

<b>Institution: University of Wolverhampton</b>
<b>Unit of Assessment: 3 - Allied Health Professions, Dentistry, Nursing and Pharmacy</b>
<b>Title of case study:</b> Organs and tissues for human transplantation: Seeking to increase deceased donation through informing public debate and influencing healthcare policy, education and practice
<b>1. Summary of the impact</b> (indicative maximum 100 words)

This case study describes the impact of Sque’s programme of research into the psychological and social concerns that impact organ/tissue donation and family members’ end of life and post mortem decision-making. This work has impacted UK national policy, which guides practice and education of health professionals about the care of families who have organ donation discussed with them, and national guidance for staff responsible for care after death (last offices). It has informed public debate internationally about care of the bereaved family and how to increase the availability of organs, from deceased persons for transplants. The reach and significance of this information ranges from an international (ELPAT) and parliamentary platform to teaching volunteer service users within the University of Wolverhampton’s Faculty of Education, Health and Wellbeing about the need for post mortem organ donation. This research has therefore impacted the public and healthcare professionals, locally, nationally and internationally.

<b>2. Underpinning research</b> (indicative maximum 500 words)
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**Context**

An aging population and the increase in lifestyle illnesses such as diabetes, which can lead to organ failure, means the demand for organ/tissue transplantation is rising inexorably in the UK and worldwide. Ten thousand people in UK could benefit from an organ transplant. In the European Union **61,000** people are waiting for lifesaving transplant operations. Sque’s programme of research launched in 1996 into the psychosocial issues that underpin organ/tissue donation and transplantation placed the topic on the UK research agenda. Previously there was no body of evidence, generated within the UK, on which healthcare professionals could base and evaluate their practice to care for bereaved families with whom organ/tissue donation was discussed, or how to increase organ/tissue availability.

**Research of relevance**

Sque’s 1996 study was a cross-sectional, mixed methods investigation of the experiences of family members who agreed to the donation of organ/tissues from a deceased relative, and the attitudes, knowledge and behaviour of UK registered nurses toward organ/tissue donation. The aim of this study was to: examine family members’ emotional reaction to the death of a relative and donation of their organs; elicit family members’ (them) perceptions of their decision-making process; assess the benefits, problems and needs that organ donation may have generated for them; gain an understanding of what the experience of organ donation meant to them; and provide a substantive theory that explained donor relatives’ experiences. The attitudes, knowledge and behaviour of 1,334 registered nurses to organ donation were elicited via a postal questionnaire. Since this springboard study Sque has led a vibrant research programme of related, externally fund projects.

Sque moved to the University of Wolverhampton in September **2010** bringing three projects. 1. Sque is Chief Investigator (CI) to British Renal Society funded, *‘Life on the list,’* **[2008-2010]** which was at dissemination stage. 2. Sque is CI to a DH-funded study exploring, *‘Bereaved families’ experiences of organ and tissue donation, and perceived influences on their decision making,* carried out **September 2011-June 2013**. 3. Sque is co-investigator, and lead for the bereaved family study, within the four-year NIHR-funded DonaTE programme **[October 2009-January 2014]** seeking to increase acceptability of organ donation among British minority ethnic populations. CI is Professor Myfanwy Morgan, at King’s College London.

Sque has continued mentorship/collaboration roles with Dr. Tracy Long-Sutehall. Long-Sutehall’s three-year NIHR Post Doctoral Fellowship, at the University of Southampton, completed **January**

## Impact case study (REF3b)

**2013**, investigated the consent discussion for tissue donation with bereaved family members, by the National Referral Centre at Speke, Liverpool. Long-Sutehall is a co-investigator to Sque's DH-funded project, commenced at Wolverhampton.

The University of Wolverhampton provided the opportunity to work with linguist Professor Dariusz Galasinski. Using linguistic techniques a secondary analysis was carried out on previously collected interview transcripts to develop new insights into cognitive processes behind the reasons why bereaved families decline organ donation [**published 2013**].

These studies are the research from which impact has arisen since **2010**, and are the foundation upon which significant work, that has reached multiple audiences, is based.

### 3. References to the research (indicative maximum of six references)

#### Grants

Sque M (CI). Long-Sutehall T. Morgan M. Randahawa G. and Warrens A. *Bereaved families' experiences of organ and tissue donation, and perceived influences on their decision making*. Department of Health. [September 2011-June 2013], **£182,240**. Commissioned work by the Department of Health Consortium on Organ Donation.

Peer review by Department of Health, Triona Norman, Policy Lead for Organ Transplantation, 13.08.2013: "*Many thanks for sending me your research – I found some of it very moving...NHSBT have recently (11 July 2013) launched the new UK organ donation and transplantation strategy Taking organ transplantation to 2020. A key part of the strategy will be work to increase consent rates which as you know have remained frustratingly the same (around 60%) for the whole of the Taskforce implementation. I would like your work to feed into the development of the implementation plan.*" Implementation meetings with the BME community are now underway.

Morgan M (CI), Jones R. Sque M. Newton T. Farsides B. Randahawa G. McGuire A. Scoble J. Banerjee D. and Rudge C. *Increasing the acceptability and rates of organ donation among ethnic groups*. NIHR Programme Grants for Applied Research [October 2009-January 2014], **£863,068**. NIHR competitive tendering process, with peer review.

#### Publications

Sque M. and Galasinski D. (2013) 'Keeping her whole': Bereaved families' accounts of declining a request for organ donation. *Cambridge Quarterly of Healthcare Ethics*, 22: 1, 55-63 (peer reviewed journal article submitted to REF in 2014), peer reviewer's comments: "***The piece is excellent... I would strongly encourage the publication... I think the paper adds a very original and valuable contribution to the vast body of literature on post-mortem transplants. It is rare to see papers that genuinely bring something novel in this field, and this paper...does that, and does it very well... The data itself is exceptionally rich, and some excerpts particularly taking.***"

Walker W. Broderick A. and Sque M. (2013) Factors influencing bereaved families' decisions about organ donation: An integrative review of the literature. *Western Journal of Nursing Research*, 35: 10, 1339-1359 (peer reviewed journal article submitted to REF in 2014), peer reviewer comments: "***Thank you for allowing me to review this very important paper. There is very little integrative research in the area, so this paper will make an important contribution to our understanding of this phenomenon. The paper is well written with a logical flow and clear writing style makes it easy to read.***"

Long-Sutehall T. Winstanley E. Clarkson A J. and Sque M. (2012) Evaluation of the experiences of family members whose deceased relative donated tissues at the NHSBT dedicated donation facility in Speke, Liverpool. *Cell and Tissue Banking*, 13: 4, 537-546. (doi: [10.1007/s10561-011-9269-x](https://doi.org/10.1007/s10561-011-9269-x), peer reviewed journal article).

Sque M. and Long T. (2011) Bereavement, decision-making and the family in organ donation. In Farrell AM. Price D. and Quigley M. (eds) *Organ shortage: Ethics, law and pragmatism*. Cambridge: Cambridge University Press, 67-85. Published book review: "***The jewel on the crown***"

## Impact case study (REF3b)

*for me is the chapter by Sque & Long providing some insights into the values, spiritual beliefs and the impact of organ donation on the bereaved relatives...This beautifully written chapter really brings home to the reader this key element in organ donation that clearly has to be addressed if the organ donation is to be successful..."*

### 4. Details of the impact (indicative maximum 750 words)

#### Impacting healthcare policy, education, practice

Sque's bereaved family work has impacted a number of healthcare policies which have implications for education and practice across the healthcare work force.

The Donor Family Care Policy (DFCP)<sup>1</sup> of NHS Blood and Transplant (NHSBT), underpinned by Sque's earlier work was reviewed in 2007 and **2011** in light of new research. NHSBT is a Special Health Authority of the NHS with responsibility for optimising the supply of blood, organs, plasma and tissues and raising the quality, effectiveness and efficiency of blood and transplant services. This document outlines the minimum standard of care that healthcare professionals working within NHSBT are expected, as part of their professional role, to offer family members during and post organ or tissue donation.

The DFCP is cited within the General Medical Council end of life guidance to doctors, '*Treatment and care towards the end of life: good practice in decision making*'<sup>2</sup> [2010]. "This guidance is addressed to doctors. However, it may also help patients and the public to understand what to expect of their doctors, in circumstances in which patients and those close to them may be particularly vulnerable and in need of support. Other members of the healthcare team may also benefit from it, given their crucial role in delivering end of life care" [p06].

The DFCP is referenced in NICE<sup>3</sup> clinical guideline 135 – '*Organ donation for transplantation: Improving donor identification and consent rates for deceased organ donation*' [2011].

**NHS National end of life care programme improving end of life care**<sup>4</sup> '*Guidance for staff responsible for care after death (last offices)*,' [2011] was developed by the National Nurse Consultant Group (Palliative Care). Sque was a key member of the working group involved in the development of this guidance. It is currently under review [2013] and Sque has again subscribed to this consultation in light of new insights from the DH bereaved family study. Some of these insights concern for instance, circulatory death of an organ donor.

"The Institute of Healthcare Management<sup>5</sup> carried out a review of the implementation across England of, '*Guidance for staff responsible for care after death (last offices)*' and evaluation of its impact on the ability and confidence of staff to care for the person who had died and their family." "The guidance was found to be useful in providing staff with the confidence and competence to perform care after death duties and to speak to the bereaved as well as supporting the teaching of care after death to students."

**Film Lifelines - A reflection on organ donation**<sup>6</sup> [2011] directed by Barbara Myers and Paul Loman of Homegrown Films, Brighton. The script is comprised of extracts from an interview Sque carried out with a donor father. The film **won the award for Best Foreign Documentary** at the Los Angeles 2011 Action/Cut Short Film Competition and was featured at the 2011 Brighton Film Festival. The film was adopted by NHS Blood and Transplant and 1,000 copies (DVDs) were distributed to Organ Donation Teams in all UK Hospital Trusts to be used for educational purposes.

**Impacting public debate and information** The reach and significance of Sque's work is further demonstrated by her **Invited International Chair [July 2008-July 2013]**, and membership of ELPAT's Deceased Donation Working Group. ELPAT is a European organisation based in Erasmus MC, Rotterdam. ELPAT is a European platform that brings continuity and progress in European research and dialogue on "**Ethical, Legal and Psychosocial Aspects of organ Transplantation**". It aims to integrate and structure this field of science by bringing together European professionals. These experts range from (bio)ethicists, philosophers, lawyers and psychologists to

**Impact case study (REF3b)**

clinicians, physicians, sociologists, anthropologists, policy makers and criminologists. ELPAT currently consists of over 160 experts from more than 25 European countries, who convene in seven working groups. <http://www.esot.org/elpat/content.aspx?item=10>

**Invited panel member House of Lords parliamentary seminar** (by Baroness Finlay of Llandaff), on, '*Increasing consent rates for organ donation*,' [22<sup>nd</sup> May 2012] hosted by Transplant 2013 on behalf of the All-Party Parliamentary Group for Transplantation. The purpose of the seminar was to facilitate discussion and debate on increasing consent rates with MPs, Peers, and members of the transplant community including patients and clinicians. The seminar led to the development of a set of recommendations on how an increase in donation could best be achieved.

**An information booklet**<sup>7</sup> was developed from, '*The life on the list*,' study to provide information for individuals awaiting kidney transplants and their families. The booklet was posted on the British Kidney Patients' Association (BKPA) website [2012] and an article about the research is in their *Review 2012*<sup>8</sup> magazine. Information from Suzan Yianni re BKPA's website shows that between **May 2009-October 2013** there were overall 338,455 visitors (Unique 249, 402) and the Patient Information section/Additional resources for the same period, 24,010 visitors (unique 11,197); 752 visitors (unique 488) respectively. These data give some indication of the exposure of the booklet and article.

**5. Sources to corroborate the impact** (indicative maximum of 10 references)

- 1) NHS Blood and Transplant, Donor Family Policy  
[http://www.organdonation.nhs.uk/ukt/about\\_transplants/donor\\_care/donor\\_family\\_care\\_policy/donor\\_family\\_care\\_policy\\_version2\\_23032005.pdf](http://www.organdonation.nhs.uk/ukt/about_transplants/donor_care/donor_family_care_policy/donor_family_care_policy_version2_23032005.pdf)
- 2) General Medical Council end of life guidance to doctors: *Treatment and care towards the end of life: good practice in decision making* [2010]  
[http://www.gmc-uk.org/guidance/ethical\\_guidance/end\\_of\\_life\\_care.asp](http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp)
- 3) NICE. [2011] *Organ donation for transplantation: Improving donor identification and consent rates for deceased organ donation*.  
<http://www.nice.org.uk/nicemedia/live/13628/57508/57508.pdf>
- 4) *Guidance for staff responsible for care after death (last offices)* [2011]  
[http://www.endoflifecare.nhs.uk/assets/downloads/Care\\_After\\_Death\\_guidance.pdf](http://www.endoflifecare.nhs.uk/assets/downloads/Care_After_Death_guidance.pdf)
- 5) IHM Evaluation of care after death Programme <http://www.ihm.org.uk/en/about-us/policy-and-projects/evaluation-of-care-after-death-programme/evaluation-of-care-after-death-programme.cfm>
- 6) Lifelines [film]: <http://vimeo.com/23919896>
- 7) British Kidney Patients' Association booklet – *Life on the list: An exploratory study of the life world of individuals waiting for a kidney transplant*  
<http://www.britishkidney-pa.co.uk/images/stories/downloads/additionalresources/Life-on-the-List.pdf>
- 8) *Review 2012*<sup>8</sup> magazine  
[http://www.britishkidney-pa.co.uk/images/stories/downloads/Reviews/BKPA\\_Review\\_2012.pdf](http://www.britishkidney-pa.co.uk/images/stories/downloads/Reviews/BKPA_Review_2012.pdf)