What are effective approaches to increasing rates of organ donor registration among ethnic minority populations: a systematic review

Sarah Deedat, Charlotte Kenten, Myfanwy Morgan

ABSTRACT

Objectives: To identify effective interventions to increase organ donor registration and improve knowledge about organ donation among ethnic minorities in North America and the UK.

Design: Systematic review.

Data Sources: MEDLINE, EMBASE, PsycINFO, CINAHL and Cochrane Central searched up to November 2012, together with four trials databases and the grey literature.

Review methods: A systematic search followed by assessment of eligibility and quality. An interpretive and thematic approach to synthesis was undertaken. This examined the nature and delivery of interventions in relation to a range of outcomes: verified registration, changing knowledge and a measured shift towards greater readiness.

Results: 18 studies were included in the review, comprising educational and mass media interventions. Mass media interventions alone reported no significant change in the intention or willingness to register. Educational interventions either alone or combined with mass media approaches were more effective in increasing registration rates, with a strong interpersonal component and an immediate opportunity to register identified as important characteristics in successful change.

Conclusions: Effective interventions need to be matched to the populations’ stage of readiness to register. Measured outcomes should include registration and shifts along the pathway towards this behavioural outcome.

BACKGROUND

There has been increasing debate in the UK regarding the merits of a potential shift towards a system of presumed consent for deceased organ donation to close the gap between the supply of organs for transplant and the numbers of organs required to meet the increasing demand.¹ This gap is particularly significant for members of ethnic minority populations. In the UK, Black and South Asian individuals constitute 8.4% of the population² but represent 4% of organ donors for whom ethnicity is recorded and 20% of the active kidney transplant waiting list.³ Similarly, in the USA, African Americans account for 13% of the population but constitute 34% of those waiting for a kidney,⁴ while overall ethnic minorities account for 56.3% of those waiting for a transplant in the USA.⁵

The high level of unmet need for transplantation among British and American ethnic minority populations is influenced by increased risks of end-stage renal failure and thus a high need for kidney transplantation among minority ethnic groups. This low donation rate is of particular significance given the greater prevalence among minority ethnic groups of blood groups and human leucocyte antigen types that are less common in the general population. The donation rate among minority ethnic groups has in turn been shown to be influenced by a number of modifiable barriers, including lack of knowledge of the need for donors and how to register as a donor, less favourable cultural and religious beliefs, and a lack of trust in health professionals and the fairness of the organ allocation system.⁶

Strengths and limitations of this study

- The first systematic review of evaluated interventions to increase organ donor registration and knowledge of organ donation among minority ethnic groups.
- The review examines both the outcomes achieved and issues of implementation to identify how and under what conditions a particular approach can be implemented to maximum effect.
- The number of evaluated interventions is currently small, with considerable variability in the study design, measures and outcomes assessed.
The UK’s Organ Donation Taskforce recognised an urgent need to identify and implement the most effective methods to promote organ donation and registration to the public generally and ethnic minority populations specifically. However, despite mass media campaigns and some community engagement activities, the proportion of the population on the Organ Donor Register has only increased from 25% in 2008 to 30% in 2012, while the actual number of minority ethnic registrants remains small.

This review systematically assesses the best available evidence to determine the effectiveness of interventions designed to improve rates of registration and address poor knowledge to donation among ethnic minority populations. It also examines issues of implementation and seeks to identify how, where and under what conditions a particular approach can be implemented to maximum effect.

METHODS
Systematic search
The following databases were initially searched in December 2009 and refreshed in November 2012: MEDLINE, EMBASE, PsycINFO, CINAHL and Cochrane Central. Trials databases were also searched for relevant studies as was the academic and grey literature using search engines, hand checking relevant publications and direct contact with experts in the field (box 1).

The inclusion criteria focused on intervention studies in North America and the UK that were designed to change the rates of registration, intention/willingness to become a donor or knowledge about organ donation and focused on visible ethnic minorities (box 1).

A scoping search was initially run in MEDLINE and then further developed, revised and rerun and subsequently adapted for alternative databases. Ethnicity was defined as a visible (non-white) ethnic minority, with specific ethnic categories being those attributed, with a range of terms required to identify the appropriate ethnic minority populations. Table 1 provides an overview of included studies and the databases from which they were identified.

Relevance and quality assessment
Following initial deduplication, 557 articles remained (see figure 1). Two authors (SD and CK) independently reviewed the title and abstract of all citations identified and applied the exclusion criteria. Where information was not sufficient, the full article was retrieved for review. Where interventions were not targeted specifically at ethnic minorities, studies were included if subgroup analysis by ethnicity was conducted. Studies were excluded if they did not include original data or reported a meeting abstract only. Articles rejected at this stage were mainly cross-sectional studies that did not report an intervention to either increase registration or address knowledge gaps about organ donation in ethnic minority populations.

Two members of the research team independently scored the included articles for quality (SD and MM). Quality assessment was guided by the ‘Assessment Tool for Quantitative Studies’ (http://www.city.hamilton.on.ca/phcs/EPHPP), recommended by the Cochrane Handbook for the quality assessment of reviews in public health and health promotion. This tool is applicable to randomised controlled trials, quasi-experimental studies and uncontrolled studies and both content and construct validity have been established. Using this assessment tool, five articles were rated as ‘strong’, having four or more of the six components rated as strong with no weak ratings, and were all cluster randomised trials. Ten studies were ‘moderate’ with less than four components rated as strong and one as weak, and three articles had two or more components rated as ‘weak’ and were scored as such. Critical reflection on the quality review process led us to also consider complementary criteria set out by the Medical Research Council for the development and evaluation of complex interventions. This led to further assessment of theoretical quality in terms of how the intervention was expected to cause change and the quality of implementation in terms of whether there was standardisation of delivery through study design and/or facilitator training (see table 2).

Data synthesis
Wide variations in outcomes, populations and study design of included studies precluded meta-analysis. An
<table>
<thead>
<tr>
<th>Author and country</th>
<th>Demographics sample size (n)</th>
<th>Study design</th>
<th>Mode of delivery</th>
<th>Results</th>
<th>Outcomes</th>
<th>Theoretical framework</th>
<th>Database</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allen and Stillwater, USA</td>
<td>Alaskan native N=54 Health staff N=&lt;200 students</td>
<td>Before and after study</td>
<td>PowerPoint presentation and video focused on issues about OD and Alaskan natives</td>
<td>Improved knowledge and positive attitude towards donation and intention to register post test</td>
<td>Knowledge and intention to register as a donor</td>
<td>Not mentioned</td>
<td>Hand search of book</td>
</tr>
<tr>
<td>Alvaro et al., USA (pertains to study II reported in paper)</td>
<td>Hispanic</td>
<td>Before and after study</td>
<td>On alternate weeks, employees of the local organ procurement organisation offered the attendees at a flea market an immediate opportunity to register or information about organ donation</td>
<td>Participants offered an immediate opportunity to register rather than just information about OD were significantly more likely to register (86% vs 54%)</td>
<td>Verified registration</td>
<td>The IFF model (Immediate opportunity, information, focused engagement and favourable activation)</td>
<td>MEDLINE</td>
</tr>
<tr>
<td>Andrews et al., USA</td>
<td>African American</td>
<td>Cluster randomised</td>
<td>Members of the congregation undertook discussions with lay health advisors about organ donation. DVD designed to address OD barriers for African Americans</td>
<td>Increase in verified enrolment on donor registry in intervention group. No increase in knowledge observed</td>
<td>Verified enrolment on donor registry</td>
<td>Not mentioned</td>
<td>PubMed</td>
</tr>
<tr>
<td>A Warrens, personal communication, 2013, UK</td>
<td>Multiethnic</td>
<td>Cross-sectional evaluation</td>
<td>Peer educators trained to deliver health promotion about OD</td>
<td>Increase in the percentage of people signed up to the organ donor register</td>
<td>Registration</td>
<td>Not mentioned</td>
<td>Author contact</td>
</tr>
<tr>
<td>Callender et al., USA</td>
<td>Multiethnic</td>
<td>Before and after study</td>
<td>Presentation about organ donation delivered by transplant recipients, donors, individuals on transplant lists healthcare professionals who are ethnically similar to the target population.</td>
<td>Improvements in knowledge and attitudes towards OD, high reporting of willingness to discuss OD with family</td>
<td>Willingness to donate organs for oneself and loved ones after death</td>
<td>Not mentioned</td>
<td>EMBASE</td>
</tr>
<tr>
<td>Thornton et al., USA</td>
<td>Multiethnic</td>
<td>Cluster randomised</td>
<td>5 min Video about OD prior to collecting driver’s licence. Controls obtained</td>
<td>Cases more likely to register as donors compared to controls (76% vs 54%)</td>
<td>Verified enrolment on donor registry</td>
<td>Not Mentioned</td>
<td>EMBASE</td>
</tr>
</tbody>
</table>

Continued

Table 1 Overview of studies included in the review
## Table 1

<table>
<thead>
<tr>
<th>Author and country</th>
<th>Demographics sample size (n)</th>
<th>Study design</th>
<th>Mode of delivery</th>
<th>Results</th>
<th>Outcomes</th>
<th>Theoretical framework</th>
<th>Database</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fahrenwald et al.</td>
<td>American Indians N=1580</td>
<td>Before and after study</td>
<td>licence in the usual manner. Out-reach coordinators facilitate delivery to small groups who were required to read and discuss a 1 page brochure. This was followed by a 13 min video and a group discussion facilitated by the coordinator</td>
<td>Significant change in stage of motivational readiness to become an OD postintervention</td>
<td>Stage of motivational readiness to serve as an organ donor</td>
<td>Transtheoretical model of behaviour change</td>
<td>PubMed</td>
</tr>
<tr>
<td>Resnicow et al.</td>
<td>African American Intervention n=1370 Control n=1419</td>
<td>Cluster randomised</td>
<td>Hairstylists trained as lay health advisors used motivational interviewing to discuss OD with participants Presentation about the need for transplant and information about donation lead by a local organ procurement organisation</td>
<td>Participants receiving the intervention were 4 times more likely to join the register than the controls</td>
<td>Self-reported donation status Verified enrolment on state registry</td>
<td>Not Mentioned</td>
<td>PubMed and EMBASE</td>
</tr>
<tr>
<td>Salim et al.</td>
<td>Hispanic N=341</td>
<td>Before and after study</td>
<td>Presentation about the need for transplant and information about donation lead by a local organ procurement organisation</td>
<td>Increase in knowledge, perceptions and beliefs. No difference willingness to discuss donation with family or intent to donate</td>
<td>Change in knowledge and attitude Donation intent</td>
<td>Not mentioned</td>
<td>PubMed</td>
</tr>
<tr>
<td>Cárdenas et al.</td>
<td>Multiethnic Intervention n=96 Control n=91</td>
<td>Cluster randomised</td>
<td>Transplant surgeons and young recipients gave a presentation followed by a Q&amp;A session and a video</td>
<td>Knowledge increase postintervention was the strongest predictor of positive change in opinion about OD</td>
<td>Knowledge, attitudes and awareness of OD</td>
<td>None mentioned</td>
<td>MEDLINE</td>
</tr>
<tr>
<td>Feeley et al.</td>
<td>Multiethnic</td>
<td>Before and after study</td>
<td>Peer educators delivered a range of campus-based activities</td>
<td>Increased donor registration</td>
<td>Self-reported registration</td>
<td>Not mentioned</td>
<td>Embase, MEDLINE, PubMed</td>
</tr>
<tr>
<td>Arriola et al.</td>
<td>African American Intervention n=175 Control n=162</td>
<td>Cluster randomised</td>
<td>Video and written materials mailed to participants</td>
<td>Greater readiness to sign a donor card, register through a driver’s licence or talk to family about wishes in the intervention group</td>
<td>Readiness to express donation intent through a driver’s licence, donor card and discussion with family</td>
<td>Transtheoretical model of behaviour change</td>
<td>EMBASE, PubMed and MEDLINE</td>
</tr>
<tr>
<td>Media</td>
<td>Hispanic N=2401</td>
<td>Before and after study</td>
<td>4×30 s television 2×60 s radio ads.</td>
<td>Greater reporting of prodonation beliefs and</td>
<td>Self-reported registration status</td>
<td>Not mentioned</td>
<td></td>
</tr>
<tr>
<td>Author and country</td>
<td>Demographics</td>
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<tr>
<td>Frates et al.</td>
<td>Hispanic</td>
<td>Before and after study</td>
<td>Prime time television and radio slots</td>
<td>Year on year increase in Hispanic OD consent rates (overall 10% increase). Increase in knowledge/attitudes</td>
<td>Consent rates from organ procurement organisation No valid measures to assess attitudes to OD</td>
<td>Transtheoretical model</td>
<td>EMBASE, MEDLINE and PsycINFO</td>
</tr>
<tr>
<td>Salim et al.</td>
<td>Hispanic</td>
<td>Before and after study</td>
<td>Prime time television and radio slots</td>
<td>Improved knowledge postcampaign when compared to baseline</td>
<td>Awareness, perception and belief about OD</td>
<td>Not mentioned</td>
<td>EMBASE and MEDLINE</td>
</tr>
<tr>
<td>Radosevich et al.</td>
<td>African American</td>
<td>Before and after study</td>
<td>Media campaign conveyed through television, radio, targeted print media. Donor families and healthcare professionals were interviewed on television and radio</td>
<td>Significant increase in knowledge and attitude about organ donation postcampaign No significant change in intention and willingness to become a donor</td>
<td>Change in knowledge, attitudes and willingness to become a donor</td>
<td>Theory of Reasoned Action</td>
<td>Hand Search of Book</td>
</tr>
<tr>
<td>Harrison et al.</td>
<td>African American</td>
<td>Before and after study</td>
<td>Billboards in the vicinity of vehicle licensing offices and radio adverts. Trained volunteers with links to donation at vehicle licensing offices to engage in conversation</td>
<td>Overall 700% increase above baseline in sign up to the donor register. The magnitude of the increase was greatest when one-to-one promotion was combined with other medium</td>
<td>Verified registration Communication design</td>
<td>PubMed</td>
<td></td>
</tr>
<tr>
<td>Hebert et al.</td>
<td>Chinese American</td>
<td>Before and after study</td>
<td>Media campaign Grass roots community outreach</td>
<td>Significant increase in stated intention to donate in the intervention area vs the control area</td>
<td>Joining a donor registry Express a desire to become an organ donor Communicating wishes to family</td>
<td>Not mentioned</td>
<td>Hand search of book</td>
</tr>
</tbody>
</table>

OD, organ donation; Q&A, question and answer.
interpretive and thematic approach to synthesis was therefore undertaken and examined the nature and delivery of interventions as well as the outcomes achieved. Studies were initially classified by: date, country, population studied and intervention type and study design. The second step involved classifying the media and education interventions in terms of the aims of the interventions and the outcomes achieved. Third, we examined the relationship between characteristics of the interventions from the outcomes. Data were extracted into tables and these were verified by two of the authors (SD and MM).

RESULTS

Study characteristics

The 18 included studies were conducted between 1993 and 2012. These either evaluated the effects of an ethnically targeted mass media campaign or community-based education. With the exception of one UK study, all were undertaken with ethnic minority populations in the USA, mainly African Americans or Hispanics.12–16 Whereas most interventions adopted a pre-evaluation and postevaluation design (table 1), studies published since 2009 mainly employed a cluster randomised design.12–14 17 18 Outcomes assessed were verified registration, self-reported registration status or knowledge about organ donation (see table 1).

Educational interventions

Eleven articles reported educational interventions. Recruitment was mainly through or conducted at places of worship and/or educational establishments, and delivered by a range of individuals including recipient families, trained lay individuals or organ transplant and procurement staff. Six studies were designed for a specific ethnic group, with the remainder aimed at a multi-ethnic audience (see table 2).

Verified registration

Three cluster randomised trials reported an outcome of verified enrolment on a donor register.12 13 17 Two of these studies trained individuals embedded within community settings to deliver the intervention,12 13 with both these interventions having a strong interpersonal element and being delivered in familiar settings of a local church or hairdresser. Peer educators in Andrews’ study13 mostly had a medical background and were involved in a Church Health Committee. They undertook a 4 h training package that comprised general information about
organ donation and tips on integrating the topic into church discussions. In Resnicow’s study, hair stylists were trained over 2 days in practical techniques to facilitate communication (motivational interviewing) and general organ donation information. There were wide variations in the duration of these study interventions: participants in the Church study were exposed over a period of 12 months, while interventions with a hair stylist ran for 1 session/month for 4 months. In contrast, the third intervention in this category did not have a strong interpersonal element, and trialled the use of a 5 min educational film to address common barriers to organ donation that was targeted at those attending the state vehicle licensing office.17 Across all three interventions, the exposed group were significantly more likely to register than the controls, although the effects of the video intervention among vehicle licensing office attendees were significant for White and African Americans but not Hispanic participants, possibly reflecting their small number (n=−28).

Further, three community educational studies based on a follow-up or cross-sectional design reported strategies to increase organ donor registration. Feeley et al reported a 1.6% increase in new organ donor registrations following campus-led peer education among students from six university campuses in the USA that were selected as having a high percentage of minority student enrolment. Similarly, a study in Arizona focused on Hispanics attending a large community event found that advertising and offering an immediate opportunity to register produced significantly greater registration rates compared with the use of a generic slogan and offering general information about organ donation (86% vs 54%).20 A further UK community-based educational intervention study focused on attendees at a range of venues and community events selected to maximise engagement with Black and minority (BME) communities (A Warrens, personal communication, 2013). The authors report that following discussion with a trained BME Peer Educator and the availability of facilities for

<table>
<thead>
<tr>
<th>Authors</th>
<th>Theoretical quality</th>
<th>Standardisation of delivery</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Warrens, personal communication, 2013</td>
<td>Minimally grounded</td>
<td>Authors allow for and explain variation in intervention delivery</td>
</tr>
<tr>
<td>Allen and Stillwater</td>
<td>Minimally grounded</td>
<td>Standard training offered to educators delivering intervention</td>
</tr>
<tr>
<td>Alvaro et al</td>
<td>Moderately grounded</td>
<td>Authors indicate variation</td>
</tr>
<tr>
<td>Alvaro et al</td>
<td>Well grounded</td>
<td>Strict standardisation (due to intervention design)</td>
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<td>Cárdenas et al</td>
<td>Moderately grounded</td>
<td>Authors indicate variation</td>
</tr>
<tr>
<td>Thornton et al</td>
<td>No theoretical grounding</td>
<td>Strict standardisation</td>
</tr>
<tr>
<td>Fahrenwald et al</td>
<td>Well grounded</td>
<td>Authors allow for and explain variation</td>
</tr>
<tr>
<td>Feeley et al</td>
<td>Moderately grounded</td>
<td>Strict standardisation (due to intervention design)</td>
</tr>
<tr>
<td>Frates et al</td>
<td>Moderately grounded</td>
<td>Strict standardisation (due to intervention design)</td>
</tr>
<tr>
<td>Harrison et al</td>
<td>Well grounded</td>
<td>Strict standardisation of media and print info. Variation but no explanation or assessment of variation in interpersonal elements</td>
</tr>
<tr>
<td>Hebert et al</td>
<td>Moderately grounded</td>
<td>Strict standardisation (due to intervention design)</td>
</tr>
<tr>
<td>Radosevich et al</td>
<td>Moderately grounded</td>
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</tr>
<tr>
<td>Resnicow et al</td>
<td>Moderately grounded</td>
<td>Strict standardisation. Standard training offered to educators delivering intervention</td>
</tr>
<tr>
<td>Salim et al</td>
<td>Minimally grounded</td>
<td>Strict standardisation (due to intervention design)</td>
</tr>
<tr>
<td>Salim et al</td>
<td>Minimally grounded</td>
<td>Strict standardisation</td>
</tr>
</tbody>
</table>
registering, 9% of those not already on the Organ Donor Register joined on the day. The intervention was also shown to be most effective among those who had previously considered signing up but who did not know how to go about it. These community educational studies thus identify important influences on registration as both the individual’s prior readiness and access to registration (table 3).

### Changing knowledge

Previous research has shown that knowledge about organ donation is associated with attitudes, intention to donation and willingness to discuss organ donation intentions with family.21-25 Among the included studies, knowledge was assessed by asking participants to indicate whether a range of statements regarding organ donation were true or false. These studies conceived knowledge as comprising five facets (1) general knowledge about donation; (2) knowledge of the relevance of donation to the ethnic minority population; (3) knowledge about the procurement and allocation of organs; (4) religious and cultural knowledge about organ donation and (5) knowledge about the financial costs of organ donation. Presentations to participants were delivered by ethnic minority transplant surgeons and donor/recipient families. Interventions tended to be one-off and commonly lasted 1 h, with immediate follow-up questionnaires administered to participants.

Two studies tested the relationship between knowledge about organ donation and willingness to become an organ donor. These studies found that significant improvements in knowledge increased the willingness among participants to state that they intended to register as a donor. Among Hispanic participants, knowledge relating to the fair allocation of organs was a significant independent predictor of willingness24 (see table 4), while among a multiethnic sample of high school students improvements in composite knowledge scores significantly predicted a willingness to donate organs in the intervention group.18

The remaining two studies assessed a range of knowledge items before and after the delivery of an educational intervention. In a multiethnic sample of adults, a significant increase in knowledge was achieved for half of all knowledge items (see table 4).25 Of particular note, African Americans who comprised 60% of the sample achieved the greatest change postintervention in relation to trust in doctors when compared to trust scores for other ethnic groups. Overall, postintervention, participants in this study reported being significantly more likely to state that they were willing to donate their own and their family’s organs after death (p<0.000).25 Unlike the aforementioned studies which focused on the lay population, Allen and Stillwater’s26 holistic interventions addressed knowledge gaps and misinformation among Alaskan Community Health aides and school children. The authors do not report details about individual aspects of knowledge addressed but report a significant increase in knowledge among both students from 58% to 95% correct (p<0.0001) and community health practitioners (p<0.0001).

Table 4 shows the number of items where a significant increase in knowledge was observed post-test. All four interventions reported that it is possible to address knowledge deficits among participants. However, no assessment was made about the extent to which gains in knowledge are maintained and whether increased willingness necessarily results in actual donor registration.

### Measured shift towards greater readiness

Two educational interventions were informed by the transtheoretical model (TTM) of behaviour change27 and measured change in an individual’s ‘readiness to become an organ donor’.14 28 Both studies aimed to measure change across the five TTM stages from precontemplation to maintenance (box 2). In Fahrenwald’s study, 56.9% of participants progressed to a more advanced stage post-test and none regressed, while Arriola reported that intervention participants were 1.53

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**Table 3 Absolute difference (95% CI) between intervention and control groups for verified registration across ethnic groups**

<table>
<thead>
<tr>
<th>Study</th>
<th>Target population/setting</th>
<th>Intervention</th>
<th>African American</th>
<th>Hispanic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resnicow et al12*</td>
<td>African American setting: Hair Dressers</td>
<td>Intervention: Brief motivational intervention delivered by hairdresser</td>
<td>2.8 (2.2 to 3.2), p=0.0001</td>
<td>2.2 (9 to 35), p=0.0009</td>
</tr>
<tr>
<td>Thornton et al17</td>
<td>All ethnic groups including white setting: outside motor Vehicle registration office</td>
<td>Intervention: 5 min video addressing ethnic concerns about OD</td>
<td>29 (−8 to 65), p=0.12</td>
<td></td>
</tr>
<tr>
<td>Andrews et al13</td>
<td>African American Setting: African American churches</td>
<td>Intervention: Focused discussions about donation followed by a DVD aimed at African American concerns about donation</td>
<td>18.7 (16.6 to 20.8), p&lt;0.0001</td>
<td></td>
</tr>
</tbody>
</table>

*This study also reported that the intervention group was 1.7 times more likely to report being signed up to a donor register after adjustment for a range of sociodemographic and attitudinal factors (pre-test attitude scores, city, age, sex, insurance group, education and clustering by salon); however, this result was not statistically significant.

OD, organ donation.
<table>
<thead>
<tr>
<th>Study</th>
<th>Target population</th>
<th>Duration and length of follow-up postintervention</th>
<th>Number of items with a significant improvement post-test</th>
<th>Percentage of items where significant increase in knowledge recorded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cárdenas et al&lt;sup&gt;18&lt;/sup&gt;</td>
<td>High school students, multiethnic</td>
<td>60 min Immediate follow-up</td>
<td>12/16 75%</td>
<td>Greater improvements in composite knowledge score predicted a willingness to donate in the intervention group (OR 1.42, CI 1.18–1.71, p&lt;0.001)</td>
</tr>
<tr>
<td>Callender et al&lt;sup&gt;25&lt;/sup&gt;</td>
<td>Multi ethnic adults</td>
<td>Not reported Immediate follow-up</td>
<td>4/8 50%</td>
<td>Significant improvement in 4 knowledge items (1) Knowledge about higher rates of kidney disease among BME (2) Longer wait times for transplant for BME (3) Less likely to believe doctors would hasten death if they knew donor status of patient (4) Less likely to state that god needs ‘whole’ bodies for the afterlife</td>
</tr>
<tr>
<td>Salim et al, USA&lt;sup&gt;24&lt;/sup&gt;</td>
<td>Hispanic Adults</td>
<td>45–60 min</td>
<td>15/25 60%</td>
<td>Independent positive predictors of willingness to donate: (1) Knowledge of a national matching system (AOR 3.36, CI 1.43–7.88, p=0.005) (2) Not perceiving that wealthy people are more likely to receive a transplant (AOR 5.39, 2.02–14.37 p=0.0008)</td>
</tr>
<tr>
<td>Allen and Stillwater, USA&lt;sup&gt;26&lt;/sup&gt;</td>
<td>Alaskan Natives School Children</td>
<td>Not specified</td>
<td>n/r</td>
<td>Scores for knowledge about donation and transplantation increased significantly pretest 58% correct vs 95% post-test p&lt;0.001 Participants were significantly more likely to state they would be a donor p=0.021</td>
</tr>
<tr>
<td></td>
<td>Community Health Aids &amp; Practitioners (adults)</td>
<td>3 h presentation as part of CPD</td>
<td>n/r</td>
<td>Significant increase in factual knowledge score p&lt;0.001—mean knowledge scores doubled post-test Significant greater awareness of how and where to get information about organ donation p&lt;0.001</td>
</tr>
</tbody>
</table>

AOR, adjusted OR; n/r, Not reported.
involved a specific focus on religious objections to organ donation, involvement of the church pastors and the use of a well-known gospel choir to present the intervention video, whereas Fahrenwald et al. included respected members of Native American tribes and their storytelling traditions to convey donation messages. There were significant differences in participant exposure; participants in Arriola’s study were exposed to intervention materials in the home at several time points over a year (e.g., through video, pamphlets and greetings cards), whereas Fahrenwald’s participants received a short intervention lasting between 30 and 60 min that involved watching a video about organ donation followed by a group discussion.

Although these studies provide evidence of positive movement towards readiness to become an organ donor, sign a donor card or talk to family members about their preferences, whether those at a later stage of readiness actually signed a donor card is less clear. This issue is reflected in the UK community study where only a small proportion of participants who stated an intention to register in the future had done so at follow-up (A Warrens, personal communication, 2013).

**Mass media interventions**

All media interventions attempted to detect changes in the willingness or intention to join a donor register or sign a donor card. However, interventions that solely utilised the mass media reported no significant change in the intention or willingness to register as an organ donor, despite focusing on a single ethnic group and undertaking formative research in the target population (see table 4 below). In contrast, a high level of success was achieved by one study which innovatively combined mass media techniques with interpersonal communication. This was conducted at the vehicle licensing office, a setting where individuals are able to join a state donor registry. Harrison et al. set out with the clear aim of focusing on members of the population categorised as passive positives (i.e., those favourable to organ donation but not yet joined the register). To determine the effect of each component of the intervention on registrations, the campaign occurred in three stages, each lasting 3 months. The interpersonal component of the intervention accounted for the greatest increase in registrants from 444 in the previous year to 5588 post campaign. Overall, the combined effect of the intervention components increased registrations by 700% (table 5).

**CONCLUSION**

This review identified 18 evaluated intervention studies focusing on ethnic minorities that were educational in nature, delivered in community settings or disseminated through the mass media. All but one study was conducted in the USA, with possible implications for generalising findings to different cultural contexts and minority populations. Other limitations of the review arise from the heterogeneity of study populations, measures and outcome variables, as well as the frequent use of unvalidated measures of knowledge. Also, there were limited data on the impact of specific facets of knowledge on registration or intent to register, thus failing to identify which ‘knowledge gaps’ are most important to address and whether this differs between ethnic groups. It is also notable that few studies explicitly mentioned an attempt to connect with the target population during the developmental phase and access acceptability. Reporting of important contextual information relating to the interventions was also sparse. Similar limitations of a lack of rigour and theory have also been noted in a recent review of smoking-related and obesity-related health promotion interventions adapted for ethnic minority populations. However, a detailed analysis of the process as well as the outcomes allowed us to identify some messages regarding effective approaches for increasing the acceptability and effectiveness of these interventions.

First, community-based educational interventions exhibited a higher level of success in terms of verified registration than those solely reliant on the mass media. Characteristics of interventions that were successful in increasing registration also tended to comprise a strong interpersonal element that focused on the particular population’s concerns, delivered by members of the local community in familiar environments or in a context where individuals are required to make an immediate decision about registration. In contrast, mass media campaigns designed to promote organ donation to Hispanic and African American populations did not achieve an increase in registration. However, there was some evidence that media interventions successfully

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**Box 2 Prochaska and Velicer’s Stages of Change adapted for Organ Donation**

- **Precontemplation:** Have not considered registering as an organ donor
- **Contemplation:** Considered organ donation, but not taken steps towards registration or addressing unresolved issues/concerns
- **Preparation:** Able to recognise the benefits of registration and have taken action to find out more
- **Action:** Expressed their wishes about donation by either signing the organ donor register or discussed wishes with immediate family/kin
- **Maintenance:** Occasionally reinforce statement of wishes to family members/kin
addressed knowledge gaps and misconceptions about organ donation.\textsuperscript{15, 30, 31}

Second, there are questions of whether registration always represents an appropriate outcome, given that ethnic minorities and those from socioeconomically deprived backgrounds are consistently shown to have more negative views, greater concerns and less knowledge about organ donation and transplantation compared with the general population.\textsuperscript{34–36} Interventions should therefore consider the intermediary steps through which individuals may need to pass before the desired endpoint of registration can be achieved, and also identify clearly at the outset the stage of readiness among the intervention participants and match interventions accordingly. Moving some sections of the population from an early stage of increased knowledge to actual registration may require multiple interventions that reinforce and build on each other over a period of time. In contrast, people who are further along the pathway and have reached an action stage may only require a limited ‘nudge’ or ‘prompt’ to register as an organ donor, through interventions involving behavioural prompts, cues to action and, where possible, an immediate opportunity to register. Indeed, our recent findings from a detailed focus group study of 229 Black and South Asian participants in London found that the majority of participants possessed extremely limited knowledge about organ donation, lacking specific knowledge about how to register and the elevated need for transplant among their ethnic group.\textsuperscript{37} While the focus group opened up a dialogue about donation and registration, it is unlikely that many participants would have been ready to sign up immediately for a variety of reasons including the need to discuss with their family, and for some people the desire to seek clarification from faith representatives. This is particularly prescient in the UK as recent data show 25\% of ethnic minority families of potential donors who had formally signed the donor register refuse assent,\textsuperscript{38} with the current practice being to respect the wishes of the family regarding donation decisions even if this does not accord with those of the patient.

<table>
<thead>
<tr>
<th>Author</th>
<th>Target population</th>
<th>Language</th>
<th>Media</th>
<th>Duration</th>
<th>Self-reported registration intention to be a donor</th>
<th>Pretest (%)</th>
<th>Post-test (%)</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frates et al,\textsuperscript{29} USA Hispanic Spanish</td>
<td>TV and radio</td>
<td>3 years</td>
<td>Have decided to be a donor Signed a donor card</td>
<td>27</td>
<td>31</td>
<td>0.163</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Salim et al,\textsuperscript{30} USA Hispanic English and Spanish</td>
<td>TV and radio</td>
<td>1 year</td>
<td>Intent to donate (% likely or very likely)</td>
<td>32</td>
<td>30</td>
<td>0.488</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radosevich et al,\textsuperscript{16} USA African American English</td>
<td>TV, radio and print media</td>
<td>1 year</td>
<td>Donor designation on driver’s licence</td>
<td>33</td>
<td>40</td>
<td>0.123</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alvaro et al,\textsuperscript{31} USA Hispanic Spanish</td>
<td>TV and radio</td>
<td>1 year</td>
<td>Have you personally told anybody that you would like to be an organ donor (%yes)</td>
<td>28.5</td>
<td>27.2</td>
<td>0.723</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hebert et al\textsuperscript{32*} Chinese American Not Stated</td>
<td>Print media</td>
<td>1 year</td>
<td>I do not intend to donate my organ at my death</td>
<td>11</td>
<td>21</td>
<td>0.001</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Harrison et al\textsuperscript{15} African American English</td>
<td>Bill Boards in the vicinity of vehicle licensing office radio ads Face-to-face contacts with donor families</td>
<td></td>
<td>Verified registration (counts of registrants in postcode areas with a population &gt;80% African American)</td>
<td>0.1</td>
<td>1.2</td>
<td>0.001</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*During this campaign, a major scandal reported that a funeral home near to the intervention location had been procuring tissue from cadavers without family consent. This story was covered on national and local media.
Third, the review suggests that effective interventions for those in the precontemplation or contemplation phase are those undertaken in familiar community settings and delivered by appropriately trained lay individuals. In this context, lay health promoters have the benefit of an established rapport with the target population and the potential for gradual delivery of information that can be reinforced over time. Providing easy access to registration also has a significant impact on achieving increased sign-up, particularly for those at a later stage of the pathway from contemplation to behavioural outcome.

Current efforts to encourage organ donor registration in the UK have largely relied on mass media campaigns with some ‘community engagement’. Although these have not been formally evaluated, there is little evidence of significant changes in overall registration rates. However, the present review suggests that these campaigns may have contributed to changes in knowledge, thus producing some shift along the pathway, although having less effect on registration practices. For the future, there is a need for rigorously conducted studies to assess the impact of specific facets of knowledge on registration or intent to register. There is also a need to develop robust intervention studies that take account of the population’s readiness to sign the donor register, with approaches ranging from personal interaction and discussion with members of the lay community and facilitating a sign-up process in practice.

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Contributors MM designed the review. SD led on the assessment of relevance and quality with CK and MM contributing. SD and MM analysed the data and drafted the manuscript, with CK contributing. All authors approved the final version. MM is the guarantor.

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Data sharing statement No additional data are available.

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REFERENCES
<table>
<thead>
<tr>
<th>Database, Years Searched</th>
<th>Search Strategy</th>
</tr>
</thead>
</table>
| Medline OVID 1980-2012   | 1. randomized controlled trial/ or clinical trial/ or controlled clinical trial/ or multicenter study/ or single blind method/ or double blind method/ or random allocation/ or chi square distribution/ or control groups/ or Cross-Sectional Studies/ or Cohort Studies/  
|                          | 2. (randomized controlled trial or controlled clinical trial or multicenter study).pt.  
|                          | 3. (random adj2 allocat*).tw.  
|                          | 4. (control* adj2 (clinical or group* or trial* or study or studies or design* or methods or random*)).ti,ab.  
|                          | 5. ((multicent* or multi-cent* or multisite? or multi-site?) adj (study or studies or trial*)).ti,ab.  
|                          | 6. (random* or quasi* or "before and after").ti,ab.  
|                          | 7. randomized controlled trials as topic/ or clinical trials as topic/  
|                          | 8. ((single or double or treble or triple) adj (blind* or mask*)).ti,ab.  
|                          | 9. chi-square?.ti,ab.  
|                          | 10. Chi-Square Distribution/  
|                          | 11. Research Design/  
|                          | 12. Matched-Pair Analysis/  
|                          | 13. matched pair*.ti,ab.  
|                          | 14. Meta-Analysis/  
|                          | 15. meta analy*.ti,ab.  
|                          | 16. "Outcome Assessment (Health Care)"/  
|                          | 17. (outcome* stud* or intervention* stud*).ti,ab.  
|                          | 18. Intervention Studies/  
|                          | 19. follow up studies/ or pilot projects/ or prospective studies/  
|                          | 20. Evaluation Studies as Topic/  
|                          | 21. Evaluation Studies/  
|                          | 22. (effective adj3 intervention*).ti,ab.  
|                          | 23. (evaluat* adj3 intervention*).ti,ab.  
|                          | 24. (outcome* adj3 measure*).ti,ab.  
|                          | 25. primary outcome*.ti,ab.  
|                          | 26. secondary outcome*.ti,ab.  
|                          | 27. Comparative Study/  
|                          | 28. evaluat*.tw.  
|                          | 29. or/1-28  
|                          | 30. exp "Tissue and Organ Procurement"/  
|                          | 31. ((cadaver or deceased or dead) adj2 (donor* or donat*)).ti,ab.  
|                          | 32. ((organ or organs) adj3 (donor* or donat*)).ti,ab.  
|                          | 33. ((cadaver or deceased) adj2 (donat* or donor*)).ti,ab.  
|                          | 34. ((postmortem or post mortem) adj2 (donat* or donor*)).ti,ab.  
|                          | 35. ("organ donor" or "organ donors" or "organ donation").ti,ab.  
|                          | 36. or/30-35  
|                          | 37. Indians, North American/  
|                          | 38. African Americans/ or Asian Americans/  
|                          | 39. "native american*".tw.  
|                          | 40. (race or racial or ethnic* or native american* or native canadian* or native alaskan* or american indian* or canadian indian* or amerind* or negro* or afro* or african* or black or blacks or arab* or asian* or chinese or japanese or oriental* or thai* or philipino* or filipino* or taiwanese* or...
indian* or bengali* or kashmiri* or gujarati* or tamil* or bangladeshi* or pakistani* or sri lankan* or hispanic* or latino* or nonwhite* or non-white* or multiracial or multi-racial).tw.
41. Hispanic Americans/
42. Mexican Americans/
43. ethnic groups/
44. (culture or cultural or faith* or relig* or sikh* or hindu* or muslim* or islam* or christian* or catholic* or judaism or jew* or buddhis* or jehovah* or evangelical or evangelist* or adventist* or pentacostal).tw.
45. Minority Groups/
46. Continental Population Groups/
47. Asian Continental Ancestry Group/
48. Asian Continental Ancestry Group/ or African Continental Ancestry Group/ or Ethnic Groups/
49. british asian*.tw.
50. british african*.tw.
51. or/37-50
52. 29 and 36 and 51
53. (consent* adj3 (increas* or accept* or participat* or encourag* or facilitat* or influenc* or promot* or chang* or focus* or motivat*)).tw.
54. informed consent/
55. cultural competency/
56. decision making/
57. Communication/ or Communication Barriers/
58. Communications Media/
59. (media or message* or communicat* or television or radio or broadcast* or internet or campaign* or program* or leaflet* or questionnaire* or literature or pamphlet* or resource*).tw.
60. ((register* or registration) adj3 (increas* or accept* or encourag* or facilitat* or influenc* or promot* or chang* or focus* or motivat*)).tw.
61. ((register* or registration or registry or registries) adj3 (increas* or accept* or encourag* or facilitat* or influenc* or promot* or chang* or focus* or motivat*)).tw.
62. (intervention* or multiintervention* or multi-intervention* or postintervention* or post-intervention* or preintervention* or pre-intervention*).tw.
63. Patient Education Handout/ or Health Education/ or Education/ or Patient Education as Topic/
64. Patient Participation/ or intention/
65. Attitude to Health/
66. Health Knowledge, Attitudes, Practice/
67. "Attitude of Health Personnel"/
68. Health Personnel/ed [Education]
69. Health Policy/ or "Delivery of Health Care"/
70. (policy or policies or practice or practices).tw.
71. or/53-70
72. 29 and 36 and 51 and 71
73. ("tissue donor" or "tissue donors" or "tissue donation").tw.
74. 72 not 73
75. *living donors/
76. 74 not 75

Added line 77 as a double safety check to see if the live donor papers included any live and dead donors – 2 selected.
<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>77. 74 not 76</td>
<td></td>
</tr>
<tr>
<td>78. from 77 keep 16,30</td>
<td></td>
</tr>
</tbody>
</table>