

BMJ Open Barriers towards organ donor registration and consent among people of Indian origin living globally: a systematic review and integrative synthesis – protocol

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ABSTRACT

Introduction The need for organs is comparatively higher among people of Indian origin due to the higher prevalence of end-stage organ failure. In spite of the higher need, they have a lower number of organ donors. Studies have been carried out among people of Indian origin living globally to understand the reasons for the low donation rate, but there has been no systematic review that has integrated all of these studies to synthesise the current literature. Therefore, the purpose of this review is to examine the barriers towards organ donor registration and consent among Indians living globally.

Methods and analysis A systematic search will be conducted using the following relevant databases namely CINHALL, MEDLINE, PsycINFO, Scopus, Web of Science, PubMed Central, Global Health and Grey literature. Studies from 1994 that satisfy our inclusion criteria will be included. Two reviewers will conduct the screening, data extraction and quality assessment of the studies; in event of any disagreement between the two reviewers at any stage, the third reviewer will reconcile any disagreements and consensus will be made.

Ethics and dissemination As this study includes only secondary data, ethical approval for secondary data usage has been sought. This study will use Preferred Reporting Items for Systematic Review and Meta-Analysis guidelines to report and the study outcomes will be disseminated through a relevant peer-review publication, related conferences and also to various non-governmental organisations globally which are working with this particular community; following which further research can be developed based on this evidence and also helps in building a culturally competent strategy.

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INTRODUCTION

The need for an organ transplant is mainly due to the end-stage organ failure majorly caused by non-communicable diseases (NCD) such as diabetes and hypertension.^{1 2} This is highly prevalent among people of Indian origin.^{3–5} The higher prevalence of NCD such as diabetes and hypertension among people

Strengths and limitations of the study

- Using integrative synthesis is one of the strengths of this systematic review as it gives the power to combine both quantitative and qualitative studies to have a better understanding of the research question.
- Relevant quality appraisal adds strength to this study to generate a strong and high-quality outcome.
- Review with other authors helps in the consistency of the outcomes in the study.
- Limiting articles to only written in English may serve as a drawback to this study.

of Indian origin gives them a greater likelihood on the need for organs.⁶ This high need for organs is contrasted with poor donation rates within the same community. In India, 220 000 of the population suffer from end-stage renal failure and wait for an organ, but only 15 000 of these people receive one, others die while waiting or become unfit for a transplant and it is a similar situation with the liver, where an estimation of 100 000 of the population suffers from end-stage liver disease and requires an organ transplant, but only less than 1000 of these people ever receive one.⁷ This shows the gap between demand and supply. Also, the shortage of organs is high in India similar to the other parts of the world.^{8 9} The national organ donation rate (ODR) is 0.8 per million population (pmp) ranging from 41.69 pmp to 0.04 pmp across the country.⁹

Interestingly, a similar pattern can be observed in many other countries, such as the UK, where people of Indian origin are disproportionately over-represented on the transplant waiting list and less likely to become organ donors or be present on the organ donor register.¹⁰ This shows the similarity that exists between people of Indian



origin living in India and the UK in the context of organ donation. Given the ethnic diversity of the UK population, it is important to seek culturally competent solutions.¹¹

In countries where there is an opt-in system for procuring organs, either the deceased should have registered to donate organs or the next of kin should give consent to retrieve organs after the death has occurred. These countries require a good level of information regarding organ donation among the public, since they can donate only if they are aware of organ donation and have a positive attitude which ultimately helps in the improvement of the ODR in this community.^{12 13}

There have been many studies conducted on organ donation among varied communities within people of Indian origin.^{14–36} However, to date, there has been no integration of these studies (searched the following databases such as CINHALL, MEDLINE, PsycINFO, Scopus, Web of Science, PubMed Central, Global Health and Google Scholar using the search string (“Organ Donation” AND “India*” AND “Systematic Review” OR “Scoping Review”). Therefore, this systematic review would help in collecting and collating all of the studies on this topic to understand the barriers towards organ donor registration and consent among people of Indian origin living globally.

A systematic review was proposed as there are many studies available,^{14–36} specific research question, transparent and explicit methods to critically appraise the individual studies,³⁷ more systematic and rigour protocols followed, attempts to validate all the studies that meet the eligibility criteria and also validate the findings of the study through quality appraisal,³⁸ better quality conclusions can be made on this topic when compared with a scoping review,³⁹ a clear understanding and strong evidence can be generated that will be useful for the stakeholders involved in this field.³⁸

This systematic review will be conducted on studies undertaken among the people of Indian origin living globally. This study will map the evidence on the barriers towards organ donor registration and consent. Hence, through this systematic review, the literature/evidence present on this topic will be critically appraised and some informative conclusions can be made, based on which further research can be carried out by identifying the gaps and can be used by stakeholders to make evidence-based policy decisions to inform culturally competent organ donation information initiatives. This study will also generate information that will help governments, policymakers, non-governmental organisation (NGO) and research groups working towards the improvement of ODR among people of Indian origin.

Research question

What are the barriers towards organ donor registration and consent among people of Indian origin living globally?

METHODS AND ANALYSIS

Protocol

The protocol for this systematic review is designed as per the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) Protocol.⁴⁰ The reporting of this systematic review will follow PRISMA guidelines⁴¹ in order to ensure high calibre of this review.

Patient and public involvement

No patients and public were involved in the design of the protocol.

Inclusion criteria

The inclusion criteria for this systematic review are

1. Population: this review will include people of Indian origin living globally of aged 18 years or older.
2. Settings: studies conducted in any settings such as public, educational institutes (both healthcare and non-healthcare related), hospital, NGO, workplace, religious community and any public gathering will be included.
3. Study design: this review will include cross-sectional studies and qualitative studies; commentary articles that address the aim.
4. Type of donation: this review will include studies related to deceased organ donation.
5. Language of publication: the language of the articles should be in English.
6. Outcome: any barriers that may include knowledge: on organ donation/law/waiting list/registration; attitude: willingness to be a donor/willingness to talk with family members/conversation on organ/worries and concerns towards organ donation; religious views/cultural practices/norms towards organ donation/political framework/manpower/organogram or others that serve to be barriers will be included.
7. This review will include studies from 1994 to 31 December 2019. This time period has been chosen as 1994 appears to be the year when the first studies regarding organ donation and people of Indian origin started to get published.

Exclusion criteria

1. Studies conducted among other Indian ethnic group such as America’s native Indians or Red Indians
2. Any studies with participants not to be considered relating to the country India.
3. Articles not peer reviewed.
4. Interventional studies in regards to organ donation.

Search strategy

The search words that will be used for capturing the studies include the following related terms: organ tissue donation, Consent, India*, barrier*, facilitat*, knowledge, awareness, attitude, perception, practice, cultur*, religio*, brain death. Relevant truncation commands, Boolean and proximity operators will be used while searching with the help of a librarian expert. The final search strategy will be documented and the number

of articles included in each level will be recorded. The search strategy has been tested for replicability. This will also be altered in relevance to the database. The search strategy in respect to PubMed for this protocol can be found in the online supplementary file 1 (see additional file 1).

Information sources

The following databases such as CINHAI, MEDLINE, PsycINFO, Scopus, Global Health, Web of Science and PubMed Central will be used for a comprehensive literature search. Additional literature will be gathered from *Indian Journal of Transplantation* and individually contacting the relevant authors and experts in the field of organ donation for published and peer-reviewed manuscripts.

Data management and selection process

Using the above-mentioned databases, the literature will be exported to RefWorks (<https://refworks.proquest.com/>). For further scrutiny for eligibility, excel sheets will also be used to manage literatures and filter the studies based on each stage. Two reviewers will work independently to screen the title and abstracts based on the inclusion criteria (stage 1). Any missed duplicates will also be identified and excluded. In case of abstract absence in any studies, studies will be excluded only if a strong decision can be made only based on the title of the study. After the selection of the studies based on the title and abstract, full text will be obtained. Two reviewers will independently assess the full text in order to examine whether they satisfy the inclusion criteria and answer the research question (stage 2). Before proceeding forward, if there are any disagreements between the two reviewers, a third reviewer will reconcile any disagreements and consensus will be made on the inclusion or exclusion of the respective studies. The PRISMA flow diagram will be used to define the process of studies included and excluded.⁴¹

Data collection process

A pre-designed form in excel format will be used for data extraction. Two reviewers will extract the data independently from the studies included for review finally. The form will also be pilot tested to ensure whether it captures the data that it is intended for. Any disagreements on the data extracted by the two reviewers will be reconciled by the third reviewer. The following information will be extracted from the study included for review: author name, year of publication, study site, setting of the study (in terms of rural/urban/slums/college/hospital, etc), participant socioeconomic status (if available), journal name, DOI number, study design (type of the study, study tool, sample size, sampling technique and inclusion/exclusion criteria), main findings as explained in the Data synthesis section below, limitations and other comments will be extracted.

Quality assessment

Joanna Briggs Institute's critical appraisal tools will be used to assess the quality for quantitative studies. This enables us to assess the quality of all types of research published including both quantitative and qualitative methods.⁴² Two reviewers will undertake the quality assessment using the tools mentioned above independently. If there are any disagreements over the quality of the study, it would be referred to the third author and consensus would be made. The quality of the paper will be classified as thin, moderate and strong. The emphasis will be given based on the quality of the study. The thin-quality studies will be included but emphasis will be very minimal in regards to such studies. Also the quality assessment of the final paper included for review will be displayed.

Data synthesis

Data synthesis will be based on narrative synthesis developed by Popay *et al.*⁴³ The synthesis will follow the method of narrative synthesis that has four steps, namely: (1) systematic search and quality appraisal, (2) grouping and clustering of included studies, (3) developing a textual summary of the data and (4) assessment and interpretation. Narrative synthesis is a flexible approach giving freedom to include both quantitative and qualitative studies. Initially, the synthesis will be separate for quantitative and qualitative studies after which they would be integrated. For quantitative studies, the findings will be tabulated and indexed in terms of types of barriers. Later each study will be compared across to learn how they are related. This will produce a descriptive synthesis of quantitative studies. For qualitative studies, a similar approach will be taken where the synthesis will be descriptive, where the data would be coded and themes will be generated. The data captured from quantitative studies will be identified and provided for the initial framework, and the data from qualitative studies will be used to elaborate and develop explanation descriptively.^{44 45}

DISCUSSION

This will be the first systematic review that will synthesise the barriers towards organ donor registration and consent among people of Indian origin living globally. The strength of this study is the combination of quantitative and qualitative studies using the narrative synthesis as proposed by Popay *et al.*⁴³ This will enable a better understanding of the low organ donation rate problem, based on the available research.

This will be an important step forward in collectively understanding this population that will help identify any research gaps and inform future research. Through this systematic review, we will also be able to gather evidence to aid policymakers to frame culturally competent strategy according to the need of this particular population.

The limitation of this review is the heterogeneity of the studies and settings. Also, this study does not aim to generalise the outcome of the studies but will present the

available knowledge regarding the barriers towards organ donor registration and consent among this population.

ETHICS AND DISSEMINATION

The study is approved by the Institute for Health Research Ethics Committee (IHREC), University of Bedfordshire, UK (IHREC931). It is expected to be completed by the end of June 2020. The study outcomes will be disseminated through a relevant peer-review publication, related conferences and also to various NGOs globally working with this community with a view to showing the barriers among people of Indian origin living globally; following which further research can be developed based on this evidence and also help in building a culturally competent strategy.

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Contributors BPV drafted the protocol. The protocol was then reviewed and revised in consultation with GR and EC. All authors have read and approved the protocol. The corresponding author guarantees the paper and that the statement of authorship is correct.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

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