Evaluation of the experiences of family members whose deceased relative donated tissues at the NHSBT dedicated donation facility in Speke, Liverpool.

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1.0 INTRODUCTION

Donation of human tissue for transplant and research has historically been facilitated within the hospital mortuary. In a bid to control the conditions under which tissue for transplantation is retrieved and in response to European guidance on quality[1], NHSBT Tissue Services opened a facility dedicated to the retrieval of tissues under strictly controlled conditions in Speke, Liverpool. The Dedicated Donation Facility [DDF] in Speke, Liverpool opened in 2006 and was the first of its kind in the UK.

2.0 BACKGROUND

In considering opening this facility it was recognised that there needed to be a clear distinction between the consented retrieval of tissues for transplantation and research, and the un-consented retrieval and retention of tissue and organs that had occurred in the past[a]. In view of the dedicated facility being sited in Liverpool, a City closely associated with the Alder Hey retention scandal, NHSBT Tissue Services consulted widely about the proposed DDF; and in conjunction with the Royal College of Pathologists commissioned an independent market research company to explore the attitudes of donor families to their deceased relative being transferred to the new facility for tissue donation. As this consultation gained positive responses regarding moving potential donors to the dedicated facility, it was agreed that a two year pilot study of donor transfer would be undertaken.

The pilot study was guided by a Steering Group which included representatives from the: Royal Collage of Pathology, the Coroners' Society, British Medical Association Ethics Committee and donor families. The pilot study included identifying hospital sites within a 40 mile radius of the DDF that could facilitate potential tissue donors.

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[a] For a detailed report see Sque et al [2008][2]

The Alliance Site Model [ASM]

In order to facilitate donation at the DDF, three hospitals from Liverpool were signed up as Alliance Sites. This necessitated discussions with Trust Boards and the development of close working relationships as the model of referral for the Alliance Sites removes the responsibility for discussing and requesting tissue and corneal donation with a bereaved family from the health professionals who are providing and facilitating end of life care within the Alliance Site Hospitals. Health professionals within the Alliance Sites are instead tasked with: providing family members with a leaflet discussing tissue donation, telling the family that they may receive a call from TS and notifying the National Referral Centre [NRC] of all deaths occurring within their ward areas and supplying contact details of the next of kin to the NRC. The request to the family for corneal and multi tissue donation is therefore made by specially trained registered nurses based in the NRC.

Operationally, the facility has been deemed a success and therefore NHSBT Tissue Services now intend to expand the DDF model to a larger geographical area. Before doing so, and as part of the two year pilot study, the experiences and views of family members who had agreed and experienced the transfer of their deceased relative to the DDF for tissue retrieval were explored and assessed. To this end an independent evaluation team at the University of Southampton was requested to carry out an audit of the experiences of family members whose deceased relative had donated tissues at the NHSBT DDF in Speke, Liverpool. This report documents the process and outcome of that evaluation.

3.0 AIM OF THE EVALUATION

Aim 1: To understand the decision-making process of those family members who agreed to their deceased relative being moved to the DDF at Speke so that tissue retrieval could take place.

Aim 2: To identify any concerns that family members had about their relative being moved and their views on how these concerns were addressed.

Aim 3: To gain insight into the perceptions of family members regarding the 'service' provided to them by NHSBT Tissue Services.

4.0 DESIGN AND METHODS

A service evaluation applying qualitative data collection methods and framework analysis[3] were the methods chosen. The framework approach has been developed specifically for applied or policy relevant qualitative research in which the objectives of the investigation are typically set in advance and shaped by the information requirements of the funding body/service organisation[4], in this case NHSBT Tissue Services.

4.1 Sample

Recruitment aimed for a purposive sample of 20 relatives of deceased multi tissue donors. This sample size was based on: i) the number of deceased donors who had been transferred to the DDF in Speke between October 1st 2006 and April 31st 2009 [n=69], and ii) response rates in research requesting participation in a study discussing a sensitive topic [response rate 38%][*].

4.2 Data collection

Data collection was facilitated by face-to-face interviews with family members [n = 8.] The original proposal indicated that face to face interviews and focus groups would be carried out, but as no family

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[*] Sque [1996][5]

member selected participating in a focus group, these did not take place.

Interviews were carried out at a place and time acceptable to the participant and lead evaluator.

Interview questions were based on the aims of the evaluation and sought to explore the issues indicated.

4.3 Data analysis

Following each interview, the digital-recording was listened to several times, until familiarity with the data was established. Recorded interviews were transcribed. Familiarity facilitated recognition of important ideas and patterns such as sequencing or repetition of experiences, views and opinions. Similarities and differences in the data and developing themes were noted in memos and formed a preliminary analysis of the data. Analysis drew on modified framework analysis techniques[3] a method of analysing qualitative data developed specifically for policy studies. The analysis therefore focused on the way people thought about multi tissue donation, the pattern of reasoning and the connections they made to other issues when agreeing to their family member’s body being moved to the dedicated facility, and how they interpreted the information provided to them by NHSBT Tissue Services. Key themes were identified, coded and categorised. Atlas ti version 5.2, a qualitative software data package was used to store the collected data and support the coding process.

5.0 SUPPORT AND QUALITY ISSUES

5.1 Evaluation Team

Mr Anthony Clarkson is an experienced Tissue Coordinator and as Head of Clinical Development has experience of carrying out health service evaluations. The lead evaluator Dr. Long-Sutehall and co-evaluator, Dr. Magi Sque have successfully collaborated on a number of projects in the area of organ donation and transplantation and are aware of the challenges of managing such a project. Dr. Long-Sutehall and Dr. Sque have extensive experience in using the data collection method [face-to-face interviews] and analytic techniques, and of exploring what have been termed 'sensitive issues' such as: the request for organ donation, end of life decision making, and the experiences of family members whose deceased relatives had organs and tissues retained. As such they were well qualified to carry out this evaluation. Dr. Long-Sutehall had day-to-day and overall responsibility for carrying out the evaluation, collecting data/analysis and writing the final report. Dr Sque analysed a random sample of transcripts, and contributed to and edited the final report.

5.2 Support for participants

The aim of the interviews was to ask family members to reflect on their experiences and decision-making when requested to give their permission for NHSBT Tissue Services to move the body of their deceased relative to the DDF at Speke for tissue retrieval. No matter how much time may have elapsed since the death, family members could have been upset during the interviews, or after as they replay the activities within it. Therefore it was essential that the evaluation team were able to facilitate interviews in such a way as to support any family members who became upset. The lead evaluator is an experienced researcher and health psychologist who has also undertaken counselling training and was therefore both trained and able to support family members. Participants were reminded that they could stop the interview at any time if they felt that they do not want to proceed.

The lead evaluator telephoned participants following the interview to check that the participant had been comfortable with the manner and content of the interview. Thank you letters were sent to participants after completion of the interview. Family members were offered a summary of the final evaluation, and all accepted this offer.

5.3 Clinical Governance

Approval to carry out this evaluation was given by the Senior Management Team of NHSBT Tissue Services.

6.0 FINDINGS

6.1 Response to recruitment initiatives

All families that had agreed to the donation of their relatives' tissues being carried out at the DDF since it opened on 1st October 2006, until two months before the planned start of the evaluation 31st April 2009, were considered for participation in the evaluation. During this time line there were 69 donation operations carried out at the DDF in Speke.

Of the 69 potential participants, 50 received recruitment letters [72%]. Nineteen family members [27%] were not sent recruitment letters for the reasons listed in Table 1. Recruitment letters [Appendix 1] were enclosed with a Participant Information Sheet [Appendix 2] explaining the aim of the evaluation, a reply slip [Appendix 3] by which potential participants could respond to the lead evaluator indicating their: agreement to be contacted, their preferred mode and time of contact and their preference regarding participation in an interview or focus group. A pre-addressed, stamped envelope for return of the reply slip to the lead evaluator was also included.

Ten responses to recruitment letters were received [20%]. Of these 10, nine requested an interview and one participant indicated that they did not want to talk about their relative's death, but were willing to answer questions sent to them by e-mail. Despite initial e-mail contact and an agreement to accept the interview questions [Appendix 4] there was no further response from this participant [3 attempts to contact]. As no participants indicated they were willing to participate in a focus group the decision was taken to interview all potential participants who responded.

Table 1. Potential study sample

Potential sample	**N [%]**
Potential participants	69
No. of family members not contacted	19 [27%]
Reasons for non contact	**N [%]**
Families requested no follow-up communication after the donation.	10 [53%]
Donor files unavailable	4 [21%]
Consent not taken by Tissue Services	2 [11%]
Family conflict	1 [5%]
Eye only donor	1 [5%]
No next of kin address available	1 [5%]
Response Rate	**N [%]**
No of recruitment letters sent out	50 [72%]
No of positive responses	10 [20%]

6.2 Participants

Of the 10 participants who responded, eight were women and two were men. Table 2 indicates the relationship of the participants to the deceased and the mode of interview. Nine participants were contacted via the medium indicated on the reply slip [e-mail or telephone] and a time and place for the interview to be carried out was agreed. Interviews were spread over a three month period [July – September 2009] due to one participant working out of the country four days out of five and one participant being out of the country for two months.

Table 2. Mode of interview and relationship of participant to the deceased

Participant No.	Gender	Mode of Interview	Relationship to deceased
01	Male	Telephone	Wife
02	Female	Telephone	Father
03	Female	Telephone	Father
04	Female	Face to face	Father
05	Female	Telephone	Husband
06	Male	Telephone	Brother
07	Female	Face to Face	Father
08	Female	Telephone	Father
09	Female	Telephone	Husband

6.3 Procedure for interviews

Two participants were available for face to face interviews. One interview took place at Tissue Services, Speke, Liverpool and the other at the home of the participant.

All other interviews [n = 7] were carried out over the telephone, either from Speke, Liverpool, or the University of Southampton.

Before commencement of the interview all participants were asked if they had any questions that they wished to ask. After any questions were answered to their satisfaction, all participants consented [Appendix 4] to the interview to take place. Consent was either signed in person at interview [n = 2] or recorded over the telephone [n = 7] with a subsequent hard copy being sent to the participant and returned to the lead evaluator.

All participants were asked the questions listed in the interview Schedule [Appendix 5] and all participants received a ‘Thank you’ letter from the evaluation lead [Appendix 6].

No participants withdrew from the evaluation and follow up telephone calls indicated that whilst participants had been reminded of sad issues at the time of being asked to donate tissues, they were also positive regarding the opportunity to offer some feedback to Tissue Services.

6.4 Findings from interviews

6.4.1 Preamble

As is usual in qualitative analysis the findings and discussion will run in parallel. As the aim of this evaluation was to answer the questions that were set *a priori*, the findings from interview data are presented in the following section and are reported in direct response to the aims. The themes developed during analysis are listed in Table 3 [Appendix 7 and 8] and are linked to the topic guide for easy reference by the reader. Exemplar quotes are used to illustrate a theme developed during analysis. The findings are then summarised and followed by recommendations for practice and service provision.

6.4.2 Factors underpinning agreement to tissue donation

Aim 1: To understand the decision-making process of those family members who agreed to their deceased relative being moved to the DDF at Speke so that tissue retrieval could take place.

As all participants had agreed to tissue donation [and although not a specific aim of the evaluation] the findings section will commence with a brief overview of contextualising information aimed at explicating some of the antecedents to agreement for tissue donation.

All but one participant was pro donation seeing it as a positive initiative in that it had the potential to help others[b]. The negative stance was linked to wanting to leave the world 'with all they had come in to it with'. Two participants were on the NHS Organ Donor Register and one carried a donor card.

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[b] One participant family had been involved in publicity initiatives organised by Tissue Services.

Four participants knew the wishes of the deceased regarding organ donation prior to death [three via family discussion and one via joint registration on the Organ Donor Register], and the rest did not know the wishes of the deceased. Their positive decision appeared to be based on 'the kind of person the deceased was' whereby they were perceived to be 'caring' people who having helped others during their lifetime would wish to do so after their death.

> " I have got nothing to add only the fact that I am really happy that we did it [donate tissues] and I know that my [deceased] would have been happy as well because that's the sort of person that he was and I just feel that if you can help people in a small way without like blowing your own trumpet because that's what we are probably like as a family and my [deceased] was always a giver he would give rather than receive so and we are a bit like that also I think that it is a good thing" [2:16 (114:114)].

In one case the participant was unaware that her deceased relative had signed a donor card until she was told this by a tissue coordinator. This information led directly to the donation as the participant was unwilling [at the time of interview] to consider donation for herself.

> " that was the first time I knew that he was a donor and then of course in the process of the shock of [deceased] having died is trying to focus on what I was being told on the phone, also working with your own thought processes of [what a] donor card meant to me, organs, didn't mean at the time blood tissue eyes bone whatever, but she was very very good she dealt with me very empathetically, she was very friendly, she was very respectful, very sincere and very grateful that I had sort of said yes and I said I am saying yes because my [deceased] had a donor card; you need to be aware that perhaps I would think differently if you were asking me to make a decision if he hadn't got a donor card" [7:4 (7:7) – 7:6 (7:7)].

An important issue from the analysis regarding decision making was the fact that a positive decision was made in the light of very little or no knowledge of tissue donation by all but one of the participants[c].

> "So I think that when they gave me that leaflet and when they explained what it was for I was quite happy to go ahead with that [tissue donation] because to me he is living on through somebody else and he has helped someone and I think it is good but I had never heard of it before to be truthful I have heard of organ donation but not tissue donation" [9:6(41:41)].

Apart from one well informed individual, participants were very much less aware of tissue donation, and were often surprised about what could be donated[d].

> "the first I had any knowledge of tissue donation was a phone call from Liverpool … I was actually amazed that well how many different pieces that they could take how many slivers that they could actually utilise" [6:2(40:40)-6:14 (169:169)].

In seeking to illuminate these positive donation responses in the light of little knowledge and the majority of participants not knowing the wishes of the deceased, analysis focussed on exploring the role of pre-emptive information given to family members by hospital staff, and contact by the tissue coordination staff within the National Recruitment Centre [NRC] in the DDF.

Two participants were in receipt of a leaflet about tissue donation that had been handed to them by Accident and Emergency [A&E] staff. Two participants raised the issue of donation with health professionals when their family member was admitted to A&E. One participant had noticed a poster within the A&E department and after a family discussion had then contacted Tissue Services. Four participants received a 'cool call' from tissue coordination staff within the NRC.

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[c] One participants' cousin had received two kidney transplants in the past and this individual was very well informed about tissue donation.

[d] One participant had received a transplant and whilst being well informed about solid organ donation was poorly informed about tissue donation.

> "I think it might have been at the hospital yes at the hospital I think they gave us, I am not, I can't say 100% sure because it is a bit hazy, a lot happened around that time but I am sure that the nurse gave us some information about it and then maybe somebody called us" [3:2 (15:15)].

> "and it was actually the nursing sister in casualty who gave us a leaflet and all she said was, obviously we had had a cup of tea etc and we had seen [the deceased] and that, and then she said about this she gave us this leaflet for tissue donation and would we accept it and at the time I just said oh yes and I just sort of had all the paperwork together and got back to [the deceased] and then it was the next day in this house that I got a call off somebody to say that we had been given this leaflet and would we be interested and so then what I did after that because obviously I had forgotten all about being given the leaflet to be truthful at that point, but what I did was I asked them to explain what it entailed, which they did, and then I said I would discuss it with my mum, so they arranged to ring me back" [2:2(41:41)]

Clearly, whilst both participants did not read the leaflet provided at the time it was given to them, the fact that the term 'tissue donation' had been raised was registered by them, and whilst the topic of tissue donation was not discussed by A&E staff, neither of these participants were 'shocked' by a call coming from tissue services. This was not the case with those who received a 'cool call'.

> "I found the experience traumatic. It came as a bit of a shock luckily I had my family around me so when I finished the conversation on the phone we had a chat together, but having said all that I couldn't think of any other way that they could approach it. I can't think how it could have been bettered, but it was traumatic definitely. The reason is that I was fourteen and a half when he was born and so he was like my own child as it were he was like six when we got married so it is not like a sibling type thing, but of course they weren't to know. I did find it quite traumatic but how they did it and what they did was not, it was not a problem, it wasn't a problem it was just the whole process I did find difficult" [6:3 (53:53)].

> "She was very good and I have made some notes about how she handled me. She explained everything to me explained

> who she was, where she was from, the fact that was I aware that my [deceased] had a donor card, I said no, and she was telling me what she wanted to take and that was done in, information was being passed to me, but it was very much a telling and it was quite graphic, graphic in the sense of she wanted, I think, to ensure that I fully understood what the process involved and what would be taken, why it was taken and what would happen to it, and this part of course is a very personal thing because for each and every individual everyone is different, and for me I am quite visual, so she was very articulate in the descriptions that she was using so I could picture some of the things she was asking and I found that very ghoulish" [7:5 (7:7)].

All participants found a cool call difficult, usually describing it in terms such as 'traumatic' 'difficult', 'shocking' but as noted above, whilst the topic of the call was distressing or difficult, as was some of the content, the manner in which the calls were carried out was overwhelmingly positive.

> " It was excellent because I do remember, it was a lady, I don't remember her name, but she was really lovely and she was very patient and obviously it was something that I had never ever thought was going to happen, I never realised that I would be doing something like that because I didn't know anything about it, but because she was very experienced in the job that she does and she was very knowledgeable the way she put the questions across, when she had to do the very long questionnaire regarding things like have you ever been in contact with Aids etc she was putting me at ease because she sort of pre-warned me that this question might upset me slightly or this is not so intended to offend, so it was questions like stuff that I would never imagine my [deceased] to be around but they have got to ask that because obviously they couldn't go ahead and do the tissue donation if that was the case, so what I am saying is the way she put the questions across the way she explained everything it was fine I could understand exactly what she was on about she was very good on the phone I would say" [2:11 (74:74)].

> "I just think they have all been absolutely brilliant and I think they should be commended for the way they deal with people and the caring attitude they all have towards the family member" [4:4 (102:102)].

There is very little empirical work exploring the interaction between tissue coordinators and family members who are approached and requested to consider tissue donation and of this almost all focuses on corneal donation[6-10]. One of only two studies investigating the interaction between family members and tissue coordinators was carried out in Australia by Beard et al [2002][11]. Like this evaluation Beard and colleagues [2002] aimed to explore family members experiences and to 'use this information to improve the existing service' [p:43]. Beard et al (2002) sent out questionnaires to 339 family members of deceased tissue donors gaining 197 responses [58%]. The majority of participants had been approached about tissue donation via the telephone [44.9%][sic] and the majority of participants held a positive view of donation prior to the request for tissue donation [35.2%][sic].

Findings supported other work looking at the needs of family members approached about organ donation, as identified needs included: the approach to be made in a sensitive manner[12-15], information to be provided in a manner that facilitated families' understanding of what was required[16], and to be sufficient in both quality and quantity[17], as well as being delivered in a manner that facilitates understanding[18, 19].

Specifically related to tissue donation their findings indicated that family members were aided in decision making if they knew the wishes of the deceased, and were positive about the interaction with tissue coordination staff. In asking family members to comment on what could be improved, Beard et al [2002] listed the following four areas, i) the need to know the outcome of donation[e], ii) the need for education about tissue donation to minimise shock, iii) how too much detailed information was given, and iv) rephrasing 'harsh' questions, such as, 'whether my father has sex with another man' [p:46]. This latter point

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[e] Also an issue in solid organ donation, see Sque et al, [2005][15]

is one that has not been addressed in research and yet the discomfort that family members express is a frequent anecdotal comment by tissue coordinators. This evaluation provides three instances where family members thought there was too much detail about procedures, or that information was shared that they did not feel they needed at this time.

> "You know to a point I didn't really want to know. I think what I wanted to do was put myself in their hands and put my [deceased] in their hands and entrust her body to them and say well you know what you are doing and I have to kind of get on with it… so I became quite practical I think so to a point I was I would have been happy actually to just say do what you want" [1:9 (94:94)]

Whilst there are legal, policy, safety and quality requirements underpinning such questioning it may be necessary to review the impact that these questions and detailed information about processes have on consent rates due to: i) the shocking nature of the questions, ii) the inability of the individual asked to answer these questions, iii) the 'social acceptability' of such questions being asked post death. Experts may argue that these questions are asked of blood donors on a daily basis [without causing distress], but this view ignores the role that death and bereavement play in the emotional response of family members. A blood donor can answer said questions for themselves; a deceased donor cannot, therefore placing the next of kin in the position of talking about sensitive issues without: i) a prior discussion with the deceased, and ii) at a time when they are emotionally and cognitively ill equipped to answer them. As this evaluation has indicated that family members know little about tissue donation, we may propose that it is likely that they know nothing about the nature of the questions that are asked during the request for multi tissue donation, thereby increasing the potential for this questioning to have a negative impact on both consent rates and bereavement.

6.4.3 Moving potential donors to the DDF

Aim 2: To identify any concerns that family members had about their relative being moved and their views on how these concerns were addressed.

The decision making process underpinning agreement by family members for their deceased relative's body to be moved to the DDF for tissue donation appeared to be linked to: i) a positive rapport with the coordinator, ii) satisfaction with the information provided to the family about what would happen, and iii) trust in that what was being said would happen. The main concern was whether their deceased relative would be successfully moved and returned.

> "I suppose you know in hindsight then it is a reasonable request you know, just I suppose you worry about things like that don't you when you are in shock, like oh God is everything going to be alright he is going to be moved you know, it was just a non familiar thing isn't it, but no I think it was alright" [3:5 (49:49)].

> "I think because it is done in such a caring manner and they take into account the emotional state of the people concerned that it was done very smoothly and I think because we had so much to do on that day as well it gave us the opportunity to carry on with all the organising and banks and the death certificate and all the rest of it so by the time all that had been sorted out she was back at the hospital again" [8:2 (59:59)].

Participants indicated that they felt that the tissue coordinators were aware of the anxieties that family members may have as they dealt with all the post death administration and funeral arrangements.

> "So then we took it from there and they went through all the questions etc on the phone and then explained that he obviously had to have post mortem because of the cause of death. Well they explained in full detail very informative that he would then be taken to a place in Speke where they were to remove his, it was his corneas, and explained what they would use those tissues for from the eye, and part of his leg, skin, which would I think it was the calf if I am right, which would help children with spinal injuries etc so at the time we felt that was lovely because at least he would be helping

> other people so that's I was, we were happy to go ahead and do that" [5:5(41:41)].

> "They talked me through what would happen and they dealt with all that [questions and concerns] I am sure. They did let me know when his body could be released so we could sort out get my [deceased] death certificate etc but they kept us informed as things were happening they did it all they arranged everything" [7:9 (61:61)].

Participants felt well informed about all aspects of the donation procedure, but there were two instances where participants were distressed by what they saw when they viewed the body post donation. In the situation articulated in this first quote the participant is 'upset' that what she had been told [and had passed on to other family members] was not what happened. As the person who suggested donation, and facilitated it, this placed her in an uncomfortable position with her family.

> "Well when I spoke to the lady initially about it and I said I didn't want for them to take anything that you would know that it had been taken, you know, I didn't want, if you were going to see my [deceased] afterwards I didn't want it to be obvious that something was missing and she assured me that it wouldn't be. Now when my sister came back from the where they were holding my [deceased] when they went to have a look at him, I said how did he look, and she said it looked like there was something wrong with, he didn't look like he had legs. Now I was a bit like oh they assured me that he would look alright, that that wouldn't be the case or, that would be the only thing that I would bring up about it to be honest and I would say that was a bit upsetting really I didn't speak to my mother about it so that was a bit upsetting" [3:6 (57:57) 3:7(61:61)]

> "and then he said they would take the bones of the legs, well he said they would take them from the thighs to the knees. He said that it wouldn't be noticed because they would pad them out and what have you. Well when I, I was quite upset over that, could have been down to the funeral director, could have been down to the hospital, I just don't know you know and that was the only thing that really sort of cracked me over the whole issue you know because he looked that he had none, he was flat you see and I looked and he had no shape there at all and when we did say we

> were going to go ahead with the donations, that was fine and he did say that he wouldn’t look any way disfigured or anything because they would pad them out and things like that, but when I saw his body I was quite disappointed, it is not fair for the kids because they said ‘oh my [deceased] got no legs’ I said he has I said they have only took the bones. It was a bit upsetting the rest of him looked fine, yes as I expected, they warned me about the bruising under his eyes because they were taking his eyes, there was no bruising or anything. He has come back lovely bar for his legs; it was the only thing that I was disappointed in actually” [5:5 (69:69)5:6(73:73) 5:7 (81:81) 5:8 (85:85)].

This situation puts the tissue coordinator in an invidious position as he/she is not in control of how the body looks post donation[f]. It is essential that if the present methods of reconstruction[g] are falling short of family member’s expectation then a review of current practice is undertaken. As audits of family members’ experiences and views post donation are not routinely carried out this could be an issue that leads to negative ‘local’ publicity about tissue donation. This is to be avoided as bereaved family members may become community educators in relation to organ and tissue donation[20], as is the case for one participant in this evaluation. The ‘evidence’ going into the community needs to underline the ‘message’ going to the family that the deceased is accorded dignity and respect during and after tissue donation.

An influential factor in these positive responses to deceased donors being moved to the DDF was the service provided by funeral directors. Two participants indicated that the funeral directors were ‘very knowledgeable’ about tissue donation often supporting and expanding on what the tissue coordinator had said. This ‘reinforcement’ of information appeared to be of help to family members and supports

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[f] Queries from retrieval teams are discussed within the CGM and issues such as this can be raised there, but only if TS know of such problems. As neither of these families had contacted TS with their concerns this underlines the importance of regularly auditing families so that issues such as these do not go unaddressed.

the evidence that indicates that a greater awareness of both tissue donation, and the processes that are required for it to be facilitated is needed, and that by providing this [via publicity etc] the ‘shock’ family members experience when asked to consider tissue donation may be modified.

6.4.4 Family members’ view of the service provided to them by NHSBT Tissue Services

Aim 3: To gain insight into the perceptions of family members regarding the ‘service’ provided to them by NHSBT Tissue Services.

As has been articulated in the quotes above the overwhelming message from families was that the service they received from the NRC was good. However, the two instances of poor reconstruction of lower limbs would indicate that there are areas that would warrant further exploration and review. One further area, commented on above, but expanded here was raised during interviews and that is the amount of detail about the donation processes.

Tissue coordinators are in a situation that they cannot know what response they will have to their request. Using negative case analysis [a case that varies from the norm identified in analysis] what we see is that what works for one participant may not work for another in fulfilling their needs. Table 3 highlights some of the positive and negative elements of the approach and discussion re tissue donation and moving the deceased donor to the dedicated facility. Elements are listed under the following headings, manner, content, timing.

Table 3. Positive and negative elements of the approach to family members

	Positive	**Negative**
Manner	Tone of voice is calm, confident, professional	Feeling of being told and not asked, Deferential, Hesitant
	Language used/ Plain English	Jargon used and not explained
	Expressed sympathy	Sympathy not expressed
	Sincere	
	Respectful	
	Understanding	
Content	Warning re lifestyle questions	Too much detail of processes
	Checking understanding	Lack of checks re understanding
	Clarification	Lack of clarification
	Checking whether family member needs a break	Lack of check re knowledge
	Time constraints mentioned	Lack of check re emotional impact of interaction
	Gratitude/Thanks	
	Well informed	Poorly informed
Timing	Unhurried pace	Hurried pace
	Suggesting a call back so family discussion facilitated	Participant felt pressure to make decision
	Pauses	Lack of pauses

In reviewing these elements it is important to acknowledge that it is rarely a case of the element being present or absent from discussions, but usually a matter of degree to which they are important to the individual family member. This indicates that a degree of flexibility is needed when questioning family members underpinned by an assessment of the family member’s knowledge base and donation stance. At the present time there is no comparative empirical work available exploring the interactions that are successful and those that are not; this is an important issue for future research.

In this evaluation all but one participant was pro donation and this clearly impacted on how family members rationalised certain difficulties that arose, for example being asked difficult lifestyle questions, and hearing about what has to be done to facilitate tissue donation. Bearing in mind the low response rate for this evaluation, and the fact that no family who declined donation was approached to participate, we have only one lens to view the service provided. Having said this it should be acknowledged that family members were positive about the interactions with tissue coordinators.

6.5 Further findings

A further three issues not indicated in the aims of the study, but acknowledged as questions that were pending are: the impact of 'list shock' on the interaction with tissue coordinators, follow up of family members [letters of thanks, and contact from recipients], and the longer term impact of tissue donation on bereaved family members.

6.5.1 List shock

List shock refers to the reaction of family members to the 'listing' of tissues [or organs] that can be donated. The hypothesis being that as the list increases the inclination to donate decreases due to the information load that has to be imparted for every tissue [or organ]. Participants were asked if they found the listing of tissues difficult, to which all but one said no, but from analysis there is an acknowledgement that whilst this was not an issue for these two well informed participants, it might be. A question for future research would be whether the combination of holding a pro donation stance, and knowing the wishes of the deceased to be a donor, lessens the impact of list shock.

> "I wasn't shocked by it but I can see how someone else will have been" [1:4(63:63)].

> "No not [a problem] for me personally my brother and sister I think the way they were at the time they might not have been able to deal with it" [4:10 (19:190)].

6.5.2 Follow up and correspondence from recipients

All participants indicated that they would like to hear about the use of the donated tissue and that they would want to receive any correspondence [thank you letters] from recipients of donated tissue.

> "Because I think they did say that there is a process that happens when the tissue, oh I can't remember now it is such a blur, but something about when they take the tissue it may or it may not be used, I seem to remember something like that, and I thought oh well if we have gone to this trouble I do hope that it has been used for somebody, but of course if it hasn't for whatever reason then so be it sort of thing, we wouldn't feel like oh we shouldn't have done it, but I think it would be nice to find out" [3:10 (85:85)]
>
> "Well you do hear when people donate organs that people can pass those letters on I am not aware that people can do that with tissue donation and if they were I think it would be lovely I would be delighted, but I don't know whether that is possible for people to do that" [2:14(106:106)].
>
> "As you can see I am a bit of a reflector, how do I feel about that, it has got to be nothing but positive and if a letter dropped through on the mat, pick it up, and find that it is somebody who [deceased] in some way has helped because yes I think it would have to be a good positive, yes" [7:21 (178:178)]

At present forwarding letters from recipients is not the default position for Tissue Services; due in part to concerns about data protection, and ensuring that family members are pre-warned about the content of letters. However as participants were aware that this is a possibility for family members of solid organ donation it may be time to standardise practice across NHSBT.

6.5.3 Longer term outcomes for family members

Empirical work from the field of organ donation has reported that family members gain comfort from the knowledge that the organs that they have donated have helped another person, this feeling holds even if the family is made aware that the recipient had died[15]. We have evidence from this evaluation that families who donated tissue also gained some comfort from what their deceased relative may have achieved.

> “but there was one thing that I remember, and I think that as an anecdote is possibly quite valuable, was to do with the skin and they mentioned that they would take some skin from her back and so on which again is explicit, but I think about a week or ten days later there was a story on the radio about a child that had been burned whilst sleeping in their cot and I sure the story could be traced it would have been sometime in the winter of 2006 and there was a pipe or something that ran parallel with the baby’s cot or something and the baby was scalded and I remember thinking well tissue donations like hers that would be used possibly for that kind of, it was explained to me quite explicitly how the tissue would be used for burns and I thought well that’s exactly what she would have wanted and it is just a bit of a coincidence that I should have heard that little story around that time” [1:5 (63:63)].

It may well be, as indicated above, that it will not be for some time after the bereavement that such positive emotional feedback is received, but it is clear that if tissue donation had not been facilitated for this individual and his relative, he would never had had this support to draw on in his bereavement.

7.0 DISCISSION

Findings from this evaluation have clearly indicated that family members know very little about multi tissue donation before they were approached to consider it. This lack of knowledge contributes to the reaction that tissue coordinators face when they request that family members consider and consent to tissue donation. Reactions were more extreme in those family members who received a cool call. Pre-emptive information/discussions, a pro donation stance, and knowing the wishes of the deceased prior to request appeared to moderate reactions and would suggest that initiatives linked to these findings may, potentially, increase consent rates.

The process of reasoning behind both agreeing to tissue donation and movement of the deceased to the DDF by family members was fundamentally, ‘the benefit to others’ that tissue donation would bring, and fulfilling the wishes of the deceased [when known]. An enabling factor within this process was the positive rapport that was developed between the tissue coordinator and family member during the approach and request for multi tissue donation[h]. Family members ‘trusted’ that their deceased relative would be treated with respect and dignity, and that they [family member] would be kept fully informed about the location of their family member. This trust was damaged when post tissue donation reconstruction procedures fell short of family members’ expectations which were based on information provided by tissue coordinators.

A rather worrying finding was the fact that elements of the approach and request were ‘blurry’ or poorly remembered by family members. Whilst this is not surprising in light of the recent bereavement and the focus of their thoughts being on their loss and the demands of the usual post death rites and rituals, it is of concern in relation to family members recollection of what was consented to. Bearing in mind the ‘shock’ experienced by those family members who received a cool call as opposed to a traditional approach, future work should explore whether there is greater recollection of the approach for tissue donation in those families who receive a traditional approach compared to those who received a cool call.

Also in view of the finding that two family members were ‘disappointed’ with the reconstruction of their relative post donation, and the fact that this issue was not reported back to TS until family members were interviewed for this evaluation only underlines the need

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[h] Reported in work with solid organ donation, see Sque et al [2005] [15]

for regular family audits which may elicit other ‘unknown’ family concerns[i].

8.0 RECOMMENDATIONS FOR PRACTICE AND SERVICE PROVISION:

Tissue Services

- Tissue coordinators are trained in therapeutic questioning skills.
- Reconstruction techniques for bone donation are reviewed in light of findings from this evaluation.
- A process is in place whereby thank you letters from recipients are forwarded to family members.
- Regular audits of the experiences and views of family members are carried out and the information gained used to underpin changes and developments in policy and practice.
- That there is an increase in initiatives that facilitate pre-emptive information being offered to family members.

NHSBT

- Standardisation of procedures re contact from recipients.
- Publicity highlighting the possibility and benefits of tissue donation, to include what may be asked of family members, is facilitated[j].

9.0 CRITIQUE OF EVALUATION

The caveat that must frame the findings of this evaluation is the low response rate and the fact that all but one participant held a pro-donation stance. Whilst this may not be important in relation to decision making about whether to expand the geographic area from

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[i] The issue of this reconstruction was investigated by the manger of the NRC. The retrieval team indicated that both bodies had fully reconstructed legs [that did not look flat] when they left the DDF. There was then discussion about the possibility of the prothstesis moving during the transfer back to the hospital mortuary, and thence onto the funeral directors. If this is the case then the utility of present modes of reconstruction may need to reviewed.

[j] As indicated in the EC Directive [2004]/23/EC of the European Parliament and of the Council on Setting Standards of Quality and Safety for the Donation, Procurement, Testing, Processing, Preservation, Storage and Distribution of Human Tissues and Cells.[1]

which deceased donors can be moved to the DDF [as family members can refuse] it is a constraint in relation to comments regarding participants' satisfaction with the service provided.

10.0 FUTURE WORK

Based on this evaluation, a two year programme of auditing family members' experiences of tissue donation, seeking feedback to underpin practice development, would be of great value in addressing some of the issue raised in the findings.

A survey aiming to recruit from the population of family members approached about tissue donation [those who say yes, and those who say no] via the NRC should be carried out with the aim of using this information to guide practice review and development, for example: the nature of the questions posed to family members and the core characteristics required in the information shared. As tissue donation is a time limited, once only, opportunity it is essential that families are supported in making decisions that are right for them.

Appendices

Appendix 1.

NHS
Blood and Transplant

UNIVERSITY OF
Southampton
School of Health Sciences

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Evaluation lead:
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Senior Research Fellow
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University of Southampton
Southampton, SO17 1BJ.
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E-mail T.Long@soton.ac.uk

Dear [name of family member]

Re: Evaluation of the experiences of family members whose deceased relative donated tissue at the NHSBT dedicated donation facility in Speke, Liverpool.

I am writing to you on behalf of the Tissue Service department of NHSBT and the School of Health Sciences at University of Southampton, to invite you to participate in an evaluation of the views and experiences of family members who agreed for their family member to be a tissue donor and for the tissue retrieval operation to be undertaken at the dedicated donation facility in Speke, Liverpool.

The purpose of the evaluation is explained in the enclosed participant information sheet and I would be grateful if you would read this information before deciding whether you would like to participate. The information sheet also outlines what your role in the evaluation would be if you agree to participate.

If, after reading the participant information sheet, you are willing to participate in this evaluation, would you please complete and return the enclosed Reply Slip in the stamped addressed envelope provided by Friday 10th July 2009. On receiving your response, Tracy Long-Sutehall, from the evaluation team will contact you to make all the necessary arrangements. Tracy will be happy to answer any questions you might have, before you make any final decision.

Thank you for taking the time to read this letter and for your support of tissue donation.

Yours sincerely

Anthony J. Clarkson

Appendix 2.

PARTICIPANT INFORMATION SHEET

Evaluation of the experiences of family members whose deceased relative donated tissues at the NHSBT dedicated donation facility in Speke, Liverpool.

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Evaluation lead:
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Senior Research Fellow
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Dear family member

You are invited to take part in an evaluation of the service provided by NHSBT Tissue Services, Speke, Liverpool. Before you decide, it is important for you to understand why the evaluation is being done and what it will involve. Please take time to read the following information carefully. Talk to others if you wish. This evaluation is being organised by staff at Tissue Services, Speke, Liverpool and the School of Health Sciences, University of Southampton.

What is the purpose of this evaluation?

The dedicated donation facility in Speke was opened over two years ago and was the first of its kind in the UK. To gain confidence in this approach to donation we limited its use to donors in the North West of England. Operationally the facility has been a success and we would like to expand its use. Before doing this it is important that we explore the experiences and views of family members who agreed to their deceased relative being transferred to the dedicated facility for tissue retrieval.

Aims:

1) To understand the decision-making process of those family members who agreed to their deceased relative being moved to the dedicated donation facility at Speke so that tissue retrieval could take place.
2) To identify any concerns that family members had about their relative being moved and their views on how these concerns were addressed.
3) To gain insight into the perceptions of family members regarding the ‘service’ provided to them by NHSBT Tissue Services.

Do I have to take part?

No, you do not have to take part in this evaluation. We are asking you to consider being involved as you have had first hand experience of the service provided by Tissue Services.

What will happen to me if I take part?

You will either take part in a one to one interview or a focus group.

If you agree to be part of a focus group

The focus group would involve 7-9 people [including the facilitator and observer] who, like you, agreed for their family member to donate tissues at the dedicated donation facility, Speke, Liverpool. The focus group would be held at Tissue Services in Speke at a time convenient to all participants. Before the focus group commences the evaluation team will explain what will happen during the focus group and you would have the opportunity to ask questions.

If you agree to a one to one interview

A member of the evaluation team will contact you and request to arrange a meeting for the interview to take place. The interview can be at Tissue Services, or at a location that is acceptable to you and the evaluation team member. Interviews are expected to take no longer than one hour but could be longer.

Prior to participating in either a focus group or interview you will be asked to sign a consent form agreeing to participate in the evaluation and for the information gained from focus group/interview to be used in a report and possibly publications under the terms stated on the consent form. The focus group/interview will be audio-recorded to provide an accurate record of the experiences you share with us. After the focus group/interview the audio-recording will be transcribed. The transcription of the focus group/interview will then be analysed by the evaluation team. Audio-recordings will be destroyed after analysis is complete. If you take part in the evaluation you are completely free to withdraw from the evaluation at any time, without giving reasons.

As talking about sensitive topics such as tissue donation may be upsetting we are keen that you have someone who you can talk to after the focus group/interview has ended. We would ask that you identify a friend or other family member who, if needed, can support you at this time or accompany you to the focus group if you would like them to.

Will my taking part in this evaluation be kept confidential?

Yes, your participation in this evaluation will be kept confidential. Also anything you say would be treated as confidential. All information collected would be kept in the strictest confidence and would be secured against unauthorised access. All transcripts are anonymised and no individual would be identifiable from the published findings.

What happens after the focus group/ interview?

The evaluation team will contact you after the focus group/interview to thank you for your participation and to request your feedback regarding the focus group/interview. Findings from the evaluation will be made available to NHSBT in the form of a full report, which they may choose to disseminate more widely. The results of this evaluation may also be published in health care journals and presented at national and international conferences. You will also be offered a summary of the evaluation.

What do I do now?
If, having read this information, you would like to participate then please contact Tracy Long-Sutehall [details at top of page] or return the reply slip in the envelope provided. If you have any questions, please feel free to contact Tracy.

Thank you for taking the time to read this information.

Anthony J. Clarkson	Dr. T. Long-Sutehall

Appendix 3.

UNIVERSITY OF
Southampton
School of Health Sciences

Reply Slip

Evaluation of the experiences of family members whose deceased relative donated tissue at the dedicated donation facility in Speke, Liverpool.

I am willing to talk about my experiences in a focus group/interview facilitated by Tracy Long-Sutehall.

Your Name (Please print)____

Signature____________________________________

Your telephone contact no.______________________

or

E-mail address_________________________________

Best time to control you and preferred contact method? E.g. Telephone or E-mail

____

Please return in the stamped addressed envelop provided

Appendix 4.

CONSENT FORM

Evaluation of the experiences of family members whose deceased relative donated tissue at the NHSBT dedicated donation facility in Speke, Liverpool.

NHS Blood and Transplant

University of Southampton
School of Health Sciences

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Please initial box

1. I confirm that I have read and understood the 'Participant Information Sheet' for this evaluation and have had the opportunity to ask questions. ☐

2. I understand that my participation in this evaluation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐

3. I agree to direct [anonymised] quotes being used in any presentation of the evaluation [verbal presentation or paper publication]. ☐

4. I agree to take part in the above evaluation. ☐

Name of Participant

Signature

Date

Name of Evaluator

Signature

Date

Appendix 5

Interview schedule Dedicated Donor Facility Evaluation

Preamble

As I do not have any details about your deceased relative, would you mind telling me a little about who we will be talking about?

1. How was the issue of tissue donation raised with you?
2. What were your feelings when asked to donate your relatives' tissues?
3. Were you aware of tissue donation before you were contacted?
4. When you were asked for permission for your relative to be moved to the dedicated donation facility in Speke, what was your reaction?

Prompts if needed:

Did you have concerns?
What questions did you ask?
Were these questions answered to your satisfaction?
How did other family members react?

5. Could you tell me a little about the whole experience, how did you feel about it?
6. Do you feel the staff at the NRC were 'good at their job?'
7. Is there anything that you feel was not done well?
8. Is there anything that you feel was done well?
9. Could you tell me a little about your reasons for saying yes to tissue donation?
10. Finally, if Tissue Services received a thank you from the recipient family would you want to receive this communication?

Appendix 6.

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Evaluation lead:
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Senior Research Fellow
School of Health Sciences
University of Southampton
Southampton, SO17 1BJ.
Direct Telephone No. 023 8059 8224
E-mail T.Long@soton.ac.uk

Dear [participants name]

Re: Evaluation of the experiences of family members whose deceased relative donated tissue at the NHSBT dedicated donation facility in Speke, Liverpool.

Thank you for talking to me [date] and participating in the above evaluation. I very much appreciate the time you have made available to me and your contribution to this study.

As discussed please find enclosed two copies of the consent form. One is for your records. Could you please initial and sign the second copy and return to me in the SAE enclosed[k].

Yours sincerely

Tracy Long-Sutehall

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[k] Only for those participants were undertook a telephone interview.

Appendix 7

Table 4. The topic guide that supported aims 1 and 2 with the themes identified in analysis.

Topic guide	**Themes from analysis**
Were you aware of tissue donation before you were contacted?	Attitudes toward donation Previous knowledge or exposure to organ donation Knowledge regarding tissue donation.
How was the issue of tissue donation raised with you?	Family request Pre emptive information Cool call
What were your feelings when asked to donate your relatives' tissues?	Cognitive elements: Knowledge of deceased wishes, attitudes towards organ and tissue donation, rapport with health professionals, altruism Emotional elements: Benefit to others, view of deceased as 'caring person', seeking a positive out of negative of death, reactions to interaction with tissue coordinators, memorialisation
When you were asked for permission for your relative to be moved to the dedicated donation facility in Speke, what was your reaction?	View of request by tissue coordinators Trust in Tissue Services personnel Attitudes toward tissue donation Being kept informed View of extended family Concerns

Appendix 8.

Table 5. The topic guide that supported aim 3 with the themes identified in analysis.

Could you tell me a little about the whole experience, how did you feel about it?	Positive experiences Negative experiences Exemplars
Do you feel the staff at the NRC were 'good at their job?'	View of interaction with tissue coordinators Positive elements of approach Negative elements to approach Exemplars
Is there anything that you feel was not done well?	Negative element to approach Interaction with tissue coordinators Exemplars
Is there anything that you feel was done well?	Positive elements to approach Interaction with tissue coordinators Exemplars

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