

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)

Myfanwy Morgan,^{1*} Charlotte Kenten,¹
Sarah Deedat,¹ Bobbie Farsides,² Tim Newton,³
Gurch Randhawa,⁴ Jessica Sims¹ and Magi Sque⁵

¹Division of Health and Social Care Research, King's College London, London, UK

²Brighton and Sussex Medical School, University of Sussex, Brighton, UK

³Dental Institute, King's College London, London, UK

⁴Institute for Health Research, University of Bedfordshire, Luton, UK

⁵Faculty of Education, Health and Wellbeing, University of Wolverhampton and Royal Wolverhampton NHS Trust, Wolverhampton, UK

*Corresponding author

Declared competing interests of authors: Membership of the following committees was declared: Professor M Morgan: National Black, Asian and Minority Ethnic Transplant Alliance; Professor B Farsides: UK Donation Ethics Committee; Professor Gurch Randhawa: UK Donation Ethics Committee; Human Tissue Authority; National Institute for Health and Care Excellence Evidence Update Group (Organ Donation Guidelines); National Black, Asian and Minority Ethnic Transplant Alliance; Transplant 2020 Stakeholder Group (chairperson).

Published March 2016

DOI: 10.3310/pgfar04040

Scientific summary

Organ donation among minority ethnic groups

Programme Grants for Applied Research 2016; Vol. 4: No. 4

DOI: 10.3310/pgfar04040

NIHR Journals Library www.journalslibrary.nihr.ac.uk

Scientific summary

Background

People of African/Caribbean and Asian descent are significantly over-represented on waiting lists for organ transplantation, reflecting a relatively high need but low donation rate, leading to a particular shortage of well-matched organs. This research programme responds to the recommendation of the Organ Donation Taskforce (2008) for work to be undertaken to understand how best to encourage consent to donation, particularly from the black, Asian and minority ethnic (BAME) group population.

Aim

To increase the acceptability and rates of deceased donation among minority ethnic groups and thus reduce waiting times for transplantation.

Objectives

- (a) To identify barriers to organ donor registration and the characteristics of effective community interventions.
- (b) To identify requirements for increasing family consent to donation among the BAME population.
- (c) To develop and evaluate a training package to enhance communication and support provided to ethnic minority families in intensive care units (ICUs).

Methods: community studies and registration as an organ donor

Study 1: systematic review of the barriers to organ donor registration

A systematic literature search was conducted to identify current knowledge of barriers to deceased organ donation among minority ethnic groups. Following appraisal of relevance and quality, 26 studies were retained (14 quantitative and 12 qualitative studies). These were integrated and synthesised around five key emerging issues: (1) level of awareness and knowledge regarding deceased donation and registration as a donor; barriers to registration arising from (2) faith and cultural beliefs; (3) bodily concerns; (4) willingness to discuss donation/registration with family members; and (5) trust in doctors and the health system.

Study 2: focus group study of attitudes and beliefs relating to registration as a donor

This study aimed to identify the reasons for a continuing low level of knowledge about both need for organ donation among minority ethnic groups and how to register as a donor, and to examine the variations in beliefs and attitudes to donation between and within ethnic groups.

A total of 22 focus groups were held in six multiethnic areas of London with 228 participants from six ethnic/faith groups (who identified as West African Christian, black Caribbean Christian, Indian Sikh, Indian Hindu, Pakistani Islamic and Bangladeshi Islamic). There were separate focus groups for older people (> 40 years) and younger (18–40 years), and for men and women among older South Asian people.

Study 3: systematic review of effective community interventions

This study identified the characteristics of effective interventions in increasing knowledge or rates of sign-up to the Organ Donor Register (ODR) among ethnic minorities in the UK and North America. Following appraisal of relevance and quality, 18 studies were available for synthesis, of which all but one were conducted in the USA.

Key findings: community studies

- The focus groups indicated that, despite national donation campaigns focusing specifically on minority ethnic groups, the majority had little awareness and knowledge. This was explained by ethnic minorities' perception of campaign images and messages as lacking relevance for them, reflecting their lack of a prior stock of knowledge regarding deceased donation, perceptions of transplantation as a 'white' issue and beliefs in the bodily strength of their own ethnic group. The importance of specific factors in limiting perceived 'relevance' was, however, shown to vary in relation to ethnicity/faith, age and socioeconomic position.
- Key beliefs that may constrain registration were identified as faith and cultural beliefs regarding permissibility, concerns about the body being cut, lack of willingness to talk with family about donation and lack of trust in health professionals and the health system. For the small number of people who were further along the registration pathway, the main constraint to registering was inertia attributed to the other priorities in their lives.
- A very small number were certain they had registered, with larger numbers being uncertain if they had checked the box indicating willingness to join the ODR.
- The synthesis of interventions identified the greater effectiveness of community education campaigns compared with media campaigns alone. Key characteristics of effective educational interventions were delivery in familiar community settings, a strong interpersonal element and presentation by trained lay individuals, together with the availability of immediate access to registration.

Methods: hospital studies and consent to donation

Two studies were undertaken at five NHS trusts to identify staff views regarding family consent to donation and current policies and practices, whereas a third study aimed to identify the perceptions and experiences of bereaved ethnic minority families.

Study 1: interview and observational study at five NHS trusts

This examined the attitudes and practices of ICU staff and hospital chaplains of different faiths in relation to communication and support provided to ethnic minority families, which has been identified as influencing consent decisions. It was based on observation of the activities of the ICU and work of the specialist nurses for organ donation (SNODs) and semistructured tape-recorded interviews with ICU consultants, junior doctors, SNODs, senior and bedside nurses, and hospital chaplains.

Study 2: ethics discussion groups with staff

Ten discussion groups were held with ICU staff and members of the local Organ Donation Committee facilitated by Professor Bobbie Farsides to identify views and practices regarding donation and ethnicity, and to discuss key ethical issues raised. Taped discussions were fully transcribed, coded and analysed thematically.

Study 3: interviews with bereaved families from black and minority ethnic groups

This study aimed to identify those aspects of end-of-life care and support that families particularly valued or viewed negatively, as well as other influences on their donation decision. The study aimed to interview 24 families from minority ethnic groups: 12 who consented to organ donation and 12 who did not consent to organ donation. However, restrictions on recruitment meant that, despite attempting different approaches, we were only able to conduct semistructured interviews with 13 consenting families drawn from a range of minority ethnic groups.

Key findings: hospital studies

- Intensive care unit staff often lacked confidence in communicating with ethnic minority families, particularly at times of emotional distress, with bedside nurses most commonly identifying a need for training. Key areas of concern for staff were varying forms of emotional expression, faith and cultural beliefs and practices, managing large families, and language and communication. These, therefore, formed central elements of the training package.
- The significant proportion of consent discussions that continue to be undertaken by the clinician alone rather than through a collaborative discussion with SNODs was explained by clinicians' beliefs in their own expertise and responsibility, a lack of trust in SNODs' expertise, the culture of the ICU and lack of formal requirement to engage in recommended collaborative discussions, together with the particular uncertainties and requirements of donations after cardiac death that influenced clinicians' desire to manage these cases themselves.
- Hospital chaplains' perception of their role and involvement in end-of-life care identified members of this group as a potential resource in supporting families during end-of-life care, although there were varying views regarding involvement in donation discussions and in the availability for those with only part-time hospital appointments.
- Only consenting families could be interviewed and these 13 families were very positive about the communication and support that they received and the lack of pressure to make a decision. However, most of these families would have appreciated an update from SNODs to know whether or not the recipients were healthy and able to get on with their lives.

Methods: intervention development and evaluation

Focus and content of package

The digital versatile disk (DVD) was informed by the theory of planned behaviour (TPB). It aimed to change behavioural intentions and practices, thus enhancing the quality of cross-cultural communication and support through changes in attitudes, subjective norms and perceived behavioural change. It had a medical presenter and 12 'talking heads' comprising doctors, nurses, hospital chaplains, patients and families.

The DVD begins with a brief introduction to ethnic minorities in the UK, focusing on their heterogeneity and history, and then focuses on five key social aspects of interactions [termed the Donation, Transplantation and Ethnicity (DonaTE) dimensions] identified in the hospital studies as presenting particular challenges for staff. These are responding to families' emotional expression; faith and cultural beliefs; difficulties of language and communication; managing extended family and visitors; and responding to families' anxieties and concerns about organ donation. The talking heads describe the range of beliefs and responses that they commonly encounter in relation to each DonaTE dimension and provide examples of good practices. This is followed by a short drama that gives an in-depth view of these issues for families. An accompanying workbook identifies the key messages and encourages personal reflection and plans.

Evaluation

This comprised three components: (1) a brief feedback questionnaire completed at the end of sessions; (2) an evaluation of changes in staff attitudes and practices based on TPB questionnaires completed at baseline and 3 months; and (3) an evaluation of changes in consent rates by ethnic minority families between study sites and non-study hospitals in the same region based on 12-month NHS Blood and Transplant (NHSBT) activity data.

Key findings: evaluation of intervention

- Feedback from all grades of ICU staff was very positive.
- The before-and-after evaluation identified a significant positive effect on attitudes but no significant effect over the 3-month period on subjective norms and perceived behavioural change.
- Consent rates increased across both intervention and non-intervention sites over the 12-month period with a greater increase among ethnic minority families. However, the increase was not significantly higher compared with white families or for intervention compared with control sites, with this possibly reflecting broader changes across all hospitals in the study regions.
- The DVD was nominated for the national Learning on Screen Awards 2014 and was highly commended.

Implications for policy and practice

1. Community interventions require to be informed by the populations' 'stage of change' and particular faith/cultural beliefs, and would often benefit from greater use of personalised case studies and for messages to be delivered by trained lay individuals or community representatives in familiar settings. Achieving actual registration may also require multiple interventions that reinforce each other over a period of time and, when possible, an immediate opportunity to register, such as through the availability of cards and a 'post box' to place in surgeries, places of work or at community/faith organisations.
2. Many focus group participants, particularly of Caribbean origin, wished to discuss organ donation and joining the ODR with a practice nurse or general practitioner and to have access to registration at general practices. The feasibility and cost-effectiveness of this primary care-based approach could be piloted.
3. The views of Islamic faith leaders regarding organ donation have an important influence on the views practices of the older generation, with a need to achieve a consensus regarding permissibility and associated guidance (fatwa).
4. Many people were uncertain whether or not they had checked the relevant donation box on their driving licence, Boots Advantage Card or passport application and preferred a donor card. The provision of a card could act as confirmation of being on the ODR.
5. There is a need to ensure that campaigns address the particular beliefs and concerns of different minority ethnic groups, while the spatial targeting of campaigns would be assisted by more complete recording of ethnicity in relation to registration as a donor (only 18% of registrations now have ethnicity recorded).
6. Addressing clinicians' views and concerns regarding 'collaborative requesting' and developing consensus-based guidance regarding donation after circulatory (or cardiac) death donations is likely to increase clinicians' willingness to involve SNODs with families at an early stage.
7. Hospital chaplains' role in supporting families in ICUs could be developed with appropriate training and form a resource to address concerns about organ donation at both a hospital and community level.

8. Members of the ethics discussion groups valued the opportunity to discuss sensitive issues in a safe and constructive setting, including different approaches to increasing donor numbers, particularly of BAME groups. The general view was that staff working in ethically challenging areas should be given a regular opportunity to discuss and reflect on practice in a confidential and non-judgemental setting. An example is the successful introduction of Schwartz Centre Rounds® (The Schwartz Center for Compassionate Healthcare, Boston, MA, USA), which allow NHS staff to get together once a month to reflect on the stresses and dilemmas that they have faced while caring for patients. See www.gov.uk/government/news/expansion-of-groundbreaking-scheme-to-support-nhs-staff.
9. The DonaTE training package was designed for use as part of ICU induction or ongoing education delivered by SNODs or by critical care networks to increase the cultural confidence and competence of junior ICU staff. Interest in the core DVD has also been shown by community organisations to increase knowledge and trust in donation and by hospital chaplains to increase knowledge of issues of ethnicity and organ donation. The DVD is available on the National Institute for Health Research YouTube (YouTube, LLC, San Bruno, CA, USA) channel: www.youtube.com/watch?v=ueaR6XYkeVM&feature=youtu.be.

Implications for further research

1. A greater emphasis in the UK on the evaluation of community campaigns is required to increase knowledge of the most effective formats and forms of delivery for different groups in the population.
2. Identifying the stage on the 'donation pathway' of different ethnic groups, and variations in beliefs by age, faith, socioeconomic status and country of origin is important for effective targeting. Data could be obtained by a large purpose-designed survey or adding questions to existing national surveys.
3. A better understanding of the interaction of age, ethnicity and socioeconomic status on organ donor registration may be achieved through electronic surveys conducted among employees at different levels of large organisations, such as the Civil Service or commercial companies.
4. Increased understanding of the reasons for non-consent to donation among ethnic minority families could be achieved through secondary analysis of the more detailed information now recorded by SNODs on reasons for refusal. Primary research could also be undertaken if NHSBT is able to give permission to approach bereaved families on a retrospective basis.

Funding

Funding for this study was provided by the Programme Grants for Applied Research programme of the National Institute for Health Research.

Programme Grants for Applied Research

ISSN 2050-4322 (Print)

ISSN 2050-4330 (Online)

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: nihredit@southampton.ac.uk

The full PGfAR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/pgfar. Print-on-demand copies can be purchased from the report pages of the NIHR Journals Library website: www.journalslibrary.nihr.ac.uk

Criteria for inclusion in the *Programme Grants for Applied Research* journal

Reports are published in *Programme Grants for Applied Research* (PGfAR) if (1) they have resulted from work for the PGfAR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

Programme Grants for Applied Research programme

The Programme Grants for Applied Research (PGfAR) programme, part of the National Institute for Health Research (NIHR), was set up in 2006 to produce independent research findings that will have practical application for the benefit of patients and the NHS in the relatively near future. The Programme is managed by the NIHR Central Commissioning Facility (CCF) with strategic input from the Programme Director.

The programme is a national response mode funding scheme that aims to provide evidence to improve health outcomes in England through promotion of health, prevention of ill health, and optimal disease management (including safety and quality), with particular emphasis on conditions causing significant disease burden.

For more information about the PGfAR programme please visit the website: <http://www.nihr.ac.uk/funding/programme-grants-for-applied-research.htm>

This report

The research reported in this issue of the journal was funded by PGfAR as project number RP-PG-0707-10123. The contractual start date was in April 2009. The final report began editorial review in July 2014 and was accepted for publication in July 2015. As the funder, the PGfAR programme agreed the research questions and study designs in advance with the investigators. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The PGfAR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, CCF, NETSCC, PGfAR or the Department of Health. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the PGfAR programme or the Department of Health.

© Queen's Printer and Controller of HMSO 2016. This work was produced by Morgan *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).

Programme Grants for Applied Research Editor-in-Chief

Professor Paul Little Professor of Primary Care Research, University of Southampton, UK

NIHR Journals Library Editor-in-Chief

Professor Tom Walley Director, NIHR Evaluation, Trials and Studies and Director of the HTA Programme, UK

NIHR Journals Library Editors

Professor Ken Stein Chair of HTA Editorial Board and Professor of Public Health, University of Exeter Medical School, UK

Professor Andree Le May Chair of NIHR Journals Library Editorial Group (EME, HS&DR, PGfAR, PHR journals)

Dr Martin Ashton-Key Consultant in Public Health Medicine/Consultant Advisor, NETSCC, UK

Professor Matthias Beck Chair in Public Sector Management and Subject Leader (Management Group), Queen's University Management School, Queen's University Belfast, UK

Professor Aileen Clarke Professor of Public Health and Health Services Research, Warwick Medical School, University of Warwick, UK

Dr Tessa Crilly Director, Crystal Blue Consulting Ltd, UK

Dr Peter Davidson Director of NETSCC, HTA, UK

Ms Tara Lamont Scientific Advisor, NETSCC, UK

Professor Elaine McColl Director, Newcastle Clinical Trials Unit, Institute of Health and Society, Newcastle University, UK

Professor William McGuire Professor of Child Health, Hull York Medical School, University of York, UK

Professor Geoffrey Meads Professor of Health Sciences Research, Health and Wellbeing Research and Development Group, University of Winchester, UK

Professor John Norrie Health Services Research Unit, University of Aberdeen, UK

Professor John Powell Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK

Professor James Raftery Professor of Health Technology Assessment, Wessex Institute, Faculty of Medicine, University of Southampton, UK

Dr Rob Riemsma Reviews Manager, Kleijnen Systematic Reviews Ltd, UK

Professor Helen Roberts Professor of Child Health Research, UCL Institute of Child Health, UK

Professor Jonathan Ross Professor of Sexual Health and HIV, University Hospital Birmingham, UK

Professor Helen Snooks Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

Professor Jim Thornton Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

Please visit the website for a list of members of the NIHR Journals Library Board:
www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact: nihredit@southampton.ac.uk