Policy brief

Identifying interventions to increase organ donation rates in people from minority ethnic backgrounds

Summary

- In the UK, 30% of people on the organ transplant list are from a black, Asian and minority ethnic (BAME) background. For many people, the best match for an organ will come from a donor of the same ethnicity. However, the proportion of deceased donors from BAME backgrounds stands at 7%, compared to 11% in the general population.
- This project was conducted in response to a request from NIHR to update the evidence on interventions to increase organ donation rates in people from BAME backgrounds. It built on previous work to (i) articulate the reasons why people from BAME backgrounds might not donate organs; (ii) understand the motivations people have for donating organs; and (iii) identify interventions that target these barriers and enhance or re-direct motivation towards organ donation.
- Published systematic reviews about the barriers to donation, facilitators and interventions to encourage donation in people from BAME backgrounds were updated and built on using a behaviour change framework to suggest types of interventions that could be effective. A rapid best evidence synthesis was carried out to expand the evidence beyond organ donation and retrieve systematic reviews that evaluated interventions that address these barriers in different areas of health and social care.
- The evidence suggests that that other characteristics than ethnicity be considered when planning interventions; that organ donation be considered a pathway not an event; and that different interventions be used for people at an early stage of the pathway (unaware) compared to late (considering joining the register). Intervention evaluations should measure the appropriate outcome for their place on the pathway: knowledge and awareness for the early stages and registrations for later.
- This work was conducted using robust evidence synthesis methods and a published behaviour change framework. The evidence from the review updates is complete and up to date; the evidence from the behaviour change framework and best evidence synthesis is robust and provided systematic review level evidence about three prioritised barriers.

This project is funded by the National Institute for Health Research (NIHR)

Introduction

In the UK, 30% of people on the organ transplant list are from a BAME background. For many people, the best match for an organ will come from a donor of the same ethnicity. However, the proportion of deceased donors from BAME backgrounds stands at 7%, compared to 11% in the general population.[1,2] Building on previous work, this study was conducted to identify and explore barriers, facilitators and interventions concerning organ donation in people from BAME backgrounds. NIHR previously funded a programme of work (DonaTE) seeking ways to increase the acceptability and rates of organ donation among people from BAME backgrounds.[3] It contained three phases, the first of which contained a systematic review of barriers to organ donation, and a systematic review aiming to identify characteristics of effective interventions in terms of increased knowledge of organ donation and rates of organ donor registry registration.[4,5] These reviews were updated and expanded in this work.

About the research study

The overall aim of this evidence synthesis study was to update and build on the DonaTE work to identify potentially useful methods for increasing the number of people from BAME backgrounds who join the organ donor register. The following phases of work were completed:

- The DonaTE systematic reviews about barriers and interventions were updated, and expanded to also capture facilitators.
- Discussion groups were held with people from BAME backgrounds to enhance the picture of relevant barriers and facilitators according to their experiences and views, and understand their opinions about potential interventions.
- A novel mapping exercise involving the behaviour change wheel was carried out to explore how potential intervention functions could mitigate key barriers.
- A rapid best evidence synthesis was conducted to retrieve examples of interventions that targeted barriers.

Design and methods

The systematic reviews were updated by repeating the reported searches and methods to incorporate recent studies matching the original eligibility criteria.[4,5] This provides the most up-to-date evidence base on the barriers, facilitators and interventions concerning organ donation in people from BAME backgrounds.

Based on the results of the updated reviews, an initial visualisation of key barriers and facilitators was developed. Framed within the constructs of social ecological modelling (SEM), barriers and facilitators extracted from the evidence base were mapped to one of three core SEM levels: ‘individual’, ‘interpersonal’, and ‘community’.[6] Key determinants associated with each barrier and facilitator, as indicated by the evidence, were included for added context. The initial model was presented to people from BAME backgrounds at two patient and public involvement (PPI) discussion groups and updated based on their input.

A novel mapping exercise was conducted using the behaviour change wheel to expand barriers beyond the topic of organ donation, and map them to general intervention functions (i.e. broad categories of means by which particular interventions can change behaviour; an intervention can contain several ‘intervention functions’).[7] At the hub of the behaviour change wheel are ‘capability, opportunity, motivation- behaviour’ (COM-B) model components. Barriers lifted from the updated logic model were broken down into detailed descriptive elements and mapped to an appropriate COM-B component and TDF domain. From here, barriers could then be linked to intervention functions.

This project is funded by the National Institute for Health Research (NIHR)

A rapid best evidence synthesis was carried out to identify systematic reviews that evaluated interventions that addressed prioritised barriers in areas of health care outside organ donation.[8,9] For each barrier, a robust literature search was carried out, relevant systematic reviews were critically appraised using the ROBIS tool,[10] and data about the aim of the review, its included studies, the included participants, evaluated interventions and effect estimates were extracted. Examples of interventions were discussed by people from BAME backgrounds at two further PPI discussion groups.

Study results

The updated evidence on barriers and facilitators to organ donation in people from BAME backgrounds comprised 16 studies (eight from the original Morgan 2013 review and eight additional studies identified by our update searches). Six barriers were captured from the evidence, including one additional barrier ('donate to friends and family only') not identified by the original review. In addition, four facilitators were identified from the update, none of which were explicitly captured by the original review (figure 1).

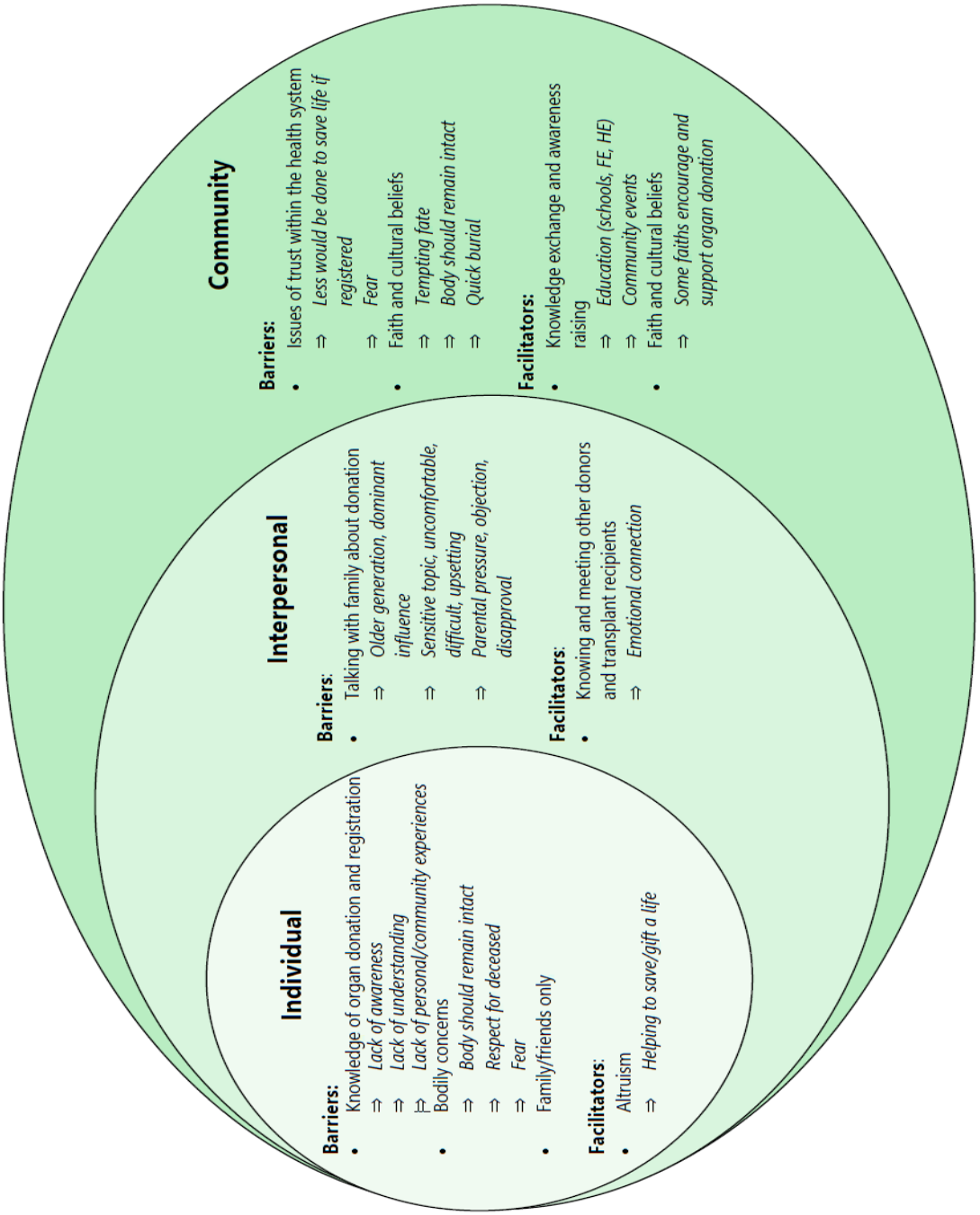
The updated evidence on currently available interventions to encourage organ donation in people from BAME backgrounds comprises five UK (four newly identified) and 17 US studies (two newly identified), most of which assessed educational and media-based approaches. The majority of evaluated interventions for encouraging organ donation were education based (for example peer educators) or media campaigns. Educational interventions took place in a variety of community locations, such as educational and faith establishments, hairdressers and government departments. Their effectiveness in terms of increasing registrations was variable (with a range of 8-30% of participants registering after the events), and educational interventions were reported to be more effective than media interventions in terms of increasing donor registrations. However, media interventions can raise awareness and fill knowledge gaps.

The mapping exercise using the behaviour change wheel showed that, contrary to most existing interventions which focus on 'education' or 'training' intervention functions, 'persuasion', 'modelling' (providing the opportunity to watch desired behaviour) and 'enablement' (active learning opportunities rather than passive information-giving) were the most common potentially effective intervention functions linked to the barriers.

Prioritised barriers for the rapid best evidence synthesis were 'talking to family', 'knowledge and awareness (at community level)', and 'trust in the health care system'. Three systematic reviews evaluated 16 interventions that aimed to improve family communication about difficult or taboo topics, most of which comprised educational sessions with one multimedia advertising intervention. Most of the educational interventions reported success in increasing both communication self-efficacy and frequency of communication compared to control groups. Four reviews evaluated interventions for engaging communities and increasing awareness, and provide guidance for involving people in activities within their communities and maintaining interest. Three looked at interventions addressing issues of trust but provided little evidence (at systematic review level) of interventions for increasing trust in organisations.

This project is funded by the National Institute for Health Research (NIHR)

Figure 1: Visualising barriers and facilitators to organ donation in people from BAME backgrounds



This project is funded by the National Institute for Health Research (NIHR)

The evidence suggests that organ donation should be considered as a pathway rather than an event. Further, different interventions should be used for people early on the pathway to raise awareness and normalise organ donation, versus those who are considering donation. For example, positive awareness can be created with 'edutainment' shows on radio, television or YouTube, by influencers on social media, and by promoting organ donation in different community settings. For people later on the pathway, interventions that contain active learning, persuasion and modelling of behaviour can help them to talk to their families, understand the process, and join the register.

It is not always appropriate to target people only according to their ethnicity. People from BAME backgrounds are not a homogenous group and ethnicity is not necessarily a person's own most important or defining characteristic. This study found that not all the identified facilitators and barriers are specific only to ethnicity.

Strengths and limitations

This was a robust piece of work that followed established systematic review methods and used published behaviour change tools. It also benefited from two sessions of public involvement and input at advisory group level from a lay member. The short time scale meant that only three prioritised barriers could be explored in the later phases, and interventions not evaluated in systematic reviews have not been considered here.

Key findings

- The updated evidence comprised 16 studies that provided detail about six barriers and four facilitators (figure 1).
- The updated evidence also comprised 5 UK and 17 US studies which evaluated the effectiveness of mostly educational and media-based interventions. Educational interventions were reported to be more effective in terms of increasing registrations, but media interventions can raise awareness and fill knowledge gaps.
- Public engagement discussion groups were valuable to ensure the findings were relevant and applicable to people from BAME backgrounds.
- Mapping core behavioural influences associated with barriers using the behaviour change wheel provided a robust, theory-based mechanism to expand the scope of the search for evidence beyond organ donation. It suggested persuasion, modelling and enablement as potentially effective alternatives to existing (mostly educational) interventions.
- The best evidence synthesis found a range of existing educational interventions for improving communication in families. It also provided a range of strategies for engaging communities and maintaining involvement. Little systematic review evidence was found about increasing trust in an organisation.
- The phrase 'people from BAME backgrounds' includes a richly diverse mix of people, who may or may not consider ethnicity to be a priority characteristic of their identity. Barriers and facilitators to organ donation are not all concerned with ethnicity, and focusing only on ethnicity when designing interventions is unlikely to be appropriate.
- Joining the organ donation register should be viewed as a pathway rather than an event. People at different points on the pathway (unaware – considering – ready to join) may respond best to different types of interventions.
- For people who are early on the pathway and unaware of organ donation, interventions that help to raise awareness and normalise organ donation, such as carefully designed media campaigns and 'edutainment' interventions may be most appropriate. Awareness campaigns can address knowledge gaps and myths and need to be visible in a variety of physical and digital spaces where people gather (for example festivals, shopping centres, schools, local radio, WhatsApp and

This project is funded by the National Institute for Health Research (NIHR)

YouTube). Facilitating partnerships between community and faith leaders, organ donation ambassadors, influencers and local people can enable the message to be spread.

- For people who are aware of and considering organ donation, more individually targeted interventions that contain elements of active learning, persuasion, and modelling of behaviour could be used to help them discuss with family, understand the process and know how to register.
- Further research should look at ways to apply these ideas to the organ donation space, particularly in terms of engaging whole communities, as well as successfully recruiting individuals considering donation to more intensive, targeted interventions. Further investigation of ways to engender trust in organisations is also needed.

Key Recommendations

The evidence suggests that the following should be considered when planning interventions to encourage organ donation:

- Use other characteristics in addition to ethnicity when designing and targeting interventions.
- Consider joining the organ donation register as a pathway not an event.
- Tailor interventions to people's position on the pathway and level of awareness, avoiding a 'one size fits all' approach.
- Use population level interventions such as targeted media advertising or 'edutainment' in addition to community partnerships to engage the unaware group.
- Recruit and facilitate a range of people to talk about organ donation and work within their communities to create interventions relevant to those communities.
- Provide information about organ donation in different settings (schools, markets, festivals, clubs, places of worship, online).
- Use educational interventions that incorporate active learning, persuasion and modelling of behaviour to target particular aspects of the process for people who are potentially considering joining the organ donor register.
- Intervention evaluations should measure the appropriate outcome for their place on the pathway: knowledge and awareness for the early stages and registration rates for later.

Acknowledgements

The research team would like to sincerely thank:

- the participants who gave up their time to come along to the discussion groups and openly share their opinions and experiences
- the project advisory group: Rachel Johnson, Dr Gail Miflin, Ammar Mirza CBE, Andrea Ttofa and Dr Nick Watkins for giving their time, research materials, helpful advice and contacts
- Millie Banerjee CBE for helpful advice and discussion
- Public and Patient Research Panel of NHS BT Research Unit in Organ Donation and Transplantation, for providing helpful comment on the publicity materials for the discussion groups
- Barbara Armstrong OBE, ACCL, FCMI CMgr for exceptional facilitation of the discussion groups
- Jan Legge for unfailing administrative support

This project is funded by the National Institute for Health Research (NIHR)

- Patience Kunonga and Tumi Sotire for helping with discussion group recruitment
- Angela Ditchfield (Specialist Nurse in Organ Donation) for presenting at discussion groups
- Eugenie Johnson for invaluable support with copy-editing and formatting of the report

Research Team

Dr Chris Marshall, Madeleine Still, Jenny Hasenfuss, Akvile Stoniute, Jodie Crooks, Professor Dawn Craig, Professor Falko F Sniehotta, Professor Catherine Exley, Professor Andrew Fisher, Fiona R Beyer

References

1. NHS Blood and Transplant. *Organ Donation and Transplantation data for Black, Asian and Minority Ethnic (BAME) communities: report for 2017/2018*; 2017. https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/12048/bame-organ-donation-and-transplantation-data-2017-18.pdf (accessed 15 Jul 2019).

2. NHS Blood and Transplant. *Statistics about organ donation*. 2019. URL: https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/statistics-about-organ-donation/ (accessed 15 Jul 2019).

3. Morgan M, Kenten C, Deedat S, Farsides B, Newton T, Randhawa G*, et al.* 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. Morgan M, Kenten C, Deedat S, Team DP. Attitudes to deceased organ donation and registration as a donor among minority ethnic groups in North America and the UK: a synthesis of quantitative and qualitative research. *Ethnicity & Health* 2013;**18**:367-90.

5. Deedat S, Kenten C, Morgan M. What are effective approaches to increasing rates of organ donor registration among ethnic minority populations: a systematic review. *BMJ Open* 2013;**3**.

6. Okoye PU. Improving the safety performance of Nigeria construction workers: a social ecological approach. *Universal Journal of Engineering Science* 2016;**4**:22-37.

7. Michie S, Atkins L, West R. *The behaviour change wheel: a guide to desiging interventions*. UK: Silverback Publishing; 2014.

8. Slavin RE. Best evidence synthesis: An intelligent alternative to meta-analysis. *Journal of Clinical Epidemiology* 1995;**48**:9-18.

9. Ogilvie D, Egan M, Hamilton V, Petticrew M. Systematic reviews of health effects of social interventions: 2. Best available evidence: how low should you go? *Journal of Epidemiology & Community Health* 2005;**59**:886-92.

10. Whiting P, Savović J, Higgins JPT, Caldwell DM, Reeves BC, Shea B*, et al.* ROBIS: A new tool to assess risk of bias in systematic reviews was developed. *Journal of Clinical Epidemiology* 2016;**69**:225-34.

This project is funded by the National Institute for Health Research (NIHR)