

BMJ Open

BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (<http://bmjopen.bmj.com>).

If you have any questions on BMJ Open's open peer review process please email info.bmjopen@bmj.com

BMJ Open

Barriers toward deceased organ donation among Indians living in India and the United Kingdom: An integrative systematic review using narrative synthesis.

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2021-056094
Article Type:	Original research
Date Submitted by the Author:	03-Aug-2021
Complete List of Authors:	Vincent, Britzer Paul; University of Bedfordshire Faculty of Health and Social Sciences, Institute for Health Research Randhawa, Gurch; University of Bedfordshire, Institute for Health Research Cook, Erica; University of Bedfordshire, Department of Psychology
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, ETHICS (see Medical Ethics), TRANSPLANT MEDICINE

SCHOLARONE™
Manuscripts



I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our [licence](#).

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which [Creative Commons](#) licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

1
2
3 **Title:** Barriers toward deceased organ donation among Indians living in India and the United
4
5 Kingdom: An integrative systematic review using narrative synthesis.
6
7

8 **Abstract**
9

10 **Objectives:** To understand the barriers toward deceased organ donation among Indians living
11 globally. However, the studies reviewed were only among Indians living in India and UK, due
12 to methodological issues. Therefore, this review is based only among Indians living in India
13 and UK.
14
15

16 **Design:** Integrative systematic review using narrative synthesis
17
18

19 **Data sources:** CINAHL, MEDLINE, PsycINFO, Scopus, Global Health, Web of Science, and
20 PubMed Central, Indian Journal of Transplantation and Google scholar.
21
22

23 **Participants:** Individuals of Indian origin living in India and UK.
24
25

26 **Results:** Sixty-one studies were included with more than 20,000 participants and quality was
27 assessed using Joanna Briggs Institute's critical appraisal tool. Though majority of the
28 participants had knowledge toward organ donation with a positive influence on willingness,
29 the gap between knowledge and willingness was huge, with minimal registration. The findings
30 showed that organ donation behaviour among this particular population is influenced by the
31 complex interactions between the individual and the socio-cultural constructs. Various
32 constructs of the society such as fear and mistrust, family, religion, bodily issues play a vital
33 role. Also, differences in willingness to donate and registration were identified between
34 southern and other regions of India.
35
36
37
38
39
40
41
42
43
44
45
46
47
48

49 **Conclusion:** Though this study showed the complex relationship, and its influences on organ
50 donation behaviour, lacunae were identified to further understand how such complex
51 interactions determine or inform the behaviour. Also, methodological issues were identified,
52 where this particular population outside India were collectively studied with their neighbouring
53 population which are not homogenous. Studies in India majorly addressed a similar aim using
54
55
56
57
58
59
60

1
2
3 similar methods which produced repetition of studies leading to lack of diversified, wider, and
4
5 in-depth research. Therefore, while this systematic review addressed the barriers toward organ
6
7 donor registration among Indians in India and UK, it also informs various gaps in research and
8
9 also methodological issues.
10
11

12 **PROSPERO registration number:** CRD42019155274
13

14 **Keywords:** Organ donation, Indians, UK, Integrative systematic review; Narrative synthesis,
15
16
17 Registration
18
19

20 **Strengths and Limitations:**
21

- 22
- 23 1. This is the first systematic review about barriers toward deceased organ donation
24 among Indians living in India and UK, registered with PROSPERO, and published.
25
 - 26 2. Both quantitative and qualitative studies were included to address the aim of the review
27 using integrative approach and narrative synthesis, an appropriate methodology.
28
 - 29 3. Included studies that exclusively represented the Indian population and excluded
30 studies that collectively studied with the heterogenous South Asian or Asian population,
31 thereby keeping the rigour of this study and identifying methodological issues involved.
32
 - 33 4. Findings are based on the quality of each studies appraised using appropriate tools, and
34 the assessment is also made available to the view of the readers.
35
 - 36 5. Studies were limited only to English language, and commentaries were excluded.
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Main text

Introduction

Since the first deceased organ transplantation performed by Joseph Murray in 1960s, the science of transplantation has witnessed exponential growth [1]. However, the gap between demand and supply of organs has represented a significant challenge [2], particularly among the Asian population who live both within and outside their continent [3-5]. India located in the South of Asia is the second largest populous country in the world [6] having largest migrating population in Asia [7], and also has the highest prevalence of diabetes, hypertension, and many other comorbidities [8]. Such non-communicable diseases (NCD) among Indians [9, 10] leading them to end-stage organ failure [11, 12] increases their need for organs.

Whilst the need for organ donors is high among the Indian population, the actual number of donors remain too low to satisfy the number of recipients on the waiting list [13], with the Indian national organ donation rate (ODR) less than one per million population (pmp) [14]. Reluctance to donate organs among this ethnic population might not be isolated just within Indian border [15], with evidence suggesting that Indian population from the United Kingdom is also disproportionately impacted, where they continue to be over-represented in the recipient waiting list but under-represented in the donor list [16]. Therefore, both in India and UK, people of Indian origin show higher reluctance to organ donation which is reflected both in registration and consent.

There have been a larger number of studies conducted among the Indian population living globally to understand the factors that influence organ donor registration. However, to date, there has been no systematic review conducted to synthesize the available evidence to understand the barriers toward organ donor registration among the individuals of Indian origin.

1
2
3 Therefore, a systematic review was proposed with an aim to address this gap to gain a deeper
4 insight into the barriers toward organ donor registration among this particular population [17].
5
6
7

8
9 The protocol proposed to include Indians living globally [17], but this review represents Indian
10 population living only in India and UK. There had been studies globally that had included
11 Indian ethnic group to examine the barriers of organ donation. However, many of them did not
12 report the results exclusively for Indians but rather combined this population with those from
13 other Asian countries and few had no sufficient findings, therefore excluded. However, on the
14 other side, two studies were included from UK that had the potential to be included. Therefore,
15 this systematic review will address the barriers toward organ donor registration among the
16 Indian population living in Indian and UK, identify gaps in evidence to further research and
17 help stakeholders in furthering strategies to improve organ donation.
18
19
20
21
22
23
24
25
26
27
28
29

30 **Method**

31 **Protocol and registration**

32
33 This systematic review's protocol has been registered in PROSPERO (CRD42019155274) and
34 also published [17].
35
36
37
38
39

40 **Systematic search**

41
42 Search strategy was developed collaboratively with the research team and a subject specialist
43 librarian. Databases namely CINAHL, MEDLINE, PsycINFO, Scopus, Global Health, Web
44 of Science, and PubMed Central were utilised along with other sources such as Indian Journal
45 of Transplantation and Google scholar. Key words and MeSH terms related to organ donation
46 were first identified from studies published along with search terms used in other systematic
47 review on organ donation [18,19] and were tested in different combinations in the
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 forementioned databases. Final search terms and search string was confirmed seeking to
4 capture the most appropriate studies to answer the aim of this review (supplementary file 1).
5
6
7

8 The systematic review included studies with individuals of Indian origin living both within and
9 outside India (i.e., migrant / first / second generation), aged 18 years and above from varied
10 settings [17]. Cross-sectional and qualitative study design were included as they were mostly
11 employed to understand the barriers toward deceased organ donation. Search strategy was
12 restricted between 1st of January 1994 (i.e., the year when the first law toward organ donation
13 was implemented in India) and 30th of July 2021 (i.e., a recent day before the submission) and
14 was restricted only to studies published in English. However, interventional studies,
15 commentary or opinion papers, studies on blood, bone marrow, body, sperm, and egg donation
16 were excluded alongside any studies which addressed only living donation.
17
18
19
20
21
22
23
24
25
26
27
28
29

30 **Search outcome**

31
32 Following a stage-by-stage exclusion from 1,015 studies initially extracted, 61 studies were
33 included in final review (Figure 1). The studies were initially exported to RefWorks
34 (<https://refworks.proquest.com/>). Microsoft excel was used to keep a record of studies
35 excluded by duplicates, title, abstract, and full text. All the 1,015 studies were screened by two
36 authors independently and the final 61 studies included were in-agreement with all the authors.
37
38 However, during the process, studies conducted among Indians living outside India were
39 identified to be collectively studied as South Asians or with other Asian population. For
40 instance, a study conducted among Indo-Canadians in Canada included all neighbouring ethnic
41 groups of India [20]. In UK, Indian population was collectively studied as South-Asians [4,
42 21]. In Malaysia, though sampling was distinguished their results were not sufficiently
43 addressed [22]. However, concerning organ donation, the perspective of deceased organ
44 donation varies even within India's nearest neighbouring country [4, 23]. Therefore, this review
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 included only the studies which exclusively reported the findings from Indian population, thus
4 making this systematic review address Indians living in India and UK.
5
6
7

8 **Quality assessment**

9
10
11 Appropriate critical appraisal tools from Joanna Briggs Institute (JBI) were used to critique the
12 rigour of each studies included [24], also used in other organ donation systematic review
13 [18,25]. Comprehensive reporting on the quality assessment for both cross-sectional and
14 qualitative studies are reported in figure 2. Quality assessment was initially carried out by the
15 primary researcher after which it was reviewed by the other two authors independently. Both
16 the authors along with the primary researcher agreed upon the quality assessment as mentioned
17 in figure 2. The review included all studies; however minimal emphasis was given for those
18 studies that demonstrated only fewer items in the quality assessment checklist.
19
20
21
22
23
24
25
26
27
28
29

30 **Data synthesis**

31
32
33 This systematic review followed an integrative review with narrative synthesis approach
34 enabling to synthesise complex information toward the phenomena of interest [26], a
35 methodology also employed in another systematic review on organ donation that reviewed both
36 quantitative and qualitative studies [19]. Narrative synthesis primarily depends on words and
37 texts to summarise the findings with four process elements such as 1) systematic search and
38 quality appraisal, 2) grouping and clustering of the studies reviewed, 3) text summary
39 development, and 4) assessment and interpretation [27].
40
41
42
43
44
45
46
47
48
49

50 Firstly, following the systematic search and quality appraisal, summary data was collected for
51 each study, and they were recorded across a table which had information needed to cluster the
52 studies to compare and study across (Table 1). Secondly, with the cross-sectional studies,
53 numerical results from each study were tabulated across a matrix and were compared across to
54 study their relationship in terms of barriers. Later, full synthesis of the four qualitative studies
55
56
57
58
59
60

was undertaken by coding the findings and discussion sections using NVivo11. Codes were then organised into themes to address the barriers appropriately.

Table 1: Evidence table

Author (s) (Year)	Study Site	Study Country	Aim	Study setting	Study design	Study sample size	Sampling technique
Adithyan et al, (2017)	Kerala	India	To assess the knowledge and attitude of medical students regarding organ donation	Final year Undergraduate Medical students	Cross-sectional	194	Not specified
Ahlawat et al, (2013)	Chandigarh	India	To assess the attitude of healthcare professionals employed in intensive or emergency care units of our hospital towards organ donation, and the influence of various factors on willingness for self-organ donation after death	Health workers in intensive units	Cross-sectional	361	Not specified
Alex et al, (2017)	Karnataka	India	To assess the knowledge and attitude regarding organ donation and transplantation among the medical students	Medical college	Cross-sectional	510	Convenient sampling
Alex et al, (2019)	Pan India	India	To assess the general public's knowledge and attitude towards organ donation over two decades	General public	Cross-sectional	3914 (i.e., 1461 in group I; 2453 in group II)	Not specified
Amaliyar et al, (2019)	Gujarat	India	To assess the knowledge, attitude, and practice towards organ donation among medical, arts and commerce students	Students from last 4 semester groups from medical, arts and commerce college	Cross-sectional	300 (i.e. 100 from each college)	Purposive sampling for centres; Random for participants
Balajee et al, (2016)	Pondicherry	India	To assess the awareness and attitudes regarding organ donation among rural people from 4 villages	General public	Cross-sectional	360	Systematic random sampling and random participant selection
Balwani et al, (2015)	Gujarat	India	To study the awareness and belief towards organ donation and its allocation in chronic kidney disease patients in western India	Tertiary care centre	Cross-sectional	85	Not specified
Balwani et al, (2015)	Gujarat	India	To determine the knowledge, attitude, and practice regarding organ donation in western India	Adult participants from a residential area around a tertiary healthcare centre	Cross-sectional	200	Random sampling
Bansal et al, (2019)	Chandigarh	India	To analyse socio-demographic profile of the decision makers for organ donation in potential deceased donors//To determine the level of awareness regarding organ donation in decision makers and the correlation with the socio-demographic variables	Tertiary care teaching hospital among family members who consented to donate the organs of their loved ones	Quantitative	59	Purposive sampling

Bapat et al (2010)	Karnataka	India	To understand the awareness, attitudes, and belief towards organ donation among post-graduate medical students	Post-graduate medical students	Cross-sectional	123	Volunteer sampling
Basavaraj egowda et al (2021)	Pan India	India	To study the knowledge difference between the knowledge and attitude about organ donation among blood donors compared to non-blood donors	General public	Cross-sectional	803	Purposive sampling
Bathija et al, (2017)	Karnataka	India	To investigate the knowledge and attitude towards organ donation among post-graduates, and interns; to know the reasons for donation one's organs	Post-graduate and medical interns	Cross-sectional	300	Not specified
Bharambe et al, (2015)	Maharashtra	India	To assess the knowledge and attitude of the people living in an urban city in India towards organ donation	Out-patient department	Cross-sectional	65	Not specified
Bharambe et al, (2016)	Maharashtra	India	To study the knowledge and attitude of a medical student doing internship with regards to organ donation	Medical college internship students	Cross-sectional	43	Not specified
Bharambe et al, (2018)	Maharashtra	India	To assess the knowledge and attitude of healthcare professionals from a rural part of India regarding organ donation	Healthcare professionals attending a medical association meeting	Cross-sectional	32	Not specified
Bharambe et al, (2018)	Maharashtra	India	To assess the knowledge and attitude of people from a rural part of India regarding organ donation.	Rural community members	Cross-sectional	201	Not specified
Bhargavi et al, (2019)	Kerala	India	To check the level of awareness and attitude of 2nd year medical, dental, and nursing students at Govt. Medical College, Thiruvananthapuram Campus towards organ donation and whole-body donation using a questionnaire-based study.	Medical and nursing students	Cross-sectional	177	Convenience sampling
Chakradhar et al, (2016)	Telangana	India	To assess and compare the knowledge, attitude, and practice regarding organ donation among dental students based on gender, year of study and religion	Dental college Undergraduate students	Cross-sectional	298	Not specified
Da Silva et al (2021)	West Bengal	India	To assess the knowledge, attitude, and practices of health-care professionals toward cadaveric organ donation and to know their awareness regarding legislations pertaining to cadaveric organ donation.	Healthcare professionals	Cross-sectional	400	Stratified random sampling
Darlington et al, (2019)	Tamil Nadu	India	To study the knowledge, attitude, and practice towards organ donation	Medical students	Cross-sectional	425	Voluntary
Dasgupta et al, (2014)	West Bengal	India	To ascertain the knowledge and attitude of the people regarding organ donation and to elicit the determinants of their knowledge and attitude in an urban community of west Bengal	Slum area residents	Cross-sectional	110	Simple random sampling
Deshpande et al, (2018)	Maharashtra and Madhya Pradesh	India	To determine the knowledge, attitude, and practice of pharmacy students about organ donation	Pharmacy college	Cross-sectional	160	Not specified

Gauher et al, (2013)	London	The United Kingdom	To determine the attitude towards organ donation among Indian and Pakistan students	Medical and Non-Medical students	Qualitative	9 focus group discussion (i.e. 50 participants) and 8 Semi-structured Interviews	Purposive sampling - Stratified sampling for groups
Gupta et al, (2018)	Jammu & Kashmir	India	To assess the awareness and attitude of medical students regarding organ donation	Medical college Undergraduate students	Cross-sectional	280	Not specified
Gupta et al, (2021)	Maharashtra	India	To assess the pre-existing understanding, beliefs, perception, and attitude, about deceased organ donation	College teachers and Students	Cross-sectional	80	Purposive sampling
Jayabharathi et al, (2019)	Tamil Nadu	India	To assess the knowledge and attitude on organ donation among selected community area	Community area	Cross-sectional	60	convenient sampling
Joshi et al, (2011)	The United Kingdom	The United Kingdom	To investigate the organ donor attitudes and donor card behaviour of young adult UK citizens with particular focus on those of South Asian origin	Higher education institutes in the UK	Cross-sectional	382	Purposive sampling
Jothula et al, (2018)	Telangana	India	To assess the knowledge, attitude, and practice towards organ donation among medical students	Medical college Undergraduate students	Cross-sectional	160	Not specified
Kachappillil et al (2020)	Kerala	India	To assess the attitude of general population towards organ donation residing in a rural community	General public	Cross-sectional	100	Convenient sampling
Kadam et al (2021)	Maharashtra	India	To study the knowledge and attitude of first-year medical students towards organ donation.	First year medical students	Cross-sectional	130	Not specified
Kaistha et al, (2016)	New Delhi	India	To determine the knowledge, attitude, and practice regarding organ donation	Patient attendants attending out-patient department	Cross-sectional	119	Convenience
Kalmath et al (2020)	Karnataka	India	To assess the level of knowledge, preparedness, and commitment towards organ donation.	Youth public	Cross-sectional	300	Probability stratified random sampling
Kennedy et al, (2002)	Kerala	India	To study the attitudes and beliefs about organ donation in India from the perspectives of the doctors and the public	Doctors and public	Qualitative	8 semi-structured interviews	Purposive
Khan et al (2020)	Jammu and Kashmir	India	To know the knowledge and attitude towards organ donation amongst the students	Student population	Cross-sectional	200	Not specified
Kundu et al (2021)	Chhattisgarh	India	To investigate the willingness to become an organ donor and the religious and cultural attitude of healthcare professionals	Medical and paramedical students	Cross-sectional	630	Not specified
Mani, (2016)	Tamil Nadu	India	To identify the perceptions and practices related to organ donation in a rural population of Tamil Nadu, India	Rural population	Cross-sectional	100	Simple random sampling
Meghana et al, (2018)	Karnataka	India	To assess the knowledge of organ donation among the final year medical, dental, and nursing students and to study the attitude, religious beliefs of the healthcare professionals regarding	Medical, dental, nursing students	Cross-sectional	150	Not specified

			organ donation and transplantation, to find out the effect of motivation, towards organ donation					
7	Minz et al, (1998)	Chandigarh	India	To find out the extent of awareness and attitudes, to help us formulate a further plan of action	Healthcare professionals	Survey	204	Not specified
11	Mithra et al, (2013)	Karnataka	India	To assess the perceptions and attitudes of the people seeking health care in tertiary care centres towards organ donation in Mangalore, India.	People seeking general healthcare as outpatients	Cross-sectional	863	Simple Random Sampling and convenient sampling
15	Mohan et al, (2019)	Tamil Nadu	India	To establish the role of perceived awareness, family support, perceived individual value, and religiosity on organ donation intention	Public	Cross-sectional	247	Convenience sampling
21	Mondal et al (2016)	West Bengal	India	To assess the knowledge and attitude of people towards organ donation in a rural community of West Bengal and to study the association of socio-demographic factors with the knowledge and attitude towards organ donation	Rural community	Cross-sectional	110	Simple random sampling
27	Paul et al, (2019)	West Bengal	India	To understand the knowledge, attitude, and practice pattern of organ donation among the participants and to find out the association between the knowledge of organ donation with selected variables of interest	Urban field practice area of medical college	Cross-sectional	206	Not specified
33	Poreddi et al, (2017)	Karnataka	India	To assess the knowledge, attitude, and willingness to donate organs among the general population	Patients attending outpatient department	Cross-sectional	193	Lottery method
37	Rajan (2020)	West Bengal	India	To assess the knowledge and attitude regarding blood and organ donation among adolescents	Adolescent population	Cross-sectional	100	Non-probability purposive sampling
41	Rani et al (2020)	New Delhi	India	To assess the knowledge and attitude of general population towards organ donation	General public	Cross-sectional	1089	Purposive non-probability sampling
44	Ray et al (2020)	West Bengal	India	To assess the knowledge and attitude of certain populations like medical students with respect to organ donation	Medical students	Cross-sectional	134	Random sampling
48	Sachdeva et al, (2017)	Delhi	India	To assess knowledge, attitude, and practice regarding organ donation / tissue donation among adult visitors of a government hospital in Delhi, India	patient or accompanying attendant of a government hospital	Cross-sectional	450	Convenience sampling
53	Sam et al, (2018)	Tamil Nadu	India	To assess the awareness and attitude regarding Organ Donation among final year students of medical, dental, engineering, and arts and science students in Thirivallur and Chennai	Medical, dental, engineering, and arts and science students	Cross-sectional	486	Not specified
57	Sarveswaran et al, (2018)	Puducherry	India	To determine the knowledge, attitude, and practice regarding organ donation	Urban community members	Cross-sectional	257	Random

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60
Seetharaman et al (2020)	Maharashtra	India	To evaluate the knowledge, attitudes, and beliefs of licensed medical doctors and undergraduate medical students	Medical doctors and students	Cross-sectional	532	Non-probability convenient sampling																																																				
Singh et al, (2002)	Uttar Pradesh	India	To study level of awareness in hospital staff about transplantation, brain death, and organ donation, as well as factors that may be associated with this awareness	Hospital staffs	Cross-sectional	266 (i.e., 166 paramedics, 100 administration staff)	Simple Random Sampling																																																				
Soni et al, (2018)	Madhya Pradesh	India	To understand correlation between knowledge and attitude towards organ donation among medical and non-medical students and identify barriers to deceased organ donation; to look into participants perception for adoption of presumed consent policy in Indian context; and understanding the acceptance of donor acknowledgement in the form of organ incentivization	Medical and Engineering students	Cross-sectional	600 (i.e. 300 medical; 300 engineering students)	Random																																																				
Swamy et al (2020)	Karnataka	India	To assess the awareness and attitude of the young graduates in medical and engineering streams	Medical and Engineering students	Cross-sectional	400	Not specified																																																				
Swani et al (2020)	Uttarakhand	India	To know the awareness, perceived threat and factors affecting the willingness to donate organs	first-and second-degree relatives of deceased	Cross-sectional	166	Complete sampling																																																				
Tamuli et al, (2019)	Assam	India	To determine awareness and knowledge of educated (Undergraduate and postgraduate students) population towards organ donation; To find out factors impeding the organ donation program in this part of the country; To observe differences between findings of Undergraduate students and postgraduate degree holders (faculty)	Undergraduate and postgraduate students	Cross-sectional	360 (i.e., 180 undergraduate and 180 postgraduate students)	Not specified																																																				
Thyagarajan et al (2020)	Tamil Nadu	India	To assess the police officers' knowledge of the organ donation process and their practice toward it.	Police officers	Cross-sectional	627	Purposive sampling																																																				
Vijayalakshmi et al, (2015)	Karnataka	India	To investigate nurses' attitude towards organ donation	Nurses directly involved in patient care at a tertiary care hospital in South India	Cross-sectional	184	Non-probability convenience																																																				
Vijayalakshmi et al, (2016)	Karnataka	India	To assess the gender differences in perceptions and attitude of general population toward organ donation	Relatives of patients attending the outpatient department	Cross-sectional	193	Lottery method																																																				
Vincent et al (2019a)	Pondicherry	India	To understand the subjective views on barriers in the process of deceased organ donation among the stakeholders and their suggestions to improve in a government tertiary care teaching hospital	Transplant unit stakeholders	Qualitative	6 In-depth interviews	Purposive sampling																																																				

Vincent et al (2019b)	Pondicherry	India	To assess the knowledge, attitude, and perception on organ donation among undergraduate medical and nursing students	Under-graduate medical and nursing students	Cross-sectional	620 (i.e., 375 medical students and 245 nursing students)	Convenient sampling for population and voluntary for participants
Yadav et al (2020)	Haryana	India	To determine the knowledge and attitude of faculty members of a university	Faculty members	Cross-sectional	170	Not specified

While comparing and studying across the studies included in the review to understand their relationship, various elements such as what the study is about, type of study, their approach, the findings, study settings, and population studied were also considered. Noblit and Hare (1988) described this as 'Reciprocal translation', also used in other similar methodological approaches [28-32]. Thirdly, full syntheses of both cross-sectional and qualitative studies were studied across to understand the supporting and refuting evidence collectively. For each section of the findings, quantitative studies provided the initial context following which findings from qualitative studies were used to elaborate and explain. With limited qualitative study narratives to support or refute the cross-sectional study findings, they were incorporated into the integration of the findings wherever possible. Both convergent and divergent findings are explained in this review, whereby if divergent findings were identified explanatory factors such as type of study or setting, or population were provided to facilitate better understanding [19].

Findings

Grouping and clustering

Among the 61 studies reviewed, majority (97%) were conducted among Indians living in India (n=59) while other two studies were among people of Indian origin living in UK. Cross-sectional studies (n=57) included various settings such as general community (30%), education institutions (44%) and hospital setting (30%) (Table 1). Qualitative studies (n=4) consisted of in-depth interviews (75%) and focus group discussion (50%) (Table 1). Among the 20,340 individuals involved in the retained studies, 19,900 individuals (97.8%) were from studies

1
2
3 conducted in India. Among the studies conducted in UK, only one study distinguished 107
4 individuals as Indians, whereas the other with 60 individuals had no evidence on the sample
5 number of Indian participants involved.
6
7
8
9

10 **Findings**

11 **Integration and relationship**

12
13
14
15
16 Based on the narrative synthesis, findings are described under the following six themes namely:

17
18 1) knowledge and awareness toward deceased organ donation and registration, 2) willingness
19 and actual behaviour toward deceased organ donor registration, 3) familial influence, 4) fear
20 and mistrust, 5) religious influences, and 6) bodily issues.
21
22
23
24
25

26 **Knowledge and awareness of deceased organ donation and registration**

27
28
29 Being the commonest theme studied across, findings showed that knowledge had a positive
30 correlation with willingness and practice [33-38]. Both among Indians in India and UK, younger
31 adults, participants from higher socio-economic status, and with higher education or healthcare
32 education demonstrated higher knowledge toward deceased organ donation [39-51,79] and
33 individuals from southern region of India showed higher knowledge compared to other regions
34 in India [52-57].
35
36
37
38
39
40
41
42
43

44 Whilst majority of the studies confirmed that almost all the participants had heard about organ
45 donation (Figure 3) and had higher awareness, knew what organs can be donated [35, 47-51,
46 58-70] and that organs can be donated to anyone [40,52], the knowledge and understanding on
47 brain death was less well understood [43,55,59,60,66,71,72]. A qualitative study from an urban
48 area in the southern region of India also found brain death as a new concept for many and hard
49 to accept among the public [73]. Also, much were not aware about the organ donor card [58,
50 74-76], where and how to register and obtain an organ donor card [36,44,47,61,62,49,50] - an
51
52
53
54
55
56
57
58
59
60

1
2
3 important component for organ donor registration. In addition, knowledge on the law that
4 governs organ donation was also found to be low [36,62,75,77,78].
5
6
7

8
9 Though a study among Indians living in UK showed that disinterest, emotional distaste, family
10 opposition and religion to be the underlying cause for reluctance to register [79], among Indians
11 living in India, the awareness on brain death, organ donor card, where and how to register are
12 also important factors serving as barriers to individuals who are willing to register
13 [36,43,44,47,49,55,58,60-62,63,71,74-77,80].
14
15
16
17
18
19

20 21 **Willingness and registration toward deceased organ donation**

22
23 Greater knowledge showed positive influence on the attitude and willingness across all Indian
24 regions [37,44,75,81-85]. Similar to higher knowledge among individuals from southern region
25 of India, willingness to register, to donate and to accept organs for transplant was also shown
26 to be higher [34,39,40,43,57,59,75,81,83]. However, though knowledge had a positive
27 association toward attitude and willingness, the proportion of individuals willing to register,
28 and actual registration was very low and similar across every study included (Figure 2).
29 Correspondingly, even a study conducted among Indian students living in UK revealed that
30 55% of the individuals doubted if they would go ahead with registration [79]. With such
31 reluctance, Indians living in India and UK considered fear of misuse and family refusal as a
32 major reason, alongside minor reasons like emotional barriers, bodily issues, and religion
33 [40,47,49,54,56,60,62,63,65,66,70,78,79,82]. On contrary, commonest reasons to donate an
34 organ was to save someone's life, closely followed by elongate someone's life, social
35 commitment, altruistic deed, and that at least their deceased one's organs can live
36 [63,66,74,81,86-88].
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54

55
56 Higher proportion of participants were willing to receive compared to donating
57 [34,39,40,59,79,81,83] both among Indians from India and UK. Furthermore, studies revealed
58
59
60

1
2
3 that among those who were willing to donate, majority were only willing to donate specific
4 organs namely eye / cornea and kidneys [40,52,53], which may be related to the knowledge on
5 what organs can be donated [58-63,67-69,71]. Nonetheless, majority of the participants were
6
7 willing to support and promote organ donation in their region and was similar across India
8
9 [49,51,74,81,86,87].
10
11
12
13

14
15 Younger adults, participants from higher socio-economic status and participants with higher
16 education or healthcare education demonstrated higher willingness toward deceased organ
17 donation both among Indians in India and UK [23,39,41,42,47,52,79]. However, this was not
18 consistent during the time of actual behaviour. Studies showed that there was almost equal
19 distribution of participants from lower socio-economic status and lower education, who did
20 give consent and actually signed for deceased organ donation [41,77]. However, this
21 conclusion is based only from few studies showed to be similar in north and south of India
22 [41,77].
23
24
25
26
27
28
29
30
31
32
33

34 **Familial influence**

35
36 In-spite of willingness to register for organ donation (Figure 2), larger proportion of individuals
37 have not initiated a conversation or discussed their willingness with their family members, an
38 important behaviour for a successful donation [46,56,59,62,76,82,89,90] - however opted
39 family as the major barriers toward organ donation [40,54,56,60,63,82]. A qualitative study
40 conducted in India and UK revealed the main reasons surrounded a lack of confidence in
41 initiating conversations around sudden deaths, and with these conversations perceived
42 unwelcome by their parents and elders [23,73]. However, another qualitative study conducted
43 among Indian students who were born and grew in UK revealed that they are less concerned
44 of sharing their views compared to their older generations (i.e., mostly migrant generation) and
45 were more willing to discuss their wishes with their families [23], which could be related to
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 acculturation. On the other side, a qualitative study conducted in southern India among urban
4
5 living adults suggested that such conversation only occurred when individuals read or viewed
6
7 such events [73]. Also, during the time of consent request, unknown will of the deceased
8
9 showed to be a significant challenge during the decision-making process [77], making such
10
11 discussion very important during the crucial decision-making moments.
12
13

14
15 Willingness to support family members was shown to be higher among healthcare students
16
17 compared to other students [49,91] and lower among family members from rural areas [81,90].
18
19 However, while higher proportion of individuals were willing to support family members for
20
21 organ donation [34,52,62,75,83], only very few families actually supported this decision when
22
23 families were approached for consent [73].
24
25

26
27 Though studies included found no association based on marital status [34,39,83], one study
28
29 found that unmarried individuals appeared to be more willing to donate compared to married
30
31 couples [83]. Also, participants who were aware of their spouse's approval opinion, they were
32
33 more willing to donate compared to those unaware of their spouse's opinion [39]. Among the
34
35 type of family, individuals from 'joint' families had higher knowledge, while willingness to
36
37 donate was found to be higher among nuclear families [34,42,44].
38
39

40 41 42 **Fear and Mistrust** 43

44
45 Fear on misuse of organs by the healthcare team, revealing lack of trust was the other major
46
47 barrier reported [23,36,42,49,54,55,59,60,62,63,78,69]. Some participants relate organ
48
49 donation to organ trafficking and misuse which leads them to fear and mistrust [43,56,81]. A
50
51 qualitative study also revealed increased ambivalence that while on one side participants
52
53 perceived organ donation as a noble act, on the other side they were also fearful of organ misuse
54
55 due to the information that they hear through news and media on organ trafficking and
56
57 exchange of money for organs [73].
58
59
60

1
2
3 Also in UK, among Indian participants, a mother was afraid to see an organ donor card in his
4 child's wallet as she was thinking if doctors will come to see it, then they may deviate the
5 process toward donation and give less care toward saving her child [23]. In parallel, general
6 population from India also feared pre-mature declaration of death for the need of organs
7 [35,81,91]. However, healthcare population groups were less likely to believe that there will
8 be any premature declaration of death by the doctors [34,62,72].
9

17 **Religious influence**

20 Overall, majority of the participants favoured organ donation [23,34,40,41,43,52,83,86].
21 However, when further looked based on religion, different studies showed different religious
22 groups to be more willing to donate compared to individuals from another religious group
23 [39,42,52,64,92], showing no consistency on which particular religion is more supportive or
24 rejective [39,42,46,52,92]. In parallel, a qualitative study conducted among UK university
25 students of Indian descendants showed lack of homogeneity even within one same religion.
26 Some agreed that body needs to be intact for reincarnation, while other participants believed
27 that body and soul are two different entities and that only the soul counts while body is left to
28 decay in this earth [23,78].
29

30 However, though there were differences of opinion across and within the religion, majority of
31 the participants agreed that organ donation is not against religious views
32 [34,59,63,73,78,83,86] and also considered religion as the very least barrier toward organ
33 donation [39,54,56,59,73,89,93]. A qualitative study conducted among UK students with
34 Indian origin showed that though individuals felt religion may influence their decision it was
35 not the only factor that that will be considered in such decisions [23]. Yet, favourable opinion
36 of religion toward organ donation was found to be positively correlating with their willingness
37 to donate [34,46].
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 A Qualitative study conducted in UK with Indian students revealed that younger generations
4 were less bothered about religious views compared to older generations, which could have
5 occurred due to acculturation [23]. Also, participants preferred that religion should not be a
6 criterion based on which allocation can be decided [42,59,86,89] and that organ of a deceased
7 person can be donated to a recipient from any religion [42,59,86,89].
8
9

10
11
12
13
14
15 However, during the time of consent, a stakeholder from a qualitative study said that families
16 who were not willing to donate use the concept of religion as a pre-framed reason to decline
17 donation, though none of the religion is against organ donation. In the same qualitative study,
18 public participants from different religious group felt that their religion supports organ donation
19 [73].
20
21
22
23
24
25

26 27 **Bodily issues**

28
29
30 Majority of the individuals from the reviewed studies were not concerned about bodily issues
31 though it has to undergo incisions while explanting [34-36,39,40,52,74,78]. However, on the
32 other side, majority also agreed that it is an individual's complete right to have the organs
33 within the body when dead [43,72]. Whilst majority of individuals were not concerned about
34 incisions in the body, a qualitative study found that in the real time of consent, stakeholders
35 found it easy to get approval for corneal donation and not solid organs as it may have many
36 incisions over the body and disfigure it [63]. In relation to funeral practices involving the
37 deceased body, majority were aware that normal funeral practices can be conducted even after
38 donating organs [34,43,52,72,74,89], contrast findings were also evident [43,49,72]. However,
39 majority opted body disfigurement as one of the least reasons to be a barrier toward organ
40 donation [40,54,56,60,82].
41
42
43
44
45
46
47
48
49
50
51
52
53
54

55 56 **Discussion**

1
2
3 To the best of our knowledge, this is the first systematic review that reviewed barriers toward
4 organ donation among Indians in India and UK, while other potential studies were excluded
5 due to methodological issues. Also, this is one of the few systematic reviews in organ donation
6 that used integrative methodology.
7
8
9
10
11

12
13 While majority in India have heard or are aware of organ donation, and had a positive
14 correlation with willingness, their gap is wide. This indicates that there could be various factors
15 other than knowledge which need to be studied in more detail. Organ donation being more
16 embedded with health behaviour, there is a need to understand the relationship between
17 behaviour and behavioural intention adopting appropriate principles. This aids the specificity
18 of policy and campaigns to address organ donor registration behaviour in the population.
19
20
21
22
23
24
25
26

27
28 Though gaps identified in majority of the quantitative studies merit qualitative studies, only
29 very few qualitative studies were undertaken in India [72,73,78]. For instance, though majority
30 individuals were willing to be an organ donor, majority have not initiated any such conversation
31 with their family members and considered family to be the major barrier [21,40,54,56,60,82].
32 However, no further studies were exclusively undertaken to understand how a construct like
33 family interferes in the decision making toward registration and consent. Such studies will aid
34 in developing and testing hypothesis or developing appropriate interventions to increase such
35 conversation with family members. Such conversations play a very important role as the
36 awareness on the willingness of the deceased plays a vital role in decision-making during
37 consent [77]. However, the influence of family can be different among Indians in India and UK
38 as the latter may have influences based on acculturation and enculturation [23,79] while the
39 prior maybe more concerned toward communication issues [46,56,59,73,76,82,89,90].
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54

55
56 This review shows that there are various complex interactions that happen in the society where
57 an individual lives rather than just knowledge. Fear and mistrust have shown to influence the
58
59
60

1
2
3 uncertainty in decision-making for a very long time [23,36,42,49,54,55,59,60,62,63,69,78]
4
5 however, studies failed to address how fear influences organ donation, what is the source of
6
7 fear and how a construct like fear can be addressed. Also, while majority of the studies show
8
9 influence of religion on organ donation, there is a greater need to understand how a religion
10
11 influences organ donation in India. Is it the misconception, or the lack of enabling religious
12
13 community, or reluctance to take such conversation, or lack of information from the religious
14
15 leaders or their physical practices that does not allow donation? Such in-depth studies need to
16
17 be undertaken to gain a deeper understanding into the phenomena. Therefore, at the moment,
18
19 there is a need to study further how the interaction of the individuals with such a complex
20
21 socio-cultural and institutional structures influences the organ donation behaviour.
22
23
24
25

26
27 Various factors such as age, sex, education, and socio-economic status showed greater
28
29 influence on willingness to donate [23,39,41,42,47,52,79]. However, when studies showed that
30
31 they did not hold true during the time of consent [41,77], they also showed that there is some
32
33 shift in behaviour during registration and consent making the time period of these two-event
34
35 having different impact in their behavioural intention and behaviour. This again probes to
36
37 further the understanding on what happens during the time of consent, and why such a shift is
38
39 seen in the intention to donate between these two time periods.
40
41
42

43
44 Methodologically, studies conducted among the Indian ethnic group outside India were
45
46 collectively identified as South-Asians or Asians [19,20,94] while they differ culturally,
47
48 socially, politically, economically, and even religiously [95]. Two studies included from UK
49
50 in this review have clearly shown such a difference with the neighbouring country (i.e., India,
51
52 and Pakistan) [23]. Therefore, there is a need to address this population with such specificity
53
54 in future research that can strengthen the practices even more efficiently. Also, with this
55
56 population to be the largest migrating population in the world [7] it is important to understand
57
58 their behaviour outside India. Studies show difference between various migration generations
59
60

1
2
3 from the same ethnicity [23,79]. This cannot happen without the influence of time elapsed since
4 immigration, immigrant generation (i.e., first, second, or higher), acculturation, enculturation,
5 perceived discrimination, attitudes / mistrust toward healthcare system, community barriers,
6 socio-cultural influence and many such complex determinants which adds further complexity
7 to the issue of organ donation among such a population. Therefore, such specific research
8 among this community is also needed to address the disproportionate representation between
9 waiting list and donor list from this ethnic population outside the country of origin.
10
11
12
13
14
15
16
17
18
19

20 **Conclusion**

21
22
23 This review showed that majority of the participants from India and of Indian origin hold
24 positive attitude toward registration but show lower willingness and even lower practice of
25 registration. Though this study showed the complex relationship and influences toward organ
26 donation behaviour, lacunae were identified for further deeper understanding into such
27 complex interactions determining the behaviour. There is also a lack of methodological rigour
28 to study this particular population outside India, being collectively studied with their
29 neighbouring population which are not homogenous. Also, within India, majority of the studies
30 employed similar aims and methods leading to repetition of studies rather than diversified,
31 wider, and in-depth research. Therefore, this systematic review addressed the barriers toward
32 organ donor registration among Indians in India and UK and also identified gaps both in
33 methodological and research perspectives that merits future research to examine the
34 phenomena of interest from multiple lenses.
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Funding sources: This review is led by the principal investigator Britzer Paul Vincent who is a PhD scholar at the Institute for Health Research, University of Bedfordshire funded by their Global Challenges Research Fund.

Authorship Contribution:

	Vincent, Britzer Paul	Randhawa, Gurch	Cook, Erica
Conception	Yes	Yes	Yes
Design of the work	Yes	Yes	Yes
Acquisition	Yes	Yes	Yes
Analysis	Yes	Yes	Yes
Interpretation	Yes	Yes	Yes
Revision	Yes	Yes	Yes
Final Approval	Yes	Yes	Yes
Accountability	Yes	Yes	Yes

Acknowledgement: We would like to thank our librarian Mr. David Abdy from Institute for Health Research, University of Bedfordshire for his contribution with the development of the search strategy.

Data availability: None

Conflict of Interest: None declared.

Patient and Public involvement: None as this is a systematic review

Ethics approval details: Institute for Health Research Ethics Committee from the University of Bedfordshire approved this study (IHREC931).

References:

- Merrill, J.P., Murray, J.E., Takacs, F.J., Hager, E.B., Wilson, R.E. and Dammin, G.J., 1963. Successful transplantation of kidney from a human cadaver. *Jama*, 185(5), pp.347-353.
- Rudge C, Matesanz R, Delmonico FL, Chapman J. International practices of organ donation. *British journal of anaesthesia*. 2012 Jan 1;108(suppl_1):i48-55.

- 1
2
3 3. Alden, D.L. and Cheung, A.H., 2000. Organ donation and culture: a comparison of
4 Asian American and European American beliefs, attitudes, and behaviors. *Journal of*
5
6 *Applied Social Psychology*, 30(2), pp.293-314.
7
8
- 9
10 4. Karim A, Jandu S, Sharif A. A survey of South Asian attitudes to organ donation in the
11 United Kingdom. *Clinical transplantation*. 2013 Sep;27(5):757-63.
12
13
- 14 5. Lo, C.M., 2012. Deceased donation in Asia: challenges and opportunities. *Liver*
15 *Transplantation*, 18(S2), pp.S5-S7.
16
17
- 18 6. United Nations. Department of Economics and social affairs. Population dynamics.
19 Available at: <https://population.un.org/wpp/Download/Standard/Population/>. Last
20 viewed: 03 April 2021
21
22
23
24
25
- 26 7. World Migration Report. 2020. Available at:
27 https://www.un.org/sites/un2.un.org/files/wmr_2020.pdf. Last viewed 03 April 2021
28
29
- 30 8. Ramachandran, A., Ma, R.C.W. and Snehalatha, C., 2010. Diabetes in asia. *The*
31 *Lancet*, 375(9712), pp.408-418.
32
33
- 34 9. Ramachandran, A., Snehalatha, C., Shetty, A.S. and Nanditha, A., 2012. Trends in
35 prevalence of diabetes in Asian countries. *World journal of diabetes*, 3(6), p.110.
36
37
38
- 39 10. Singh, R.B., Suh, I.L., Singh, V.P., Chaithiraphan, S., Laothavorn, P., Sy, R.G.,
40 Babilonia, N.A., Rahman, A.R.A., Sheikh, S., Tomlinson, B. and Sarraf-Zadigan, N.,
41 2000. Hypertension and stroke in Asia: prevalence, control and strategies in developing
42 countries for prevention. *Journal of human hypertension*, 14(10), pp.749-763.
43
44
45
46
47
48
- 49 11. Ritz E, Rychlík I, Locatelli F, Halimi S. End-stage renal failure in type 2 diabetes: a
50 medical catastrophe of worldwide dimensions. *American journal of kidney diseases*.
51 1999 Nov 1;34(5):795-808.
52
53
54
55
- 56 12. Weisstuch JM, Dworkin LD. Does essential hypertension cause end-stage renal
57 disease?. *Kidney international Supplement*. 1992 May 2(36).
58
59
60

- 1
2
3 13. Navin S, Shroff S, Niranjana S. 'Deceased Organ Donation in India'. Available:
4
5 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
6
7 [donation-in-india.asp](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)> [Accessed 18 March 2021].
8
9
- 10 14. National Deceased Donor Transplantation, Mohan Foundation. 2017. Available:
11
12 <https://www.mohanfoundation.org/deceased-organdonation-in-india.asp> [Accessed
13
14 18 March 2021].
15
16
- 17 15. Kumar, V., Ahlawat, R., Gupta, A.K., Sharma, R.K., Minz, M., Sakhuja, V. and Jha,
18
19 V., 2014. Potential of organ donation from deceased donors: study from a public sector
20
21 hospital in India. *Transplant International*, 27(10), pp.1007-1014.
22
23
- 24 16. NHSBT. Organ Donation and Transplantation data for Black, Asian and Minority
25
26 Ethnic (BAME) Communities. 2018. Available at:
27
28 [https://nhsbtdeb.blob.core.windows.net/umbraco-assets-corp/12048/bame-organ-](https://nhsbtdeb.blob.core.windows.net/umbraco-assets-corp/12048/bame-organ-donation-and-transplantation-data-2017-18.pdf)
29
30 [donation-and-transplantation-data-2017-18.pdf](https://nhsbtdeb.blob.core.windows.net/umbraco-assets-corp/12048/bame-organ-donation-and-transplantation-data-2017-18.pdf). Last viewed: 03 April 2021
31
32
- 33 17. Vincent BP, Randhawa G, Cook E. Protocol: Barriers towards organ donor registration
34
35 and consent among people of Indian origin living globally: a systematic review and
36
37 integrative synthesis—protocol. *BMJ Open*. 2020;10(6).
38
39
- 40 18. Irving, M.J., Tong, A., Jan, S., Cass, A., Rose, J., Chadban, S., Allen, R.D., Craig, J.C.,
41
42 Wong, G. and Howard, K., 2012. Factors that influence the decision to be an organ
43
44 donor: a systematic review of the qualitative literature. *Nephrology dialysis*
45
46 *transplantation*, 27(6), pp.2526-2533.
47
48
- 49 19. Morgan, M., Kenten, C., Deedat, S. and Donate Programme Team, 2013. Attitudes to
50
51 deceased organ donation and registration as a donor among minority ethnic groups in
52
53 North America and the UK: a synthesis of quantitative and qualitative
54
55 research. *Ethnicity & health*, 18(4), pp.367-390.
56
57
58
59
60

- 1
2
3 20. Molzahn, A.E., Starzomski, R., McDonald, M. and O'Loughlin, C., 2005. Indo-
4 Canadian beliefs regarding organ donation. *Progress in Transplantation*, 15(3),
5 pp.233-239.
6
7
8
9
10 21. Randhawa, G., 1998. An exploratory study examining the influence of religion on
11 attitudes towards organ donation among the Asian population in Luton,
12 UK. *Nephrology, dialysis, transplantation: official publication of the European*
13 *Dialysis and Transplant Association-European Renal Association*, 13(8), pp.1949-
14 1954.
15
16
17
18
19
20
21 22. Wong, L.P., 2010. Information needs, preferred educational messages and channel of
22 delivery, and opinion on strategies to promote organ donation: a multicultural
23 perspective. *Singapore medical journal*, 51(10), p.790.
24
25
26
27
28 23. Gauher ST, Khehar R, Rajput G, Hayat A, Bakshi B, Chawla H, Cox BM, Warrens AN.
29 The factors that influence attitudes toward organ donation for transplantation among
30 UK university students of Indian and Pakistani descent. *Clinical transplantation*. 2013
31 May;27(3):359-67.
32
33
34
35
36
37 24. JBI Critical Appraisal Tools. Available at: <https://jbi.global/critical-appraisal-tools>.
38 Last viewed: 03 April 2021
39
40
41
42 25. Gao, W., Plummer, V. and Williams, A., 2017. Perioperative nurses' attitudes towards
43 organ procurement: a systematic review. *Journal of clinical nursing*, 26(3-4), pp.302-
44 319.
45
46
47
48 26. Brown SJ. Knowledge for health care practice: A guide to using research evidence.
49 Saunders; 1999.
50
51
52
53 27. Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, Britten N, Roen K,
54 Duffy S. Guidance on the conduct of narrative synthesis in systematic reviews. A
55 product from the ESRC methods programme Version. 2006 Apr 1;1:b92.
56
57
58
59
60

- 1
2
3 28. Noblit GW, Hare RD. Meta-ethnography: synthesizing qualitative studies, vol. 11.
4
5 California: Sage Publications; 1988.
6
7
8 29. Campbell R, Pound P, Pope C, Britten N, Pill R, Morgan M, Donovan J. Evaluating
9
10 meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes
11
12 and diabetes care. *Soc Sci Med*. 2003;56(4):671–84.
13
14
15 30. Campbell, R., Pound, P., Morgan, M., Daker-White, G., Britten, N., Pill, R., Yardley,
16
17 L., Pope, C. and Donovan, J., 2012. Evaluating meta ethnography: systematic analysis
18
19 and synthesis of qualitative research.
20
21
22 31. Nye E, Melendez-Torres GJ, Bonnell C. Origins, methods, and advances in qualitative
23
24 meta-synthesis. *Review of Education*. 2016;4(1):57–79.
25
26
27 32. Garside R. A comparison of methods for the systematic review of qualitative research:
28
29 two examples using Meta-ethnography and Meta-study. UK: University of Exeter;
30
31 2008.
32
33 33. Alex P, Kiran KG, Baisil S, Badiger S. Knowledge and attitude regarding organ
34
35 donation and transplantation among medical students of a medical college in South
36
37 India. *Int J Community Med Public Health*. 2017 Sep;4(9):3449-54p.
38
39
40 34. Bapat U, Kedlaya PG. Organ donation, awareness, attitudes and beliefs among post
41
42 graduate medical students. *Saudi Journal of Kidney Diseases and Transplantation*. 2010
43
44 Jan 1;21(1):174.
45
46
47 35. Chakradhar K, Doshi D, Reddy BS, Kulkarni S, Reddy MP, Reddy SS. Knowledge,
48
49 attitude and practice regarding organ donation among Indian dental students.
50
51 *International journal of organ transplantation medicine*. 2016;7(1):28.
52
53
54 36. Gupta RK, Singh P, Akhtar N, Kumari R, Gupta C, Gupta R. Gender based perspectives
55
56 about organ donation among students in a medical school in North India. *International*
57
58 *Journal of Research in Medical Sciences*. 2018 May;6(5):1710.
59
60

- 1
2
3 37. Jayabharathi B, Devika M, Akila M. Assessment of knowledge and attitude on organ
4 donation among adults in selected areas. *International Journal of Research in*
5
6 *Pharmaceutical Sciences*. 2019 Apr 15;10(2):782-6.
7
8
9
10 38. Singh P, Kumar A, Pandey CM, Chandra H. Level of awareness about transplantation,
11 brain death and cadaveric organ donation in hospital staff in India. *Progress in*
12
13 *Transplantation*. 2002 Dec;12(4):289-92.
14
15
16
17 39. Ahlawat R, Kumar V, Gupta AK, Sharma RK, Minz M, Jha V. Attitude and knowledge
18 of healthcare workers in critical areas towards deceased organ donation in a public
19 sector hospital in India. *The National medical journal of India*. 2013 Jan 1;26(6):322-
20
21
22
23 6.
24
25
26 40. Balajee KL, Ramachandran N, Subitha L. Awareness and attitudes toward organ
27 donation in rural Puducherry, India. *Annals of Medical and Health Sciences Research*.
28
29
30
31 2016;6(5):286-90.
32
33 41. Bansal N, Koushal V, Mehra A. A study of sociodemographic profile and level of
34 awareness of the decision makers for organ donation of deceased organ donors in a
35 Tertiary Care Hospital. *Indian Journal of Transplantation*. 2019 Jan 4;13(2):82.
36
37
38
39 42. Dasgupta A, Shahbabu B, Sarkar K, Sarkar I, Das S, Kumar Das M. Perception of organ
40 donation among adults: A community based study in an urban community of West
41 Bengal. *Scholars J Appl Med Sci*. 2014;2(6A):2016-1.
42
43
44
45
46 43. Poreddi V, Sunitha TS, Thimmaiah R, Math SB. Gender differences in perceptions and
47 attitudes of general population towards organ donation: An Indian perspective. *Saudi*
48
49
50
51
52 *Journal of Kidney Diseases and Transplantation*. 2017 May 1;28(3):599.
53
54 44. Sarveswaran G, Sakthivel MN, Krishnamoorthy Y, Arivarasan Y, Ramakrishnan J.
55 Knowledge, attitude, and practice regarding organ donation among adult population of
56 urban Puducherry, South India. *Journal of education and health promotion*. 2018;7.
57
58
59
60

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
45. Tamuli RP, Sarmah S, Saikia B. Organ donation—"attitude and awareness among undergraduates and postgraduates of North-East India". *Journal of family medicine and primary care*. 2019 Jan;8(1):130.
46. Vijayalakshmi P, Sunitha TS, Gandhi S, Thimmaiah R, Math SB. Knowledge, attitude and behaviour of the general population towards organ donation: an Indian perspective. *The National medical journal of India*. 2016 Sep 1;29(5):257.
47. Swain, R., Prasad, H., Lalwani, S. and Pooniya, S., 2020. Awareness, perceived barriers and factors affecting willingness for Organ Donation among the first-and second-degree relatives of deceased in a tertiary care hospital of Northern India. *The Official Publication of Indian Academy of Forensic Medicine*, 42(4), pp.261-264.
48. Kadam, S., Shinde, S., Shroff, G. and Gulanikar, S., 2021. Knowledge and Attitude About Organ Donation Among Medical Students: An Observational Study from Aurangabad, Maharashtra. *Int J Cur Res Rev* | Vol, 13(01), p.121.
49. Kundu, S., 2021. Attitudes and Myths regarding Posthumous whole Body Bequest and Organ Donation among Medical Professionals and Health Care Personnel of Tribal Chhattisgarh—A Broad Questionnaire Based Review. *Sch J App Med Sci*, 6, pp.1093-1116.
50. Swamy, R.M., Kalaburgi, R.A., Manjunath, G.N., Lavanya, R. and Kousalya, R., Knowledge and Attitude towards Organ donation among the Medical and Engineering students in Tumakuru, Karnataka. *IOSR Journal of Dental and Medical Sciences (IOSR-JDMS)* e-ISSN: 2279-0853, p-ISSN: 2279-0861. Volume 19, Issue 5 Ser.2 (May. 2020), PP 31-36
51. Gupta, P., Sodhani, S., & Bhate, K. (2021). Organ donation perception and beliefs: a cross sectional study amongst degree college students and teachers in Mumbai, Maharashtra, India. *International Journal of Advances in Medicine*, 8(3), 399-403.

- 1
2
3 52. Mithra P, Ravindra P, Unnikrishnan B, Rekha T, Kanchan T, Kumar N, Papanna M,
4 Kulkarni V, Holla R, Divyavaraprasad K. Perceptions and attitudes towards organ
5 donation among people seeking healthcare in tertiary care centers of coastal South
6 India. *Indian journal of palliative care*. 2013 May;19(2):83.
7
8
9
10
11
12 53. Balwani MR, Gumber MR, Shah PR, Kute VB, Patel HV, Engineer DP, Gera DN,
13 Godhani U, Shah M, Trivedi HL. Attitude and awareness towards organ donation in
14 western India. *Renal failure*. 2015a Apr 21;37(4):582-8.
15
16
17
18
19 54. Bathija GV, Ananthesh BG, Bant DD. Study to assess knowledge and attitude towards
20 organ donation among interns and post graduates of a medical college in Karnataka,
21 India. *Natl J Community Med*. 2017;8(5):236-40.
22
23
24
25
26 55. Bharambe VK, Sakshi S, Gaurav B, Feroz A. Awareness regarding body and organ
27 donation amongst the population of an urban city in India. *Nitte University Journal of*
28 *Health Science*. 2015 Dec 1;5(4).
29
30
31
32
33 56. Minz M, Sood S, Kumar A, Bansal V, Mehra S. Impact of organ trade on attitudes
34 toward organ donation: knowledge and attitudes toward cadaveric organ donation in
35 north India. *InTransplantation proceedings 1998 (Vol. 30, No. 7)*.
36
37
38
39
40 57. Mohan G, Aswathy AA. Organ donation in India—A social marketing perspective.
41 *International Journal of Nonprofit and Voluntary Sector Marketing*. 2019
42 May;24(2):e1637.
43
44
45
46
47 58. Alex A, Shroff S, Paul VB, Navin S, Ramesh P, Michael J, Menon S. Did an increase
48 in knowledge and awareness about organ donation improve organ donation rate in India
49 over the past two decades?. *Indian Journal of Transplantation*. 2019 Jul 1;13(3):173.
50
51
52
53
54 59. Bharambe VK, Arole VU, Puranam V, Manvikar P, Rathod HK. Organ Donation: from
55 Point of View of Students Doing Medical Internship in India. *BANTAO Journal*. 2016
56 Dec 1;14(2):67-72.
57
58
59
60

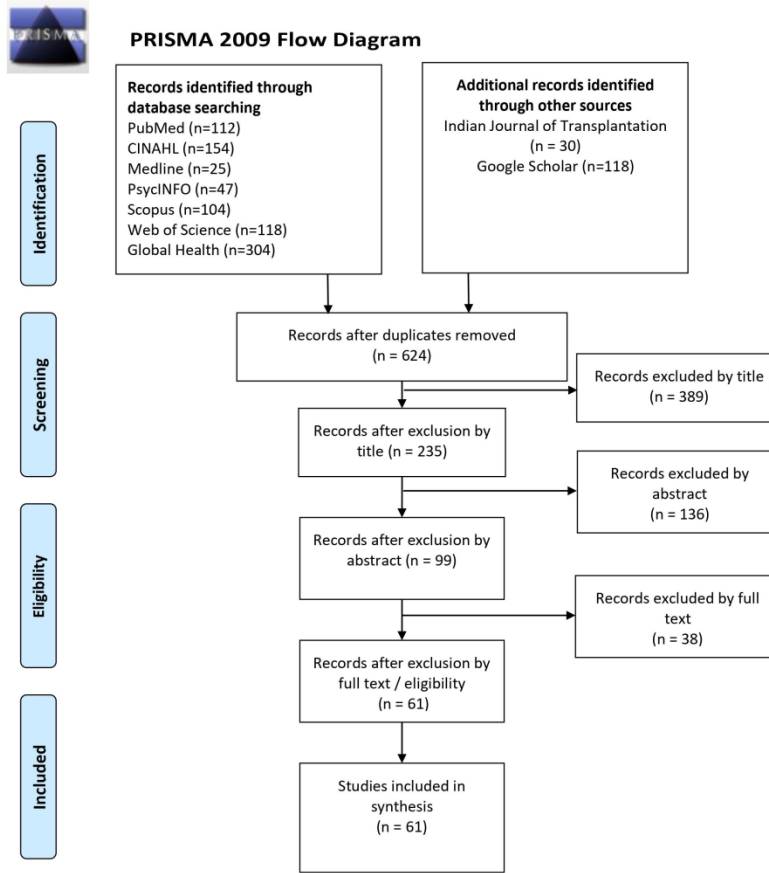
- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
60. Bharambe VK, Arole VU, Puranam V, Kulkarni PP, Kulkarni PB. Knowledge and attitude toward organ donation among people in Lanja: A rural town in India. *Saudi Journal of Kidney Diseases and Transplantation*. 2018a Jan 1;29(1):160.
61. Deshpande PR, Damle P, Bihani G, Khadabadi SS, Naik AN, Pawar AP. Knowledge, attitude, and practice of organ donation among pharmacy students. *Indian Journal of Transplantation*. 2018 Apr 1;12(2):113.
62. Da Silva, K.X., Dsouza, D.B., Mascarenhas, V.R., Kankonkar, P.N., Vaz, F.S. and Kulkarni, M.S., 2021. Perceptions and attitude toward cadaveric organ donation among health-care professionals at a tertiary health-care setting: A cross-sectional study. *Indian Journal of Transplantation*, 15(1), p.56.
63. Basavarajegowda, A., Arjunan, C., Nalini, Y.C., Parameshwaran, S. and Kannan, S., 2021. A comparative study of knowledge, attitude, and practices about organ donation among blood donors and nonblood donors. *Asian Journal of Transfusion Science*, 15(1), p.37.
64. Kachappillil, A.J. and Thankachan, A., 2020. Attitude of General Population towards Organ Donation in a Rural Community of Ernakulam District. *International Journal of Healthcare Education & Medical Informatics (ISSN: 2455-9199)*, 7(1&2), pp.16-20.
65. Kalmath, S. and Peerapur, S.M., 2020. A Study to Determine the Knowledge, Preparedness and Commitment Regarding Organ Donation among the Youths of Hubli, Karnataka. *International journal of Innovative science and research technology*, 5(5).
66. Khan, F., Latif, M. and Bashir, S., 2020. Attitude and Knowledge toward Organ Donation among Arts and Science Students. *Indian Journal of Forensic Medicine & Toxicology*, 14(4).

- 1
2
3 67. Rani, S., Mishra, A. and Dagar, N., 2020. Community Based Study to Assess the
4 Knowledge and Attitude of General Population towards Organ Donation. *International*
5 *Journal of Nursing Education*, 12(4).
6
7
8
9
10 68. Ray, M.K. and Ghosh, T., 2020. Assessment of Knowledge and Attitude of Medical
11 Students Regarding Body and Organ Donation. *Religion*, 115, pp.85-8.
12
13
14 69. Seetharaman, R.V., Rane, J.R. and Dingre, N.S., 2021. Assessment of knowledge and
15 attitudes regarding organ donation among doctors and students of a tertiary care
16 hospital. *Artificial Organs*, 45(6), pp.625-632.
17
18
19
20
21 70. Yadav, N., Jain, M., Sharma, A., Jain, V., Chahar, P. and Verma, N., 2020. Perceptions
22 of a university's faculty members on organ donation. *The National Medical Journal of*
23 *India*, 33(5), p.302.
24
25
26
27
28 71. Bharambe, V.K., Arole, V.U., Puranam, V., Kulkarni, P.P. and Kulkarni, P.S., 2018b.
29 Knowledge and attitude toward organ donation among health-care professionals in a
30 rural town in India. *Saudi Journal of Kidney Diseases and Transplantation*, 29(3),
31 p.671.
32
33
34
35
36
37 72. Vincent BP, Kumar G, Parameswaran S, Kar SS. Barriers and suggestions towards
38 deceased organ donation in a government tertiary care teaching hospital: Qualitative
39 study using socio-ecological model framework. *Indian Journal of Transplantation*.
40 2019a Jul 1;13(3):194.
41
42
43
44
45
46 73. Kennedy K. Organ donation and transplantation in India: An inquiry in Kerala. *Journal*
47 *of Social Distress and the Homeless*. 2002 Jan 1;11(1):41-67.
48
49
50
51 74. Amaliyar J, Patel P. Awareness about organ donation in medical and non medical
52 students in Patan city of Gujarat, India. *Int J Community Med Public Health*. 2019
53 Jun;6:2435-9.
54
55
56
57
58
59
60

- 1
2
3 75. Jothula KY, Sreeharshika D. Study to assess knowledge, attitude and practice regarding
4 organ donation among interns of a medical college in Telangana, India. *Int J*
5 *Community Med Public Health*. 2018 Apr;5(4):1339-45.
6
7
8
9
10 76. Vijayalakshmi P, Nagarajaiah, Ramachandra, Math SB. Indian ICU nurses' perceptions
11 of and attitudes towards organ donation. *British Journal of Nursing*. 2015 Jul
12 9;24(13):694-7.
13
14
15
16 77. Vincent BP, Kumar G, Parameswaran S, Kar SS. Knowledge, attitude, and perception
17 on organ donation among undergraduate medical and nursing students at a tertiary care
18 teaching hospital in the southern part of India: A cross-sectional study. *Journal of*
19 *education and health promotion*. 2019b;8.
20
21
22
23 78. Misra, P., Malhotra, S., Sharma, N., Misra, M.C., Vij, A. and Pandav, C.S., 2021. A
24 qualitative approach to understand the knowledge, beliefs, and barriers toward organ
25 donation in a rural community of Haryana-A community based cross-sectional
26 study. *Indian Journal of Transplantation*, 15(1), p.19.
27
28
29
30
31
32
33 79. Joshi MS. Whose decision is it? Organ donation attitudes among young UK South
34 Asians. *Psychological Studies*. 2011 Mar 1;56(1):86-97.
35
36
37
38
39 80. Thyagarajan, I., Shroff, S., Vincent, B.P., Rajendran, J., Kanvinde, H., Shankar, S. and
40 Aneesh, K., 2020. Knowledge and practice of organ donation among police personnel
41 in Tamil Nadu: A cross-sectional study. *Indian Journal of Transplantation*, 14(2),
42 p.141.
43
44
45
46
47
48 81. Mondal, S., Paul, A., Malick, S. and Saha, P., 2016. Perception of organ donation
49 among adults: A community based study in rural West Bengal, India. *Sch J Appl Med*
50 *Sci*, 4, pp.4473-8.
51
52
53
54
55 82. Sam N, Ganesh R, Indrapriyadarshini V, Jeyamarthan S, Nandhini CK. Awareness,
56 knowledge, and attitude regarding organ donation among final year students of medical,
57
58
59
60

- Dental, Engineering, and Arts and Science Colleges in Thiruvallur and Chennai City, India. *Indian Journal of Transplantation*. 2018 Jan 1;12(1):25.
83. Soni S, Samal J, Baghel SS, Vaghela S, Chundawat MS. Knowledge and attitude toward organ donation among medical and nonmedical (Engineering) students in Bhopal, India. *The Saudi Journal of Forensic Medicine and Sciences*. 2018 May 1;1(2):35.
84. Rajan, J.K., 2020. Assessment of Knowledge and Attitude of Adolescents Regarding Blood and Organ Donation in Selected Rural Areas of Shimla, Himachal Pradesh, India. *Medico Legal Update*, 20(1), pp.101-105.
85. Sachdeva S. Knowledge, Attitude, and Practices regarding organ donation among adult visitors in a public hospital in Delhi, India. *Indian J Transplant*. 2017 Dec 20;11:127-32.
86. Balwani MR, Kute VB, Patel H, Shah PR, Goswami J, Ghule P, Shah M, Gattani V, Trivedi HL. Awareness and beliefs towards organ donation in chronic kidney disease patients in western India. *Journal of Nephro pharmacology*. 2015b;4(2):57.
87. Kaistha M, Kaistha S, Mahajan A. A study of factors influencing decisions on organ donation among patient attendees in a Tertiary Care Hospital in North India. *CHRISMED Journal of Health and Research*. 2016 Apr 1;3(2):101.
88. Paul S, Som TK, Saha I, Ghose G, Bera A, Singh A. Knowledge, attitude, and practice regarding organ donation among adult Population of an Urban field practice area of a medical college in Durgapur, West Bengal, India. *Indian Journal of Transplantation*. 2019 Jan 1;13(1):15.
89. Adithyan GS, Mariappan M, Nayana KB. A study on knowledge and attitude about organ donation among medical students in Kerala. *Indian Journal of Transplantation*. 2017 Jul 1;11(3):133.

- 1
2
3 90. Mani G. Perceptions and practices related to organ donation among a rural population
4 of Kancheepuram district, Tamil Nadu, India Geetha Mani¹, Raja Danasekaran¹,
5 Kalaivani Annadurai¹. *Journal of Comprehensive Health*. 2016 Jan;4(1):72.
6
7
8
9
10 91. Meghana S, Subramanian M, Atmakuri SA, Tarun S, Bera P, Nelson J. A study on
11 knowledge, attitude and practice regarding organ donation and transplantation among
12 final year health science students in Bengaluru, Karnataka, India. *Int J Commun Med*
13 *Pub Health*. 2018 Apr;5:1529-34.
14
15
16
17
18
19 92. Darlington D, Anitha FS, Joseph C. Study of Knowledge, Attitude, and Practice of
20 Organ Donation Among Medical Students in a Tertiary Care Centre in South India.
21 *Cureus*. 2019 Jun;11(6).
22
23
24
25
26 93. Bhargavi UD, Govindapillai UK. Knowledge and attitude of decond year medical,
27 dental and nursing students in Thiruvananthapuram government medical college
28 campus towards organ and whole body donation. *Journal of Evolution of Medical and*
29 *Dental Sciences*. 2019 Apr 8;8(14):1153-6.
30
31
32
33
34
35 94. Ahmed, W., Harris, S. and Brown, E., 1999. Attitudes to organ donation among South
36 Asians in an English high street. *Journal of the Royal Society of Medicine*, 92(12),
37 pp.626-627.
38
39
40
41
42 95. Syed, J. and Èzbilgin, M.F. eds., 2010. *Managing cultural diversity in Asia: A research*
43 *companion*. Edward Elgar Publishing.
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60



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(7): e1000097. doi:10.1371/journal.pmed1000097

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

215x279mm (300 x 300 DPI)

	1	2	3	4	5	6	7	8
Adithyan, Mariappan and Nayana, 2017	✓	✓	✓	✓	✗	✗	✓	✓
Ahlatwat et al, 2013	-	✓	✓	✓	✗	✗	✓	✓
Alex et al, 2017	✓	✓	✓	✓	✗	✗	✓	✓
Alex et al, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Amalivar and Patel, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Balajee, Ramachandran and Subitha, 2016	-	✓	✓	✓	✗	✗	✓	✓
Balwani et al, 2015a	-	✓	✓	✓	✗	✗	✓	✓
Balwani et al, 2015b	✓	✓	✓	✓	✗	✗	✓	✓
Bansal, Koushal and Mehra, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Bapat and Kedlaya, 2010	-	✓	✓	✓	✗	✗	✓	✓
Basavarajegowda et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Bathija, Ananthesh, and Bant, 2017	-	✓	✓	✓	✗	✗	✓	✓
Bharambe et al, 2015	✗	✓	✓	✓	✗	✗	✓	✓
Bharambe et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Bharambe et al, 2018a	✓	✓	✓	✓	✗	✗	✓	✓
Bharambe et al, 2018b	✓	✓	✓	✓	✗	✗	✓	✓
Bhargavi and Govindapillai, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Chakrabhar et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Da Silva et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Darlington, Anitha and Joseph, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Dasgupta et al, 2014	✓	✓	✓	✓	✗	✗	✓	✓
Deshpande et al, 2018	-	✓	✓	✓	✗	✗	✓	✓
Gupta et al, 2018	✓	✓	✓	✓	✗	✗	✓	✓
Gupta et al, 2021	✗	-	✓	✓	✗	✗	✓	✓
Jayabharathi, Devika and Akila, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Joshi, 2011	✓	✓	✓	✓	✗	✗	✓	✓
Jothula and Sreerashika, 2018	✓	✓	✓	✓	✗	✗	✓	✓
Kachappillil et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Kadam et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Kaistha, Kaistha, and Mahajan, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Kamath et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Khan et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Kundu et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Mani, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Meghana et al, 2018	✓	✓	✓	✓	✗	✗	✓	✓
Minz et al, 1998	✗	-	✓	✓	✗	✗	✓	✓
Mithra et al, 2013	✓	✓	✓	✓	✗	✗	✓	✓
Mohan and Aswathy, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Mondal et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Paul et al, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Poreddi et al, 2017	✓	✓	✓	✓	✗	✗	✓	✓
Rajan, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Rani et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Ray et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Sachdeva, 2017	-	✓	✓	✓	✗	✗	✓	✓
Sam et al, 2018	✓	✓	✓	✓	✗	✗	✓	✓
Sarveswaran et al, 2018	✓	✓	✓	✓	✗	✗	✓	✓
Seetharaman et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Singh et al, 2002	✓	✓	✓	✓	✗	✗	✓	✓
Soni et al, 2018	-	✓	✓	✓	✗	✗	✓	✓
Swain et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Swamy et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Tamili, Sarmah and Saikia, 2019	✗	✓	✓	✓	✗	✗	✓	✓
Thyagarajan et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Vijayalakshmi et al, 2015	✓	✓	✓	✓	✗	✗	✓	✓
Vijayalakshmi et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Vincent et al, 2019b	✓	✓	✓	✓	✗	✗	✓	✓
Yadav et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓

Ref	Vincent et al, 2019	Kennedy, 2002	Gumber et al, 2013	Misra et al, 2021
1	✓	✓	✓	✓
2	✓	✓	✓	✓
3	✓	✓	✓	✓
4	✓	✓	✓	✓
5	✓	✓	✓	✓
6	✓	✗	✓	✗
7	✗	✗	✗	✗
8	✓	✗	✓	✗
9	✓	✗	✓	✗
10	✓	✓	✓	✓

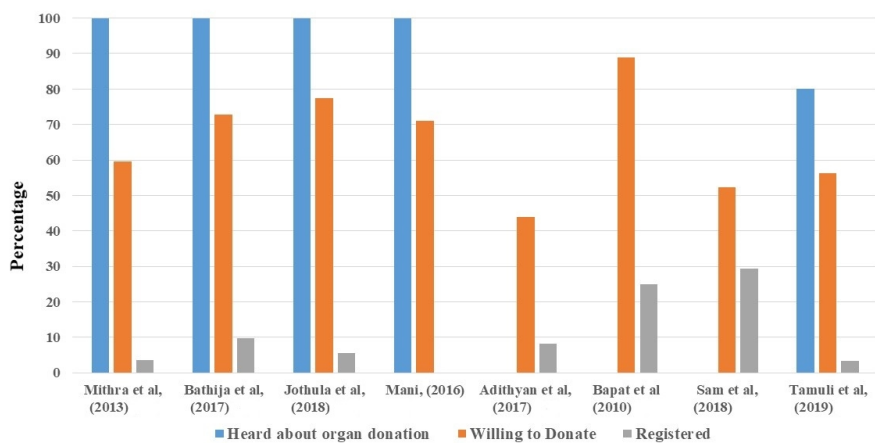
- 1 Is there congruity between the stated philosophical perspective and the research methodology?
- 2 Is there congruity between the research methodology and the research question or objective?
- 3 Is there congruity between the research methodology and the methods used to collect data?
- 4 Is there congruity between the research methodology and the representation and analysis of data?
- 5 Is there congruity between the research methodology and the interpretation of results?
- 6 Is there a statement locating the researcher culturally or theoretically?
- 7 Is the influence of the researcher on the research, and vice-versa, addressed?
- 8 Are participants, and their voices, adequately represented?
- 9 Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
- 10 Do the conclusion drawn in the research report flow from the analysis, or interpretation, of the data?

Mentioned ✓ Not mentioned ✗ Unclear -

Quality appraisal for qualitative studies

Quality appraisal for cross-sectional studies

209x297mm (300 x 300 DPI)



451x254mm (72 x 72 DPI)

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Search Strategy

1. Organ
2. Tissue
3. Donation
4. ((1 OR 2) AND 3) .ti,ab
5. Consent
6. Regist*
7. Brain Death
8. Deceased
9. Posthumous
10. Donation after Brain Death
11. DBD
12. (5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11) .ti,ab
13. India*
14. South Asia*
15. Asia*
16. (14 OR 15 OR 16) .ti,ab
17. Knowledge
18. Awareness
19. Attitude
20. Perception
21. Practice
22. Barrier
23. Challenge*
24. Cultur*
25. Religi*
26. Famil*
27. Discuss*
28. Sign*
29. Pledge*
30. (17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29) .ti,ab
31. 4 AND 12 AND 16 AND 30
32. Filter year: 1st January 1994 to 30th July 2021



PRISMA 2020 checklist

1136/bmjopen-2021-056094 on 27 May 2022. Downloaded from <http://bmjopen.bmj.com/> on April 20, 2022 by guest. Protected by copyright.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Pg. 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Pg. 1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Pg. 3-4
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Pg. 3-4
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Pg. 5
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Pg. 4
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Pg. 5
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Pg. 5
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Pg. 5
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Pg. 5-7
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	NA
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Pg. 6
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	NA
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Pg. 5
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	NA
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Pg. 6-7
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Pg. 6-7
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	NA
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	NA
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Pg. 6
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	NA



PRISMA 2020 checklist

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

Section and Topic	Item #	Checklist item	Location where item is reported
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Figure 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Pg. 5
Study characteristics	17	Cite each included study and present its characteristics.	Table 1
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Figure 2
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	NA
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Figure 2
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	NA
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	NA
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	NA
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	NA
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	NA
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Pg. 13-16
	23b	Discuss any limitations of the evidence included in the review.	Pg. 13-16
	23c	Discuss any limitations of the review processes used.	Pg. 13-16
	23d	Discuss implications of the results for practice, policy, and future research.	Pg. 13-16
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Pg. 1
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Pg. 1
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Pg. 1
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Title page
Competing interests	26	Declare any competing interests of review authors.	Title page
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Title page

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71

For peer review only - <http://bmjopen.bmj.com/site/about/guidelines.xhtml>
For more information, visit: <http://www.prisma-statement.org/>

BMJ Open

Barriers toward deceased organ donation among Indians living in India and the United Kingdom: An integrative systematic review using narrative synthesis.

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2021-056094.R1
Article Type:	Original research
Date Submitted by the Author:	07-Feb-2022
Complete List of Authors:	Vincent, Britzer Paul; University of Bedfordshire Faculty of Health and Social Sciences, Institute for Health Research Randhawa, Gurch; University of Bedfordshire Faculty of Health and Social Sciences, Institute for Health Research Cook, Erica; University of Bedfordshire - Luton Campus, Department of Psychology
Primary Subject Heading:	Health policy
Secondary Subject Heading:	Health services research
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, ETHICS (see Medical Ethics), TRANSPLANT MEDICINE

SCHOLARONE™
Manuscripts



I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our [licence](#).

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which [Creative Commons](#) licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Title Page

Title: Barriers toward deceased organ donation among Indians living in India and the United Kingdom: An integrative systematic review using narrative synthesis.

Full name of all authors:

As per the order of the authorship

1. Britzer Paul (Given Name) Vincent (Family Name)
PhD Student, Institute for Health Research, Faculty of Health and Social Sciences, University of Bedfordshire, England, The United Kingdom
ORCID id: <https://orcid.org/0000-0001-7681-1430>
2. Gurch (Given Name) Randhawa (Family Name)
Professor of Diversity in Public Health and Director - Institute for Health Research, Faculty of Health and Social Sciences, University of Bedfordshire, England, The United Kingdom
3. Erica (Given Name) Cook (Family Name)
Senior Lecturer in Health Psychology,
Department of Psychology, University of Bedfordshire, England, The United Kingdom

Corresponding author:

Gurch (Given Name) Randhawa (Family Name)

gurch.randhawa@beds.ac.uk

University of Bedfordshire

Putteridge Bury Campus

Hitchin Road

Luton, LU2 8LE

England

Keywords: Organ donation, Indians, UK, Integrative systematic review; Narrative synthesis,

Registration

Word count

Abstract: 303

Manuscript: 4192

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30 **Title:** Barriers toward deceased organ donation among Indians living in India and the United
31 Kingdom: An integrative systematic review using narrative synthesis.
32
33

34
35 **Abstract**

36
37 **Objectives:** To understand the barriers toward deceased organ donation among Indians living
38 globally. However, the studies reviewed were only among Indians living in India and UK, due
39 to methodological issues. Therefore, this review is based only among Indians living in India
40 and UK.
41
42
43
44
45

46 **Design:** Integrative systematic review using narrative synthesis

47
48 **Data sources:** CINAHL, MEDLINE, PsycINFO, Scopus, Global Health, Web of Science, and
49 PubMed Central, Indian Journal of Transplantation and Google scholar.
50
51

52 **Time period:** 1st January 1994 to 31st December 2021

53
54 **Participants:** Individuals of Indian origin living in India and UK.
55
56
57
58
59
60

1
2
3 **Results:** Seventy-one studies were included with more than 24,000 participants and quality
4 were assessed using Joanna Briggs Institute's critical appraisal tool. Though majority of the
5 participants had knowledge toward organ donation with a positive influence on willingness,
6 the gap between knowledge and willingness was huge, with minimal registration. The findings
7 showed that organ donation behaviour among this particular population is influenced by the
8 complex interactions between the individual and the socio-cultural constructs. Various
9 constructs of the society such as fear and mistrust, family, religion, bodily issues play a vital
10 role. Also, differences in willingness to donate and registration were identified between
11 southern and other regions of India.
12
13
14
15
16
17
18
19
20
21
22

23 **Conclusion:** Though this study showed the complex relationship, and its influences on organ
24 donation behaviour, lacunae were identified to further understand how such complex
25 interactions determine or inform the behaviour. Also, methodological issues were identified,
26 where this particular population outside India were collectively studied with their neighbouring
27 population which are not homogenous. Studies in India majorly addressed a similar aim using
28 similar methods which produced repetition of studies leading to lack of diversified, wider, and
29 in-depth research. Therefore, while this systematic review addressed the barriers toward organ
30 donor registration among Indians in India and UK, it also informs various gaps in research and
31 also methodological issues.
32
33
34
35
36
37
38
39
40
41
42
43

44 **PROSPERO registration number:** CRD42019155274

45
46
47 **Keywords:** Organ donation, Indians, UK, Integrative systematic review; Narrative synthesis,
48
49 Registration
50

51 **Strengths and Limitations:**

- 52 1. This is the first systematic review about barriers toward deceased organ donation
53
54
55 among Indians living in India and UK, registered with PROSPERO, and published.
56
57
58
59
60

2. Both quantitative and qualitative studies were included to address the aim of the review using integrative approach and narrative synthesis, an appropriate methodology.
3. Included studies that exclusively represented the Indian population and excluded studies that collectively studied with the heterogenous South Asian or Asian population, thereby keeping the rigour of this study and identifying methodological issues involved.
4. Findings are based on the quality of each studies appraised using appropriate tools, and the assessment is also made available to the view of the readers.
5. Studies were limited only to English language, and commentaries were excluded.

Main text

Introduction

Since the first deceased organ transplantation performed by Joseph Murray in 1960s, the science of transplantation has witnessed exponential growth [1]. However, the gap between demand and supply of organs has represented a significant challenge [2], particularly among the Asian population who live both within and outside their continent [3-5]. India located in the South of Asia is the second largest populous country in the world [6] having largest migrating population in Asia [7], and also has the highest prevalence of diabetes, hypertension, and many other comorbidities [8]. Such non-communicable diseases (NCD) among Indians [9, 10] leading them to end-stage organ failure [11, 12] increases their need for organs.

1
2
3 Whilst the need for organ donors is high among the Indian population, the actual number of
4 donors remain too low to satisfy the number of recipients on the waiting list [13], with the
5 Indian national organ donation rate (ODR) less than one per million population (pmp) [14].
6
7 Reluctance to donate organs among this ethnic population might not be isolated just within
8 Indian border [15], with evidence suggesting that Indian population from the United Kingdom
9 is also disproportionately impacted, where they continue to be over-represented in the recipient
10 waiting list but under-represented in the donor list [16]. Therefore, both in India and UK, people
11 of Indian origin show higher reluctance to organ donation which is reflected both in registration
12 and consent.
13
14

15
16
17 There have been a larger number of studies conducted among the Indian population living
18 globally to understand the factors that influence organ donor registration. However, to date,
19 there has been no systematic review conducted to synthesize the available evidence to
20 understand the barriers toward organ donor registration among the individuals of Indian origin.
21 Therefore, a systematic review was proposed with an aim to address this gap to gain a deeper
22 insight into the barriers toward organ donor registration among this particular population [17].
23
24

25
26
27 The protocol proposed to include Indians living globally [17], but this review represents Indian
28 population living only in India and UK. There had been studies globally that had included
29 Indian ethnic group to examine the barriers of organ donation. However, many of them did not
30 report the results exclusively for Indians but rather combined this population with those from
31 other Asian countries and few had no sufficient findings, therefore excluded. However, on the
32 other side, two studies were included from UK that had the potential to be included. Therefore,
33 this systematic review will address the barriers toward organ donor registration among the
34 Indian population living in Indian and UK, identify gaps in evidence to further research and
35 help stakeholders in furthering strategies to improve organ donation.
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Method

Protocol and registration

This systematic review's protocol has been registered in PROSPERO (CRD42019155274) and also published [17].

Systematic search

Search strategy was developed collaboratively with the research team and a subject specialist librarian. Databases namely CINAHL, MEDLINE, PsycINFO, Scopus, Global Health, Web of Science, and PubMed Central were utilised. Key terms related to organ donation were first identified from studies published along with search terms used in other systematic review on organ donation [18,19] and were tested in different combinations. Later, for each database, the search terms were then customised seeking to capture the most appropriate studies to answer the aim of this review (supplementary file 1) [20]. However, for other resources like google scholar and the Indian journal of transplantation other strategies were employed. All the published papers from January 1994 to December 2021 were searched from the archives of the Indian journal of transplantation archives to find relevant studies. With regard to google scholar, we searched using two methods. The first one used the word "Organ Donation AND India" in title; and the second one used the say keywords but searched anywhere in the article. However, due to very high number of search results in the second method, we limited the search until we found no further relevant studies (an approach used by other published systematic reviews) [21]

The systematic review included studies with individuals of Indian origin living both within and outside India (i.e., migrant / first / second generation), aged 18 years and above from varied settings [17]. Cross-sectional and qualitative study design were included as they were mostly employed to understand the barriers toward deceased organ donation. For all the databases,

1
2
3 search strategy was restricted between 1st of January 1994 (i.e., the year when the first law
4 toward organ donation was implemented in India) and 31st of December 2021 (i.e., a recent
5 day before the submission) and was restricted only to studies published in English. However,
6
7
8
9
10 interventional studies, commentary or opinion papers, studies on blood, bone marrow, body,
11
12 sperm, and egg donation were excluded alongside any studies which addressed only living
13
14
15 donation.

16 17 18 **Search outcome**

19
20 Following a stage-by-stage exclusion from 3,179 studies initially extracted from the main
21
22 databases, 31 studies were included in final review along with 40 studies included from other
23
24 sources (Figure 1). The studies were initially exported to RefWorks
25
26 (<https://refworks.proquest.com/>). Microsoft excel was used to keep a record of studies
27
28 excluded by duplicates, title, abstract, and full text. All the 3,179 studies along with studies
29
30 from other sources were screened by two authors independently and the final 71 studies
31
32 included were in-agreement with all the authors.
33
34
35

36
37 However, during the process, studies conducted among Indians living outside India were
38
39 identified to be collectively studied as South Asians or with other Asian population. For
40
41 instance, a study conducted among Indo-Canadians in Canada included all neighbouring ethnic
42
43 groups of India [22]. In UK, Indian population was collectively studied as South-Asians [4,
44
45 23]. In Malaysia, though sampling was distinguished their results were not sufficiently
46
47 addressed [24]. However, concerning organ donation, the perspective of deceased organ
48
49 donation varies even within India's nearest neighbouring country [4, 25]. Therefore, this review
50
51 included only the studies which exclusively reported the findings from Indian population, thus
52
53 making this systematic review address Indians living in India and UK.
54
55
56
57

58 59 **Quality assessment**

60

1
2
3 Appropriate critical appraisal tools from Joanna Briggs Institute (JBI) were used to critique the
4 rigour of each studies included [26], also used in other organ donation systematic review
5 [18,27]. Comprehensive reporting on the quality assessment for both cross-sectional and
6 qualitative studies are reported in figure 2. Quality assessment was initially carried out by the
7 primary researcher after which it was reviewed by the other two authors independently. Both
8 the authors along with the primary researcher agreed upon the quality assessment as mentioned
9 in figure 2. The review included all studies; however minimal emphasis was given for those
10 studies that demonstrated only fewer items in the quality assessment checklist.
11
12
13
14
15
16
17
18
19
20
21

22 **Data synthesis**

23
24 This systematic review followed an integrative review with narrative synthesis approach
25 enabling to synthesise complex information toward the phenomena of interest [28], a
26 methodology also employed in another systematic review on organ donation that reviewed both
27 quantitative and qualitative studies [19]. Narrative synthesis primarily depends on words and
28 texts to summarise the findings with four process elements such as 1) systematic search and
29 quality appraisal, 2) grouping and clustering of the studies reviewed, 3) text summary
30 development, and 4) assessment and interpretation [29].
31
32
33
34
35
36
37
38
39
40
41

42 Firstly, following the systematic search and quality appraisal, summary data was collected for
43 each study, and they were recorded across a table which had information needed to cluster the
44 studies to compare and study across (Table 1). Secondly, with the cross-sectional studies,
45 numerical results from each study were tabulated across a matrix and were compared across to
46 study their relationship in terms of barriers. Later, full synthesis of the four qualitative studies
47 was undertaken by coding the findings and discussion sections using NVivo11. Codes were
48 then organised into themes to address the barriers appropriately.
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 While comparing and studying across the studies included in the review to understand their
4 relationship, various elements such as what the study is about, type of study, their approach,
5 the findings, study settings, and population studied were also considered. Noblit and Hare
6 (1988) described this as 'Reciprocal translation', also used in other similar methodological
7 approaches [30-34]. Thirdly, full syntheses of both cross-sectional and qualitative studies were
8 studied across to understand the supporting and refuting evidence collectively. For each section
9 of the findings, quantitative studies provided the initial context following which findings from
10 qualitative studies were used to elaborate and explain. With limited qualitative study narratives
11 to support or refute the cross-sectional study findings, they were incorporated into the
12 integration of the findings wherever possible. Both convergent and divergent findings are
13 explained in this review, whereby if divergent findings were identified explanatory factors such
14 as type of study or setting, or population were provided to facilitate better understanding [19].
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Table 1: Evidence table

Author (s) (Year)	Study Site	Study Country	Aim	Study setting	Study design	Study sample size	Sampling technique
Adithyan et al, (2017)	Kerala	India	To assess the knowledge and attitude of medical students regarding organ donation	Final year Undergraduate Medical students	Cross-sectional	194	Not specified
Ahlawat et al, (2013)	Chandigarh	India	To assess the attitude of healthcare professionals employed in intensive or emergency care units of our hospital towards organ donation, and the influence of various factors on willingness for self-organ donation after death	Health workers in intensive units	Cross-sectional	361	Not specified
Alex et al, (2017)	Karnataka	India	To assess the knowledge and attitude regarding organ donation and transplantation among the medical students	Medical college	Cross-sectional	510	Convenient sampling
Alex et al, (2019)	Pan India	India	To assess the general public's knowledge and attitude towards organ donation over two decades	General public	Cross-sectional	3914 (i.e., 1461 in group I; 2453 in group II)	Not specified
Amaliyar et al, (2019)	Gujarat	India	To assess the knowledge, attitude, and practice towards organ donation among medical, arts and commerce students	Students from last 4 semester groups from medical, arts and commerce college	Cross-sectional	300 (i.e. 100 from each college)	Purposive sampling for centres; Random for participants
Balajee et al, (2016)	Pondicherry	India	To assess the awareness and attitudes regarding organ donation among rural people from 4 villages	General public	Cross-sectional	360	Systematic random sampling and random participant selection
Balwani et al, (2015)	Gujarat	India	To study the awareness and belief towards organ donation and its allocation in chronic kidney disease patients in western India	Tertiary care centre	Cross-sectional	85	Not specified
Balwani et al, (2015)	Gujarat	India	To determine the knowledge, attitude, and practice regarding organ donation in western India	Adult participants from a	Cross-sectional	200	Random sampling

				residential area around a tertiary healthcare centre			
Bansal et al, (2019)	Chandigarh	India	To analyse socio-demographic profile of the decision makers for organ donation in potential deceased donors//To determine the level of awareness regarding organ donation in decision makers and the correlation with the socio-demographic variables	Tertiary care teaching hospital among family members who consented to donate the organs of their loved ones	Quantitative	59	Purposive sampling
Bapat et al (2010)	Karnataka	India	To understand the awareness, attitudes, and belief towards organ donation among post-graduate medical students	Post-graduate medical students	Cross-sectional	123	Volunteer sampling
Basavarajegowda et al (2021)	Pan India	India	To study the knowledge difference between the knowledge and attitude about organ donation among blood donors compared to non-blood donors	General public	Cross-sectional	803	Purposive sampling
Bathija et al, (2017)	Karnataka	India	To investigate the knowledge and attitude towards organ donation among post-graduates, and interns; to know the reasons for donation one's organs	Post-graduate and medical interns	Cross-sectional	300	Not specified
Bharambe et al, (2015)	Maharashtra	India	To assess the knowledge and attitude of the people living in an urban city in India towards organ donation	Out-patient department	Cross-sectional	65	Not specified
Bharambe et al, (2016)	Maharashtra	India	To study the knowledge and attitude of a medical student doing internship with regards to organ donation	Medical college internship students	Cross-sectional	43	Not specified
Bharambe et al, (2018)	Maharashtra	India	To assess the knowledge and attitude of healthcare professionals from a rural part of India regarding organ donation	Healthcare professionals attending a medical association meeting	Cross-sectional	32	Not specified

Bharambe et al, (2018)	Maharashtra	India	To assess the knowledge and attitude of people from a rural part of India regarding organ donation.	Rural community members	Cross-sectional	201	Not specified
Bhargavi et al, (2019)	Kerala	India	To check the level of awareness and attitude of 2nd year medical, dental, and nursing students at Govt. Medical College, Thiruvananthapuram Campus towards organ donation and whole-body donation using a questionnaire-based study.	Medical and nursing students	Cross-sectional	177	Convenience sampling
Chakradhar et al, (2016)	Telangana	India	To assess and compare the knowledge, attitude, and practice regarding organ donation among dental students based on gender, year of study and religion	Dental college Undergraduate students	Cross-sectional	298	Not specified
Da Silva et al (2021)	West Bengal	India	To assess the knowledge, attitude, and practices of health-care professionals toward cadaveric organ donation and to know their awareness regarding legislations pertaining to cadaveric organ donation.	Healthcare professionals	Cross-sectional	400	Stratified random sampling
Darlington et al, (2019)	Tamil Nadu	India	To study the knowledge, attitude, and practice towards organ donation	Medical students	Cross-sectional	425	Voluntary
Dasgupta et al, (2014)	West Bengal	India	To ascertain the knowledge and attitude of the people regarding organ donation and to elicit the determinants of their knowledge and attitude in an urban community of west Bengal	Slum area residents	Cross-sectional	110	Simple random sampling
Deshpande et al, (2018)	Maharashtra and Madhya Pradesh	India	To determine the knowledge, attitude, and practice of pharmacy students about organ donation	Pharmacy college	Cross-sectional	160	Not specified
Flower et al (2013)	Pondicherry	India	To explore the general publics perceived barriers and facilitating factors of organ donation	General public	Cross-sectional	400	Random sampling
Gauher et al, (2013)	London	The United Kingdom	To determine the attitude towards organ donation among Indian and Pakistan students	Medical and Non-Medical students	Qualitative	9 focus group discussion (i.e. 50 participants) and 8 Semi-structured Interviews	Purposive sampling - Stratified sampling for groups
Ghose et al (2021)	Pune	India	To study knowledge and attitude toward organ donation among medical and nursing students with objectives to determine level of awareness about death	Medical and nursing students	Cross-sectional	400	Population proportion to size

criteria and need for organ donation and also to determine the attitude towards the same

Gupta et al, (2018)	Jammu & Kashmir	India	To assess the awareness and attitude of medical students regarding organ donation	Medical college Undergraduate students	Cross-sectional	280	Not specified
Gupta et al, (2021)	Maharashtra	India	To assess the pre-existing understanding beliefs, perception, and attitude, about deceased organ donation	College teachers and Students	Cross-sectional	80	Purposive sampling
Hakeem et al (2021)	Tamil Nadu	India	To assess knowledge, attitude, and perception of organ donation and transplant	Medical students and junior doctors	Cross-sectional	996	Not specified
Jayabharathi et al, (2019)	Tamil Nadu	India	To assess the knowledge and attitude on organ donation among selected community area	Community area	Cross-sectional	60	convenient sampling
Joshi et al, (2011)	The United Kingdom	The United Kingdom	To investigate the organ donor attitudes and donor card behaviour of young adult UK citizens with particular focus on those of South Asian origin	Higher education institutes in the UK	Cross-sectional	382	Purposive sampling
Jothula et al, (2018)	Telangana	India	To assess the knowledge, attitude, and practice towards organ donation among medical students	Medical college Undergraduate students	Cross-sectional	160	Not specified
Kachappillil et al (2020)	Kerala	India	To assess the attitude of general population towards organ donation residing in a rural community	General public	Cross-sectional	100	Convenient sampling
Kadam et al (2021)	Maharashtra	India	To study the knowledge and attitude of first-year medical students towards organ donation.	First year medical students	Cross-sectional	130	Not specified
Kaistha et al, (2016)	New Delhi	India	To determine the knowledge, attitude, and practice regarding organ donation	Patient attendants attending out-patient department	Cross-sectional	119	Convenience
Kalmath et al (2020)	Karnataka	India	To assess the level of knowledge, preparedness, and commitment towards organ donation.	Youth public	Cross-sectional	300	Probability stratified random sampling
Kaur et al (2021)	Punjab	India	To know the knowledge, attitude, and practices regarding organ donation among medical students of Punjab	Medical students	Cross-sectional	380	Not specified
Kennedy et al, (2002)	Kerala	India	To study the attitudes and beliefs about organ donation in India from the perspectives of the doctors and the public	Doctors and public	Qualitative	8 semi-structured interviews	Purposive

Khan et al (2020)	Jammu and Kashmir	India	To know the knowledge and attitude towards organ donation amongst the students	Student population	Cross-sectional	200	Not specified
Kundu et al (2021)	Chhattisgarh	India	To investigate the willingness to become an organ donor and the religious and cultural attitude of healthcare professionals	Medical and paramedical students	Cross-sectional	630	Not specified
Lokesh Kumar et al (2021)	Tamil Nadu	India	To determine the awareness of organ donation concerning organ donation amidst the rural population and to assess the attitude towards the organ donation	Rural public	Cross-sectional	203	Two stages random sampling
Mani, (2016)	Tamil Nadu	India	To identify the perceptions and practices related to organ donation in a rural population of Tamil Nadu, India	Rural population	Cross-sectional	100	Simple random sampling
Meghana et al, (2018)	Karnataka	India	To assess the knowledge of organ donation among the final year medical, dental, and nursing students and to study the attitude, religious beliefs of the healthcare professionals regarding organ donation and transplantation, to find out the effect of motivation, towards organ donation	Medical, dental, nursing students	Cross-sectional	150	Not specified
Minz et al, (1998)	Chandigarh	India	To find out the extent of awareness and attitudes, to help us formulate a further plan of action	Healthcare professionals	Survey	204	Not specified
Misra et al (2021)	Haryana	India	To understand the beliefs and knowledge of a rural community toward organ donation and the identification of barriers for organ donation	Rural public	Qualitative	4 FGDs with 48 participants	Simple random sampling
Misra et al (2021)	Haryana	India	To assess awareness about brain death and attitude towards organ donation in a rural community setting.	Rural public	Cross-sectional	947	Simple random sampling
Mithra et al, (2013)	Karnataka	India	To assess the perceptions and attitudes of the people seeking health care in tertiary care centres towards organ donation in Mangalore, India.	People seeking general healthcare as outpatients	Cross-sectional	863	Simple Random Sampling and convenient sampling
Mohan et al, (2019)	Tamil Nadu	India	To establish the role of perceived awareness, family support, perceived individual value, and religiosity on organ donation intention	Public	Cross-sectional	247	Convenience sampling
Mondal et al (2016)	West Bengal	India	To assess the knowledge and attitude of people towards organ donation in a rural community of West Bengal and to study the association of socio-demographic factors with the knowledge and attitude towards organ donation	Rural community	Cross-sectional	110	Simple random sampling
Panwar et al (2016)	New Delhi	India	To assess the awareness of the brain death and the concept of deceased organ donation among lay people and to identify the potential reasons for the low rates of deceased organ donation	General public	Cross-sectional	352	Not specified

Parmar et al (2021)	Gujarat	India	To assess the awareness among subjects regarding body donation and cadaveric dissection and their willingness to donate body	Patients	Cross-sectional	130	Not specified
Paul et al, (2019)	West Bengal	India	To understand the knowledge, attitude, and practice pattern of organ donation among the participants and to find out the association between the knowledge of organ donation with selected variables of interest	Urban field practice area of medical college	Cross-sectional	206	Not specified
Poreddi et al (2016)	Karnataka	India	To assess Indian undergraduate nursing students' attitude, knowledge, and willingness to donate organs	Nursing students	Cross-sectional	267	Non-probability convenience sampling
Poreddi et al, (2017)	Karnataka	India	To assess the knowledge, attitude, and willingness to donate organs among the general population	Patients attending outpatient department	Cross-sectional	193	Lottery method
Rajan (2020)	West Bengal	India	To assess the knowledge and attitude regarding blood and organ donation among adolescents	Adolescent population	Cross-sectional	100	Non-probability purposive sampling
Rani et al (2020)	New Delhi	India	To assess the knowledge ad attitude of general population towards organ donation	General public	Cross-sectional	1089	Purposive non-probability sampling
Ray et al (2020)	West Bengal	India	To assess the knowledge and attitude of certain populations like medical students with respect to organ donation	Medical students	Cross-sectional	134	Random sampling
Sachdeva et al, (2017)	Delhi	India	To assess knowledge, attitude, and practice regarding organ donation / tissue donation among adult visitors of a government hospital in Delhi, India	patient or accompanying attendant of a government hospital	Cross-sectional	450	Convenience sampling
Sam et al, (2018)	Tamil Nadu	India	To assess the awareness and attitude regarding Organ Donation among final year students of medical, dental, engineering, and arts and science students in Thirivallur and Chennai	Medical, dental, engineering, and arts and science students	Cross-sectional	486	Not specified
Sarveswaran et al, (2018)	Puducherry	India	To determine the knowledge, attitude, and practice regarding organ donation	Urban community members	Cross-sectional	257	Random

Seetharaman et al (2020)	Maharashtra	India	To evaluate the knowledge, attitudes, and beliefs of licensed medical doctors and undergraduate medical students	Medical doctors and students	Cross-sectional	532	Non-probability convenient sampling
Singh et al, (2002)	Uttar Pradesh	India	To study level of awareness in hospital staff about transplantation, brain death, and organ donation, as well as factors that may be associated with this awareness	Hospital staff	Cross-sectional	266 (i.e., 166 paramedics, 100 administration staff)	Simple Random Sampling
Soni et al, (2018)	Madhya Pradesh	India	To understand correlation between knowledge and attitude towards organ donation among medical and non-medical students and identify barriers to deceased organ donation; to look into participants perception for adoption of presumed consent policy in Indian context; and understanding the acceptance of donor acknowledgement in the form of organ incentivization	Medical and Engineering students	Cross-sectional	600 (i.e. 300 medical; 300 engineering students)	Random
Swamy et al (2020)	Karnataka	India	To assess the awareness and attitude of the young graduates in medical and engineering streams	Medical and Engineering students	Cross-sectional	400	Not specified
Swani et al (2020)	Uttarakhand	India	To know the awareness, perceived threat and factors affecting the willingness to donate organs	first-and second-degree relatives of deceased	Cross-sectional	166	Complete sampling
Tamuli et al, (2019)	Assam	India	To determine awareness and knowledge of educated (Undergraduate and postgraduate students) population towards organ donation; To find out factors impeding the organ donation program in this part of the country; To observe differences between findings of Undergraduate students and postgraduate degree holders (faculty)	Undergraduate and postgraduate students	Cross-sectional	360 (i.e., 180 undergraduate and 180 postgraduate students)	Not specified
Thyagarajan et al (2020)	Tamil Nadu	India	To assess the police officers' knowledge of the organ donation process and their practice toward it.	Police officers	Cross-sectional	627	Purposive sampling
Vijayalakshmi et al, (2015)	Karnataka	India	To investigate nurses' attitude towards organ donation	Nurses directly involved in patient care at a tertiary care hospital in South India	Cross-sectional	184	Non-probability convenience
Vijayalakshmi et al, (2016)	Karnataka	India	To assess the gender differences in perceptions and attitude of general population toward organ donation	Relatives of patients attending the	Cross-sectional	193	Lottery method

				outpatient department			
Vincent et al (2019a)	Pondicherry	India	To understand the subjective views on barriers in the process of deceased organ donation among the stakeholders and their suggestions to improve in a government tertiary care teaching hospital	Transplant unit stakeholders	Qualitative	6 In-depth interviews	Purposive sampling
Vincent et al (2019b)	Pondicherry	India	To assess the knowledge, attitude, and perception on organ donation among undergraduate medical and nursing students	Under-graduate medical and nursing students	Cross-sectional	620 (i.e., 375 medical students and 245 nursing students)	Convenient sampling for population and voluntary for participants
Yadav et al (2020)	Haryana	India	To determine the knowledge and attitude of faculty members of a university	Faculty members	Cross-sectional	170	Not specified

6/bmjopen-2021-056094 on 27 May 2022. Downloaded from <http://bmjopen.bmj.com/> on April 20, 2024 by guest. Protected by copyright.

Findings

Grouping and clustering

Among the 71 studies reviewed; majority (97%) were conducted among Indians living in India (n=69) while other two studies were among people of Indian origin living in UK. Cross-sectional studies (n=67) included various settings such as general community (30%), education institutions (44%) and hospital setting (30%) (Table 1). Qualitative studies (n=4) consisted of in-depth interviews (75%) and focus group discussion (50%) (Table 1). Among the 24,463 individuals involved in the retained studies, 24,023 individuals (98.2%) were from studies conducted in India. Among the studies conducted in the UK, only one study distinguished 107 individuals as Indians, whereas the other with 60 individuals had no evidence on the sample number of Indian participants involved.

Findings

Integration and relationship

Based on the narrative synthesis, findings are described under the following six themes namely:

1) knowledge and awareness toward deceased organ donation and registration, 2) willingness and actual behaviour toward deceased organ donor registration, 3) familial influence, 4) fear and mistrust, 5) religious influences, and 6) bodily issues.

Knowledge and awareness of deceased organ donation and registration

Being the commonest theme studied across, findings showed that knowledge had a positive correlation with willingness and practice [35-41]. Both among Indians in India and UK, younger adults, participants from higher socio-economic status, and with higher education or healthcare education demonstrated higher knowledge toward deceased organ donation [41-57] and

1
2
3 individuals from southern region of India showed higher knowledge compared to other regions
4
5 in India [58-63].
6
7

8
9 Whilst majority of the studies confirmed that almost all the participants had heard about organ
10
11 donation (Figure 3) and had higher awareness, knew what organs can be donated [37,50-52,
12
13 64-78] and that organs can be donated to anyone [43,58,77], the knowledge and understanding
14
15 on brain death was less well understood [46,61,65,66,72,79,80]. A qualitative study from an
16
17 urban area in the southern region of India also found brain death as a new concept for many
18
19 and hard to accept among the public [81]. Also, many were not aware about the organ donor
20
21 card [64, 82-85], where and how to register and obtain an organ donor card
22
23 [38,,47,50,67,68,52,53,85] - an important component for organ donor registration. In addition,
24
25 knowledge on the law that governs organ donation was also found to be low [38,68,83,86,87].
26
27
28

29
30 Though a study among Indians living in UK showed that disinterest, emotional distaste, family
31
32 opposition and religion to be the underlying cause for reluctance to register [55], among Indians
33
34 living in India, the awareness on brain death, organ donor card, where and how to register are
35
36 also important factors serving as barriers to individuals who are willing to register
37
38 [38,46,47,50,52,61,64,66-69,79,82-86,88].
39
40
41

42 **Willingness and registration toward deceased organ donation**

43
44

45
46 Greater knowledge showed positive influence on the attitude and willingness across all Indian
47
48 regions [39,41,,47,83,89-93]. Similar to higher knowledge among individuals from southern
49
50 region of India, willingness to register, to donate and to accept organs for transplant was also
51
52 shown to be higher [36,42,43,46,63,65,83,89,91]. However, though knowledge had a positive
53
54 association toward attitude and willingness, the proportion of individuals willing to register,
55
56 and actual registration was very low and similar across every study included (Figure 2).
57
58 Correspondingly, even a study conducted among Indian students living in UK revealed that
59
60

1
2
3 55% of the individuals doubted if they would go ahead with registration [55]. With such
4
5 reluctance, Indians living in India and UK considered fear of misuse and family refusal as a
6
7 major reason, alongside minor reasons like emotional barriers, bodily issues, and religion
8
9 [43,50,52,55,60,62,66,68,69,71,72,76,85,87,90,94]. On contrary, commonest reasons to
10
11 donate an organ was to save someone's life, closely followed by elongate someone's life, social
12
13 commitment, altruistic deed, and that at least their deceased one's organs can live
14
15 [69,72,82,89,94-97].

16
17
18
19
20 Higher proportion of participants were willing to receive compared to donating
21
22 [36,42,43,55,65,,89,91,98] both among Indians from India and UK. Furthermore, studies
23
24 revealed that among those who were willing to donate, majority were only willing to donate
25
26 specific organs namely eye / cornea and kidneys [43,58,59], which may be related to the
27
28 knowledge on what organs can be donated [64-69,73-75,79]. Nonetheless, majority of the
29
30 participants were willing to support and promote organ donation in their region and was similar
31
32 across India [52,54,82,89,95,96].

33
34
35
36
37 Younger adults, participants from higher socio-economic status and participants with higher
38
39 education or healthcare education demonstrated higher willingness toward deceased organ
40
41 donation both among Indians in India and UK [25,41,42,44,45,50,55-58]. However, this was
42
43 not consistent during the time of actual behaviour. Studies showed that there was almost equal
44
45 distribution of participants from lower socio-economic status and lower education, who did
46
47 give consent and actually signed for deceased organ donation [44,86]. However, this
48
49 conclusion is based only from few studies showed to be similar in north and south of India
50
51 [44,86].
52
53

54 55 56 **Familial influence** 57 58 59 60

1
2
3 In-spite of willingness to register for organ donation (Figure 2), larger proportion of individuals
4 have not initiated a conversation or discussed their willingness with their family members, an
5 important behaviour for a successful donation [49,62,65,68,84,90,99,100] - however opted
6 family as the major barriers toward organ donation [43,60,62,66,69,85,90,92]. A qualitative
7 study conducted in India and UK revealed the main reasons surrounded a lack of confidence in
8 initiating conversations around sudden deaths, and with these conversations perceived
9 unwelcome by their parents and elders [25,81]. However, another qualitative study conducted
10 among Indian students who were born and grew in UK revealed that they are less concerned
11 of sharing their views compared to their older generations (i.e., mostly migrant generation) and
12 were more willing to discuss their wishes with their families [25,78,101], which could be
13 related to acculturation. On the other side, a qualitative study conducted in southern India
14 among urban living adults suggested that such conversation only occurred when individuals
15 read or viewed such events [81]. Also, during the time of consent request, unknown will of the
16 deceased showed to be a significant challenge during the decision-making process [86], making
17 such discussion very important during the crucial decision-making moments.

18
19 Willingness to support family members was shown to be higher among healthcare students
20 compared to other students [52,102] and lower among family members from rural areas
21 [89,100]. However, while higher proportion of individuals were willing to support family
22 members for organ donation [36,58,68,83,91,101], only very few families actually supported
23 this decision when families were approached for consent [81].

24
25 Though studies included found no association based on marital status [36,42,91], one study
26 found that unmarried individuals appeared to be more willing to donate compared to married
27 couples [91]. Also, participants who were aware of their spouse's approval opinion, they were
28 more willing to donate compared to those unaware of their spouse's opinion [42]. Among the
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 type of family, individuals from 'joint' families had higher knowledge, while willingness to
4 donate was found to be higher among nuclear families [36,45,47].
5
6
7

8 **Fear and Mistrust**

9
10
11 Fear on misuse of organs by the healthcare team, revealing lack of trust was the other major
12 barrier reported [25,38,45,52,60,61,65,66,68,69,75,85,87,94]. Some participants relate organ
13 donation to organ trafficking and misuse which leads them to fear and mistrust [46,62,89]. A
14 qualitative study also revealed increased ambivalence that while on one side participants
15 perceived organ donation as a noble act, on the other side they were also fearful of organ misuse
16 due to the information that they hear through news and media on organ trafficking and
17 exchange of money for organs [81].
18
19
20
21
22
23
24
25
26
27

28 Also in UK, among Indian participants, a mother was afraid to see an organ donor card in his
29 child's wallet as she was thinking if doctors will come to see it, then they may deviate the
30 process toward donation and give less care toward saving her child [25]. In parallel, general
31 population from India also feared pre-mature declaration of death for the need of organs
32 [37,89,102]. However, healthcare population groups were less likely to believe that there will
33 be any premature declaration of death by the doctors [36,68,80].
34
35
36
37
38
39
40
41
42

43 **Religious influence**

44
45 Overall, majority of the participants favoured organ donation [25,36,43,44,46,58,77,78,91,95].
46 However, when further looked based on religion, different studies showed different religious
47 groups to be more willing to donate compared to individuals from another religious group
48 [42,45,58,70,103], showing no consistency on which particular religion is more supportive or
49 rejective [42,45,49,58,103]. In parallel, a qualitative study conducted among UK university
50 students of Indian descendants showed lack of homogeneity even within one same religion.
51 Some agreed that body needs to be intact for reincarnation, while other participants believed
52
53
54
55
56
57
58
59
60

1
2
3 that body and soul are two different entities and that only the soul counts while body is left to
4 decay in this earth [25,87].
5
6
7

8
9 However, though there were differences of opinion across and within the religion, majority of
10 the participants agreed that organ donation is not against religious views
11 [36,65,69,81,87,91,95] and also considered religion as the very least barrier toward organ
12 donation [42,60,62,65,81,99,104]. A qualitative study conducted among UK students with
13 Indian origin showed that though individuals felt religion may influence their decision it was
14 not the only factor that that will be considered in such decisions [25]. Yet, favourable opinion
15 of religion toward organ donation was found to be positively correlating with their willingness
16 to donate [36,49].
17
18
19
20
21
22
23
24
25
26

27 A Qualitative study conducted in UK with Indian students revealed that younger generations
28 were less bothered about religious views compared to older generations, which could have
29 occurred due to acculturation [25]. Also, participants preferred that religion should not be a
30 criterion based on which allocation can be decided [45,65,95,99] and that organ of a deceased
31 person can be donated to a recipient from any religion [45,65,95,99].
32
33
34
35
36
37
38
39

40 However, during the time of consent, a stakeholder from a qualitative study said that families
41 who were not willing to donate use the concept of religion as a pre-framed reason to decline
42 donation, though none of the religion is against organ donation. In the same qualitative study,
43 public participants from different religious group felt that their religion supports organ donation
44 [81].
45
46
47
48
49
50

51 **Bodily issues**

52 Majority of the individuals from the reviewed studies were not concerned about bodily issues
53 though it has to undergo incisions while explanting [36-38,42,43,58,82,87,101]. However, on
54 the other side, majority also agreed that it is an individual's complete right to have the organs
55
56
57
58
59
60

1
2
3 within the body when dead [46,80]. Whilst majority of individuals were not concerned about
4 incisions in the body, a qualitative study found that in the real time of consent, stakeholders
5 found it easy to get approval for corneal donation and not solid organs as it may have many
6 incisions over the body and disfigure it [69]. In relation to funeral practices involving the
7 deceased body, majority were aware that normal funeral practices can be conducted even after
8 donating organs [36,46,58,80,82,99], contrast findings were also evident [46,52,80]. However,
9 majority opted body disfigurement as one of the least reasons to be a barrier toward organ
10 donation [43,60,62,66,90].
11
12
13
14
15
16
17
18
19
20
21

22 **Discussion**

23
24
25 To the best of our knowledge, this is the first systematic review that reviewed barriers toward
26 organ donation among Indians in India and UK, while other potential studies were excluded
27 due to methodological issues. Also, this is one of the few systematic reviews in organ donation
28 that used integrative methodology. While majority in India have heard or are aware of organ
29 donation, and had a positive correlation with willingness, their gap is wide. This indicates that
30 there could be various factors other than knowledge which need to be studied in more detail.
31 Organ donation being more embedded with health behaviour, there is a need to understand the
32 relationship between behaviour and behavioural intention by adopting appropriate principles.
33 This aids the specificity of policy and campaigns to address organ donor registration behaviour
34 in this particular population.
35
36
37
38
39
40
41
42
43
44
45
46
47
48

49 Though gaps identified in majority of the quantitative studies merit qualitative studies, only
50 very few qualitative studies were undertaken in India [80,81,87]. For instance, though majority
51 individuals were willing to be an organ donor, majority have not initiated any such conversation
52 with their family members yet considered family to be the major barrier [23,43,60,62,66,90].
53
54
55
56
57
58 However, no further studies were exclusively undertaken to understand how a construct like
59
60

1
2
3 family interferes in the decision making toward registration and consent. Such studies will aid
4
5 in developing and testing hypothesis or developing appropriate interventions to increase such
6
7 conversation with family members. Such conversations play a very important role as the
8
9 awareness on the willingness of the deceased plays a vital role in decision-making during
10
11 consent [86]. However, the influence of family can be different among Indians in India and UK
12
13 as the latter may have influences based on acculturation and enculturation [25,55] while the
14
15 prior maybe more concerned toward communication issues [49,62,65,81,84,90,99,100]. While
16
17 majority were willing to be an organ donor [25,41,42,44,45,50,55-58], they were unaware on
18
19 how to register to be an organ donor [38,47,50,52,53,67,68,85]. Therefore, further campaigns
20
21 on registration procedure information and centralised registries will enable to improve organ
22
23 donation in India.
24
25
26
27
28

29 This review shows that there are various complex interactions that happen in the society where
30
31 an individual lives rather than just knowledge influencing organ donation decision. Fear and
32
33 mistrust have shown to influence the uncertainty in decision-making for a very long time
34
35 [25,38,45,52,60,61,65,66,68,69,75,87]. However, studies failed to address how fear influences
36
37 organ donation, what is the source of fear and how a construct like fear can be addressed. This
38
39 fear could be due to the news or information that they hear on illegal organ donation and
40
41 transplants practices around them or any other reasons [105], but not much have been studied
42
43 why such fear exist among this population.
44
45
46
47

48 Also, while majority of the studies show influence of religion on organ donation, there is a
49
50 greater need to understand how a religion influences organ donation in India. Is it the
51
52 misconception, or the lack of enabling religious community, or reluctance to take such
53
54 conversation, or lack of information from the religious leaders or their physical practices that
55
56 does not allow donation? Such in-depth studies need to be undertaken to gain a deeper
57
58 understanding into the phenomena. Therefore, at the moment, there is a need to study further
59
60

1
2
3 how the interaction of the individuals with such a complex socio-cultural and institutional
4 structures influences the organ donation behaviour.
5
6

7
8 Various other factors such as age, sex, education, and socio-economic status showed greater
9 influence on willingness to donate [25,42,44,45,50,55,58]. However, studies showed that they
10 did not hold true during the time of consent [44,86]. This review therefore showed that there is
11 some shift in behaviour during registration and the actual consent. This again probes to further
12 the understanding on what happens during the time of consent, and why such a shift is seen in
13 the intention to donate between these two time periods.
14
15
16
17
18
19
20
21
22

23 Methodologically, studies conducted among the Indian ethnic group outside India were
24 collectively identified as South-Asians or Asians [19,22,106] while they differ culturally,
25 socially, politically, economically, and even religiously [107]. Two studies included from UK
26 in this review have clearly shown such a difference with the neighbouring country (i.e., India,
27 and Pakistan) [25]. Therefore, there is a need to address this population with such specificity
28 in future research that can strengthen the practices even more efficiently. Also, with this
29 population to be the largest migrating population in the world [7] it is important to understand
30 their behaviour outside India. Studies show difference between various migration generations
31 from the same ethnicity [25,55]. This cannot happen without the influence of time elapsed since
32 immigration, immigrant generation (i.e., first, second, or higher), acculturation, enculturation,
33 perceived discrimination, attitudes / mistrust toward healthcare system, community barriers,
34 socio-cultural influence and many such complex determinants which adds further complexity
35 to the issue of organ donation among such a population. Therefore, such specific research
36 among this community is also needed to address the disproportionate representation between
37 waiting list and donor list from this ethnic population outside the country of origin. Though
38 narrative synthesis is criticised for its lack of transparency, this study has tried to be as
39 transparent as possible to strengthen its validity and credibility of the review and synthesis
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 [28,108]. The PRISMA flow chart, search strategy, data synthesis and analysis methods are
4
5 clearly explained in this study to overcome those limitations.
6
7

8 **Conclusion**

9
10
11 This review showed that majority of the participants from India and of Indian origin hold
12
13 positive attitude toward registration but show lower willingness and even lower practice of
14
15 registration. Though this study showed the complex relationship and influences toward organ
16
17 donation behaviour, lacunae were identified for further deeper understanding into such
18
19 complex interactions determining the behaviour. There is also a lack of methodological rigour
20
21 to study this particular population outside India, being collectively studied with their
22
23 neighbouring population which are not homogenous. Also, within India, majority of the studies
24
25 employed similar aims and methods leading to repetition of studies rather than diversified,
26
27 wider, and in-depth research.
28
29
30
31
32

33 **Funding sources:** This review is led by the principal investigator Britzer Paul Vincent who is
34 a PhD scholar at the Institute for Health Research, University of Bedfordshire funded by their
35 Global Challenges Research Fund.
36

37 **Authorship Contribution:**

38 All authors BP, GR & EC contributed to – conception of the study, design of work, data
39 acquisition, data analysis, data interpretation, writing of the article, final approval, and
40 accountability of the study.
41
42

43 **Acknowledgement:** We would like to thank our librarian Mr. David Abdy from Institute for
44 Health Research, University of Bedfordshire for his contribution with the development of the
45 search strategy.
46
47

48 **Data availability:** None
49

50 **Conflict of Interest:** None declared.
51
52

53 **Patient and Public involvement:** None as this is a systematic review
54

55 **Ethics approval details:** Institute for Health Research Ethics Committee from the University
56 of Bedfordshire approved this study (IHREC931).
57
58
59
60

References:

1. Merrill, J.P., Murray, J.E., Takacs, F.J., Hager, E.B., Wilson, R.E. and Dammin, G.J., 1963. Successful transplantation of kidney from a human cadaver. *Jama*, 185(5), pp.347-353.
2. Rudge C, Matesanz R, Delmonico FL, Chapman J. International practices of organ donation. *British journal of anaesthesia*. 2012 Jan 1;108(suppl_1):i48-55.
3. Alden, D.L. and Cheung, A.H., 2000. Organ donation and culture: a comparison of Asian American and European American beliefs, attitudes, and behaviors. *Journal of Applied Social Psychology*, 30(2), pp.293-314.
4. Karim A, Jandu S, Sharif A. A survey of South Asian attitudes to organ donation in the United Kingdom. *Clinical transplantation*. 2013 Sep;27(5):757-63.
5. Lo, C.M., 2012. Deceased donation in Asia: challenges and opportunities. *Liver Transplantation*, 18(S2), pp.S5-S7.
6. United Nations. Department of Economics and social affairs. Population dynamics. Available at: <https://population.un.org/wpp/Download/Standard/Population/>. Last viewed: 03 April 2021
7. World Migration Report. 2020. Available at: https://www.un.org/sites/un2.un.org/files/wmr_2020.pdf. Last viewed 03 April 2021
8. Ramachandran, A., Ma, R.C.W. and Snehalatha, C., 2010. Diabetes in asia. *The Lancet*, 375(9712), pp.408-418.
9. Ramachandran, A., Snehalatha, C., Shetty, A.S. and Nanditha, A., 2012. Trends in prevalence of diabetes in Asian countries. *World journal of diabetes*, 3(6), p.110.
10. Singh, R.B., Suh, I.L., Singh, V.P., Chaithiraphan, S., Laothavorn, P., Sy, R.G., Babilonia, N.A., Rahman, A.R.A., Sheikh, S., Tomlinson, B. and Sarraf-Zadigan, N.,

- 1
2
3 2000. Hypertension and stroke in Asia: prevalence, control and strategies in developing
4 countries for prevention. *Journal of human hypertension*, 14(10), pp.749-763.
5
6
7
8 11. Ritz E, Rychlík I, Locatelli F, Halimi S. End-stage renal failure in type 2 diabetes: a
9 medical catastrophe of worldwide dimensions. *American journal of kidney diseases*.
10 1999 Nov 1;34(5):795-808.
11
12
13
14 12. Weisstuch JM, Dworkin LD. Does essential hypertension cause end-stage renal
15 disease?. *Kidney international Supplement*. 1992 May 2(36).
16
17
18
19 13. Navin S, Shroff S, Niranjana S. 'Deceased Organ Donation in India'. Available:
20 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
21 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
22 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
23 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
24 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
25 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
26 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
27 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
28 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
29 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
30 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
31 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
32 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
33 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
34 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
35 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
36 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
37 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
38 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
39 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
40 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
41 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
42 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
43 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
44 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
45 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
46 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
47 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
48 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
49 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
50 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
51 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
52 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
53 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
54 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
55 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
56 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
57 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
58 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
59 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
60 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
14. National Deceased Donor Transplantation, Mohan Foundation. 2017. Available:
<https://www.mohanfoundation.org/deceased-organdonation-in-india.asp> [Accessed
18 March 2021].
15. Kumar, V., Ahlawat, R., Gupta, A.K., Sharma, R.K., Minz, M., Sakhuja, V. and Jha,
V., 2014. Potential of organ donation from deceased donors: study from a public sector
hospital in India. *Transplant International*, 27(10), pp.1007-1014.
16. NHSBT. Organ Donation and Transplantation data for Black, Asian and Minority
Ethnic (BAME) Communities. 2018. Available at:
[https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/12048/bame-organ-](https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/12048/bame-organ-donation-and-transplantation-data-2017-18.pdf)
donation-and-transplantation-data-2017-18.pdf. Last viewed: 03 April 2021
17. Vincent BP, Randhawa G, Cook E. Protocol: Barriers towards organ donor registration
and consent among people of Indian origin living globally: a systematic review and
integrative synthesis—protocol. *BMJ Open*. 2020;10(6).
18. Irving, M.J., Tong, A., Jan, S., Cass, A., Rose, J., Chadban, S., Allen, R.D., Craig, J.C.,
Wong, G. and Howard, K., 2012. Factors that influence the decision to be an organ

- 1
2
3 donor: a systematic review of the qualitative literature. *Nephrology dialysis*
4 *transplantation*, 27(6), pp.2526-2533.
5
6
7
8 19. Morgan, M., Kenten, C., Deedat, S. and Donate Programme Team, 2013. Attitudes to
9 deceased organ donation and registration as a donor among minority ethnic groups in
10 North America and the UK: a synthesis of quantitative and qualitative
11 research. *Ethnicity & health*, 18(4), pp.367-390.
12
13
14
15 20. Kotha, S., Lawendy, B., Asim, S., Gomes, C., Yu, J., Orchanian-Cheff, A., Tomlinson,
16 G., & Bhat, M. (2021). Impact of immunosuppression on incidence of post-transplant
17 diabetes mellitus in solid organ transplant recipients: Systematic review and meta-
18 analysis. *World journal of transplantation*, 11(10), 432–442.
19 <https://doi.org/10.5500/wjt.v11.i10.432>
20
21
22
23
24
25 21. Piasecki, J., Waligora, M., & Dranseika, V. (2017). What Do Ethical Guidelines for
26 Epidemiology Say About an Ethics Review? A Qualitative Systematic Review. *Science*
27 *and engineering ethics*, 23(3), 743–768. <https://doi.org/10.1007/s11948-016-9829-3>
28
29
30
31 22. Molzahn, A.E., Starzomski, R., McDonald, M. and O'Loughlin, C., 2005. Indo-Canadian
32 beliefs regarding organ donation. *Progress in Transplantation*, 15(3), pp.233-239.
33
34 23. Randhawa, G., 1998. An exploratory study examining the influence of religion on
35 attitudes towards organ donation among the Asian population in Luton, UK. *Nephrology,*
36 *dialysis, transplantation: official publication of the European Dialysis and Transplant*
37 *Association-European Renal Association*, 13(8), pp.1949-1954.
38
39
40
41 24. Wong, L.P., 2010. Information needs, preferred educational messages and channel of
42 delivery, and opinion on strategies to promote organ donation: a multicultural
43 perspective. *Singapore medical journal*, 51(10), p.790.
44
45
46 25. Gauher ST, Khehar R, Rajput G, Hayat A, Bakshi B, Chawla H, Cox BM, Warrens AN.
47 The factors that influence attitudes toward organ donation for transplantation among UK
48 university students of Indian and Pakistani descent. *Clinical transplantation*. 2013
49 May;27(3):359-67.
50
51
52
53 26. JBI Critical Appraisal Tools. Available at: <https://jbi.global/critical-appraisal-tools>. Last
54 viewed: 03 April 2021
55
56
57 27. Gao, W., Plummer, V. and Williams, A., 2017. Perioperative nurses' attitudes towards
58 organ procurement: a systematic review. *Journal of clinical nursing*, 26(3-4), pp.302-
59 319.
60

- 1
2
3 28. Brown SJ. Knowledge for health care practice: A guide to using research evidence.
4 Saunders; 1999.
- 5
6 29. Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, Britten N, Roen K,
7 Duffy S. Guidance on the conduct of narrative synthesis in systematic reviews. A product
8 from the ESRC methods programme Version. 2006 Apr 1;1:b92.
- 9
10 30. Noblit GW, Hare RD. Meta-ethnography: synthesizing qualitative studies, vol. 11.
11 California: Sage Publications; 1988.
- 12
13 31. Campbell R, Pound P, Pope C, Britten N, Pill R, Morgan M, Donovan J. Evaluating meta-
14 ethnography: a synthesis of qualitative research on lay experiences of diabetes and
15 diabetes care. *Soc Sci Med*. 2003;56(4):671–84.
- 16
17 32. Campbell, R., Pound, P., Morgan, M., Daker-White, G., Britten, N., Pill, R., Yardley, L.,
18 Pope, C. and Donovan, J., 2012. Evaluating meta ethnography: systematic analysis and
19 synthesis of qualitative research.
- 20
21 33. Nye E, Melendez-Torres GJ, Bonnell C. Origins, methods, and advances in qualitative
22 meta-synthesis. *Review of Education*. 2016;4(1):57–79.
- 23
24 34. Garside R. A comparison of methods for the systematic review of qualitative research:
25 two examples using Meta-ethnography and Meta-study. UK: University of Exeter; 2008.
- 26
27 35. Alex P, Kiran KG, Baisil S, Badiger S. Knowledge and attitude regarding organ donation
28 and transplantation among medical students of a medical college in South India. *Int J*
29 *Community Med Public Health*. 2017 Sep;4(9):3449-54p.
- 30
31 36. Bapat U, Kedlaya PG. Organ donation, awareness, attitudes and beliefs among post
32 graduate medical students. *Saudi Journal of Kidney Diseases and Transplantation*. 2010
33 Jan 1;21(1):174.
- 34
35 37. Chakradhar K, Doshi D, Reddy BS, Kulkarni S, Reddy MP, Reddy SS. Knowledge,
36 attitude and practice regarding organ donation among Indian dental students.
37 *International journal of organ transplantation medicine*. 2016;7(1):28.
- 38
39 38. Gupta RK, Singh P, Akhtar N, Kumari R, Gupta C, Gupta R. Gender based perspectives
40 about organ donation among students in a medical school in North India. *International*
41 *Journal of Research in Medical Sciences*. 2018 May;6(5):1710.
- 42
43 39. Jayabharathi B, Devika M, Akila M. Assessment of knowledge and attitude on organ
44 donation among adults in selected areas. *International Journal of Research in*
45 *Pharmaceutical Sciences*. 2019 Apr 15;10(2):782-6.
- 46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
40. Singh P, Kumar A, Pandey CM, Chandra H. Level of awareness about transplantation, brain death and cadaveric organ donation in hospital staff in India. *Progress in Transplantation*. 2002 Dec;12(4):289-92.
 41. Panwar, R., Pal, S., Dash, N.R., Sahni, P., Vij, A. and Misra, M.C., 2016. Why are we poor organ donors: a survey focusing on attitudes of the lay public from northern India. *Journal of clinical and experimental hepatology*, 6(2), pp.81-86.
 42. Ahlawat R, Kumar V, Gupta AK, Sharma RK, Minz M, Jha V. Attitude and knowledge of healthcare workers in critical areas towards deceased organ donation in a public sector hospital in India. *The National medical journal of India*. 2013 Jan 1;26(6):322-6.
 43. Balajee KL, Ramachandran N, Subitha L. Awareness and attitudes toward organ donation in rural Puducherry, India. *Annals of Medical and Health Sciences Research*. 2016;6(5):286-90.
 44. Bansal N, Koushal V, Mehra A. A study of sociodemographic profile and level of awareness of the decision makers for organ donation of deceased organ donors in a Tertiary Care Hospital. *Indian Journal of Transplantation*. 2019 Jan 4;13(2):82.
 45. Dasgupta A, Shahbabu B, Sarkar K, Sarkar I, Das S, Kumar Das M. Perception of organ donation among adults: A community based study in an urban community of West Bengal. *Scholars J Appl Med Sci*. 2014;2(6A):2016-1.
 46. Poreddi V, Sunitha TS, Thimmaiah R, Math SB. Gender differences in perceptions and attitudes of general population towards organ donation: An Indian perspective. *Saudi Journal of Kidney Diseases and Transplantation*. 2017 May 1;28(3):599.
 47. Sarveswaran G, Sakthivel MN, Krishnamoorthy Y, Arivarasan Y, Ramakrishnan J. Knowledge, attitude, and practice regarding organ donation among adult population of urban Puducherry, South India. *Journal of education and health promotion*. 2018;7.
 48. Tamuli RP, Sarmah S, Saikia B. Organ donation—"attitude and awareness among undergraduates and postgraduates of North-East India". *Journal of family medicine and primary care*. 2019 Jan;8(1):130.
 49. Vijayalakshmi P, Sunitha TS, Gandhi S, Thimmaiah R, Math SB. Knowledge, attitude and behaviour of the general population towards organ donation: an Indian perspective. *The National medical journal of India*. 2016 Sep 1;29(5):257.
 50. Swain, R., Prasad, H., Lalwani, S. and Pooniya, S., 2020. Awareness, perceived barriers and factors affecting willingness for Organ Donation among the first-and second-degree

- relatives of deceased in a tertiary care hospital of Northern India. *The Official Publication of Indian Academy of Forensic Medicine*, 42(4), pp.261-264.
51. Kadam, S., Shinde, S., Shroff, G. and Gulanikar, S., **2021**. Knowledge and Attitude About Organ Donation Among Medical Students: An Observational Study from Aurangabad, Maharashtra. *Int J Cur Res Rev| Vol, 13(01)*, p.121.
52. Kundu, S., **2021**. Attitudes and Myths regarding Posthumous whole Body Bequest and Organ Donation among Medical Professionals and Health Care Personnel of Tribal Chhattisgarh—A Broad Questionnaire Based Review. *Sch J App Med Sci*, 6, pp.1093-1116.
53. Swamy, R.M., Kalaburgi, R.A., Manjunath, G.N., Lavanya, R. and Kousalya, R., Knowledge and Attitude towards Organ donation among the Medical and Engineering students in Tumakuru, Karnataka. *IOSR Journal of Dental and Medical Sciences (IOSR-JDMS)* e-ISSN: 2279-0853, p-ISSN: 2279-0861. Volume 19, Issue 5 Ser.2 (May. 2020), PP 31-36
54. Gupta, P., Sodhani, S., & Bhate, K. (2021). Organ donation perception and beliefs: a cross sectional study amongst degree college students and teachers in Mumbai, Maharashtra, India. *International Journal of Advances in Medicine*, 8(3), 399-403.
55. Joshi MS. Whose decision is it? Organ donation attitudes among young UK South Asians. *Psychological Studies*. 2011 Mar 1;56(1):86-97.
56. Misra, P., Malhotra, S., Sharma, N., Misra, M.C., Vij, A. and Pandav, C.S., 2021. Awareness about brain death and attitude towards organ donation in a rural area of Haryana, India. *Journal of Family Medicine and Primary Care*, 10(8), p.3084.
57. Parmar, K.M., Vaisnani, H., Chavda, N., Sharma, P. and Jethava, K., 2021. A Questionnaire Based Study Evaluating Awareness for Organ and Body Donation and Cadaveric Dissection among the General Population Attending Medical and Dental Hospital. *Medico Legal Update*, 21(1), pp.835-839.
58. Mithra P, Ravindra P, Unnikrishnan B, Rekha T, Kanchan T, Kumar N, Papanna M, Kulkarni V, Holla R, Divyavaraprasad K. Perceptions and attitudes towards organ donation among people seeking healthcare in tertiary care centers of coastal South India. *Indian journal of palliative care*. 2013 May;19(2):83.
59. Balwani MR, Gumber MR, Shah PR, Kute VB, Patel HV, Engineer DP, Gera DN, Godhani U, Shah M, Trivedi HL. Attitude and awareness towards organ donation in western India. *Renal failure*. 2015a Apr 21;37(4):582-8.

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
60. Bathija GV, Ananthesh BG, Bant DD. Study to assess knowledge and attitude towards organ donation among interns and post graduates of a medical college in Karnataka, India. *Natl J Community Med.* 2017;8(5):236-40.
61. Bharambe VK, Sakshi S, Gaurav B, Feroz A. Awareness regarding body and organ donation amongst the population of an urban city in India. *Nitte University Journal of Health Science.* 2015 Dec 1;5(4).
62. Minz M, Sood S, Kumar A, Bansal V, Mehra S. Impact of organ trade on attitudes toward organ donation: knowledge and attitudes toward cadaveric organ donation in north India. *InTransplantation proceedings 1998 (Vol. 30, No. 7).*
63. Mohan G, Aswathy AA. Organ donation in India—A social marketing perspective. *International Journal of Nonprofit and Voluntary Sector Marketing.* 2019 May;24(2):e1637.
64. Alex A, Shroff S, Paul VB, Navin S, Ramesh P, Michael J, Menon S. Did an increase in knowledge and awareness about organ donation improve organ donation rate in India over the past two decades?. *Indian Journal of Transplantation.* 2019 Jul 1;13(3):173.
65. Bharambe VK, Arole VU, Puranam V, Manvikar P, Rathod HK. Organ Donation: from Point of View of Students Doing Medical Internship in India. *BANTAO Journal.* 2016 Dec 1;14(2):67-72.
66. Bharambe VK, Arole VU, Puranam V, Kulkarni PP, Kulkarni PB. Knowledge and attitude toward organ donation among people in Lanja: A rural town in India. *Saudi Journal of Kidney Diseases and Transplantation.* 2018a Jan 1;29(1):160.
67. Deshpande PR, Damle P, Bihani G, Khadabadi SS, Naik AN, Pawar AP. Knowledge, attitude, and practice of organ donation among pharmacy students. *Indian Journal of Transplantation.* 2018 Apr 1;12(2):113.
68. Da Silva, K.X., Dsouza, D.B., Mascarenhas, V.R., Kankonkar, P.N., Vaz, F.S. and Kulkarni, M.S., 2021. Perceptions and attitude toward cadaveric organ donation among health-care professionals at a tertiary health-care setting: A cross-sectional study. *Indian Journal of Transplantation, 15(1), p.56.*
69. Basavarajegowda, A., Arjunan, C., Nalini, Y.C., Parameshwaran, S. and Kannan, S., 2021. A comparative study of knowledge, attitude, and practices about organ donation among blood donors and nonblood donors. *Asian Journal of Transfusion Science, 15(1), p.37.*

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
70. Kachappillil, A.J. and Thankachan, A., 2020. Attitude of General Population towards Organ Donation in a Rural Community of Ernakulam District. *International Journal of Healthcare Education & Medical Informatics (ISSN: 2455-9199)*, 7(1&2), pp.16-20.
71. Kalmath, S. and Peerapur, S.M., 2020. A Study to Determine the Knowledge, Preparedness and Commitment Regarding Organ Donation among the Youths of Hubli, Karnataka. *International journal of Innovative science and research technology*, 5(5).
72. Khan, F., Latif, M. and Bashir, S., 2020. Attitude and Knowledge toward Organ Donation among Arts and Science Students. *Indian Journal of Forensic Medicine & Toxicology*, 14(4).
73. Rani, S., Mishra, A. and Dagar, N., 2020. Community Based Study to Assess the Knowledge and Attitude of General Population towards Organ Donation. *International Journal of Nursing Education*, 12(4).
74. Ray, M.K. and Ghosh, T., 2020. Assessment of Knowledge and Attitude of Medical Students Regarding Body and Organ Donation. *Religion*, 115, pp.85-8.
75. Seetharaman, R.V., Rane, J.R. and Dingre, N.S., 2021. Assessment of knowledge and attitudes regarding organ donation among doctors and students of a tertiary care hospital. *Artificial Organs*, 45(6), pp.625-632.
76. Yadav, N., Jain, M., Sharma, A., Jain, V., Chahar, P. and Verma, N., 2020. Perceptions of a university's faculty members on organ donation. *The National Medical Journal of India*, 33(5), p.302.
77. Ghose, T.K., Deo, J., Dutt, V., Agarwal, R., Patel, B.B., Ganesh, M., More, V.K., Pandya, K.H., Sharma, R., Sharma, D. and Singh, H., 2021. Knowledge and attitude towards organ donation: a study among medical and nursing students of a medical college. *International Journal of Community Medicine and Public Health*, 8(11), p.5398.
78. Poreddi, V., Katyayani, B.V., Gandhi, S., Thimmaiah, R. and Badamath, S., 2016. Attitudes, knowledge, and willingness to donate organs among Indian nursing students. *Saudi Journal of kidney diseases and transplantation*, 27(6), p.1129.
79. Bharambe, V.K., Arole, V.U., Puranam, V., Kulkarni, P.P. and Kulkarni, P.S., 2018b. Knowledge and attitude toward organ donation among health-care professionals in a rural town in India. *Saudi Journal of Kidney Diseases and Transplantation*, 29(3), p.671.
80. Vincent BP, Kumar G, Parameswaran S, Kar SS. Barriers and suggestions towards deceased organ donation in a government tertiary care teaching hospital: Qualitative study using socio-ecological model framework. *Indian Journal of Transplantation*. 2019a Jul 1;13(3):194.

- 1
2
3 81. Kennedy K. Organ donation and transplantation in India: An inquiry in Kerala. *Journal*
4 *of Social Distress and the Homeless*. 2002 Jan 1;11(1):41-67.
5
6 82. Amaliyar J, Patel P. Awareness about organ donation in medical and non medical
7 students in Patan city of Gujarat, India. *Int J Community Med Public Health*. 2019
8 Jun;6:2435-9.
9
10 83. Jothula KY, Sreeharshika D. Study to assess knowledge, attitude and practice regarding
11 organ donation among interns of a medical college in Telangana, India. *Int J Community*
12 *Med Public Health*. 2018 Apr;5(4):1339-45.
13
14 84. Vijayalakshmi P, Nagarajaiah, Ramachandra, Math SB. Indian ICU nurses' perceptions
15 of and attitudes towards organ donation. *British Journal of Nursing*. 2015 Jul
16 9;24(13):694-7.
17
18 85. Lokesh KSS, Raja D, and Sharath U. 2021. Organ Donation'-Awareness, Perspective
19 and Practices among Adults-A Cross Sectional Study in Rural Tamil Nadu. *Journal of*
20 *Pharmaceutical Research International*. 33(55B); 29-34.
21
22 86. Vincent BP, Kumar G, Parameswaran S, Kar SS. Knowledge, attitude, and perception on
23 organ donation among undergraduate medical and nursing students at a tertiary care
24 teaching hospital in the southern part of India: A cross-sectional study. *Journal of*
25 *education and health promotion*. 2019b;8.
26
27 87. Misra, P., Malhotra, S., Sharma, N., Misra, M.C., Vij, A. and Pandav, C.S., 2021. A
28 qualitative approach to understand the knowledge, beliefs, and barriers toward organ
29 donation in a rural community of Haryana-A community based cross-sectional
30 study. *Indian Journal of Transplantation*, 15(1), p.19.
31
32 88. Thyagarajan, I., Shroff, S., Vincent, B.P., Rajendran, J., Kanvinde, H., Shankar, S. and
33 Aneesh, K., 2020. Knowledge and practice of organ donation among police personnel in
34 Tamil Nadu: A cross-sectional study. *Indian Journal of Transplantation*, 14(2), p.141.
35
36 89. Mondal, S., Paul, A., Malick, S. and Saha, P., 2016. Perception of organ donation among
37 adults: A community based study in rural West Bengal, India. *Sch J Appl Med Sci*, 4,
38 pp.4473-8.
39
40 90. Sam N, Ganesh R, Indrapriyadarshini V, Jeyamarthan S, Nandhini CK. Awareness,
41 knowledge, and attitude regarding organ donation among final year students of medical,
42 Dental, Engineering, and Arts and Science Colleges in Thiruvallur and Chennai City,
43 India. *Indian Journal of Transplantation*. 2018 Jan 1;12(1):25.
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 91. Soni S, Samal J, Baghel SS, Vaghela S, Chundawat MS. Knowledge and attitude toward
4 organ donation among medical and nonmedical (Engineering) students in Bhopal, India.
5 The Saudi Journal of Forensic Medicine and Sciences. 2018 May 1;1(2):35.
6
7
- 8 92. Rajan, J.K., 2020. Assessment of Knowledge and Attitude of Adolescents Regarding
9 Blood and Organ Donation in Selected Rural Areas of Shimla, Himachal Pradesh,
10 India. *Medico Legal Update*, 20(1), pp.101-105.
11
12
- 13 93. Sachdeva S. Knowledge, Attitude, and Practices regarding organ donation among adult
14 visitors in a public hospital in Delhi, India. *Indian J Transplant*. 2017 Dec 20;11:127-32.
15
16
- 17 94. Flower, J.R.L. and Balamurugan, E., 2013. A study on public intention to donate organ:
18 Perceived barriers and facilitators. *British Journal of Medical Practitioners*, 6(4), pp.6-
19 10.
20
21
- 22 95. Balwani MR, Kute VB, Patel H, Shah PR, Goswami J, Ghule P, Shah M, Gattani V,
23 Trivedi HL. Awareness and beliefs towards organ donation in chronic kidney disease
24 patients in western India. *Journal of Nephro pharmacology*. 2015b;4(2):57.
25
26
- 27 96. Kaistha M, Kaistha S, Mahajan A. A study of factors influencing decisions on organ
28 donation among patient attendees in a Tertiary Care Hospital in North India. *CHRISMED*
29 *Journal of Health and Research*. 2016 Apr 1;3(2):101.
30
31
- 32 97. Paul S, Som TK, Saha I, Ghose G, Bera A, Singh A. Knowledge, attitude, and practice
33 regarding organ donation among adult Population of an Urban field practice area of a
34 medical college in Durgapur, West Bengal, India. *Indian Journal of Transplantation*.
35 2019 Jan 1;13(1):15.
36
37
38
- 39 98. Hakeem, A.R., Ramesh, V., Sapkota, P., Priya, G., Rammohan, A., Narasimhan, G.,
40 Reddy, M.S. and Rela, M., 2021. Enlightening Young Minds: A Small Step in the
41 Curriculum, a Giant Leap in Organ Donation—A Survey of 996 Respondents on Organ
42 Donation and Transplantation. *Transplantation*, 105(3), pp.459-463.
43
44
45
- 46 99. Adithyan GS, Mariappan M, Nayana KB. A study on knowledge and attitude about organ
47 donation among medical students in Kerala. *Indian Journal of Transplantation*. 2017 Jul
48 1;11(3):133.
49
50
- 51 100. Mani G. Perceptions and practices related to organ donation among a rural population
52 of Kancheepuram district, Tamil Nadu, India Geetha Mani1, Raja Danasekaran1,
53 Kalaiivani Annadurai1. *Journal of Comprehensive Health*. 2016 Jan;4(1):72.
54
55
- 56 101. Kaur, A., Devgun, P. and Gill, K.P., 2021. A Cross-sectional Study to Assess the
57 Knowledge, Attitude and Practices about Organ Donation among the Medical Students
58 of Punjab. *Annals of Community Health*, 8(4), pp.2-8.
59
60

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
102. Meghana S, Subramanian M, Atmakuri SA, Tarun S, Bera P, Nelson J. A study on knowledge, attitude and practice regarding organ donation and transplantation among final year health science students in Bengaluru, Karnataka, India. *Int J Commun Med Pub Health*. 2018 Apr;5:1529-34.
103. Darlington D, Anitha FS, Joseph C. Study of Knowledge, Attitude, and Practice of Organ Donation Among Medical Students in a Tertiary Care Centre in South India. *Cureus*. 2019 Jun;11(6).
104. Bhargavi UD, Govindapillai UK. Knowledge and attitude of decond year medical, dental and nursing students in Thiruvananthapuram government medical college campus towards organ and whole body donation. *Journal of Evolution of Medical and Dental Sciences*. 2019 Apr 8;8(14):1153-6.
105. Budiani-Saberi, D.A., Raja, K.R., Findley, K.C., Kerketta, P. and Anand, V., 2014. Human trafficking for organ removal in India: a victim-centered, evidence-based report. *Transplantation*, 97(4), pp.380-384.
106. Ahmed, W., Harris, S. and Brown, E., 1999. Attitudes to organ donation among South Asians in an English high street. *Journal of the Royal Society of Medicine*, 92(12), pp.626-627.
107. Syed, J. and Èzbilgin, M.F. eds., 2010. *Managing cultural diversity in Asia: A research companion*. Edward Elgar Publishing.
108. Campbell, M., Katikireddi, S.V., Sowden, A. and Thomson, H., 2019. Lack of transparency in reporting narrative synthesis of quantitative data: a methodological assessment of systematic reviews. *Journal of clinical epidemiology*, 105, pp.1-9.

57
58
59
60

Figure legends / captions:

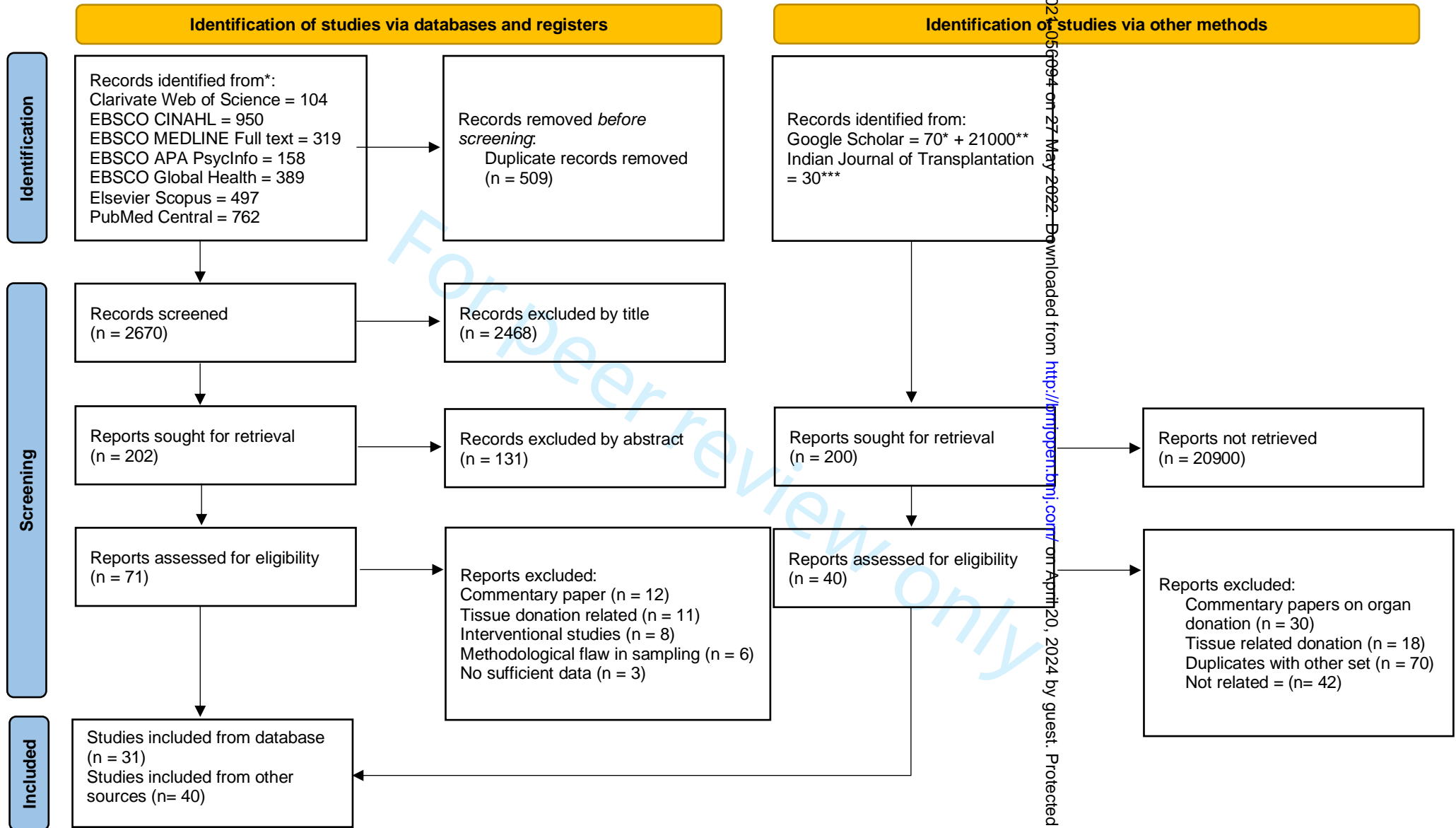
Figure 1: PRISMA flowchart

1
2
3 **Figure 2:** Quality appraisal checklist
4

5 **Figure 3:** Graphical representation of studies showing gap between knowledge, attitude, and
6 registration practices.
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

616/mjopen-2021-015694 on 27 May 2022. Downloaded from http://bmjopen.bmj.com/ on April 20, 2024 by guest. Protected by copyright.



*Google scholar method 1 explained in method section of the manuscript; **Google scholar method 2 explained in the method section of the manuscript; ***Indian journal of Transplantation – All issues were manually searched from 1994

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: <http://www.prisma-statement.org/>

	1	2	3	4	5	6	7	8	9	10
Adithyan et al, 2017	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Ahlawat et al, 2013	-	✓	✓	✓	✗	✗	✓	✓	✓	✓
Alex et al, 2017	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓
Alex et al, 2019	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Amaliyar et al, 2019	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓
Balajee et al, 2016	-	✓	✓	✓	✓	✗	✓	✓	✓	✓
Balwani et al, 2015a	-	✓	✓	✓	✗	✗	✓	✓	✓	✓
Balwani et al, 2015b	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Bansal et al, 2019	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Bapat et al, 2010	-	✓	✓	✓	✗	✗	✓	✓	✓	✓
Basavarajegowda et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Bathija et al, 2017	-	✓	✓	✓	✗	✓	✓	✓	✓	✓
Bharambe et al, 2015	✗	✓	✓	✓	✗	✗	✓	✓	✓	✓
Bharambe et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Bharambe et al, 2018a	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Bharambe et al, 2018b	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Bhargavi et al, 2019	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓
Chakradhar et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Da Silva et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Darlington et al, 2019	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Dasgupta et al, 2014	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Deshpande et al, 2018	-	✓	✓	✓	✗	✗	✓	✓	✓	✓
Flower et al, 2013	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Ghose et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Gupta et al, 2018	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓
Gupta et al, 2021	✗	-	✓	✓	✗	✗	✓	✓	✓	✓
Hakeem et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Jayabharathi et al, 2019	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Joshi, 2011	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Jothula et al, 2018	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Kachappillil et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Kadam et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Kaistha et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Kamlath et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Kaur et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Khan et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Kundu et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Lokesh et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Mani, 2016	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Meghana et al, 2018	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓
Minz et al, 1998	✗	✓	-	✓	✗	✗	✓	✓	✓	✓
Misra et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Mithra et al, 2013	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Mohan et al, 2019	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Mondal et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Panwar et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Paramr et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Paul et al, 2019	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Poreddi et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Poreddi et al, 2017	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Rajan, 2021	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Rani et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Ray et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Sachdeva, 2017	-	✓	✓	✓	✗	✗	✓	✓	✓	✓
Sam et al, 2018	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Sarveswaran et al, 2018	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Seetharaman et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Singh et al, 2002	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Soni et al, 2018	-	✓	✓	✓	✗	✓	✓	✓	✓	✓
Swain et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Swamy et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Tamuli et al, 2019	✗	✓	✓	✓	✗	✗	✓	✓	✓	✓
Thyagarajan et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Vijayalakshmi et al, 2015	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Vijayalakshmi et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓
Vincent et al, 2019b	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Yadav et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓

Ref	Vincent et al, 2019	Kennedy, 2002	Gauther et al, 2013	Misra et al, 2021
1	✓	✓	✓	✓
2	✓	✓	✓	✓
3	✓	✓	✓	✓
4	✓	✓	✓	✓
5	✓	✓	✓	✓
6	✓	✗	✓	✗
7	✗	✗	✗	✗
8	✓	✗	✓	✗
9	✓	✗	✓	✓
10	✓	✓	✓	✓

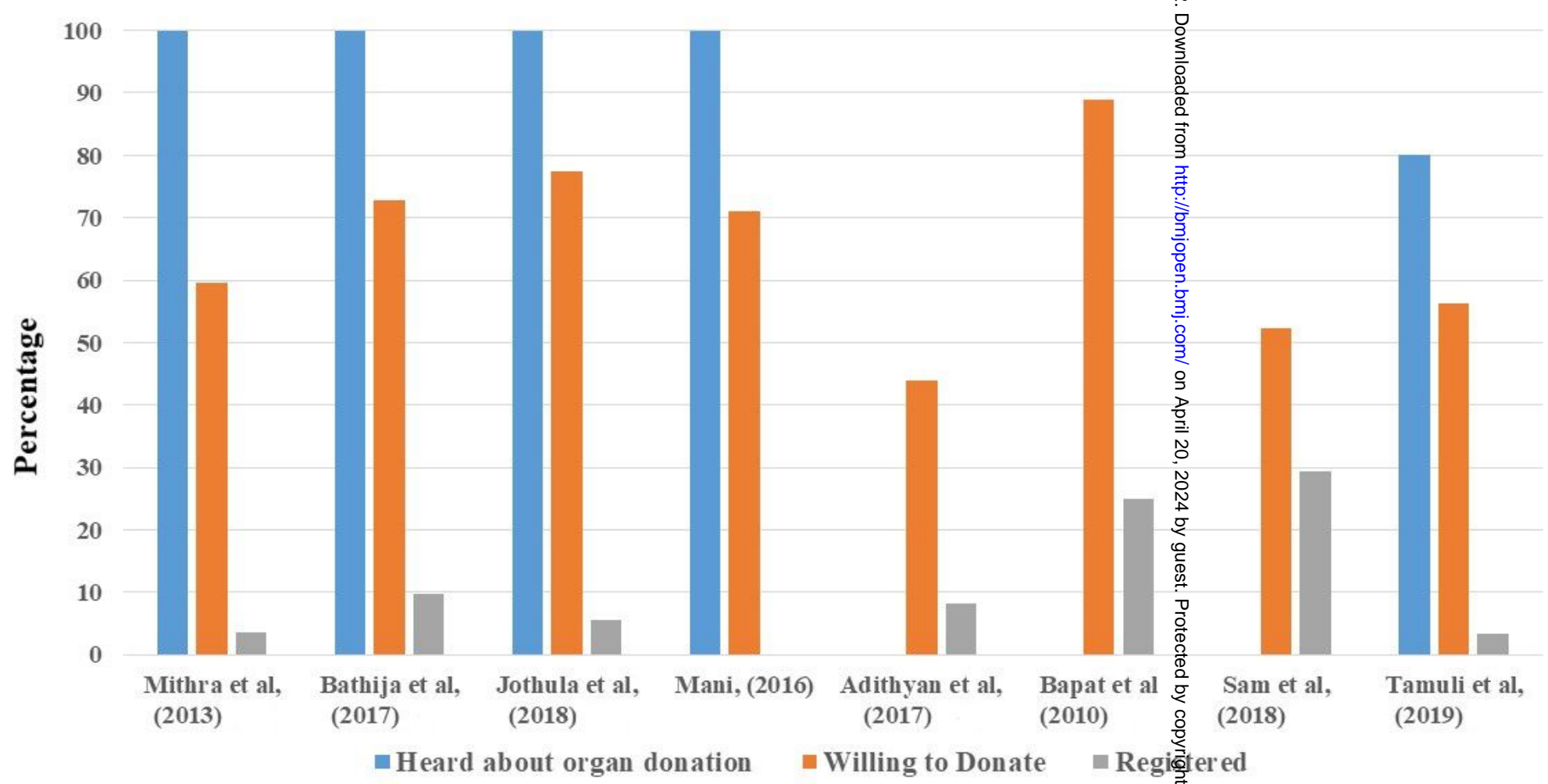
- 1 Is there congruity between the stated philosophical perspective and the research methodology?
- 2 Is there congruity between the research methodology and the research question or objective?
- 3 Is there congruity between the research methodology and the methods used to collect data?
- 4 Is there congruity between the research methodology and the representation and analysis of data?
- 5 Is there congruity between the research methodology and the interpretation of results?
- 6 Is there a statement locating the researcher culturally or theoretically?
- 7 Is the influence of the researcher on the research, and vice-versa, addressed?
- 8 Are participants, and their voices, adequately represented?
- 9 Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
- 10 Do the conclusion drawn in the research report flow from the analysis, or interpretation, of the data?

Mentioned	✓	Not mentioned	✗
-----------	---	---------------	---

Quality appraisal for qualitative studies

1. Were the criteria for inclusion in the sample clearly defined?
2. Were the study subjects and the setting described in detail?
3. Was the exposure measured in a valid and realistic way?
4. Were the objectives, standard criteria used for measurement of the conditions?
5. Were the confounding factors identified?
6. Were strategies to deal with confounding factors stated?
7. Were the outcomes measured in a valid and reliable way?
8. Was appropriate statistical analysis used?

Mentioned ✓ Not mentioned ✗ Unclear -



7 May 2022. Downloaded from <http://bmjopen.bmj.com/> on April 20, 2024 by guest. Protected by copyright.

Supplementary I: Search strategy

Database: Clarivate Web of Science <1 January 1994 to 31 December 2021>

Search strategy

1. (ALL) Organ (931356)
2. (ALL) Tissue (2044844)
3. 1 OR 2 (2828541)
4. (ALL) Donation (81986)
5. (ALL) Procurement (35057)
6. (ALL) Donor (452066)
7. (ALL) Registration (142852)
8. (ALL) Pledge (4245)
9. 4 OR 5 OR 6 OR 7 OR 8 (679088)
10. Brain death (93353)
11. Posthumous (2234)
12. Deceased (27866)
13. 10 OR 11 OR 12 (122185)
14. India (1905243)
15. Asia (460895)
16. South Asia (111493)
17. 14 OR 15 OR 16 (2322980)
18. Knowledge (1815596)
19. Attitude (408659)
20. Practice (1974880)
21. Awareness (294873)
22. Perception (704502)
23. Barrier (696152)
24. Challenge (2000813)
25. Religion (121682)
26. Family (1815478)
27. Discuss (3004676)
28. Sign (496082)
29. 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 (10776639)

1
2
3 30. 3 AND 9 AND 13 AND 17 AND 29 (104)
4
5

6 (((ALL=(Organ OR Tissue)) AND ALL=(Donation OR Procurement OR Donor OR
7 Registration OR Pledge)) AND ALL=(Brain Death OR Posthumous OR Deceased)) AND
8 ALL=(India OR Asia OR South Asia)) AND ALL=(Knowledge, attitudes, practice OR
9 Awareness OR Perception OR Barrier OR Challenge OR Religion OR Family OR Discuss OR
10 Sign)
11
12
13
14
15

16 -----
17 **Database:** EBSCO CINAHL Complete < 1994 January to December 2021>
18

19 Search strategy
20
21

-
- 22 1. TI Organ (12792)
 - 23 2. TI Tissue (35138)
 - 24 3. 1 OR 2 (46731)
 - 25 4. TI Donation (5003)
 - 26 5. TI Donor (9786)
 - 27 6. 4 or 5 (14299)
 - 28 7. AB Knowledge (220735)
 - 29 8. AB Awareness (72886)
 - 30 9. AB Attitude (75081)
 - 31 10. AB Perception (114073)
 - 32 11. AB Practice (405101)
 - 33 12. AB Registration (58662)
 - 34 13. AB Consent (24494)
 - 35 14. AB Culture (77169)
 - 36 15. AB Religion (6986)
 - 37 16. 7 OR 8 OR 9 OR 10 OR 12 OR 13 OR 14 OR 15 (842904)
 - 38 17. 3 OR 6 OR 16 (950)

39
40
41
42
43
44
45
46
47
48
49
50
51
52 TI (Organ OR Tissue) AND TI (Donation OR Donor) AND AB (Knowledge OR Awareness
53 OR Attitude OR Perception OR Practice OR Registration OR Consent OR Culture OR Religion
54)
55
56
57
58
59
60

1
2
3
4
5
6 **Database:** EBSCO MEDLINE With full text Complete < 1994 January to December 2021>
7

8 Search strategy
9

- 10 1. TX Organ (1209295)
- 11 2. TX Tissue (2836964)
- 12 3. 1 OR 2 (3517194)
- 13 4. TX Donation (72543)
- 14 5. TX Donor (492893)
- 15 6. TX Registration (190162)
- 16 7. 4 OR 5 OR 6 (702757)
- 17 8. TX India (847970)
- 18 9. TX Asia (291953)
- 19 10. TX South Asia (44218)
- 20 11. 8 OR 9 OR 10 (1080319)
- 21 12. TX health knowledge, attitudes, practice (119021)
- 22 13. 3 AND 7 AND 11 AND 12 (319)

23 TX (Organ OR Tissue) AND TX (Donation OR Donor OR Registration) AND TX (India
24 OR Asia OR South Asia) AND TX health knowledge, attitudes, practice
25
26
27
28
29
30
31
32
33

34 **Database:** EBSCO APA PsycInfo < 1994 January to December 2021>
35

36 Search strategy
37
38

- 39 1. TI Organ (1723)
 - 40 2. TI Tissue (2644)
 - 41 3. 1 OR 2 (4326)
 - 42 4. TI Donation (1318)
 - 43 5. TI Donor (1100)
 - 44 6. 4 OR 5 (2297)
 - 45 7. KW Knowledge (51470)
 - 46 8. KW Awareness (19810)
 - 47 9. KW Attitude (9853)
- 48
49
50
51
52
53
54
55
56
57
58
59
60

10. KW Perception (62192)
11. KW Practice (58248)
12. KW Registration (829)
13. KW Consent (4319)
14. KW Culture (34255)
15. KW Religion (11715)
16. 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 (234219)
17. 3 AND 6 AND 16 (158)

TI (Organ OR Tissue) AND TI (Donation OR Donor) AND KW (Knowledge OR Awareness OR Perception OR Practice OR Registration OR Consent OR Culture OR Religion)

Database: EBSCO Global Health < January 1994 to December 2021>

Search strategy

1. TI Organ (5703)
2. TI Tissue (24236)
3. 1 OR 2 (29712)
4. TX Donation (4174)
5. TX Donor (27588)
6. 4 OR 5 (29050)
7. TX Registration (9802)
8. TX Pledge (189)
9. TX Knowledge (157636)
10. TX Awareness (49745)
11. TX Attitude (82125)
12. TX Perception (52839)
13. TX Practice (203547)
14. TX Consent (10210)
15. TX Barrier (57133)
16. TX Challenge (116441)
17. TX Facilitator (5697)
18. TX Religion (6883)

1
2
3 19. TX Culture (195775)

4
5 20. 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 18 OR 19 (722134)

6
7 21. 3 AND 6 AND 20 (389)

8
9 TI (Organ OR Tissue) AND TX (Donation OR Donor) AND TX (Registration OR Pledge
10 OR Knowledge OR Awareness OR Attitude OR Perception OR Practice OR Consent OR
11 Barrier OR Challenge OR Facilitator OR Religion OR Culture)
12
13

14
15 -----
16
17 **Database:** Elsevier Scopus PUBYEAR > 1993 AND PUBYEAR <2022

18
19
20 Search strategy

- 21
22
23 1. TITLE-ABS-KEY Organ (756450)
24 2. TITLE-ABS-KEY Tissue (3946763)
25 3. 1 OR 2 (4390243)
26 4. TITLE-ABS-KEY Donation (49710)
27 5. TITLE-ABS-KEY Donor (465356)
28 6. TITLE-ABS-KEY Registration (204600)
29 7. TITLE-ABS-KEY Pledge (4315)
30 8. 4 OR 5 OR 6 OR 7 (693065)
31 9. TITLE-ABS-KEY India (437307)
32 10. TITLE-ABS-KEY Asia (352898)
33 11. TITLE-ABS-KEY South Asia (85909)
34 12. 9 OR 10 OR 11 (352898)
35 13. 3 AND 8 AND 12 (497)

36
37
38 (TITLE-ABS-KEY (organ OR tissue) AND TITLE-ABS-KEY (donation OR donor OR
39 registration OR pledge) AND TITLE-ABS-KEY (India OR Asia OR south Asia)) AND
40 PUBYEAR > 1993 AND PUBYEAR <2022
41
42
43
44

45
46 -----
47
48 **Database:** PubMed Central < 1994 January to December 2021>

49
50
51 Search strategy
52
53
54
55
56
57
58
59
60

1
2
3 **Search:** (((((Organ[Title/Abstract] OR Tissue[Title/Abstract]) AND (Donation[Title/Abstract]
4 OR Donor[Title/Abstract])) AND (Knowledge[Title/Abstract] OR Awareness[Title/Abstract]
5 OR Attitude[Title/Abstract] OR Perception[Title/Abstract] OR Practice[Title/Abstract] OR
6 Registration[Title/Abstract] OR Consent[Title/Abstract] OR Barrier[Title/Abstract] OR
7 Challenges[Title/Abstract] OR Religion[Title/Abstract] OR Culture[Title/Abstract]))) AND
8 ((India OR South Asia OR Southeast Asia OR Asia[MeSH Terms])
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only



PRISMA 2020 checklist

1136/bmjopen-2021-056094 on 27 May 2022. Downloaded from <http://bmjopen.bmj.com/> on April 20, 2024 by guest. Protected by copyright.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Pg. 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Pg. 1-2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Pg. 3-4
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Pg. 4
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Pg. 5
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Pg. 4 -5
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Supplementary file & PRISMA 2020
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Pg. 6
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Pg. 5-7
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	NA
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	NA
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Pg. 6
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	NA
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	NA
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	NA
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Table 1
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Pg. 6-7
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	NA
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	NA
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	NA



PRISMA 2020 checklist

Section and Topic	Item #	Checklist item	Location where item is reported
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	NA
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Figure 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Figure 1, Pg. 6
Study characteristics	17	Cite each included study and present its characteristics.	Table 1
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Quality appraisal: Figure 2
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	NA
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	NA
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	NA
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	NA
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	NA
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	NA
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	NA
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	22-25
	23b	Discuss any limitations of the evidence included in the review.	24-25
	23c	Discuss any limitations of the review processes used.	24-25
	23d	Discuss implications of the results for practice, policy, and future research.	22-25
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Pg. 2
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Pg. 2
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Pg. 4
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Pg. 25
Competing interests	26	Declare any competing interests of review authors.	Pg. 25
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Supplementary file 1.



PRISMA 2020 checklist

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: <http://www.prisma-statement.org/>

For peer review only

1136/bmjopen-2021-056094 on 27 May 2022. Downloaded from <http://bmjopen.bmj.com/> on April 20, 2024 by guest. Protected by copyright.

BMJ Open

Barriers toward deceased organ donation among Indians living globally: An integrative systematic review using narrative synthesis

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2021-056094.R2
Article Type:	Original research
Date Submitted by the Author:	11-Apr-2022
Complete List of Authors:	Vincent, Britzer Paul; University of Bedfordshire Faculty of Health and Social Sciences, Institute for Health Research Randhawa, Gurch; University of Bedfordshire Faculty of Health and Social Sciences, Institute for Health Research Cook, Erica; University of Bedfordshire - Luton Campus, Department of Psychology
Primary Subject Heading:	Health policy
Secondary Subject Heading:	Health services research
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, ETHICS (see Medical Ethics), TRANSPLANT MEDICINE

SCHOLARONE™
Manuscripts



I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our [licence](#).

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which [Creative Commons](#) licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Title Page

Title: Barriers toward deceased organ donation among Indians living globally: An integrative systematic review using narrative synthesis.

Full name of all authors:

As per the order of the authorship

1. Britzer Paul (Given Name) Vincent (Family Name)
PhD Student, Institute for Health Research, Faculty of Health and Social Sciences, University of Bedfordshire, England, The United Kingdom
ORCID id: <https://orcid.org/0000-0001-7681-1430>
2. Gurch (Given Name) Randhawa (Family Name)
Professor of Diversity in Public Health and Director - Institute for Health Research, Faculty of Health and Social Sciences, University of Bedfordshire, England, The United Kingdom
3. Erica (Given Name) Cook (Family Name)
Senior Lecturer in Health Psychology,
Department of Psychology, University of Bedfordshire, England, The United Kingdom

Authorship Contribution:

All authors BP, GR & EC contributed to – conception of the study, design of work, data acquisition, data analysis, data interpretation, writing of the article, final approval, and accountability of the study.

Funding sources: This review is led by the principal investigator Britzer Paul Vincent who is a PhD scholar at the Institute for Health Research, University of Bedfordshire funded by the Global Challenge Research Fund.

Acknowledgement: We would like to thank our librarian Mr. David Abdy from Institute for Health Research, University of Bedfordshire for his contribution with the development of the search strategy.

Corresponding author:

Gurch (Given Name) Randhawa (Family Name)

gurch.randhawa@beds.ac.uk

University of Bedfordshire

Putteridge Bury Campus

Hitchin Road

Luton, LU2 8LE

England

Running title:

Barriers to Deceased Organ Donation among Indians globally: An Integrative Systematic Review

Abbreviations:

NCD – Non-Communicable Disease

pmp – per million population

1
2
3 ODR – Organ Donation Rate
4 JBI - Joanna Briggs Institute's
5

6 **Conflict of Interest:**
7
8 None declared.
9

10 **Word count**
11 **Abstract:** 300
12 **Manuscript:** 4,381
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

1
2
3 **Title:** Barriers toward deceased organ donation among Indians living globally: An integrative
4 systematic review using narrative synthesis.
5
6
7

8 **Abstract**
9

10 **Objectives:** To understand the barriers toward deceased organ donation among Indians living
11 globally.
12
13

14 **Design:** Integrative systematic review using narrative synthesis
15

16 **Data sources:** CINAHL, MEDLINE, PsycINFO, Scopus, Global Health, Web of Science, and
17 PubMed Central, Indian Journal of Transplantation and Google scholar.
18
19

20 **Time period:** 1st January 1994 to 31st December 2021
21
22

23 **Participants:** Individuals of Indian origin living globally
24
25

26 **Results:** Eighty-nine studies were included with more than 29,000 participants and quality of
27 the studies were assessed using Joanna Briggs Institute's critical appraisal tool. Though
28 majority of the participants had knowledge toward organ donation with a positive influence on
29 willingness, the gap between knowledge and willingness was huge, with minimal registration
30 influenced by the complex socio-cultural constructs. Various socio-cultural constructs such as
31 fear and mistrust, family, religion, bodily issues play a vital role. Differences were identified
32 in willingness to donate and register between southern and other regions of India. Indian's
33 organ donation behaviour in other geographical locations differed based on the socio-religious
34 background of the country they lived in such as in Malaysia, Canada, and the UK. However,
35 they were collective in decision-making and had complex socio-cultural interference
36 irrespective of the country the individual lived which differed only in their next generations.
37
38
39
40
41
42
43
44
45
46
47
48
49
50

51 **Conclusion:** Though this study showed the complex relationship, and its influences on organ
52 donation behaviour, lacunae were identified to further understand how such complex
53 interactions determine or inform the behaviour. Also, methodological issues were identified,
54 where this particular population outside India were collectively studied with their neighbouring
55
56
57
58
59
60

1
2
3 population which are not homogenous. Studies in India majorly addressed a similar aim using
4 similar methods which produced repetition of studies leading to lack of diversified, broader,
5 and in-depth research. Therefore, while this systematic review addressed the barriers toward
6 organ donation among Indians living globally, it also informs various gaps in research and
7 methodologies.
8
9

10
11
12
13
14
15 **PROSPERO registration number:** CRD42019155274

16
17 **Keywords:** Organ donation, India, UK, Integrative systematic review; Narrative synthesis,
18
19 Registration
20
21

22 **Strengths and Limitations:**

- 23
24
25 1. This is the first systematic review on the barriers toward deceased organ donation
26 among Indians living globally, registered with PROSPERO, and published.
- 27
28
29 2. Both quantitative and qualitative studies were included to address the aim of the review
30 using integrative approach and narrative synthesis, an appropriate methodology.
- 31
32
33 3. Included studies exclusively represented the Indian population and studies that
34 collectively studied Indians with heterogenous South Asian or Asian population were
35 excluded, thereby keeping the rigour of this study, and identifying methodological
36 issues involved.
- 37
38
39 4. Findings are based on the quality of each studies appraised using appropriate tools, and
40 the assessment is also made available to the view of the readers.
- 41
42
43 5. Studies were limited only to English language, and commentaries were excluded.
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Main text

Introduction

Since the first deceased organ transplantation performed by Joseph Murray in 1960s, the science of transplantation has witnessed exponential growth [1]. However, the gap between demand and supply of organs has represented a significant challenge [2], particularly among the Asian population who live both within and outside their continent [3-5]. India located in the South of Asia is the second largest populous country in the world [6] having largest migrating population in Asia [7], and also has the highest prevalence of diabetes, hypertension, and many other comorbidities [8]. Such non-communicable diseases (NCD) among Indians [9, 10] leading them to end-stage organ failure [11, 12] increases their need for organs.

Whilst the need for organ donors is high among the Indian population, the actual number of donors remain too low to satisfy the number of recipients on the waiting list [13], with the Indian national organ donation rate (ODR) less than one per million population (pmp) [14]. Reluctance to donate organs among this ethnic population might not be isolated just within Indian border [15], with evidence suggesting that Indian population from the United Kingdom is also disproportionately impacted, where they continue to be over-represented in the recipient waiting list but under-represented in the donor list [16]. This behaviour is again identified in Canada [17]. Therefore, Indian population has demonstrated higher reluctance to organ donation both within and outside the border.

There have been a larger number of studies conducted among the Indian population living globally to understand the factors that influence their organ donation behaviour. However, to date, there has been no systematic review conducted to synthesize the available evidence to understand the barriers toward organ donation among the individuals of Indian origin. Therefore, a systematic review was proposed with an aim to address this gap to gain a deeper

1
2
3 insight into the barriers toward deceased organ donation behaviour among this particular
4
5 population living globally [18].
6
7

8 **Method**

9 **Protocol and registration**

10
11
12 This systematic review's protocol has been registered in PROSPERO (CRD42019155274) and
13
14 also published [18].
15
16
17

18 **Systematic search**

19
20 Search strategy was developed collaboratively with the research team and a subject specialist
21
22 librarian. Databases namely CINAHL, MEDLINE, PsycINFO, Scopus, Global Health, Web
23
24 of Science, and PubMed Central were utilised. Key terms related to organ donation were first
25
26 identified from studies published along with search terms used in other systematic review on
27
28 organ donation [19,20] and were tested in different combinations. Later, for each database, the
29
30 search terms were then customised seeking to capture the most appropriate studies to answer
31
32 the aim of this review (supplementary file 1) [21]. However, for other resources like google
33
34 scholar and the Indian journal of transplantation other strategies were employed. All the
35
36 published papers from 1st of January 1994 to 31st of December 2021 were searched from the
37
38 archives of the Indian journal of transplantation to identify relevant studies. With regard to
39
40 google scholar, we searched using two methods. The first method used the word "Organ
41
42 Donation AND India" in title; and the second method used the same keywords but searched
43
44 anywhere in the article. However, due to very high number of search results in the second
45
46 method, we limited the search until we found no further relevant studies (an approach used by
47
48 other published systematic reviews) [22].
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 The systematic review included studies with individuals of Indian origin living both within and
4 outside India (i.e., migrant / first / second generation), aged 18 years and above from varied
5 settings [18]. Cross-sectional and qualitative study design were included as they were mostly
6 employed to understand the barriers toward deceased organ donation. For all the databases,
7 search strategy was restricted between 1st of January 1994 (i.e., the year when the first law
8 toward organ donation was implemented in India) and 31st of December 2021 (i.e., a recent
9 day before the submission) and was restricted only to studies published in English. However,
10 interventional studies, commentary or opinion papers, studies on blood, bone marrow, body,
11 sperm, and egg donation were excluded alongside any studies which addressed only living
12 donation.
13
14
15
16
17
18
19
20
21
22
23
24
25
26

27 **Search outcome**

28
29 Following a stage-by-stage exclusion from 8,655 studies initially extracted from the main
30 databases, 51 studies were included in final review along with 38 studies included from other
31 sources (Figure 1). The studies were initially exported to RefWorks
32 (<https://refworks.proquest.com/>). Microsoft excel was used to keep a record of studies
33 excluded by duplicates, title, abstract, and full text. All the 8,655 studies along with studies
34 from other sources were screened by two authors independently and the final 89 studies
35 included were in-agreement with all the authors.
36
37
38
39
40
41
42
43
44
45

46 However, during the process, studies conducted among Indians living outside India were
47 identified to be collectively studied as South Asians or with other Asian population. For
48 instance, a study conducted among Indo-Canadians in Canada included all neighbouring ethnic
49 groups of India [23]. Also, in other countries like the UK and Malaysia, Indian population was
50 collectively studied along with other ethnic groups and the results were not distinctively shown
51 [24-26], therefore eight studies had to be excluded due to these methodological limitations. The
52
53
54
55
56
57
58
59
60

1
2
3 perspective of deceased organ donation varies even within India's nearest neighbouring
4 country [4, 27]. Therefore, this review included only the studies which exclusively reported the
5 findings among Indian population.
6
7
8
9

10 **Quality assessment**

11
12
13
14 Appropriate critical appraisal tools from Joanna Briggs Institute (JBI) were used to critique the
15 rigour of each studies included [28], also used in other organ donation systematic review
16 [19,29]. Comprehensive reporting on the quality assessment for both cross-sectional and
17 qualitative studies, are reported in figure 2 and 3. Quality assessment was initially carried out
18 by the primary researcher after which it was reviewed by the other two authors independently.
19
20 Both the authors along with the primary researcher agreed upon the quality assessment as
21 mentioned in figure 2 and 3. The review included all studies; however minimal emphasis was
22 given for those studies that demonstrated only fewer items in the quality assessment checklist.
23
24
25
26
27
28
29
30
31
32

33 **Data synthesis**

34
35
36 This systematic review followed an integrative review with narrative synthesis approach
37 enabling to synthesise complex information toward the phenomena of interest [30], a
38 methodology also employed in another systematic review on organ donation that reviewed both
39 quantitative and qualitative studies [20]. Narrative synthesis primarily depends on words and
40 texts to summarise the findings with four process elements such as 1) systematic search and
41 quality appraisal, 2) grouping and clustering of the studies reviewed, 3) text summary
42 development, and 4) assessment and interpretation [31].
43
44
45
46
47
48
49
50
51

52
53 Firstly, following the systematic search and quality appraisal, summary data was collected for
54 each study, and they were recorded across a table which had information needed to cluster the
55 studies to compare and study across (Table 1). Secondly, with the cross-sectional studies,
56 numerical results from each study were tabulated across a matrix and were compared across to
57
58
59
60

1
2
3 study their relationship in terms of barriers. Later, full synthesis of the qualitative studies was
4
5 undertaken by coding the findings sections using NVivo11. Codes were then organised into
6
7 themes to address the barriers appropriately.
8
9

10 While comparing and studying across the studies included in the review to understand their
11
12 relationship, various elements such as what the study is about, type of study, their approach,
13
14 the findings, study settings, and population studied were also considered. Noblit and Hare
15
16 (1988) described this as 'Reciprocal translation', also used in other similar methodological
17
18 approaches [32-36]. Thirdly, full syntheses of both cross-sectional and qualitative studies were
19
20 studied across to understand the supporting and refuting evidence collectively. For each section
21
22 of the findings, quantitative studies provided the initial context following which findings from
23
24 qualitative studies were used to elaborate and explain. With limited qualitative study narratives
25
26 to support or refute the cross-sectional study findings, they were incorporated into the
27
28 integration of the findings wherever possible. Both convergent and divergent findings are
29
30 explained in this review, whereby if divergent findings were identified explanatory factors such
31
32 as type of study or setting, or population were provided to facilitate better understanding [20].
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Table 1: Evidence table

Author (s) (Year)	Study Site	Study Country	Aim	Study setting	Study design	Study sample size	Sampling technique
Adithyan et al, (2017)	Kerala	India	To assess the knowledge and attitude of medical students regarding organ donation	Final year Undergraduate Medical students	Cross-sectional	194	Not specified
Ahlawat et al, (2013)	Chandigarh	India	To assess the attitude of healthcare professionals employed in intensive or emergency care units of our hospital towards organ donation, and the influence of various factors on willingness for self-organ donation after death	Health workers in intensive units	Cross-sectional	361	Not specified
Alex et al, (2017)	Karnataka	India	To assess the knowledge and attitude regarding organ donation and transplantation among the medical students	Medical college	Cross-sectional	510	Convenient sampling
Alex et al, (2019)	Pan India	India	To assess the general public's knowledge and attitude towards organ donation over two decades	General public	Cross-sectional	3914	Not specified
Amaliyar et al, (2019)	Gujarat	India	To assess the knowledge, attitude, and practice towards organ donation among medical, arts and commerce students	Students from last 4 semester groups from medical, arts and commerce college	Cross-sectional	300	Purposive sampling for centres; Random for participants
Balajee et al, (2016)	Pondicherry	India	To assess the awareness and attitudes regarding organ donation among rural people from 4 villages	General public	Cross-sectional	360	Systematic random sampling and random participant selection
Balwani et al, (2015)	Gujarat	India	To study the awareness and belief towards organ donation and its allocation in chronic kidney disease patients in western India	Tertiary care centre	Cross-sectional	85	Not specified
Balwani et al, (2015)	Gujarat	India	To determine the knowledge, attitude, and practice regarding organ donation in western India	Adult participants from a residential area around a tertiary healthcare centre	Cross-sectional	200	Random sampling
Bansal et al, (2019)	Chandigarh	India	To analyse socio-demographic profile of the decision makers for organ donation in	Tertiary care teaching hospital	Cross-sectional	59	Purposive sampling

			potential deceased donors//To determine the level of awareness regarding organ donation in decision makers and the correlation with the socio-demographic variables	among family members who consented to donate the organs of their loved ones			
Bapat et al (2010)	Karnataka	India	To understand the awareness, attitudes, and belief towards organ donation among post-graduate medical students	Post-graduate medical students	Cross-sectional	123	Volunteer sampling
Basavarajegowda et al (2021)	Pan India	India	To study the knowledge difference between the knowledge and attitude about organ donation among blood donors compared to non-blood donors	General public	Cross-sectional	803	Purposive sampling
Bathija et al, (2017)	Karnataka	India	To investigate the knowledge and attitude towards organ donation among post-graduates, and interns; to know the reasons for donation one's organs	Post-graduate and medical interns	Cross-sectional	300	Not specified
Bharambe et al, (2015)	Maharashtra	India	To assess the knowledge and attitude of the people living in an urban city in India towards organ donation	Out-patient department	Cross-sectional	65	Not specified
Bharambe et al, (2016)	Maharashtra	India	To study the knowledge and attitude of a medical student doing internship with regards to organ donation	Medical college internship students	Cross-sectional	43	Not specified
Bharambe et al, (2018)	Maharashtra	India	To assess the knowledge and attitude of healthcare professionals from a rural part of India regarding organ donation	Healthcare professionals attending a medical association meeting	Cross-sectional	32	Not specified
Bharambe et al, (2018)	Maharashtra	India	To assess the knowledge and attitude of people from a rural part of India regarding organ donation.	Rural community members	Cross-sectional	201	Not specified
Bhargavi et al, (2019)	Kerala	India	To check the level of awareness and attitude of 2nd year medical, dental, and nursing students at Govt. Medical College, Thiruvananthapuram Campus towards organ donation and whole-body donation using a questionnaire-based study.	Medical and nursing students	Cross-sectional	177	Convenience sampling
Chakradhar et al, (2016)	Telangana	India	To assess and compare the knowledge, attitude, and practice regarding organ	Dental college Undergraduate students	Cross-sectional	298	Not specified

			donation among dental students based on gender, year of study and religion					
Da Silva et al (2021)	West Bengal	India	To assess the knowledge, attitude, and practices of health-care professionals toward cadaveric organ donation and to know their awareness regarding legislations pertaining to cadaveric organ donation.	Healthcare professionals	Cross-sectional	400	Stratified random sampling	
Darbari et al (2020)	Uttarakhand	India	To assess the knowledge on organ donation among undergraduate medical students	Undergraduate medical students	Cross-sectional	197	NA	
Darlington et al, (2019)	Tamil Nadu	India	To study the knowledge, attitude, and practice towards organ donation	Medical students	Cross-sectional	425	Voluntary	
Darr et al (1999)	Luton	England	To assess the attitudes on organ donation and transplantation among south Asians	South Asian general public	Qualitative	64	Purposive sampling	
Dasgupta et al, (2014)	West Bengal	India	To ascertain the knowledge and attitude of the people regarding organ donation and to elicit the determinants of their knowledge and attitude in an urban community of west Bengal	Slum area residents	Cross-sectional	110	Simple random sampling	
Deshpande et al, (2018)	Maharashtra and Madhya Pradesh	India	To determine the knowledge, attitude, and practice of pharmacy students about organ donation	Pharmacy college	Cross-sectional	160	Not specified	
Exley et al (1996)	Coventry	England	To examine the religious, cultural, and social context of organ donation	Sikh Asian community members	Qualitative	22	Judgemental sampling	
Flower et al (2013)	Pondicherry	India	To explore the general publics perceived barriers and facilitating factors of organ donation	General public	Cross-sectional	400	Random sampling	
Gauher et al, (2013)	London	The United Kingdom	To determine the attitude towards organ donation among Indian and Pakistan students	Medical and Non-Medical students	Qualitative	58	Purposive sampling - Stratified sampling for groups	
Ghose et al (2021)	Pune	India	To study knowledge and attitude toward organ donation among medical and nursing students with objectives to determine level of awareness about death criteria and need for organ donation and also to determine the attitude towards the same	Medical and nursing students	Cross-sectional	400	Population proportion to size	

Gupta et al, (2018)	Jammu & Kashmir	India	To assess the awareness and attitude of medical students regarding organ donation	Medical college Undergraduate students	Cross-sectional	280	Not specified
Gupta et al, (2021)	Maharashtra	India	To assess the pre-existing understanding beliefs, perception, and attitude, about deceased organ donation	College teachers and Students	Cross-sectional	80	Purposive sampling
Hakeem et al (2021)	Tamil Nadu	India	To assess knowledge, attitude, and perception of organ donation and transplant	Medical students and junior doctors	Cross-sectional	996	Not specified
Huern et al (2016)	Melaka	Malaysia	To assess the knowledge, attitude, and perception to determine the relationship between various sociodemographic data on knowledge, attitude, and perception toward organ donation	Undergraduate medical students	Cross-sectional	72	NA
Jagadeesh et al (2018)	Karnataka	India	To assess the knowledge, attitude, and beliefs toward organ donation and factors affecting willingness to donate	Professional drivers	Cross-sectional	300	convenient sampling
Jayabharathi et al, (2019)	Tamil Nadu	India	To assess the knowledge and attitude on organ donation among selected community area	Community area	Cross-sectional	60	convenient sampling
Joshi et al, (2011)	The United Kingdom	The United Kingdom	To investigate the organ donor attitudes and donor card behaviour of young adult UK citizens with particular focus on those of South Asian origin	Higher education institutes in the UK	Cross-sectional	382	Purposive sampling
Jothula et al, (2018)	Telangana	India	To assess the knowledge, attitude, and practice towards organ donation among medical students	Medical college Undergraduate students	Cross-sectional	160	Not specified
Kachappillil et al (2020)	Kerala	India	To assess the attitude of general population towards organ donation residing in a rural community	General public	Cross-sectional	100	Convenient sampling
Kadam et al (2021)	Maharashtra	India	To study the knowledge and attitude of first-year medical students towards organ donation.	First year medical students	Cross-sectional	130	Not specified
Kaistha et al, (2016)	New Delhi	India	To determine the knowledge, attitude, and practice regarding organ donation	Patient attendants attending out-patient department	Cross-sectional	119	Convenience
Kalmath et al (2020)	Karnataka	India	To assess the level of knowledge, preparedness, and commitment towards organ donation.	Youth public	Cross-sectional	300	Probability stratified random sampling

1								
2								
3								
4	Karim et al (2013)	The United Kingdom	The United Kingdom	To explore the south Asians attitudes toward organ donation	South Asian general public	Cross-sectional	147	Not specified
5								
6								
7	Kaur et al (2021)	Punjab	India	To know the knowledge, attitude, and practices regarding organ donation among medical students of Punjab	Medical students	Cross-sectional	380	Not specified
8								
9								
10	Kennedy et al, (2002)	Kerala	India	To study the attitudes and beliefs about organ donation in India from the perspectives of the doctors and the public	Doctors and public	Qualitative	8	Purposive
11								
12								
13	Khan et al (2020)	Jammu and Kashmir	India	To know the knowledge and attitude towards organ donation amongst the students	Student population	Cross-sectional	200	Not specified
14								
15								
16	Kundu et al (2021)	Chhattisgarh	India	To investigate the willingness to become an organ donor and the religious and cultural attitude of healthcare professionals	Medical and paramedical students	Cross-sectional	630	Not specified
17								
18								
19	Li et al (2016)	Ontario	Canada	To determine the registration status from deceased organ donation and tissue donation	Migrant population	Cross-sectional	NA*	NA
20								
21								
22	Loch et al (2010)	Kuala Lumpur	Malaysia	To examine the knowledge, attitude, and perception toward organ donation	General public	Cross-sectional	272	NA
23								
24	Lokesh Kumar et al (2021)	Tamil Nadu	India	To determine the awareness of organ donation concerning organ donation amidst the rural population and to assess the attitude towards the organ donation	Rural public	Cross-sectional	203	Two stages random sampling
25								
26								
27								
28	Mani, (2016)	Tamil Nadu	India	To identify the perceptions and practices related to organ donation in a rural population of Tamil Nadu, India	Rural population	Cross-sectional	100	Simple random sampling
29								
30								
31								
32	Meghana et al, (2018)	Karnataka	India	To assess the knowledge of organ donation among the final year medical, dental, and nursing students and to study the attitude, religious beliefs of the healthcare professionals regarding organ donation and transplantation, to find out the effect of motivation, towards organ donation	Medical, dental, nursing students	Cross-sectional	150	Not specified
33								
34								
35								
36								
37	Minz et al, (1998)	Chandigarh	India	To find out the extent of awareness and attitudes, to help us formulate a further plan of action	Healthcare professionals	Cross-sectional	204	Not specified
38								
39								
40								
41								
42								
43								
44								
45								
46								

Mishra et al (2016)	Odisha	India	To evaluate the awareness of organ donation	College students	Cross-sectional	430	NA
Misra et al (2021)	Haryana	India	To understand the beliefs and knowledge of a rural community toward organ donation and the identification of barriers for organ donation	Rural public	Qualitative	48	Simple random sampling
Misra et al (2021)	Haryana	India	To assess awareness about brain death and attitude towards organ donation in a rural community setting.	Rural public	Cross-sectional	947	Simple random sampling
Mithra et al, (2013)	Karnataka	India	To assess the perceptions and attitudes of the people seeking health care in tertiary care centres towards organ donation in Mangalore, India.	People seeking general healthcare as outpatients	Cross-sectional	863	Simple Random Sampling and convenient sampling
Mohan et al, (2019)	Tamil Nadu	India	To establish the role of perceived awareness, family support, perceived individual value, and religiosity on organ donation intention	Public	Cross-sectional	247	Convenience sampling
Mondal et al (2016)	West Bengal	India	To assess the knowledge and attitude of people towards organ donation in a rural community of West Bengal and to study the association of socio-demographic factors with the knowledge and attitude towards organ donation	Rural community	Cross-sectional	110	Simple random sampling
Morgan et al (2015)	London	England	Identify ways in which minority ethnic group habitus appears to limit attitude and knowledge of the system of organ donation and shape attitude toward registration	South Asian minority ethnic general public	Qualitative	79	NA
Panwar et al (2016)	New Delhi	India	To assess the awareness of the brain death and the concept of deceased organ donation among lay people and to identify the potential reasons for the low rates of deceased organ donation	General public	Cross-sectional	352	Not specified
Parmar et al (2017)	Gujarat	India	To assess perception of undergraduate students toward organ donation	Undergraduate students	Cross-sectional	100	Randomisation
Parmar et al (2021)	Gujarat	India	To assess the awareness among subjects regarding body donation and cadaveric dissection and their willingness to donate body	Patients	Cross-sectional	130	Not specified

Paul et al, (2019)	West Bengal	India	To understand the knowledge, attitude, and practice pattern of organ donation among the participants and to find out the association between the knowledge of organ donation with selected variables of interest	Urban field practice area of medical college	Cross-sectional	206	Not specified
Poreddi et al (2016)	Karnataka	India	To assess Indian undergraduate nursing students' attitude, knowledge, and willingness to donate organs	Nursing students	Cross-sectional	267	Non-probability convenience sampling
Poreddi et al, (2017)	Karnataka	India	To assess the knowledge, attitude, and willingness to donate organs among the general population	Patients attending outpatient department	Cross-sectional	193	Lottery method
Pradeep et al (2019)	Nort west of England	England	To explore the attitudes and beliefs toward organ donation	General public	Cross-sectional	593	Convenience sampling
Rajan (2020)	West Bengal	India	To assess the knowledge and attitude regarding blood and organ donation among adolescents	Adolescent population	Cross-sectional	100	Non-probability purposive sampling
Randhawa et al (1998)	Luton	England	To examine the influence of religious beliefs, amongst other things, on the extent and directions of public attitudes toward organ donation	South Asian general public	Qualitative	64	Focused sampling
Rani et al (2020)	New Delhi	India	To assess the knowledge ad attitude of general population towards organ donation	General public	Cross-sectional	1089	Purposive non-probability sampling
Ray et al (2020)	West Bengal	India	To assess the knowledge and attitude of certain populations like medical students with respect to organ donation	Medical students	Cross-sectional	134	Random sampling
Reddy et al (2003)	New Delhi	India	To assess the awareness and the attitude of Indian patients, the public, doctors, and nurses toward organ donation	Public, doctors, and nurses	Cross-sectional	990	Randomisation
Sachdeva et al, (2017)	Delhi	India	To assess knowledge, attitude, and practice regarding organ donation / tissue donation among adult visitors of a government hospital in Delhi, India	patient or accompanying attendant of a government hospital	Cross-sectional	450	Convenience sampling
Sam et al, (2018)	Tamil Nadu	India	To assess the awareness and attitude regarding Organ Donation among final year students of medical, dental, engineering,	Medical, dental, engineering, and arts and science students	Cross-sectional	486	Not specified

			and arts and science students in Thirivallur and Chennai					
Sarveswaran et al, (2018)	Puducherry	India	To determine the knowledge, attitude, and practice regarding organ donation	Urban community members	Cross-sectional	257	Random	
Seetharaman et al (2020)	Maharashtra	India	To evaluate the knowledge, attitudes, and beliefs of licensed medical doctors and undergraduate medical students	Medical doctors and students	Cross-sectional	532	Non-probability convenient sampling	
Singh et al, (2002)	Uttar Pradesh	India	To study level of awareness in hospital staff about transplantation, brain death, and organ donation, as well as factors that may be associated with this awareness	Hospital staffs	Cross-sectional	266	Simple Random Sampling	
Soni et al, (2018)	Madhya Pradesh	India	To understand correlation between knowledge and attitude towards organ donation among medical and non-medical students and identify barriers to deceased organ donation; to look into participants perception for adoption of presumed consent policy in Indian context; and understanding the acceptance of donor acknowledgement in the form of organ incentivization	Medical and Engineering students	Cross-sectional	600	Random	
Swamy et al (2020)	Karnataka	India	To assess the awareness and attitude of the young graduates in medical and engineering streams	Medical and Engineering students	Cross-sectional	400	Not specified	
Swani et al (2020)	Uttarakhand	India	To know the awareness, perceived threat and factors affecting the willingness to donate organs	first-and second-degree relatives of deceased	Cross-sectional	166	Complete sampling	
Tamuli et al, (2019)	Assam	India	To determine awareness and knowledge of educated (Undergraduate and postgraduate students) population towards organ donation; To find out factors impeding the organ donation program in this part of the country; To observe differences between findings of Undergraduate students and postgraduate degree holders (faculty)	Undergraduate and postgraduate students	Cross-sectional	360	Not specified	
Thyagarajan et al (2020)	Tamil Nadu	India	To assess the police officers' knowledge of the organ donation process and their practice toward it.	Police officers	Cross-sectional	627	Purposive sampling	

Verma et al (2020)		India	To assess knowledge, attitude, and perception toward organ donation	Undergraduate medical students	Cross-sectional	1463	Stratified sampling
Vijayalakshmi et al, (2015)	Karnataka	India	To investigate nurses' attitude towards organ donation	Nurses directly involved in patient care at a tertiary care hospital in South India	Cross-sectional	184	Non-probability convenience
Vijayalakshmi et al, (2016)	Karnataka	India	To assess the gender differences in perceptions and attitude of general population toward organ donation	Relatives of patients attending the outpatient department	Cross-sectional	193	Lottery method
Vincent et al (2019a)	Pondicherry	India	To understand the subjective views on barriers in the process of deceased organ donation among the stakeholders and their suggestions to improve in a government tertiary care teaching hospital	Transplant unit stakeholders	Qualitative	6	Purposive sampling
Vincent et al (2019b)	Pondicherry	India	To assess the knowledge, attitude, and perception on organ donation among undergraduate medical and nursing students	Under-graduate medical and nursing students	Cross-sectional	620	Convenient sampling for population and voluntary for participants
Wong et al (2010a)	Klang Valley	Malaysia	To understand the cultural and religious factors limiting organ donation in three ethnic group	Ethnic population	Qualitative	22	NA
Wong et al (2010b)	Klang Valley	Malaysia	To assess public knowledge and attitude with regard to deceased organ donation	General public	Qualitative	22	NA
Wong et al (2011)	Selangor	Malaysia	To explore the knowledge, attitude, perception and barriers toward deceased organ donation	General public	Cross-sectional	259	NA
Yadav et al (2020)	Haryana	India	To determine the knowledge and attitude of faculty members of a university	Faculty members	Cross-sectional	170	Not specified

* This study was based on the population data; the findings were based on national Indian population which was 228,879. Since it would over-represent the actual studies, this study sample size is not mentioned in the evidence table but in the notes here.

Findings

Grouping and clustering

Among the 89 studies reviewed; majority (84%) were conducted among Indians living in India (n=75) while other fourteen studies were among people of Indian origin living in the UK (n=8), Malaysia (n=5), and Canada (n=1). Cross-sectional studies (n=79) included various settings such as general community, education institutions and hospital setting (Table 1). Qualitative studies (n=10) used methods like in-depth interviews and focus group discussion (Table 1). Among the 29,385 individuals involved in the retained studies, 27,503 individuals (94%) were from studies conducted in India. Among the studies conducted in the UK, there were 1,235 individuals in total, however, one study had no evidence on the sample number of Indian participants involved [27], and the Malaysian studies had 647 individuals in total. The study participants from the Canadian study were not included since they were information taken from national registry which had around 228,879 Indian individuals.

Findings

Integration and relationship

Based on the narrative synthesis, findings are described under the following six themes namely:

1) knowledge and awareness toward deceased organ donation, 2) willingness and actual behaviour toward deceased organ donation, 3) familial influence, 4) fear and mistrust, 5) religious influences, and 6) bodily issues.

Knowledge and awareness of deceased organ donation

Being the commonest theme studied across, findings showed that knowledge had a positive correlation with willingness and practice [37-44]. Both among Indians living in India and outside, younger adults, participants from higher socio-economic status, and with higher

1
2
3 education or healthcare education demonstrated higher knowledge toward deceased organ
4 donation [43-60] and individuals from southern region of India showed higher knowledge
5 compared to other regions in India [61-66].
6
7
8
9

10 Whilst majority of the studies confirmed that almost all the participants had heard about organ
11 donation (Figure 3) and had higher awareness, knew what organs can be donated [4,39,44,53-
12 55,67-85] and that organs can be donated to anyone [46,61,80], the knowledge and
13 understanding on brain death was less well understood [49,64,68,69,75,86-89]. A qualitative
14 study from an urban area in the southern region of India also found brain death as a new concept
15 for many and hard to accept among the public [90]. Also, many were not aware about the organ
16 donor card [67,83,88,91-94], where and how to register and obtain an organ donor card
17 [40,50,53,55,56,70,71,94,95] - an important component for organ donor registration. In
18 addition, knowledge on the law that governs organ donation was also found to be low
19 [40,71,92,96,97].
20
21
22
23
24
25
26
27
28
29
30
31
32
33

34 Though a study among Indians living in UK showed that disinterest, emotional distaste, family
35 opposition and religion to be the underlying cause for reluctance to register [58], among Indians
36 living in India, the awareness on brain death, organ donor card, where and how to register were
37 reported as important factors serving as barriers to individuals who are willing to register
38 [40,49,50,53,55,64,67,69-72,86,91-96,98].
39
40
41
42
43
44
45
46

47 **Willingness and actual behaviour toward deceased organ donation**

48
49 Greater knowledge showed positive influence on the attitude and willingness across all Indian
50 regions [17,41,43,44,50,92,99-103]. Similar to higher knowledge among individuals from
51 southern region of India, willingness to register, to donate and to accept organs for transplant
52 was also shown to be higher [38,45,46,49,66,68,92,99,101]. However, though knowledge had
53 a positive association toward attitude and willingness, the proportion of individuals willing to
54
55
56
57
58
59
60

1
2
3 register, and actual registration was very low and similar across every study included.
4
5 Correspondingly, even a study conducted among Indian students living in UK revealed that
6
7 55% of the individuals doubted if they would go ahead with registration [58]. With such
8
9 reluctance, Indians living in India, UK, and Malaysia considered fear of misuse and family
10
11 refusal as a major reason, alongside minor reasons like emotional barriers, bodily issues, and
12
13 religion [68,75,79,94,97,100,104,44,105,106,95,107,]. On contrary, commonest reasons to
14
15 donate an organ was to save someone's life, closely followed by prolong someone's life, social
16
17 commitment, altruistic deed, and to keep at-least the organs alive [72,75,91,99,104-111].

18
19
20
21
22 Higher proportion of participants were willing to receive compared to donating
23
24 [38,45,46,58,68,99,101,112-114] among Indians living globally. Furthermore, studies revealed
25
26 that among those who were willing to donate, majority were only willing to donate specific
27
28 organs namely eye / cornea and kidneys [46,61,62], which may be related to the knowledge on
29
30 what organs can be donated [67-72,76-78,86]. Nonetheless, majority of the participants were
31
32 willing to support and promote organ donation in their region and was similar across India
33
34 [55,57,91,99,109,110].

35
36
37
38
39 Younger adults, participants from higher socio-economic status and participants with higher
40
41 education or healthcare education demonstrated higher willingness toward deceased organ
42
43 donation among Indians living globally [17,27,43,45,47,48,53,58-61, 108]. However, this was
44
45 not consistent during the time of actual behaviour. Studies showed that there was almost equal
46
47 distribution of participants from lower socio-economic status and lower education, who gave
48
49 consent and actually signed for deceased organ donation [47,96]. However, this conclusion is
50
51 based only from few studies which showed to be similar in north and south of India [47,96].
52
53
54
55
56
57
58
59
60

Familial influence

In spite of willingness to register for organ donation, larger proportion of individuals have not initiated a conversation or discussed their willingness with their family members, an important behaviour for a successful donation [52,65,68,71,82,93,100,115,116] - however opted family as the major barriers toward organ donation [46,63,65,69,72,94,100,102], this was identified even among Indians living outside India [27,117]. Qualitative studies conducted in India, the UK and Malaysia revealed the main reasons was their lack of confidence in initiating conversations around sudden deaths, and with these conversations perceived unwelcomed by their parents and elders [27,90,95,4,85].

However, other few qualitative studies conducted among Indians who were born and grew in another country (i.e., UK and Canada) revealed that they are less concerned of sharing their views compared to their older generations (i.e., mostly migrant generation) and were more willing to discuss their wishes with their families [17,27,81,118], which could be related to acculturation. On the other side, qualitative studies conducted in southern India and the UK suggested that such conversation only occurred when individuals read or viewed such events [90,119]. Also, during the time of consent request, unknown will of the deceased showed to be a significant challenge during the decision-making process [96], making such discussion very important during the crucial decision-making moments.

Willingness to support family members was shown to be higher among healthcare students compared to other students [55,120] and lower among family members from rural areas [99,116]. However, while higher proportion of individuals were willing to support family members for organ donation [38,44,61,71,88,92,101,118], only very few families actually supported this decision when families were approached for consent [90].

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Though studies included found no association based on marital status [38,45,101], one study found that unmarried individuals appeared to be more willing to donate compared to married couples [101]. Also, participants who were aware of their spouse's approval opinion, they were more willing to donate compared to those unaware of their spouse's opinion [45]. Among the type of family, individuals from 'joint' families had higher knowledge, while willingness to donate was found to be higher among nuclear families and also was identified to be highly influenced by the family [4,17,38,48,50]. This was a similarity identified in India, Canada, and the UK, showing it to be a collectivist decision making, where involvement of the extended family is identified to be a part of decision making among this population irrespective of the country they live [4,17,38,48,53,117]. And involvement of extended family was identified to be a barrier among Indians in the UK, in this process [4].

Fear and Mistrust

32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Fear on misuse of organs by the healthcare team, and lack of trust was the other major barrier reported [55,63,64,68,69,71,72,78,83,89,94,97,104,105]. Some participants relate organ donation to organ trafficking and misuse which leads them to fear and mistrust [49,58,65,99,105]. A qualitative study also revealed increased ambivalence that while on one side participants perceived organ donation as a noble act, on the other side they were also fearful of organ misuse due to the information that they hear through news and media on organ trafficking and exchange of money for organs [90].

Also similar in the UK, among Indian participants, a mother was afraid to see an organ donor card in his child's wallet as she was thinking if doctors will come to see it, then they may deviate the process toward donation and give less care toward saving her child [27]. In parallel, general population from India also feared pre-mature declaration of death for the need of organs

1
2
3 [39,99,120]. However, healthcare population groups were less likely to believe that there will
4
5 be any premature declaration of death by the doctors [38,71,85,87].
6
7

8 **Religious influence**

9

10
11 Overall, majority of the participants favoured organ donation
12
13 [27,38,46,47,49,61,80,81,101,106,108,109]. However, when further looked based on religion,
14
15 different studies showed different religious groups to be more willing to donate compared to
16
17 individuals from another religious group [45,48,61,73,121], showing no consistency on which
18
19 particular religion is more supportive or rejective [45,48,52,61,121]. In parallel, a qualitative
20
21 study conducted among UK university students of Indian descendants showed lack of
22
23 homogeneity even within one same religion. Some agreed that body needs to be intact for
24
25 reincarnation, while other participants believed that body and soul are two different entities
26
27 and that only the soul counts while body is left to decay in this earth [27,97]. However, among
28
29 studies undertaken outside India, Indian Muslim participants were identified to be less likely
30
31 or supportive toward organ donation [4,44,95,106,117]. Qualitative studies from outside India
32
33 identified that lack of the standpoint of religion as one of the reasons leading to such reluctance
34
35 and not the individual's opinion [108,117].
36
37
38
39
40
41

42 However, though there were differences of opinion across and within the religion, majority of
43
44 the participants agreed that organ donation is not against religious views
45
46 [38,68,72,88,90,97,101,109] and also considered religion as the very least barrier toward organ
47
48 donation [44,45,63,65,68,90,115,122,114]. A qualitative study conducted among UK students
49
50 with Indian origin showed that though individuals felt religion may influence their decision it
51
52 was not the only factor that that will be considered in such decisions [27]. Yet, favourable
53
54 opinion of religion toward organ donation was found to be positively correlating with their
55
56 willingness to donate [38,52].
57
58
59
60

1
2
3 A Qualitative study conducted in UK with Indian students revealed that younger generations
4 were less bothered about religious views compared to older generations, which could have
5 occurred due to acculturation [27]. Also, participants preferred that religion should not be a
6 criterion based on which allocation can be decided [48,68,109,115] and that organ of a
7 deceased person can be donated to a recipient from any religion [48,68,109,115].
8
9

10
11
12 However, during the time of consent, a stakeholder from a qualitative study said that families
13 who were not willing to donate use the concept of religion as a reason to decline donation,
14 though none of the religion is against organ donation. In the same qualitative study, public
15 participants from various religious group felt that their religion supports organ donation [90].
16
17
18
19
20
21
22
23
24

25 **Bodily issues**

26
27
28 Majority of the individuals from the reviewed studies were not concerned about bodily issues
29 though it has to undergo incisions while explanting [38-40,45,46,61,91,97,118]. However, on
30 the other side, majority also agreed that it is an individual's complete right to have the organs
31 within the body when dead [49,87]. Whilst majority of individuals were not concerned about
32 incisions in the body, a qualitative study found that in the real time of consent, stakeholders
33 found it easy to get approval for corneal donation and not solid organs as it may have many
34 incisions over the body and disfigure it [72]. In relation to funeral practices involving the
35 deceased body, majority were aware that normal funeral practices can be conducted even after
36 donating organs [38,49,61,87,91,115], contrast findings were also evident [49,55,87].
37
38
39 However, majority opted body disfigurement, but less proportion, as one of the least reasons
40 to be a barrier toward organ donation, both within and outside the borders of India
41 [46,63,65,69,83,100,106,108].
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Discussion

To the best of our knowledge, this is the first systematic review that reviewed barriers toward organ donation among Indians living globally. Also, this is one of the few systematic reviews in organ donation that used integrative methodology. While majority in India have heard or are aware of organ donation, and had a positive correlation with willingness, their gap is wide. This indicates that there could be various factors other than knowledge which need to be studied in more detail. Organ donation being more embedded with health behaviour, there is a need to understand the relationship between behaviour and behavioural intention by adopting appropriate principles. This aids the specificity of policy and campaigns to address organ donor registration behaviour in this particular population.

Though gaps identified in majority of the quantitative studies merit qualitative studies, only very few qualitative studies were undertaken in India [87,90,97]. For instance, though majority individuals were willing to be an organ donor, majority have not initiated any such conversation with their family members yet considered family to be the major barrier [46,63,65,69,100,117]. However, no further studies were exclusively undertaken to understand how a construct like family interferes in the decision making toward registration and consent. Such studies will aid in developing and testing hypothesis or developing appropriate interventions to increase such conversation with family members. Such conversations play a very important role as the awareness on the willingness of the deceased plays a vital role in decision-making during consent [96]. However, the influence of family can be different among Indians in India and outside India as the latter may have influences based on acculturation and enculturation [27,58] while the prior maybe more concerned toward communication issues [52,65,68,90,93,100,115,116]. While majority were willing to be an organ donor [27,43,45,47,48,53,58-61], they were unaware on how to register to be an organ donor

1
2
3 [40,50,53,55,56,70,71,94]. Therefore, further campaigns on registration procedure information
4 will enable to improve organ donation in India.
5
6

7
8 This review showed that there are various complex interactions that happen in the society
9 where an individual lives rather than just knowledge influencing organ donation decision. Fear
10 and mistrust have shown to influence the uncertainty in decision-making for a very long time
11 [27,40,48,55,63,64,68,69,71,72,78,97]. However, studies failed to address how fear influences
12 organ donation, what is the source of fear and how a construct like fear can be addressed. This
13 fear could be due to the news or information that they hear on illegal organ donation and
14 transplants practices around them or any other reasons [123], but not much have been studied
15 why such fear exist among this population.
16
17

18 Also, while majority of the studies show influence of religion on organ donation, there is a
19 greater need to understand how a religion influences organ donation in India. Is it the
20 misconception, or the lack of enabling religious community, or reluctance to take such
21 conversation, or lack of information from the religious leaders or their physical practices that
22 does not allow donation? Such in-depth studies need to be undertaken to gain a deeper
23 understanding into the phenomena. Therefore, there is an urgent need, to study further how the
24 interaction of the individuals with such a complex socio-cultural and institutional structures
25 influences the organ donation behaviour [124].
26
27

28 Various other factors such as age, sex, education, and socio-economic status showed greater
29 influence on willingness to donate [27,45,47,48,53,58,61]. However, studies showed that they
30 did not hold true during the time of consent [47,96]. This review therefore showed that there is
31 some shift in behaviour during registration and the actual consent. This again probes to further
32 the understanding on what happens during the time of consent, and why such a shift is seen in
33 the intention to donate between these two time periods.
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 Overall, based on the studies undertaken among Indians living in India, the UK, Canada, and
4
5 Malaysia, similarities and differences were identified. The willingness and registration
6
7 behaviour differed according to the geographical location where Indians lived in comparison
8
9 to their native population. While Indians were considered to have higher attitude and
10
11 willingness in Malaysia [84,114], Indians living in the UK and Canada were considered to have
12
13 lower attitude and willingness [17,117]. This could have been due to their respective socio-
14
15 cultural practices of Muslim major country [i.e., Malaysia] and Christian major country [i.e.,
16
17 Canada and the UK] with Hindu major population [i.e., Indians]. This argument is also
18
19 supported by a study that compared organ donation willingness between Christian, Hindu, and
20
21 Muslim major native population [58]. The similarity identified was that, irrespective of their
22
23 geographical location, this was a collectivist decision and not an individual's decision
24
25 [4,85,117] with family, fear and mistrust, and bodily issues identified to be the major barrier
26
27 [44,83,85,95,105,107,108].
28
29
30
31
32

33
34 Methodologically, studies conducted among the Indian ethnic group outside India were
35
36 collectively identified as South-Asians or Asians [23-26,106] while they differ culturally,
37
38 socially, politically, economically, and even religiously [125]. Two studies included from UK
39
40 in this review have clearly shown such a difference with the neighbouring country (i.e., India,
41
42 and Pakistan) [27]. Therefore, there is a need to address this population with such specificity
43
44 in future research that can strengthen the practices even more efficiently. Also, with this
45
46 population to be the largest migrating population in the world [7] it is important to understand
47
48 their behaviour outside India. Studies show difference between various migration generations
49
50 from the same ethnicity [27,58]. This cannot happen without the influence of time elapsed since
51
52 immigration, immigrant generation (i.e., first, second, or higher), acculturation, enculturation,
53
54 perceived discrimination, attitudes / mistrust toward healthcare system, community barriers,
55
56 socio-cultural influence and many such complex determinants which adds further complexity
57
58
59
60

1
2
3 to the issue of organ donation among such a population. Therefore, such specific research
4
5 among this community is also needed to address the disproportionate representation between
6
7 waiting list and donor list from this ethnic population outside the country of origin.
8
9

10
11 Though narrative synthesis is criticised for its lack of transparency, this study has tried to be as
12
13 transparent as possible to strengthen its validity and credibility of the review and synthesis
14
15 [30,126]. The PRISMA flow chart, search strategy, data synthesis and analysis methods are
16
17 clearly explained in this study to overcome those limitations.
18
19

20 **Conclusion**

21
22
23 This review showed that majority of the participants from India and of Indian origin hold
24
25 positive attitude toward registration but show lower willingness and even lower practice of
26
27 registration. Though this study showed the complex relationship and influences toward organ
28
29 donation behaviour, lacunae were identified for further deeper understanding into such
30
31 complex interactions determining the behaviour. There is also a lack of methodological rigour
32
33 to study this population outside India, being collectively studied with their neighbouring
34
35 population which are not homogenous. Also, within India, majority of the studies employed
36
37 similar aims and methods leading to repetition of studies rather than diversified, wider, and in-
38
39 depth research.
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 **Funding sources:** This review is led by the principal investigator Britzer Paul Vincent who is
4 a PhD scholar at the Institute for Health Research, University of Bedfordshire funded by their
5 Global Challenges Research Fund.
6

7
8 **Authorship Contribution:**

9 All authors BP, GR & EC contributed to – conception of the study, design of work, data
10 acquisition, data analysis, data interpretation, writing of the article, final approval, and
11 accountability of the study.
12

13
14 **Acknowledgement:** We would like to thank our librarian Mr. David Abdy from Institute for
15 Health Research, University of Bedfordshire for his contribution with the development of the
16 search strategy.
17

18
19 **Data availability:** None
20

21 **Conflict of Interest:** None declared.
22

23
24 **Patient and Public involvement:** None as this is a systematic review
25

26 **Ethics approval details:** Institute for Health Research Ethics Committee from the University
27 of Bedfordshire approved this study (IHREC931).
28
29

30
31 **References:**
32

- 33
34 1. Merrill, J.P., Murray, J.E., Takacs, F.J., Hager, E.B., Wilson, R.E. and Dammin, G.J.,
35 1963. Successful transplantation of kidney from a human cadaver. *Jama*, 185(5), pp.347-
36 353.
37
38 2. Rudge C, Matesanz R, Delmonico FL, Chapman J. International practices of organ
39 donation. *British journal of anaesthesia*. 2012 Jan 1;108(suppl_1):i48-55.
40
41 3. Alden, D.L. and Cheung, A.H., 2000. Organ donation and culture: a comparison of Asian
42 American and European American beliefs, attitudes, and behaviors. *Journal of Applied*
43 *Social Psychology*, 30(2), pp.293-314.
44
45 4. Karim A, Jandu S, Sharif A. A survey of South Asian attitudes to organ donation in the
46 United Kingdom. *Clinical transplantation*. 2013 Sep;27(5):757-63.
47
48 5. Lo, C.M., 2012. Deceased donation in Asia: challenges and opportunities. *Liver*
49 *Transplantation*, 18(S2), pp.S5-S7.
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 6. United Nations. Department of Economics and social affairs. Population dynamics.
4 Available at: <https://population.un.org/wpp/Download/Standard/Population/>. Last
5 viewed: 03 April 2021
6
7
- 8
9
10 7. World Migration Report. 2020. Available at:
11 https://www.un.org/sites/un2.un.org/files/wmr_2020.pdf. Last viewed 03 April 2021
12
13
- 14
15 8. Ramachandran, A., Ma, R.C.W. and Snehalatha, C., 2010. Diabetes in asia. *The*
16 *Lancet*, 375(9712), pp.408-418.
17
- 18
19 9. Ramachandran, A., Snehalatha, C., Shetty, A.S. and Nanditha, A., 2012. Trends in
20 prevalence of diabetes in Asian countries. *World journal of diabetes*, 3(6), p.110.
21
22
- 23
24 10. Singh, R.B., Suh, I.L., Singh, V.P., Chaithiraphan, S., Laothavorn, P., Sy, R.G.,
25 Babilonia, N.A., Rahman, A.R.A., Sheikh, S., Tomlinson, B. and Sarraf-Zadigan, N.,
26 2000. Hypertension and stroke in Asia: prevalence, control and strategies in developing
27 countries for prevention. *Journal of human hypertension*, 14(10), pp.749-763.
28
29
- 30
31 11. Ritz E, Rychlík I, Locatelli F, Halimi S. End-stage renal failure in type 2 diabetes: a
32 medical catastrophe of worldwide dimensions. *American journal of kidney diseases*.
33 1999 Nov 1;34(5):795-808.
34
35
- 36
37 12. Weisstuch JM, Dworkin LD. Does essential hypertension cause end-stage renal disease?.
38 *Kidney international Supplement*. 1992 May 2(36).
39
- 40
41 13. Navin S, Shroff S, Niranjana S. 'Deceased Organ Donation in India'. Available:
42 <[http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)
43 [donation-in-india.asp](http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp)> [Accessed 18 March 2021].
44
45
- 46
47 14. National Deceased Donor Transplantation, Mohan Foundation. 2017. Available:
48 <https://www.mohanfoundation.org/deceased-organ-donation-in-india.asp> [Accessed
49 18 March 2021].
50
51
52
53
54
55
56
57
58
59
60

15. Kumar, V., Ahlawat, R., Gupta, A.K., Sharma, R.K., Minz, M., Sakhuja, V. and Jha, V., 2014. Potential of organ donation from deceased donors: study from a public sector hospital in India. *Transplant International*, 27(10), pp.1007-1014.
16. NHSBT. Organ Donation and Transplantation data for Black, Asian and Minority Ethnic (BAME) Communities. 2018. Available at: <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/12048/bame-organ-donation-and-transplantation-data-2017-18.pdf>. Last viewed: 03 April 2021
17. Li, A.H.T., Lam, N.N., Dhanani, S., Weir, M., Prakash, V., Kim, J., Knoll, G. and Garg, A.X., 2016. Registration for deceased organ and tissue donation among Ontario immigrants: a population-based cross-sectional study. *Canadian Medical Association Open Access Journal*, 4(4), pp.E551-E561.
18. Vincent BP, Randhawa G, Cook E. Protocol: Barriers towards organ donor registration and consent among people of Indian origin living globally: a systematic review and integrative synthesis—protocol. *BMJ Open*. 2020;10(6).
19. Irving, M.J., Tong, A., Jan, S., Cass, A., Rose, J., Chadban, S., Allen, R.D., Craig, J.C., Wong, G. and Howard, K., 2012. Factors that influence the decision to be an organ donor: a systematic review of the qualitative literature. *Nephrology dialysis transplantation*, 27(6), pp.2526-2533.
20. Morgan, M., Kenten, C., Deedat, S. and Donate Programme Team, 2013. Attitudes to deceased organ donation and registration as a donor among minority ethnic groups in North America and the UK: a synthesis of quantitative and qualitative research. *Ethnicity & health*, 18(4), pp.367-390.
21. Kotha, S., Lawendy, B., Asim, S., Gomes, C., Yu, J., Orchanian-Cheff, A., Tomlinson, G., & Bhat, M. (2021). Impact of immunosuppression on incidence of post-transplant diabetes mellitus in solid organ transplant recipients: Systematic review and meta-analysis. *World journal of transplantation*, 11(10), 432–442. <https://doi.org/10.5500/wjt.v11.i10.432>

- 1
 - 2
 - 3
 - 4
 - 5
 - 6
 - 7
 - 8
 - 9
 - 10
 - 11
 - 12
 - 13
 - 14
 - 15
 - 16
 - 17
 - 18
 - 19
 - 20
 - 21
 - 22
 - 23
 - 24
 - 25
 - 26
 - 27
 - 28
 - 29
 - 30
 - 31
 - 32
 - 33
 - 34
 - 35
 - 36
 - 37
 - 38
 - 39
 - 40
 - 41
 - 42
 - 43
 - 44
 - 45
 - 46
 - 47
 - 48
 - 49
 - 50
 - 51
 - 52
 - 53
 - 54
 - 55
 - 56
 - 57
 - 58
 - 59
 - 60
22. Piasecki, J., Waligora, M., & Dranseika, V. (2017). What Do Ethical Guidelines for Epidemiology Say About an Ethics Review? A Qualitative Systematic Review. *Science and engineering ethics*, 23(3), 743–768. <https://doi.org/10.1007/s11948-016-9829-3>
23. Molzahn, A.E., Starzomski, R., McDonald, M. and O'Loughlin, C., 2005. Indo-Canadian beliefs regarding organ donation. *Progress in Transplantation*, 15(3), pp.233-239.
24. Morgan, M., Hooper, R., Mayblin, M. and Jones, R., 2006. Attitudes to kidney donation and registering as a donor among ethnic groups in the UK. *Journal of Public Health*, 28(3), pp.226-234.
25. Ahmed, W., Harris, S. and Brown, E., 1999. Attitudes to organ donation among South Asians in an English high street. *Journal of the Royal Society of Medicine*, 92(12), pp.626-627.
26. Rasiyah, R., Manikam, R., Chandarsekaran, S.K., Thangiah, G., Puspharajan, S. and Swaminathan, D., 2014. The influence of socioeconomic and demographic variables on willingness to donate cadaveric human organs in Malaysia. *Medicine*, 93(23).
27. Gauher ST, Khehar R, Rajput G, Hayat A, Bakshi B, Chawla H, Cox BM, Warrens AN. The factors that influence attitudes toward organ donation for transplantation among UK university students of Indian and Pakistani descent. *Clinical transplantation*. 2013 May;27(3):359-67.
28. JBI Critical Appraisal Tools. Available at: <https://jbi.global/critical-appraisal-tools>. Last viewed: 03 April 2021
29. Gao, W., Plummer, V. and Williams, A., 2017. Perioperative nurses' attitudes towards organ procurement: a systematic review. *Journal of clinical nursing*, 26(3-4), pp.302-319.
30. Brown SJ. Knowledge for health care practice: A guide to using research evidence. Saunders; 1999.
31. Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, Britten N, Roen K, Duffy S. Guidance on the conduct of narrative synthesis in systematic reviews. A product from the ESRC methods programme Version. 2006 Apr 1;1:b92.

- 1
- 2
- 3 32. Noblit GW, Hare RD. *Meta-ethnography: synthesizing qualitative studies*, vol. 11.
- 4 California: Sage Publications; 1988.
- 5
- 6 33. Campbell R, Pound P, Pope C, Britten N, Pill R, Morgan M, Donovan J. *Evaluating meta-*
- 7 *ethnography: a synthesis of qualitative research on lay experiences of diabetes and*
- 8 *diabetes care*. *Soc Sci Med*. 2003;56(4):671–84.
- 9
- 10 34. Campbell, R., Pound, P., Morgan, M., Daker-White, G., Britten, N., Pill, R., Yardley, L.,
- 11 Pope, C. and Donovan, J., 2012. *Evaluating meta ethnography: systematic analysis and*
- 12 *synthesis of qualitative research*.
- 13
- 14 35. Nye E, Melendez-Torres GJ, Bonnell C. *Origins, methods, and advances in qualitative*
- 15 *meta-synthesis*. *Review of Education*. 2016;4(1):57–79.
- 16
- 17 36. Garside R. *A comparison of methods for the systematic review of qualitative research:*
- 18 *two examples using Meta-ethnography and Meta-study*. UK: University of Exeter; 2008.
- 19
- 20 37. Alex P, Kiran KG, Baisil S, Badiger S. *Knowledge and attitude regarding organ donation*
- 21 *and transplantation among medical students of a medical college in South India*. *Int J*
- 22 *Community Med Public Health*. 2017 Sep;4(9):3449-54p.
- 23
- 24 38. Bapat U, Kedlaya PG. *Organ donation, awareness, attitudes and beliefs among post*
- 25 *graduate medical students*. *Saudi Journal of Kidney Diseases and Transplantation*. 2010
- 26 Jan 1;21(1):174.
- 27
- 28 39. Chakradhar K, Doshi D, Reddy BS, Kulkarni S, Reddy MP, Reddy SS. *Knowledge,*
- 29 *attitude and practice regarding organ donation among Indian dental students*.
- 30 *International journal of organ transplantation medicine*. 2016;7(1):28.
- 31
- 32 40. Gupta RK, Singh P, Akhtar N, Kumari R, Gupta C, Gupta R. *Gender based perspectives*
- 33 *about organ donation among students in a medical school in North India*. *International*
- 34 *Journal of Research in Medical Sciences*. 2018 May;6(5):1710.
- 35
- 36 41. Jayabharathi B, Devika M, Akila M. *Assessment of knowledge and attitude on organ*
- 37 *donation among adults in selected areas*. *International Journal of Research in*
- 38 *Pharmaceutical Sciences*. 2019 Apr 15;10(2):782-6.
- 39
- 40 42. Singh P, Kumar A, Pandey CM, Chandra H. *Level of awareness about transplantation,*
- 41 *brain death and cadaveric organ donation in hospital staff in India*. *Progress in*
- 42 *Transplantation*. 2002 Dec;12(4):289-92.
- 43
- 44
- 45
- 46
- 47
- 48
- 49
- 50
- 51
- 52
- 53
- 54
- 55
- 56
- 57
- 58
- 59
- 60

- 1
2
3 43. Panwar, R., Pal, S., Dash, N.R., Sahni, P., Vij, A. and Misra, M.C., 2016. Why are we
4 poor organ donors: a survey focusing on attitudes of the lay public from northern
5 India. *Journal of clinical and experimental hepatology*, 6(2), pp.81-86.
6
7
- 8
9
10 44. Jagadeesh, A.T., Puttur, A., Mondal, S., Ibrahim, S., Udupi, A., Prasanna, L.C. and
11 Kamath, A., 2018. Devising focused strategies to improve organ donor registrations: A
12 cross-sectional study among professional drivers in coastal South India. *PLoS*
13 *one*, 13(12), p.e0209686.
14
15
- 16
17 45. Ahlawat R, Kumar V, Gupta AK, Sharma RK, Minz M, Jha V. Attitude and knowledge
18 of healthcare workers in critical areas towards deceased organ donation in a public sector
19 hospital in India. *The National medical journal of India*. 2013 Jan 1;26(6):322-6.
20
21
- 22 46. Balajee KL, Ramachandran N, Subitha L. Awareness and attitudes toward organ
23 donation in rural Puducherry, India. *Annals of Medical and Health Sciences Research*.
24 2016;6(5):286-90.
25
26
- 27 47. Bansal N, Koushal V, Mehra A. A study of sociodemographic profile and level of
28 awareness of the decision makers for organ donation of deceased organ donors in a
29 Tertiary Care Hospital. *Indian Journal of Transplantation*. 2019 Jan 4;13(2):82.
30
31
- 32 48. Dasgupta A, Shahbabu B, Sarkar K, Sarkar I, Das S, Kumar Das M. Perception of organ
33 donation among adults: A community based study in an urban community of West
34 Bengal. *Scholars J Appl Med Sci*. 2014;2(6A):2016-1.
35
36
- 37 49. Poreddi V, Sunitha TS, Thimmaiah R, Math SB. Gender differences in perceptions and
38 attitudes of general population towards organ donation: An Indian perspective. *Saudi*
39 *Journal of Kidney Diseases and Transplantation*. 2017 May 1;28(3):599.
40
41
- 42 50. Sarveswaran G, Sakthivel MN, Krishnamoorthy Y, Arivarasan Y, Ramakrishnan J.
43 Knowledge, attitude, and practice regarding organ donation among adult population of
44 urban Puducherry, South India. *Journal of education and health promotion*. 2018;7.
45
46
- 47 51. Tamuli RP, Sarmah S, Saikia B. Organ donation—“attitude and awareness among
48 undergraduates and postgraduates of North-East India”. *Journal of family medicine and*
49 *primary care*. 2019 Jan;8(1):130.
50
51
- 52 52. Vijayalakshmi P, Sunitha TS, Gandhi S, Thimmaiah R, Math SB. Knowledge, attitude
53 and behaviour of the general population towards organ donation: an Indian perspective.
54 *The National medical journal of India*. 2016 Sep 1;29(5):257.
55
56
57
58
59
60

- 1
 - 2
 - 3
 - 4
 - 5
 - 6
 - 7
 - 8
 - 9
 - 10
 - 11
 - 12
 - 13
 - 14
 - 15
 - 16
 - 17
 - 18
 - 19
 - 20
 - 21
 - 22
 - 23
 - 24
 - 25
 - 26
 - 27
 - 28
 - 29
 - 30
 - 31
 - 32
 - 33
 - 34
 - 35
 - 36
 - 37
 - 38
 - 39
 - 40
 - 41
 - 42
 - 43
 - 44
 - 45
 - 46
 - 47
 - 48
 - 49
 - 50
 - 51
 - 52
 - 53
 - 54
 - 55
 - 56
 - 57
 - 58
 - 59
 - 60
53. Swain, R., Prasad, H., Lalwani, S. and Pooniya, S., 2020. Awareness, perceived barriers and factors affecting willingness for Organ Donation among the first-and second-degree relatives of deceased in a tertiary care hospital of Northern India. *The Official Publication of Indian Academy of Forensic Medicine*, 42(4), pp.261-264.
54. Kadam, S., Shinde, S., Shroff, G. and Gulanikar, S., 2021. Knowledge and Attitude About Organ Donation Among Medical Students: An Observational Study from Aurangabad, Maharashtra. *Int J Cur Res Rev| Vol, 13(01)*, p.121.
55. Kundu, S., 2021. Attitudes and Myths regarding Posthumous whole Body Bequest and Organ Donation among Medical Professionals and Health Care Personnel of Tribal Chhattisgarh—A Broad Questionnaire Based Review. *Sch J App Med Sci*, 6, pp.1093-1116.
56. Swamy, R.M., Kalaburgi, R.A., Manjunath, G.N., Lavanya, R. and Kousalya, R., Knowledge and Attitude towards Organ donation among the Medical and Engineering students in Tumakuru, Karnataka. *IOSR Journal of Dental and Medical Sciences (IOSR-JDMS)* e-ISSN: 2279-0853, p-ISSN: 2279-0861. Volume 19, Issue 5 Ser.2 (May. 2020), PP 31-36
57. Gupta, P., Sodhani, S., & Bhate, K. (2021). Organ donation perception and beliefs: a cross sectional study amongst degree college students and teachers in Mumbai, Maharashtra, India. *International Journal of Advances in Medicine*, 8(3), 399-403.
58. Joshi MS. Whose decision is it? Organ donation attitudes among young UK South Asians. *Psychological Studies*. 2011 Mar 1;56(1):86-97.
59. Misra, P., Malhotra, S., Sharma, N., Misra, M.C., Vij, A. and Pandav, C.S., 2021. Awareness about brain death and attitude towards organ donation in a rural area of Haryana, India. *Journal of Family Medicine and Primary Care*, 10(8), p.3084.
60. Parmar, K.M., Vaisnani, H., Chavda, N., Sharma, P. and Jethava, K., 2021. A Questionnaire Based Study Evaluating Awareness for Organ and Body Donation and Cadaveric Dissection among the General Population Attending Medical and Dental Hospital. *Medico Legal Update*, 21(1), pp.835-839.
61. Mithra P, Ravindra P, Unnikrishnan B, Rekha T, Kanchan T, Kumar N, Papanna M, Kulkarni V, Holla R, Divyavaraprasad K. Perceptions and attitudes towards organ donation among people seeking healthcare in tertiary care centers of coastal South India. *Indian journal of palliative care*. 2013 May;19(2):83.

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
62. Balwani MR, Gumber MR, Shah PR, Kute VB, Patel HV, Engineer DP, Gera DN, Godhani U, Shah M, Trivedi HL. Attitude and awareness towards organ donation in western India. *Renal failure*. 2015a Apr 21;37(4):582-8.
 63. Bathija GV, Ananthesh BG, Bant DD. Study to assess knowledge and attitude towards organ donation among interns and post graduates of a medical college in Karnataka, India. *Natl J Community Med*. 2017;8(5):236-40.
 64. Bharambe VK, Sakshi S, Gaurav B, Feroz A. Awareness regarding body and organ donation amongst the population of an urban city in India. *Nitte University Journal of Health Science*. 2015 Dec 1;5(4).
 65. Minz M, Sood S, Kumar A, Bansal V, Mehra S. Impact of organ trade on attitudes toward organ donation: knowledge and attitudes toward cadaveric organ donation in north India. *InTransplantation proceedings 1998 (Vol. 30, No. 7)*.
 66. Mohan G, Aswathy AA. Organ donation in India—A social marketing perspective. *International Journal of Nonprofit and Voluntary Sector Marketing*. 2019 May;24(2):e1637.
 67. Alex A, Shroff S, Paul VB, Navin S, Ramesh P, Michael J, Menon S. Did an increase in knowledge and awareness about organ donation improve organ donation rate in India over the past two decades?. *Indian Journal of Transplantation*. 2019 Jul 1;13(3):173.
 68. Bharambe VK, Arole VU, Puranam V, Manvikar P, Rathod HK. Organ Donation: from Point of View of Students Doing Medical Internship in India. *BANTAO Journal*. 2016 Dec 1;14(2):67-72.
 69. Bharambe VK, Arole VU, Puranam V, Kulkarni PP, Kulkarni PB. Knowledge and attitude toward organ donation among people in Lanja: A rural town in India. *Saudi Journal of Kidney Diseases and Transplantation*. 2018a Jan 1;29(1):160.
 70. Deshpande PR, Damle P, Bihani G, Khadabadi SS, Naik AN, Pawar AP. Knowledge, attitude, and practice of organ donation among pharmacy students. *Indian Journal of Transplantation*. 2018 Apr 1;12(2):113.
 71. Da Silva, K.X., Dsouza, D.B., Mascarenhas, V.R., Kankonkar, P.N., Vaz, F.S. and Kulkarni, M.S., 2021. Perceptions and attitude toward cadaveric organ donation among health-care professionals at a tertiary health-care setting: A cross-sectional study. *Indian Journal of Transplantation*, 15(1), p.56.
 72. Basavarajegowda, A., Arjunan, C., Nalini, Y.C., Parameshwaran, S. and Kannan, S., 2021. A comparative study of knowledge, attitude, and practices about organ donation

- 1
2
3 among blood donors and nonblood donors. *Asian Journal of Transfusion Science*, 15(1),
4 p.37.
5
6
7 73. Kachappillil, A.J. and Thankachan, A., 2020. Attitude of General Population towards
8 Organ Donation in a Rural Community of Ernakulam District. *International Journal of*
9 *Healthcare Education & Medical Informatics (ISSN: 2455-9199)*, 7(1&2), pp.16-20.
10
11 74. Kalmath, S. and Peerapur, S.M., 2020. A Study to Determine the Knowledge,
12 Preparedness and Commitment Regarding Organ Donation among the Youths of Hubli,
13 Karnataka. *International journal of Innovative science and research technology*, 5(5).
14
15 75. Khan, F., Latif, M. and Bashir, S., 2020. Attitude and Knowledge toward Organ Donation
16 among Arts and Science Students. *Indian Journal of Forensic Medicine &*
17 *Toxicology*, 14(4).
18
19 76. Rani, S., Mishra, A. and Dagar, N., 2020. Community Based Study to Assess the
20 Knowledge and Attitude of General Population towards Organ Donation. *International*
21 *Journal of Nursing Education*, 12(4).
22
23 77. Ray, M.K. and Ghosh, T., 2020. Assessment of Knowledge and Attitude of Medical
24 Students Regarding Body and Organ Donation. *Religion*, 115, pp.85-8.
25
26 78. Seetharaman, R.V., Rane, J.R. and Dingre, N.S., 2021. Assessment of knowledge and
27 attitudes regarding organ donation among doctors and students of a tertiary care
28 hospital. *Artificial Organs*, 45(6), pp.625-632.
29
30 79. Yadav, N., Jain, M., Sharma, A., Jain, V., Chahar, P. and Verma, N., 2020. Perceptions
31 of a university's faculty members on organ donation. *The National Medical Journal of*
32 *India*, 33(5), p.302.
33
34 80. Ghose, T.K., Deo, J., Dutt, V., Agarwal, R., Patel, B.B., Ganesh, M., More, V.K., Pandya,
35 K.H., Sharma, R., Sharma, D. and Singh, H., 2021. Knowledge and attitude towards
36 organ donation: a study among medical and nursing students of a medical
37 college. *International Journal of Community Medicine and Public Health*, 8(11), p.5398.
38
39 81. Poreddi, V., Katyayani, B.V., Gandhi, S., Thimmaiah, R. and Badamath, S., 2016.
40 Attitudes, knowledge, and willingness to donate organs among Indian nursing
41 students. *Saudi Journal of kidney diseases and transplantation*, 27(6), p.1129.
42
43 82. Darbari, A., Naithani, M., Sharma, S.K., Gupta, A., Kumar, A. and Satsangi, D.K., 2020.
44 Current knowledge status and attitude on heart transplantation among undergraduate
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 medical students of a tertiary care medical institute in India. *Indian Journal of*
4 *Transplantation*, 14(1), p.30.
- 5
6
7
8 83. Darr, A. and Randhawa, G., 1999. Awareness and attitudes towards organ donation and
9 transplantation among the Asian population. *Transplant international*, 12(5), pp.365-
10 371.
- 11
12
13
14 84. Huern, S.Y., Yee, K.C., Rajah, J.S., Ponniah, M.P. and Sapini, M.I.B., 2016. Knowledge,
15 awareness and attitudes on organ donation among undergraduate medical students in
16 Malaysia: An analytical cross sectional study. *Br J Med Med Res*, 16(3), pp.1-14.
- 17
18
19
20 85. Parmar, P.B., Bharpoda, K., Bhensdadia, V., Bhokan, P., Bhut, P. and Chaudhary, B.,
21 2016. Study of undergraduate students' perceptions towards organ donation. *Journal of*
22 *Indian Academy of Forensic Medicine*, 38(4), pp.437-440.
- 23
24
25
26 86. Bharambe, V.K., Arole, V.U., Puranam, V., Kulkarni, P.P. and Kulkarni, P.S., 2018b.
27 Knowledge and attitude toward organ donation among health-care professionals in a rural
28 town in India. *Saudi Journal of Kidney Diseases and Transplantation*, 29(3), p.671.
- 29
30
31
32 87. Vincent BP, Kumar G, Parameswaran S, Kar SS. Barriers and suggestions towards
33 deceased organ donation in a government tertiary care teaching hospital: Qualitative
34 study using socio-ecological model framework. *Indian Journal of Transplantation*. 2019a
35 Jul 1;13(3):194.
- 36
37
38
39 88. Verma, M., Sharma, P., Ranjan, S., Sahoo, S.S., Aggarwal, R., Mehta, K., Tariq, R.,
40 Kanwale, S., Mittal, A., Das, A. and Galhotra, A., 2020. The perspective of our future
41 doctors towards organ donation: a national representative study from India. *International*
42 *Journal of Adolescent Medicine and Health*.
- 43
44
45
46 89. Loch, A., Hilmi, I.N., Mazam, Z., Pillay, Y. and Choon, D.S.K., 2010. Differences in
47 attitude towards cadaveric organ donation: observations in a multiracial Malaysian
48 society. *Hong Kong Journal of Emergency Medicine*, 17(3), pp.236-243.
- 49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
90. Kennedy K. Organ donation and transplantation in India: An inquiry in Kerala. *Journal of Social Distress and the Homeless*. 2002 Jan 1;11(1):41-67.
 91. Amaliyar J, Patel P. Awareness about organ donation in medical and non medical students in Patan city of Gujarat, India. *Int J Community Med Public Health*. 2019 Jun;6:2435-9.
 92. Jothula KY, Sreeharshika D. Study to assess knowledge, attitude and practice regarding organ donation among interns of a medical college in Telangana, India. *Int J Community Med Public Health*. 2018 Apr;5(4):1339-45.
 93. Vijayalakshmi P, Nagarajaiah, Ramachandra, Math SB. Indian ICU nurses' perceptions of and attitudes towards organ donation. *British Journal of Nursing*. 2015 Jul 9;24(13):694-7.
 94. Lokesh KSS, Raja D, and Sharath U. 2021. Organ Donation'-Awareness, Perspective and Practices among Adults-A Cross Sectional Study in Rural Tamil Nadu. *Journal of Pharmaceutical Research International*. 33(55B); 29-34.
 95. Wong, L.P., 2010, June. Factors limiting deceased organ donation: focus groups' perspective from culturally diverse community. In *Transplantation proceedings* (Vol. 42, No. 5, pp. 1439-1444). Elsevier.
 96. Vincent BP, Kumar G, Parameswaran S, Kar SS. Knowledge, attitude, and perception on organ donation among undergraduate medical and nursing students at a tertiary care teaching hospital in the southern part of India: A cross-sectional study. *Journal of education and health promotion*. 2019b;8.
 97. Misra, P., Malhotra, S., Sharma, N., Misra, M.C., Vij, A. and Pandav, C.S., 2021. A qualitative approach to understand the knowledge, beliefs, and barriers toward organ donation in a rural community of Haryana-A community based cross-sectional study. *Indian Journal of Transplantation*, 15(1), p.19.
 98. Thyagarajan, I., Shroff, S., Vincent, B.P., Rajendran, J., Kanvinde, H., Shankar, S. and Aneesh, K., 2020. Knowledge and practice of organ donation among police personnel in Tamil Nadu: A cross-sectional study. *Indian Journal of Transplantation*, 14(2), p.141.
 99. Mondal, S., Paul, A., Malick, S. and Saha, P., 2016. Perception of organ donation among adults: A community based study in rural West Bengal, India. *Sch J Appl Med Sci*, 4, pp.4473-8.

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
100. Sam N, Ganesh R, Indrapriyadarshini V, Jeyamarthan S, Nandhini CK. Awareness, knowledge, and attitude regarding organ donation among final year students of medical, Dental, Engineering, and Arts and Science Colleges in Thiruvallur and Chennai City, India. *Indian Journal of Transplantation*. 2018 Jan 1;12(1):25.
 101. Soni S, Samal J, Baghel SS, Vaghela S, Chundawat MS. Knowledge and attitude toward organ donation among medical and nonmedical (Engineering) students in Bhopal, India. *The Saudi Journal of Forensic Medicine and Sciences*. 2018 May 1;1(2):35.
 102. Rajan, J.K., 2020. Assessment of Knowledge and Attitude of Adolescents Regarding Blood and Organ Donation in Selected Rural Areas of Shimla, Himachal Pradesh, India. *Medico Legal Update*, 20(1), pp.101-105.
 103. Sachdeva S. Knowledge, Attitude, and Practices regarding organ donation among adult visitors in a public hospital in Delhi, India. *Indian J Transplant*. 2017 Dec 20;11:127-32.
 104. Flower, J.R.L. and Balamurugan, E., 2013. A study on public intention to donate organ: Perceived barriers and facilitators. *British Journal of Medical Practitioners*, 6(4), pp.6-10.
 105. Mishra, P.R., Mohakud, S. and Barik, M., 2016. A Comparison Between Medical and Non-Medical Students in India for Cadaveric Organ Donation (COD): A Questionnaire Based Study. *Journal of Forensic Medicine and Toxicology*, 33(1), pp.12-15.
 106. Pradeep, A., Ormandy, P., Augustine, T., Randhawa, G. and Whitling, M., 2019. Attitudes and beliefs regarding organ donation among South Asian people in the UK. *Journal of Kidney Care*, 4(4), pp.184-198.
 107. Wong, L.P., 2010. Information needs, preferred educational messages and channel of delivery, and opinion on strategies to promote organ donation: a multicultural perspective. *Singapore medical journal*, 51(10), p.790.
 108. Exley, C., Sim, J., Reid, N., Jackson, S. and West, N., 1996. Attitudes and beliefs within the Sikh community regarding organ donation: a pilot study. *Social Science & Medicine*, 43(1), pp.23-28.

109. Balwani MR, Kute VB, Patel H, Shah PR, Goswami J, Ghule P, Shah M, Gattani V, Trivedi HL. Awareness and beliefs towards organ donation in chronic kidney disease patients in western India. *Journal of Nephro pharmacology*. 2015b;4(2):57.
110. Kaistha M, Kaistha S, Mahajan A. A study of factors influencing decisions on organ donation among patient attendees in a Tertiary Care Hospital in North India. *CHRISMED Journal of Health and Research*. 2016 Apr 1;3(2):101.
111. Paul S, Som TK, Saha I, Ghose G, Bera A, Singh A. Knowledge, attitude, and practice regarding organ donation among adult Population of an Urban field practice area of a medical college in Durgapur, West Bengal, India. *Indian Journal of Transplantation*. 2019 Jan 1;13(1):15.
112. Hakeem, A.R., Ramesh, V., Sapkota, P., Priya, G., Rammohan, A., Narasimhan, G., Reddy, M.S. and Rela, M., 2021. Enlightening Young Minds: A Small Step in the Curriculum, a Giant Leap in Organ Donation—A Survey of 996 Respondents on Organ Donation and Transplantation. *Transplantation*, 105(3), pp.459-463.
113. Reddy, A.V.R., Guleria, S.A., Khazanchi, R.K., Bhardwaj, M., Aggarwal, S. and Mandal, S., 2003. Attitude of patients, the public, doctors, and nurses toward organ donation. In *Transplantation proceedings* (Vol. 1, No. 35, p. 18).
114. Wong, L.P., 2011. Knowledge, attitudes, practices and behaviors regarding deceased organ donation and transplantation in Malaysia's multi-ethnic society: A baseline study. *Clinical transplantation*, 25(1), pp.E22-E31.
115. Adithyan GS, Mariappan M, Nayana KB. A study on knowledge and attitude about organ donation among medical students in Kerala. *Indian Journal of Transplantation*. 2017 Jul 1;11(3):133.
116. Mani G. Perceptions and practices related to organ donation among a rural population of Kancheepuram district, Tamil Nadu, India Geetha Mani¹, Raja Danasekaran¹, Kalaivani Annadurai¹. *Journal of Comprehensive Health*. 2016 Jan;4(1):72.
117. Randhawa, G., 1998. An exploratory study examining the influence of religion on attitudes towards organ donation among the Asian population in Luton, UK. *Nephrology*,

- 1
2
3 *dialysis, transplantation: official publication of the European Dialysis and Transplant*
4 *Association-European Renal Association, 13(8), pp.1949-1954.*
5
6
7
8 118. Kaur, A., Devgun, P. and Gill, K.P., 2021. A Cross-sectional Study to Assess the
9 Knowledge, Attitude and Practices about Organ Donation among the Medical Students
10 of Punjab. *Annals of Community Health, 8(4), pp.2-8.*
11
12
13
14
15 119. Morgan, M., Deedat, S. and Kenten, C., 2015. 'Nudging' registration as an organ donor:
16 Implications of changes in choice contexts for socio-cultural groups. *Current*
17 *Sociology, 63(5), pp.714-728.*
18
19
20
21
22 120. Meghana S, Subramanian M, Atmakuri SA, Tarun S, Bera P, Nelson J. A study on
23 knowledge, attitude and practice regarding organ donation and transplantation among
24 final year health science students in Bengaluru, Karnataka, India. *Int J Commun Med*
25 *Pub Health. 2018 Apr;5:1529-34.*
26
27
28
29 121. Darlington D, Anitha FS, Joseph C. Study of Knowledge, Attitude, and Practice of Organ
30 Donation Among Medical Students in a Tertiary Care Centre in South India. *Cureus.*
31 *2019 Jun;11(6).*
32
33
34 122. Bhargavi UD, Govindapillai UK. Knowledge and attitude of decond year medical, dental
35 and nursing students in Thiruvananthapuram government medical college campus
36 towards organ and whole body donation. *Journal of Evolution of Medical and Dental*
37 *Sciences. 2019 Apr 8;8(14):1153-6.*
38
39
40
41 123. Budiani-Saberi, D.A., Raja, K.R., Findley, K.C., Kerketta, P. and Anand, V., 2014.
42 Human trafficking for organ removal in India: a victim-centered, evidence-based
43 report. *Transplantation, 97(4), pp.380-384.*
44
45
46
47 124. Ahmed, W., Harris, S. and Brown, E., 1999. Attitudes to organ donation among South
48 Asians in an English high street. *Journal of the Royal Society of Medicine, 92(12),*
49 *pp.626-627.*
50
51
52 125. Syed, J. and Ezbilgin, M.F. eds., 2010. *Managing cultural diversity in Asia: A research*
53 *companion.* Edward Elgar Publishing.
54
55
56
57
58
59
60

- 1
2
3 126. Campbell, M., Katikireddi, S.V., Sowden, A. and Thomson, H., 2019. Lack of
4 transparency in reporting narrative synthesis of quantitative data: a methodological
5 assessment of systematic reviews. *Journal of clinical epidemiology*, 105, pp.1-9.
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

1
2
3 **Figure legends / captions:**
4

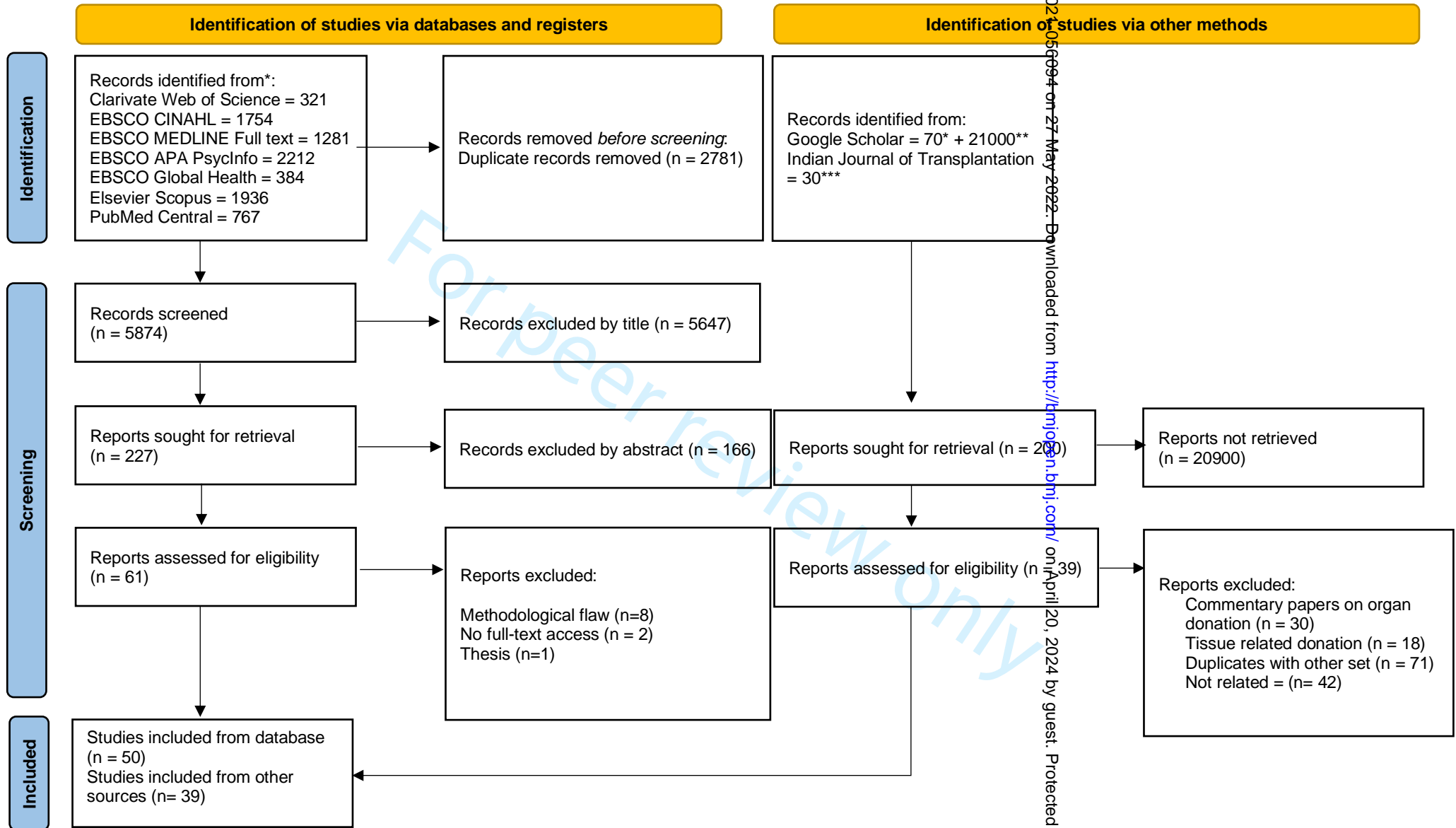
5 **Figure 1:** PRISMA flowchart
6

7 **Figure 2:** Quality appraisal checklist – Quantitative studies
8

9 **Figure 3:** Quality appraisal checklist – Qualitative studies
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

616/mjopen-2021-056994 on 27 May 2022. Downloaded from http://bmjopen.bmj.com/ on April 20, 2024 by guest. Protected by copyright.



*Google scholar method 1 explained in method section of the manuscript; **Google scholar method 2 explained in the method section of the manuscript; ***Indian journal of Transplantation – All issues were manually searched from 1994

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: <http://www.prisma-statement.org/>

	1	2	3	4	5	6	7	8
Adithyan et al, 2017	✓	✓	✓	✓	✗	✓	✓	✓
Ahlawat et al, 2013	-	✓	✓	✓	✗	✗	✓	✓
Alex et al, 2017	✓	✓	✓	✓	✗	✓	✓	✓
Alex et al, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Amaliyar et al, 2019	✓	✓	✓	✓	✗	✓	✓	✓
Balajee et al, 2016	-	✓	✓	✓	✓	✗	✓	✓
Balwani et al, 2015a	-	✓	✓	✓	✗	✗	✓	✓
Balwani et al, 2015b	✓	✓	✓	✓	✗	✗	✓	✓
Bansal et al, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Bapat et al, 2010	-	✓	✓	✓	✗	✗	✓	✓
Basavarajegowda et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Bathija et al, 2017	-	✓	✓	✓	✗	✓	✓	✓
Bharambe et al, 2015	✗	✓	✓	✓	✗	✗	✓	✓
Bharambe et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Bharambe et al, 2018a	✓	✓	✓	✓	✗	✗	✓	✓
Bharambe et al, 2018b	✓	✓	✓	✓	✗	✗	✓	✓
Bhargavi et al, 2019	✓	✓	✓	✓	✗	✓	✓	✓
Chakradhar et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Da Silva et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Darbari et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Darlington et al, 2019	✓	✓	✓	✓	✓	✓	✓	✓
Dasgupta et al, 2014	✓	✓	✓	✓	✗	✗	✓	✓
Deshpande et al, 2018	-	✓	✓	✓	✗	✗	✓	✓
Flower et al, 2013	✓	✓	✓	✓	✗	✗	✓	✓
Ghose et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Gupta et al, 2018	✓	✓	✓	✓	✗	✓	✓	✓
Gupta et al, 2021	✗	-	✓	✓	✗	✗	✓	✓
Hakeem et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Huern et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Jagadeesh et al, 2018	✓	✓	✓	✓	✗	✗	✓	✓
Jayabharathi et al, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Joshi, 2011	✓	✓	✓	✓	✓	✓	✓	✓
Jothula et al, 2018	✓	✓	✓	✓	✗	✗	✓	✓
Kachappillil et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Kadam et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Kaistha et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Kamlath et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Karim et al, 2013	✓	✓	✓	✓	✗	✗	✓	✓
Kaur et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓

	1	2	3	4	5	6	7	8
Khan et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Kundu et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Li et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Loch et al, 2010	✓	✓	✓	✓	✗	✗	✓	✓
Lokesh et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Mani, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Meghana et al, 2018	✓	✓	✓	✓	✗	✓	✓	✓
Minz et al, 1998	✗	✓	-	✓	✗	✗	✓	✓
Mishra et al, 2016	✗	✓	✗	✗	✗	✗	✗	✗
Misra et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Mithra et al, 2013	✓	✓	✓	✓	✗	✗	✓	✓
Mohan et al, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Mondal et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Panwar et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Paramr et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Paul et al, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Poreddi et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Poreddi et al, 2017	✓	✓	✓	✓	✗	✗	✓	✓
Pradeep et al, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Rajan, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Rani et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Ray et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Reddy et al, 2003	✓	✓	✓	✓	✗	✗	✓	✓
Sachdeva, 2017	-	✓	✓	✓	✗	✗	✓	✓
Sam et al, 2018	✓	✓	✓	✓	✗	✗	✓	✓
Sarveswaran et al, 2018	✓	✓	✓	✓	✗	✗	✓	✓
Seetharaman et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Singh et al, 2002	✓	✓	✓	✓	✗	✗	✓	✓
Soni et al, 2018	-	✓	✓	✓	✗	✓	✓	✓
Swain et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Swamy et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Tamuli et al, 2019	✗	✓	✓	✓	✗	✗	✓	✓
Thyagarajan et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Verma et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Vijayalakshmi et al, 2015	✓	✓	✓	✓	✗	✗	✓	✓
Vijayalakshmi et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Vincent et al, 2019b	✓	✓	✓	✓	✓	✓	✓	✓
Wong et al, 2011	✓	✓	✓	✓	✗	✗	✓	✓
Yadav et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓

1. Were the criteria for inclusion in the sample clearly defined?
2. Were the study subjects and the setting described in detail?
3. Was the exposure measured in a valid and realistic way?
4. Were the objectives, standard criteria used for measurement of the conditions?
5. Were the confounding factors identified?
6. Were strategies to deal with confounding factors stated?
7. Were the outcomes measured in a valid and reliable way?
8. Was appropriate statistical analysis used?

✓	Mentioned
✗	Not mentioned
-	Unclear

Page	Ref	1	2	3	4	5	6	7	8	9	10
	Vincent et al, 2019	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓
1	Kennedy, 2002	✓	✓	✓	✓	✓	✗	✗	✗	✗	✓
2	Gauher et al, 2013	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓
3	Misra et al, 2021	✓	✓	✓	✓	✓	✗	✗	✗	✓	✓
4	Darr et al, 1999	✓	✓	✓	✓	✓	✗	✗	✗	✓	✓
5	Exley et al, 1996	✓	✓	✓	✓	✓	✗	✗	✗	✓	✓
6	Morgan et al, 2015	✓	✓	✓	✓	✓	✓	✓	✗	✓	✓
7	Wong et al, 2010a	✓	✓	✓	✓	✓	✓	✗	✗	✓	✓
8	Wong et al, 2010b	✓	✓	✓	✓	✓	✓	✗	✗	✓	✓
9	Randhawa et al, 1998	✓	✓	✓	✓	✓	✓	✗	✗	✓	✓
10											

- 13
- 14
- 15 **1** Is there congruity between the stated philosophical perspective and the research methodology?
- 16 **2** Is there congruity between the research methodology and the research question or objective?
- 17 **3** Is there congruity between the research methodology and the methods used to collect data?
- 18 **4** Is there congruity between the research methodology and the representation and analysis of data?
- 19 **5** Is there congruity between the research methodology and the interpretation of results?
- 20 **6** Is there a statement locating the researcher culturally or theoretically?
- 21 **7** Is the influence of the researcher on the research, and vice-versa, addressed?
- 22 **8** Are participants, and their voices, adequately represented?
- 23 **9** Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
- 24 **10** Do the conclusion drawn in the research report flow from the analysis, or interpretation, of the data?

25 Mentioned ✓ Not mentioned ✗

30

31

32

33

34

35

36

37

38

39

40

41

42

43

44

45

46

47

48

49

50

51

52

53

54

55

56

57

58

59

60

Supplementary I: Search strategy

Database: Clarivate Web of Science <1 January 1994 to 31 December 2021>

Search strategy

1. (ALL) Organ* (4464520)
2. (ALL) Tissue* (2072420)
3. 1 OR 2
4. (ALL) Donation* (92568)
5. (ALL) Procurement* (36067)
6. (ALL) Donor* (471190)
7. (ALL) Regist* (607949)
8. (ALL) Pledge* (5168)
9. 4 OR 5 OR 6 OR 7 OR 8
10. (ALL) "Brain death" (6,922)
11. (ALL) Posthumous* (3317)
12. (ALL) Deceased* (28469)
13. 10 OR 11 OR 12 (122185)
14. (ALL) India* (2374803)
15. (ALL) Asia* (869365)
16. (ALL) "South Asia*" (34481)
17. 14 OR 15 OR 16
18. (ALL) Knowledge (1860768)
19. (ALL) Attitude* (423103)
20. (ALL) Practice* (2018451)
21. (ALL) Aware* (484659)
22. (ALL) Perception* (725428)
23. (ALL) Barrier* (711626)
24. (ALL) Challenge* (1684045)
25. (ALL) Religi* (258116)
26. (ALL) Famil* (2081795)
27. (ALL) Discuss* (4419231)
28. (ALL) Sign* (11546529)
29. 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28
30. 3 AND 9 AND 13 AND 17 AND 29 (321)

(((((ALL=(Organ* OR Tissue*)) AND ALL=(Donation* OR Procurement* OR Donor* OR Regist* OR Pledge*)) AND ALL=("Brain Death" OR Posthumous* OR Deceased*)) AND ALL=(India* OR Asia* OR "South Asia*")) AND ALL=(Knowledge* OR Attitude* OR Practice* OR Aware* OR Perception* OR Barrier* OR Challenge* OR Religi* OR Famil* OR Discuss* OR Sign*))

Database: EBSCO CINAHL Complete < 1994 January to December 2021>

Search strategy

No.	Terms	Title	Abstract
1	Organ*	45587	254692
2	Tissue*	35642	171599
3	1 OR 2	47408	214967
4	Donation*	5126	7255
5	Procurement	733	2440
6	Donor	10046	24599
7	Regist	28751	171623
8	Pledge	906	909
9	4 OR 5 OR 6 OR 7 OR 8	44740	200368
10	India	29146	35077
11	Asia	13516	35961
12	South Asia	1896	3440
13	10 OR 11 OR 12	42022	67778
14	Knowledge	40561	228058
15	Attitude	30320	76214
16	Practice	171844	417435
17	Aware*	16453	106579
18	Perception	47156	116209
19	Barrier	23209	93116
20	Challenge	52643	179284
21	Religi*	7106	20082
22	Famil*	28758	120172
23	Discuss*	12336	525753
24	Sign	60885	1299673
25	Brain Death	811	1176
26	Posthumous	101	157
27	Deceased	725	5381
28	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27	460837	2330155
29	3 AND 9 AND 13 AND 28	697	1057

Database: EBSCO MEDLINE With full text Complete < 1994 January to December 2021>

Search strategy

No.	Terms	Title	Abstract
1	Organ*	245699	1493730
2	Tissue*	223470	1550014
3	1 OR 2	465190	2862275
4	Donation*	11156	25326
5	Procurement	1825	8302
6	Donor*	58569	260805
7	Regist*	52468	371535
8	Pledge	591	1401
9	4 OR 5 OR 6 OR 7 OR 8	122076	641620
10	India*	79797	128377
11	Asia*	37333	145090
12	South Asia*	3406	9277
13	10 OR 11 OR 12	115447	260763
14	Knowledge	62353	725944
15	Attitude*	44690	132711
16	Practice*	192866	758688
17	Aware*	23266	233256
18	Perception*	73637	238754
19	Barrier*	56399	301446
20	Challenge*	107816	654171
21	Religi*	8586	32213
22	Famil*	62713	341944
23	Discuss*	19872	1196575
24	Sign*	402535	6834667
25	Brain Death	2322	4478
26	Posthumous	201	475
27	Deceased	2643	20262
28	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27	1012657	9432506
29	3 AND 9 AND 13 AND 28	61	1220

Database: EBSCO APA PsycInfo < 1994 January to December 2021>

Search strategy

No.	Terms	Title	Abstract
1	Organ*	52775	314055
2	Tissue*	2650	33891
3	1 OR 2	55359	344532
4	Donation*	1328	3862
5	Procurement	260	1126
6	Donor*	1103	6196
7	Regist*	4746	41654
8	Pledge	65	479
9	4 OR 5 OR 6 OR 7 OR 8	7304	51337
10	India*	12921	26606
11	Asia*	9722	31810
12	South Asia*	1130	2606
13	10 OR 11 OR 12	22183	55698
14	Knowledge	37077	273907
15	Attitude*	40138	146530
16	Practice*	77921	427695
17	Aware*	12620	117029
18	Perception*	74077	238811
19	Barrier*	12054	74349
20	Challenge*	24193	208260
21	Religi*	18072	57819
22	Famil*	31536	174669
23	Discuss*	7449	675256
24	Sign*	32524	1050671
25	Brain Death	192	383
26	Posthumous	55	451
27	Deceased	211	3514
28	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27	345985	2324405
29	3 AND 9 AND 13 AND 28	1049	1163

Database: EBSCO Global Health < January 1994 to December 2021>

Search strategy

No.	Terms	Title	Abstract
1	Organ*	34990	281202
2	Tissue*	24264	166199
3	1 OR 2	58782	426568
4	Donation*	851	4044
5	Procurement	276	2063
6	Donor*	5877	26460
7	Regist*	6306	654425
8	Pledge	39	298
9	4 OR 5 OR 6 OR 7 OR 8	13197	94877
10	India*	42961	84021
11	Asia*	11593	56374
12	South Asia*	1307	4386
13	10 OR 11 OR 12	53980	134135
14	Knowledge	21618	146105
15	Attitude*	14175	40544
16	Practice*	32467	149036
17	Aware*	6261	61511
18	Perception*	15315	46000
19	Barrier*	10039	55500
20	Challenge*	18770	113171
21	Religi*	1303	9881
22	Famil*	6241	56096
23	Discuss*	2171	225453
24	Sign*	34744	179950
25	Brain Death	41	179
26	Posthumous	4	29
27	Deceased	238	2971
28	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27	144587	1664816
29	3 AND 9 AND 13 AND 28	5	379

Database: Elsevier Scopus PUBYEAR > 1993 AND PUBYEAR <2022

Search strategy

No.	Terms	Title-Abstract-Keywords
1	Organ*	757636
2	Tissue*	3956065
3	1 OR 2	8523116
4	Donation*	49781
5	Procurement	57632
6	Donor*	465751
7	Regist*	690378
8	Pledge	6915
9	4 OR 5 OR 6 OR 7 OR 8	1214290
10	India*	630668
11	Asia*	614524
12	South Asia*	47204
13	10 OR 11 OR 12	1178235
14	Knowledge	2199485
15	Attitude*	834803
16	Practice*	2961509
17	Aware*	663440
18	Perception*	885170
19	Barrier*	765952
20	Challenge*	2076205
21	Religi*	274948
22	Famil*	776708
23	Discuss*	5121400
24	Sign*	14005232
25	Brain Death	11526
26	Posthumous	7120
27	Deceased	30117
28	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27	24234423
29	3 AND 9 AND 13 AND 28	1936

1
2
3 **Database:** PubMed Central < 1994 January to December 2021>
4

5 Search strategy
6

7 **Search:** (((((Organ[Title/Abstract] OR Tissue[Title/Abstract]) AND (Donation[Title/Abstract]
8 OR Donor[Title/Abstract])) AND (Knowledge[Title/Abstract] OR Awareness[Title/Abstract]
9 OR Attitude[Title/Abstract] OR Perception[Title/Abstract] OR Practice[Title/Abstract] OR
10 Registration[Title/Abstract] OR Consent[Title/Abstract] OR Barrier[Title/Abstract] OR
11 Challenges[Title/Abstract] OR Religion[Title/Abstract] OR Culture[Title/Abstract]))) AND
12
13
14
15 ((India OR South Asia OR Southeast Asia OR Asia[MeSH Terms])
16
17

1136/bmjopen-2021-056094 on 27 May 2022. Downloaded from <http://bmjopen.bmj.com/> on April 20, 2024 by guest. Protected by copyright.



PRISMA 2020 checklist

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Pg. 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Pg. 1-2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Pg. 3-4
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Pg. 3-4
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Pg. 4-6
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Pg. 4 -5
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Supplementary file & PRISMA 2020
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Pg. 5-6
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Pg. 5-7
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	NA
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	NA
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Pg. 6
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	NA
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	NA
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	NA
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Table 1
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Pg. 6-7
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	NA
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	NA
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	NA



PRISMA 2020 checklist

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

1136/bmjopen-2021-056094 on 27 May 2022. Downloaded from <http://bmjopen.bmj.com/> on April 20, 2024 by guest. Protected by copyright.

Section and Topic	Item #	Checklist item	Location where item is reported
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	NA
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Figure 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Figure 1, Pg. 5-6
Study characteristics	17	Cite each included study and present its characteristics.	Table 1
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Quality appraisal: Figure 2 & 3
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	NA
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	NA
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	NA
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	NA
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	NA
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	NA
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	NA
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	24-27
	23b	Discuss any limitations of the evidence included in the review.	26-27
	23c	Discuss any limitations of the review processes used.	26-27
	23d	Discuss implications of the results for practice, policy, and future research.	24-27
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Pg. 2
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Pg. 2
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Pg. 4
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Pg. 25
Competing interests	26	Declare any competing interests of review authors.	Pg. 25
Availability of data, code and	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review	Supplementary file 1.



PRISMA 2020 checklist

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

Section and Topic	Item #	Checklist item	Location where item is reported
other materials			

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: <http://www.prisma-statement.org/>

For peer review only

1136/bmjopen-2021-056094 on 29 May 2022. Downloaded from <http://bmjopen.bmj.com/> on April 20, 2024 by guest. Protected by copyright.

BMJ Open

Barriers toward deceased organ donation among Indians living globally: An integrative systematic review using narrative synthesis

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2021-056094.R3
Article Type:	Original research
Date Submitted by the Author:	27-Apr-2022
Complete List of Authors:	Vincent, Britzer Paul; University of Bedfordshire Faculty of Health and Social Sciences, Institute for Health Research Randhawa, Gurch; University of Bedfordshire Faculty of Health and Social Sciences, Institute for Health Research Cook, Erica; University of Bedfordshire - Luton Campus, Department of Psychology
Primary Subject Heading:	Health policy
Secondary Subject Heading:	Health services research
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, ETHICS (see Medical Ethics), TRANSPLANT MEDICINE

SCHOLARONE™
Manuscripts



I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our [licence](#).

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which [Creative Commons](#) licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Title Page

Title: Barriers toward deceased organ donation among Indians living globally: An integrative systematic review using narrative synthesis.

Full name of all authors:

As per the order of the authorship

1. Britzer Paul (Given Name) Vincent (Family Name)
PhD Student, Institute for Health Research, Faculty of Health and Social Sciences, University of Bedfordshire, England, The United Kingdom
ORCID id: <https://orcid.org/0000-0001-7681-1430>
2. Gurch (Given Name) Randhawa (Family Name)
Professor of Diversity in Public Health and Director - Institute for Health Research, Faculty of Health and Social Sciences, University of Bedfordshire, England, The United Kingdom
3. Erica (Given Name) Cook (Family Name)
Senior Lecturer in Health Psychology,
Department of Psychology, University of Bedfordshire, England, The United Kingdom

Authorship Contribution:

All authors BP, GR & EC contributed to – conception of the study, design of work, data acquisition, data analysis, data interpretation, writing of the article, final approval, and accountability of the study.

Funding sources: This systematic review is part of a PhD studentship funded by the Global Challenge Research Fund to the principal investigator Britzer Paul Vincent, a PhD scholar at the Institute for Health Research, University of Bedfordshire, UK.

Acknowledgement: We would like to thank our librarian Mr. David Abdy from Institute for Health Research, University of Bedfordshire for his contribution with the development of the search strategy.

Corresponding author:

Gurch (Given Name) Randhawa (Family Name)

gurch.randhawa@beds.ac.uk

University of Bedfordshire

Putteridge Bury Campus

Hitchin Road

Luton, LU2 8LE

England

Running title:

Barriers to Deceased Organ Donation among Indians globally: An Integrative Systematic Review

Abbreviations:

APA – American Psychological Association

EBSCO – Elton B Stephens Company

1
2
3 JBI - Joanna Briggs Institute's
4 NCD – Non-Communicable Disease
5 NIH – National Institute of Health
6 NLM – National Library of Medicine
7 ODR – Organ Donation Rate
8 pmp – per million population
9
10
11

12 **Conflict of Interest:**

13 None declared.
14

15 **Word count**

16 **Abstract:** 308

17 **Manuscript:** 4,404

18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

1
2
3 **Title:** Barriers toward deceased organ donation among Indians living globally: An integrative
4 systematic review using narrative synthesis.
5
6

7
8 **Abstract**
9

10 **Objectives:** To understand the barriers toward deceased organ donation among Indians living
11 globally.
12
13

14 **Design:** Integrative systematic review using narrative synthesis
15

16 **Data sources:** CINAHL, MEDLINE Full-Text, PsycInfo, Scopus, Global Health, Web of
17 Science, and PubMed Central, Indian Journal of Transplantation and Google scholar.
18
19

20 **Time period:** 1st January 1994 to 31st December 2021
21
22

23 **Participants:** Individuals of Indian origin living globally
24
25

26 **Results:** Eighty-nine studies were included with more than 29,000 participants and quality of
27 the studies were assessed using Joanna Briggs Institute's critical appraisal tool. Though
28 majority of the participants had knowledge toward organ donation with a positive influence on
29 willingness, the gap between knowledge and willingness was huge, with minimal registration
30 influenced by the complex socio-cultural constructs. Various socio-cultural constructs such as
31 family, fear and mistrust, religion, and bodily issues play a vital role. Differences were
32 identified in willingness to donate and register between southern and other regions of India.
33 Indian's organ donation behaviour in other geographical locations differed based on the socio-
34 religious background of the country they lived in such as in Malaysia, Canada, and the UK.
35 However, they were collective in decision-making and had complex socio-cultural interference
36 irrespective of the country the individual lived which differed only in their next generations.
37
38
39
40
41
42
43
44
45
46
47
48
49
50

51 **Conclusion:** Though this study showed the complex relationship, and its influences on organ
52 donation behaviour, lacunae were identified to further understand how such complex
53 interactions determine or inform the behaviour. Also, methodological issues were identified,
54 where this particular population outside India were collectively studied with their neighbouring
55
56
57
58
59
60

1
2
3 population which are not homogenous. Studies in India majorly addressed a similar aim using
4 similar methods which produced repetition of studies leading to lack of diversified, wider, and
5 in-depth research. Therefore, while this systematic review addressed the barriers toward organ
6 donation among Indians living globally, it also informs various gaps in research and also
7 methodological issues.
8
9

10
11
12
13
14 **PROSPERO registration number:** CRD42019155274

15
16
17 **Keywords:** Organ donation, India, UK, Integrative systematic review; Narrative synthesis,
18
19 Registration
20

21
22 **Strengths and Limitations:**
23

- 24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
1. This is the first systematic review on the barriers toward deceased organ donation among Indians living globally, registered with PROSPERO, and published.
 2. Both quantitative and qualitative studies were included to address the aim of the review using integrative approach and narrative synthesis, an appropriate methodology.
 3. Included studies exclusively represented the Indian population and studies that collectively studied Indians with heterogenous South Asian, or Asian population were excluded, thereby keeping the rigour of this study, and identifying methodological issues involved.
 4. Findings are based on the quality of each studies appraised using appropriate tools, and the assessment is also made available to the view of the readers.
 5. Studies were limited only to English language, and commentaries were excluded.

Main text

Introduction

Since the first deceased organ transplantation performed by Joseph Murray in 1960s, the science of transplantation has witnessed exponential growth [1]. However, the gap between demand and supply of organs has represented a significant challenge [2], particularly among the Asian population who live both within and outside their continent [3-5]. India located in the South of Asia is the second largest populated country in the world [6] having largest migrating population in Asia [7], and also has the highest prevalence of diabetes and hypertension [8]. Such non-communicable diseases (NCD) among Indians [9, 10] leading them to end-stage organ failure [11, 12] increases their need for organs.

Whilst the need for organ donors is high among the Indian population, the actual number of donors remain too low to satisfy the number of recipients on the waiting list [13], with the Indian national organ donation rate (ODR) less than one per million population (pmp) [14]. Reluctance to donate organs among this ethnic population might not be isolated just within Indian border [15], with evidence suggesting that Indian population from the United Kingdom is also disproportionately impacted, where they continue to be over-represented in the recipient waiting list but under-represented in the donor list [16]. This behaviour is again identified in Canada [17]. Therefore, globally, Indian population has demonstrated lower organ donor registration and consent both within and outside the border.

There have been a larger number of studies conducted among the Indian population living globally to understand the factors that influence their organ donation behaviour. However, to date, there has been no systematic review conducted to synthesize the available evidence to understand the barriers toward organ donation among the individuals of Indian origin. Therefore, a systematic review was proposed with an aim to address this gap to gain a deeper

1
2
3 insight into the barriers toward deceased organ donation behaviour among this particular
4 population living globally [18].
5
6
7

8 **Method**

9 **Protocol and registration**

10
11
12 This systematic review's protocol has been registered in PROSPERO (CRD42019155274) and
13 also published [18].
14
15
16
17
18

19 **Systematic search**

20
21
22 Search strategy was developed collaboratively with the research team and a subject specialist
23 librarian. Databases namely CINAHL, MEDLINE Full-Text, APA PsycInfo, and Global
24 Health were accessed through EBSCO platform, Clarivate for Web of Science, Elsevier for
25 Scopus, and US National Library of Medicine – National Institute of Health for PubMed
26 Central were utilised. Key terms related to organ donation were first identified from studies
27 published along with search terms used in other systematic review on organ donation [19,20]
28 and were tested in different combinations. Later, for each database, the search terms were then
29 customised seeking to capture the most appropriate studies to answer the aim of this review
30 (supplementary file 1) [21]. However, for other resources like google scholar and the Indian
31 journal of transplantation other strategies were employed. All the published papers from 1st of
32 January 1994 to 31st of December 2021 were searched from the archives of the Indian journal
33 of transplantation to identify relevant studies. With regard to google scholar, we searched using
34 two methods. The first method used the word “Organ Donation AND India” in title; and the
35 second method used the same keywords but searched anywhere in the article. However, due to
36 very high number of search results in the second method, we limited the search until we found
37 no further relevant studies (an approach used by other published systematic reviews) [22].
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 The systematic review included studies with individuals of Indian origin living both within and
4 outside India (i.e., migrant / first / second generation), aged 18 years and above from varied
5 settings [18]. Cross-sectional and qualitative study design were included as they were mostly
6 employed to understand the barriers toward deceased organ donation. For all the databases,
7 search strategy was restricted between 1st of January 1994 (i.e., the year when the first law
8 toward organ donation was implemented in India) and 31st of December 2021 (i.e., a recent
9 day before the submission) and was restricted only to studies published in English. However,
10 interventional studies, commentary or opinion papers, studies on blood, bone marrow, body,
11 sperm, and egg donation were excluded alongside any studies which addressed only living
12 donation.
13
14
15
16
17
18
19
20
21
22
23
24
25
26

27 **Search outcome**

28
29 Following a stage-by-stage exclusion from 8,655 studies initially extracted from the main
30 databases, 50 studies were included in final review along with 39 studies included from other
31 sources (Figure 1). The studies were initially exported to RefWorks
32 (<https://refworks.proquest.com/>). Microsoft excel was used to keep a record of studies
33 excluded by duplicates, title, abstract, and full text. All the 8,655 studies along with studies
34 from other sources were screened by two authors independently and the final 89 studies
35 included were in-agreement with all the authors.
36
37
38
39
40
41
42
43
44
45

46 However, during the process, studies conducted among Indians living outside India were
47 identified to be collectively studied as South Asians or with other Asian population. For
48 instance, a study conducted among Indo-Canadians in Canada included all neighbouring ethnic
49 groups of India [23]. Also, in other countries like the UK and Malaysia, Indian population was
50 collectively studied along with other ethnic groups and the results were not distinctively shown
51 [24-26], therefore eight studies had to be excluded due to these methodological limitations. The
52
53
54
55
56
57
58
59
60

1
2
3 perspective of deceased organ donation varies even within India's nearest neighbouring
4 country [4, 27]. Therefore, this review included only the studies which exclusively reported the
5 findings among Indian population.
6
7
8
9

10 **Quality assessment**

11
12
13
14 Appropriate critical appraisal tools from Joanna Briggs Institute (JBI) were used to critique the
15 rigour of each studies included [28], also used in other organ donation systematic review
16 [19,29]. Comprehensive reporting on the quality assessment for both cross-sectional and
17 qualitative studies, are reported in figure 2 and 3. Quality assessment was initially carried out
18 by the primary researcher after which it was reviewed by the other two authors independently.
19
20
21 Both the authors along with the primary researcher agreed upon the quality assessment as
22 mentioned in figure 2 and 3. The review included all studies; however minimal emphasis was
23 given for those studies that demonstrated only fewer items in the quality assessment checklist.
24
25
26
27
28
29
30
31
32

33 **Data synthesis**

34
35
36 This systematic review followed an integrative review with narrative synthesis approach
37 enabling to synthesise complex information toward the phenomena of interest [30], a
38 methodology also employed in another systematic review on organ donation that reviewed both
39 quantitative and qualitative studies [20]. Narrative synthesis primarily depends on words and
40 texts to summarise the findings with four process elements such as 1) systematic search and
41 quality appraisal, 2) grouping and clustering of the studies reviewed, 3) text summary
42 development, and 4) assessment and interpretation [31].
43
44
45
46
47
48
49
50
51

52
53 Firstly, following the systematic search and quality appraisal, summary data was collected for
54 each study, and they were recorded across a table which had information needed to cluster the
55 studies to compare and study across (Table 1). Secondly, with the cross-sectional studies,
56 numerical results from each study were tabulated across a matrix and were compared across to
57
58
59
60

1
2
3 study their relationship in terms of barriers. Later, full synthesis of the qualitative studies was
4
5 undertaken by coding the findings sections using NVivo11. Codes were then organised into
6
7 themes to address the barriers appropriately.
8
9

10 While comparing and studying across the studies included in the review to understand their
11
12 relationship, various elements such as what the study is about, type of study, their approach,
13
14 the findings, study settings, and population studied were also considered. Noblit and Hare
15
16 (1988) described this as 'Reciprocal translation', also used in other similar methodological
17
18 approaches [32-36]. Thirdly, full syntheses of both cross-sectional and qualitative studies were
19
20 studied across to understand the supporting and refuting evidence collectively. For each section
21
22 of the findings, quantitative studies provided the initial context following which findings from
23
24 qualitative studies were used to elaborate and explain. With limited qualitative study narratives
25
26 to support or refute the cross-sectional study findings, they were incorporated into the
27
28 integration of the findings wherever possible. Both convergent and divergent findings are
29
30 explained in this review, whereby if divergent findings were identified explanatory factors such
31
32 as type of study or setting, or population were provided to facilitate better understanding [20].
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Table 1: Evidence table

Author (s) (Year)	Study Site	Study Country	Aim	Study setting	Study design	Study sample size	Sampling technique
Adithyan et al, (2017)	Kerala	India	To assess the knowledge and attitude of medical students regarding organ donation	Final year Undergraduate Medical students	Cross-sectional	194	Not specified
Ahlawat et al, (2013)	Chandigarh	India	To assess the attitude of healthcare professionals employed in intensive or emergency care units of our hospital towards organ donation, and the influence of various factors on willingness for self-organ donation after death	Health workers in intensive units	Cross-sectional	361	Not specified
Alex et al, (2017)	Karnataka	India	To assess the knowledge and attitude regarding organ donation and transplantation among the medical students	Medical college	Cross-sectional	510	Convenient sampling
Alex et al, (2019)	Pan India	India	To assess the general public's knowledge and attitude towards organ donation over two decades	General public	Cross-sectional	3914	Not specified
Amaliyar et al, (2019)	Gujarat	India	To assess the knowledge, attitude, and practice towards organ donation among medical, arts and commerce students	Students from last 4 semester groups from medical, arts and commerce college	Cross-sectional	300	Purposive sampling for centres; Random for participants
Balajee et al, (2016)	Pondicherry	India	To assess the awareness and attitudes regarding organ donation among rural people from 4 villages	General public	Cross-sectional	360	Systematic random sampling and random participant selection
Balwani et al, (2015)	Gujarat	India	To study the awareness and belief towards organ donation and its allocation in chronic kidney disease patients in western India	Tertiary care centre	Cross-sectional	85	Not specified
Balwani et al, (2015)	Gujarat	India	To determine the knowledge, attitude, and practice regarding organ donation in western India	Adult participants from a residential area around a tertiary healthcare centre	Cross-sectional	200	Random sampling
Bansal et al, (2019)	Chandigarh	India	To analyse socio-demographic profile of the decision makers for organ donation in	Tertiary care teaching hospital	Cross-sectional	59	Purposive sampling

			potential deceased donors//To determine the level of awareness regarding organ donation in decision makers and the correlation with the socio-demographic variables	among family members who consented to donate the organs of their loved ones			
Bapat et al (2010)	Karnataka	India	To understand the awareness, attitudes, and belief towards organ donation among post-graduate medical students	Post-graduate medical students	Cross-sectional	123	Volunteer sampling
Basavarajegowda et al (2021)	Pan India	India	To study the knowledge difference between the knowledge and attitude about organ donation among blood donors compared to non-blood donors	General public	Cross-sectional	803	Purposive sampling
Bathija et al, (2017)	Karnataka	India	To investigate the knowledge and attitude towards organ donation among post-graduates, and interns; to know the reasons for donation one's organs	Post-graduate and medical interns	Cross-sectional	300	Not specified
Bharambe et al, (2015)	Maharashtra	India	To assess the knowledge and attitude of the people living in an urban city in India towards organ donation	Out-patient department	Cross-sectional	65	Not specified
Bharambe et al, (2016)	Maharashtra	India	To study the knowledge and attitude of a medical student doing internship with regards to organ donation	Medical college internship students	Cross-sectional	43	Not specified
Bharambe et al, (2018)	Maharashtra	India	To assess the knowledge and attitude of healthcare professionals from a rural part of India regarding organ donation	Healthcare professionals attending a medical association meeting	Cross-sectional	32	Not specified
Bharambe et al, (2018)	Maharashtra	India	To assess the knowledge and attitude of people from a rural part of India regarding organ donation.	Rural community members	Cross-sectional	201	Not specified
Bhargavi et al, (2019)	Kerala	India	To check the level of awareness and attitude of 2nd year medical, dental, and nursing students at Govt. Medical College, Thiruvananthapuram Campus towards organ donation and whole-body donation using a questionnaire-based study.	Medical and nursing students	Cross-sectional	177	Convenience sampling
Chakradhar et al, (2016)	Telangana	India	To assess and compare the knowledge, attitude, and practice regarding organ	Dental college Undergraduate students	Cross-sectional	298	Not specified

			donation among dental students based on gender, year of study and religion					
Da Silva et al (2021)	West Bengal	India	To assess the knowledge, attitude, and practices of health-care professionals toward cadaveric organ donation and to know their awareness regarding legislations pertaining to cadaveric organ donation.	Healthcare professionals	Cross-sectional	400	Stratified random sampling	
Darbari et al (2020)	Uttarakhand	India	To assess the knowledge on organ donation among undergraduate medical students	Undergraduate medical students	Cross-sectional	197	Not specified	
Darlington et al, (2019)	Tamil Nadu	India	To study the knowledge, attitude, and practice towards organ donation	Medical students	Cross-sectional	425	Voluntary	
Darr et al (1999)	Luton	England	To assess the attitudes on organ donation and transplantation among south Asians	South Asian general public	Qualitative	64	Purposive sampling	
Dasgupta et al, (2014)	West Bengal	India	To ascertain the knowledge and attitude of the people regarding organ donation and to elicit the determinants of their knowledge and attitude in an urban community of west Bengal	Slum area residents	Cross-sectional	110	Simple random sampling	
Deshpande et al, (2018)	Maharashtra and Madhya Pradesh	India	To determine the knowledge, attitude, and practice of pharmacy students about organ donation	Pharmacy college	Cross-sectional	160	Not specified	
Exley et al (1996)	Coventry	England	To examine the religious, cultural, and social context of organ donation	Sikh Asian community members	Qualitative	22	Judgemental sampling	
Flower et al (2013)	Pondicherry	India	To explore the general publics perceived barriers and facilitating factors of organ donation	General public	Cross-sectional	400	Random sampling	
Gauher et al, (2013)	London	The United Kingdom	To determine the attitude towards organ donation among Indian and Pakistan students	Medical and Non-Medical students	Qualitative	58	Purposive sampling - Stratified sampling for groups	
Ghose et al (2021)	Pune	India	To study knowledge and attitude toward organ donation among medical and nursing students with objectives to determine level of awareness about death criteria and need for organ donation and also to determine the attitude towards the same	Medical and nursing students	Cross-sectional	400	Population proportion to size	

Gupta et al, (2018)	Jammu & Kashmir	India	To assess the awareness and attitude of medical students regarding organ donation	Medical college Undergraduate students	Cross-sectional	280	Not specified
Gupta et al, (2021)	Maharashtra	India	To assess the pre-existing understanding beliefs, perception, and attitude, about deceased organ donation	College teachers and Students	Cross-sectional	80	Purposive sampling
Hakeem et al (2021)	Tamil Nadu	India	To assess knowledge, attitude, and perception of organ donation and transplant	Medical students and junior doctors	Cross-sectional	996	Not specified
Huern et al (2016)	Melaka	Malaysia	To assess the knowledge, attitude, and perception to determine the relationship between various sociodemographic data on knowledge, attitude, and perception toward organ donation	Undergraduate medical students	Cross-sectional	72	Not specified
Jagadeesh et al (2018)	Karnataka	India	To assess the knowledge, attitude, and beliefs toward organ donation and factors affecting willingness to donate	Professional drivers	Cross-sectional	300	convenient sampling
Jayabharathi et al, (2019)	Tamil Nadu	India	To assess the knowledge and attitude on organ donation among selected community area	Community area	Cross-sectional	60	convenient sampling
Joshi et al, (2011)	The United Kingdom	The United Kingdom	To investigate the organ donor attitudes and donor card behaviour of young adult UK citizens with particular focus on those of South Asian origin	Higher education institutes in the UK	Cross-sectional	382	Purposive sampling
Jothula et al, (2018)	Telangana	India	To assess the knowledge, attitude, and practice towards organ donation among medical students	Medical college Undergraduate students	Cross-sectional	160	Not specified
Kachappillil et al (2020)	Kerala	India	To assess the attitude of general population towards organ donation residing in a rural community	General public	Cross-sectional	100	Convenient sampling
Kadam et al (2021)	Maharashtra	India	To study the knowledge and attitude of first-year medical students towards organ donation.	First year medical students	Cross-sectional	130	Not specified
Kaistha et al, (2016)	New Delhi	India	To determine the knowledge, attitude, and practice regarding organ donation	Patient attendants attending out-patient department	Cross-sectional	119	Convenience
Kalmath et al (2020)	Karnataka	India	To assess the level of knowledge, preparedness, and commitment towards organ donation.	Youth public	Cross-sectional	300	Probability stratified random sampling

1								
2								
3								
4	Karim et al (2013)	The United Kingdom	The United Kingdom	To explore the south Asians attitudes toward organ donation	South Asian general public	Cross-sectional	147	Not specified
5								
6								
7	Kaur et al (2021)	Punjab	India	To know the knowledge, attitude, and practices regarding organ donation among medical students of Punjab	Medical students	Cross-sectional	380	Not specified
8								
9								
10	Kennedy et al, (2002)	Kerala	India	To study the attitudes and beliefs about organ donation in India from the perspectives of the doctors and the public	Doctors and public	Qualitative	8	Purposive
11								
12								
13	Khan et al (2020)	Jammu and Kashmir	India	To know the knowledge and attitude towards organ donation amongst the students	Student population	Cross-sectional	200	Not specified
14								
15								
16	Kundu et al (2021)	Chhattisgarh	India	To investigate the willingness to become an organ donor and the religious and cultural attitude of healthcare professionals	Medical and paramedical students	Cross-sectional	630	Not specified
17								
18								
19	Li et al (2016)	Ontario	Canada	To determine the registration status from deceased organ donation and tissue donation	Migrant population	Cross-sectional	NA*	Not specified
20								
21								
22	Loch et al (2010)	Kuala Lumpur	Malaysia	To examine the knowledge, attitude, and perception toward organ donation	General public	Cross-sectional	272	Not specified
23								
24	Lokesh Kumar et al (2021)	Tamil Nadu	India	To determine the awareness of organ donation concerning organ donation amidst the rural population and to assess the attitude towards the organ donation	Rural public	Cross-sectional	203	Two stages random sampling
25								
26								
27								
28	Mani, (2016)	Tamil Nadu	India	To identify the perceptions and practices related to organ donation in a rural population of Tamil Nadu, India	Rural population	Cross-sectional	100	Simple random sampling
29								
30								
31								
32	Meghana et al, (2018)	Karnataka	India	To assess the knowledge of organ donation among the final year medical, dental, and nursing students and to study the attitude, religious beliefs of the healthcare professionals regarding organ donation and transplantation, to find out the effect of motivation, towards organ donation	Medical, dental, nursing students	Cross-sectional	150	Not specified
33								
34								
35								
36								
37	Minz et al, (1998)	Chandigarh	India	To find out the extent of awareness and attitudes, to help us formulate a further plan of action	Healthcare professionals	Cross-sectional	204	Not specified
38								
39								
40								
41								
42								
43								
44								
45								
46								

Mishra et al (2016)	Odisha	India	To evaluate the awareness of organ donation	College students	Cross-sectional	430	Not specified
Misra et al (2021)	Haryana	India	To understand the beliefs and knowledge of a rural community toward organ donation and the identification of barriers for organ donation	Rural public	Qualitative	48	Simple random sampling
Misra et al (2021)	Haryana	India	To assess awareness about brain death and attitude towards organ donation in a rural community setting.	Rural public	Cross-sectional	947	Simple random sampling
Mithra et al, (2013)	Karnataka	India	To assess the perceptions and attitudes of the people seeking health care in tertiary care centres towards organ donation in Mangalore, India.	People seeking general healthcare as outpatients	Cross-sectional	863	Simple Random Sampling and convenient sampling
Mohan et al, (2019)	Tamil Nadu	India	To establish the role of perceived awareness, family support, perceived individual value, and religiosity on organ donation intention	Public	Cross-sectional	247	Convenience sampling
Mondal et al (2016)	West Bengal	India	To assess the knowledge and attitude of people towards organ donation in a rural community of West Bengal and to study the association of socio-demographic factors with the knowledge and attitude towards organ donation	Rural community	Cross-sectional	110	Simple random sampling
Morgan et al (2015)	London	England	Identify ways in which minority ethnic group habitus appears to limit attitude and knowledge of the system of organ donation and shape attitude toward registration	South Asian minority ethnic general public	Qualitative	79	Not specified
Panwar et al (2016)	New Delhi	India	To assess the awareness of the brain death and the concept of deceased organ donation among lay people and to identify the potential reasons for the low rates of deceased organ donation	General public	Cross-sectional	352	Not specified
Parmar et al (2017)	Gujarat	India	To assess perception of undergraduate students toward organ donation	Undergraduate students	Cross-sectional	100	Randomisation
Parmar et al (2021)	Gujarat	India	To assess the awareness among subjects regarding body donation and cadaveric dissection and their willingness to donate body	Patients	Cross-sectional	130	Not specified

Paul et al, (2019)	West Bengal	India	To understand the knowledge, attitude, and practice pattern of organ donation among the participants and to find out the association between the knowledge of organ donation with selected variables of interest	Urban field practice area of medical college	Cross-sectional	206	Not specified
Poreddi et al (2016)	Karnataka	India	To assess Indian undergraduate nursing students' attitude, knowledge, and willingness to donate organs	Nursing students	Cross-sectional	267	Non-probability convenience sampling
Poreddi et al, (2017)	Karnataka	India	To assess the knowledge, attitude, and willingness to donate organs among the general population	Patients attending outpatient department	Cross-sectional	193	Lottery method
Pradeep et al (2019)	Nort west of England	England	To explore the attitudes and beliefs toward organ donation	General public	Cross-sectional	593	Convenience sampling
Rajan (2020)	West Bengal	India	To assess the knowledge and attitude regarding blood and organ donation among adolescents	Adolescent population	Cross-sectional	100	Non-probability purposive sampling
Randhawa et al (1998)	Luton	England	To examine the influence of religious beliefs, amongst other things, on the extent and directions of public attitudes toward organ donation	South Asian general public	Qualitative	64	Focused sampling
Rani et al (2020)	New Delhi	India	To assess the knowledge ad attitude of general population towards organ donation	General public	Cross-sectional	1089	Purposive non-probability sampling
Ray et al (2020)	West Bengal	India	To assess the knowledge and attitude of certain populations like medical students with respect to organ donation	Medical students	Cross-sectional	134	Random sampling
Reddy et al (2003)	New Delhi	India	To assess the awareness and the attitude of Indian patients, the public, doctors, and nurses toward organ donation	Public, doctors, and nurses	Cross-sectional	990	Randomisation
Sachdeva et al, (2017)	Delhi	India	To assess knowledge, attitude, and practice regarding organ donation / tissue donation among adult visitors of a government hospital in Delhi, India	patient or accompanying attendant of a government hospital	Cross-sectional	450	Convenience sampling
Sam et al, (2018)	Tamil Nadu	India	To assess the awareness and attitude regarding Organ Donation among final year students of medical, dental, engineering,	Medical, dental, engineering, and arts and science students	Cross-sectional	486	Not specified

			and arts and science students in Thirivallur and Chennai					
5	Sarveswaran et al, (2018)	Puducherry	India	To determine the knowledge, attitude, and practice regarding organ donation	Urban community members	Cross-sectional	257	Random
8	Seetharaman et al (2020)	Maharashtra	India	To evaluate the knowledge, attitudes, and beliefs of licensed medical doctors and undergraduate medical students	Medical doctors and students	Cross-sectional	532	Non-probability convenient sampling
11	Singh et al, (2002)	Uttar Pradesh	India	To study level of awareness in hospital staff about transplantation, brain death, and organ donation, as well as factors that may be associated with this awareness	Hospital staffs	Cross-sectional	266	Simple Random Sampling
18	Soni et al, (2018)	Madhya Pradesh	India	To understand correlation between knowledge and attitude towards organ donation among medical and non-medical students and identify barriers to deceased organ donation; to look into participants perception for adoption of presumed consent policy in Indian context; and understanding the acceptance of donor acknowledgement in the form of organ incentivization	Medical and Engineering students	Cross-sectional	600	Random
24	Swamy et al (2020)	Karnataka	India	To assess the awareness and attitude of the young graduates in medical and engineering streams	Medical and Engineering students	Cross-sectional	400	Not specified
27	Swani et al (2020)	Uttarakhand	India	To know the awareness, perceived threat and factors affecting the willingness to donate organs	first-and second-degree relatives of deceased	Cross-sectional	166	Complete sampling
32	Tamuli et al, (2019)	Assam	India	To determine awareness and knowledge of educated (Undergraduate and postgraduate students) population towards organ donation; To find out factors impeding the organ donation program in this part of the country; To observe differences between findings of Undergraduate students and postgraduate degree holders (faculty)	Undergraduate and postgraduate students	Cross-sectional	360	Not specified
38	Thyagarajan et al (2020)	Tamil Nadu	India	To assess the police officers' knowledge of the organ donation process and their practice toward it.	Police officers	Cross-sectional	627	Purposive sampling

1	Verma et al (2020)		India	To assess knowledge, attitude, and perception toward organ donation	Undergraduate medical students	Cross-sectional	1463	Stratified sampling
2								
3	Vijayalakshmi et al, (2015)	Karnataka	India	To investigate nurses' attitude towards organ donation	Nurses directly involved in patient care at a tertiary care hospital in South India	Cross-sectional	184	Non-probability convenience
4								
5	Vijayalakshmi et al, (2016)	Karnataka	India	To assess the gender differences in perceptions and attitude of general population toward organ donation	Relatives of patients attending the outpatient department	Cross-sectional	193	Lottery method
6								
7	Vincent et al (2019a)	Pondicherry	India	To understand the subjective views on barriers in the process of deceased organ donation among the stakeholders and their suggestions to improve in a government tertiary care teaching hospital	Transplant unit stakeholders	Qualitative	6	Purposive sampling
8								
9	Vincent et al (2019b)	Pondicherry	India	To assess the knowledge, attitude, and perception on organ donation among undergraduate medical and nursing students	Under-graduate medical and nursing students	Cross-sectional	620	Convenient sampling for population and voluntary for participants
10								
11	Wong et al (2010a)	Klang Valley	Malaysia	To understand the cultural and religious factors limiting organ donation in three ethnic group	Ethnic population	Qualitative	22	NA
12								
13	Wong et al (2010b)	Klang Valley	Malaysia	To assess public knowledge and attitude with regard to deceased organ donation	General public	Qualitative	22	NA
14								
15	Wong et al (2011)	Selangor	Malaysia	To explore the knowledge, attitude, perception, and barriers toward deceased organ donation	General public	Cross-sectional	259	NA
16								
17	Yadav et al (2020)	Haryana	India	To determine the knowledge and attitude of faculty members of a university	Faculty members	Cross-sectional	170	Not specified
18								

* This study was based on the population data; the findings were based on national Indian population which was 228,879. Since it would over-represent the actual studies, this study sample size is not mentioned in the evidence table but in the notes here.

Findings

Grouping and clustering

Among the 89 studies reviewed; majority (84%) were conducted among Indians living in India (n=75) while other fourteen studies were among people of Indian origin living in the UK (n=8), Malaysia (n=5), and Canada (n=1). Cross-sectional studies (n=79) included various settings such as general community, education institutions and hospital setting (Table 1). Qualitative studies (n=10) used methods like in-depth interviews and focus group discussion (Table 1). Among the 29,385 individuals involved in the retained studies, 27,503 individuals (94%) were from studies conducted in India. Among the studies conducted in the UK, there were 1,235 individuals in total, however, one study had no evidence on the sample number of Indian participants involved [27], and the Malaysian studies had 647 individuals in total. The study participants from the Canadian study were not included since they were information taken from national registry which had around 228,879 Indian individuals [17].

Findings

Integration and relationship

Based on the narrative synthesis, findings are described under the following six themes namely:

1) knowledge and awareness toward deceased organ donation, 2) willingness and actual behaviour toward deceased organ donation, 3) familial influence, 4) fear and mistrust, 5) religious influences, and 6) bodily issues.

Knowledge and awareness of deceased organ donation

Being the commonest theme studied across, findings showed that knowledge had a positive correlation with willingness and practice [37-44]. Both among Indians living in India and outside, younger adults, participants from higher socio-economic status, and with higher

1
2
3 education or healthcare education demonstrated higher knowledge toward deceased organ
4 donation [43-60] and individuals from southern region of India showed higher knowledge
5 compared to other regions in India [61-66].
6
7
8
9

10 Whilst majority of the studies confirmed that almost all the participants had heard about organ
11 donation and had higher awareness, knew what organs can be donated [4,39,44,53-55,67-85]
12 and that organs can be donated to anyone [46,61,80], the knowledge and understanding on
13 brain death was less well understood [49,64,68,69,75,86-89]. A qualitative study from an urban
14 area in the southern region of India also found brain death as a new concept for many and hard
15 to accept among the public [90]. Also, many were not aware about the organ donor card
16 [67,83,88,91-94], where and how to register and obtain an organ donor card
17 [40,50,53,55,56,70,71,94,95] - an important component for organ donor registration. In
18 addition, knowledge on the law that governs organ donation was also found to be low
19 [40,71,92,96,97]. Though a study among Indians living in UK showed that disinterest,
20 emotional distaste, family opposition and religion to be the underlying cause for reluctance to
21 register [58], among Indians living in India, the awareness on brain death, organ donor card,
22 where and how to register were reported as important factors along with family and religion
23 among individuals who were willing to register [40,49,50,53,55,64,67,69-72,86,91-96,98].
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42

43 **Willingness and actual behaviour toward deceased organ donation**

44
45
46 Greater knowledge showed positive influence on the attitude and willingness across all Indian
47 regions [17,41,43,44,50,92,99-103]. Similar to higher knowledge among individuals from
48 southern region of India, willingness to register, to donate and to accept organs for transplant
49 was also shown to be higher [38,45,46,49,66,68,92,99,101]. However, though knowledge had
50 a positive association toward attitude and willingness, the proportion of individuals willing to
51 register, and actual registration was very low and similar across every study included.
52
53
54
55
56
57
58
59
60

1
2
3 Correspondingly, even a study conducted among Indian students living in UK revealed that
4
5 55% of the individuals doubted if they would go ahead with registration [58]. With such
6
7 reluctance, Indians living in India, UK, and Malaysia considered fear of misuse and family
8
9 refusal as a major reason, alongside minor reasons like emotional barriers, bodily issues, and
10
11 religion [44,68,75,79,94,95,97,100,104,105,106,107]. On contrary, commonest reasons to
12
13 donate an organ was to save someone's life, closely followed by prolong someone's life, social
14
15 commitment, altruistic deed, and to keep at-least the organs alive [72,75,91,99,104-111].

16
17
18
19
20 Higher proportion of participants were willing to receive compared to donating
21
22 [38,45,46,58,68,99,101,112-114] among Indians living globally. Furthermore, studies revealed
23
24 that among those who were willing to donate, majority were only willing to donate specific
25
26 organs namely eye / cornea and kidneys [46,61,62], which may be related to the knowledge on
27
28 what organs can be donated [67-72,76-78,86]. Nonetheless, majority of the participants were
29
30 willing to support and promote organ donation in their region and was similar across India
31
32 [55,57,91,99,109,110].

33
34
35
36
37 Younger adults, participants from higher socio-economic status and participants with higher
38
39 education or healthcare education demonstrated higher willingness toward deceased organ
40
41 donation among Indians living globally [17,27,43,45,47,48,53,58-61,108]. However, this was
42
43 not consistent during the time of actual behaviour. Studies showed that there was almost equal
44
45 distribution of participants from lower socio-economic status and lower education, who gave
46
47 consent and actually signed for deceased organ donation [47,96]. However, this conclusion is
48
49 based only from few studies which showed to be similar in north and south of India [47,96].

50 51 52 53 **Familial influence**

54
55
56 In-spite of willingness to register for organ donation, larger proportion of individuals have not
57
58 initiated a conversation or discussed their willingness with their family members, an important
59
60

1
2
3 behaviour for a successful donation [52,65,68,71,82,93,100,115,116] - however opted family
4 as the major barriers toward organ donation [46,63,65,69,72,94,100,102], this was identified
5 even among Indians living outside India [27,117]. Qualitative studies conducted in India, the
6 UK and Malaysia revealed the main reasons was their lack of confidence in initiating
7 conversations around sudden deaths, and with these conversations perceived unwelcomed by
8 their parents and elders [4,27,90,95].
9

10
11
12 However, other few qualitative studies conducted among Indians who were born and grew in
13 another country (i.e., UK and Canada) revealed that they are less concerned of sharing their
14 views compared to their older generations (i.e., mostly migrant generation) and were more
15 willing to discuss their wishes with their families [17,27,81,118], which could be related to
16 acculturation. On the other side, qualitative studies conducted in southern India and the UK
17 suggested that such conversation only occurred when individuals read or viewed such events
18 [90,119]. Also, during the time of consent request, unknown will of the deceased showed to be
19 a significant challenge during the decision-making process [96], making such discussion very
20 important during the crucial decision-making moments.
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38

39 Willingness to support family members was shown to be higher among healthcare students
40 compared to other students [55,56,100,120] and lower among family members from rural areas
41 [99,116]. However, while higher proportion of individuals were willing to support family
42 members for organ donation [38,44,61,71,88,92,101,118], only very few families actually
43 supported this decision when families were approached for consent [90].
44
45
46
47
48
49
50

51 Though studies included found no association based on marital status [38,45,101], one study
52 found that unmarried individuals appeared to be more willing to donate compared to married
53 couples [101]. Also, participants who were aware of their spouse's approval opinion, they were
54 more willing to donate compared to those unaware of their spouse's opinion [45]. Among the
55
56
57
58
59
60

1
2
3 type of family, individuals from 'joint' families had higher knowledge, while willingness to
4 donate was found to be higher among nuclear families and also was identified to be highly
5 influenced by the family [4,17,38,48,50]. This was a similarity identified in India, Canada, and
6 the UK, showing it to be a collectivist decision making, where involvement of the extended
7 family is identified to be a part of decision making among this population irrespective of the
8 country they live [4,17,38,48,53,117]. And involvement of extended family was identified to
9 be a barrier among Indians in the UK, in this process [4].

10 11 12 13 14 15 16 17 18 19 20 **Fear and Mistrust**

21
22
23 Fear on misuse of organs by the healthcare team, and lack of trust was the other major barrier
24 reported [55,63,64,68,69,71,72,78,83,89,94,97,104,105]. Participants from several studies
25 relate organ donation to organ trafficking and misuse which leads them to fear and mistrust
26 [49,58,65,99,105]. A qualitative study also revealed increased ambivalence that while on one
27 side participants perceived organ donation as a noble act, on the other side they were also
28 fearful of organ misuse due to the information that they hear through news and media on organ
29 trafficking and exchange of money for organs [90].

30
31
32 Also similar in the UK, among Indian participants, a mother was afraid to see an organ donor
33 card in her child's wallet as she was thinking if doctors will come to see it, then they may
34 deviate the process toward donation and give less care toward saving her child [27]. In parallel,
35 general population from India also feared pre-mature declaration of death for the need of organs
36 [39,99,120]. However, healthcare population groups were less likely to believe that there will
37 be any premature declaration of death by the doctors [38,71,85,87].

38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 **Religious influence**

55
56
57 Overall, majority of the participants favoured organ donation
58 [27,38,46,47,49,61,80,81,101,106,108,109]. However, when further looked based on religion,
59
60

1
2
3 different studies showed different religious groups to be more willing to donate compared to
4 individuals from another religious group [45,48,61,73,121], showing no consistency on which
5 particular religion is more supportive or rejective [45,48,52,61,121]. In parallel, a qualitative
6 study conducted among UK university students of Indian descendants showed lack of
7 homogeneity even within one same religion. Some agreed that body needs to be intact for
8 reincarnation, while other participants believed that body and soul are two different entities
9 and that only the soul counts while body is left to decay in this earth [27,97]. However, among
10 studies undertaken outside India, Indian Muslim participants were identified to be less likely
11 or supportive toward organ donation [4,44,95,106,117]. Qualitative studies from outside India
12 identified that lack of the standpoint of religion as one of the reasons leading to such reluctance
13 and not the individual's opinion [108,117].

14
15 However, though there were differences of opinion across and within the religion, majority of
16 the participants agreed that organ donation is not against religious views
17 [38,68,72,88,90,97,101,109] and also considered religion as the very least barrier toward organ
18 donation [44,45,63,65,68,90,114,115,122]. A qualitative study conducted among UK students
19 with Indian origin showed that though individuals felt religion may influence their decision it
20 was not the only factor that that will be considered in such decisions [27]. Yet, favourable
21 opinion of religion toward organ donation was found to be positively correlating with their
22 willingness to donate [38,52].

23
24 A Qualitative study conducted in UK with Indian students revealed that younger generations
25 were less bothered about religious views compared to older generations, which could have
26 occurred due to acculturation [27]. Also, participants preferred that religion should not be a
27 criterion based on which allocation can be decided [48,68,109,115] and that organ of a
28 deceased person can be donated to a recipient from any religion [48,68,109,115].

1
2
3 However, during the time of consent, a stakeholder from a qualitative study said that families
4 who were not willing to donate use the concept of religion as a reason to decline donation,
5
6 though none of the religion is against organ donation. In the same qualitative study, public
7
8 participants from various religious group felt that their religion supports organ donation [90].
9
10
11

12 13 **Bodily issues**

14
15
16 Majority of the individuals from the reviewed studies were not concerned about bodily issues
17 though it has to undergo incisions while explanting [38-40,45,46,61,91,97,118]. However, on
18
19 the other side, majority also agreed that it is an individual's complete right to have the organs
20
21 within the body when dead [49,87]. Whilst majority of individuals were not concerned about
22
23 incisions in the body, a qualitative study found that in the real time of consent, stakeholders
24
25 found it easy to get approval for corneal donation and not solid organs as it may have many
26
27 incisions over the body and disfigure it [72]. In relation to funeral practices involving the
28
29 deceased body, majority were aware that normal funeral practices can be conducted even after
30
31 donating organs [38,49,61,87,91,115], contrast findings were also evident [49,55,87].
32
33 However, majority opted body disfigurement, but less proportion, as one of the least reasons
34
35 to be a barrier toward organ donation, both within and outside the borders of India
36
37 [46,63,65,69,83,100,106,108].
38
39
40
41
42
43
44
45
46
47
48
49

50 **Discussion**

51
52
53 To the best of our knowledge, this is the first systematic review that reviewed barriers toward
54 organ donation among Indians living globally. Also, this is one of the few systematic reviews
55
56 in organ donation that used integrative methodology. While majority in India have heard or are
57
58 aware of organ donation, and had a positive correlation with willingness, their gap is wide.
59
60

1
2
3 This indicates that there could be various factors other than knowledge which need to be studied
4
5 in more detail. Organ donation being more embedded with health behaviour, there is a need to
6
7 understand the relationship between behaviour and behavioural intention by adopting
8
9 appropriate principles. This aids the specificity of policy and campaigns to address organ donor
10
11 registration behaviour in this particular population.
12
13

14
15 Though gaps identified in majority of the quantitative studies merit qualitative studies, only
16
17 very few qualitative studies were undertaken in India [87,90,97]. For instance, though majority
18
19 individuals were willing to be an organ donor, majority have not initiated any such conversation
20
21 with their family members yet considered family to be the major barrier [46,63,65,69,100,117].
22
23 However, no further studies were exclusively undertaken to understand how a construct like
24
25 family interferes in the decision making toward registration and consent. Such studies will aid
26
27 in developing and testing hypothesis or developing appropriate interventions to increase such
28
29 conversation with family members. Such conversations play a very important role as the
30
31 awareness on the willingness of the deceased plays a vital role in decision-making during
32
33 consent [96]. However, the influence of family can be different among Indians in India and
34
35 outside India as the latter may have influences based on acculturation and enculturation [27,58]
36
37 while the prior maybe more concerned toward communication issues
38
39 [52,65,68,90,93,100,115,116]. While majority were willing to be an organ donor
40
41 [27,43,45,47,48,53,58-61], they were unaware on how to register to be an organ donor
42
43 [40,50,53,55,56,70,71,94]. Therefore, further campaigns on registration procedure information
44
45 will enable to improve organ donation in India.
46
47
48
49
50
51

52
53 This review showed that there are various complex interactions that happen in the society
54
55 where an individual lives rather than just knowledge influencing organ donation decision. Fear
56
57 and mistrust have shown to influence the uncertainty in decision-making for a very long time
58
59 [27,40,48,55,63,64,68,69,71,72,78,97]. However, studies failed to address how fear influences
60

1
2
3 organ donation, what is the source of fear and how a construct like fear can be addressed. This
4
5 fear could be due to the news or information that they hear on illegal organ donation and
6
7 transplants practices around them or any other reasons [123], but not much have been studied
8
9 why such fear exist among this population.
10
11

12
13 Also, while majority of the studies show influence of religion on organ donation, there is a
14
15 greater need to understand how a religion influences organ donation in India. Is it the
16
17 misconception, or the lack of enabling religious community, or reluctance to take such
18
19 conversation, or lack of information from the religious leaders or their physical practices that
20
21 does not allow donation? Such in-depth studies need to be undertaken to gain a deeper
22
23 understanding into the phenomena. Therefore, there is an urgent need, to study further how the
24
25 interaction of the individuals with such a complex socio-cultural and institutional structures
26
27 influences the organ donation behaviour.
28
29

30
31
32 Various other factors such as age, sex, education, and socio-economic status showed greater
33
34 influence on willingness to donate [27,45,47,48,53,58,61]. However, studies showed that they
35
36 did not hold true during the time of consent [47,96]. This review therefore showed that there is
37
38 some shift in behaviour during registration and the actual consent. This again probes to further
39
40 the understanding on what happens during the time of consent, and why such a shift is seen in
41
42 the intention to donate between these two time periods.
43
44

45
46 Overall, based on the studies undertaken among Indians living in India, the UK, Canada, and
47
48 Malaysia, similarities and differences were identified. The willingness and registration
49
50 behaviour differed according to the geographical location where Indians lived in comparison
51
52 to their native population. While Indians were considered to have higher attitude and
53
54 willingness in Malaysia [84,114], Indians living in the UK and Canada were considered to have
55
56 lower attitude and willingness [17,117]. This could have been due to their respective socio-
57
58
59
60

1
2
3 cultural practices of Muslim major country [i.e., Malaysia] and Christian major country [i.e.,
4 Canada and the UK] with Hindu major population [i.e., Indians]. This argument is also
5 supported by a study that compared organ donation willingness between Christian, Hindu, and
6 Muslim major native population [58]. The similarity identified was that, irrespective of their
7 geographical location, this was a collectivist decision and not an individual's decision
8 [4,85,117] with family, fear and mistrust, and bodily issues identified to be the major barrier
9 [44,83,85,95,105,107,108].

10 Methodologically, studies conducted among the Indian ethnic group outside India were
11 collectively identified as South-Asians or Asians [23-26,106] while they differ culturally,
12 socially, politically, economically, and even religiously [124]. Two studies included from UK
13 in this review have clearly shown such a difference with the neighbouring country (i.e., India,
14 and Pakistan) [27,58]. Therefore, there is a need to address this population with such specificity
15 in future research that can strengthen the practices even more efficiently. Also, with this
16 population to be the largest migrating population in the world [7] it is important to understand
17 their behaviour outside India. Studies show difference between various migration generations
18 from the same ethnicity [27,58]. This cannot happen without the influence of time elapsed since
19 immigration, immigrant generation (i.e., first, second, or higher), acculturation, enculturation,
20 perceived discrimination, attitudes / mistrust toward healthcare system, community barriers,
21 socio-cultural influence and many such complex determinants which adds further complexity
22 to the issue of organ donation among such a population. Therefore, such specific research
23 among this community is also needed to address the disproportionate representation between
24 waiting list and donor list from this ethnic population outside the country of origin.

25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65
66
67
68
69
70
71
72
73
74
75
76
77
78
79
80
81
82
83
84
85
86
87
88
89
90
91
92
93
94
95
96
97
98
99
100
101
102
103
104
105
106
107
108
109
110
111
112
113
114
115
116
117
118
119
120
121
122
123
124
125
126
127
128
129
130
131
132
133
134
135
136
137
138
139
140
141
142
143
144
145
146
147
148
149
150
151
152
153
154
155
156
157
158
159
160
161
162
163
164
165
166
167
168
169
170
171
172
173
174
175
176
177
178
179
180
181
182
183
184
185
186
187
188
189
190
191
192
193
194
195
196
197
198
199
200
201
202
203
204
205
206
207
208
209
210
211
212
213
214
215
216
217
218
219
220
221
222
223
224
225
226
227
228
229
230
231
232
233
234
235
236
237
238
239
240
241
242
243
244
245
246
247
248
249
250
251
252
253
254
255
256
257
258
259
260
261
262
263
264
265
266
267
268
269
270
271
272
273
274
275
276
277
278
279
280
281
282
283
284
285
286
287
288
289
290
291
292
293
294
295
296
297
298
299
300
301
302
303
304
305
306
307
308
309
310
311
312
313
314
315
316
317
318
319
320
321
322
323
324
325
326
327
328
329
330
331
332
333
334
335
336
337
338
339
340
341
342
343
344
345
346
347
348
349
350
351
352
353
354
355
356
357
358
359
360
361
362
363
364
365
366
367
368
369
370
371
372
373
374
375
376
377
378
379
380
381
382
383
384
385
386
387
388
389
390
391
392
393
394
395
396
397
398
399
400
401
402
403
404
405
406
407
408
409
410
411
412
413
414
415
416
417
418
419
420
421
422
423
424
425
426
427
428
429
430
431
432
433
434
435
436
437
438
439
440
441
442
443
444
445
446
447
448
449
450
451
452
453
454
455
456
457
458
459
460
461
462
463
464
465
466
467
468
469
470
471
472
473
474
475
476
477
478
479
480
481
482
483
484
485
486
487
488
489
490
491
492
493
494
495
496
497
498
499
500
501
502
503
504
505
506
507
508
509
510
511
512
513
514
515
516
517
518
519
520
521
522
523
524
525
526
527
528
529
530
531
532
533
534
535
536
537
538
539
540
541
542
543
544
545
546
547
548
549
550
551
552
553
554
555
556
557
558
559
560
561
562
563
564
565
566
567
568
569
570
571
572
573
574
575
576
577
578
579
580
581
582
583
584
585
586
587
588
589
590
591
592
593
594
595
596
597
598
599
600
601
602
603
604
605
606
607
608
609
610
611
612
613
614
615
616
617
618
619
620
621
622
623
624
625
626
627
628
629
630
631
632
633
634
635
636
637
638
639
640
641
642
643
644
645
646
647
648
649
650
651
652
653
654
655
656
657
658
659
660
661
662
663
664
665
666
667
668
669
670
671
672
673
674
675
676
677
678
679
680
681
682
683
684
685
686
687
688
689
690
691
692
693
694
695
696
697
698
699
700
701
702
703
704
705
706
707
708
709
710
711
712
713
714
715
716
717
718
719
720
721
722
723
724
725
726
727
728
729
730
731
732
733
734
735
736
737
738
739
740
741
742
743
744
745
746
747
748
749
750
751
752
753
754
755
756
757
758
759
760
761
762
763
764
765
766
767
768
769
770
771
772
773
774
775
776
777
778
779
780
781
782
783
784
785
786
787
788
789
790
791
792
793
794
795
796
797
798
799
800
801
802
803
804
805
806
807
808
809
810
811
812
813
814
815
816
817
818
819
820
821
822
823
824
825
826
827
828
829
830
831
832
833
834
835
836
837
838
839
840
841
842
843
844
845
846
847
848
849
850
851
852
853
854
855
856
857
858
859
860
861
862
863
864
865
866
867
868
869
870
871
872
873
874
875
876
877
878
879
880
881
882
883
884
885
886
887
888
889
890
891
892
893
894
895
896
897
898
899
900
901
902
903
904
905
906
907
908
909
910
911
912
913
914
915
916
917
918
919
920
921
922
923
924
925
926
927
928
929
930
931
932
933
934
935
936
937
938
939
940
941
942
943
944
945
946
947
948
949
950
951
952
953
954
955
956
957
958
959
960
961
962
963
964
965
966
967
968
969
970
971
972
973
974
975
976
977
978
979
980
981
982
983
984
985
986
987
988
989
990
991
992
993
994
995
996
997
998
999
1000

Though narrative synthesis is criticised for its lack of transparency, this study has tried to be as transparent as possible to strengthen its validity and credibility of the review and synthesis

1
2
3 [30,125]. The PRISMA flow chart, search strategy, data synthesis and analysis methods are
4
5 clearly explained in this study to overcome those limitations.
6
7

8 **Conclusion**

10
11 This review showed that majority of the participants from India and of Indian origin hold
12
13 positive attitude toward registration but show lower willingness and even lower practice of
14
15 registration. Though this study showed the complex relationship and influences toward organ
16
17 donation behaviour, lacunae were identified for further deeper understanding into such
18
19 complex interactions determining the behaviour. There is also a lack of methodological rigour
20
21 to study this population outside India, being collectively studied with their neighbouring
22
23 population which are not homogenous. Also, within India, majority of the studies employed
24
25 similar aims and methods leading to repetition of studies rather than diversified, wider, and in-
26
27 depth research.
28
29
30
31

32
33 **Funding sources:** This review is led by the principal investigator Britzer Paul Vincent who is
34
35 a PhD scholar at the Institute for Health Research, University of Bedfordshire funded by their
36
37 Global Challenges Research Fund.

38 **Authorship Contribution:**

39 All authors BPV, GR & EC contributed to – conception of the study, design of work, data
40
41 acquisition, data analysis, data interpretation, writing of the article, final approval, and
42
43 accountability of the study.

44
45 **Acknowledgement:** We would like to thank our librarian Mr. David Abdy from Institute for
46
47 Health Research, University of Bedfordshire for his contribution with the development of the
48
49 search strategy.

50
51 **Data availability:** None

52
53 **Conflict of Interest:** None declared.

54
55 **Patient and Public involvement:** None as this is a systematic review

56
57 **Ethics approval details:** Institute for Health Research Ethics Committee from the University
58
59 of Bedfordshire approved this study (IHREC931).
60

References:

1. Merrill, J.P., Murray, J.E., Takacs, F.J., Hager, E.B., Wilson, R.E. and Dammin, G.J., 1963. Successful transplantation of kidney from a human cadaver. *Jama*, 185(5), pp.347-353.
2. Rudge C, Matesanz R, Delmonico FL, Chapman J. International practices of organ donation. *British journal of anaesthesia*. 2012 Jan 1;108(suppl_1):i48-55.
3. Alden, D.L. and Cheung, A.H., 2000. Organ donation and culture: a comparison of Asian American and European American beliefs, attitudes, and behaviors. *Journal of Applied Social Psychology*, 30(2), pp.293-314.
4. Karim A, Jandu S, Sharif A. A survey of South Asian attitudes to organ donation in the United Kingdom. *Clinical transplantation*. 2013 Sep;27(5):757-63.
5. Lo, C.M., 2012. Deceased donation in Asia: challenges and opportunities. *Liver Transplantation*, 18(S2), pp.S5-S7.
6. United Nations. Department of Economics and social affairs. Population dynamics. Available at: <https://population.un.org/wpp/Download/Standard/Population/>. Last viewed: 03 April 2021
7. World Migration Report. 2020. Available at: https://www.un.org/sites/un2.un.org/files/wmr_2020.pdf. Last viewed 03 April 2021
8. Ramachandran, A., Ma, R.C.W. and Snehalatha, C., 2010. Diabetes in asia. *The Lancet*, 375(9712), pp.408-418.
9. Ramachandran, A., Snehalatha, C., Shetty, A.S. and Nanditha, A., 2012. Trends in prevalence of diabetes in Asian countries. *World journal of diabetes*, 3(6), p.110.
10. Singh, R.B., Suh, I.L., Singh, V.P., Chaithiraphan, S., Laothavorn, P., Sy, R.G., Babilonia, N.A., Rahman, A.R.A., Sheikh, S., Tomlinson, B. and Sarraf-Zadigan, N.,

2000. Hypertension and stroke in Asia: prevalence, control and strategies in developing countries for prevention. *Journal of human hypertension*, 14(10), pp.749-763.
11. Ritz E, Rychlík I, Locatelli F, Halimi S. End-stage renal failure in type 2 diabetes: a medical catastrophe of worldwide dimensions. *American journal of kidney diseases*. 1999 Nov 1;34(5):795-808.
 12. Weisstuch JM, Dworkin LD. Does essential hypertension cause end-stage renal disease?. *Kidney international Supplement*. 1992 May 2(36).
 13. Navin S, Shroff S, Niranjana S. 'Deceased Organ Donation in India'. Available: <<http://www.mohanfoundation.org/organ-donationtransplant-resources/organ-donation-in-india.asp>> [Accessed 18 March 2021].
 14. National Deceased Donor Transplantation, Mohan Foundation. 2017. Available: <https://www.mohanfoundation.org/deceased-organdonation-in-india.asp> [Accessed 18 March 2021].
 15. Kumar, V., Ahlawat, R., Gupta, A.K., Sharma, R.K., Minz, M., Sakhuja, V. and Jha, V., 2014. Potential of organ donation from deceased donors: study from a public sector hospital in India. *Transplant International*, 27(10), pp.1007-1014.
 16. NHSBT. Organ Donation and Transplantation data for Black, Asian and Minority Ethnic (BAME) Communities. 2018. Available at: <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/12048/bame-organ-donation-and-transplantation-data-2017-18.pdf>. Last viewed: 03 April 2021
 17. Li, A.H.T., Lam, N.N., Dhanani, S., Weir, M., Prakash, V., Kim, J., Knoll, G. and Garg, A.X., 2016. Registration for deceased organ and tissue donation among Ontario immigrants: a population-based cross-sectional study. *Canadian Medical Association Open Access Journal*, 4(4), pp.E551-E561.

- 1
2
3 18. Vincent BP, Randhawa G, Cook E. Protocol: Barriers towards organ donor registration
4 and consent among people of Indian origin living globally: a systematic review and
5 integrative synthesis—protocol. *BMJ Open*. 2020;10(6).
6
7
- 8
9
10 19. Irving, M.J., Tong, A., Jan, S., Cass, A., Rose, J., Chadban, S., Allen, R.D., Craig, J.C.,
11 Wong, G. and Howard, K., 2012. Factors that influence the decision to be an organ donor:
12 a systematic review of the qualitative literature. *Nephrology dialysis*
13 *transplantation*, 27(6), pp.2526-2533.
14
- 15 20. Morgan, M., Kenten, C., Deedat, S. and Donate Programme Team, 2013. Attitudes to
16 deceased organ donation and registration as a donor among minority ethnic groups in
17 North America and the UK: a synthesis of quantitative and qualitative research. *Ethnicity*
18 *& health*, 18(4), pp.367-390.
19
- 20 21. Kotha, S., Lawendy, B., Asim, S., Gomes, C., Yu, J., Orchanian-Cheff, A., Tomlinson,
21 G., & Bhat, M. (2021). Impact of immunosuppression on incidence of post-transplant
22 diabetes mellitus in solid organ transplant recipients: Systematic review and meta-
23 analysis. *World journal of transplantation*, 11(10), 432–442.
24 <https://doi.org/10.5500/wjt.v11.i10.432>
25
26
- 27 22. Piasecki, J., Waligora, M., & Dranseika, V. (2017). What Do Ethical Guidelines for
28 Epidemiology Say About an Ethics Review? A Qualitative Systematic Review. *Science*
29 *and engineering ethics*, 23(3), 743–768. <https://doi.org/10.1007/s11948-016-9829-3>
30
31
- 32 23. Molzahn, A.E., Starzomski, R., McDonald, M. and O'Loughlin, C., 2005. Indo-Canadian
33 beliefs regarding organ donation. *Progress in Transplantation*, 15(3), pp.233-239.
34
- 35 24. Morgan, M., Hooper, R., Mayblin, M. and Jones, R., 2006. Attitudes to kidney donation
36 and registering as a donor among ethnic groups in the UK. *Journal of Public*
37 *Health*, 28(3), pp.226-234.
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
25. Ahmed, W., Harris, S. and Brown, E., 1999. Attitudes to organ donation among South Asians in an English high street. *Journal of the Royal Society of Medicine*, 92(12), pp.626-627.
 26. Rasiyah, R., Manikam, R., Chandarsekaran, S.K., Thangiah, G., Puspharajan, S. and Swaminathan, D., 2014. The influence of socioeconomic and demographic variables on willingness to donate cadaveric human organs in Malaysia. *Medicine*, 93(23).
 27. Gauher ST, Khehar R, Rajput G, Hayat A, Bakshi B, Chawla H, Cox BM, Warrens AN. The factors that influence attitudes toward organ donation for transplantation among UK university students of Indian and Pakistani descent. *Clinical transplantation*. 2013 May;27(3):359-67.
 28. JBI Critical Appraisal Tools. Available at: <https://jbi.global/critical-appraisal-tools>. Last viewed: 03 April 2021
 29. Gao, W., Plummer, V. and Williams, A., 2017. Perioperative nurses' attitudes towards organ procurement: a systematic review. *Journal of clinical nursing*, 26(3-4), pp.302-319.
 30. Brown SJ. Knowledge for health care practice: A guide to using research evidence. Saunders; 1999.
 31. Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, Britten N, Roen K, Duffy S. Guidance on the conduct of narrative synthesis in systematic reviews. A product from the ESRC methods programme Version. 2006 Apr 1;1:b92.
 32. Noblit GW, Hare RD. Meta-ethnography: synthesizing qualitative studies, vol. 11. California: Sage Publications; 1988.
 33. Campbell R, Pound P, Pope C, Britten N, Pill R, Morgan M, Donovan J. Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Soc Sci Med*. 2003;56(4):671-84.

- 1
2
3 34. Campbell, R., Pound, P., Morgan, M., Daker-White, G., Britten, N., Pill, R., Yardley, L.,
4
5 Pope, C. and Donovan, J., 2012. Evaluating meta ethnography: systematic analysis and
6
7 synthesis of qualitative research.
8
9
- 10 35. Nye E, Melendez-Torres GJ, Bonnell C. Origins, methods, and advances in qualitative
11
12 meta-synthesis. *Review of Education*. 2016;4(1):57–79.
13
14
- 15 36. Garside R. A comparison of methods for the systematic review of qualitative research:
16
17 two examples using Meta-ethnography and Meta-study. UK: University of Exeter; 2008.
18
19
- 20 37. Alex P, Kiran KG, Baisil S, Badiger S. Knowledge and attitude regarding organ donation
21
22 and transplantation among medical students of a medical college in South India. *Int J*
23
24 *Community Med Public Health*. 2017 Sep;4(9):3449-54p.
25
26
- 27 38. Bapat U, Kedlaya PG. Organ donation, awareness, attitudes and beliefs among post
28
29 graduate medical students. *Saudi Journal of Kidney Diseases and Transplantation*. 2010
30
31 Jan 1;21(1):174.
32
- 33 39. Chakradhar K, Doshi D, Reddy BS, Kulkarni S, Reddy MP, Reddy SS. Knowledge,
34
35 attitude and practice regarding organ donation among Indian dental students.
36
37 *International journal of organ transplantation medicine*. 2016;7(1):28.
38
39
- 40 40. Gupta RK, Singh P, Akhtar N, Kumari R, Gupta C, Gupta R. Gender based perspectives
41
42 about organ donation among students in a medical school in North India. *International*
43
44 *Journal of Research in Medical Sciences*. 2018 May;6(5):1710.
45
46
- 47 41. Jayabharathi B, Devika M, Akila M. Assessment of knowledge and attitude on organ
48
49 donation among adults in selected areas. *International Journal of Research in*
50
51 *Pharmaceutical Sciences*. 2019 Apr 15;10(2):782-6.
52
53
- 54 42. Singh P, Kumar A, Pandey CM, Chandra H. Level of awareness about transplantation,
55
56 brain death and cadaveric organ donation in hospital staff in India. *Progress in*
57
58 *Transplantation*. 2002 Dec;12(4):289-92.
59
60

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
43. Panwar, R., Pal, S., Dash, N.R., Sahni, P., Vij, A. and Misra, M.C., 2016. Why are we poor organ donors: a survey focusing on attitudes of the lay public from northern India. *Journal of clinical and experimental hepatology*, 6(2), pp.81-86.
 44. Jagadeesh, A.T., Puttur, A., Mondal, S., Ibrahim, S., Udupi, A., Prasanna, L.C. and Kamath, A., 2018. Devising focused strategies to improve organ donor registrations: A cross-sectional study among professional drivers in coastal South India. *PloS one*, 13(12), p.e0209686.
 45. Ahlawat R, Kumar V, Gupta AK, Sharma RK, Minz M, Jha V. Attitude and knowledge of healthcare workers in critical areas towards deceased organ donation in a public sector hospital in India. *The National medical journal of India*. 2013 Jan 1;26(6):322-6.
 46. Balajee KL, Ramachandran N, Subitha L. Awareness and attitudes toward organ donation in rural Puducherry, India. *Annals of Medical and Health Sciences Research*. 2016;6(5):286-90.
 47. Bansal N, Koushal V, Mehra A. A study of sociodemographic profile and level of awareness of the decision makers for organ donation of deceased organ donors in a Tertiary Care Hospital. *Indian Journal of Transplantation*. 2019 Jan 4;13(2):82.
 48. Dasgupta A, Shahbabu B, Sarkar K, Sarkar I, Das S, Kumar Das M. Perception of organ donation among adults: A community based study in an urban community of West Bengal. *Scholars J Appl Med Sci*. 2014;2(6A):2016-1.
 49. Poreddi V, Sunitha TS, Thimmaiah R, Math SB. Gender differences in perceptions and attitudes of general population towards organ donation: An Indian perspective. *Saudi Journal of Kidney Diseases and Transplantation*. 2017 May 1;28(3):599.
 50. Sarveswaran G, Sakthivel MN, Krishnamoorthy Y, Arivarasan Y, Ramakrishnan J. Knowledge, attitude, and practice regarding organ donation among adult population of urban Puducherry, South India. *Journal of education and health promotion*. 2018;7.

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
51. Tamuli RP, Sarmah S, Saikia B. Organ donation—“attitude and awareness among undergraduates and postgraduates of North-East India”. *Journal of family medicine and primary care*. 2019 Jan;8(1):130.
52. Vijayalakshmi P, Sunitha TS, Gandhi S, Thimmaiah R, Math SB. Knowledge, attitude and behaviour of the general population towards organ donation: an Indian perspective. *The National medical journal of India*. 2016 Sep 1;29(5):257.
53. Swain, R., Prasad, H., Lalwani, S. and Pooniya, S., 2020. Awareness, perceived barriers and factors affecting willingness for Organ Donation among the first-and second-degree relatives of deceased in a tertiary care hospital of Northern India. *The Official Publication of Indian Academy of Forensic Medicine*, 42(4), pp.261-264.
54. Kadam, S., Shinde, S., Shroff, G. and Gulanikar, S., 2021. Knowledge and Attitude About Organ Donation Among Medical Students: An Observational Study from Aurangabad, Maharashtra. *Int J Cur Res Rev| Vol, 13(01)*, p.121.
55. Kundu, S., 2021. Attitudes and Myths regarding Posthumous whole Body Bequest and Organ Donation among Medical Professionals and Health Care Personnel of Tribal Chhattisgarh—A Broad Questionnaire Based Review. *Sch J App Med Sci*, 6, pp.1093-1116.
56. Swamy, R.M., Kalaburgi, R.A., Manjunath, G.N., Lavanya, R. and Kousalya, R., Knowledge and Attitude towards Organ donation among the Medical and Engineering students in Tumakuru, Karnataka. *IOSR Journal of Dental and Medical Sciences (IOSR-JDMS)* e-ISSN: 2279-0853, p-ISSN: 2279-0861. Volume 19, Issue 5 Ser.2 (May. 2020), PP 31-36
57. Gupta, P., Sodhani, S., & Bhate, K. (2021). Organ donation perception and beliefs: a cross sectional study amongst degree college students and teachers in Mumbai, Maharashtra, India. *International Journal of Advances in Medicine*, 8(3), 399-403.

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
58. Joshi MS. Whose decision is it? Organ donation attitudes among young UK South Asians. *Psychological Studies*. 2011 Mar 1;56(1):86-97.
59. Misra, P., Malhotra, S., Sharma, N., Misra, M.C., Vij, A. and Pandav, C.S., 2021. Awareness about brain death and attitude towards organ donation in a rural area of Haryana, India. *Journal of Family Medicine and Primary Care*, 10(8), p.3084.
60. Parmar, K.M., Vaisnani, H., Chavda, N., Sharma, P. and Jethava, K., 2021. A Questionnaire Based Study Evaluating Awareness for Organ and Body Donation and Cadaveric Dissection among the General Population Attending Medical and Dental Hospital. *Medico Legal Update*, 21(1), pp.835-839.
61. Mithra P, Ravindra P, Unnikrishnan B, Rekha T, Kanchan T, Kumar N, Papanna M, Kulkarni V, Holla R, Divyavaraprasad K. Perceptions and attitudes towards organ donation among people seeking healthcare in tertiary care centers of coastal South India. *Indian journal of palliative care*. 2013 May;19(2):83.
62. Balwani MR, Gumber MR, Shah PR, Kute VB, Patel HV, Engineer DP, Gera DN, Godhani U, Shah M, Trivedi HL. Attitude and awareness towards organ donation in western India. *Renal failure*. 2015a Apr 21;37(4):582-8.
63. Bathija GV, Ananthesh BG, Bant DD. Study to assess knowledge and attitude towards organ donation among interns and post graduates of a medical college in Karnataka, India. *Natl J Community Med*. 2017;8(5):236-40.
64. Bharambe VK, Sakshi S, Gaurav B, Feroz A. Awareness regarding body and organ donation amongst the population of an urban city in India. *Nitte University Journal of Health Science*. 2015 Dec 1;5(4).
65. Minz M, Sood S, Kumar A, Bansal V, Mehra S. Impact of organ trade on attitudes toward organ donation: knowledge and attitudes toward cadaveric organ donation in north India. *InTransplantation proceedings* 1998 (Vol. 30, No. 7).

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
66. Mohan G, Aswathy AA. Organ donation in India—A social marketing perspective. *International Journal of Nonprofit and Voluntary Sector Marketing*. 2019 May;24(2):e1637.
67. Alex A, Shroff S, Paul VB, Navin S, Ramesh P, Michael J, Menon S. Did an increase in knowledge and awareness about organ donation improve organ donation rate in India over the past two decades?. *Indian Journal of Transplantation*. 2019 Jul 1;13(3):173.
68. Bharambe VK, Arole VU, Puranam V, Manvikar P, Rathod HK. Organ Donation: from Point of View of Students Doing Medical Internship in India. *BANTAO Journal*. 2016 Dec 1;14(2):67-72.
69. Bharambe VK, Arole VU, Puranam V, Kulkarni PP, Kulkarni PB. Knowledge and attitude toward organ donation among people in Lanja: A rural town in India. *Saudi Journal of Kidney Diseases and Transplantation*. 2018a Jan 1;29(1):160.
70. Deshpande PR, Damle P, Bihani G, Khadabadi SS, Naik AN, Pawar AP. Knowledge, attitude, and practice of organ donation among pharmacy students. *Indian Journal of Transplantation*. 2018 Apr 1;12(2):113.
71. Da Silva, K.X., Dsouza, D.B., Mascarenhas, V.R., Kankonkar, P.N., Vaz, F.S. and Kulkarni, M.S., 2021. Perceptions and attitude toward cadaveric organ donation among health-care professionals at a tertiary health-care setting: A cross-sectional study. *Indian Journal of Transplantation*, 15(1), p.56.
72. Basavarajegowda, A., Arjunan, C., Nalini, Y.C., Parameshwaran, S. and Kannan, S., 2021. A comparative study of knowledge, attitude, and practices about organ donation among blood donors and nonblood donors. *Asian Journal of Transfusion Science*, 15(1), p.37.

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
73. Kachappillil, A.J. and Thankachan, A., 2020. Attitude of General Population towards Organ Donation in a Rural Community of Ernakulam District. *International Journal of Healthcare Education & Medical Informatics (ISSN: 2455-9199)*, 7(1&2), pp.16-20.
74. Kalmath, S. and Peerapur, S.M., 2020. A Study to Determine the Knowledge, Preparedness and Commitment Regarding Organ Donation among the Youths of Hubli, Karnataka. *International journal of Innovative science and research technology*, 5(5).
75. Khan, F., Latif, M. and Bashir, S., 2020. Attitude and Knowledge toward Organ Donation among Arts and Science Students. *Indian Journal of Forensic Medicine & Toxicology*, 14(4).
76. Rani, S., Mishra, A. and Dagar, N., 2020. Community Based Study to Assess the Knowledge and Attitude of General Population towards Organ Donation. *International Journal of Nursing Education*, 12(4).
77. Ray, M.K. and Ghosh, T., 2020. Assessment of Knowledge and Attitude of Medical Students Regarding Body and Organ Donation. *Religion*, 115, pp.85-8.
78. Seetharaman, R.V., Rane, J.R. and Dingre, N.S., 2021. Assessment of knowledge and attitudes regarding organ donation among doctors and students of a tertiary care hospital. *Artificial Organs*, 45(6), pp.625-632.
79. Yadav, N., Jain, M., Sharma, A., Jain, V., Chahar, P. and Verma, N., 2020. Perceptions of a university's faculty members on organ donation. *The National Medical Journal of India*, 33(5), p.302.
80. Ghose, T.K., Deo, J., Dutt, V., Agarwal, R., Patel, B.B., Ganesh, M., More, V.K., Pandya, K.H., Sharma, R., Sharma, D. and Singh, H., 2021. Knowledge and attitude towards organ donation: a study among medical and nursing students of a medical college. *International Journal of Community Medicine and Public Health*, 8(11), p.5398.

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
81. Poreddi, V., Katyayani, B.V., Gandhi, S., Thimmaiah, R. and Badamath, S., 2016. Attitudes, knowledge, and willingness to donate organs among Indian nursing students. *Saudi Journal of kidney diseases and transplantation*, 27(6), p.1129.
82. Darbari, A., Naithani, M., Sharma, S.K., Gupta, A., Kumar, A. and Satsangi, D.K., 2020. Current knowledge status and attitude on heart transplantation among undergraduate medical students of a tertiary care medical institute in India. *Indian Journal of Transplantation*, 14(1), p.30.
83. Darr, A. and Randhawa, G., 1999. Awareness and attitudes towards organ donation and transplantation among the Asian population. *Transplant international*, 12(5), pp.365-371.
84. Huern, S.Y., Yee, K.C., Rajah, J.S., Ponniah, M.P. and Sapini, M.I.B., 2016. Knowledge, awareness and attitudes on organ donation among undergraduate medical students in Malaysia: An analytical cross sectional study. *Br J Med Med Res*, 16(3), pp.1-14.
85. Parmar, P.B., Bharpoda, K., Bhensdadia, V., Bhokan, P., Bhut, P. and Chaudhary, B., 2016. Study of undergraduate students' perceptions towards organ donation. *Journal of Indian Academy of Forensic Medicine*, 38(4), pp.437-440.
86. Bharambe, V.K., Arole, V.U., Puranam, V., Kulkarni, P.P. and Kulkarni, P.S., 2018b. Knowledge and attitude toward organ donation among health-care professionals in a rural town in India. *Saudi Journal of Kidney Diseases and Transplantation*, 29(3), p.671.
87. Vincent BP, Kumar G, Parameswaran S, Kar SS. Barriers and suggestions towards deceased organ donation in a government tertiary care teaching hospital: Qualitative study using socio-ecological model framework. *Indian Journal of Transplantation*. 2019a Jul 1;13(3):194.
88. Verma, M., Sharma, P., Ranjan, S., Sahoo, S.S., Aggarwal, R., Mehta, K., Tariq, R., Kanwale, S., Mittal, A., Das, A. and Galhotra, A., 2020. The perspective of our future

- doctors towards organ donation: a national representative study from India. *International Journal of Adolescent Medicine and Health*.
89. Loch, A., Hilmi, I.N., Mazam, Z., Pillay, Y. and Choon, D.S.K., 2010. Differences in attitude towards cadaveric organ donation: observations in a multiracial Malaysian society. *Hong Kong Journal of Emergency Medicine*, 17(3), pp.236-243.
90. Kennedy K. Organ donation and transplantation in India: An inquiry in Kerala. *Journal of Social Distress and the Homeless*. 2002 Jan 1;11(1):41-67.
91. Amaliyar J, Patel P. Awareness about organ donation in medical and non medical students in Patan city of Gujarat, India. *Int J Community Med Public Health*. 2019 Jun;6:2435-9.
92. Jothula KY, Sreeharshika D. Study to assess knowledge, attitude and practice regarding organ donation among interns of a medical college in Telangana, India. *Int J Community Med Public Health*. 2018 Apr;5(4):1339-45.
93. Vijayalakshmi P, Nagarajaiah, Ramachandra, Math SB. Indian ICU nurses' perceptions of and attitudes towards organ donation. *British Journal of Nursing*. 2015 Jul 9;24(13):694-7.
94. Lokesh KSS, Raja D, and Sharath U. 2021. Organ Donation'-Awareness, Perspective and Practices among Adults-A Cross Sectional Study in Rural Tamil Nadu. *Journal of Pharmaceutical Research International*. 33(55B); 29-34.
95. Wong, L.P., 2010, June. Factors limiting deceased organ donation: focus groups' perspective from culturally diverse community. In *Transplantation proceedings* (Vol. 42, No. 5, pp. 1439-1444). Elsevier.
96. Vincent BP, Kumar G, Parameswaran S, Kar SS. Knowledge, attitude, and perception on organ donation among undergraduate medical and nursing students at a tertiary care

- 1
2
3 teaching hospital in the southern part of India: A cross-sectional study. *Journal of*
4 *education and health promotion.* 2019b;8.
5
6
7
8 97. Misra, P., Malhotra, S., Sharma, N., Misra, M.C., Vij, A. and Pandav, C.S., 2021. A
9 qualitative approach to understand the knowledge, beliefs, and barriers toward organ
10 donation in a rural community of Haryana-A community based cross-sectional
11 study. *Indian Journal of Transplantation*, 15(1), p.19.
12
13
14
15
16
17 98. Thyagarajan, I., Shroff, S., Vincent, B.P., Rajendran, J., Kanvinde, H., Shankar, S. and
18 Aneesh, K., 2020. Knowledge and practice of organ donation among police personnel in
19 Tamil Nadu: A cross-sectional study. *Indian Journal of Transplantation*, 14(2), p.141.
20
21
22
23
24 99. Mondal, S., Paul, A., Malick, S. and Saha, P., 2016. Perception of organ donation among
25 adults: A community based study in rural West Bengal, India. *Sch J Appl Med Sci*, 4,
26 pp.4473-8.
27
28
29
30
31 100. Sam N, Ganesh R, Indrapriyadarshini V, Jeyamarthan S, Nandhini CK. Awareness,
32 knowledge, and attitude regarding organ donation among final year students of medical,
33 Dental, Engineering, and Arts and Science Colleges in Thiruvallur and Chennai City,
34 India. *Indian Journal of Transplantation*. 2018 Jan 1;12(1):25.
35
36
37
38
39
40 101. Soni S, Samal J, Baghel SS, Vaghela S, Chundawat MS. Knowledge and attitude toward
41 organ donation among medical and nonmedical (Engineering) students in Bhopal, India.
42 *The Saudi Journal of Forensic Medicine and Sciences*. 2018 May 1;1(2):35.
43
44
45
46
47 102. Rajan, J.K., 2020. Assessment of Knowledge and Attitude of Adolescents Regarding
48 Blood and Organ Donation in Selected Rural Areas of Shimla, Himachal Pradesh,
49 India. *Medico Legal Update*, 20(1), pp.101-105.
50
51
52
53
54 103. Sachdeva S. Knowledge, Attitude, and Practices regarding organ donation among adult
55 visitors in a public hospital in Delhi, India. *Indian J Transplant*. 2017 Dec 20;11:127-32.
56
57
58
59
60

- 1
2
3 104. Flower, J.R.L. and Balamurugan, E., 2013. A study on public intention to donate organ:
4 Perceived barriers and facilitators. *British Journal of Medical Practitioners*, 6(4), pp.6-
5 10.
6
7
8
9
10 105. Mishra, P.R., Mohakud, S. and Barik, M., 2016. A Comparison Between Medical and
11 Non-Medical Students in India for Cadaveric Organ Donation (COD): A Questionnaire
12 Based Study. *Journal of Forensic Medicine and Toxicology*, 33(1), pp.12-15.
13
14
15
16
17 106. Pradeep, A., Ormandy, P., Augustine, T., Randhawa, G. and Whitling, M., 2019.
18 Attitudes and beliefs regarding organ donation among South Asian people in the
19 UK. *Journal of Kidney Care*, 4(4), pp.184-198.
20
21
22
23
24 107. Wong, L.P., 2010. Information needs, preferred educational messages and channel of
25 delivery, and opinion on strategies to promote organ donation: a multicultural
26 perspective. *Singapore medical journal*, 51(10), p.790.
27
28
29
30
31 108. Exley, C., Sim, J., Reid, N., Jackson, S. and West, N., 1996. Attitudes and beliefs within
32 the Sikh community regarding organ donation: a pilot study. *Social Science &*
33 *Medicine*, 43(1), pp.23-28.
34
35
36
37
38 109. Balwani MR, Kute VB, Patel H, Shah PR, Goswami J, Ghule P, Shah M, Gattani V,
39 Trivedi HL. Awareness and beliefs towards organ donation in chronic kidney disease
40 patients in western India. *Journal of Nephro pharmacology*. 2015b;4(2):57.
41
42
43
44
45 110. Kaistha M, Kaistha S, Mahajan A. A study of factors influencing decisions on organ
46 donation among patient attendees in a Tertiary Care Hospital in North India. *CHRISMED*
47 *Journal of Health and Research*. 2016 Apr 1;3(2):101.
48
49
50
51
52 111. Paul S, Som TK, Saha I, Ghose G, Bera A, Singh A. Knowledge, attitude, and practice
53 regarding organ donation among adult Population of an Urban field practice area of a
54 medical college in Durgapur, West Bengal, India. *Indian Journal of Transplantation*.
55 2019 Jan 1;13(1):15.
56
57
58
59
60

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
112. Hakeem, A.R., Ramesh, V., Sapkota, P., Priya, G., Rammohan, A., Narasimhan, G., Reddy, M.S. and Rela, M., 2021. Enlightening Young Minds: A Small Step in the Curriculum, a Giant Leap in Organ Donation—A Survey of 996 Respondents on Organ Donation and Transplantation. *Transplantation*, 105(3), pp.459-463.
113. Reddy, A.V.R., Guleria, S.A., Khazanchi, R.K., Bhardwaj, M., Aggarwal, S. and Mandal, S., 2003. Attitude of patients, the public, doctors, and nurses toward organ donation. In *Transplantation proceedings* (Vol. 1, No. 35, p. 18).
114. Wong, L.P., 2011. Knowledge, attitudes, practices and behaviors regarding deceased organ donation and transplantation in Malaysia's multi-ethnic society: A baseline study. *Clinical transplantation*, 25(1), pp.E22-E31.
115. Adithyan GS, Mariappan M, Nayana KB. A study on knowledge and attitude about organ donation among medical students in Kerala. *Indian Journal of Transplantation*. 2017 Jul 1;11(3):133.
116. Mani G. Perceptions and practices related to organ donation among a rural population of Kancheepuram district, Tamil Nadu, India Geetha Mani¹, Raja Danasekaran¹, Kalaivani Annadurai¹. *Journal of Comprehensive Health*. 2016 Jan;4(1):72.
117. Randhawa, G., 1998. An exploratory study examining the influence of religion on attitudes towards organ donation among the Asian population in Luton, UK. *Nephrology, dialysis, transplantation: official publication of the European Dialysis and Transplant Association-European Renal Association*, 13(8), pp.1949-1954.
118. Kaur, A., Devgun, P. and Gill, K.P., 2021. A Cross-sectional Study to Assess the Knowledge, Attitude and Practices about Organ Donation among the Medical Students of Punjab. *Annals of Community Health*, 8(4), pp.2-8.

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
119. Morgan, M., Deedat, S. and Kenten, C., 2015. 'Nudging' registration as an organ donor: Implications of changes in choice contexts for socio-cultural groups. *Current Sociology*, 63(5), pp.714-728.
 120. Meghana S, Subramanian M, Atmakuri SA, Tarun S, Bera P, Nelson J. A study on knowledge, attitude and practice regarding organ donation and transplantation among final year health science students in Bengaluru, Karnataka, India. *Int J Commun Med Pub Health*. 2018 Apr;5:1529-34.
 121. Darlington D, Anitha FS, Joseph C. Study of Knowledge, Attitude, and Practice of Organ Donation Among Medical Students in a Tertiary Care Centre in South India. *Cureus*. 2019 Jun;11(6).
 122. Bhargavi UD, Govindapillai UK. Knowledge and attitude of decond year medical, dental and nursing students in Thiruvananthapuram government medical college campus towards organ and whole body donation. *Journal of Evolution of Medical and Dental Sciences*. 2019 Apr 8;8(14):1153-6.
 123. Budiani-Saberi, D.A., Raja, K.R., Findley, K.C., Kerketta, P. and Anand, V., 2014. Human trafficking for organ removal in India: a victim-centered, evidence-based report. *Transplantation*, 97(4), pp.380-384.
 124. Syed, J. and Èzbilgin, M.F. eds., 2010. *Managing cultural diversity in Asia: A research companion*. Edward Elgar Publishing.
 125. Campbell, M., Katikireddi, S.V., Sowden, A. and Thomson, H., 2019. Lack of transparency in reporting narrative synthesis of quantitative data: a methodological assessment of systematic reviews. *Journal of clinical epidemiology*, 105, pp.1-9.

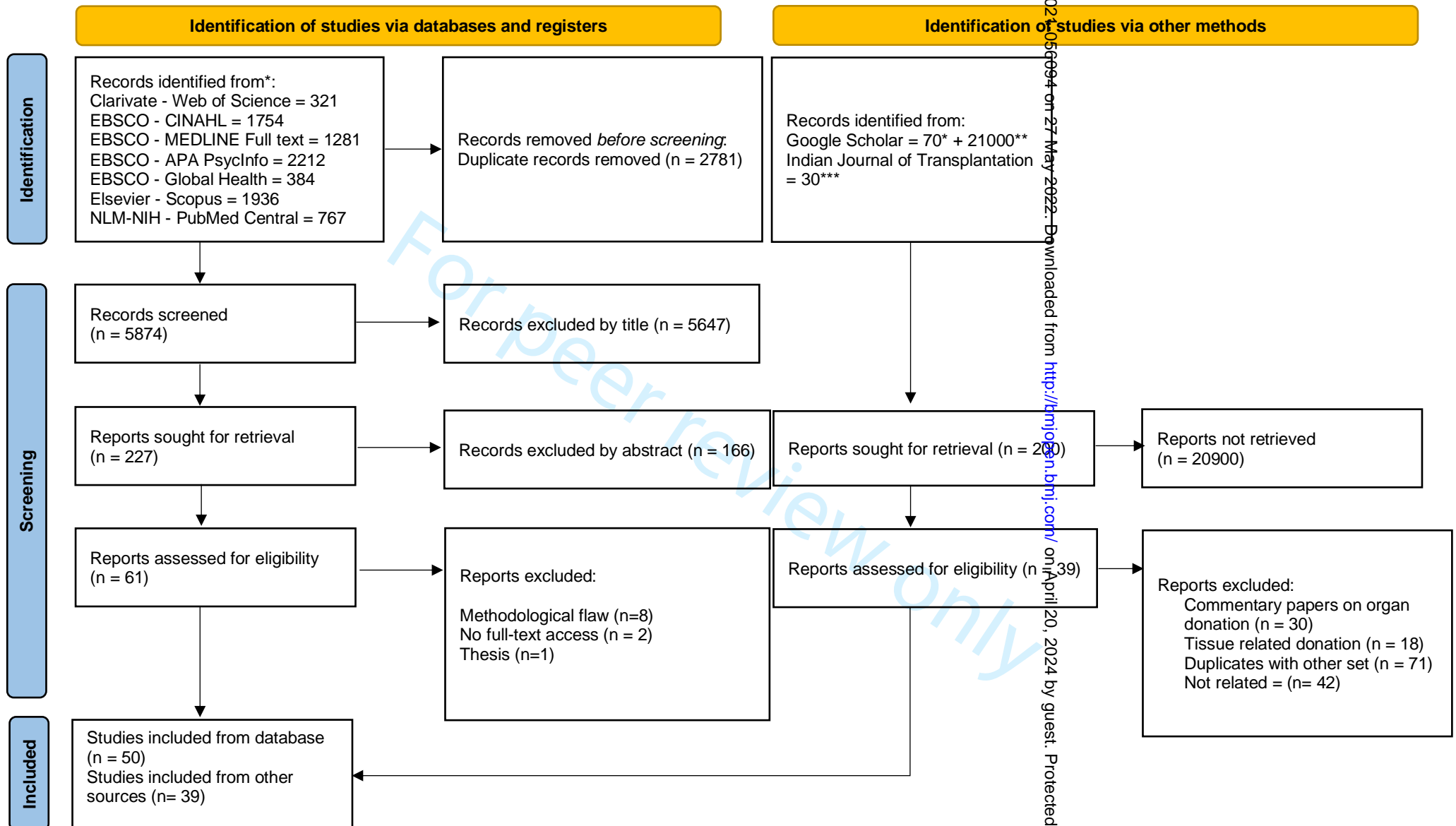
1
2
3 **Figure legends / captions:**
4

5 **Figure 1:** PRISMA flowchart
6

7 **Figure 2:** Quality appraisal checklist – Quantitative studies
8

9 **Figure 3:** Quality appraisal checklist – Qualitative studies
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only



*Google scholar method 1 explained in method section of the manuscript; **Google scholar method 2 explained in the method section of the manuscript; ***Indian journal of Transplantation – All issues were manually searched from 1994

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: <http://www.prisma-statement.org/>

6/bmjopen-2024-056994 on 27 May 2022. Downloaded from <http://bmjopen.bmj.com/> on April 20, 2024 by guest. Protected by copyright.

	1	2	3	4	5	6	7	8
Adithyan et al, 2017	✓	✓	✓	✓	✗	✓	✓	✓
Ahlawat et al, 2013	-	✓	✓	✓	✗	✗	✓	✓
Alex et al, 2017	✓	✓	✓	✓	✗	✓	✓	✓
Alex et al, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Amaliyar et al, 2019	✓	✓	✓	✓	✗	✓	✓	✓
Balajee et al, 2016	-	✓	✓	✓	✓	✗	✓	✓
Balwani et al, 2015a	-	✓	✓	✓	✗	✗	✓	✓
Balwani et al, 2015b	✓	✓	✓	✓	✗	✗	✓	✓
Bansal et al, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Bapat et al, 2010	-	✓	✓	✓	✗	✗	✓	✓
Basavarajegowda et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Bathija et al, 2017	-	✓	✓	✓	✗	✓	✓	✓
Bharambe et al, 2015	✗	✓	✓	✓	✗	✗	✓	✓
Bharambe et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Bharambe et al, 2018a	✓	✓	✓	✓	✗	✗	✓	✓
Bharambe et al, 2018b	✓	✓	✓	✓	✗	✗	✓	✓
Bhargavi et al, 2019	✓	✓	✓	✓	✗	✓	✓	✓
Chakradhar et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Da Silva et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Darbari et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Darlington et al, 2019	✓	✓	✓	✓	✓	✓	✓	✓
Dasgupta et al, 2014	✓	✓	✓	✓	✗	✗	✓	✓
Deshpande et al, 2018	-	✓	✓	✓	✗	✗	✓	✓
Flower et al, 2013	✓	✓	✓	✓	✗	✗	✓	✓
Ghose et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Gupta et al, 2018	✓	✓	✓	✓	✗	✓	✓	✓
Gupta et al, 2021	✗	-	✓	✓	✗	✗	✓	✓
Hakeem et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Huern et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Jagadeesh et al, 2018	✓	✓	✓	✓	✗	✗	✓	✓
Jayabharathi et al, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Joshi, 2011	✓	✓	✓	✓	✓	✓	✓	✓
Jothula et al, 2018	✓	✓	✓	✓	✗	✗	✓	✓
Kachappillil et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Kadam et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Kaistha et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Kamlath et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Karim et al, 2013	✓	✓	✓	✓	✗	✗	✓	✓
Kaur et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓

	1	2	3	4	5	6	7	8
Khan et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Kundu et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Li et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Loch et al, 2010	✓	✓	✓	✓	✗	✗	✓	✓
Lokesh et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Mani, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Meghana et al, 2018	✓	✓	✓	✓	✗	✓	✓	✓
Minz et al, 1998	✗	✓	-	✓	✗	✗	✓	✓
Mishra et al, 2016	✗	✓	✗	✗	✗	✗	✗	✗
Misra et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Mithra et al, 2013	✓	✓	✓	✓	✗	✗	✓	✓
Mohan et al, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Mondal et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Panwar et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Paramr et al, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Paul et al, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Poreddi et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Poreddi et al, 2017	✓	✓	✓	✓	✗	✗	✓	✓
Pradeep et al, 2019	✓	✓	✓	✓	✗	✗	✓	✓
Rajan, 2021	✓	✓	✓	✓	✗	✗	✓	✓
Rani et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Ray et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Reddy et al, 2003	✓	✓	✓	✓	✗	✗	✓	✓
Sachdeva, 2017	-	✓	✓	✓	✗	✗	✓	✓
Sam et al, 2018	✓	✓	✓	✓	✗	✗	✓	✓
Sarveswaran et al, 2018	✓	✓	✓	✓	✗	✗	✓	✓
Seetharaman et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Singh et al, 2002	✓	✓	✓	✓	✗	✗	✓	✓
Soni et al, 2018	-	✓	✓	✓	✗	✓	✓	✓
Swain et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Swamy et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Tamuli et al, 2019	✗	✓	✓	✓	✗	✗	✓	✓
Thyagarajan et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Verma et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓
Vijayalakshmi et al, 2015	✓	✓	✓	✓	✗	✗	✓	✓
Vijayalakshmi et al, 2016	✓	✓	✓	✓	✗	✗	✓	✓
Vincent et al, 2019b	✓	✓	✓	✓	✓	✓	✓	✓
Wong et al, 2011	✓	✓	✓	✓	✗	✗	✓	✓
Yadav et al, 2020	✓	✓	✓	✓	✗	✗	✓	✓

1. Were the criteria for inclusion in the sample clearly defined?
2. Were the study subjects and the setting described in detail?
3. Was the exposure measured in a valid and realistic way?
4. Were the objectives, standard criteria used for measurement of the conditions?
5. Were the confounding factors identified?
6. Were strategies to deal with confounding factors stated?
7. Were the outcomes measured in a valid and reliable way?
8. Was appropriate statistical analysis used?

✓	Mentioned
✗	Not mentioned
-	Unclear

Ref	1	2	3	4	5	6	7	8	9	10
Vincent et al, 2019	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓
Kennedy, 2002	✓	✓	✓	✓	✓	✗	✗	✗	✗	✓
Gauher et al, 2013	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓
Misra et al, 2021	✓	✓	✓	✓	✓	✗	✗	✗	✓	✓
Darr et al, 1999	✓	✓	✓	✓	✓	✗	✗	✗	✓	✓
Exley et al, 1996	✓	✓	✓	✓	✓	✗	✗	✗	✓	✓
Morgan et al, 2015	✓	✓	✓	✓	✓	✓	✓	✗	✓	✓
Wong et al, 2010a	✓	✓	✓	✓	✓	✓	✗	✗	✓	✓
Wong et al, 2010b	✓	✓	✓	✓	✓	✓	✗	✗	✓	✓
Randhawa et al, 1998	✓	✓	✓	✓	✓	✓	✗	✗	✓	✓

- 1 Is there congruity between the stated philosophical perspective and the research methodology?
- 2 Is there congruity between the research methodology and the research question or objective?
- 3 Is there congruity between the research methodology and the methods used to collect data?
- 4 Is there congruity between the research methodology and the representation and analysis of data?
- 5 Is there congruity between the research methodology and the interpretation of results?
- 6 Is there a statement locating the researcher culturally or theoretically?
- 7 Is the influence of the researcher on the research, and vice-versa, addressed?
- 8 Are participants, and their voices, adequately represented?
- 9 Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
- 10 Do the conclusion drawn in the research report flow from the analysis, or interpretation, of the data?

Mentioned ✓ Not mentioned ✗

Supplementary I: Search strategy

Database: Clarivate for Web of Science <1 January 1994 to 31 December 2021>

Search strategy

1. (ALL) Organ* (4464520)
2. (ALL) Tissue* (2072420)
3. 1 OR 2
4. (ALL) Donation* (92568)
5. (ALL) Procurement* (36067)
6. (ALL) Donor* (471190)
7. (ALL) Regist* (607949)
8. (ALL) Pledge* (5168)
9. 4 OR 5 OR 6 OR 7 OR 8
10. (ALL) "Brain death" (6,922)
11. (ALL) Posthumous* (3317)
12. (ALL) Deceased* (28469)
13. 10 OR 11 OR 12 (122185)
14. (ALL) India* (2374803)
15. (ALL) Asia* (869365)
16. (ALL) "South Asia*" (34481)
17. 14 OR 15 OR 16
18. (ALL) Knowledge (1860768)
19. (ALL) Attitude* (423103)
20. (ALL) Practice* (2018451)
21. (ALL) Aware* (484659)
22. (ALL) Perception* (725428)
23. (ALL) Barrier* (711626)
24. (ALL) Challenge* (1684045)
25. (ALL) Religi* (258116)
26. (ALL) Famil* (2081795)
27. (ALL) Discuss* (4419231)
28. (ALL) Sign* (11546529)
29. 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28
30. 3 AND 9 AND 13 AND 17 AND 29 (321)

(((((ALL=(Organ* OR Tissue*)) AND ALL=(Donation* OR Procurement* OR Donor* OR Regist* OR Pledge*)) AND ALL=("Brain Death" OR Posthumous* OR Deceased*)) AND ALL=(India* OR Asia* OR "South Asia*")) AND ALL=(Knowledge* OR Attitude* OR Practice* OR Aware* OR Perception* OR Barrier* OR Challenge* OR Religi* OR Famil* OR Discuss* OR Sign*))

Database: EBSCO for CINAHL Complete < 1994 January to December 2021>

Search strategy

No.	Terms	Title	Abstract
1	Organ*	45587	254692
2	Tissue*	35642	171599
3	1 OR 2	47408	214967
4	Donation*	5126	7255
5	Procurement	733	2440
6	Donor	10046	24599
7	Regist*	28751	171623
8	Pledge	906	909
9	4 OR 5 OR 6 OR 7 OR 8	44740	200368
10	India*	29146	35077
11	Asia*	13516	35961
12	“South Asia*”	1896	3440
13	10 OR 11 OR 12	42022	67778
14	Knowledge	40561	228058
15	Attitude*	30320	76214
16	Practice*	171844	417435
17	Aware*	16453	106579
18	Perception	47156	116209
19	Barrier*	23209	93116
20	Challenge*	52643	179284
21	Religi*	7106	20082
22	Famil*	28758	120172
23	Discuss*	12336	525753
24	Sign	60885	1299673
25	“Brain Death”	811	1176
26	Posthumous	101	157
27	Deceased	725	5381
28	SU Organ Donation		191
29	SU Tissue and Organ Procurement		437
30	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29	460837	2330155
31	3 AND 9 AND 13 AND 28	697	1057

Database: EBSCO for MEDLINE With full text Complete < 1994 January to December 2021>

Search strategy

No.	Terms	Title	Abstract
1	Organ*	245699	1493730
2	Tissue*	223470	1550014
3	1 OR 2	465190	2862275
4	Donation*	11156	25326
5	Procurement	1825	8302
6	Donor*	58569	260805
7	Regist*	52468	371535
8	Pledge	591	1401
9	4 OR 5 OR 6 OR 7 OR 8	122076	641620
10	India*	79797	128377
11	Asia*	37333	145090
12	“South Asia*”	3406	9277
13	10 OR 11 OR 12	115447	260763
14	Knowledge	62353	725944
15	Attitude*	44690	132711
16	Practice*	192866	758688
17	Aware*	23266	233256
18	Perception*	73637	238754
19	Barrier*	56399	301446
20	Challenge*	107816	654171
21	Religi*	8586	32213
22	Famil*	62713	341944
23	Discuss*	19872	1196575
24	Sign*	402535	6834667
25	“Brain Death”	2322	4478
26	Posthumous	201	475
27	Deceased	2643	20262
28	MH Organ Donation	13951	
29	MH Tissue and Organ Procurement	19560	
30	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29	1012657	9432506
31	3 AND 9 AND 13 AND 28	61	1220

Database: EBSCO for APA PsycInfo < 1994 January to December 2021>

Search strategy

No.	Terms	Title	Abstract
1	Organ*	52775	314055
2	Tissue*	2650	33891
3	1 OR 2	55359	344532
4	Donation*	1328	3862
5	Procurement	260	1126
6	Donor*	1103	6196
7	Regist*	4746	41654
8	Pledge	65	479
9	4 OR 5 OR 6 OR 7 OR 8	7304	51337
10	India*	12921	26606
11	Asia*	9722	31810
12	“South Asia*”	1130	2606
13	10 OR 11 OR 12	22183	55698
14	Knowledge	37077	273907
15	Attitude*	40138	146530
16	Practice*	77921	427695
17	Aware*	12620	117029
18	Perception*	74077	238811
19	Barrier*	12054	74349
20	Challenge*	24193	208260
21	Religi*	18072	57819
22	Famil*	31536	174669
23	Discuss*	7449	675256
24	Sign*	32524	1050671
25	“Brain Death”	192	383
26	Posthumous	55	451
27	Deceased	211	3514
28	SU Organ Donation		729
29	SU Tissue and Organ Procurement		619
30	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29	345985	2324405
31	3 AND 9 AND 13 AND 28	1049	1163

Database: EBSCO for Global Health < January 1994 to December 2021 >

Search strategy

No.	Terms	Title	Abstract
1	Organ*	34990	281202
2	Tissue*	24264	166199
3	1 OR 2	58782	426568
4	Donation*	851	4044
5	Procurement	276	2063
6	Donor*	5877	26460
7	Regist*	6306	654425
8	Pledge	39	298
9	4 OR 5 OR 6 OR 7 OR 8	13197	94877
10	India*	42961	84021
11	Asia*	11593	56374
12	“South Asia*”	1307	4386
13	10 OR 11 OR 12	53980	134135
14	Knowledge	21618	146105
15	Attitude*	14175	40544
16	Practice*	32467	149036
17	Aware*	6261	61511
18	Perception*	15315	46000
19	Barrier*	10039	55500
20	Challenge*	18770	113171
21	Religi*	1303	9881
22	Famil*	6241	56096
23	Discuss*	2171	225453
24	Sign*	34744	179950
25	“Brain Death”	41	179
26	Posthumous	4	29
27	Deceased	238	2971
28	SU Organ Donation		475
29	SU Tissue and Organ Procurement		313
30	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29	144587	1664816
31	3 AND 9 AND 13 AND 28	5	379

Database: Elsevier for Scopus PUBYEAR > 1993 AND PUBYEAR <2022

Search strategy

No.	Terms	Title-Abstract-Keywords
1	Organ*	757636
2	Tissue*	3956065
3	1 OR 2	8523116
4	Donation*	49781
5	Procurement	57632
6	Donor*	465751
7	Regist*	690378
8	Pledge	6915
9	4 OR 5 OR 6 OR 7 OR 8	1214290
10	India*	630668
11	Asia*	614524
12	“South Asia*”	47204
13	10 OR 11 OR 12	1178235
14	Knowledge	2199485
15	Attitude*	834803
16	Practice*	2961509
17	Aware*	663440
18	Perception*	885170
19	Barrier*	765952
20	Challenge*	2076205
21	Religi*	274948
22	Famil*	776708
23	Discuss*	5121400
24	Sign*	14005232
25	“Brain Death”	11526
26	Posthumous	7120
27	Deceased	30117
28	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27	24234423
29	3 AND 9 AND 13 AND 28	1936

1
2
3 **Database:** US National Library of Medicine National Institute of Health for PubMed Central
4 < 1994 January to December 2021>
5

6
7 Search strategy
8

9 **Search:** (((((Organ[Title/Abstract] OR Tissue[Title/Abstract]) AND (Donation[Title/Abstract]
10 OR Donor[Title/Abstract])) AND (Knowledge[Title/Abstract] OR Awareness[Title/Abstract]
11 OR Attitude[Title/Abstract] OR Perception[Title/Abstract] OR Practice[Title/Abstract] OR
12 Registration[Title/Abstract] OR Consent[Title/Abstract] OR Barrier[Title/Abstract] OR
13 Challenges[Title/Abstract] OR Religion[Title/Abstract] OR Culture[Title/Abstract]))) AND
14 ((India OR South Asia OR Southeast Asia OR Asia[MeSH Terms])
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60



PRISMA 2020 checklist

1136/bmjopen-2021-056094 on 27 May 2022. Downloaded from <http://bmjopen.bmj.com/> on April 20, 2024 by guest. Protected by copyright.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Pg. 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Pg. 1-2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Pg. 3-4
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Pg. 3-4
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Pg. 4-6
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Pg. 4 -5
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Supplementary file & PRISMA 2020
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Pg. 5-6
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Pg. 5-7
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	NA
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	NA
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Pg. 6
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	NA
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	NA
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	NA
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Table 1
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Pg. 6-7
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	NA
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	NA
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	NA



PRISMA 2020 checklist

1136/bmjopen-2021-056094 on 27 May 2022. Downloaded from <http://bmjopen.bmj.com/> on April 20, 2024 by guest. Protected by copyright.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

Section and Topic	Item #	Checklist item	Location where item is reported
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	NA
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Figure 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Figure 1, Pg. 5-6
Study characteristics	17	Cite each included study and present its characteristics.	Table 1
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Quality appraisal: Figure 2 & 3
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	NA
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	NA
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	NA
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	NA
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	NA
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	NA
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	NA
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	24-27
	23b	Discuss any limitations of the evidence included in the review.	26-27
	23c	Discuss any limitations of the review processes used.	26-27
	23d	Discuss implications of the results for practice, policy, and future research.	24-27
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Pg. 2
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Pg. 2
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Pg. 4
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Pg. 25
Competing interests	26	Declare any competing interests of review authors.	Pg. 25
Availability of data, code and	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review	Supplementary file 1.



PRISMA 2020 checklist

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

Section and Topic	Item #	Checklist item	Location where item is reported
other materials			

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: <http://www.prisma-statement.org/>

For peer review only

1136/bmjopen-2021-056094 on 29 May 2022. Downloaded from <http://bmjopen.bmj.com/> on April 20, 2024 by guest. Protected by copyright.