

Impact case study (REF3)

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| Institution: University of Bedfordshire | | |
| Unit of Assessment: A3 | | |
| Title of case study: Equality, Diversity & Inclusion with Organ Donation | | |
| Period when the underpinning research was undertaken: 2000 onwards | | |
| 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: |
| Gurch Randhawa | Professor, Diversity in Public Health | September 1993 to date |
| Chris Papadopoulos | Principal Lecturer in Public Health | September 2011 to date |
| Erica Cook | Senior Lecturer in Health Psychology | September 2012 to date |
| Period when the claimed impact occurred: 1 st August 2013 to date | | |
| Is this case study continued from a case study submitted in 2014? No | | |
| 1. Summary of the impact (indicative maximum 100 words) | | |
| <p>There is a shortage of organ donors for transplant, specifically from Black, Asian and Minority Ethnic (BAME) communities. Our research has led to an increase in organ donor registrations from diverse communities. The research shows the need for culturally competent approaches to policy and interventions development. Our research has led to the development and implementation of a range of evidence-based interventions within the <i>Taking Transplantation to 2020 Strategy</i> (2013-2020) via the launch of Department of Health's Organ Donor Community Investment Scheme, schools BAME and organ donation education resources-pack, implementation of the Faith Action Plan, and BAME organ donation engagement plan.</p> | | |
| 2. Underpinning research (indicative maximum 500 words) | | |
| <p>The Organ Donation & Transplant Research Centre (ODTC) under Professor Randhawa's leadership has focussed on 2 key areas – (i) designed to increase knowledge, develop the evidence-base, and (ii) inform interventions to increase the organ donors from the UK's diverse population</p> | | |
| (i) Public engagement campaigns | | |
| <p>ODTC's work on addressing supply and demand for organ donors among multi-ethnic and multi-faith communities over the last 25 years has led to several prestigious commissions that have informed the development and implementation of public organ donation campaigns: In 2009, commissioned by NHS Blood & Transplant to carry out a national study examining the reasons and circumstances in which individuals make gifts and donations and exploring the relevance to increasing organ donation among the UK's multi-ethnic and multi-faith community. This was followed up in 2010 by a commission from the Department of Health/Organ Donation Taskforce Implementation Group – Promoting an improved understanding of organ donation amongst the UK's multi-ethnic and multi-faith population: The potential contribution of Faith and Belief Leaders. Alongside, this NHS Blood & Transplant funded a PhD studentship for Professor Randhawa to examine the views of UK Polish migrants towards organ donation (3.1). Subsequently commissioned by NHS Blood & Transplant in 2013 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). The Faith and Organ Donation Action Plan now serves as a blueprint for many countries – Spain,</p> | | |

India, UAE - engaging with diverse ethnic and faith communities in relation to organ donation and stimulating international research (3.3).

(ii) Professional training and practice

ODTC were co-applicants to a NIHR Programme Grant – 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) study; and were co-applicants on a Department of Health grant focussing on bereaved families views towards organ donation. This work (3.4 and 3.5) 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 training 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. This research is also being used within NHS Blood & Transplant's 'Consent and Authorisation- Developing a Family Approach' training to ensure staff training and professional practice to be cognisant of the diversity of potential organ donor families. ODTC's research examining the role of primary care in organ donation has led to the world's first feasibility study to examine whether a GP practice intervention to increase organ donation registration among BAME communities in the UK (3.6).

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

- 3.1** Sharp C & Randhawa G: "Cultural Attitudes towards Death Practices, the Body after Death and Life after Death in Deceased Organ Donation - A UK Polish Migrant Perspective", *Journal of Palliative Care and Medicine*, 2016, 6:262, DOI:10.4172/2165-7386.1000262
- 3.2** Randhawa G & Neuberger J: "Role of Religion in Organ Donation—Development of the United Kingdom Faith and Organ Donation Action Plan", *Transplantation Proceedings*, 2016, 48: 3, 689–694, DOI:10.1016/j.transproceed.2015.10.074
- 3.3** Paul Vincent B, Randhawa G, Cook E: "Barriers towards organ donor registration and consent among people of Indian origin living globally: a systematic review and integrative synthesis—protocol", *BMJ Open*, 10(6), 2020, DOI: 10.1136/bmjopen-2019-035360
- 3.4** Morgan M, Kenten C, Deedat S, Farsides B, Newton T, Randhawa G, Sims J, Sque M.: "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*, 2016, 4(4). DOI:10.3310/pgfar04040
- 3.5** Sque M, Rodney A, Randhawa G, Walker W, Long-Sutehall T, Morgan M: "Bereaved donor families' experiences of organ and tissue donation, and perceived influences on their decision making", *Journal of Critical Care*, 2018, 45, 82-89. DOI:10.1016/j.jcrc.2018.01.002
- 3.6** Jones C, Papadopoulos C, Asghar Z & Randhawa G: "Improving access to organ donor registration in general practice – A feasibility study", *British Journal of General Practice*, 70 (696), 2020, DOI: 10.3399/bjgp20X709601

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

Following on from the ODTC's previous research and impact on improving equality, diversity and inclusion with organ donation, the work since 2013 has become of greater national and international prominence:

Public engagement activities – The work of the ODTC underpinned the public engagement theme of the Taking Transplant to 2020 Strategy published in 2013. ODTC's research has led to the development and implementation of a range of evidence-based interventions within this

Theme (2013-2020). It is of great significance that the evidence to inform the Strategy makes reference to ODTC's research works (5.1). The Strategy refers to ODTC's work *'Increase Black, Asian and Minority Ethnic communities' awareness for the need of donation, to benefit their own communities and provide better support for people in these communities to donate.'* (5.2). 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 to deliver the Strategy. A range of culturally competent initiatives that have been developed since 2013 to deliver the Strategy, have been underpinned by the ODTC's Faith and Organ Donation Action Plan. Notable examples are the Faith and belief donor cards; Faith & beliefs declaration; the development of a MPs BAME toolkit, the schools organ donation pack – that incorporates BAME case-studies (5.3; 5.4; 5.5). The inception, implementation and evaluation on NHS Blood & Transplant's Community Investment Scheme draws upon ODTC's research findings relating to taking a grass-roots approach to organ donation conversations. Professor Randhawa was subsequently appointed to be on NHSBT Community Investment Scheme Advisory Panel. The Community Investment Scheme Evaluation Report specifically cites the role of Randhawa's Faith & Action Plan in informing the success of the scheme: *'Over recent years there have been recommendations made from community organisations, researchers and politicians for the funding of community delivered activity. This approach has also been endorsed by the UK's faith leaders as exemplified with the NHSBT Faith & Organ Donation Action Plan. The funding provided to NHS Blood and Transplant in 2018/19 through the Government's campaign to address the urgent need for black, Asian and ethnic minority organ donors could make it a reality.'* (5.6).

In 2018, the Government launched a consultation on a change in a law regarding organ donation, and the public consultation document drew upon ODTC's work, and specifically cited Randhawa's work: *'Faith and culture play an important part globally in people's decisions to donate organs. (See 'Death and organ donation: meeting the needs of multi-ethnic and multi-faith populations', Randhawa G (2012), British Journal of Anaesthesia)* (5.7). Professor Randhawa was subsequently appointed to serve on the NHSBT Organ Donation Deemed Consent Campaign Advisory Group.

Professional training for all donation and transplant staff – The research findings from the DONATE study, and ODTC's work with faith leaders and different ethnic communities has informed the development and implementation of NICE guidance to ensure staff are supported and trained to approach all families. ODTC has contributed to NHSBT's National Deceased Donation Course for Intensive Care Medicine trainees (5.8). The recently completed feasibility study of a GP practice intervention to increase organ donation registration among BAME communities in the UK, has led to the development of a range of primary care training resources (Papadopoulos & Randhawa).

The NHSBT 5 year periodic review (2015/16-2019/20) of BAME communities shows the positive impact of ODTC's research influencing NHSBT's culturally competent public engagement organ donation approach –

- 32% increase in the proportion of opt-in registrations from BAME communities added to the Organ Donor Register (ODR), from 5.9% to 7.8% of the ODR
- 20% increase in BAME family consent rates, from 35% to 42%
- 67% increase in BAME deceased organ donors, from 67 in 2015/16 to 112 in 2019/20
- 24% increase in the number of transplants in BAME people (5.9)

In summary, ODTC's research has led to the development of culturally competent policy and practice to contribute to the increase in organ donor registrations from diverse populations in the UK and in many other countries, for example Spain, India, and the UAE (5.10). ODTC are a regular contributor at national and international policy meetings as well as regular expert speakers in the media when organ donation matters are featured, having frequently appeared on programmes such as BBC National News, Radio 4, etc.

ODTC's work has informed the recently published (Feb 2021) 4 UK Department of Health's strategy 'Organ donation & transplantation: Meeting the need' – A 10 year vision for organ donation and transplantation in the United Kingdom. Notably, Diversity & Inclusion, is one of the 6 Themes of the strategy, and the strategy document makes numerous references to the evidence-base that ODTC's research has generated to shaping policy and practice, and informing future culturally competent public engagement interventions.

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

- 5.1 https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/4255/nhsbt_organ_donation_public_behaviour_change_summary_of_research-1.pdf
- 5.2 https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/4240/nhsbt_organ_donor_strategy_long.pdf
- 5.3 <https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/download-digital-materials/faith-and-belief-donor-cards/>
- 5.4 <https://www.nhsbt.nhs.uk/news/faith-and-beliefs-declaration/>
- 5.5 <https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/download-digital-materials/organ-donation-teaching-resources/>
- 5.6 <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/19105/community-investment-scheme-progress-report2.pdf>
- 5.7 <https://www.gov.uk/government/consultations/introducing-opt-out-consent-for-organ-and-tissue-donation-in-england/consultation-on-introducing-opt-out-consent-for-organ-and-tissue-donation-in-england>
- 5.8 <https://www.odt.nhs.uk/deceased-donation/best-practice-guidance/consent-and-authorisation-the-family-approach/>
- 5.9 <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/19692/bame-report-201920.pdf>
- 5.10 <https://www.elperiodico.com/es/sanidad/20181001/gurch-randhawa-debemos-normalizar-el-hablar-sobre-donacion-de-organos-7053878>