

Institution: University of Bedfordshire
Unit of Assessment: 3 - Allied Health Professions, Dentistry, Nursing and Pharmacy
Title of case study: Inequalities in organ donation: challenges and opportunities
<p>1. Summary of the impact</p> <p>Professor Randhawa's research has made significant impact upon government policy and practice in relation to public engagement and professional training in the field of organ donation. The Government's Organ Donation Taskforce made 14 recommendations, one of which was to ensure organ donation was made more visible among BME communities. Subsequently, NICE Guidelines specifically referred to the need to address faith and cultural issues for families and relevant training for staff. This has informed specific national campaigns by targeting different communities and providing relevant staff training which has led to an increase in organ donor registrations from diverse communities.</p>
<p>2. Underpinning research</p> <p>The Organ Donation & Transplant Research Centre (ODTC) under Professor Randhawa's leadership (work carried out at the University of Bedfordshire throughout) has focussed on 2 key areas designed to increase knowledge, develop the evidence-base and inform intervention to increase the organ donors from the UK's diverse population</p> <p>(1) Public engagement campaigns</p> <p>ODTC's work on addressing supply and demand for organ donors among multi-ethnic and multi-faith communities has led to several prestigious commissions that have informed the development and implementation of public organ donation campaigns:</p> <p>Commissioned by the Kings Fund in 1995 to undertake the first ever UK study to examine views of different South Asian faith communities which led to UK Transplant's campaigns with BME communities (3.1). Subsequently commissioned by the Department of Health to undertake pioneering dialogue with Faith Leaders at national level to discuss organ donation and how best to engage with faith communities which has led to NHSBT's current BME and Faith campaigns (3.2; 3.3). He has recently completed a study funded by NHS Blood & Transplant exploring 'gifting' in faith communities and its potential relevance to organ donation. He also received a prestigious commission by the Race Equality Foundation to write a Health Policy Briefing Paper (3.4) which has been widely cited, and specifically informs some of the recommendations in the Nuffield Council of Bioethics Report – Human Bodies – Donation for medicine and research (5.1). Most recently, NHS Blood & Transplant funded a PhD studentship for Professor Randhawa to examine the views of UK Polish migrants towards organ donation (PhD completion in Sep 2013).</p> <p>(2) Professional training and practice</p> <p>ODTC's work (3.5 and 3.6) on the need for relevant staff training and education regarding faith/cultural/end-of-life care issues has led to the inclusion of the topic as part of the Masterclass curriculum offered by NHS Blood and Transplant to all of its Specialist Nurses in Organ Donation, Clinical Leads for Organ Donation, and Organ Donation Committee Chairs across the UK. NHSBT have commissioned Professor Randhawa to provide this training. In addition, Professor Randhawa's work is specifically cited in the National Institute for Clinical Excellence (NICE) Guidelines for Organ Donation to inform their recommendation for staff training and practice to be cognisant of the diversity of potential organ donor families (5.2).</p> <p>Professor Randhawa's work has informed both policy and practice and has also led to his appointment to key national and international working groups reflecting the research impact of his work. Most recently, he was invited by the 4 UK Departments of Health (England, Wales, Scotland, and Northern Ireland) to be Chairman of the Transplant 2020 Stakeholder Group to take forward engagement with various sectors – business, education, health, and voluntary – in promoting conversations about organ donation. Professor Randhawa's policy appointments include:</p> <ul style="list-style-type: none"> • <i>Authority Member, Human Tissue Authority Board (Current)</i> • <i>National member, Academy of Medical Royal Colleges' UK Donation Ethics Committee (Current)</i> • <i>Co-Chairman, European Working Party on Public Issues in Organ Donation (Current)</i>

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- *National Member, NICE Evidence Update Advisory Group – Organ Donation (Current)*
- *Chairman, End-of-life care for Advanced Kidney Disease Project Board, Department of Health*
- *National advisory member, Minister of State for Health Services’ Commissioned - Organ Donation Taskforce, Department of Health*
- *National advisory Chair, Minister of State for Health Services’ Commissioned - Organ Donation Taskforce, Department of Health, sub-group – Cultural issues and consent models*
- *National Member, NICE Guidelines Development Group – Organ Donation*
- *Non-Executive Director, UK Transplant*

3. References to the research

- 3.1 Randhawa G. (1998) An exploratory study examining the influence of religion on attitudes towards organ donation among the Asian population in Luton, UK. *Nephrology Dialysis Transplantation*. 13, 1949-54.
- 3.2 Randhawa G, Brocklehurst A, Pateman R, Kinsella S, Parry V (2010) ‘Opting-in or Opting-out?’ The views of the UK’s Faith leaders in relation to organ donation. *Journal of Health Policy*. 96, 36-44.
- 3.3 Randhawa G, Brocklehurst A, Pateman R, Kinsella S, Parry V (2010) Faith leaders united in their support for organ donation – Findings from the Organ Donation Taskforce’s Study of attitudes of UK faith and belief group leaders to an opt-out system. *Transplant International*. 23, 140-146.
- 3.4 Randhawa G (2007) Tackling health inequalities for minority ethnic groups: challenges and opportunities. *Better Health Briefing 6*, Race Equality Foundation & Department for Communities and Local Government.
- 3.5 Randhawa G. (1998) Coping with grieving relatives and making a request for organs: Principles for staff training. *Medical Teacher*. 20, 247-249
- 3.6 Randhawa G (2012) Death and organ donation – meeting the needs of multi-ethnic and multi-faith populations. *British Journal of Anaesthesia*, 108, 88-91.

4. Details of the impact

(1) Public engagement campaigns

Professor Randhawa was appointed through open national competition as a Non-Executive Director to UK Transplant (2001-2005) in recognition of his research expertise and to inform research analysis and public campaign work. This led to the inception of a series of Organ Donation Campaigns that specifically were aimed at BME communities. In 2008, Professor Randhawa was invited to become a Member of the Organ Donation Taskforce. It is of great significance that the Organ Donation Taskforce made explicit recommendations to tackle the needs of the UK’s multi-ethnic and multi-faith population:

“Recommendation 13: There is an urgent requirement to identify and implement the most effective methods through which organ donation and the “gift of life” can be promoted to the general public, and specifically to the BME (Black and minority ethnic) population. Research should be commissioned through Department of Health Research and Development funding.” (5.3).

Furthermore, The Taskforce was asked to examine the impact of introducing an opt-out system. In recognition of Professor Randhawa’s reputation in the field, he was asked to meet with national faith leaders (3.2; 3.3) and this led to a further Government recommendation “The Taskforce strongly recommends that the programme delivery Board builds on the foundations of the interviews with faith and belief groups, reported in annex m, to ensure that the valuable dialogue that was established is maintained.” (5.4).

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Professor Randhawa led the dialogue with Faith Leaders on behalf of the Taskforce and was subsequently commissioned by the Department of Health to build upon this work and this has led to a series of faith community events which has led to increased numbers of organ donor registrations (5.5).

Professor Randhawa was commissioned by NHS Blood and Transplant in 2012 to work with national Faith leaders to design and author written materials relating to faith and organ donation. These Faith leaflets were launched at a national event (5.6). Subsequently, these materials have been used at public engagement events to increase organ donor registrations.

In 2012, Professor Randhawa was invited to become a Member of the Department of Health's National Black and Minority Ethnic Transplant Alliance (he is the only academic on the Group). The Alliance is pulling together the most recent evidence-base around the world regarding public engagement campaigns and making it available to the public and policy makers to inform future community engagement events in order to increase organ donor registrations (5.7).

At international level, Professor Randhawa was invited to provide Oral Evidence to House of Lords European Union Select Committee examining the impact of the European Organ Donation Directive in 2008 - Cultural and faith issues in organ donation and transplantation. The House of Lords Report subsequently made specific recommendations relating to the EU needing to focus on demand and supply issues among different ethnic and faith communities (5.8).

In recognition of his standing in the field, Professor Randhawa was invited to Co-Chair the European Working Party on Public Issues in Organ Donation by the European Society for Transplantation in 2011. Professor Randhawa co-edited a book in 2013 that provides the first comprehensive analysis of public engagement issues in organ donation from all around the world (5.9).

Most recently, Professor Randhawa was invited by the 4 UK Departments of Health (England, Wales, Scotland, and Northern Ireland) to be Chairman of the Transplant 2020 Stakeholder Group to take forward engagement with various sectors – business, education, health, and voluntary – in promoting conversations about organ donation.

(2) Professional training and practice

Professor Randhawa was invited to become a Member of the National Institute for Clinical Excellence (NICE) Guidelines Development Group for Organ Donation to provide insight into demographic, ethnic, cultural and faith issues. The NICE Guideline has specific recommendations relating to the need for staff training and practice to take cognisance of faith and ethnicity issues of potential donors and their families (5.2). Professor Randhawa's work (3.5 and 3.6) on the need for relevant staff training and education regarding faith/cultural/end-of-life care issues has led to the inclusion of the topic as part of the Masterclass curriculum offered by NHS Blood and Transplant to all of its Specialist Nurses in Organ Donation, Clinical Leads for Organ Donation, and Organ Donation Committee Chairs across the UK. NHSBT have commissioned Professor Randhawa to provide this training. This has led to increase in the number of families agreeing to organ donation.

Professor Randhawa is also a Member of the UK Donation Ethics Committee (UKDEC) with a specific remit to provide faith/ethnic research expertise. This has led to specific recommendations and implementation of staff training and practice regarding diversity issues within UKDEC policy guidance documents (5.10).

In summary, Professor Randhawa's research has informed policy and practice to contribute to the increase in organ donor registrations from diverse populations in the UK and in many other countries. He is a regular contributor at national and international policy meetings as well as regular expert speaker in the media, having appeared on programmes such as BBC Newsnight with Jeremy Paxman, Radio 4, etc.

Impact case study (REF3b)**5. Sources to corroborate the impact**

The following key sources can be used to identify the impact of this programme of work:

- 5.1 Nuffield Council of Bioethics (2011) Human bodies – donation for medicine and research. Nuffield Council, London.
- 5.2 National Institute for Health and Clinical Excellence (2011) Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation. London: National Institute for Health and Clinical Excellence. Available from www.nice.org.uk/guidance/CG135
- 5.3 *“Recommendation 13: There is an urgent requirement to identify and implement the most effective methods through which organ donation and the “gift of life” can be promoted to the general public, and specifically to the BME (Black and minority ethnic) population. Research should be commissioned through Department of Health Research and Development funding.”* Department of Health, Organs for Transplants: A report from the Organ Donation Taskforce. London, Department of Health, 2008.
- 5.4 *“The Taskforce strongly recommends that the programme delivery Board builds on the foundations of the interviews with faith and belief groups, reported in annex m, to ensure that the valuable dialogue that was established is maintained.”* Department of Health, The potential impact of an opt-out system for organ donation in the UK – An independent report from the Organ Donation Taskforce, London, Department of Health, 2008.
- 5.5 DH commissioned Faith community event led by Prof Randhawa, Media coverage - www.guardian.co.uk/healthcare-network/2011/jul/12/communications-strategy
- 5.6 NHSBT Commissioned launch of Faith and Organ Donation leaflets led by Prof Randhawa – media coverage: www.organdonation.nhs.uk:8001/ukt/newsroom/news_releases/article.asp?releaseld=304
- 5.7 National BAME Transplant Alliance (2012) NBTA report Black, Asian and Minority Ethnic Organ Donation and Transplantation Data, Department of Health, London.
- 5.8 Increasing the supply of donor organs within the European Union (17th Report, Session 2007-08, HL Paper 123); to be debated on 14 November 2008 www.publications.parliament.uk/pa/ld200708/ldselect/ldcom/123/123i.pdf
- 5.9 Randhawa G & Schicktanz S (Eds) (2013) Public Engagement in organ donation and transplantation. Pabst Science Publishers.
- 5.10 UK Donation Ethics Committee (2011) An ethical framework for controlled donation after circulatory death. Academy of Medical Royal Colleges, London. Available from www.aomrc.org.uk/publications/reports-a-guidance.html