from relatives or transplant patients provide HCPs with a personal insight into the benefits of donation that can enhance future behaviour and participation of HCPs in donation.

RQ1 b: What is the knowledge base of registered nurses, doctors and operating department practitioners (ODPs) working in ICU, ED and OT towards organ and tissue donation?

1. There were knowledge deficits in the sample relating to being aware of the absolute contraindications for solid organ donation as well as the contraindications for tissue donation. However doctors were more likely to be aware of contraindications for both solid organs and tissue donation compared to nurses and ODPs;
2. There was direct correlation between the seniority of the doctor or nurse, the more aware of the contraindications to tissue donation. Focus group data identified the importance of having experiential and situational learning relating to donation and the significance of senior practitioners to support junior staff;
3. 80.3% of the sample have been involved in 5 or less tissue donors in their career. It was evident that despite there being a national shortage of tissues available for donation the overwhelming majority of HCPs are infrequently involved in tissue donation. Focus group discussions revealed that this is due to lack of awareness and education;
4. There is a statistical difference that the more educationally prepared the HCP is, the more likely they are to participate in tissue donation, view supported by qualitative data discussions;
5. A statistical difference found that doctors feel that they can more effectively explain BSD than nurses and ODPs to bereaved relatives;
6. The results found that participants lack perceived knowledge and confidence in effectively explaining BSD to relatives;
7. There was a significant statistical influence at the $p < 0.001$ level that if the HCP had received CPD education they felt more effective at explaining BSD to a relatives;

8. The sample lacked knowledge and understanding between DBD and DCD organ donation and its clinical management with a mean score of 5.38. Statistical analysis found that doctors believed they were more aware of the differences in management between the two donation retrieval techniques compared to nurses or ODPs. The focus group identified a clear relationship that education was vital to develop confidence and understanding of donation;
9. There was a significant statistical relationship at the $p < 0.001$ level that if the HCP had received CPD education they were more aware of the difference in management between DBD and DCD donation.

RQ1 c: What is the attitude of these acute health care professionals towards organ and tissue donation?

1. Despite the survey finding doctors being more positive towards donation than the other two professions, this was not statistically significant ($p = 0.093$);
2. Overall mean score of 9.16 (Likert score 0-10) showing that the sample view organ donation as being positive. This positive attitude was also evident in the focus group interviews;
3. Correlation between the more senior the doctor, the more positive they were towards donation, with consultants viewing donation as being the most positive within the sample. This was not apparent with nurses;
4. There was no statistical difference in attitude towards organ donation between staff who worked in a transplant hospital compared to a non-transplant hospital;
5. The results found that 78.2% of HCPs would recommend a family member to join the ODR, with 4.6% stating they would not recommend a family member and 17.1% being unsure. No statistical difference was found between the three health care professions.

RQ 2: Research Question 2: How does the education received by the groups determine the decision making and management of the organ donation process:

1. Focus group findings clearly identified that nurses are more likely to change their behaviour and discuss tissue donation options routinely following a study event that has involved relatives discussing the benefits they have gained from giving donation consent;
2. The focus group established deficits in knowledge relating to tissue donation due to limited education and training opportunities with lack of awareness found to be the main obstacle to why tissue donation does not occur as part of routine end of life care.

RQ2 b: What is the nature and extent of pre-registration education received by these professions in relation to organ and tissue donation?

1. The majority of the sample (61%) had received no training on donation in pre-registration programmes with a further (n=178) 15.3% stating they were unsure. There was no difference between doctors and nurses who had received training to those who had not. However it was evident that ODPs were less likely to receive donation education at pre-registration;
2. None of the nurses in the focus group had been provided with donation education as a student. However, they highlighted the importance of having an awareness of donation which could allow further development during CPD;
3. The most likely teaching delivery method for those provided with pre-registration education consisted of a lecture and the average time allocated to donation was between 1-2hours. There was no difference between the three professions in teaching delivery method or time allocated;
4. It was evident that HCPs believe that their pre-registration education did not prepare them for identifying and managing both tissue or solid organ donors and that pre-registration should have emphasis upon an awareness of donation which

can be further developed within CPD but provide the notion that donation is part of usual end of life care.

RQ2 c: What is the nature and extent of post registration education received by these professions as part of their CPD in relation to organ and tissue donation?

1. 56.2% (n=638) of the sample had received donation CPD compared to 38.2% (n=434) who had received no CPD training on the subject with a further (n=64) 5.6% stating they were unsure. Doctors were more likely to have received CPD education but this was not statistically different. All participants of the focus group had received CPD donation education;
2. ODPs were significantly less likely to have received any CPD donation education compared to doctors and nurses;
3. Despite DH (2008) and NICE (2011) stating that all clinical staff potentially involved in donation should have training which is regularly updated, the results found that this was not occurring and no staff stated that there was mechanisms in place for regular updating. The focus group data revealed that regular mandatory updates would raise the profile of donation within the workplace;
4. A statistical difference ($p < 0.001$) was found that if staff worked within ICU they were more likely to have received CPD on donation compared to ED and OT;
5. The most common method of CPD delivery was by the SNOD giving teaching within the department (30.2%), then 24.6% having informal in-house training, 18% attended a formal donation study day, 16.5% through personal reading and then 9.8% through formal post-registration university education;
6. There is no national course or education programme available for donation but appears that CPD education was run in house and pre-dominantly led by the hospitals SNOD;

7. 24.4% (n=125) could not remember how many hours of CPD they had undertaken, 12.5% (n=64) had spent less than 1 hour on the topic with the highest number (31.6% n=162) of HCPs undertaking between 1-2 hours and only 1.2% (n=6) spending more than 10 hours of time. There was no difference between professions in how many hours of CPD had been undertaken;
8. Statistically doctors perceived that their CPD education compared to nurses and ODPs was more effective than the other two professions in identifying and managing potential solid organ donors;
9. With the mean score of 4.92 (SD= 3.228) across the sample it suggests that post registration CPD has not effectively prepared them to identify and manage solid organ donors;
10. There was direct correlation between the more senior the doctor or nurse the more positive they were that the CPD education provided had prepared them to manage solid organ donors. This was also supported by the qualitative findings;
11. There was no difference between if a HCP worked in a transplant hospital versus non transplant hospital, that they were more likely to have received post registration CPD.

RQ3: What are the implications for education and training for health care professionals in general?

1. The qualitative findings found that emphasis should be placed on the awareness and benefits of donation in general at a pre-registration stage of a health professional's career. This will embrace the notion that if student HCPs are provided with donor education before registration that the viewpoint of donation is seen as usual rather than unusual as dictated by the DH (2008);
2. HCPs working in critical care should have protected mandatory training relating to donation as part of their CPD;

3. Education strategies in terms of both formal and informal learning need to be provided to HCPs particularly at a post-registration level and these should be delivered by the SNOD;
4. That e-learning alone should not be used as an educational strategy as this would not allow in-depth discussion, interaction and reflection amongst practitioners.

Chapter 5 – Conclusion and recommendations

5.1 Conclusion

This study concludes that there were knowledge deficits relating to HCPs knowledge, education and training towards organ and tissue donation. The findings revealed a range of knowledge deficits relating to the absolute contraindications for solid organ donation, ability to discuss BSD to bereaved relatives, deficits relating to contraindications for tissue donation and limited understanding of the differences in clinical management between DBD and DCD donation. This was concerning as the participants all worked in critical care areas where potential or actual organ donors are clinically managed. Hence, these practitioners may not have the suitable knowledge to identify and refer potential donors and support families with the complex decision making involved. This might have a negative impact upon organs and tissues being available for transplantation. The UK has one of the highest transplant waiting lists in Europe, with currently 7,000 people in the UK waiting for a transplant (NHSBT 2013). If the UK wants to reduce the number of patients dying whilst waiting for a transplant then a concerted effort needs to be made at addressing HCPs knowledge deficits as this will hopefully increase the number of potential donors identified and subsequently increase the number of life-saving transplants.

The knowledge deficits are not surprising as the data revealed limited donation education of only 23.7% of participants receiving donation education during their pre-registration training and only 56.2% stating they received it as part of post-registration CPD. This is despite the DH (2008) stating that relevant education should be mandatory for all practitioners potentially involved in donation. This may account for the reasons why these health professionals have limited knowledge and confidence when managing donor patients if education opportunities are not being provided. This study has established that the DH (2008) recommendations for mandatory donation training have not been implemented into the NHS and that HCPs are not being provided with regular updates.

Again this provides more evidence to support the argument that if education is not being targeted to health care professionals it is not a surprise that transplant waiting lists continue to increase.

The findings concluded that participants had a generally positive attitude towards donation, with no statistical difference in attitude within the three professions. The results concluded that 78.2% (n=910) of participants would recommend a family member join the ODR, again there was no difference between professions. Conclusions from statistical correlation established the more senior the doctor the more positive they were towards donation but this was not apparent within nurses. Further conclusions from statistical analysis relate to the influence that post registration CPD education has on producing a more positive attitude towards donation. When this was compared to whether a health professional received pre-registration donation education there was no influence on participants' attitude. This study concludes that if education is targeted and emphasised to HCPs as part of their CPD this will then produce a more positive attitude of staff towards donation.

Conclusions drawn from the questionnaires and focus group found that all three HCPs have limited education opportunities at both pre-registration and post registration CPD levels. The findings found a direct link between the more education that a professional is provided at post-registration, the more knowledge, confidence and involvement the practitioner has with a potential donor. With the majority of patients who die being eligible for tissue donation conclusions are drawn from statistical and focus group data that HCPs are infrequently involved in tissue donation and those who do have received more education than those who do not participate. The results found that education influences HCPs' participation in donor care with this in mind if all staff working in critical care were

provided with regular education relating to donation this will lead to more staff participating in donor care.

Education strategies in terms of both formal and informal learning need to be provided to HCPs particularly at post-registration but providing awareness to pre-registration students. The study concludes that HCPs should be provided with instruction on donation with particularly emphasis on tissue donation and the benefits of donation in general at a pre-registration stage of a health professional's career. This will embrace the notion that if student HCPs are provided with donor education before registration that the viewpoint of donation is seen as usual rather than unusual as dictated by the DH (2008). Further emphasis needs to be provided on learning and teaching strategies used for post-registration CPD as there is clear evidence that this makes a difference to attitude, knowledge acquisition and participation in donor management amongst critical care practitioners.

This study concludes that doctors consistently appear more confident and knowledgeable relating to donation compared to nurses or ODPs. A recurring theme that was evident throughout the research was that ODPs were provided with the least training and had the most knowledge deficits compared to doctors and nurses. However, generally ODPs will not be identifying donors or communicating with bereaved families compared to the other two professions but will still be involved in donation retrieval within the operating theatre.

The study has concluded that there was a recurring and consistent theme that the more experienced and senior the practitioner was the more knowledge, participation and awareness they had relating to aspects of donation. The findings highlighted that education was important but also so was the practical exposure of learning and reflecting upon participating in the care of donor patients in the workplace. The qualitative focus

group data revealed the significance of learning from experimental exposure which also involved informal teaching in the workplace from SNOD. This recurring theme follows the theories of situational learning as advocated by Eraut (1994; 2000 and 2007) and Dreyfus (1980 and 1986) relating to the more exposure of relevant situations that has allowed critical reflection of decision making and the development of tacit knowledge, the more knowledge and awareness of donation the HCP has acquired. This supports the notions by Eraut (2000 and 2010) that often informal workplace learning is often under-estimated within education and that professional knowledge and competence is very dependent upon these informal learning opportunities which appears to be evident with HCPs when developing knowledge and competence. The study established a relationship between the theories of tacit knowledge and situational learning as advocated by Eraut (1994; 2000 and 2007) and Dreyfus (1980 and 1986) which demonstrated a continuum of how HCPs learn from being a novice to expert and reflect upon situational exposure as well as learning within the formal setting.

Data concluded that the majority of education was delivered by SNODs within the workplace with very limited education opportunities being available within higher education institutions. This relates to what Eraut (1994 and 2007) would define as learning from informal learning within the workplace. With this in mind, higher education institutions need to review their curricula to ensure that donation education relating to tissue donation is provided within pre-registration education and post-registration health professionals. In relation to Eraut (1994 and 2007) formal definitions of learning, post registration higher education courses in critical care and end of life care have emphasis placed on identifying and managing potential organ and tissue donors to ensure that a culture of this being routine for end of life care. That NHS Trusts ensure that the DH (2008) recommendations that all HCPs potentially involved in a donor patient undertake mandatory training in donation as this study has highlighted this is not happening. Further, that staff are also

provided with regular update training as part of yearly mandatory training for all HCPs working within critical care as this study has established. More emphasis needs to be placed on providing more formal education opportunities such as a national accredited donation course using a similar education model used in Australia and Spain (ADAPT 2012 and Lopez-Montesinos *et al* 2010). Therefore, if effective rigorous educational programmes were embraced across the UK this would potentially make a difference to the number of potential donors and have an impact on reducing the transplant waiting list.

In conclusion, this study has established that education plays a pivotal role in supporting and facilitating health professionals' knowledge, confidence, attitude and participation in managing donor patients. This study aims to inform policy makers, NHS Trusts, professional bodies and education establishments relating to enhancing and delivering educational and learning strategies for health professionals who are likely to be involved in donation. By adopting the strategy of embracing education for all HCPs may increase the number of organs and tissues that become available and reduce the transplant waiting list and literally save lives.

5.2) Original contribution to knowledge

This study has made an original contribution to knowledge by comparing three health care professions working in different clinical areas, attitude, knowledge and education from a multisite sample within England, which has not been undertaken before. The study found contemporary and original results in that there was no statistical difference in three HCPs attitude towards donation. Results established that doctors have more knowledge and confidence relating to donation compared to nurses and ODPs. The study provided novel comparisons between different professions and clinical workplaces in terms of confidence and knowledge deficits. From evaluating the literature, these comparisons between

different professions, workplace departments and the health professionals experience has not been analysed and statistically correlated.

The research also provided originality as no study had been undertaken evaluating the provision and education uptake of HCPs since the DH (2008) recommended that all health professionals potentially involved in donation should be provided with mandatory education. The results established that only 56.2% of participants have been provided with education and there was no evidence that regular updates exist. Therefore it would appear the DH (2008) recommendations have not been fully adopted into practice.

Further examples of originality is that the study concluded that there was a direct link between post-registration CPD education influencing a more positive attitude and participation in donor care of the HCP. Additional original results established that there was no difference in both attitude and education opportunities of practitioners who worked in a UK transplant hospital compared to those that worked in non-transplant hospital.

The study found unique relationships between how the more experienced and senior the doctor or nurse was, the more knowledge and confidence the practitioner had. The application of the theoretical theories of Eraut (1994; 2000 and 2007) and Dreyfus (1980 and 1986) to professional and situational learning also provide an original component to this study and how these theories relate to findings of situational experience and workplace learning. This mixed methods research design study using three HCPs from a multi-site UK sample using quantitative and qualitative data analysis presented in this study demonstrates originality which meets the requirements of doctoral study. As this is an original investigation it is envisaged that this study will be presented and published to inform policy makers to enhance future education and training of HCPs within the UK.

5.3) Limitations

The questionnaires were circulated to a large number of HCPs across numerous hospital sites in an attempt to reduce potential biases within particular hospitals. However, a limitation of questionnaire research is that often the opinions of a highly motivated section of the population, who may have either strong or negative opinions on the subject matter, take the time to complete and return the questionnaire (Marshall 2005). This is a limitation with this study as the questionnaires returned would be from those staff members who are either likely to have strong opinions either positively or negatively towards donation, motivating these participants to return their questionnaires due to their strong opinion. With the response rate of the questionnaires being 31.05%, this sample may not have represented HCPs with average viewpoints towards donation and education. However, as Marshall (2005) discusses this is a known limitation of using questionnaire research and this could not be avoided.

This similar limitation could also be applied to staff attending the focus group interviews which relating to (Fern 2001 and Marshall 2005) would mean that any participants taking time out to attend an interview would have motivated opinions that could be either positive or negative towards the subject that influences their decision to participate. This was apparent within the focus group as the entire sample appeared extremely enthusiastic and passionate towards donation and education within the workplace. Unfortunately these are known limitations that have to be acknowledged when undertaking these methods of research.

A further limitation is that the focus group involved only one health profession; therefore, the focus group data only reflects the views from the nursing profession. This was despite the author sending out 97 e-mails inviting participants from all three professions to attend a focus group interview. On the day only nurses attended. This was beyond the control of

the author as no doctors or ODPs decided to attend the focus group interviews. This does mean that the data obtained and analysed from the focus group is only applicable to nurses and therefore there are biases to the nursing profession which may not be applicable to the other two professions involved in the quantitative data analysis. It was envisaged that the focus group would have representatives from the three professions, enabling multi-professional discussions which may have given more insight into how the different professions generate workplace knowledge and learning relating to donation. These multi-professional discussions may have also provided a more collaborative approach to generating potential solutions to how education and training opportunities could be enhanced for health care professionals instead of as occurred providing a viewpoint only from the nurses' perspective. The focus group also consisted more of ICU nurses with only one ED nurse so the data was biased towards ICU nurses' opinions and perceptions. Unfortunately the author could not have amended this limitation without breaching ethical considerations on influencing attendance. Despite, the focus group only involving nurses which lost an opportunity for doctors and ODPs to discuss their perceptions and experiences of donation education, there was a wealth of quantitative data that allowed comparisons across the three professions that was used to answer the research questions.

Following advice from the statistician it was apparent that due to the smaller sample size of ODPs that returned questionnaires, it was not always possible to undertake statistical tests involving comparisons and correlations with ODPs due to the difference in the professions sample size. In contrast, due to the larger sample sizes of the doctors and nurses these samples could be statistically correlated against one another.

The study found that the majority of participants had received no donation education at pre-registration level because they had been qualified on average for 14.48 years, periods

of time which did not include donation in the curriculum. This does not necessarily provide evidence that current and existing pre-registration curriculums do not include donation education, however, what it does show is that the majority of the sample when students, did not receive pre-registration donation education.

5.4) Recommendations

There are a range of recommendations that arise from this study in relation to developments in practice, evaluating education and learning strategies and future research within this field of study. Those being:-

- **An examination of pre and post registration curricula:** That an in-depth multi-site study investigates the curricula and the nature of its delivery in higher education schools of medicine and health within universities, used to deliver pre and post registration education relating to donation and transplantation.
- **Creation of additional teaching resources:** In order to promote donation to pre-registration students, it is recommended that a DVD programme is commissioned which involves relatives and transplant recipients talking about their experiences of donation, thus visually demonstrating the benefits of donation. This DVD should also be developed with a question and answer lesson plan that stimulates class discussion following watching the DVD. If this education strategy was delivered to all pre-registration health students then a standardised educational approach of raising awareness and options of donation to all students would be established.
- **Focused CPD:** Efforts need to be made on establishing CPD education for all HCPs with potential exposure to donor patients as this will improve participation in donor care and policy makers need to ensure that commitment and resources are concentrated towards donation education.

- **Workplace education:** SNODs continue to deliver informal workplace education that supports the acquisition of both theoretical and workplace practical exposure to donation in order to ensure theory is applied to practice.
- **Mandatory education for HPCs relating to donation:** Education relating to donation should be mandatory for HCPs working within critical care with regular updates provided as advocated by DH (2008) and NICE (2011) recommendations.
- **Improved teaching delivery:** Education strategies should be developed that allow effective interaction, discussion and involvement of relatives and patients who can discuss the benefits of donation. This will provide HCPs with opportunities to critically reflect and enhance their attitude and involvement in donation.
- **Managed use of e-Learning:** Education strategies should not be delivered by e-learning alone and if e-learning is developed this should not be used as the sole method of delivering donation education as this provides little opportunity to allow interaction and discussion amongst peers and credible facilitators. If an e-learning package was developed this should not be used in isolation and blended learning strategies should be used which promote interaction and discussion.
- **Ensuring that donation is embedded into routine end of life care:** The results suggest that donation is not embedded into routine end of life care. Concerted efforts need to be made from the DH, NHS Trusts, professional regulatory bodies and educational institutions to embrace the culture that donation options are to be routine for end of life care as recommended by the GMC (2010) and DH (2008).
- **Future research:** Whilst this study does include a multi-site sample, the recruitment was biased towards hospitals within London and the south east of England. Further research could be undertaken using a national multi-site sample from hospitals in different regions from England, Wales, Scotland and Northern Ireland which would provide a more comprehensive assessment of attitude, education and training within the UK. A study using similar methodology could also

be undertaken internationally involving comparisons across a number of different countries but also compare whether there was a relationship between health care professionals education and whether there was any influence on that particular country's consent rates for donation and transplantation waiting list.

5.5) Dissemination

As this research provides an original contribution to knowledge and with the literature review establishing limited contemporary studies, it is essential that the results from this research are widely disseminated. The author plans to present the research at the National Organ Donation Committee which will target policy makers from the Department of Health, NHS England and NHS Blood and Transplant in order to try and implement the recommendations from this thesis. In collaboration with the author's academic supervisors, the research will be published in a credible peer reviewed journal with a high impact factor in order to enable the originality of this work to be available and endorsed by an academic journal in order to implement changes in health care education and clinical practice. As there is limited UK and International research on this subject, the thesis does inform both UK and international practice. In light of this the author will focus on publishing and presenting at both UK and International conferences and journals. Despite differences in culture and education policy between UK and other countries, the thesis does inform international practice that there are established links between education, attitude and HCP participation in donation management. The author will also disseminate the results of this thesis to professional organisations such as NICE, GMC, NMC, Intensive Care Society and British Association of Critical Care Nurses to allow wider dissemination of the results and recommendations. This research has a number of recommendations which will both enhance future donation education and practice but ultimately through wide dissemination

and changes in practice will hopefully increase the availability of organs for transplantation and literally save lives.

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Appendix 1:

Summary of Dreyfus (1980) Model of Skills Acquisition

<p>Level 1 Novice Rigid adherence to taught rules or plans Little situational perception No discretionary judgement</p>
<p>Level 2 Advanced Beginner Guidelines for action based on attributes or aspects (aspects are global characteristics of situations recognisable only after some prior experience) Situational perception is still limited All attributes and aspects are treated separately and given equal importance</p>
<p>Level 3 Competent Coping with crowdedness Now sees actions at least partially in terms of longer-term goals Conscious deliberate planning Standardised and routinized procedures</p>
<p>Level 4 Proficient See situations holistically rather than in terms of aspects See what is most important in a situation Perceives deviations from the normal pattern Decision-making less laboured Uses maxims for guidance, whose meaning varies according to the situation</p>
<p>Level 5 Expert No longer relies on rules, guidelines or maxims Intuitive grasp of situations based on deep tacit understanding Analytic approaches used only in novel situations or when problems occur Vision of what is possible</p>

Dreyfus & Dreyfus (1980) summary of Dreyfus Model of Skills Acquisition p124

Appendix 2-

A Framework of Questions to be Asked of Research Evidence Rees (2003)

Heading	Question to be asked
Focus	In broad terms what is the theme of the article? Is the title a good indicator of the focus?
Background	What argument or evidence does the researcher provide that suggests this topic is worth exploring? Is there a critical review of previous research on the subject? Are the gaps in the literature or inadequacies with previous methods highlighted? Are local problems or changes that justify the study presented? Is there a trigger that answers the question 'why did they do it then?'
Terms of Reference	Does the researcher state the terms of reference; the aim or hypothesis? Are there concept and operational definitions for the key concepts?
Study design	What is the broad research approach? Is the study design appropriate to the terms of reference/hypothesis/research question? Have the strengths and weaknesses of the study design been highlighted?
Data collection methods	What tool of data collection has been used? Has a pilot study been conducted? Have strengths and limitations been recognised by the author?
Ethical considerations	Were the issues of informed consent and confidentiality addressed? Was any harm or discomfort to individuals balanced against benefits? Did a local ethics committee consider the study?
Sample	Who or what makes up the sample? Were there clear inclusion and exclusion criteria? What method of sampling was used? Are those in the sample typical and representative or are there any obvious elements of bias? On how many people/things/events are the results based?
Data presentation	In what form are the results presented? Does the author explain and comment on these? Can sense be made of the way the results have been presented or could the author have provided more explanation?
Main findings	What are the most important results that relate to the term of reference/hypothesis/research questions?
Conclusions and recommendations	What is the answer to the terms of reference/research questions? Are the conclusions made based on and supported by the results? What recommendations are made for practice? Are these relevant, feasible, and specific?
Readability	How easy is it to read? Is it written in a clear, interesting or 'heavy' style? Does it assume a great deal of technical knowledge about the subject and/or research procedures?
Practical implications	How could the results be related to practice? Who might find it relevant and in what way? What questions does it raise for practice and further study?

Appendix 3- NIHR approval letter:

Dear Mr Collins,

Re: IRAS Ref: 73680 Study ID 11637 Organ donation: an evaluation of health workers knowledge & education

We are pleased to inform you that the above study has been assessed as eligible for consideration for CRN support. This study has been included on the National Institute for Health Research Clinical Research Network (NIHR CRN) Portfolio. The NIHR is committed to providing the CRN support requirements needed for your study to be successfully delivered in the NHS, this includes access to a local network of dedicated, skilled research support staff including research nurses and other allied health professionals, who can help identify eligible patients, arrange consent to participate in the study and monitor patients as they progress through the study. Other ways of ensuring the success of the study in the NHS include access to pharmacy, imaging and pathology services and the possibility of securing protected time for NHS staff to conduct research.

It is the responsibility of the relevant Local Research Network to consider your study's requirement for CRN support at each site and for multi-centre studies this process will be coordinated by a Lead Network on your behalf.

Your unique Portfolio Study ID number is detailed above and can be used to search for the record for this study on the NIHR CRN Portfolio.

Your study will be categorised within the NIHR Comprehensive Clinical Research Network's Portfolio of non-commercial clinical research studies. The NIHR Comprehensive Clinical Research Network (CCRN) is the largest of the eight networks that constitute the NIHR CRN. As such, your study will be supported by the CCRN and its Specialty Groups, which are here to support you throughout the life of your study and can provide you with help and advice if you encounter any problems which adversely affect the start-up and subsequent recruitment into the study.

Recruitment Data

If your study is accessing CRN support, you are required to upload recruitment data on a monthly basis. This is essential to ensuring that the NIHR can report accurately to the Department of Health the number of people actively participating in research. Recruitment data is measured against key performance indicators which are used to monitor the success of the Clinical Research Network and will feed into the process of allocating future funding for NHS infrastructure for research to Comprehensive Local Research Networks (CLRNs). This ensures that infrastructure resources are directed to where they are required for the most patient benefit. The reporting of recruitment data also helps the

Specialty Groups to identify studies which are struggling to recruit and to provide support for these studies. If you are required to upload recruitment data you will be sent instructions on how to do this.

International Standard Randomised Controlled Trial Number (ISRCTN)

One of the Department of Health's policies is to encourage transparency and promote public access to information about research and research findings affecting health and social care. Accordingly, the Department of Health strongly encourages voluntary registration of both interventional and observational clinical research studies on its preferred public register, the International Standard Randomised Controlled Trial Number (ISRCTN) Register, which is the World Health Organization's primary registry for the UK and is administered by Current Controlled Trials Ltd.

The NIHR CRN Coordinating Centre has developed a process which enables automatic and seamless registration of all new UK Clinical Research Network (UK CRN) Portfolio studies via the UK CRN Portfolio.

New non-commercial studies with an interventional component included on the National Institute for Health Research (NIHR) Clinical Research Network (CRN) Portfolio, which are not currently registered with ISRCTN or ClinicalTrials.gov, will be registered 'free' if they choose to register via the UK CRN Portfolio functionality.

Observational, industry-sponsored and devolved administrations studies (i.e. studies without English sites) are encouraged to use the UK CRN Portfolio functionality to register with the ISRCTN; however for these studies ISRCTN registration will incur a fee payable by the relevant organisation/company and invoiced directly from Current Controlled Trials Ltd.

To register for an ISRCTN via the UK CRN Portfolio functionality, log onto the Portfolio database via <https://portal.ukcrn.org.uk/login/> and select 'yes I wish to register for an ISRCTN' and complete the extended minimum dataset required for ISRCTN registration.

The details of your study will be forwarded to Current Controlled Trials and the ISRCTN editorial team will contact you in due course. **Please do not apply directly to Current Controlled Trials if you are registering for an ISRCTN via the UK CRN Portfolio.**

Acknowledgement of Clinical Research Network support

Acknowledgement of Network support must be made when publishing study findings.

It is your responsibility to ensure that the following standard text is used to acknowledge the support of the Clinical Research Network when publishing your study findings in peer-review journals, or any other form of publication:

[Research team or organisation] acknowledge the support of the National Institute for Health Research, through the Comprehensive Clinical Research Network Please do not

hesitate to contact the CCRN Portfolio team should you require further information
ccrn.portfolio@nihr.ac.uk

Best Wishes

Joanna Knee

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NIHR Clinical Research Coordinating Centre (NIHR CRN CC)
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Appendix 4 – Participant questionnaire:



Organ and Tissue donation: an evaluation of health care professionals' knowledge and training and implications for education

This questionnaire seeks your understanding, knowledge, training and attitude towards organ donation and asks your views on how future education can be enhanced. It will contribute to a Doctoral study being completed at the University of Greenwich, School of Education with the aim of identifying the training needs of health care professionals.

Your comments will be used purely for the purpose of research and you as an individual will not be identified in any way.

The questionnaire is divided into four sections:

- Section 1:** About yourself.
- Section 2:** Your attitudes towards organ & tissue donation
- Section 3:** Your education & training relating to donation
- Section 4:** Focus group interview invitation

Thank you for your contribution Tim Collins

Please can you return questionnaire by:

Section 1: About yourself

1. What is your health care profession?

(please tick the appropriate box)

Registered Nurse

Doctor

ODP

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

2. Are you male or female?

(please tick the appropriate box)

Male

Female

3. How old are you?..... years

(please state in years)

4. How many years have you been a registered

health care professional? *(please state in years)* years

5. Where did you undertake your initial pre-registration training?

United Kingdom

Europe

International

6. What academic Higher Education qualifications do you currently possess?

(please tick appropriate boxes)

No academic qualification

Diploma in Higher Education

BSc or Bachelors Degree

BM & BS (equivalent)

MSc/MA (Higher Degree)

Other.....

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

7. Please identify your current band or post :

For Nurses & Operating Department Practitioners (ODP) Band *(please circle)*

4 5 6 7 8a 8b 8c Other (please state).....

For Doctors *(please circle)*

F1 F2 SHO Registrar Senior Registrar Staff Grade Consultant

Other (please state).....

8. Which hospital department do you do most of your work in?

(please tick the appropriate box)

Intensive Care (ICU)

Emergency Department (ED)

Theatres

9. Do you work in a hospital which regularly undertakes organ transplantation (e.g. either liver, renal, heart transplants)? Yes No

Section 2: Attitude towards organ and tissue donation

With 0 being the most negative and 10 being the most positive - please circle the following responses to the questions:

10. Do you feel that organ donation is positive and produces benefits to patient outcomes? *(please circle)*

Strongly negative 0 1 2 3 4 5 6 7 8 9 10 **Strongly positive**

11. Would you recommend to a friend or family member to join the Organ Donor Register?

Yes No Unsure

12. How many multi organ donor patients have you cared for in your career? *(please circle)*

0 1 2 3 4 5 6 7 8 9 10 other (please state)

.....

13. How many occasions have you been involved in the management of a patient donating their tissues? *(please tick)*

never 1 2 3 4 5 other (please state)

.....

14. How many occasions have you approached a family asking for tissue donation consent? *(please tick)*

never 1 2 3 4 5 other (please state)

.....

15. Are you discouraged from asking relatives for donation as you perceive this could increase their distress?

Strongly disagree 0 1 2 3 4 5 6 7 8 9 10 **Strongly agree**

16. Do you consider the option of organ and tissue donation as part of end of life care? *(please circle)*

Strongly disagree 0 1 2 3 4 5 6 7 8 9 10 **Strongly agree**

Section 3: Your education and training

17a. Were you given any education on organ/tissue donation in your initial pre-registration training? (please tick) Yes No Unsure

b. If yes, please could you tick how this education was delivered?

Lecture Seminar Group work Directed study Personal reading
Problem Based Learning Other (please state)..... Cannot remember

c. If you received pre- registration education on organ/tissue donation how many hours did this equate to?

(please state).....hours or cannot remember (please tick)

18a. Have you had any education on organ/tissue donation as part of your post registration Continuing Professional Development (CPD)?

Yes No Unsure

b. If yes, please could you tick how this education was delivered?

Post registration University Education In house Trust training programmes
Personal reading Teaching from in-house Specialist Nurse for Organ Donation
Study days Other (please state).....

c. If you were given CPD education on organ/tissue donation – please specify the number of hours and the date/year this took place:

Date/year: **No of hours** or if cannot remember exact no-
do you think it was
< 2 hours 2-5 hours 5-10 hours cannot remember

19. Did the education in your initial pre-registration training adequately prepare you for identifying & managing potential tissue donors as part of end of life care? (please circle)

Strongly disagree 0 1 2 3 4 5 6 7 8 9 10 **Strongly agree**

20. The education given in initial pre-registration training has adequately prepared me to identify and manage potential solid organ donors (please circle).

Strongly disagree 0 1 2 3 4 5 6 7 8 9 10 **Strongly agree**

21. The education given in post registration CPD has adequately prepared me to identify and manage potential organ donors (please circle).

Strongly disagree 0 1 2 3 4 5 6 7 8 9 10 **Strongly agree**

22. Do you feel you can effectively explain brain stem death to a relative?
(please circle)

Strongly disagree 0 1 2 3 4 5 6 7 8 9 10 **Strongly agree**

23. Do you feel that you can explain the differences between organ and tissue donation to a relative (please circle).

Strongly disagree 0 1 2 3 4 5 6 7 8 9 10 **Strongly agree**

24. I am aware of the differences in management between donation following Brain Death (DBD) and donation following Circulatory Death (DCD) (please circle)

Strongly disagree 0 1 2 3 4 5 6 7 8 9 10 **Strongly agree**

25. The majority of patients who die can at least donate one tissue
(please circle)

Strongly disagree 0 1 2 3 4 5 6 7 8 9 10 **Strongly agree**

26. Are you aware of the absolute contraindications for solid organ donation?

Yes No Unsure

Please state the absolute contraindications for solid organ donation (if unsure please leave blank).

.....
.....

27. I am aware of the contraindications to tissue donation (please circle)

Strongly disagree 0 1 2 3 4 5 6 7 8 9 10 **Strongly agree**

28. I feel that I have been adequately educationally prepared to ask consent for tissue donation from bereaved relatives (please circle).

Strongly disagree 0 1 2 3 4 5 6 7 8 9 10 **Strongly agree**

29. I have enough knowledge and understanding of donation issues to explain the process to bereaved relatives (please circle).

Strongly disagree 0 1 2 3 4 5 6 7 8 9 10 Strongly agree

30. I understand the role of the embedded Specialist Nurse in Organ Donation within my hospital (please circle)

Strongly disagree 0 1 2 3 4 5 6 7 8 9 10 Strongly agree

31. I know how to contact my embedded Specialist Nurse in Organ Donation (please circle)

Strongly disagree 0 1 2 3 4 5 6 7 8 9 10 Strongly agree

Please use this box to tell me how you think future education and training relating to organ and tissue donation could be improved

Section 4: Focus Group Participation

Opportunity to take part in focus group interview

The focus group will aim to generate discussions relating to health professionals views on their knowledge and education relating to donation which will hopefully provide more descriptive data that may not necessarily be captured in the questionnaire. The interview will be taped recorded and discussions will be transcribed into manuscripts. This will be used solely for the purposes of the research study and confidentiality and anonymity will be assured.

I would be willing to take part in a focus group interview (please tick)

Yes

No

If you ticked YES, that you would like to take part in a focus group, please provide your e-mail address below:

.....

Please note that your e-mail address will only be used for the purposes of this research and will not be shared with any other parties. Confidentiality will be assured but will be overridden in cases of serious malpractice or patient abuse.

Please can you return your completed questionnaire by ***** (date) to Tim Collins in the internal mail using the pre-addressed envelope provided.

Thank you for completing this questionnaire.

**Tim Collins (tim.collins@nhs.net)
ICU Clinical Nurse Educator,**

Appendix 5 – Questionnaire introduction letter



Dear Colleague,

I am currently studying for a Doctorate in Education at the University of Greenwich and would like to invite you to take part in a research study as part of my thesis. This study aims to evaluate acute health care professionals' knowledge and training relating to organ and tissue donation and its implications for education.

This research is being conducted under the supervision of Franca Kinchington, (F.Kinchington@greenwich.ac.uk), Principal Lecturer at the School of Education & Dr Paul Street (P.A.Street@greenwich.ac.uk), Principal Lecturer in Health and Social Care at the University of Greenwich. The research has been granted full NHS Research Ethical Committee approval.

I would be grateful if you would complete the attached questionnaire and return it to me via the internal post in the pre-addressed envelope. Please return the questionnaire by the *****. You do not have to participate in this study and you are free to withdraw at any time with no repercussions. All questionnaire responses will be anonymous unless you would be willing to take part in a focus group interview and in that case you would be asked to provide an e-mail address. This e-mail address will be used solely for the purposes of this research and would not be shared with any other parties. Confidentiality will be assured but will be overridden in cases of serious malpractice or patient abuse.

It is hoped that the results of this research will inform future developments in the education and training of health care professionals relating to organ and tissue donation. This will hopefully enhance future education which will increase health professionals' knowledge and confidence in donation management which will ideally influence patient care.

Thank you very much for reading this letter and hope that you will agree to take part in this study. If you have any questions please do not hesitate to contact me.
Yours sincerely

Tim Collins
Intensive Care Clinical Nurse Educator,
Intensive Care Unit,

Questionnaires

I would like to invite you to take part in a research project which is looking at evaluating acute health care professionals' knowledge and training relating to organ and tissue donation and its implications for education. This leaflet gives you more information about the study – please read it carefully before deciding whether to take part or not.

If you would like to take part in the study:

- You will need to fill in a paper copy questionnaire that will be sent to you
- This questionnaire can be filled in anonymously if you do not wish to be interviewed as part of a focus group

What is the purpose of the study?

Currently there is a national shortage of organs and tissues available for transplantation. The transplantation waiting list continues to get longer and outstrips supply (DH 2008). An organ or tissue transplant has been proven to be an effective life enhancing treatment for end-stage organ or tissue failure. Most organ donors come from patients being managed in critical care areas such as Intensive Care and Emergency Departments. Therefore, it is vital that health care professionals recognise, manage and identify potential organ & tissue donors in these clinical areas. In 2008, the Department of Health (DH) recommended that all health care staff who are potentially involved in the care of donor patients should receive appropriate education and training. This research aims to evaluate staffs perception of this training and education and assess if this perceived knowledge is applied to clinical practice. There has been no UK multi-professional research evaluating staff education and knowledge towards donation management. This research will aim to evaluate staff education and provide future recommendations to enhance learning and training strategies for health care staff. This research does not involve any patients or body tissues themselves.

Why have I been invited?

The majority of organ donor patients are identified and managed in critical care areas such as Intensive Care Units (ICU), Emergency Departments (ED) & Operating Theatres (OT). This study will be recruiting participants from acute hospitals within England. All Registered Nurses, Operating Department Practitioners and Doctors who work in ICU, ED, OT within hospitals in the sample sites will be invited to take part in this study.

Do I have to take part?

No. It is up to you to decide whether or not to take part. Before you decide, I ask that you read this information leaflet. If there is anything that is not clear or you would like more information, please contact the researcher using the details at the end of this leaflet. If you decide not to take part, you do not need to give a reason and this will not affect you in any way. In this case, please disregard the questionnaire.

How do I volunteer to take place or withdraw from the research?

If you would like to take part please complete the questionnaire and return this in the self reply envelope. The questionnaire will be anonymous unless you would be willing to take part in a focus group interview. The interviews will aim to generate discussions relating to health professionals views on their knowledge and education relating to donation which

will hopefully provide more descriptive data that may not necessarily be captured in the questionnaire. Only complete the personal data section if you are happy to be interviewed. If you agree to be interviewed you will be given a consent form to sign. As the questionnaires are anonymous once you have sent back your questionnaire you will not be able to withdrawal from the research. If you decide to take part in the focus group interviews you can withdraw from the research at any time.

What will happen if I take part?

You will be sent a paper copy of a questionnaire via your workplace. If you wish to take part in this research, please complete the questionnaire and return it in the self reply envelope provided. The researcher will never have contact with you unless you agree to be interviewed. If you do not wish to be interviewed, completing the questionnaire will be all that you need to do, all data will be anonymous. If you do wish to be interviewed please put your name and e mail address on the questionnaire by the relevant section and the researcher will contact you to arrange a convenient time and place for you to attend a focus group interview, again all data will be anonymous and confidential.

What are the benefits of taking part?

There will be no real benefits to you, but you will have knowledge that you are taking part in research that aims to enhance future training and education relating to organ and tissue donation. This research will provide front-line staff, the opportunity to generate solutions and identify future strategies that will revise and change future education programmes. This research may lead to new education programmes which will aim to increase staffs knowledge and confidence which will hopefully improve donation management as well as possibly influence the availability of organs for transplantation. This research will be published which will ensure the results are disseminated widely to ensure future developments are undertaken.

What are the disadvantages of taking part?

You will have to spend time reading this leaflet, completing the questionnaire and maybe attend an interview.

Will my information be kept confidential?

Yes, any information collected from you during this research will be kept strictly confidential. The questionnaires are anonymous and no names or hospitals will be identified in the writing up of the research. This research has been granted full NHS Research Ethics Committee approval. Academic supervision is being given by Francia Kinchington, (contact details), Principal Lecturer at the School of Education & Dr Paul Street (contact details), Principal Lecturer in Health and Social Care at the University of Greenwich.

What will happen with the results?

The researcher will give you the opportunity to have a copy of the results if you wish to read them. The results will be published in health journals at the end of the study.

For further information on any aspects of the study contact:

Tim Collins with contact details

Phone:

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

Appendix 7 – Reminder letter for questionnaires



Dear Colleague,

Questionnaire reminder:

Recently you were sent a questionnaire inviting you to take part in a research study that aims to evaluate acute health care professionals' knowledge and training relating to organ and tissue donation and its implications for education.

This is a gentle reminder in case you have not had chance to complete and return your questionnaire. If you have already returned your questionnaire, thank you very much. As all the questionnaires are anonymous and confidential, I do not know if you have returned your questionnaire and this letter aims to be a general reminder to all staff who have been invited to take part in the study.

If you would still like to take part in the study, there is still time to submit your questionnaire.

This research study has full NHS research ethics committee approval and is a registered National Institute for Health Research (NIHR) portfolio study. It is hoped that the results of this research will inform future developments in the education and training of health care professionals relating to organ and tissue donation. This will hopefully enhance future education which will increase health professionals' knowledge and confidence in donation management which will ideally influence patient care.

You do not have to participate in this study and you are free to withdraw at any time with no repercussions. If you have decided not to complete your questionnaire, I apologise that you have been sent a reminder letter.

Thank you very much for reading this letter and hope that you will agree to take part in this study by finding time to complete and return your anonymous questionnaire.

Tim Collins
Intensive Care Clinical Nurse Educator,
Contact details inserted here

Appendix 8 – Focus group invite letter



Dear Colleague,

I am currently studying for a Doctorate in Education at the University of Greenwich and would like to invite you to take part in a research study as part of my thesis. This study aims to evaluate acute health care professionals' knowledge and training relating to organ and tissue donation and its implications for education.

This research is being conducted under the supervision of Francina Kinchington, Principal Lecturer at the School of Education & Dr Paul Street, Principal Lecturer in Health and Social Care at the University of Greenwich. The research has been granted NHS ethical approval.

Thank you for returning your completed questionnaire for this research study. In the questionnaire, you kindly agreed that you would be willing to take part in a focus group. The focus group will aim to generate discussions relating to health professionals views on their knowledge and education relating to donation which will hopefully provide more descriptive data that may not necessarily be captured in the questionnaire.

The focus group will taking place on the following date and time. The location of the meeting will be at**** It is envisaged that the focus group meeting should take no more than 1hour.

The focus group will be taped recorded and discussions will be transcribed into manuscripts. This will be used solely for the purposes of the research study and confidentiality and anonymity will be assured. However, if a case of malpractice or patient abuse is suspected, any confidentiality agreement would be overridden. A consent form is attached to this letter and you will be asked to sign this form prior to taking part in any focus group discussions.

If you would like to participate in this focus group, please can you confirm in e-mail to me by ***** Following no reply after this date a second reminder letter will be e-mailed to you. If for any reason you would like to opt out of receiving a second reminder, please e-mail me stating that you would like to opt out. You do not have to participate in this focus group despite you initially acknowledging this on the returned questionnaire and you are free to withdraw at any time with no repercussions.

It is hoped that the results of this research will inform future developments in the education and training of health care professionals relating to organ and tissue donation. This will hopefully enhance future education which will increase health professionals' knowledge and confidence in donation management which will ideally influence patient care.

I very much hope that you will agree to take part in this focus group. If you have any questions please do not hesitate to contact me.

Yours sincerely

Tim Collins - contact details inserted here

Appendix 9 – Participant information sheet for focus groups:



PARTICIPANT INFORMATION LEAFLET Focus Group Interviews

I would like to invite you to take part in a research project which is looking at evaluating acute health care professionals' knowledge and training relating to organ and tissue donation and its implications for education. This leaflet gives you more information about the study and taking part in the focus group interviews– please read it carefully before deciding whether to take part or not.

If you would like to take part in the study:

- If you are happy to be interviewed you will have provided your contact details on the relevant section of the questionnaire that you have already completed.
- You will be contacted via e-mail with further details relating to the interviews.
- Even if you have stated your intent to take part in an interview when you completed your questionnaire, you can still change your mind and do not have to provide any explanation to your decision.

Currently there is a national shortage of organs and tissues available for transplantation. The transplantation waiting list continues to get longer and outstrips supply (DH 2008). An organ or tissue transplant has been proven to be an effective life enhancing treatment for end-stage organ or tissue failure. Most organ donors come from patients being managed in critical care areas such as Intensive Care and Emergency Departments. Therefore, it is vital that health care professionals recognise, manage and identify potential organ & tissue donors in these clinical areas. In 2008, the Department of Health (DH) recommended that all health care staff who are potentially involved in the care of donor patients should receive appropriate education and training. This research aims to evaluate staffs perception of this education and assess if this perceived knowledge is applied to clinical practice. There has been no UK multi-professional research evaluating staff education and knowledge towards donation management. This research will aim to evaluate staff education and provide future recommendations to enhance learning and training strategies for health care staff. This research does not involve any patients or body tissues themselves.

Why have I been invited?

Thank you for completing and returning your questionnaire which you stated that you would be willing to take part in a focus group interview. The focus group will aim to have between 8 to 12 health care professionals who are either Registered Nurses, Operating Department Practitioners and Doctors who work within Intensive Care Units (ICU), Emergency Departments (ED) & Operating Theatres (OT). This study will be recruiting participants from acute hospitals within England. You have been invited to participate as you expressed an interest in taking part in the focus groups when you completed your questionnaire.

What is involved in taking part?

Participants who take part in the focus group interviews will contribute to discussions on evaluating education and training relating to organ and tissue donation. The interviews will take place on NHS Trust property away from the clinical environment and should last for approximately 1 hour. The focus group will be tape recorded and discussions will be transcribed into manuscripts. This will be used solely for the purposes of the research study and confidentiality and anonymity will be assured. However, if a case of malpractice or patient abuse is suspected, any confidentiality agreement would be overridden. All data will be kept securely and will only be accessible to the researchers. All data will be destroyed following completion of the research study. Prior to the focus group commencing you will be required to

sign a consent form. The consent form will ask participants to declare that any conversations in the focus groups are to remain in the room and are not to be discussed outside of the interviews.

Do I have to take part?

No. It is up to you to decide whether or not to take part. Before you decide, I ask that you read this information leaflet. If there is anything that is not clear or you would like more information, please contact the researcher using the details at the end of this leaflet. If you decide not to take part, you do not need to give a reason and this will not affect you in any way.

How do I volunteer to take place or withdraw from the research?

If you expressed an interest in taking part in the focus group interviews when completing your questionnaire, the researcher will contact you with further information relating to the focus group. If you decide to take part in the focus group interviews you can withdraw from the research at any time with no ramifications.

What will happen if I take part?

The researcher will contact you to arrange a convenient time and place for you to attend a focus group interview, again all data will be anonymous and confidential. You can change your mind at anytime if you do not wish to take part in the interviews with no ramifications.

What are the benefits of taking part?

There will be no real benefits to you, but you will have knowledge that you are taking part in research that aims to enhance future training and education relating to organ and tissue donation. This research will provide front-line staff, the opportunity to generate solutions and identify future strategies that will revise and change future education programmes. This research may lead to new education programmes which will aim to increase staffs knowledge and confidence which will hopefully improve donation management as well as possibly influence the availability of organs for transplantation. This research will be published which will ensure the results are disseminated widely to ensure future developments are undertaken.

What are the disadvantages of taking part?

You will have to spend time reading this leaflet and attend approximately 1 hour interview.

Will my information be kept confidential?

Yes, any information collected from you during this research will be kept strictly confidential. Discussions will remain anonymous and no names or hospitals will be identified in the writing up of the research. This research has been given full NHS Research Ethics Committee approval. Academic supervision is being given by Francia Kinchington, (contact details inserted), Principal Lecturer at the School of Education & Dr Paul Street (contact details inserted), Principal Lecturer in Health and Social Care at the University of Greenwich.

What will happen with the results?

The researcher will give you the opportunity to have a copy of the results if you wish to read them. The results will be published in health journals at the end of the study.

For further information on any aspects of the study contact:

Tim Collins,	Phone:
ICU Clinical Nurse Educator,	E-mail:
Contact details inserted here	

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



Appendix 10 – Focus group participant consent form

Study title: Organ and Tissue donation: an evaluation of health care professionals’ knowledge and training and implications for education

Participant Identification Number for this study:.....

CONSENT FORM FOR FOCUS GROUP.

Title of Project: Organ and Tissue donation: an evaluation of health care professionals’ knowledge and training and implications for education.

Name of Researcher: Tim Collins

Please initial box

I have been consulted about participation in the research project. I have had the opportunity to ask questions about the study and understand what is involved and give my consent.

I understand that I can withdraw from the study and focus group at anytime, without giving any reason and without any repercussions or legal rights being affected.

I give consent for my conversations to be taped recorded and to be used solely for the research study only. I am aware that my discussions will be transcribed into manuscripts solely for the research.

I give consent for direct quotes to be used in the research thesis. I am aware that the direct quotes will be anonymous and will not mention any details which could identify the individual or workplace. I am aware that if any cases of malpractice or patient abuse is suspected, any confidentiality agreement would be overridden

I understand that all discussions within the focus groups are to remain confidential and will not be repeated outside of the interviews.

Name of participant:

Signature of participant:

Date:

Researcher seeking consent:

Signature of researcher:

Date:

Appendix 11 – Focus group interview schedule

Study title: Organ & Tissue donation: an evaluation of health care professionals' knowledge and training and implications for education.

Chief Investigator: Tim Collins

Please find below interview schedule for focus groups. More specifics relating to the focus group interviews have previously been submitted to REC and have been approved.

Time (mins)	Question	Comments
0-10	Introduction & welcome, Consent of staff attending. Ensuring that informed consent for attendees is obtained. Explain that interviews will be taped recorded for research purposes only. Confidentiality of discussions within the interviews. Thank staff for attending.	Set the aims of the research Ensure that each staff member attending has been given the Participant Information Sheet (PIS) and has been given enough information to make an informed decision to sign the consent form. Explain about recording of conversations and transcripts being used for research purposes only. Confidentiality within the interviews as stipulated on consent form.
10 -20	Do you feel that providing mandatory education in pre-registration health professional training towards organ donation would increase staffs confidence in donation?	
20 -30	Do you feel that providing mandatory yearly training for all registered critical care professionals as part of CPD would enhance confidence in organ donation?	
30 -40	What donation education and training do you feel needs to be concentrated upon relating to this subject?	
40 -50	What role do you feel education and training has in ensuring that donation is considered as part of routine end of life care?	
50 -60	Why do you feel that Health care professionals are not provided with education and training on donation?	
60 – 70	What do you feel is the most important component to enhancing donation rates in the UK?	
70 – 75	Conclusions & thank you for attending. Summarising the key discussions of the meeting.	

Appendix 12- Guidelines for conducting interviews

Guidelines for conducting interviews taken from Cohen et al (2007) p. 366.

- Interviews are an interpersonal matter
- Avoid saying “I want to know.....”; try not to make the group feel as though they are being interrogated
- How to follow up on questions/answers
- How to keep people on track and moving forward
- Show your group respect
- Ensure you divide your attention as an interviewer to share out the interviewees responses- giving them all a chance to speak in a group interview
- Do you ask everyone in a group interview to give a response to a question?
- Who is looking at whom
- If you need to look at your watch, then maybe comment on this publicly
- Try not to refer to your interview schedule; if you need to refer to it then comments on this publicly (e.g. “let me just check that I have covered the points that I wanted”).
- Avoid using your pen as a threatening weapon, pointing it at the interviewees
- Consider your non-verbal communication, eye contact, signs of anxiety, showing respect.
- Give people time to think- don't interrupt if there is silence.
- How to pass over from one interviewee to another in the group
- How to give feedback and acceptance to the interviewees
- Should you write responses down- what messages does this give?
- Put yourself in the shoes of the interviewee
- What are the effects of losing eye contact or of maintaining it for too long?
- Think of your body posture- not too laid back & not too menacing
- How to interpret & handle silence
- Avoid looking away from the respondent
- Avoid judging the respondent in his or her response
- Avoid interrupting the respondent
- The interviewer should summarise and clarify issues and build on them- this shows respect.
- How to give signs of acceptance to what people are saying & how to avoid being judgemental.
- Take care of timing- too long can be boring
- Give interviewees the final chance to add any comments and thank them at the end.
- Plan how to arrange the chairs and tables; tables may provide a barrier to communication.
- Take time to “manage” the interview & keep the group aware of whats happening and where it is going.
- Vary the volume/tone of your voice
- Avoid giving your own view or opinion; be neutral
- Who is saying more the interviewer or interviewees – should be interviewees
- Think of prompts & probes.
- How to respond to people who say little?
- Consider the social & physical difference between the interviewer and the rest of the group.
- Consider layout of the furniture- circle, oval, straight or what?

- Have a clear introduction which makes it clear how the interview will be conducted & how the interviewees can respond.
- Make sure you summarise and clarify every so often
- Do you have males interviewing females & vice versa (think of age/gender/race etc of group)
- Give some feedback to respondents every so often
- What is the interview doing that cannot be done in a questionnaire?
- Plan what to do if the interviewees become upset or angry in the interview
- Make the group aware that the interviews are anonymous & confidential unless patient safety issues are highlighted and confidentiality would be breached due to code of professional conduct in by protecting the public from harm.
- Plan what to do if powerful interviewees don't answer your questions; maybe you need to admit that you haven't understood very well and ask for clarification.
- Be very prepared, so that you don't need to look at your schedule.
- Know your subject matter well.
- If people speak fast then try and slow down everything.
- As an interviewer, you have the responsibility for making sure the interview runs well.

Flo Panel-Coates,
Director of Nursing,
Maidstone & Tunbridge Wells NHS Trust,
Hermitage Lane,
Maidstone,
Kent
ME16 9QQ
26/4/11

Dear Sir/Madam,

Re: Tim Collins, Doctorate of Education Thesis, Integrated Research Application for Ethical Approval.

I wish to confirm that Tim Collins has discussed his proposed plans for his research titled; “Organ and Tissue donation: an evaluation of health care professionals’ knowledge and training and implications for education”. As Director of Nursing for the Trust, I support Tim with his application for this research which he is undertaking as part of his thesis for the Doctorate of Education at the University of Greenwich.

The research aims to undertake an evaluation of health care professionals’ knowledge and education following attending training relating to organ donation. This research will help to inform future education and training relating to this subject which I am sure will help to enhance future patient care and staff experience.

I support Tim with his ethics application and look forward to seeing the research results.

Kind regards

Flo- Panel Coates,
Director of Nursing,
Maidstone & Tunbridge Wells NHS Trust

Appendix 16 – Focus group interview transcript:

Transcript of FOCUS GROUP interviews:

Date: 4th October 2012

Start time: 11:09

Chief Investigator: Tim Collins

CI: Whenever we talk can we just say Nurse 1, Nurse 2 or Chief Investigator (which will be me).

Thank you very much first of all for attending I can now say that you all signed your consent forms and everybody is willing to be here.

(Another Nurse walked in at this point)

CI: Hello. I was just gaining consent from everybody. I'm just going to have to repeat that again. You're going to be Nurse 8 and I need you to sign a consent form.

Nurse 8: I've brought the letter.

CI: Thank you. If you could fill that out and sign it, are you quite happy that we're going to be tape recording?

Nurse 8: Yes.

CI: Brilliant. It's going to be completely confidential so it's not going to be related to your name, your Trust or your hospital. We're all nurses here. Thank you very much to everybody for attending. I'm going to ask a few questions and then I want a discussion from you and before you talk can you just say Nurse 8, Nurse 5 or whatever just for the transcript. I just need to make that clear.

So, what I'm going to do is just ask you a few questions and I just want to clarify first of all about attitude towards organ donation and just throw this question to you – do you think that education and training produces an attitude made in favour or produce a negative effect towards organ donation?

Nurse 8: Yes I think education can take on a favourable attitude on organ donation because I think there is a lack of knowledge and you may not have an opinion either way so I think more education will help your attitude become more favourable towards organ donation.

CI: Ok, do we agree with that? There's a few head nods.

Nurse 8: No, I don't know if I would agree with that and it's keeping it in the kind of conscious level so its education and then its continually having discussion points so full education to a point but just keeping it at the top of the agenda at meetings and forums like that.

- CI: So from your experience then as a group do you think that people have had more education training towards organ donation have a more positive attitude towards donation?
- Nurse 2: Yes.
- Nurse 4: Agrees.
- CI: Does anybody in the room disagree with that?
- Nurse 5: I think sometimes it has, a lot to do with education, but it depends how it comes across and I think relating to practice as well a lot of people have the education but then in practice they're still not happy to actually approach or to talk about it so I don't think its always, we all agree, we have education and we're all for it but when it comes into practice sometimes that then is a problem.
- CI: Do you think there maybe a component because, especially with donation following death it's not a daily occurrence so its all well and good giving the education but its backing it up with that exposure isn't it.
- Nurses: Yes.
- Nurse 6: I think the education thing is good and does make people more aware that nothing prepares people for the individual circumstances and every individual organ donation situation or withdraw of treatment, everyone is different and nothing prepares you for that other than experience. It certainly helps that you've got the knowledge there in the first place but the circumstances are all so different and some very traumatic and nothing prepares, especially a junior nurse for that sort of situation.
- Nurse 7: Education and training is so important for nurses relating to donation. I did not really know much about this until I started in ITU. The education given to me really opened up my viewpoint towards donation and I did not know how many benefited from one donor. This is remarkable. The education given to me by the transplant nurse (SNOD) really improved my perception of donation and I went straight home after training to join the donation register. This training made such a difference to my outlook to donation.
- Nurse 3: I agree with that and sometimes you can see the family and they're grieving already and then to approach them with another issue sometimes it is difficult to do and sometimes you nurse a child and probably happy with that, it is difficult as a junior nurse to do the approaching.
- Nurse 7: I don't think it should ever be up to a junior nurse to do the approaching and it would worry and trouble me if I felt that a junior nurse was left in that situation and I would question that that would be the right approach at all because I think there is a lot of evidence to suggest that the way you approach the family has a distinct impact on whether they say yes or no and I don't think its fair at all to put that burden onto a junior member of staff who, again, lacks the experience and might have had the education but without the build of experience over time to do that. You would have to do that with reports and again what we're being encouraged to do now more

and more is make that approach with the organ donation people because they get that and its proven to be more effective so I fully understand junior nurses, I think senior nurses have the same, its just that they kind of almost have to, we do their job role almost, it is their job role to kind of bring these things up and discuss them but I can certainly discuss any difficulty than a junior member of staff...

Nurse 3: I would just like to reply to that, yes sometimes we're the ones at the bedside that would be there to approach...

Nurse 3: Yes, but we can see what the family's going through and when you do identify to the senior nurses we have to formally put forward that the family might not be in a position to be approached for that. Just thinking what the care issue is, it might not seem appropriate at that time so that's another issue that we considered.

Nurse 2: I would like to also add, if possible, that I think organ donation at the moment seems to be in a little bubble on an ITU unit that is only for deaths or for heart beating donors but potentially every death could be a possible organ donation whether its cataracts or skin or whatever so I think more education needs to be given which is obviously junior members of staff and should then be involved in that process to be able to be led by a senior nurse that has experienced maybe some of it before so that they can then identify more patients potentially an organ donation or if they can't manage it themselves then to refer it on obviously would be referred to the Organ Donation Team anyway but then to be able to refer it onto a senior member of staff before all the things happen and things could be processed a bit better.

Nurse 5: there's so much of it out there, and you're all aware about organ donation, tissue donation and I think you're then approached so I think yes, education certainly has to be involved, it's nice to have that approach where you get the chance to be involved but often its not that way in practice is it.

Nurse 8: Going back to your original question within the team, I can give you a specific example of how education helped me in my attitude towards organ or tissue donation. I went on a bereavement study day when I was a junior nurse and we had a talk from a relative and she said she hadn't been approached about an organ donation, she actually felt cheated that she hadn't been approached and that changed my whole attitude because I never thought of it that way, I felt it was a very sensitive issue I'd feel awkward discussing that with a relative when they'd just lost a loved one but when she said that I thought yes, somebody had denied her that right and didn't mention it at the time, she was too upset to even think about it and afterwards she felt cheated so its made me think and feel that I always should say something to relatives however difficult that is so for me that was a good example of how training and education changed my attitude.

CI: So do you feel then, and one of the questions was, and Nurse 2 sort of highlighted it, is tissue donation 80% of people who die can at least donate one tissue, do you think that occurs regularly within your hospitals?

Nurse 2: No

- Nurse 4: No
- CI: Why do we think that is?
- Nurse 2: Fear, from the nurse that's looking after the patient and their families, lack of understanding, lack of support not just from an ITU point of view but from a Ward perspective, when I worked on a Ward I didn't know anything about organ donation, I knew nothing that we could refer, until I worked in Intensive Care Unit I knew nothing, I didn't know the process, I didn't know how it would happen and there could be, so obviously from that point of view I think it, yes, it's just the fear of not knowing what to do.
- CI: So do you think education and training would help because 80% of people who die and they don't have to be in A&E or ITU they can be on the wards, they can be in a palliative care setting even, why do you think the major restrictions of that is not actually happening?
- Nurse 6: I think that educations always been very much focused on Intensive Care staff and A&E staff and possibly Theatre staff, I think the nurses out on the wards don't get the education that we get (Nurse 2 agrees) and there isn't the push there at all and I think it needs to change its focus a bit, resources for education are limited which we know they are, it mainly needs to now move into the general ward areas more so than in Critical Care.
- Nurse 7: Yes, I think even when in Critical Care the focus for a long time has been on organ donation as opposed to tissue donation and in fact if you speak to the Transplant Coordinator, they will say that too because that's where their targets are driven and they're not target driven on tissue donation yet so that might change but I think that there is a distinct lack of education on tissue donation relative to what we've personally received on organ donation, the focus has very much been on that and I think that the proof is that we're much better now at referring an organ donation for even in ITU there are loads of wards who have never had training at all we've failed to pick up their tissue donation time and time and time again.
- I think that education now has a real part to play because of the focus that it has gone wrong but for organ donation really.
- Nurse 6: What about education and medical staff as well? I think that's something that has been neglected and again, not just Intensive Care medical staff but medical staff in general. They, I believe, get very minimal education on tissue and organ donation.
- Nurse 7: Have any of you mentioned a donation to a doctor and he's gone "oh" because they know that it's going to create more work, it does create more work and you can see that they, I get the impression sometimes that they thought it themselves but hadn't wanted to go there and hadn't wanted to say anything and then we bring it up and of course we force them down that road and you can see they don't want it, they don't want to know, they don't want the work involved but again I think they get various education learning and its how well the nurses are trained in ITU.

- Nurse 6: And I think there's still the perception from them "oh no, I've got to do the approaching" and "I really don't want to do that." Yes they have got to partly but we have now got the Organ Donation nurses in place in all the Trusts to help them but I don't think they are really fully aware of that and it's still, the thought, they're only human, we don't want to approach relatives so they feel exactly the same and I'm sure none of them have had specific training on how to approach relatives.
- Nurse 2: It's a bereavement and death issue isn't it, it's always been such a taboo thing. We can plan for a lovely hospital stay but we can't plan for a lovely death and unfortunately death is part of life and it's something that has always been a problem for nurses and doctors I think, especially in Palliative Care and to encourage people to get home to die but all of these issues have always been so troublesome and obviously organ donation is one of those really awkward, difficult issues and one that we don't ever really want to discuss because we don't like to talk about it.
- Nurse 5: Does that need a multidisciplinary team? If you haven't got the whole team backing you up you always think the same that's when it starts all falling down isn't it and then you'll get the union, the relatives have confidence in you so I know what you're saying so if you haven't got that back up, you can just be one voice and it won't actually go forward will it.
- Nurse 1: I think some issues are related to national education as well. If there's ever anything interesting about organ donation it's on very late at night on the television and I think that there needs to be more focus on general education in the population as well as
- CI: Does everybody agree with that?
- Nurse 4: I know somebody that is a nurse who still believes that if you had a doctor that is looking at organ donations that won't save the patient as much and that's a nurse that thinks that. What are they meant to think if that's the perception?
- CI: Has anybody got any thoughts on that?
- Nurse 3: I think I believe as well that there should be part of the initial pre clinic assessment when they first come in that is a good time to actually approach, sometimes the patient can still talk to you and actually give the views on that. That would be an easy way to bridge the gap between when it comes to the end, it is easier to do it initially and just get the views.
- Nurse 8: I think that's a really good point and we were talking earlier about how it's so difficult to approach the relatives about it but I sometimes think if you can make it a bit more of a routine thing that you do, a bit like, I work in A&E and I routinely ask patients if they smoke or not, yes or no and then routinely offer them smoking cessation advice and I just do this as part of my session and a quick question "have you thought about giving up," if we made the question about organ donation or tissue donation and routine, this is what we always ask, sorry to offer but to save time do you know if you have any wishes about organ or tissue donation, just make it as a routine question. Maybe you can get ask to all.

- CI: Does anybody disagree with that? Or do you all agree with that?
- Nurse 5: No, I think it depends on what the patient comes in with especially on ITU. I think it would be nice, as you say, approaching the people on the organ donation register that could lean one way to another on the initial assessment but I think sometimes if you've got someone who's come in who's critically ill and you start going through their assessment you ask about organ donation that might actually if anything "hang on a minute" because the feedback you get, and obviously, I've been in a situation where someone's actually said to me "you are actually going to try and save whoever you're not just going to you know, because you want the organs", so its quite difficult.
- Nurse 3: I still think that its part of the assessment just coming under the initial assessment part of the spirituality religious beliefs, I think it can possibly come under that box.
- Nurse 2: I agree with both of you with what you're saying but I think that maybe it should have been done, I know a lot of people, primary care rather than secondary care because people can give their wishes obviously much earlier now which is what the organ donation card is for but we all don't know if they're on the organ donation register but I do agree with what you're saying Nurse 3 but I also agree with Nurse 5, I think that could be a very awkward situation especially if they've come in, in a very critical condition but maybe something could be done to find out much sooner.
- Nurse 6: Yes, at one time it would take a huge culture change but at one time we wouldn't ask people whether they agreed with, whether they wanted to be resuscitated. When I first started nursing you wouldn't dream of asking a patient that when they came in prior to their hysterectomy or whatever surgery they're having but nowadays people do ask what their wishes are and that took a huge culture change so I agree it would be incredibly difficult and I think it would take quite an experienced nurse to assess whether that was appropriate or not but it is something possibly for the future that we ought to think about.
- Nurse 4: I think it is GP stuff, I think they should be discussing it there; they know their patients more as or in pre-assessment. When they come into ITU if they're really ill I don't think that's necessarily a good time to ask.
- Nurse 1: I think it's something for pre-assessment or GP assessing, again, in ITU you do it on people, they're not confident in the care that's going to be provided and when, in that situation.
- CI: Just to clarify for the tape we talk very much about organ donation do we also talk about tissue donation as well so do we think that, say somebody comes in to Acute Emergency into A&E onto the Ward do you think tissue donation should be approached there?
- Nurse 3: Yes.

- Nurse 5: I think, again it's down to the individual's situation isn't it, the individual circumstances and the assessment at the time but I still agree that it should be done...
- Nurse 2: ...About having a discussion about resuscitation I think that would be an opportunist time to be able to ask about tissue and organ donation if you're going to be talking about whether they have a living Will or whether they have any wishes about whether they want to be resuscitated and whether if after their death they would like to donate their tissues, their whatever, I think that would be a good time.
- Nurse 7: I'm struggling to know what to think really because I'm kind of thinking, I'd go with the fact that its such a good thing that we talk about it on a regular basis, we are getting patients regardless if its such a normal thing to ask that it doesn't have the stigma that we are all associating with it and if we could get to that stage it would be fantastic. Not being at that stage I'm sitting here feeling really uncomfortable about talking to anybody really about whether, yes when they're well but not when they're coming in and they're sick as to "we're going to do our best for you but if we can't can we have your tissue or your organs" it just, I'm finding that difficult, I wish we were at a level where it was routing and natural and we had that discussion with everyone. Until we're there I feel very uncomfortable with mentioning that to any patient directly or their family until we knew we were in a position where we were likely to lose that patient or we were going to withdraw...
- CI: Do you think UK culture and values has a role to play with that, from a different country who, do you think it's our part of the UK culture? I don't want to try and bias you with anything here but do you think it may be viewed differently if you're from a different country?
- Nurse 3: No, I think in the UK, we're more accepting under that, people from a different country I notice a totally different issue, the majority, probably would be against it.
- Nurse 6: Just one last think that I would like to say which it's possibly being a bit negative but having done recent audits on the ward I'm finding that regularly nurses can't ask people what they're preferred name is or what food they like to eat so to actually then going for something that is so much more complicated, more emotive I think we're a very, very long way from being able to do that.
- CI: Ok, we're going to move on to another question now, thank you very much and as you're probably aware this is quite unnatural for me not to be talking so much but I try not to bias you in any way. I try and let the discussion flow and just give some points.
- I'm going to now ask specifically two questions in relation to pre-registration education and that could be for any healthcare professional, so even though you're looking at nursing we've already mention a bit about doctors training but for pre-registration and I'm going to ask another question on post-registration.

When you did your questionnaires, they were sent out to 18 hospitals across the UK and the response rate was 1,180. Does it surprise you that 23% of that sample only had education in pre-registration training on donation or tissue donation as well? Does that surprise you?

Nurse 2: No.

Nurse 5: No.

CI: So when do you think that the subject of tissue and organ donation should be taught? Should it be taught at pre-registration or at post-registration?

Nurse: Both.

CI: How should that education and training be delivered and at what level and what topics in relation to donation and I'm including tissue donation into that for pre-registration?

Nurse 3: Under the care of the acutely ill module.

CI: So we're talking nationally now, not just your local site so in a care of the acutely ill module should donation and organ...

Nurse 2: My first experience in organ donation was when I was a pre-registration nurse in the hospice and they routinely had tissue donation from the hospice so it's not obviously organ donation and yes probably in an acutely ill module but as that's part of palliative care as well. It's an all rounder, really.

Nurse 6: Yes, I think its part of the care of the dying and so maybe it should be in that sort of area that is taught.

CI: So do you think that it should be compulsory for pre-registration training?

Nurse 2: As part of palliative care and the care of the dying, yes. As part of looking after an acutely ill patient I think that should be post-registration training in my opinion because that, I feel, needs to be more education and training and all the rest of it.

Nurse 1: I think that pre-registration students need to have an awareness because it is in a care setting and they will come across the situation so I think it's the about focusing the acute pre-registration training and the palliative care but also I think it's valid almost on day one, the general awareness, because they will encounter this, these discussions, in their day to day life and they are healthier and presentative even when they're not at work.

Nurse 5: I agree.

Nurse 8: (nodded head). I agree.

CI: Anybody not agree? Anybody got any comments on anything that's been said there?

- Nurse 6: Yes, I think I agree very much with what Nurse 1 said about an awareness as opposed to very in depth full pre-registration, it needs to be an overall awareness rather than a lot of stuff to have to simulate and to remember and the other thing is should it not be taught at schools?
- CI: So public school education?
- Nurse 5: I actually went to tissue donation awareness at and that actually went down quite well. Various comments but I agree that it should be out at schools.
- CI: So would you agree then it should be compulsory school education.
- Nurse 5: Yes, because it's got to make everybody aware as you say it's not in depth it's just the awareness and then the national, them backing it up and media and so on.
- Nurse 2: when you apply for your driving licence or renew your driving licence you have to tick the box, "do I consent to being an organ donator in the event of my death" and passports as well, so you will try to specify it to nurse education or medical people that are being trained for it but you still have to have a general need to know whether you would like to be able to donate those organs if you were in a car accident.
- CI: Any more comments on that? Ok, I just want to bring it back down to pre-registration nursing as some of the interesting comments you've said, two questions, how do you think the education for pre-registration would, if you agree they should have it, should be delivered? Should it be delivered through a lecture or role-play or should it be done through directed study and also how many hours do you think should constitute that on the pre-registration programme?
- Nurse 3: I think it should be done in a seminar session like this because with a lecture you get one person's point of view and you don't get to hear the views of other people and that might help you make a decision.
- CI: So, seminar approach.
- Nurse 1: I agree with that but I also think it's good to have someone who has been in that situation and talking about it from their perspective and that helps to create discussion.
- CI: So, perhaps a bit like what Nurse 8 said in terms of she attended a study event and there was a relative there who actually felt cheated but perhaps some of you have been through the process either donated or had a transplant.
- Nurse 4: For someone who has had a transplant to come in and talk, someone could come in and actually started with how they were and then talk through how far they've got.
- Nurse 2: I went to a family of an organ donor as well because they have set up, not all of them, but I have been involved in one. The family had just been overjoyed that they could help 8 people with their Mum's organs and I think

to be able to try and put all of those across to pre-registration students it's just brilliant. I think they would understand so much more and they're interactive and they can see something visual then it's not just sitting listening to information being told to them or given to them or written or whatever. If they actually feel a part of it then it will make a great big impact on them.

Nurse 3: I think pre-registration students should definitely be given donation and transplantation education. It almost demeans something if it's not covered in your nurse training and it should be taught as so many people can benefit from donation especially tissues. When I was a student I was involved with my mentor witnessing a donation and I did not understand how many people can benefit from one donor. I spoke to the transplant coordinator (SNOD) and they gave me teaching on the unit. This made me very positive towards donation and changed by viewpoint. I think education at pre-registration focusing upon the benefits of donation would be very productive and increase students' attitude for the better.

Nurse 4: I think perhaps the organ donation people could put together some sort of video DVD where they interview lots of different people and then could use that in pre-registration and then there could be a discussion afterwards and then everybody would get the same kind of thing and there would be a bit more thought from across the country.

Nurse 8: I think that's a really good idea and I'd like to have a discussion afterwards because I think that organ and tissue donation can be quite an emotive topic and you said about doing a directive study or big group lectures, I don't think that's suitable for such an emotional topic where people might be too upset and may have had experiences themselves or may not want to talk about it.

CI: What about e-learning?

Nurses: No.

Nurse 1: I think sometimes that e-learning can be very superficial and also it creates emotions that can't be discussed and explored so could be detrimental.

Nurse 6: Yes, I agree and I think when you're doing e-learning, you're often alone; you've got nobody to bounce any ideas off or say "what do you think of this" or getting any support from. I think it's totally unsuitable for that.

CI: So we all agree with that? Everybody agrees with that. Nurse 4's idea of the video tape and the discussion does anybody disagree with that?

Nurses: All agree. Good idea.

CI: Has anybody else from the table got any other initiatives that perhaps could be used in pre-registration education.

Nurse 3: Sometimes it is difficult to give the message even in a seminar like this because although you get people's views and stuff like that, what is it actually trying to do, is it trying to convince you that it is the right thing to do

or is it trying to convince you that there should be a policy that makes it mandatory? Or you might be personally for or against it, is it ok to decide whether to enforce that view on the relatives of the patient involved?

Nurse 8: I think that's wrong.

Nurse 3: Because lots of the discussions that we have is really about finding out about all views and how we portray a patient, should it be mandatory whether to involve your personal beliefs or not?

Nurse 7: I know this is probably going to sound quite but I think it should do, I think you should put your personal beliefs aside. I think we go back to what Nurse 8 was saying earlier on about how you could cheat somebody; you could cheat a family member out of making that decision. If you denied them the opportunity to do, we're not saying that you're making the decisions to donate organs here, we're saying that you're asking a relative whether it's something that they would then choose to do and it's got to be their choice so I think that personal belief unfortunately, it sounds a bit harsh but I think we have to push that to one side and I think that's why it's really, really hard just from personal experience I know that one of the doctors that I work with, he's not comfortable with organ and tissue donation. I'm not convinced if it was he and his family he would consent to it, I think he, he's that uncomfortable with it and so for him to then have to ask family members whether it's what they would choose to do is really, really hard for him but actually I think, yes, he has an obligation to do so.

Nurse 2: I think that kind of goes with everything really, patients that have got beliefs, religious beliefs, Jehovah witness that won't accept blood, nurses might be Jehovah as well and they might not agree, it comes under the same category. You can't be judgemental, you can't be discriminatory, you have to be down the line and give everybody the same choices, the same opportunities and the same opinions.

CI: Thank you very much for that, that's good, I'm just going to go back to the second part of the question now which was how long in hours do you think time perhaps should be put into pre-registration training?

Nurse 2: I don't think you could quantify it really.

CI: You couldn't quantify it?

Nurse 2: I don't think, yes as a session and a video with maybe a couple of hours but I think it's an ongoing thing. You can't say "well there's your training, bye." I think as a pre-registration student I think yes. A good morning even a good day on organ donation would be ideal. In reality I don't know how that would work with pre-registration students but you would need continuous support and training throughout your nursing career. I don't think you could quantify it for pre-registration in hours.

Nurse 8: I understand what you're saying but I think that practicalities of planning a syllabus would have to quantify it so maybe you could give an amount of time to, say a morning or an afternoon and make it 3 hours that will give

them time and us to get more information and more support about things if they want to.

Nurse 6: Yes, I agree. I think a half day session would be about right really because then you could have Nurse 4's idea about a video and then plenty of time for discussion and what have you afterwards. That seems to sound about right, a half day session because there's a lot of competing things I'm sure a Nurse in education has got to be crammed in and would probably find it difficult to put more time over to it.

Nurse 4: Yes, you have to also consider the educators whether they're up to date with things as well because you could show the pre-registration students a video and they go and ask one of the lecturers who isn't up to date and they could undo all the good work that was done.

Nurse 8: What I think would be a good idea is having something like a video that Nurse 4 suggested, some period of time for discussion but then some actual guidelines because we were saying about how to put your emotions aside, you need to teach them how, what patients are appropriate for referral and how to quickly go about doing it. They're just some simple guidelines about how they need to do that so you're giving them an awareness of organ and tissue donation but also some practical advice on how to go about that.

Nurse 7: I think that in terms of medical pre-registration training, I think a lot of it, all of that would be a part to play and I think a little part would be about how do they do this in practice and I don't think they do enough of that of any nature in fairness, the nurse training is a communication throughout the whole spectrum of nurse training and will come back to it time and again and I'm not sure whether that's the case. I think it's better than it used to be but a huge element of it particularly the doctors and I say doctors because it is generally them when they get consulted about doing the approaching with the donation people but they just need to be better at being able to do it in an empathetic way and they struggle with that. If we could embed it early on, it would be really brilliant.

Nurse 8: I think role-play's really good for nurses in this situation so practising those situations. I don't think that's appropriate for a pre-registration nursing student. They shouldn't be put in a position where they're having to do that but the more senior people are and I think role-playing is a definite.

CI: So, we're looking at pre-registration, would you agree with role-play for doctors for pre-registration or just looking at role-play for post-registration?

Nurse: Pre-registration.

CI: Does anyone think role-play for pre-registration nursing students would be a benefit?

Nurse 1: I think it would have to be at the very end of their training and maybe in preparation for being a qualified nurse but I think role-play is probably more appropriate.

- Nurse 4: I think if you put it in the pre-registration as role-play, I think they'd almost get panicked that they're going to be put in that situation whereas I think maybe an awareness video knowing about it would be better and then they can build on it in post-registration when they are more confident.
- CI: Ok, I'm just going to ask one question till we move onto the CPD, i.e. post registration, did any of you in the room have any training or education in pre-registration on organ or tissue donation.
- Nurses: No. (All nurses said no).
- CI: Do you think that would have helped in your careers and in your confidence in approaching families for either tissue or organ donation if you had education in pre-registration?
- Nurse 4: I don't think it would have helped me approach anybody but it would have helped me personally in getting my head round it as it were so that I would feel more confident to go on and better those skills.
- Nurse 6: I don't think it would have helped me approach relatives at all but I think it would firstly be great because it would get the message out to the wider public because as nurses you often get asked about these things and also it would help if you are suddenly stuck in the situation where a relative says 'can he give his organs' and that can happen, it doesn't matter how junior you are, if you're looking after a patient, that question can come out of the blue and if you haven't had any education on how to answer that question, we've all said we don't think junior nurses should be approaching and I don't think that education at that stage would help you approach but I think that's it vital.
- Nurse 2: I think that as Nurse 6 said pre-registration training wouldn't have helped me to approach but it would've helped me to identify patients with the possibility of being able to donate and then make a referral to senior or, looking from a ward perspective as a Ward Nurse there are always many opportunities I think that could have been there and are always missed.
- CI: There's lots of head nodding, anybody disagree with that?
- Nurses: No.
- CI: So everyone in the room agrees with that. Any more comments?
- Nurse 7: I think that it's balanced if you go to the environment, and again critical care is the only environment I know with post-registration there and I arrived at a time when it was really high on the agenda. It was brilliantly managed in the hospital at the time and I got a lot of support post-registration so I didn't feel that I'd lacked pre-registration but I can only imagine if I'd gone to the ward environment where I hadn't had that ongoing education and support, I would have been of any knowledge about it at all.
- Nurse 2: I think, just going on from what you are saying, I had one experience of corneal donation in the hospice and one experience of pre-registration and

until I went into Intensive Care, absolutely nothing, not a word, I knew absolutely nothing.

CI: Why do you think tissue donation is probably not up there as being asked for like what you just said?

Nurse 2: Lack of awareness.

Nurse 3: I agree. I start a year and a half on the wards before I went to MAU and there is not one person that was ever referred in that year and a half.

CI: So how can this awareness be raised?

Nurse: Pre-registration nursing training.

Nurse 6: I think pre-registration training is vital but also the ward managers, there needs to be training for them as well so the ward leaders, the Band 7's and the Band 6's need to be leading their teams to think that way and I think their education is lacking I'm sure they're all in the same situation that we were in, they didn't have any pre-registration training so where do they get their training? We get it as Intensive Care nurses and as A&E and Theatre nurses but where do the senior staff on the ward get their training from? My thought is they probably don't get any more than the junior staff.

Nurse 8: Four or five years ago I arranged a bereavement study day for the nurses in A&E and then because we grew I put it out to the Trust as well and are absolutely inundated with people who wanted to attend it and I just did it as a one off and after that, several months afterwards, people were asking whether I was going to arrange the next one. It was really popular and I felt like there was a real lack of knowledge.

CI: Thank you for that, what we're going to do now is going to move onto CPD, so post-registration. First of all I'm just going to ask the question to you have you, being in your careers since you've been registered nurses, had post-registration education training on organ and tissue donation?

All Nurses: Yes.

CI: Everybody has. I'm just going to give you some findings from the survey, out of 1180 from the questionnaires which were returned from 18 hospitals and this was doctors and nurses and working in A&E and ITU, 56% of them had CPD donation education and the remaining hadn't. Does that surprise you?

Nurse 8: No because I don't think there is an opportunity, to me the training seems to be very ad-hoc. There doesn't seem to be any definite programme, it's not on the mandatory training that we do so it's just really depending on if you've got a good Trust Coordinator who is arranging lots of training days or if someone has a particular interest, I think it is just on an ad-hoc basis.

Nurse 6: Can I just ask of that percentage of people, the people that you asked were they mainly Critical Care nurses?

- CI: Yes, Critical Care doctors and nurses, A&E and ITU.
- Nurse 6: Yes, because if you were looking over the whole range of nurses that figure would be massively lower, even just looking at Acute Care nurses, it would be massively lower.
- CI: They were A&E and ITU predominantly. So in terms of post-registration education do you agree it is essential within those Critical Care areas?
- All nurses: Yes.
- CI: How do you think that should be delivered in terms of education strategies, how often it should be delivered if at all?
- Nurse 4: Well I've had training on organ donations as part of my ITU course on three courses and I had a locally run course here where the organ donation team were involved and of the two the second one was much more beneficial because it was a lot more personal – a relative come in and that was sort of like a bit more, I don't know, but that's where it needs to be.
- Nurse 1: I think you can target sessions using a specialist nurse for organ donation in Critical Care area and I think that gives people an opportunity to talk about their specific concerns but it also embeds the knowledge at that point in time so it's much more honest.
- Nurse 4: It's also, if you're the nurse in charge and you've got an organ donation potential or something like that, that's when a lot of education takes place as well because you just get approached by everybody so it's whoever's in charge and whatever experienced nurse is around that are really key to educating more junior members of staff and that's when it can all, like you say it embeds everything that you might have done before.
- Nurse 5: I think as well having the lead nurse, someone or group of people and they can go along to that quite a few years and actually and having all the information there and all the folders the Trust Coordinators and that made a lot of people aware and happier about it, not approach but aware.
- Nurse 6: I also think that those, whatever sessions that are arranged and whatever form it goes upon should be multi-disciplinary, it shouldn't just be nurses and it should happen together because in real life it happens. It's the multi-disciplinary team and so different people's feelings can be discussed in those so I think it's vital that it's multi-disciplinary.
- Nurse: It's often out of hours as well isn't it.
- Nurse 2: This less people around.
- CI: You mentioned about a study day, I want to home in a bit more now, you all agree that education post-registration is essential but I want to home in a little bit more about how that education training should be delivered. You were saying about study days, I'm trying not to bias you here and tell you particular methods of teaching and learning but how do you feel that message and that education training should be delivered to staff?

Nurse 4: foundation course, they should be involved with them.

CI: So formal study days?

All nurses: Yes

CI: E-learning?

All nurses: No.

CI: So formal study day.

Nurse 1: People see e-learning as a chore and I think that would be a real shame if you associated something like this with the chore of e-learning.

Nurse 4: There is so much e-learning now and it is a tick box exercise, its often done in busy working clinical environments which are not conducive to learning, you got so many distractions on the wards. I learn nothing because I have 10 things in my head for what I need to do for patients and don't absorb the learning. I also get no study time if I do it out of work. Its just so that the NHS can say they have provided training for their legal needs but on the front line its not developed my learning or knowledge. If I could be given time to go to the library and not worry about clinical pressures I would absorb the learning more

CI: Would everybody agree with that?

All nurses: Yes.

CI: Do we feel that a study day is essential in terms of seven and a half hours for all staff or do we feel there is other ways of delivering that education?

Nurse 2: I think there could be a combination of things, I think a study day is vital I think for the theory knowledge and the understanding of it but also the participation if there is the opportunity to be involved in a part of an organ donation, even sessions with the organ donation nurse that's based at the Trust to find out what they do if they have the time, maybe if the units quiet just to be able to say "I was involved with this" and just talk about experiences I think and that's the best way to learn is about learning other people's experiences but also to be involved as much as you can as part of an organ retrieval or tissue retrieval. That's the best way I found that I learnt.

Nurse 4: As part of the seven and a half hours there should be a quite a big chunk devoted at the end for discussion because you can discuss it at work and you do learn at work as well but I think when you're focused about a topic you might think of something that you need to then ask people's opinions about then and the in-house one that I did where they had a relative come in that really opened up lots and lots of discussion so I think that was beneficial.

- Nurse 1: The culture within the unit needs to be supported on formal education training but you also need to bear in mind that Trust's are under a lot of financial constraints and we do need to be creative about how we deliver that so I think that sometimes formal study and follow up on a regular basis may well need to be done in the unit environment but equally so being able to get away from that environment and attend a study day, again it's also a very important way to go about it.
- CI: Do you feel as a group or an individual that organ donation for Critical Care staff and when I say Critical Care staff that's A&E and ITU, should be mandatory each year for all staff all module professional staff?
- Nurse 8: No.
- Nurse 2: I would say yes.
- Nurse 8: I don't think it needs to be every year. I think it should be mandatory that they have some training but I don't think it needs to be repeated on a yearly basis.
- Nurse 2: I disagree. I think it should be.
- Nurse 4: I don't know what I think but you don't want it to become basic life support and all the other rubbish that you have to do and I think it should be something that is creative and you learn from it rather than being...
- Nurse: Yes, I think it needs to be kept fresh and updated and I think, like you say, mandatory study days are a bore, lets not lie and it doesn't want to become a bore but I think if you don't have refresher training and to be able to consolidate those that already have and any experiences that you have you can't then apply those to practice and I think on a yearly basis to update would be a better thing to be able to do that to be able to think back and use the knowledge that you've had before to be able to use it in a different way.
- CI: And who, if you do go down the mandatory training route and we've already said we don't think that should be e-learning, who do you think would be the best people to facilitate that?
- Nurse 2: Those that have been involved in it most.
- CI: So the specialist nurse for all donations.
- Nurse 2: The Clinical Educator, link nurses as well.
- Nurse 3: The people who are up to date, interested and well presented, not people who are there because they've got to present it. But now we've got the organ donation, people on most units, an ideal time would be round about or after a recent donation on the unit and then that, if they put a session up then you get more people that are likely that are going to want to come and will remember that they need to go so strike while the irons hot.
- CI: And how long do you think should be dedicated to that?

- Nurse 6: I think it depends who goes and where the discussion goes. What's beneficial for one person might not be for another, that's going to be a difficult one to judge, again, you don't want it to become a particular exercise they've got to get something out of it.
- Nurse 5: We've got some junior staff study days coming up and we've got the Coordinator coming along and we've discussed how to run that session and in the end we've just, we've slotted it at the question and answer session and that may not work very well but we're going to give it a go and we'll probably learn from that as to whether it works or not but it will be interesting to see how beneficial that happens to be rather than a structured form of putting slides up and giving a presentation of whatever, I'm intrigued to see, that's at the end of this month, it will be interesting to see how that works and I wouldn't suggest you do that every time but it might be something to throw in every now and again.
- CI: Any more comments on what we've just said?
- Nurse 2: Only just quickly that obviously your perception as a junior member of staff to a senior member of staff changes dramatically with your involvement of organ donation, the level of teaching you require I think and also your involvement in the whole of the organ donation process. I know that my perceptions changed vastly since I began in ITU.
- Nurse 4: I would also say that I wouldn't exclude clinical support workers. Having spoken to two clinical support workers on an organ donation day last year, they were very interested from their own personal perspective but also felt that they were better aimed to support staff when that situation rose.
- Nurse 8: You're talking mainly about it being mandatory for nurses working in the Critical Care areas but I was thinking, all of our registered nurses now attend the RN induction programme in the Trust and I know that's quite a full packed programme anyway but they have a day where they meet lots of different individuals, I don't know that they meet the transplant Coordinator then but would that be an opportunity for them to come along and introduce themselves and give a quick résumé of what they're all about and organ and tissue donation for half an hour.
- CI: I can't comment.
- Nurse 8: Because then it would increase awareness wouldn't it. Nurse 3 was saying he worked 18 months on a ward and there was no tissue donation because none of the staff knew about it. If that was in our induction programme just an introduction that might be quite good.
- CI: Thank you. I'm just going to ask one question and then we'll be closing. Do you feel, this is obviously your anecdotal feelings because you probably haven't got any rigorous quantifying evidence to support it but do you feel that if you receive and your department or your Intensive Care Unit receive good education and training on donation that would have an impact upon the number of organs and tissues available for transplantation?

- Nurse 2: Yes.
- CI: So if you had a good organ training process in place using vigorous education strategies that you feel would have an impact upon the number of organs and tissues obtained.
- Nurse 6: Yes, I think it would but I think it would be small, I think it would be a very small impact but any impact is vital really. I think it would but it needs to be multi-disciplinary because it doesn't matter how well educated the nurses are if the consultant in charge doesn't agree...
- Nurse 3: Same for me as well, I think they need to be solely focused to or something so patients are identified and are approached as mandatory, preferably earlier rather than later.
- Nurse 5: At the moment we, everybody who we now do that
- Nurse 2: It still doesn't matter what the patients requested, it's still actually the right that they will have to give their consent don't they.
- Nurse 6: I think the main impact of education would be on the wards.
- CI: Tissue donation?
- Nurse 6: Tissue donation, yes. It would be, I think there would be a small impact on ITU but we could get quite a big impact on the wards.
- Nurse 4: Also you would have to look at managerial levels looking at beds and everything else because inevitably you will have patients in A&E that are 4 hour breaching and they want the bed on the ward and you potentially may have time to the patient on the ward when you need a ward bed and I can just see the conflict that that would cause on the wards.
- Nurse 7: Again, that's an education thing because tissue donation shouldn't delay anything.
- Nurse 4: I know it shouldn't.
- Nurse 7: But I think that's an education thing too they feel that that's a reason for not going down the road of tissue donation because it might prolong things...
- Nurse 4: Which the majority needs to be the bed managers and people like that that get that education as well because they are working to targets and breach times and everything else so, you can educate all the ward nurses but if the bed manager says "no I need that bed in half an hour" that's going to go.
- CI: So what do you think are the major stumbling blocks then for the ward staff implementing tissue donation?
- Nurse 6: Lack of awareness.
- Nurse 2: Support from senior staff.

- Nurse 7: It just not being a Trust-wide ethos, it isn't there; it's not high on the agenda.
- Nurse 8: We need it to be a target.
- CI: Has anybody got any comments, anything that they want to add relating to the FOCUS GROUPS?
- Nurse 8: I've got something to add and that is, on the few occasions I've been involved in tissue donation, I think it's only tissue donation I've been involved in, in A&E, I find it really pleasing that you get feedback about what's happened. I think that's a really good thing and I'm sure that continues but that encourages you to be involved because it's nice to get feedback about what's happened and you get a letter of thanks and that's a really good thing.
- CI: It brings it all home doesn't it.
- Nurse 8: Yes and it makes you feel that it's all worthwhile; it's good to hear that. There's so many things we don't get feedback from like the nurses are always saying "we fill in an IR1 form and we don't get to hear what happens" and that's one of their biggest things and you stop doing it but when you get feedback about things and you think "oh yes, that's good" it encourages you to do that behaviour again.
- Nurse 5: One thing I wanted to ask is, some Trust's I've heard is that when they go, when someone dies and they go down to patient therapy the next day, 24 hour, 48 hour count, that they've actually approached and asked the relative's about tissue donation but does that actually in our Trust?
- CI: No.
- Nurse 5: And would that be something of a possibility because the patient that's come in has been dealt with in bereavement and dealt with, it's in that gap as well.
- Nurse 6: In this Trust they will sort things out and if the patients' relatives suggest it at that meeting they will then take it forward but I don't think they will actually approach.
- CI: Is that similar to anybody else who has worked in any other Trust? Do you think that, that happening nationally may make an impact?
- Nurse 2: Personally I think yes it probably would because if we and that person then sits there, maybe it would.
- CI: Any further questions from anybody?
- Nurse 5: I think contact with the Trust Coordinator is really beneficial, the more that can be around, the more they can be visible to all the staff and I would imagine, this is obviously going to spread them very thin, but if they were more accessible to the ward staff then they would raise the profile, how many of them are there and how can they stretch themselves around the whole Trust site but we're lucky in Intensive Care, we do look after lots but

the more you see them the better because quite frankly because they all converse with staff and on an ad-hoc basis and that really is keeping it. Education is fantastic but it is just keeping that profile high as much as anything.

CI: So do you think it would have an impact on donation rates if every hospital, not Trust, but every hospital had a Monday to Friday (not necessarily a Monday to Friday) but the whole time equivalent based on site?

Nurses: Yes.

Nurse 5: There should be a SNOD present in every hospital to maintain that presence and education at present they are a scarce resource. There needs to be more of a presence on each hospital as it will embed donation in practice if there was a consistent presence. The SNODS are so stretch covering different hospitals, they cannot achieve this and there should be more of them. They can also provide more education to both critical care areas and the wards.

Nurse 7: I'd like to think so because the ward but they don't because that's not their I don't know whether that will change or not I don't know.

Nurse 8: Can I just ask then what, we've got (Name stated and deleted for anonymity) haven't we but is he just our Trust or is he spread out?

CI: He works across the two sites but quite often they have to go to meetings within the network, go up to the NHS BT for meetings so its not like how we would structure Critical Care out for each cover which is like generally their Monday to Friday or some Trust's even more.

Nurse:1 And he does on-call for the whole of Kent.

CI: Yes.

Nurse 1: So he might be away doing those things as well.

CI: And then annual leave, study leave and all that.

Anybody else, I don't want to cut anybody else off, has anybody else got anything else to say?

Thank you very much, that was really, really helpful.

What will happen now, this all gets typed up and transcribed and then it goes into all the research that's being done and it supports the questionnaire whatever's been done as well.