

Institution: University of Wolverhampton		
Unit of Assessment: 3 Allied Health, Dentistry, Nursing and Pharmacy		
Title of case study: Enhancing professional practice and public understanding of end-of-life care and organ donation		
Period when the underpinning research was undertaken: 2010 - 2019		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Professor Magi Sque	Professor in Clinical Practice and Innovation	2010 – 2018
Dr Wendy Walker	Reader in Acute and Critical Care Nursing	2011 – 2019
Professor Dariusz Galasinski	Professor of Discourse and Cultural Studies	1992 – 2020
Period when the claimed impact occurred: August 2013 – December 2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact <p>For nearly a decade, an innovative and interdisciplinary programme of research at the University of Wolverhampton, investigating the psycho-social aspects of hospital-based, end-of-life and bereavement care, has led to impacts on professional practice, policy and public engagement. The unique research approach sought to better understand the decisions made by bereaved relatives around organ donation following unexpected death. The findings were used to inform the approaches of health organisations, including Hospice UK, Public Health England (PHE) and The Health and Safety Executive (HSE), and contributed to guidance documents from over 10 NHS Trusts. Findings were also used to inform Parliamentary debate on organ donation in Black, Asian and Minority Ethnic (BAME) communities, which have historically been underrepresented as donors. The research also led to the installation of 2 unique organ donation memorials at New Cross Hospital, Wolverhampton, and Telford's Princess Royal Hospital, with the purpose of raising public awareness of organ donation.</p>		
2. Underpinning research <p>For many years, the UK has experienced an organ donation shortfall, caused by a variety of poorly understood reasons, including various cultural and socio-economic factors. The University of Wolverhampton is one of a relatively small group of UK institutions that has actively conducted research into the reasons behind the shortfall, and has provided mitigating strategies to increase awareness of the importance of organ donation. The research led to the following key findings [F]:</p> <p><u>F1. Family decision making about organ donation following bereavement</u></p> <p>Much of the research into organ donation has focussed on family consent, a major limiting factor for successful organ donation and transplantation. By interviewing bereaved families, the research has been able to highlight key reasoning behind decision-making related to organ donation following a close family member's death. This research has shown that organ and tissue donation has the potential to provide some level of comfort to bereaved families, helping to balance hope and despair at the end-of-life when the wishes of the dying, deceased, and bereaved are fulfilled [R1]. Subsequent findings have also shown that temporally interwoven experiences appeared to influence families' decisions to donate the organs of their deceased relative for transplantation [R2]. The research highlighted a key need for increased public knowledge, as often decisions are made by family members with a lack of understanding of the organ and tissue donation process [R2].</p>		

F2. Exchanged letters highlight the 'gift' of organ donation

An alternative approach was taken to learn more regarding the psychosocial issues of organ donation, by reviewing correspondence letters exchanged between families of donors and donor recipients. This novel approach stepped away from previous studies which, as above, generally investigated this topic through direct interviews with either donor or recipient groups. Using discourse linguistic analysis, 78 letters from 4 USA organ procurement organisations were reviewed. This analysis demonstrated that donor families consistently ascribe accountability for organ donation to their deceased relative, whereas recipient families often attribute the organ donation as a 'gift' from the family of the donor [R3].

F3. BAME organ donation

A distinctive area of research focussed on addressing the differences in rates of donation between people from BAME and White backgrounds. Sque formed a key part of a multi-institutional study, using community and hospital-based research, to discover the main reasons for lower levels of organ donation across BAME communities and provide potential solutions [R4]. The research indicated key attitudinal barriers contributed to the shortfall, including uncertainties over religious permissibility, lack of trust in health professionals and lack of understanding around registration [R4]. The findings of the study highlighted the need for health professionals to develop communication skills for working with BAME families, and led to the creation of a training package to help develop cross-cultural communication [R4].

3. References to the research

All papers have undergone a stringent double-blind peer-review process.

R1. Sque, M., Walker, W. (2016). Balancing hope and despair at the end of life: The contribution of organ and tissue donation. *Journal of Critical Care*, 32:73-8.

<https://www.doi.org/10.1016/j.jcrc.2015.11.026>.

R2. Sque, M., Walker, W., Long-Sutehall, T., Morgan, M., Randhawa, G., Rodney, A. (2018). Bereaved donor families' experiences of organ and tissue donation, and perceived influences on their decision making. *Journal of Critical Care*, 45: 82–89.

<https://www.doi.org/10.1016/j.jcrc.2018.01.002>. (REF 2 Output).

R3. Galasinski, D., Sque, M. (2017). Organ donation agency: A discourse analysis of correspondence between donor and organ recipient families. *Sociology of Health and Illness: a Journal of Medical Sociology*, 38(8), 1350-13633. <https://www.doi.org/10.1111/1467-9566.12478>.

R4. Morgan M., Kenten, C., Deedat, S., Farsides, B., Newton, T., Randhawa, G., Sims, J., Sque, M. (2016). Increasing the acceptability and rates of organ donation among minority ethnic groups: a programme of observational and evaluative research on Donation, *Transplantation and Ethnicity (DonaTE)*. Programme Grants for Applied Research, 4(4).

<https://www.doi.org/10.3310/pgfar04040>.

4. Details of the impact

The underpinning research [F] has led to improvements in professional practice, contributed to ongoing contemporary debate on organ donation, and led to the co-creation of cultural artefacts, benefiting both practice staff, BAME communities and artists, through 3 key impacts [I]:

I1. Shaping professional practice

The research in organ and tissue donation [F1] has informed 'Guidance for staff responsible for care after death' [C1, C2]. Sque was a key member of the working group for the formation of the 1st edition (2011) [C1], where her research informed sections on end-of-life care and organ donation. Subsequent findings [R1] were used in the further development of the guidance, leading

to the publication of the 2nd edition in 2015 by Hospice UK [C2]. The 2nd edition, represents key guidance for working with bereaved families, with a particular focus on organ donation, and was endorsed by 3 Royal Colleges (General Practitioners, Nursing and Pathologists) and 3 national organisations (NHS, National Council for Palliative Care, National Nurse Consultant Group (Palliative Care)). The documents have been used to inform further guidance published by frontline health organisations, including HSE, PHE and Bereavement Services Association, as well as being utilised to form the end-of-life care policies of at least 10 NHS trusts, including North Devon Healthcare NHS Trust, Cheshire and Wirral Partnership NHS Foundation Trust and Surrey and Borders Partnership NHS Foundation Trust [C3]. The wide uptake of the guidance highlights their vital role in informing practitioners' strategies for working with recently bereaved families, leading to benefits derived from more effective communication and improved relatives' decision-making around organ donation. Furthermore, the research also influenced the 'Care after death – Registered nurse verification of expected death guidance (3rd edition)' [C4].

Sque and Walker's work [R1] was cited in the update to the NICE guidelines 'Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation' [C4, C5]. The update, completed in 2016, summarised the findings of the study, indicating the importance of using compassion and respect when discussing organ donation with bereaved families within the intensive care unit and identifying the value bereaved families place on the "gift" of organ donation [F2]. NICE guidelines such as these are key documents utilised by healthcare practitioners across the UK to inform their practice.

12. Influencing Parliamentary debate on BAME organ donation

The research into organ donation in BAME communities [F3] provided guidance for the effective targeting of donation campaigns focusing on minority ethnic groups. The study formed part of the review 'Ending The Silent Crisis' commissioned by a group of MPs, led by Eleanor Smith, then MP for Wolverhampton South West [C6], to seek options for increasing organ donation amongst BAME communities. This was reported across the media, including BBC Breakfast and BBC News [C7]. The review instigated further debate in July 2018 within Parliament, with then Parliamentary Under Secretary of State at the Department of Health, Jackie Doyle-Smith MP highlighting the importance of "reaching out to those (BAME) communities and engaging with them in a way that inspires them" [C8].

13. Inspiring and co-creating a new form of artistic expression

Sque and Walker developed a close partnership with Royal Wolverhampton NHS Trust, with Sque holding a joint appointment within both institutions. This afforded opportunities for research priorities to be identified with clinical colleagues, and optimisation of public and patient engagement with the research process. As a result of this partnership, an artwork was commissioned with the key message of improving public understanding of organ donation.

To our knowledge, the organ donor memorial outside of the entrance to the Emergency Department (ED) at New Cross Hospital, Wolverhampton and unveiled in January 2016 (Figures 1 & 2 below), is the first of its kind to be built on evidence obtained from donor families, and therefore represented a novel and distinctive cultural artefact. The designers, Matthew Sadler and Neal Welch, were graduates from the University of Wolverhampton who directly cite the input of Sque and Walker's research [F1, F2] on the creative process for their design, titled 'The Gift of Life' [C9]. Both artists comment on the originality of their work, highlighting their thought process:

"The structure is an abstract representation of the double helix structure of DNA, and it follows the form of an infinity loop – to represent the continuation of life. This is mounted above a pair of hands, symbolising the gifting of this life, and we feel this this encapsulates the sentiment of the words perfectly" [C9].

The artwork is also unique in that the information panels contain a QR code, which takes the user directly to the NHS Organ Donation Register website. The contribution of their work to recognise and promote organ donation was commended at an official opening of the memorial on 13th March 2016.

New Cross Hospital ED receives around 140,000 admissions a year, not including visitor numbers. With the memorial's prominent position outside of the ED building, all visitors passing the artwork have been exposed to its message.



Figure 1 (left) – The organ donation memorial at New Cross Hospital. Figure 2 (right) - one of the plaques presented around the structure, including the QR code which directs users to the NHS organ donation register website.

As a direct result of the installation of the artwork at New Cross Hospital, Shrewsbury and Telford Hospital NHS Trust also commissioned an organ donation artwork, designed by a University of Wolverhampton student [C10]. The stained-glass window was installed at Telford's Princess Royal Hospital in 2018, and a second complementary piece is due to be installed once a suitable location has been found. The head of the Hospital's Organ Donation Committee commented:

"The sculpture project was commissioned to recognise the contribution made by donors as well as to thank families and to commemorate organ donation."

These pieces of art represent a unique and powerful tool for health education located in the precise place they are most likely to have a significant impact.

5. Sources to corroborate the impact

C1. Guidance for staff responsible for care after death (1st edition)

C2. Guidance for staff responsible for care after death (2nd edition)

C3. Publicly available documents and webpages citing and/or hosting the 1st and 2nd editions of the 'Guidance to staff responsible for care after death'

C4. Hospice UK website - <https://www.hospiceuk.org/what-we-offer/clinical-and-care-support/clinical-resources>

C5. NICE guidelines "Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation" - <https://www.nice.org.uk/guidance/cg135>

C6. NICE guideline Appendix A – "Summary of New Evidence" - <https://www.nice.org.uk/guidance/cg135/evidence/appendix-a-summary-of-new-evidence-from-surveillance-pdf-2732787038>

C7. BBC News story on BAME organ donation Parliamentary discussion - <https://www.bbc.co.uk/news/health-44314885>

C8. Evidence of BAME organ donation debate in Parliament - <https://hansard.parliament.uk/Commons/2018-07-24/debates/0350569E-EEC0-4E22-B7CF-A84FA56195D9/BAMEBloodStemCellAndOrganDonors> &

<https://hansard.parliament.uk/Commons/2018-06-27/debates/5634E89E-4926-4619-9D46-BCB86D0112DD/BAMEBloodStemCellAndOrganDonation>

C9. Testimonial from artists commissioned of 'Gift of Life' memorial at New Cross Hospital, Wolverhampton

C10. Shropshire Star news story on unveiling of Royal Princess Hospital artwork - <https://www.shropshirestar.com/news/health/2019/01/01/forget-me-not-art-at-telford-hospital-a-permanent-tribute-to-organ-donors/>