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

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

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, Psychinfo, Cinahl and Cochrane Central searched to November 2012 together with four trials databases.

Review methods: An interpretive and thematic approach to synthesis was undertaken which examined the nature and delivery of interventions in relation to a rage of outcomes (verified registration, changing knowledge and measured shift towards greater readiness). The authors' independently assessed the eligibility of the identified studies and undertook a quality assessment.

Results: 18 studies were included in the review, of which all but one were conducted in North America, and comprised both educational and mass media interventions. Mass media interventions alone reported no significant change in intention or willingness to register. Educational or combined approaches with a strong interpersonal component were most likely to be effective in increasing registration rates, particularly if delivered in a familiar environment by trained lay individuals and with an immediate opportunity to register.

Conclusion: There is a need to develop robust intervention studies that match the populations' stage of readiness to register. Measured outcomes should include both registration and shifts along the pathway towards this behavioural outcome.

Key Words: ethnicity, organ donor registration, organ donation, systematic review, intervention studies, UK, North America

Abstract: 208

Article Summary

‘Article focus’

What interventions have been effective in improving knowledge about donation and rates of registration among minority ethnic groups?
How, where and under what conditions can a particular approach best be implemented?

‘Key messages’

- Community based education campaigns are more effective than media campaigns alone in increasing organ donor registration.
- Interventions need to be targeted to the population’s stage of readiness to register as a donor.
- The outcome of registering as a donor should be complemented by assessment of shifts along the pathway towards achieving this goal, with increased knowledge and attitudinal changes forming necessary stages towards registration.

‘Strengths and limitations of this study’.

Limitations of the review are the heterogeneity of study populations, measures and outcome variables and the need to extrapolate from largely North American studies. It is also notable that few studies explicitly mentioned an attempt to connect with the target population during the developmental phase and access acceptability, while reporting of important contextual information relating to the interventions was sparse.

Strengths are the systematic search covering and the detailed analysis of both process and outcomes that identified messages for increasing the acceptability and effectiveness of interventions.

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Competing Interests:

None of the authors have any competing interests. No support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years [or describe if any], no other relationships or activities that could appear to have influenced the submitted work

Background

There is a continuing debate in the UK regarding the merits of a 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 required to meet needs [1]. This gap is particularly significant for members of ethnic minority populations, with Black and South Asian people comprising 8.4% of the UK population, [2] and 20% of the active kidney transplant waiting list but only about 3% of deceased donors [3]. This is particular significance given the greater prevalence among ethnic minorities of blood groups and human leukocyte antigen (HLA) types that are less common in the general population. This shortage of well matched organs results in Black and South Asian minority groups in the UK having a median waiting time for kidney transplantation that is about twice that of the general population [3]. Similarly African Americans account for 13% of the population but constitute 34% of those waiting for a kidney in the USA, [4] reflecting both the availability of suitable organs and inequalities in access to transplantation.

Many of the barriers to donation among ethnic minorities have been identified as potentially modifiable, including lack of knowledge of the need for donors and how to donate, a lack of trust in health professionals and the fairness of the organ allocation system, together with uncertainties regarding their faith's beliefs about the acceptability of organ donation[5,6]. The UK's Organ Donation Taskforce therefore identified a particular need to identify and implement the most effective methods to promote organ donation and registration among ethnic minority populations [7].

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

Data sources & searches: The following databases were searched in December 2009 and refreshed in November 2012: Medline, Embase, Psychinfo, Cinahl and Cochrane Central. Trials databases were searched for relevant studies: UKCRN, ClincialTrials.gov, WHO international Clinical Trials Registry Platform and Health Service Research Projects in Progress.

A scoping search was initially run in Medline and then revised and re-run 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 (Fig 1 here). Further searches for academic and grey literature were made using search engines and by hand checking relevant publications and direct contact with experts in the field.

Relevance and Quality Assessment: Studies were included if they reported interventions designed to change rates of registration, intention/willingness to become a donor or to change knowledge about organ donation among ethnic minorities. Where interventions were not targeted specifically at ethnic minorities, studies were included if sub group analysis by ethnicity was conducted. Studies were excluded if they did not include original data, or reported a meeting abstract only but inclusion was not restricted by study design (see Fig 2).

Following initial de-duplication, 557 papers remained (see figure 1). Two authors (SD & 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. Papers 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.

< Fig 2 here>

Quality assessment drew on categories of the “Assessment Tool for Quantitative Studies” [8] that were applicable across studies and included criteria developed by the Medical Research Council for the development and evaluation of complex interventions [9] (see Box 1 and Table 2).

<Box 1 and table 2 here>

Data synthesis: Wide variations in outcomes, populations and study design of included studies precluded meta-analysis. An interpretive and thematic approach to synthesis was therefore undertaken and examined both the nature and delivery of interventions and the outcomes achieved.

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 [10-14]. Whereas most interventions adopted a pre and post evaluation design (Table 1), studies published since 2009 mainly employed a cluster randomised design [11-12, 14 15]. Outcomes assessed were verified registration, self reported registration status or knowledge about organ donation (see table 1).

Educational Interventions

Eleven papers reported educational interventions. Recruitment occurred through 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 table1)

Verified registration*:* Three cluster randomised trials reported an outcome of verified enrolment on a donor register [10-11 15]. Two of these studies trained individuals embedded within community settings to deliver the intervention [10 11], with both these interventions having a strong interpersonal element and were delivered in familiar settings of a local church or hairdresser. Peer educators in Andrews' study [11] mostly had a medical background and were involved in a Church Health Committee. They undertook a four-hour training package that comprised general information about organ donation and tips on integrating the topic into church discussions. In Resnicow's study [10] hair stylists were trained over two days with this including 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 per month for four months. In contrast the third intervention in this category did not have a strong interpersonal element, and trialled the use of a 5 minute educational film to address common barriers to organ donation that was targeted at those attending the state vehicle licensing office[15]. 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 [15], possibly reflecting their small number (n=-28).

Three further community educational studies with a follow-up or cross sectional design reported strategies to increase organ donor registration. Feely et al[17] reported a 1.6% increase in new organ donor registrations following campus led peer education among students from six university campuses in the US 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%) [18]. A further UK community-based educational intervention study focussed on attendees at a range of venues and community events selected to maximise engagement with 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 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*:* This formed the outcome for three educational interventions [16 19 20] and was assessed by asking participants to indicate whether a range of statements regarding organ donation were true or false. These studies conceived knowledge as comprised of five facets; *1) general knowledge about donation; 2) knowledge of the relevance of donation to 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 one hour, with immediate follow-up questionnaires administered to participants. Two studies focused on improving knowledge solely within the lay population, whereas one study in Alaska delivered training to both lay and professional groups [20] and found significant increases in knowledge among both students from 58% to 95% correct (p<.0001) and community health practitioners (p<.0001).

Table 4 shows the number of items where a significant increase in knowledge was observed post test. However, there was no assessment of the extent to which the gains in knowledge were maintained or the effects on willingness to become an organ donor or to discuss donation intent.

<TABLE 4>

Measured shift towards greater readiness: Two educational interventions were informed by the Trans Theoretical Model of Behaviour Change (TTM) to measure change in individual's 'readiness to become an organ donor' [11 21]. Both studies aimed to measure change across the five TTM stages from pre-contemplation to maintenance (box 2). In Fahrenwald's study 56.9% of participants progressed to a more advanced stage at post test and none regressed, while Arriola reported that intervention participants were 1.53 times more likely to be in a later stage of readiness than control participants.

Collaboration with members of the targeted ethnic population was undertaken to ensure the relevance and acceptability of the intervention. For Arriola et al12] this 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 [22] 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 minutes that involved watching a video about organ donation followed by a group discussion. 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, although 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 willingness or intention to join a donor register or sign a donor card [14 23-26]. However interventions that solely utilised mass media reported no significant change in intention or willingness to register 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[13] 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 year prior to 5588 post campaign. Overall, the combined effect of the intervention components increased donation by 700%.

Conclusion

This review identified 18 evaluated intervention studies focusing on ethnic minorities that were either educational in nature, delivered in community settings or disseminated through mass media. Limitations of the review include the heterogeneity of study populations, measures and outcome variables, and frequent use of unvalidated measures of knowledge. All but one study was conducted in the United States and drew attention to a neglect of formal evaluation of interventions in this area the UK despite considerable activity involving both national campaigns and local engagement.

In terms of methods it is notable that few studies explicitly mentioned an attempt to connect with the target population during the developmental phase and access acceptability, while reporting of important contextual information relating to the interventions was sparse. However detailed analysis of both the process and outcomes identified messages for increasing the acceptability and effectiveness of these interventions.

Firstly, community-based educational interventions exhibited a higher level of success in terms of verified registration than those solely reliant on mass media, with characteristics of interventions that were successful in increasing registration comprising a strong interpersonal element that focused on the particular population’s concerns, delivered by members of the local community in familiar environments, in a context were individuals are required to make an immediate decision about donation. In contrast, mass media campaigns designed to promote organ donation to Hispanic and African American populations did not appear to achieve this, although there was some evidence of that media interventions successfully addressed knowledge gaps and misconceptions about organ donation [13 24 25].

Secondly, there are questions of whether registration represents an appropriate outcome measure for all sections of the population, given that ethnic minorities and those from socio-economically deprived backgrounds are consistently shown to have more negative views, greater concerns and less knowledge about organ donation and transplantation than the general population 27-29]. Similarly, the 2010 Eurobarometer survey revealed that 20% of people polled were unable to express an opinion as to whether they would be willing to donate their organs at death, and 37% claimed to be unwilling to donate but were unsure why[30]. Such findings indicate that immediate action, such as registering as a donor, may not be an appropriate outcome for all population groups.

Interventions should therefore consider the intermediary steps that individuals may need to pass before the desired end-point of registration can be achieved and 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 therefore require multiple interventions that reinforce and build upon 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.

Thirdly, the review suggests that effective interventions for those in the pre-contemplation or contemplation phase are those undertaken in familiar community settings and delivered by appropriately trained lay individuals. Lay health promoters in this context have the benefit of an established rapport with the target population[31] and the potential for gradual delivery of information that can be reinforced over time.

Current efforts to encourage organ donor registration in the UK have largely relied on mass media campaigns with some ‘community engagement’, while although these have not been formally evaluated there is little evidence of significant changes in overall registration rates. However the present review suggests the 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 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 in practice facilitating a sign up process.

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Contributions

MM planned and supervised the study, contributed to interpretation of data and drafting the paper. SD retrieved the selected papers, was primarily responsible for study appraisal, interpreted data and undertook an initial draft. CK contributed to study appraisal, interpreted data and critically commented on drafts. All authors approved the final version.

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Competing Interests

None of the authors have any competing interests. No support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years [or describe if any], no other relationships or activities that could appear to have influenced the submitted work

Data sharing

This is a systematic review and there is therefore no additional unpublished data.

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Table 1 – Overview of studies included in the review

Author & Country	Demographics Sample Size (n)	Study Design	Mode of delivery	Results	Outcomes	Theoretical framework
EDUCATION						
Allen and Stillwater 2010, USA [20]	Alaskan Native N = 54 Health Staff N=<200 Students	Before & After Study	PowerPoint presentation & video focused on issues about to OD and Alaskan natives	Improved knowledge and positive attitude towards donation and intention to register post test	Knowledge & Intention to register as a donor	Not mentioned
Alvaro, Siegel et al. 2011, USA (pertains to study II reported in paper) [17]	Hispanic	Before & After Study	On alternate weeks employees of local organ procurement organisation offered the attendees at a flea market an immediate opportunity to register or information about organ donation	Participants offered an immediate opportunity to register rather than just information about OD were significantly more likely to register (86 vs. 54%)	Verified registration	The IFF model (Immediate opportunity, information, focused engagement & favourable activation)
Andrews, Zhang et al. 2012, USA [10]	African American Intervention n=622 Control n=632	Cluster Randomised	Members of the congregation undertook discussions with lay health advisors about organ donation. DVD designed to address OD barriers for African Americans	Increase in verified enrolment on donor registry in intervention group. No increase in knowledge observed	Verified enrolment on donor registry	Not mentioned
A Warrens, personal communication, 2013 UK	Multi-ethnic N=806	Cross Sectional Evaluation	Peer educators trained to deliver health promotion about OD	Increase in the % of people signed up to the organ donor register	Registration	Not mentioned
Callender, Hall et al. 2001, USA [18]	Multi-Ethnic N=914	Before & After Study	Presentation about organ donation delivered by transplant recipients, donors, individuals on transplant lists health care professionals that are ethnically similar to the target population.	Improvements in knowledge and attitudes towards organ donation, high reporting of willingness to discuss OD with family	Willingness to donate organs for oneself and loved ones after death No valid measures to assess attitudes to OD	Not mentioned
Daryl Thornton, Alejandro-Rodriguez et al. 2012, USA [14]	Multi Ethnic Intervention n=443 Control n=509	Cluster Randomised	5 minute video about OD prior to collecting drivers licence. Controls obtained licence in the usual manner.	Cases more likely to register as donors compared to controls. (76% vs 54%)	Verified enrolment on donor registry	Not Mentioned

Fahrenwald, Belitz et al. 2010, USA [21]	American Indians N=1580	Before & After Study	Out-reach coordinators facilitate delivery to small groups. Who were required to read & discuss a 1 page brochure. This was followed by a 13 min video and a group discussion facilitated by the coordinator	Significant change in Stage of Motivational Readiness to become an organ donor post intervention	Stage of motivational readiness to serve as an organ donor	Transtheoretical model of behaviour change
Resnicow, Andrews et al. 2010, USA [9]	African American Intervention n=1370 Control n=1419	Cluster Randomised	Hairstylists trained as lay health advisors used motivational interviewing to discuss OD with participants	Participants receiving the intervention were 4 times more likely to join the register than the controls	Self reported donation status Verified enrolment on state registry	Not Mentioned
Salim, Bery et al. 2012, USA [19]	Hispanic N=341	Before & After Study	Presentation about the need for transplant and information about donation lead by local organ procurement organisation	Increase in knowledge, perceptions and beliefs. No difference willingness to discuss donation with family or intent to donate	No validated measures to assess attitudes to OD	Not mentioned
Cárdenas, Thornton et al. 2010, USA [15]	Multi-Ethnic Intervention n=96 Control n=91	Cluster Randomised	Transplant surgeons & young recipients gave a presentation followed by Q&A session and a video	Knowledge increase post intervention was the strongest predictor of positive change in opinion about OD	Knowledge, Attitudes & Awareness of OD	None mentioned
Feeley, Anker et al. 2009, USA	Multi-ethnic	Before & After Study	Peer educators delivered a range of campus based activities	Increased donor registration	Self reported registration	Not mentioned
Arriola, Robinson et al. 2009, USA [11]	African American Intervention n=175 Control n =162	Cluster Randomised	Video & written materials mailed to participants	Greater readiness to sign a donor card, register via drivers licence or talk to family about wishes in intervention group	None, but questions based on theoretical model	Transtheoretical model of behaviour change
MEDIA						
Alvaro, Jones et al. 2006, USA [24]	Hispanic N=2401	Before & After Study	4 x 30 sec Television 2x 60sec radio ads. These highlighted positive impact of transplant on Hispanic individuals and demonstrated the substantial efforts medics undertake to save the life of a potential donor	Greater reporting of pro-donation beliefs, and family discussion post intervention	Self reported registration status. No validated measures of attitude and willingness to OD	Not mentioned
Frates, Bohrer et al. 2006, USA [22]	Hispanic N=4,500	Before & After Study	Prime time television & radio slots	Year on year increase in Hispanic OD consent rates (overall 10% increase). Increase in knowledge/attitudes	Consent rates from organ procurement organisation. No valid measures to assess attitudes to OD	Transtheoretical model

Salim, Berry et al. 2011, USA [23]	Hispanic N = 1052	Before & After Study	Prime time television & radio slots	Improved knowledge post campaign when compared to baseline	Awareness, perception & belief about OD	Not mentioned
Radosevich, Larson et al. 2010, USA [13]	African American N=465	Before & After Study	Media Campaign conveyed via television, radio, targeted print media. Donor families and health care professionals were interviewed on television and radio.	Significant increase in knowledge and attitude about organ donation post campaign No significant change in intention and willingness to become a donor	Self Reported Registration Change in Knowledge attitudes and willingness to become a donor	Theory of Reasoned Action
Media & Education						
Harrison, Morgan et al. 2011, USA [12]	African American N=626,771	Before & After Study	Billboards in the vicinity of vehicle licensing offices, and radio adverts. Placement of donor families at vehicle licensing offices and targeted written information.	Large increase in sign up to the donor register the magnitude of the increase was greatest when 1-1 promotion was combined with other medium	Verified registration	Communication design
Hebert, Rivera et al. 2010, USA [25]	Chinese American N=1134	Before & After Study	Media Campaign Grass roots community outreach	Significant increase in stated intention to donate in the intervention area vs. the control area	Joining a donor registry Express a desire to become an organ donor Communicating wishes to family	Not mentioned

Table 2: Quality Assessment of included studies

Authors	Theoretical quality	Standardisation of delivery	Identification & adjustment for confounders	Effects attributable to the intervention
A Warrens, personal communication, 2013	Minimally grounded	Authors allow for & explain variation in intervention delivery. Standard training offered to educators delivering intervention	No	Yes
Allen and Stillwater 2010 [20]	Minimally grounded	Authors indicate variation	No	Uncertain
Alvaro, Jones et al. 2006 [24]	Moderately grounded	Strict standardisation (by due of intervention design)	No	Uncertain
Alvaro, Siegel et al. 2011 [17]	Well grounded	Strict standardisation – authors undertook un announced site visits, and developed standard reporting tools for completion at intervention sites	No	Yes
Andrews, Zhang et al. 2012 [10]	Moderately grounded	Authors indicate variation	Yes	Yes
Arriola, Robinson et al. 2009 [11]	Well grounded	Strict standardisation	Yes	Yes
Callender, Hall et al. 2001 [18]	Well grounded	Authors indicate variation	Yes	Yes
Cárdenas, Thornton et al. 2010 [15]	Moderately grounded	Strict standardisation	Yes	Yes
Daryl Thornton, Alejandro-Rodriguez et al. 2012 [14]	No theoretical grounding	Strict standardisation	Yes	Yes
Fahrenwald, Belitz et al. 2010 [21]	Well grounded	Strict standardisation	No	Yes
Feeley, Anker et al. 2009 [16]	Moderately grounded	Authors allow for & explain variation	No	Yes- Effects on student campaigners No – effect on wider student body

Frates, Bohrer et al. 2006 [22]	Moderately grounded	Strict standardisation (due to intervention design)	No	Uncertain
Harrison, Morgan et al. 2011 [12]	Well grounded	Strict standardisation of media and print info. Variation but no explanation or assessment of variation interpersonal elements	No	Yes
Hebert, Rivera et al. 2010 [25]	Moderately grounded	Strict standardisation (due to intervention design)	No	Uncertain
Radosevich, Larson et al. 2010 [13]	Moderately grounded	Strict standardisation due to intervention design)	No	Uncertain
Resnicow, Andrews et al. 2010 [9]	Moderately grounded	Strict standardisation. Standard training offered to educators delivering intervention	Yes	Yes
Salim, Berry et al. 2011 [23]	Minimally grounded	Strict standardisation (due to intervention design)	Yes	Uncertain
Salim, Bery et al. 2012 [19]	Minimally grounded	Strict standardisation	No	Yes

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

Study	Target population/Setting	Intervention	African American	Hispanic
			Absolute Difference (CI 95%)	
[1] Resnicow, Andrews et al. 2010 [9]	**African American Setting**: Hair Dressers,	**Intervention:** brief motivational intervention delivered by hairdresser	**2.8 (2.2 to 3.2)**	
Daryl Thornton, Alejandro-Rodriguez et al. 2012 [14]	**All ethnic groups including white Setting:** outside motor Vehicle registration office	**Intervention:** 5 min video addressing ethnic concerns about OD	**22 (9 to 35)**	29 (-8 to 65)
Andrews, Zhang et al. 2012 [10]	**African American Setting:** African American Churches	**Intervention:** Focused discussions about donation followed by a DVD aimed at African American concerns about donation	**18.7 (16.6 to 20.8)**	

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

Table 4: Educational interventions reporting change in knowledge about organ donation

Study	Target population	Duration and length of follow up post intervention	Number of items with a significant improvement at post test	% items where significant increase in knowledge recorded
Cárdenas, Thornton et al. 2010 [15]	High School Students, Multi ethnic.	60 mins Immediate follow-up	12/16	75%
Callender, Hall et al. 2001 [18]	Multi ethnic adults	Not reported Immediate follow-up	4/8	50%
Salim, Bery et al. 2012, USA [19]	Hispanic Adults	45-60mins	15/25	60%

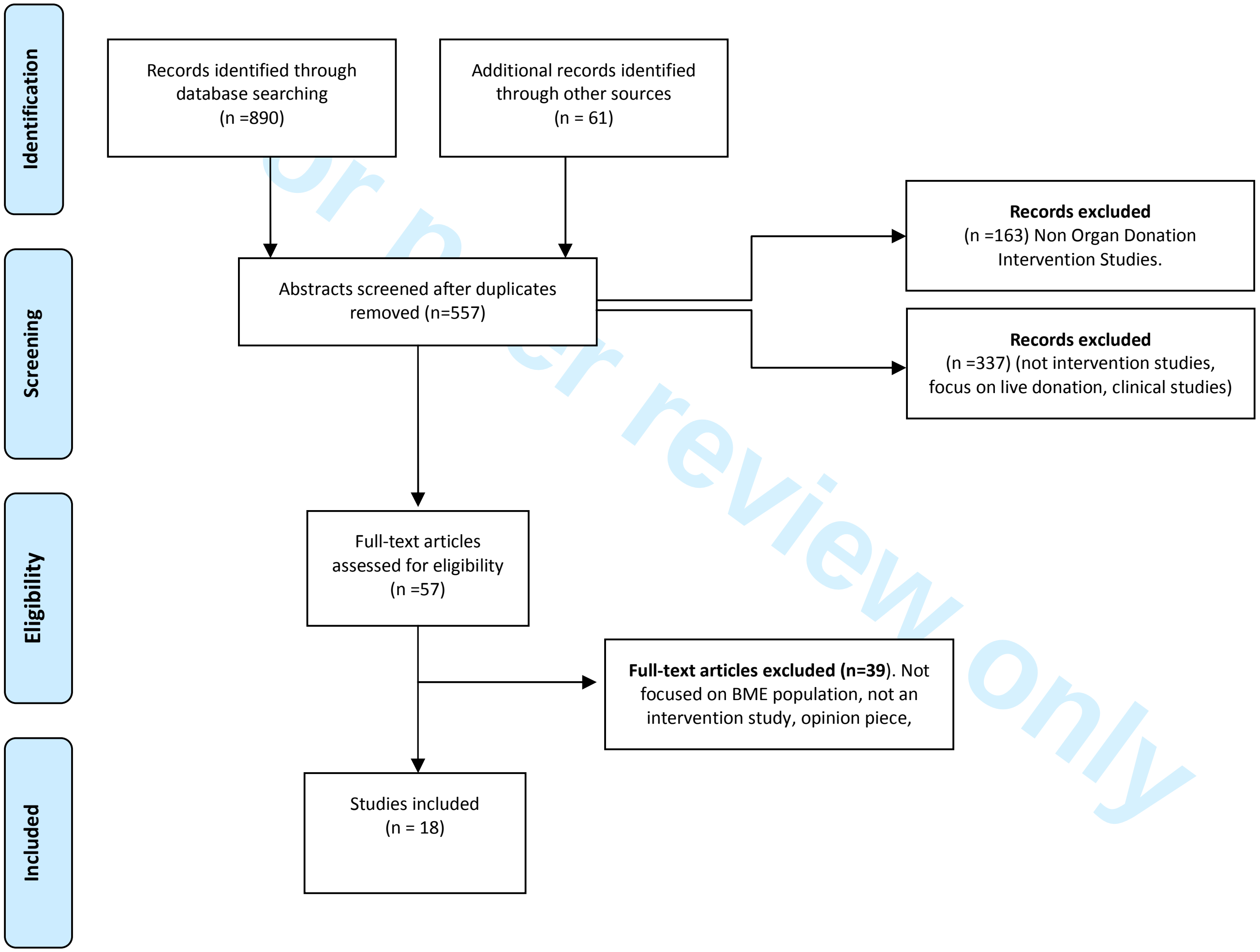
Figure 1: Data base search strategy

Database, Years Searched Date Range, Keywords Added	Search Strategy
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*)).tw. 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. 77. 74 not 76 78. from 77 keep 16,30

Figure 2: Selection of studies for inclusion in systematic review of interventions to increase organ donor registration among ethnic minority populations



Box 1: Quality Assessment Criteria

- **Theoretical quality:** Do the authors demonstrate a grounded theoretical understanding of how the intervention causes change? (Was the intervention informed by a literature review and either an established theoretical framework or empirical investigation conducted by the authors?)
- **Standardisation:** Was the delivery of the intervention standardised? If not, did authors allow for and explain variations?
- **Identification & adjustment for confounders:** Were potential confounders sought & adjusted for in the analysis
- **Effects attributible to intervention:** Was it reasonably likely the observed effects were attributable to the intervention?

Box 2: The Stages of Change

- **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.

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

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

Competing Interests: none of the authors have any competing interests. No financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

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, Psychinfo, Cinahl and Cochrane Central searched to November 2012, together with four trials databases and grey literature.

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

Results: 18 studies were included in the review, comprising both educational and mass media interventions. Mass media interventions alone reported no significant change in intention or willingness to register. Educational or combined 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.

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

Key Words: ethnicity, organ donor registration, organ donation, systematic review, intervention studies, UK, North America

Abstract: 186

What is already known on this topic?

- Minority ethnic groups have a relatively high need for organ transplantation, particularly kidney transplantation, but low donation rates and availability of well matched organs.
- Campaigns to increase organ donor registration have had limited effects.

What this study adds

- Community based education campaigns are more effective than media campaigns alone in increasing organ donor registration.
- Interventions need to be targeted to the populations' stage of readiness to register as a donor.
- The outcome of registering as a donor should be complemented by assessment of shifts along the pathway towards achieving this goal, with increased knowledge and attitudinal changes forming necessary stages towards registration.

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 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 population [2], 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 US [5].

The high level of unmet need for transplantation among British and American ethnic minority populations is influenced by both increased risks of end stage renal failure and thus a high need for kidney transplantation, together with the relatively low donation rate among minority ethnic groups which is of particular significance given the greater prevalence among minority ethnic groups of blood groups and human leukocyte antigen (HLA) 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].

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 [7]. 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[8]

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 searched in December 2009 and refreshed in November 2012: Medline, Embase, Psychinfo, Cinahl and Cochrane Central. In addition trials databases were searched for relevant studies and searches for academic and grey literature made using search engines and by hand checking relevant publications and direct contact with experts in the field (Box1).

<<<BOX 1 HERE>>>

The inclusion criteria focused on intervention studies in both North America and the UK that were designed to change rates of registration, intention/willingness to become a donor or to change 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 re-run 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.

<<TABLE 1 HERE>>

Relevance and Quality Assessment: Following initial de-duplication, 557 papers remained (see Figure 1). Two authors (SD & 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 sub group analysis by ethnicity was conducted. Studies were excluded if they did not include original data or reported a meeting abstract only. Papers 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 papers for quality (SD & 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 [9] and both content and construct validity have been established [10]. Using this assessment tool five papers 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 weak, and three papers 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 [11]. In light of this papers were assessed for theoretical quality in terms how the intervention was expected to cause change, and quality of implementation in terms of whether there was standardisation of delivery through study design and or facilitator training (see Table 2).

<Insert Table 2>

< Fig 1 FLOWCHART HERE>

Data synthesis: Wide variations in outcomes, populations and study design of included studies precluded meta-analysis. An interpretive and thematic approach to synthesis was therefore undertaken and examined both the nature and delivery of interventions and the outcomes achieved. Studies were initially classified by: date, country, population studied, and intervention type and study design. The second step involved classifying both media and education interventions in terms of the aims of the interventions and the outcomes achieved. Thirdly, 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 and post evaluation 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 papers reported educational interventions. Recruitment was 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 table2)

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 were delivered in familiar settings of a local church or hairdresser. Peer educators in Andrews' study [13] mostly had a medical background and were involved in a Church Health Committee. They undertook a four-hour training package that comprised general information about organ donation and tips on integrating the topic into church discussions. In Resnicow's study [12] hair stylists were trained over two days with this including 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 per month for four months. In contrast the third intervention in this category did not have a strong interpersonal element, and trialled the use of a 5 minute 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 [17], possibly reflecting their small number (n=-28).

Three further community educational studies based on a follow-up or cross sectional design reported strategies to increase organ donor registration. Feely et al[19] reported a 1.6% increase in new organ donor registrations following campus led peer education among students from six university campuses in the US 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 focussed on attendees at a range of venues and community events selected to maximise engagement with 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 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 [21-23]. 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 comprised of five facets; *1) general knowledge about donation; 2) knowledge of the relevance of donation to 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 one hour, 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 willingness among participants to state that they intended to register as a donor. Among Hispanic participants knowledge relating to the fair allocation of organs were significant independent predictors of willingness[24] (see table 4), while among a multi ethnic sample of high school students improvements in composite knowledge scores significantly predicted willingness to donation 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 multi-ethnic 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 post intervention in relation to trust in doctors when compared to trust scores for other ethnic groups. Overall post intervention, participants in this study reported being significantly more likely to state that they were willing to donate their own and their families organs after death (p<0.000) [25]. Unlike the aforementioned studies which focused on the lay population Allen and Stillwater's [26]holistic interventions addressed knowledge gaps and misinformation among Alaskan Community Health aides and school children. The authors do not report detail about individual aspects of knowledge addressed but report a significant increase in knowledge among both students from 58% to 95% correct (p<.0001) and community health practitioners (p<.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.

<TABLE 4>

Measured shift towards greater readiness: Two educational interventions were informed by the Trans Theoretical Model of Behaviour Change (TTM)[27] and measured change in individual's 'readiness to become an organ donor' [14 28]. Both studies aimed to measure change across the five TTM stages from pre-contemplation to maintenance (Box 2). In Fahrenwald's study 56.9% of participants progressed to a more advanced stage at post test and none regressed, while Arriola reported that intervention participants were 1.53 times more likely to be in a later stage of readiness than control participants.

Collaboration with members of the targeted ethnic population was undertaken to ensure the relevance and acceptability of the intervention. For Arriola et al[14] this 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 [28] 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 minutes 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).

<<<INSERT BOX 2 HERE>>>

Mass Media Interventions

All media interventions attempted to detect changes in willingness or intention to join a donor register or sign a donor card [16 29-32]. However interventions that solely utilised mass media reported no significant change in intention or willingness to register 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 [15] 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 year prior to 5588 post campaign. Overall, the combined effect of the intervention components increased donation by 700%.

<TABLE 5>

Conclusion

This review identified 18 evaluated intervention studies focusing on ethnic minorities that were either educational in nature, delivered in community settings or disseminated through mass media. All but one study was conducted in the United States, 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, frequent use of unvalidated measures of knowledge, and 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 and obesity related health promotion interventions adapted for ethnic minority populations [37]. However detailed analysis of both the process and outcomes allowed us to identify some messages regarding effective approaches for increasing the acceptability and effectiveness of these interventions.

Firstly, community-based educational interventions exhibited a higher level of success in terms of verified registration than those solely reliant on 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 were individuals are required to make an immediate decision about donation. 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 addressed knowledge gaps and misconceptions about organ donation [15 30 31].

Secondly, there are questions of whether registration always represents an appropriate outcome, given that ethnic minorities and those from socio-economically deprived backgrounds are consistently shown to have more negative views, greater concerns and less knowledge about organ donation and transplantation than the general population [33-35]. Interventions should therefore consider the intermediary steps that individuals may need to pass before the desired end-point of registration can be achieved, and to 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 therefore require multiple interventions that reinforce and build upon 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 (under review) 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. 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 shows 25% of ethnic minority families of potential donors who had formally signed the donor register refuse assent [38], with current practice being to respect the wishes of the family regarding donation decisions even if this does not accord with those of the patient.

Thirdly, the review suggests that effective interventions for those in the pre-contemplation or contemplation phase are those undertaken in familiar community settings and delivered by appropriately trained lay individuals. Lay health promoters in this context have the benefit of an established rapport with the target population [36] and the potential for gradual delivery of information that can be reinforced over time.

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 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 in practice facilitating a sign up process.

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Appendix: Search strategy for Medline Ovid, 1980-2012

Database, Years Searched	Search Strategy
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*)).tw. 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. 77. 74 not 76 78. from 77 keep 16,30

Figure 1: Selection of studies for inclusion in systematic review of interventions to increase organ donor registration among ethnic minority populations

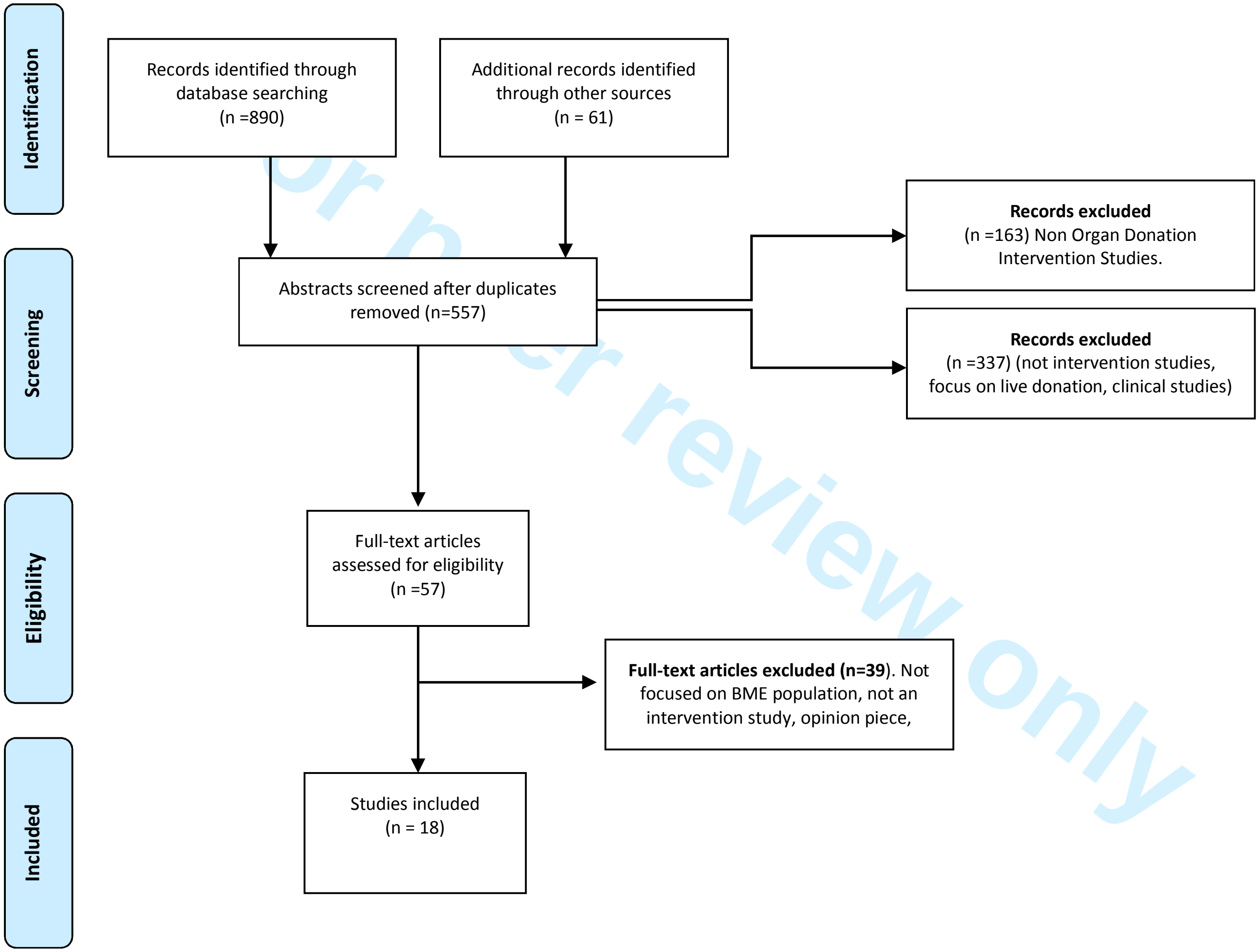

Table 1 – Overview of studies included in the review

Author & Country	Demographics Sample Size (n)	Study Design	Mode of delivery	Results	Outcomes	Theoretical framework	Database
EDUCATION							
Allen and Stillwater 2010, USA [26]	Alaskan Native N = 54 Health Staff N=<200 Students	Before & After Study	PowerPoint presentation & video focused on issues about to OD and Alaskan natives	Improved knowledge and positive attitude towards donation and intention to register post test	Knowledge & Intention to register as a donor	Not mentioned	Hand search of book
Alvaro, Siegel et al. 2011, USA (pertains to study II reported in paper) [20]	Hispanic	Before & After Study	On alternate weeks employees of local organ procurement organisation offered the attendees at a flea market an immediate opportunity to register or information about organ donation	Participants offered an immediate opportunity to register rather than just information about OD were significantly more likely to register (86 vs. 54%)	Verified registration	The IFF model (Immediate opportunity, information, focused engagement & favourable activation)	Medline
Andrews, Zhang et al. 2012, USA [13]	African American Intervention n=622 Control n=632	Cluster Randomised	Members of the congregation undertook discussions with lay health advisors about organ donation. DVD designed to address OD barriers for African Americans	Increase in verified enrolment on donor registry in intervention group. No increase in knowledge observed	Verified enrolment on donor registry	Not mentioned	PubMed
A Warrens, personal communication, 2013 UK	Multi-ethnic N=806	Cross Sectional Evaluation	Peer educators trained to deliver health promotion about OD	Increase in the % of people signed up to the organ donor register	Registration	Not mentioned	Author contact
Callender, Hall et al. 2001, USA [25]	Multi-Ethnic N=914	Before & After Study	Presentation about organ donation delivered by transplant recipients, donors, individuals on transplant lists health care professionals that are ethnically similar to the target population.	Improvements in knowledge and attitudes towards organ donation, high reporting of willingness to discuss OD with family	Willingness to donate organs for oneself and loved ones after death No valid measures to assess attitudes to OD	Not mentioned	Embase
Thornton JD, Alejandro-Rodriguez et al. 2012, USA [17]	Multi Ethnic Intervention n=443 Control n=509	Cluster Randomised	5 minute video about OD prior to collecting drivers licence. Controls obtained licence in the usual manner.	Cases more likely to register as donors compared to controls. (76% vs 54%)	Verified enrolment on donor registry	Not Mentioned	Embase
Fahrenwald, Belitz et al. 2011, USA [28]	American Indians N=1580	Before & After Study	Out-reach coordinators facilitate delivery to small groups. Who were required to read & discuss a 1 page brochure. This was followed by a 13 min video and a group discussion facilitated by the coordinator	Significant change in Stage of Motivational Readiness to become an organ donor post intervention	Stage of motivational readiness to serve as an organ donor	Transtheoretical model of behaviour change	PubMed

Resnicow, Andrews et al. 2010, USA [12]	African American Intervention n=1370 Control n=1419	Cluster Randomised	Hairstylists trained as lay health advisors used motivational interviewing to discuss OD with participants	Participants receiving the intervention were 4 times more likely to join the register than the controls	Self reported donation status Verified enrolment on state registry	Not Mentioned	PubMed & Embase
Salim, Bery et al. 2012, USA [24]	Hispanic N=341	Before & After Study	Presentation about the need for transplant and information about donation lead by local organ procurement organisation	Increase in knowledge, perceptions and beliefs. No difference willingness to discuss donation with family or intent to donate	Change in knowledge and attitude. Donation intent	Not mentioned	PubMed
Cárdenas, Thornton et al. 2010, USA [18]	Multi-Ethnic Intervention n=96 Control n=91	Cluster Randomised	Transplant surgeons & young recipients gave a presentation followed by Q&A session and a video	Knowledge increase post intervention was the strongest predictor of positive change in opinion about OD	Knowledge, Attitudes & Awareness of OD	None mentioned	Medline
Feeley, Anker et al. 2009, USA [19]	Multi-ethnic	Before & After Study	Peer educators delivered a range of campus based activities	Increased donor registration	Self reported registration	Not mentioned	Embase, Medline, PubMed
Arriola, Robinson et al. 2009, USA [14]	African American Intervention n=175 Control n =162	Cluster Randomised	Video & written materials mailed to participants	Greater readiness to sign a donor card, register via drivers licence or talk to family about wishes in intervention group	Readiness to express donation intent via a drivers licence, donor card and discussion with family	Transtheoretical model of behaviour change	Embase, PubMed & Medline
MEDIA							
Alvaro, Jones et al. 2006, USA [31]	Hispanic N=2401	Before & After Study	4 x 30 sec Television 2x 60sec radio ads. These highlighted positive impact of transplant on Hispanic individuals and demonstrated the substantial efforts medics undertake to save the life of a potential donor	Greater reporting of pro-donation beliefs, and family discussion post intervention	Self reported registration status. No validated measures of attitude and willingness to OD	Not mentioned	Embase & Medline
Frates, Bohrer et al. 2006, USA [29]	Hispanic N=4,500	Before & After Study	Prime time television & radio slots	Year on year increase in Hispanic OD consent rates (overall 10% increase). Increase in knowledge/attitudes	Consent rates from organ procurement organisation. No valid measures to assess attitudes to OD	Transtheoretical model	Embase, Medline & Psychinfo

Salim, Berry et al. 2011, USA [30]	Hispanic N = 1052	Before & After Study	Prime time television & radio slots	Improved knowledge post campaign when compared to baseline	Awareness, perception & belief about OD	Not mentioned	Embase & Medline
Radosevich, Larson et al. 2010, USA [16]	African American N=465	Before & After Study	Media Campaign conveyed via television, radio, targeted print media. Donor families and health care professionals were interviewed on television and radio.	Significant increase in knowledge and attitude about organ donation post campaign No significant change in intention and willingness to become a donor	Self Reported Registration Change in Knowledge attitudes and willingness to become a donor	Theory of Reasoned Action	Hand search of book
Media & Education							
Harrison, Morgan et al. 2011, USA [15]	African American N=626,771	Before & After Study	Billboards in the vicinity of vehicle licensing offices, and radio adverts. Placement of donor families at vehicle licensing offices and targeted written information.	Large increase in sign up to the donor register the magnitude of the increase was greatest when 1-1 promotion was combined with other medium	Verified registration	Communication design	PubMed
Hebert, Rivera et al. 2010, USA [32]	Chinese American N=1134	Before & After Study	Media Campaign Grass roots community outreach	Significant increase in stated intention to donate in the intervention area vs. the control area	Joining a donor registry Express a desire to become an organ donor Communicating wishes to family	Not mentioned	Hand search of book

Table 2: Assessment of included studies based on two components of the Medical Research Council criteria for complex interventions.

Authors	Theoretical quality	Standardisation of delivery
A Warrens, personal communication, 2013	Minimally grounded	Authors allow for & explain variation in intervention delivery. Standard training offered to educators delivering intervention
Allen and Stillwater 2010 [26]	Minimally grounded	Authors indicate variation
Alvaro, Jones et al. 2006 [31]	Moderately grounded	Strict standardisation (by due of intervention design)
Alvaro, Siegel et al. 2011 [20]	Well grounded	Strict standardisation – authors undertook un announced site visits, and developed standard reporting tools for completion at intervention sites
Andrews, Zhang et al. 2012 [13]	Moderately grounded	Authors indicate variation
Arriola, Robinson et al. 2009 [14]	Well grounded	Strict standardisation
Callender, Hall et al. 2001 [25]	Well grounded	Authors indicate variation
Cárdenas, Thornton et al. 2010 [18]	Moderately grounded	Strict standardisation
Thornton,JD Alejandro-Rodriguez et al. 2012 [17]	No theoretical grounding	Strict standardisation
Fahrenwald, Belitz et al. 2011 [28]	Well grounded	Strict standardisation
Feeley, Anker et al. 2009 [19]	Moderately grounded	Authors allow for & explain variation

Frates, Bohrer et al. 2006 [29]	Moderately grounded	Strict standardisation (due to intervention design)
Harrison, Morgan et al. 2011 [15]	Well grounded	Strict standardisation of media and print info. Variation but no explanation or assessment of variation interpersonal elements
Hebert, Rivera et al. 2010 [32]	Moderately grounded	Strict standardisation (due to intervention design)
Radosevich, Larson et al. 2010 [15]	Moderately grounded	Strict standardisation due to intervention design)
Resnicow, Andrews et al. 2010 [12]	Moderately grounded	Strict standardisation. Standard training offered to educators delivering intervention
Salim, Berry et al. 2011 [30]	Minimally grounded	Strict standardisation (due to intervention design)
Salim, Bery et al. 2012 [24]	Minimally grounded	Strict standardisation

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

Study	Target population/Setting	Intervention	African American	Hispanic
			Absolute Difference (CI 95%)	
[1] Resnicow, Andrews et al. 2010 [12]	**African American Setting**: Hair Dressers,	**Intervention:** brief motivational intervention delivered by hairdresser	**2.8 (2.2 to 3.2)**	
Thornton JD, Alejandro-Rodriguez et al. 2012 [17]	**All ethnic groups including white Setting:** outside motor Vehicle registration office	**Intervention:** 5 min video addressing ethnic concerns about OD	**22 (9 to 35)**	29 (-8 to 65)
Andrews, Zhang et al. 2012 [13]	**African American Setting:** African American Churches	**Intervention:** Focused discussions about donation followed by a DVD aimed at African American concerns about donation	**18.7 (16.6 to 20.8)**	

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

Table 4: Educational interventions reporting change in knowledge about organ donation

Study	Target population	Duration and length of follow up post intervention	Number of items with a significant improvement at post test	% items where significant increase in knowledge recorded	
Cárdenas, Thornton et al. 2010 [18]	High School Students, Multi ethnic.	60 mins Immediate follow-up	12/16	75%	Greater improvements in composite knowledge score predicted willingness to donate in the intervention group **(OR1.42, CI 1.18-1.71, $p<0.001$)**
Callender, Hall et al. 2001 [25]	Multi ethnic adults	Not reported Immediate follow-up	4/8	50%	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
Salim, Bery et al. 2012, USA [24]	Hispanic Adults	45-60mins	15/25	60%	**Independent positive predictors of willingness to donate:** 1) Knowledge of a national matching system **(AOR 3.36, CI1.43-7.88, $p=0.005$)** 2) Not perceiving that wealthy people are more likely to receive a transplant **(AOR 5.39, 2.02-14.37 $p=0.0008$)**
Allen & Stillwater, 2010, USA [26]	Alaskan Natives School Children	Not specified	n/r	n/r	**Scores for knowledge about donation and transplantation increased significantly pre-test 58% correct vs 95% post test $p<0.001$** **Students significantly more likely to state they would be a donor $p=0.021$**
	Community Health Aids & Practitioners (adults)	3 hour presentation as part of CPD.	n/r	n/r	**Significant increase in factual knowledge score $p<0.001$ – mean knowledge scores doubled post test.** **Participants were significantly more report intent to sign a donor card post test $p=0.003$.** **Significantly greater awareness of how and where to get information about organ donation $p<0.001$**

Table 5: Effect of media campaigns on donor registration

Author Target population Language	Media Duration	Self reported Registration intention to be a donor	Pre	Post	p
Frates, Bohrer et al. 2006, USA [29] Hispanic Spanish	TV & Radio 3 years	*Have decided to be a donor*	27%	31%	0.163
		Signed a donor card	14%	16%	0.376
Salim, Berry et al. 2011, USA [30] Hispanic English & Spanish	TV & Radio 1 year	*Intent to donate* (% likely or very likely)	32%	30%	0.488
Radosevich, Larson et al. 2010, USA [16] African American English	TV, Radio & Print Media 1 year	*Donor designation on drivers licence*	33%	40%	0.123
Alvaro, Jones et al. 2006, USA [31] Hispanic Spanish	TV & Radio 1 year	*Have you personally told anybody that you would like to be an organ donor (%yes)*	28.5%	27.2%	0.723
			23.2%	20.9%	0.445

Hebert, Rivera et al. 2010 [32][2] Chinese American Not Stated	Print Media 1 year	*I do not intend to donate my organ at my death*[3]	11%	21%	0.001
Harrison, Morgan et al. 2011 [15] African American English	Bill Boards in the vicinity of vehicle licensing office Radio Ads Face to face contacts with donor families	*Verified registration (counts of registrants in postcode areas with a population >80% African American)*	0.1%	1.2%	**0.001**

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[2] 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.

Box 1: Systematic Search

1. **Sources**

Databases Searched: Medline (Ovid), Embase (Ovid), PsychInfo (Ovid), Cinahl (Ebso), Cochrane Central Pubmed

Trials Databases Searched:
UKCRN, ClincialTrials.gov, WHO international Clinical Trials Registry Platform and Health Service Research Projects in Progress.

Websites Searched for Grey Literature:
National Health Service Blood & Transplant - www.nhsbt.nhs.uk
Department of Health (UK) – www.dh.gov.uk
Kidney Research (UK) – www.kidneyresearch.org.uk
US Department of Transplant (funded studies) http://www.organdonor.gov/dtcp/behavior.html

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2. **Inclusion Critera:**

Country: UK, USA
Date of Publication: 1980 – 2012
Ethnicity: Visible Ethnic Minority
Design: Intervention study, Evaluation study
Outcomes: Verified registration, willingness/intent to register, change in registration rates
Subjects: Adults and School age children
Setting: Community

Box 2: Prochaska's Stages of Change [27] 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.

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	4
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	-
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4&5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Appendix p 16
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	6&7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	6&7
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	6
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	n/a
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	n/a

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	-
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	n/a
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	fig 1 p6
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	table 1 p6
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	-
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Tables 3 &5
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	n/a
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	-
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	n/a
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	11-13
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	11-13
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	11-13
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	14

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: **www.prisma-statement.org**.

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

Competing Interests: none of the authors have any competing interests. No financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

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, Psychinfo, Cinahl and Cochrane Central searched to November 2012, together with four trials databases and grey literature.

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

Results: 18 studies were included in the review, comprising both educational and mass media interventions. Mass media interventions alone reported no significant change in intention or willingness to register. Educational or combined 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.

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

Key Words: ethnicity, organ donor registration, organ donation, systematic review, intervention studies, UK, North America

Abstract: 186

What is already known on this topic?

- Minority ethnic groups have a relatively high need for organ transplantation, particularly kidney transplantation, but low donation rates and availability of well matched organs.
- Campaigns to increase organ donor registration have had limited effects.

What this study adds

- Community based education campaigns are more effective than media campaigns alone in increasing organ donor registration.
- Interventions need to be targeted to the populations' stage of readiness to register as a donor.
- The outcome of registering as a donor should be complemented by assessment of shifts along the pathway towards achieving this goal, with increased knowledge and attitudinal changes forming necessary stages towards registration.

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 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 population [2], 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 US [5].

The high level of unmet need for transplantation among British and American ethnic minority populations is influenced by both increased risks of end stage renal failure and thus a high need for kidney transplantation, together with the relatively low donation rate among minority ethnic groups which is of particular significance given the greater prevalence among minority ethnic groups of blood groups and human leukocyte antigen (HLA) 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].

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 [7]. 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[8]

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 searched in December 2009 and refreshed in November 2012: Medline, Embase, Psychinfo, Cinahl and Cochrane Central. In addition trials databases were searched for relevant studies and searches for academic and grey literature made using search engines and by hand checking relevant publications and direct contact with experts in the field (Box1).

<<<BOX 1 HERE>>>

The inclusion criteria focused on intervention studies in both North America and the UK that were designed to change rates of registration, intention/willingness to become a donor or to change 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 re-run 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.

<<TABLE 1 HERE>>

Relevance and Quality Assessment: Following initial de-duplication, 557 papers remained (see Figure 1). Two authors (SD & 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 sub group analysis by ethnicity was conducted. Studies were excluded if they did not include original data or reported a meeting abstract only. Papers 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 papers for quality (SD & 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 [9] and both content and construct validity have been established [10]. Using this assessment tool five papers 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 weak, and three papers 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 [11]. In light of this papers were assessed for theoretical quality in terms how the intervention was expected to cause change, and quality of implementation in terms of whether there was standardisation of delivery through study design and or facilitator training (see Table 2).

<Insert Table 2>

< Fig 1 FLOWCHART HERE>

Data synthesis: Wide variations in outcomes, populations and study design of included studies precluded meta-analysis. An interpretive and thematic approach to synthesis was therefore undertaken and examined both the nature and delivery of interventions and the outcomes achieved. Studies were initially classified by: date, country, population studied, and intervention type and study design. The second step involved classifying both media and education interventions in terms of the aims of the interventions and the outcomes achieved. Thirdly, 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 and post evaluation 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 papers reported educational interventions. Recruitment was 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 table2)

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 were delivered in familiar settings of a local church or hairdresser. Peer educators in Andrews' study [13] mostly had a medical background and were involved in a Church Health Committee. They undertook a four-hour training package that comprised general information about organ donation and tips on integrating the topic into church discussions. In Resnicow's study [12] hair stylists were trained over two days with this including 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 per month for four months. In contrast the third intervention in this category did not have a strong interpersonal element, and trialled the use of a 5 minute 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 [17], possibly reflecting their small number (n=-28).

Three further community educational studies based on a follow-up or cross sectional design reported strategies to increase organ donor registration. Feely et al[19] reported a 1.6% increase in new organ donor registrations following campus led peer education among students from six university campuses in the US 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 focussed on attendees at a range of venues and community events selected to maximise engagement with 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 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 [21-23]. 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 comprised of five facets; *1) general knowledge about donation; 2) knowledge of the relevance of donation to 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 one hour, 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 willingness among participants to state that they intended to register as a donor. Among Hispanic participants knowledge relating to the fair allocation of organs were significant independent predictors of willingness[24] (see table 4), while among a multi ethnic sample of high school students improvements in composite knowledge scores significantly predicted willingness to donation 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 multi-ethnic 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 post intervention in relation to trust in doctors when compared to trust scores for other ethnic groups. Overall post intervention, participants in this study reported being significantly more likely to state that they were willing to donate their own and their families organs after death (p<0.000) [25]. Unlike the aforementioned studies which focused on the lay population Allen and Stillwater's [26]holistic interventions addressed knowledge gaps and misinformation among Alaskan Community Health aides and school children. The authors do not report detail about individual aspects of knowledge addressed but report a significant increase in knowledge among both students from 58% to 95% correct (p<.0001) and community health practitioners (p<.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.

<TABLE 4>

Measured shift towards greater readiness: Two educational interventions were informed by the Trans Theoretical Model of Behaviour Change (TTM)[27] and measured change in individual's 'readiness to become an organ donor' [14 28]. Both studies aimed to measure change across the five TTM stages from pre-contemplation to maintenance (Box 2). In Fahrenwald's study 56.9% of participants progressed to a more advanced stage at post test and none regressed, while Arriola reported that intervention participants were 1.53 times more likely to be in a later stage of readiness than control participants.

Collaboration with members of the targeted ethnic population was undertaken to ensure the relevance and acceptability of the intervention. For Arriola et al[14] this 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 [28] 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 minutes 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).

<<<INSERT BOX 2 HERE>>>

Mass Media Interventions

All media interventions attempted to detect changes in willingness or intention to join a donor register or sign a donor card [16 29-32]. However interventions that solely utilised mass media reported no significant change in intention or willingness to register 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 [15] 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 year prior to 5588 post campaign. Overall, the combined effect of the intervention components increased donation by 700%.

<TABLE 5>

Conclusion

This review identified 18 evaluated intervention studies focusing on ethnic minorities that were either educational in nature, delivered in community settings or disseminated through mass media. All but one study was conducted in the United States, 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, frequent use of unvalidated measures of knowledge, and 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 and obesity related health promotion interventions adapted for ethnic minority populations [37]. However detailed analysis of both the process and outcomes allowed us to identify some messages regarding effective approaches for increasing the acceptability and effectiveness of these interventions.

Firstly, community-based educational interventions exhibited a higher level of success in terms of verified registration than those solely reliant on 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 were individuals are required to make an immediate decision about donation. 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 addressed knowledge gaps and misconceptions about organ donation [15 30 31].

Secondly, there are questions of whether registration always represents an appropriate outcome, given that ethnic minorities and those from socio-economically deprived backgrounds are consistently shown to have more negative views, greater concerns and less knowledge about organ donation and transplantation than the general population [33-35]. Interventions should therefore consider the intermediary steps that individuals may need to pass before the desired end-point of registration can be achieved, and to 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 therefore require multiple interventions that reinforce and build upon 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 (under review) 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. 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 shows 25% of ethnic minority families of potential donors who had formally signed the donor register refuse assent [38], with current practice being to respect the wishes of the family regarding donation decisions even if this does not accord with those of the patient.

Thirdly, the review suggests that effective interventions for those in the pre-contemplation or contemplation phase are those undertaken in familiar community settings and delivered by appropriately trained lay individuals. Lay health promoters in this context have the benefit of an established rapport with the target population [36] and the potential for gradual delivery of information that can be reinforced over time.

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 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 in practice facilitating a sign up process.

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Appendix: Search strategy for Medline Ovid, 1980-2012

Database, Years Searched	Search Strategy
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*)).tw. 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. 77. 74 not 76 78. from 77 keep 16,30