

<b>Institution:</b> University of Southampton
<b>Unit of Assessment:</b> 03 Allied health professions, dentistry, nursing and midwifery, and pharmacy
<b>Title of case study:</b> 03-05 Organ and Tissue Donation: supporting the decision-makers
<p><b>1. Summary of the impact</b></p> <p>An 11-year programme of translational research carried out at the University of Southampton into the decision making of bereaved family members regarding organ and tissue donation has led to direct impacts on health care policy and practices. The research examined why families of the newly deceased decide for or against organ and tissue donation, and what support they need during this process. As a result, both the approach and service provided post donation to approximately 5,700 bereaved family members has changed. Findings have impacted on the training of approximately 250 specialist nurses working for National Health Service Blood and Transplant (NHS BT) and are challenging the current informational/documentary systems that are in place to facilitate donation. Findings from this extensive body of work are now embedded in NICE guidance, national clinical practice guidelines and public awareness initiatives.</p>
<p><b>2. Underpinning research</b></p> <p>Some 1,000 people in the UK die each year due to a shortage of organs available for transplant. These shortages are linked to 40% of family members refusing donation requests after the death of a family member, a figure rising to 70% among ethnic minorities. For tissue donations, the situation is more serious. Few people understand what tissues can be donated and why they are needed, resulting in refusal rates between 25% and 75%. This lack of knowledge impacts on the number of tissues available for use in transplant operations and research focused on developing new treatments and medications.</p> <p>The Organ/Tissue Donation Research Programme (OTDRP) based within the Faculty of Health Sciences at the University of Southampton commenced in 2001 under the leadership of Dr Magi Sque (Senior Lecturer, at Southampton 2000-2009) and is now led by Dr Tracy Long-Sutehall (Principal Research Fellow, 2001-present). The first research projects (studies 1-3) in this successful programme broke new ground in examining the decision-making process underpinning consent to organ and tissue donation, and the needs and experiences of family members before, during and after donation:</p> <p><u>Study 1:</u> The BODY study (2000-2003), led by Southampton (Sque and Long-Sutehall), with Professor Sheila Payne (University of Sheffield), was a UK wide three year study which identified factors impacting families' decisions about agreeing or declining donation and what their specific informational and support needs were over this time span [3.1].</p> <p><u>Study 2:</u> Southampton researchers (Sque, Long-Sutehall) with Allardyce (Research Fellow, Southampton 2004-05) and Payne (Sheffield), interviewed family members who had declined donation (2004-05). This research found that the pre death wishes of the deceased regarding donation did not 'guarantee' agreement to donation; family members did not articulate donation as 'a gift of life' (a slogan often attributed to donation), but as the sacrifice of an unmarked body to a potentially mutilating operation. Inability to rationalize this conflict resulted in family members declining donation [3.2].</p> <p><u>Study 3:</u> Linking to data from the BODY study, Long-Sutehall (PhD) carried out a secondary analysis of primary data sets, examining families' experience of the diagnosis of brain stem death (2004-2007). Findings indicated that family members had a poor understanding of this medical diagnosis, and that most struggled to accept that their relative was brain stem dead in view of their relative looking 'alive' and continuing to have a heartbeat [3.3, 3.4].</p> <p>In 2007, Long-Sutehall commenced a Consultancy role with NHS Blood and Transplant (NHS BT) Tissue Services, leading on two studies (studies 4 and 5) aimed at exploring the factors that impact on the consent process for multi-tissue donation (eyes, heart valves, bone, skin, tendons).</p>

**Study 4:** The first UK evaluation of the experiences of family members whose deceased relative underwent tissue retrieval at Tissue Services' dedicated donation facility in Speke, Liverpool was carried out in 2009. This ground-breaking study showed that families were very satisfied with the service provide to them by specialist nurses, but that they knew almost nothing about tissue donation, and were not alerted to the potential of tissue donation by the hospitals where the death had taken place. This was a factor prompting a decline of tissue donation [3.5].

**Study 5:** Initial findings from this evaluation underpinned the award of an NIHR Post Doc Fellowship for Long-Sutehall in 2010. This was one of the first studies worldwide to investigate the 'real time' approach and consent process, involving analysis of recorded telephone conversations and observation of initial approach conversations with family members. Findings indicated, again, that family members knew little about tissue donation, that they wanted to be asked fewer questions during the consent-seeking conversation and that the current approach and consent process was inhibiting the building of rapport with family members and impacting on decision-making [3.6].

### 3. References to the research

#### Key outputs

Those articles marked with \* are listed in the 2010 RCN survey of most influential nursing research in the past 50 years.

[http://www.rcn.org.uk/development/researchanddevelopment/rs/nursing\\_research\\_top\\_50](http://www.rcn.org.uk/development/researchanddevelopment/rs/nursing_research_top_50)

#### Publications

- \*3.1 **Long T**, Sque M, Payne S. (2006) Information sharing: its impact on donor and nondonor families' experiences in the hospital. *Progress in Transplantation*, 16 (2): 144-14  
<http://www.ncbi.nlm.nih.gov/pubmed/16789705>
- \*3.2 Sque M, **Long T**, Payne S, Allardyce D. (2008) Why relatives do not donate organs for transplants: 'sacrifice' or 'gift of life'? *Journal of Advanced Nursing*, 61 (2) 134-144  
<http://onlinelibrary.wiley.com/doi/10.1111/jan.2008.61.issue-2/issuetoc>
- \*3.3 **Long T**, Sque M, Addington-Hall, J. (2008) Conflict rationalization: how family members cope with a diagnosis of brain stem death. *Social Science & Medicine*, 67 (2): 253-261  
<http://www.sciencedirect.com/science/journal/02779536/67/2>.
- 3.4 **Long T**, Sque M, Addington-Hall J. (2008) What does a diagnosis of brain death mean to family members approached about organ donation: A review of the literature. *Progress in Transplantation*, 18: 118-126. <http://www.ncbi.nlm.nih.gov/pubmed/18615977>
- 3.5 **Long-Sutehall T**, Winstanley E, Clarkson A, Sque M. (2012) Evaluation of the experiences of family members whose deceased relative donated tissues at the NHS BT dedicated donation facility in Speke, Liverpool. *Cell Tissue Banking*, 13 (4): 537-546  
<http://www.ncbi.nlm.nih.gov/pubmed/21785945>
- 3.6 Taylor H, **Long-Sutehall T**, Whitehead J. (2012) Final report Specialist Family Approach Audit, NHS BT – Tissue Services, (available at [eprints.soton.ac.uk](http://eprints.soton.ac.uk)).

#### Key grants

1. Sque M and Payne S. The BODY study - Organ and tissue donation: Exploring the needs of families Funder: British Organ Donor Society and the Community Fund, 2000-2003 £162,640.
2. Sque M, **Long T** and Payne S. Organ and tissue donation: Exploring the needs of families who did not donate. Funder: United Kingdom Transplant. 2004-2005 £99,000.

## Impact case study (REF3b)

3. **Long T.** Brain-based criteria for diagnosing death: What does it mean to families approached about organ donation? Funder: Faculty of Health Sciences, University of Southampton. 2004-2007 £82,000.
4. **Long-Sutehall T,** Anthony Clarkson and Sque M. Evaluation of the experiences of family members whose deceased relative donated tissues at the NHS BT dedicated donation facility in Speke, Liverpool. 2009-2010 £6,483.
5. **Long-Sutehall T.** Barriers to tissue donation: what cognitive and emotional associations do bereaved family members bring to the multi tissue and corneal request interview? National Institute Health Research Post Doctoral Fellowship. 2010-2013 £297,422.

#### 4. Details of the impact

Our research has had direct impacts on policy stipulating standards of service to family members during and after solid organ and multi tissue donation, the practice of health care professionals and care staff, the care and experience of newly bereaved families in the context of organ or tissue donation, and is contributing to raising public awareness of tissue donation in particular.

##### Impact on policy

In 2012, in the light of findings from studies 4 and 5, Long-Sutehall was part of a team that carried out a process evaluation of the current documentation underpinning the consent process in both organ and tissue donation for NHS BT. The evaluation recommended that 'core minimal' information be provided to family members when approached about tissue donation, and information that is not essential be moved to other modes of communication, such as Family Information Leaflets (FILs) and websites. Both NHS BT and the Human Tissue Authority (HTA) accepted proposed changes. Subsequent to this decision, Long-Sutehall led on the design of the FILs which have been distributed to family members as of July 2013 (expected over 2,200 family members per year) [5.1a/b, 5.2]. Findings from study 2 were cited in the guideline on *Organ donation for transplantation*, issued by the National Institute for Health and Care Excellence (NICE) in 2011. The aim of this guideline is to improve donor identification and consent rates for deceased organ donation [5.3]. The House of Lords European Union Committee published its report on *Increasing the supply of donor organs within the European Union* in July 2008. The report quotes Sque and Long-Sutehall's witness statements to the Committee, based on their research, on no fewer than 12 occasions [5.4].

##### Impact on Practice

As a result of her research expertise, NHS BT asked Long-Sutehall to participate in updating the Donor Family Care Policy, and associated Management protocol; these documents stipulate the required practice for Specialist Nurses in Organ Donation [SN-OD] when in contact with potential donor families. The revised documentation was completed in 2011, reflecting findings from studies 1-3 [5.5]. Pilot testing of a new specialist family approach format developed by Long-Sutehall using findings from studies 4 and 5 has been demonstrated to increase donation. It has now been implemented into practice. In 2010, Long-Sutehall presented the findings from study 3 to the official advisory committee on ethical, legal and psychosocial aspects of organ donation and transplantation (ELPAT) of the European Society for Organ Transplantation (ESOT) comprising 100 practitioners and researchers from 25 European member states [5.6]. The incorporation of findings from studies 1-3 into the Donor Family Care Policy 2011 (see above) has led to demonstrable benefits for family members of potential donors. For example, since 2008 approximately 3,500 families have received a contact card from the donation team on the first anniversary of their relative's donation, which was a recommendation of the research. Families and support organisations (British Organ Donor Society and Donor Family Care Network) have acknowledged the importance of this contact [5.7]. As a result of findings from studies 4 and 5, the Donor Assessment Form for NHS BT's Tissue Services was re-designed in March 2013, reducing the number of questions in line with families' expressed needs and wishes [5.8].

**Impact case study (REF3b)****Improved public and practitioner awareness**

To address the findings from studies 4 and 5, that family members were not being 'alerted' to the possibility of tissue donation by health care professionals before a death occurred, the South Central Strategic Health Authority (SHA) made an online resource available in 2010 for the public and for health professionals [5.6]. Guidance to Care Home care staff within the South Central region was also developed [5.9]. A recommendation of study 4 was that a Donor Family Advisory Committee should be established by NHS BT's Tissue Services so that new initiatives (e.g. marketing strategies, information resources) aimed at increasing public awareness of the need for tissue donation, are presented to this group for discussion and review [5.10].

**5. Sources to corroborate the impact**

- 5.1 Endorsement e-mail [5.1a] from Dr Lorna M Williamson, Medical and Research Director, NHS Blood and Transplant, and excerpt from Care Committee of NHS BT [5.1b] (PDF)
- 5.2 Family information leaflets on eye. Organ and tissue donation
- 5.3 NICE guideline: <http://www.nice.org.uk/nicemedia/live/13628/57508/57508.pdf> Page 92.
- 5.4 House of Lords European Union Committee, *Increasing the supply of donor organs within the European Union*, published July 2008. Volume I: Report. <http://www.publications.parliament.uk/pa/ld200708/ldselect/ldeucom/123/123i.pdf> (Sque and Long-Sutehall quoted in paras 107, 132, 137, 146, 147, 246-248, 251, 254, 279, 305.)
- 5.5 Letter of endorsement from Dr Paula Aubrey, Chair of the Donor Family Care Policy Committee 2010-2011, NHS Blood and transplant.
- 5.6 ELPAT presentation <http://www.esot.org/Elpat/Content.aspx?item=122>
- 5.7 Confidential copy of 2011 Donor Family Care Policy (pages 1-12)
- 5.8 Letter or endorsement from Emma Winstanley, Chair of Deceased Donor Consent working party for NHS Blood and Transplant [2010-current].
- 5.9 PPP of SHA End of Life resource for health care professionals and the public <https://www.southampton.ac.uk/healthsciences/about/staff/tl3>.
- 5.10 NHS BT Tissue Services Deceased Donor Advisory Group Composition and Terms of Reference (PDF).