

## PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form ([see an example](#)) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below. Some articles will have been accepted based in part or entirely on reviews undertaken for other BMJ Group journals. These will be reproduced where possible.

### ARTICLE DETAILS

<b>TITLE (PROVISIONAL)</b>	What are effective approaches to increasing rates of organ donor registration among ethnic minority populations; a systematic review.
<b>AUTHORS</b>	Morgan, Myfanwy; Deedat, Sarah; Kenten, Charlotte

### VERSION 1 - REVIEW

<b>REVIEWER</b>	<b>Johnson, Mark</b> DeMonfort University, Mary Seacole Research Centre
<b>REVIEW RETURNED</b>	18-Jul-2013

<b>THE STUDY</b>	<p>Some of these questions really don't apply to a Literature Review!</p> <p>Overall, I liked the paper but was very concerned at the lack of citations to UK based research. I know of at least one good paper that a cursory search of the NHS Evidence base or hand-searching key journals might have revealed: it has a very strong list of other references that would make this paper much more informed about UK issues, at least - and might widen the rather narrow selection of 'minority ethnic' groups covered by their 'hits.</p> <p>Utilising faith communities in the UK to promote the organ donation debate: the views of UK faith leaders <i>Diversity in Health &amp; Care</i> 7,1 pp. 57-64 (2010) Authors: Randhawa, Gurch; Brocklehurst, Anna; Pateman, Ruth; Kinsella, Suzannah; Parry, Vivienne Which has in its reference list the following:</p> <p>Alkhawari FS, Stimson GV and Warrens AN (2005) Attitudes towards transplantation in UK Muslim Indo-Asians in West London. <i>American Journal of Transplantation</i> 5:1326-31.</p> <p>Callender CO, Hall MB and Miles PV (2002) Increasing living donations: expanding the National MOTTEP community grassroots model. <i>Minority Organ Tissue Transplant Education Program. Transplantation Proceedings</i> 34:2563-4.</p> <p>Daar A (1998) An overview of transplant issues in the Middle East. <i>Transplantation Proceedings</i> 30:3638.</p> <p>Darr A and Randhawa G (1999) Public opinion and perception of organ donation and transplantation among Asian communities: an exploratory study in Luton, UK. <i>International Journal of Health Promotion and Education</i> 37:68-74.</p> <p>Davis C and Randhawa G (2006) The influence of religion of organ donation among the Black Caribbean and Black African population - a pilot study in the UK. <i>Ethnicity and</i></p>
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	<p>Disease 16:281–5.</p> <p>Exley C, Sim J, Reid NG et al (1996) Attitudes and beliefs within the Sikh community regarding organ donation: a pilot study. <i>Social Science and Medicine</i> 43:23–8.</p> <p>Hayward C and Madill A (2003) The meanings of organ donation: Muslims of Pakistani origin and white English nationals living in North England. <i>Social Science and Medicine</i> 57:389–401.</p> <p>Khan Z and Randhawa G (1999) Informing the UK's South Asian communities on organ donation and transplantation. <i>EDTNA (European Dialysis and Transplant Nurses Association) and ERCA (European Renal Care Association) Journal</i> 25:12–14.</p> <p>Morgan M, Hooper R, Mayblin M et al (2006) Attitudes to kidney donation and registering as a donor among ethnic groups in the UK. <i>Journal of Public Health</i> 28:226–34.</p> <p>Randhawa G (1998a) The impending kidney transplant crisis for the Asian population in the UK. <i>Public Health</i> 112:265–8.</p> <p>Randhawa G (1998b) An exploratory study examining the influence of religion on attitudes towards organ donation among the Asian population in Luton, UK. <i>Nephrology Dialysis Transplantation</i> 13:1949–54.</p> <p>Randhawa G (2008) Organ donation and transplantation – the realities for minority ethnic groups in the UK. In: Weimar W, Bos MA and van Busschbach JJ (eds) <i>Organ Transplantation: ethical, legal and psychosocial aspects. Towards a common European policy</i>. Lengerich, Germany: Pabst Science Publishers.</p> <p>Randhawa G (2010) Renal health disparities in the United Kingdom: a focus on ethnicity. <i>Seminars in Nephrology</i> 30:8–11.</p> <p>Razaq S and Sajad M (2007) A cross-sectional study to investigate reasons for low organ donor rates amongst Muslims in Birmingham. <i>Internet Journal of Law, Healthcare and Ethics</i> 4:2.</p> <p>(apologies for lack of formatting)</p>
<b>RESULTS &amp; CONCLUSIONS</b>	<p>Need more context for UK/EU situation at least, and probably a bit more for N America too, although I am less familiar with that setting.</p> <p>Overall, I, like the authors, was struck by the poor quality of the papers that they located in their systematic search: I think they might like to consider the work of Netto et al, and Bhopal's team at Edinburgh (Liu et al, Davidson et al) who found a similar lack of rigour and theory in health promotion aimed at minority ethnic groups (in relation to smoking, drink and exercise).</p> <p>see <i>Adapting health promotion interventions to meet the needs of ethnic minority groups: mixed-methods evidence synthesis</i>. <i>Health Technol Assess</i> 2012; 16(44). (Liu JJ, Davidson E, Bhopal RS, White M, Johnson MRD, Netto G, et al. ) Published November 2012.</p>
<b>REPORTING &amp; ETHICS</b>	<p>Might possibly have referred to the PROGRESS+ criteria used by the Cochrane and Campbell 'Equity' strand teams?</p>
<b>GENERAL COMMENTS</b>	<p>I liked and value this paper, but felt it could be a lot stronger if it were to try and look at some of the 'grey' literature or papers in less prestigious (and less highly selective) databases! The published materials covered describe a very limited range of ethnic groups and faiths (African American churches, Hispanic, and 'native spiritism'), and seem to have overlooked for example the work of Orin Lewis</p>

	<p>and the ACLT (bone marrow, not organ, I accept) as well as Randhawa!</p> <p>That said, most of the findings and conclusions I am happy to agree and support!</p> <p>NB page 9 of 26, lines 19-23 seems to be a missing sentence or half of one? and line 38 were should be where?</p> <p>in references, please check placement of the apostrophe in Morgan &amp; Cannon citation?</p> <p>and was it american indian lower case in Fahrenwald?</p>
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<b>REVIEWER</b>	<b>Thornton, Daryl</b> Associate Professor Case Western Reserve University
<b>REVIEW RETURNED</b>	23-Jul-2013

<b>GENERAL COMMENTS</b>	<p>This is a systematic review of studies conducted in North American and the UK to increase organ donor registration and/or improve knowledge about organ donation among ethnic minorities.</p> <p>Major Comments:</p> <ol style="list-style-type: none"> <li>1.This is an important topic as highlighted by the authors in the introduction. A fact that might further emphasize the importance of the topic is that in the USA, the majority of those waiting for organs are ethnic minorities.</li> <li>2.The study question as stated in the title is quite clear. However, the authors do not sufficiently cite evidence demonstrating that increased organ donor knowledge is in the causal pathway to increased organ donor registration rates for ethnic minorities. If it is in the causal pathway, is it more important than other factors that influence donor registration? Equally unclear is what type of knowledge is most important -- knowledge regarding the process of donation, the need for donation, and/or the relative lack of donation among ethnic minorities? The effectiveness of the interventions mentioned may be influenced significantly by the emphasis placed on these variables.</li> <li>3.The authors state that interventions with interpersonal components were most likely to be effective, but there is no meta-analysis or other form of pooled analysis to support that claim. Indeed, the authors cite a study that did not use interpersonal intervention that was also effective. What made this study different but still effective?</li> <li>4.There is not enough detail regarding the quality of the included studies. Were the</li> </ol>
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	<p>randomized studies blinded? Were the CONSORT guidelines for cluster randomized trials followed? Could the GRADE guidelines be used? In other words, if one were to use this study to design an intervention among ethnic minorities, what factors should be included and what should not and what is the strength of the evidence backing that claim?</p> <p>5.The authors raise the concern that donor registration may not be an appropriate outcome measure for some members of the population as many people are less knowledgeable about organ donation. This statement seems confusing if the goal is to increase the availability of organs for those in need and donor registration is the only means to legally do so. Couldn't interventions target both knowledge and donor registration (i.e. informed donor registration which presumes sufficient knowledge to make an enlightened decision)?</p> <p>6.Figure 2 details the selection process of the included studies. It would be nice to have more detail regarding each of the databases searched and what studies were found from each database.</p> <p>7.Were the databases of dissertations and study abstracts also queried?</p> <p>Minor Comments:</p> <ol style="list-style-type: none"> <li>1. The references are not correct in the tables. For example, Radosevich's work is listed as reference 14, but in table 1, page 16, this manuscript is listed as reference 13.</li> <li>2. Reference 15 has the first name of the author listed instead of last name followed by first initial.</li> </ol>
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### VERSION 1 – AUTHOR RESPONSE

We thank Mark Johnson for his comments on the paper. We outline our responses to each of his comments below.

The lack of citations of UK based research is due to a lack of available studies from either the academic or grey literatures that fulfil the inclusion criteria used in this paper. The focus of this review is specifically the evaluation of reported interventions designed to change rates of registration, intention/willingness to become a donor or to change knowledge about organ donation among ethnic minorities in North America or the UK (Additionally wider community based intervention studies were included if sub group analysis by ethnicity was conducted).

We were aware of most of the papers suggested by Mark Johnson and have cited many in publications relating to attitudes to organ donation among ethnic minorities. However they fall outside the inclusion criteria for this systematic review as they do not report interventions. Broadly, these papers employ mostly qualitative methods to identify attitudes and barriers relating to organ donation. We have provided a reason for non-inclusion for each of the suggested studies (unformatted

references) below.

Reason for non-inclusion for each recommended study:

1. Utilising faith communities in the UK to promote the organ donation debate: the views of UK faith leaders *Diversity in Health & Care* 7,1 pp. 57-64 (2010) Randhawa, Gurch; Brocklehurst, Anna; Pateman, Ruth; Kinsella, Suzannah; Parry, Vivienne. This is not an intervention study. It is a qualitative study reporting interviews with leaders of the main UK faiths who discuss a range of issue relating to organ donation

2. Alkhawari FS, Stimson GV and Warrens AN (2005) Attitudes towards transplantation in UK Muslim Indo-Asians in West London. *American Journal of Transplantation* 5:1326–31. This is not an intervention study. This paper reports the findings of a qualitative study reporting data collected via interviews, focus groups and observation of the attitudes 'Muslim Indo-Asians' in the UK to organ donation.

3. Callender CO, Hall MB and Miles PV (2002) Increasing living donations: expanding the National MOTTEP community grassroots model. *Minority Organ Tissue Transplant Education Program. Transplantation Proceedings* 34:2563–4. This study focuses on living donation and is therefore outside the inclusion criteria that is limited to deceased donation.

4. Daar A (1998) An overview of transplant issues in the Middle East. *Transplantation Proceedings* 30:3638. This is not an intervention study.

It is a short commentary paper which argues transplantation is poorly understood in Middle Eastern countries.

5. Darr A and Randhawa G (1999) Public opinion and perception of organ donation and transplantation among Asian communities: an exploratory study in Luton, UK. *International Journal of Health Promotion and Education* 37:68–74. This is not an intervention study. It is a qualitative study using interviews and focus groups to examine issue pertinent to organ donation among Asian communities.

6. Davis C and Randhawa G (2006) The influence of religion of organ donation among the Black Caribbean and Black African population – a pilot study in the UK. *Ethnicity and Disease* 16:281–5. This is not an intervention study.

This is a qualitative study using focus groups to examine the influence of religion on attitudes toward organ donation among Black Caribbean and Black African populations.

7. Exley C, Sim J, Reid NG et al (1996) Attitudes and beliefs within the Sikh community regarding organ donation: a pilot study. *Social Science and Medicine* 43:23–8. This is not an intervention study. This paper aims to identify attitudes towards organ transplantation and views towards Dept of Health campaign materials among Muslims of Pakistani origin compared with white English nationals.

8. Hayward C and Madill A (2003) The meanings of organ donation: Muslims of Pakistani origin and white English nationals living in North England. *Social Science and Medicine* 57:389–401. This is not an intervention study. The meanings of donation are explored via focus groups conducted with Muslims of Pakistani origin and white English nationals.

9. Khan Z and Randhawa G (1999) Informing the UK's South Asian communities on organ donation and transplantation. *EDTNA (European Dialysis and Transplant Nurses Association) and ERCA (European Renal Care Association) Journal* 25:12–14. This is not an intervention study. It is a short commentary that describes informal networks as major sources of information on transplantation and

donation.

10. Morgan M, Hooper R, Mayblin M et al (2006) *Journal of Public Health* 28:226–34. This is not an intervention. This is a questionnaire study identifying attitudes to kidney donation and registering as a donor among different ethnic groups in the UK.

11. Randhawa G (1998a) The impending kidney transplant crisis for the Asian population in the UK. *Public Health* 112:265–8. This is not an intervention study. The paper is a commentary on the increasing demand for a limited supply of suitable organs in the Asian population.

12. Randhawa G (1998b) An exploratory study examining the influence of religion on attitudes towards organ donation among the Asian population in Luton, UK. *Nephrology Dialysis Transplantation* 13:1949–54. This is not an intervention study. The paper is a qualitative using focus groups and interviews to examine the influence of religious beliefs on attitudes to organ donation among the Asian population.

12. Randhawa G (2008) Organ donation and transplantation – the realities for minority ethnic groups in the UK. In: Weimar W, Bos MA and van Busschbach JJ (eds) *Organ Transplantation: ethical, legal and psychosocial aspects. Towards a common European policy*. Lengerich, Germany: Pabst Science Publishers. This is not an intervention study. This chapter is a commentary on issues associated with minority ethnic organ donation and transplantation.

13. Randhawa G (2010) Renal health disparities in the United Kingdom: a focus on ethnicity. *Seminars in Nephrology* 30:8–11. This is not an intervention study. This is paper is a commentary about the inequalities in diabetes and renal services.

14. Razaq S and Sajad M (2007) A cross-sectional study to investigate reasons for low organ donor rates amongst Muslims in Birmingham. *Internet Journal of Law, Healthcare and Ethics* 4:2. This is not an intervention study.  
This is a questionnaire study to identify barriers to organ donation among Muslims.

I think they might like to consider the work of Netto et al, and Bhopal's team at Edinburgh (Liu et al, Davidson et al) who found a similar lack of rigour and theory in health promotion aimed at minority ethnic groups (in relation to smoking, drink and exercise).

Adapting health promotion interventions to meet the needs of ethnic minority groups: mixed-methods evidence synthesis. *Health Technol Assess* 2012; 16(44). (Liu JJ, Davidson E, Bhopal RS, White M, Johnson MRD, Netto G, et al. ) Published November 2012

Thank you for bringing this to our attention we have included a reference to this very interesting report which we have cited end page 11.

Possibly have referred to the PROGRESS+ criteria used by the Cochrane and Campbell 'Equity' strand teams?

Thank you for bringing these to our attention. However, in the context of this review we did not feel the focus of the interventions was about inequalities, and therefore do not think the guidance is appropriate for this review.

I liked and value this paper, but felt it could be a lot stronger if it were to try and look at some of the 'grey' literature or papers in less prestigious (and less highly selective) databases! The published materials covered describe a very limited range of ethnic groups and faiths (African American churches, Hispanic, and 'native spiritism'), and seem to have overlooked for example the work of Orin Lewis and the ACLT (bone marrow, not organ, I accept) as well as Randhawa!

As outlined in our search strategy (see Box 1) we undertook an extensive search of the grey literature. We are aware of the important work for ACLT but from the information we found none of their drives to increase bone marrow donors were evaluated interventions. Randhawa's work is well known to the authors as he is a member of wider research programme. However, none of his work was included in this review as it did not meet the inclusion criteria in terms of reporting an evaluated intervention. Randhawa's work has been included in our other review of the barriers to organ donation for ethnic minorities which was recently published in the journal Ethnicity & Health.

With regard to your second point about a limited range of ethnic groups focused on – we did not restrict the search by any particular ethnic group. All non-white visible minorities in the UK and USA were eligible for inclusion. The groups represented in the intervention studies identified reflect the focus of the current body of research. We also went to considerable lengths to include appropriate search terms relating to ethnicity and sought advice from an experienced information specialist. (A full list of the search terms used can be found in the appendix from page 16 onwards.)

NB page 9 of 26, lines 19-23 seems to be a missing sentence or half of one? and line 38 were should be where?

Thank you for alerting us to this we have now rectified the sentence.

In references, please check placement of the apostrophe in Morgan & Cannon citation?

Thank you this has now been rectified.

Was it american indian lower case in Fahrenwald?

We have amended this in the paper to: American Indian.

We thank J. Daryl Thornton for comments on the paper. We outline our responses to each of his comments below.

1. This is an important topic as highlighted by the authors in the introduction. A fact that might further emphasize the importance of the topic is that in the USA, the majority of those waiting for organs are ethnic minorities.

We have now amended the first paragraph and cited 2013 data from \*Organ Procurement and Transplantation Network (OPTN).

Data as of May 10, 2013 <http://organdonor.gov/minortyaa/index.html>

2. The study question as stated in the title is quite clear. However, the authors do not sufficiently cite evidence demonstrating that increased organ donor knowledge is in the causal pathway to increased organ donor registration rates for ethnic minorities. If it is in the causal pathway, is it more important than other factors that influence donor registration? Equally unclear is what type of knowledge is most important - knowledge regarding the process of donation, the need for donation, and/or the relative lack of donation among ethnic minorities? The effectiveness of the interventions mentioned may be influenced significantly by the emphasis placed on these variables.

We have added greater detail in the results sections about what aspects of knowledge appeared to predict willingness to donate among ethnic minorities, and have also cited extensive literature showing that knowledge is identified as an important factor in influencing registration. Greater detail has now also been provided about what aspects of knowledge were significant predictors of registration intention. Table 4 has also been updated to provide greater information about knowledge variables for the included studies. However from this review it is not possible to determine what type

of knowledge is most important, and we have now identified this as an area for future studies to address.(see knowledge section page 8/9 and page 12 discussion last para)

3.The authors state that interventions with interpersonal components were most likely to be effective, but there is no meta-analysis or other form of pooled analysis to support that claim. Indeed, the authors cite a study that did not use interpersonal intervention that was also effective. What made this study different but still effective?

We were trying to convey the point that interpersonal components were one of a number of elements that were associated with a successful intervention. We have edited the paragraph in the discussion to reflect this sentiment (Paragraph 3 page 11).

4.There is not enough detail regarding the quality of the included studies. Were the randomized studies blinded? Were the CONSORT guidelines for cluster randomized trials followed? Could the GRADE guidelines be used? In other words, if one were to use this study to design an intervention among ethnic minorities, what factors should be included and what should not and what is the strength of the evidence backing that claim?

We have extensively increased the explanation of our quality assessment criteria (see section Relevance and Quality Assessment pages 5-6)We used the Cochrane suggested tool for assessing the quality of public health and health promotion interventions and also included quality criteria adapted from the Medical Research Council guidance for complex interventions. In terms of the cluster randomised trials none of the authors specifically state that they followed the CONSORT Guidance.

5.The authors raise the concern that donor registration may not be an appropriate outcome measure for some members of the population as many people are less knowledgeable about organ donation. This statement seems confusing if the goal is to increase the availability of organs for those in need and donor registration is the only means to legally do so. Couldn't interventions target both knowledge and donor registration (i.e. informed donor registration which presumes sufficient knowledge to make an enlightened decision)?

In the discussion we have further developed our argument to explain why immediate registration may not be the most appropriate assessed outcome for all individuals (3 paragraph page 11)

6.Figure 2 details the selection process of the included studies. It would be nice to have more detail regarding each of the databases searched and what studies were found from each database.

In Table 1 we have now added a column showing which databases papers were identified from.

7.Were the databases of dissertations and study abstracts also queried?

These were not queried as we wanted to identify trials. Instead we queried the following UKCRN: <http://public.ukcrn.org.uk/search/> (UKCRN replaced the NRR National Research Register)  
Clinicaltrials.gov, <http://www.controlled-trials.com/mrct/>  
WHO International Clinical Trials Registry Platform: <http://www.who.int/ictrp/en/>  
Clinical trials.gov (US registry) <http://www.clinicaltrials.gov/>  
You could also try: HSRProj (Health Services Research Projects in Progress which gives information about ongoing health services research and public health projects)  
[http://wwwcf.nlm.nih.gov/hsr\\_project/home\\_proj.cfm](http://wwwcf.nlm.nih.gov/hsr_project/home_proj.cfm)



Minor Comments:

1. The references are not correct in the tables. For example, Radosevich's work is listed as reference 14, but in table 1, page 16, this manuscript is listed as reference 13.

This has been rectified.

2. Reference 15 has the first name of the author listed instead of last name followed by first initial.

This has been rectified.