DOI: 10.15825/1995-1191-2022-1-117-125

Q-METHODOLOGY TO IDENTIFY PERCEPTIONS OF DECEASED ORGAN DONATION IN THE UK

R.M. Muaid, T. Chesney
University of Nottingham, Nottingham, Great Britain

Background. Attitude towards organ donation is predominantly positive in the UK, however, donation rate remains low. To develop more effective interventions, this research aims to examine the behavioural barriers in organ donations using Q methodology to elicit patterns of overlap among different barriers and motivators. **Method.** A Q methodology study was conducted with 40 participants aged 19–64 were asked to rank 47 statements on issues that are associated with organ donation. By-person factor analysis using Centroid method and Varimax rotation was conducted to bring out patterns in the way statements were ranked to obtain groupings of participants who had arranged the statements in similar fashion. **Results.** Four viewpoints were extracted: The Realist, the Optimist Hesitant, the Pessimist Determinant and the Empathetic. Salient barriers to organ donation presented in each viewpoint suggest that perceived lack of knowledge, anxiety, mistrust in the healthcare system and lack of cue to action are the main barriers to organ donation. Consensus statements suggest that religion and family agreement are inconsequential if attitude to organ donation is well formed. **Conclusion.** There are different attitudes around deceased organ donation that were uncovered using Q methodology. These results suggest that people respond to behavioural change campaigns differently depending in their own perceptions on organ donation. We argue that a paradigm shift in behavioural interventions is underpinned by understanding the overlapping yet distinctive nature perceived perspectives.

Keywords: Organ donation, Q methodology, behavioural interventions.

INTRODUCTION

Despite the joined effort of hundreds of researchers to improve the rate of organ donation, there has only been a slight increase in donation rates in the UK averaging at 2% growth rate annually (NHS, 2019b) [1].

Organ donation decision is extremely complex. It invokes countless beliefs, symbols, sentiments, and emotions as well as numerous rituals and social practices. A meta-analysis Feeley and Moon (2009) [2] and Li et al. in (2015) [3] showed weak performance and low effect size for those interventions, likely caused by the extensive emotional reactions organ donation triggers (Miller, Currie, & O'carroll, 2018) [4] that can influence information processing (Handley & Lassiter, 2002) [5] and communication (Stefanelli & Seidl, 2017) [6]. When asked about barrier to organ donation, participants usually respond with familiar notions triggered intuitively (Greene & Haidt, 2002) [7]. Religion, fear of death and «I don't know much about it» are, unsurprisingly, the most common barriers reported in qualitative studies. Most interventions to increase donation rate are based on the main modifiable barrier reported in literature, which is knowledge and information. We propose, however, that people have heterogenous views about organ donation, an amalgam of different components jumbled together to shape the attitude.

Subjective perception to barriers to donation have not been fully explored in organ donation. Literature suggests that what is considered as a barrier might act as a motivator depending on individual subjective perception. This study uses Q methodology to identify how people in UK perceive barrier to organ donation and how such perception creates distinctive views. Views on organ donation further our understanding of barriers against organ donation and inform behavioural interventions to produce more targeted and effective approaches.

MATERIALS AND METHODS

To investigate attitudes towards deceased organ donation in people residing temporarily or permanently in UK for six months or longer, we conducted a Q methodology study. Q methodology combines the strengths of both qualitative and quantitative research practises and allows for a systematic investigation of human subjectivity (McKeown & Thomas, 2013) [8]. It is neither a survey nor an interview. The sample size for Q methodology studies is small and «does not need large numbers of subjects as does survey analysis» (Smith, 2001) [9]. It is especially suitable for research with «many, potentially complex and contested answers» (Watts & Stenner, 2005) [10]. In Q methodology research, attitudes represent «prototypical exemplars» (Valenta & Wigger,

Corresponding author: Reem M Muaid. Address: Nottingham NG7 2RD, Great Britain.
Phone: +44 115 951 5151. E-mail: Reem.Muaid@nottingham.ac.uk

1997) [11] rather than disconnected, non-overlapping ideas with cut-off points such opposite to the attitudes presented in the current literature.

In a Q study, participants are presented with a set of statements around the area of study. Participants are then asked to rank those statements according to their agreement with each statement on a quasi-normal grid. Q methodology is completed through several stages (Fig. 1). The first step is to create a concourse. A concourse refers to the collection of all discussions around the topic (Stephenson, 1980) [12]. This includes statements made around the topic of organ donation collected from existing literature (interviews and surveys), social media contents, essays, publications, and any other source related to the issue.

Initially, 224 statements were collected to account for all possible views, statements and opinions around the topic (Stephenson, 1980) [12]. A comprehensive literature review using several databases was the major source of these statements, complemented by Google searches and informal conversations to enrich the collection of concourses beyond the published. Statements from social media, like Facebook comments, YouTube videos, blogs, and NHS (National Health Services in the UK) websites were collected. Concourse statements were structured into 8 themes: religion, body, death, healthcare, knowledge, awareness, recipient, and others.

The statements were then reduced to a manageable-sized list to form the Q set, 47 statements representing barriers and motivators falling under all themes. The participants sample in Q methodology, the P set; was strategically selected (Brown, 1980) [13]. P set does not represent the population, it represents the variety of views in a population, thus the sample size in Q methodology is smaller than that of a survey, and it is generalisable in representing the variety in population. Data collected from 40 participants recruited through snowball sampling strategy, aged between 19–64 years' old (45% female and 55% male). A conscious effort was put to ensure that participants hold different religions and cultural origins. Data were collected online on qmethodsoftware.com.

Participants were provided with instructions to arrange the statements from +5 (similar to what I think) to –5 (opposite to what I think) with the zero column representing statements that (do not concern me) (Brown, 1980) [13]. The grid distributions forces participants to rank statements from 2 statements per column on ends to 7 statements at the middle. The resulting outcome is the Q sort, a genuine 'operationalised' representations of personal point of views (McKeown & Thomas, 2013) [8].

RESULTS

Q sorts resulted in 7 factors initially. We used Pearson correlation for this study and opted for Varimax rotation and centroid method for analysis. This is followed by creating factors arrays, which represent a hypothetical Q sort that loads perfectly onto a factor. Kaiser-Guttman criteria, Humphrey's Rule and Scree Test were used to reduce the number of factors into distinguishable attitudes to facilitate interpretations. We found three factors that satisfy all three criteria used for factor extraction, those three factors account for 31 participants and explain 39% of total variance (Table 1).

Factors' Interpretation. Factor interpretation was carried out using the «*crib sheet*» method (Watts & Stenner, 2012) [14] to ensure systematic and holistic approach in the interpretation process. The crib sheet lists the two statements at each end (on location +5 and –5) then lists the statements ranked the lowest and the highest by that factor. The support factor interpretation and comparison between factors.

Factor Interpretation

The interpretation is conducted by applying abductive strategy in interpretation. By the end of interpretation, we created a qualitative account each viewpoint, a story to describe each viewpoint comprehensively.

Factor 1 – I want to know more; Factor 1 explains 11% of variance in the study. Eight people loaded significantly on this factor (Table 2). Only participant is registered as an organ donor (Fig. 2).

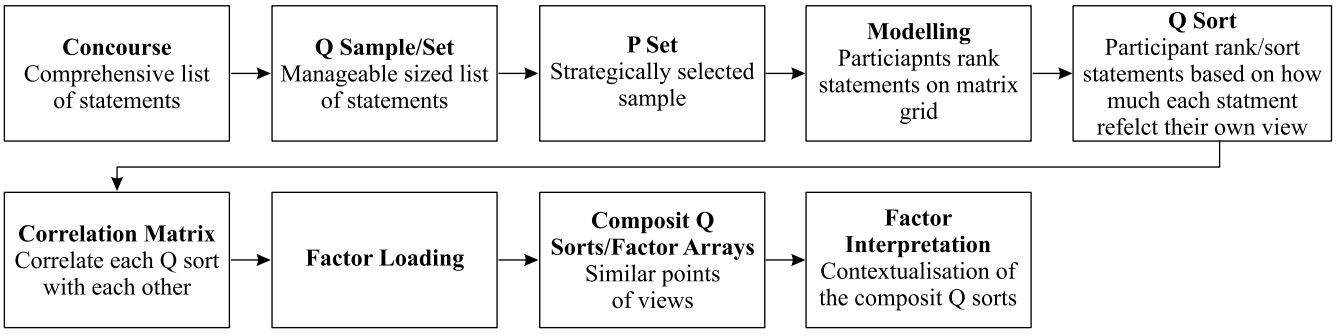

Fig. 1. Q Methodology Stages

Table 1

Statements and Factor Arrays

Statement	Factor 1	Factor 2	Factor 3
1 – I believe my religion does not allow it	–2	–1	0
2 – I think rich or famous people can receive organs before the people with the most need	–1	–2	2
3 – I do not think I have ever thought about it	–2	1	1
4 – I think the process of registration is complicated	0	–2	–1
5 – I think anyone can register and be a donor even if old or have a disease	0	1	2
6 – I think there is no special need for organs for Asian, African, and Middle Eastern groups	–3	–3	–2
7 – I think giving out organs to save someone's life is a noble act	4	4	5
8 – I think doctors might not do their best to save someone's life if they know they are on the Organ Donor Register	1	–3	–4
9 – I think I am too old to donate	–4	–2	–3
10 – I believe I will be haunted if I donate	–4	0	–2
11 – I think it is non-religious to take organs	–5	–1	0
12 – I do not know anyone who donated an organ	5	–2	4
13 – I believe there is a great need for organs especially in minority groups	2	1	3
14 – Brain death is confusing to me, but I think experts know better	1	2	2
15 – I feel I cannot decide to donate because I do not know all the facts	5	3	–1
16 – I believe transplantation results are successful and they are improving people's health	3	5	5
17 – If someone religious says it is not allowed, then I will not do it	–3	1	–5
18 – I feel talking about death and after life is important to appreciate our lives	0	3	3
19 – I think doctors will prematurely declare my death If I am a donor just so they can harvest my organs	0	–4	–2
20 – It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself	1	3	2
21 – I believe the human body is not a machine	–1	–1	0
22 – I think brain dead people can regain consciousness	1	0	1
23 – I thought about registering as a donor but I never did	2	5	1
24 – I do not want doctors or the healthcare system to be in control of my organs	3	–5	0
25 – When someone asks me to register to donate, it feels like he is waiting for my death to get my organs	–2	–5	–1
26 – I trust the donation system to be fair	–1	4	3
27 – I do not mind organ donation but my family disagree	0	0	0
28 – I trust doctors and nurses to always provide the best care they can	2	4	4
29 – I think people exaggerate on the importance of the whole organ donation subject	0	–3	–1
30 – I think people who have medical conditions cannot donate	4	–1	1
31 – I feel I have no responsibility towards anyone else	–1	–4	–3
32 – I think transplant recipients do not live more than 10 years after a transplant operation	2	–1	0
33 – People on the waiting lists are ill and I believe they need my help	1	2	4
34 – I believe donated organs can be bought and sold	–1	–3	1
35 – I might feel easy to donate because my family encourages me to donate	–2	1	2
36 – I believe the present need for transplant organs is fully covered	–3	–2	–3
37 – I believe people would not need transplants if they took better care of their health	4	–4	–4
38 – I do not mind donating some organs, but not my heart or eye	–1	2	0
39 – I believe organs are a gift from god, we are not allowed to give them away	–5	0	–5
40 – No matter how hard it is to think about organ donations, it makes me feel good about myself	2	2	3
41 – I do not think I have the courage to donate	0	3	–2
42 – I think it is just easier to say no than to think about it	3	1	–4
43 – I think my religion encourages organ donation in order save other people's lives	–3	2	–1
44 – I do not mind donating when I am alive, not when I am dead	–2	0	–3
45 – I want to be cremated and if I donated organs, I cannot do that	–4	–1	–1
46 – Talking about death is creepy	1	0	–2
47 – I think I am not dead if my heart is still beating	3	0	1

–5	–4	–3	–2	–1	0	1	2	3	4	5
39	9	17	44	31	19	8	32	42	37	15
11	10	36	25	38	41	46	23	24	30	12
	45	6	1	21	29	22	13	47	7	
		43	3	34	4	20	40	16		
			35	2	27	14	28			
				26	5	33				
					18					

Fig. 2. Factor 1 Array

People on this factor value information and hold themselves responsible for seeking information to make better decisions for themselves. They show a positive view on the success of transplantation procedures. They also have good information on the registration process, but they show a misunderstanding on the donation criteria. They tend to stay rational and in control of their emotional attachments with their bodies keep the religion influence on their decisions to minimum, their religion is personal reflects a positive relationship with their religions, however, they do not tend to follow religious leaders.

The pattern of barriers in this factor shows that both religious and non-religious individual may share similar views. It also shows that the mechanic view of the body may not be related to non-religious views. Our analysis shows that knowledge is not an abstract term, and educational campaigns targeting this view may prioritise targeting certain themes (such as eligibility criteria and the reasons for organ failures) over other aspect.

Factor 2: I need inspiration & I will never do it; Factor 2 explains 12% of variance in the study. Eight people loaded significantly on this factor (Table 3). None of them is registered as an organ donor. Three out of eight are loaded negatively on this factor, thus; interpretation will be divided into two halves, one for the positively loaded participants and then for the negatively loaded ones.

Factor 2-A: I need inspiration, People on this factor show a high level of trust in healthcare professionals and they extend this trust to the harvesting and allocation systems as well (Fig. 3).

People who loaded positively on this factor show a high level of trust[1]. They trust the healthcare professionals[2] and extend this trust to the harvesting and allocation system as well[3]. This trust acts as the main motivator for people loading positively on this factor. People loading on this factor show spiritual connections with religion[4] and with their body[5].however, they do not perceive religion as a barrier to donation[6].

Table 2

Sorts Weights on F1

Q Sort	Weight	Gender	Age	Education	Socio-Economic Class	Ethnicity	Religion	Years in UK	Donor
I6205	10	M	27	Mid	Mid	Asian (Nepalese)	N/A	2	No
I4585	5.49	M	33	Mid	Mid	Middle East British	Atheist	3	No
I4584	5.30	F	26	Mid	Mid	Netherlands	Atheist	4	No
I5931	4.10	F	19	Low	Mid	White American	Christian	2	No
I4609	4	M	25	Mid	Mid	White Ukrainian	Atheist	16	Yes
I4652	4	F	36	Mid	Mid	Middle East	Muslim	2	No
I6018	3.89	M	34	Mid	Mid	African	Christian	3	No
I4572	–6.89	M	22	Mid	Mid	Indian	Sikh	2	No

[1] Statement 16 – I believe transplantation results are successful and they are improving people's health is on +5 rank, 26 – I trust the donation system to be fair and 28 – I trust doctors and nurses to always provide the best care they can on +4 highest among factors.

[2] Statements 24 – I don't want doctors or the healthcare system to be in control of my organs and 25 – When someone asks me to register to donate, it feels like he is waiting for my death to get my organs both on –5 and distinguishing statements for this factor, 19 – I think doctors will prematurely declare my death If I am a donor just so they can harvest my organs on –4 and distinguishing factor as well and 8 – I think doctors might not do their best to save someone's life if they know they are on the Organ Donor Register on –3 both are lowest among factors.

[3] Statement 34 – I believe donated organs can be bought and sold on –3 a distinguishing statement and 2 – I think rich or famous people can receive organs before the people with the most need on –2 rank and lowest among factors.

[4] Statement 43 – I think my religion encourages organ donation in order save other people's lives on +2 and 17 – If someone religious says it is not allowed, then I will not do it on +1, both are distinguishing statements.

[5] Statement 38 – I do not mind donating some organs, but not my heart or eye on +2 and distinguishing statement and 21 – I believe the human body is not a machine on –2 and the highest among factors.

[6] Statement 17 – If someone religious says it is not allowed, then I will not do it is on +1 and a distinguishing statement, statement 11 – I think it is non-religious to take organs and 1 – I believe my religion does not allow it on –1, and 39 – I believe organs are a gift from God, we are not allowed to give them away a distinguishing statement on 0.

–5	–4	–3	–2	–1	0	1	2	3	4	5
25	31	6	9	11	39	17	43	41	26	23
24	19	34	36	45	10	3	38	18	28	16
	37	29	2	1	44	35	14	20	7	
		8	4	21	27	5	33	15		
			12	32	46	13	40			
				30	22	42				
					47					

Fig. 3. Factor 2 Array

They exhibit a significant fear from the process of organ donation[7]. Several statements show how consistent this group of people in expressing their fear from donating organs and their hesitancy to register. That fear seems to be crippling, and it might be the main barrier against donation[8]. However, positive views from their family and friends may help alleviate such fear[9].

Knowledge on brain death is not the main drive for the attitude, for people loading on this factor (both positively and negatively), related statements lie in the middle region of the grid, indicating these statements are irrelevant to the decision to donate[10]. Most knowledge related statements were ranked in the middle area of the grid (–2 to +2) indicating that these statements are not extremely relevant to their views on organ donation[11].

People loaded positively on this factor demonstrate a trustworthy view of the healthcare system and healthcare providers. They show a spiritual view of the body despite a generally positive view on organ donation. They also show brain death knowledge is not relevant to them and religion may or may not hold negative to organ donation but that does not seem to be the main drive for their attitude. Fear and emotional distress play a major role for people loaded positively on this factor. Despite a great trust in the healthcare system, they appear to be hesitant to take a positive step towards organ donation.

This pattern of barriers shows that messages on religious view on organ donation or myth busting campaigns on brain death may not be relevant. It is the irrational fear that plays the major role regardless of any information they may hold on organ donation.

Factor 2-B: I will never do it**,** this group represents the people who loaded negatively in Factor 2 (Table 3). People in this group, contrary to the group loaded positively on this factor; show a great mistrust in the healthcare system represented by healthcare providers and allocation system. They largely show an extreme negative view

Table 3

Sorts Weights on F2

Q Sort	Weight	Gender	Age	Education	Socio-Economic Class	Ethnicity	Religion	Years in UK	Donor
4567	5.18	F	46	Low	Low	White American	Christian	12	No
4616	3.98	M	29	Mid	Mid	White European	Atheist	2	No
5897	5.97	F	22	Low	Low	White European	N/A	5	No
6263	5.73	F	52	Low	Mid	White Australian	Christian	25	No
6291	7.9	F	56	Mid	Mid	Chinese	Taoism	7	No
4586	–8.66	F	26	Mid	Mid	Chinese Malaysian	Christian	7	No
6216	–10.3	M	40	Mid	Mid	Latino	Christian	3	No
4648	–13.74	M	25	Mid	Mid	White European	Christian	10	No

[7] Statement 23 – I thought about registering as a donor but I never did is on +5 and a distinguishing statement for this factor, 41 – I don't think I have the courage to donate and 20 – It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself, and 15 – I feel I cannot decide to donate because I don't know all the facts, all on +3 and are distinguishing statements as well, and 40 – No matter how hard it is to think about organ donations, it makes me feel good about myself on +2 as well as 42 – I think it is just easier to say no than to think about it on +1 and a distinguishing statement.

[8] Statement 20 – It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself a distinguishing statement and scored the highest among factors and Statement 41 – I do not think I have the courage to donate scored the highest among factors and both statements are on +3.

[9] Statement 35 – I might feel easy to donate because my family encourages me to donate on +1.

[10] Statement 44 – I do not mind donating when I am alive, not when I am dead a distinguishing statement, 47 – I think I am not dead if my heart is still beating, the lowest among factors and 22 – I think brain dead people can regain consciousness, the lowest among factors, all on 0.

[11] They ranked 13 – I believe there is a great need for organs especially in minority groups on +1, 36 – I believe the present need for transplant organs is fully covered on –2 and 6 – I think there is no special need for organs for Asian, African, and Middle Eastern groups on –3. Regarding the registration process, transplantation results and eligibility criteria, they ranked statement 4 – I think the process of registration is complicated on –2, statement 32 – I think transplant recipients do not live more than 10 years after a transplant operation on –1 and statement 30 – I think people who have medical conditions cannot donate on –1 as a distinguishing statement and 9 – I think I am too old to donate on –2.

on organ donation. They may or may not have enough knowledge about registration process, brain death or allocation system, but they certainly have strong negative attitude towards it.

This group of people seems to be determined in their decision regarding organ donation. Their mind is set potentially from death anxiety, poor knowledge or by organ donation scandals in different countries. Behavioural interventions on this group of people seems futile. Further examinations of their views might uncover individual reasons for those views. Either way, behavioural changes on this group require individualised and long-term campaigns to alter the negative views which might exhaust the limited resources for such interventions.

–5	–4	–3	–2	–1	0	1	2	3	4	5
25	31	6	9	11	39	17	43	41	26	23
24	19	34	36	45	10	3	38	18	28	16
	37	29	2	1	44	35	14	20	7	
		8	4	21	27	5	33	15		
			12	32	46	13	40			
				30	22	42				
					47					

Fig. 4. Factor 3 Array

As a group, they correlate reasonably high with each other. Moreover, Factor 2 is closer to Factor 3 than to Factor 1.

Factor 3: It is a good deed, Factor 3 explains 16% of variance in the study. Fifteen people loaded significantly on this factor (Table 4). Four of them are registered as organ donors (Fig. 4).

People on this factor view organ donation as a noble act[12] and they are willing to fight their own fear to help those who are ill and in need of those organs[13]. Their fear does not stem from death anxiety or mistrust in the healthcare system. They show trust in healthcare providers[14], while recognising possible corruption in the allocation system[15]. They are motivated by their responsibility towards others without assigning any blame towards those who fall ill[16]. Popole loaded on this factor

Table 4

Sorts Weights on F3

Q Sort	Weight	Gender	Age	Education	Socio-Economic Class	Ethnicity	Religion	Years in UK	Donor
4526	6.22	F	27	Mid	Mid	Middle East	Muslim	3	No
4527	4.40	F	26	Mid	Mid	Middle East	Christian	1	No
4565	5.42	F	34	Low	Low	African	Atheist	4	No
4583	5.15	M	38	Mid	Mid	Indian	Hindu	13	No
4606	3.611	M	46	low	High	Indian British	Sikh	46	No
4607	3.76	F	56	Mid	Mid	White British	COE	56	No
4633	4.45	M	30	Mid	Low	Indian	Hindu	2	No
4658	5.43	F	37	Mid	Mid	White British	Christian	37	Yes
4725	6.144	M	35	Mid	Mid	White European	Agnostic	11	Yes
4726	6.56	M	25	Mid	Mid	White European	Atheist	7	No
5839	4.26	M	27	Mid	High	Middle East British	Muslim	12	No
5850	3.91	F	53	Low	Mid	White British	COE	53	Yes
6271	44.25	F	24	Mid	Low	White European	Atheist	5	No
6277	5.04	M	47	Mid	Mid	Indian British	Buddhist	47	Yes
4570	–4.14	M	47	Low	Mid	Middle East British	Atheist	20	No

[12] Statement 7 – I think giving out organs to save someone's life is a noble act on +5.

[13] Statement 33 – People on the waiting lists are ill and I believe they need my help on +4 and a distinguishing statement for this factor, 40 – No matter how hard it is to think about organ donations, it makes me feel good about myself on +3 and the highest among all factors, and 20 – It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself on +2. Statement 46 – Talking about death is creepy on –2 a distinguishing statement and lowest among all factors and 42 – I think it is just easier to say no than to think about it on –4 as a distinguishing statement and the lowest among all factors as well.

[14] Statement 28 – I trust doctors and nurses to always provide the best care they can on +4, 8 – I think doctors might not do their best to save someone's life if they know they are on the Organ Donor Register on –4 and higher among all factors, 14 – Brain death is confusing to me, but I think experts know better on +2 and highest among all factors.

[15] Statement 2 – I think rich or famous people can receive organs before the people with the most need on +2, 34 – I believe donated organs can be bought and sold on +1 and 19 – I think doctors will prematurely declare my death If I am a donor just so they can harvest my organs on –2 all are distinguishing statements for this factor.

[16] Statement 31 – I feel I have no responsibility towards anyone else on –3 and the lowest among all factors and statement 37 – I believe people would not need transplants if they took better care of their health on –4.

shares a more mechanical view and they do not perceive religion to be a barrier to organ donation[17].

The awareness level in this group is high[18] with a considerable knowledge about organ donation registration criteria[19]. This awareness is mixed with a certain level of misinformation especially in information related to brain death[20]. Although they show some comfort with their knowledge level, and they do not perceive is as a barrier against becoming a donor[21].

As a group, the Q sorts loading on this factor do not correlate with each other, and they load reasonably high on their factor. This indicates that participants loading on Factor 3 have a homogenous view on organ donation. Moreover, Factor 3 is closer to Factor 1 than to Factor 2.

Consensus Statements, Consensus statements are statements with similar Z scores across factors. In this study, there were six statements that were consensus among all three factors (Table 5). Three out of the six statements are related to the general and special need of organs for minority groups. It signifies the relative awareness in the need for organ donation, possibly, brought about by the active campaigns related to the new change in law in organ donation from opt-in to opt-out system. These results suggest that future campaigns can afford to shift their focus on issues other than awareness.

Another consensus statement was statement 9 – I think I am too old to donate, it implies a that age as a criterion for donation is not a major concern for participants, even for older participants, however, other criteria such as medical conditions as an eligibility criterion to donate was important to highlight especially in Factor 1.

The last statement that surprisingly, all factors agreed upon is statement 27 – I do not mind organ donation but my family disagree on rank 0, and it was non-significant even at $P > 0.05$. This results contradicts existing literature that used the Theory of Reasoned Action where subjective norm (a function of normative beliefs) is affected by perceptions of specific salient others' preferences about behaviour (Ryan & Carr, 2010) [15]. Many campaigns to support organ donation focused on improving family approval of their loved one's decision to donate, our study suggests that is not a significant barrier against donation.

DISCUSSION

Behavioural Intervention Insights, identifying three factors (four viewpoints), each with distinguishing combination of barriers and motivators suggests that campaigns with «one size fits all» strategy are ineffective and inefficient. Building on our analysis, we uncovered

Table 5

Consensus Statements

Statement	F1		F2		F3	
	Rank	Z Score	Rank	Z Score	Rank	Z Score
Those That Do Not Distinguish Between ANY Pair of Factors						
All Listed Statements are Non-Significant at P > 0.01, and Those Flagged with an * are also Non-Significant at P > 0.05)						
6 – I think there is no special need for organs for Asian, African, and Middle Eastern groups*	–3	–0.947	–3	–0.995	–2	–0.746
9 – I think I am too old to donate	–4	–1.47	–2	–0.89	–3	–1.02
13 – I believe there is a great need for organs especially in minority groups	2	0.955	1	0.58	3	1.06
27 – I do not mind organ donation but my family disagree*	0	–0.095	0	0.087	0	–0.211
36 – I believe the present need for transplant organs is fully covered*	–3	–1.171	–2	–0.827	–3	–1.022
40 – No matter how hard it is to think about organ donations, it makes me feel good about myself*	2	0.911	2	0.773	3	1.064

[17] Statement 39 – I believe organs are a gift from god, we are not allowed to give them away and 17 – If someone religious says it is not allowed, then I will not do it which is distinguishing statement for this factor, both on –5, 11 – I think it is non-religious to take organs, 43 – I think my religion encourages organ donation in order save other people's lives on –1 and a distinguishing statement and 1 – I believe my religion does not allow it on 0.

[18] Statement 13 – I believe there is a great need for organs especially in minority groups on +3, 6 – I think there is no special need for organs for Asian, African, and Middle Eastern groups on –2 and 36 – I believe the present need for transplant organs is fully covered on –3.

[19] Statement 5 – I think anyone can register and be a donor even if old or have a disease on +2 a distinguishing statement for this group, 9 – I think I am too old to donate on –3; registration process, 4 – I think the process of registration is complicated on –1 and transplantation results, 16 – I believe transplantation results are successful and they are improving people's health on +5.

[20] Statement 30 – I think people who have medical conditions cannot donate and 47 – I think I am not dead if my heart is still beating both on +1 and are distinguishing statements, and 22 – I think brain dead people can regain consciousness on +1.

[21] Statement 15 – I feel I cannot decide to donate because I do not know all the facts on –1 as a distinguishing statement.

insights on potentially effective intervention design for each factor.

Factor 1, The hallmark for this factor is a thirst for knowledge and information with perceived lack of knowledge. For this factor, behavioural change campaigns should focus on providing detailed information about organ donation. However, information should not focus on need (S15/+5), but rather on information about eligibility criteria and brain death. Eligibility criteria might exclude people suffering from certain diseases but not necessarily age (S9/–4). For example, campaigns should focus on the fact that you can still register and even donate even if you have an illness (S30/+4). The eligibility criteria on NHS website which enlists very few diseases that excludes donation, they are Creutzfeldt-Jakob Disease (CJD), Ebola virus disease, Active cancer, and HIV. One can donate organs even if they have had cancer (but not active) or even if they cannot donate blood.

Another important part of information is brain death. Campaigns should focus on the fact that brain death is irreversible, and the patient cannot regain consciousness (S22/+1) (NHS, 2019a) [16] using preferably expert opinion (S14/+1). Campaigns should also focus on the diagnostic criteria of brain death and shows that strict measures for brain death diagnosis eliminates the risk of misdiagnosis.

The campaigns message for this group should stay away from religious messages, family agreement, and easy registration process (although this does not apply top UK anymore with the opt-out system). One effect about opt-out system however, that is important to this group, it is important to highlight that despite the opt-out system, a potential donor will not be forced to donate organs. No organ will be harvested without the permission of the family, thus, the decision to donate is still held by the hands of the person (S24/+3) as participant 4586 explains «If I die and then doctors ask my family for my organs, may be my mother would be so sad she will say no, I want to give her that chance, to say no». Messages here should encourage to communicate decision to the family if one wants to be a donor.

Q methodology analysis for this factor show that knowledge is categorical, and the level of knowledge is irrelevant to the perception of knowledge level. People may perceive their knowledge level to be low despite potentially scoring well in a survey for knowledge level. It shows how perception is at the core of behavioural barrier to organ donation. That is a similar case for religion. People may hold different religions with similar views and vice versa. To address knowledge perception, interventions that are founded on self-efficacy theory can be most relevant to this group.

Factor 2, the hallmark of this factor is the hesitation and anxiety. For this factor, behavioural change campaigns should focus on real-life stories that inspire others to become a donor. However, campaigns messages should avoid evoking images of «wasted organs» (S38/+2) but rather visuals playing a nice emotional tune that fills the heart with warmth. Examples of emotionally stimulating have been implemented globally and in the UK (NHS, 2019c; Nicholas, 2017) [17, 18].

The campaigns message for this group should focus on emotionally attractive messages to encourage people to overcome their fear and decide to become an organ donor, especially promoting organ donation as a selfless noble act that will help save or improve people's lives. Messages involve positive religious views and religious leaders advocating for organ donation might be impactful. Campaigns promoting sharing decision with family might be helpful as well, especially if the family holds positive views as that would help ease the tension when it comes to considering donating.

This group shows anxiety as the main barrier to donation. Consistently, they show a great emotional reaction throughout the array. For this group, Terror Management Theory may be the most effective theory to be used in behavioural interventions. A study used this theory to alter organ donation behaviour showed that misconceptions mediate the relationship between death thoughts and organ donation intention, this study supports that finding and shows people loaded on this factor perceive their information on organ donation to be insufficient. Interventions to address the hesitancy and death anxiety in this groups should promote organ donation as a selfless noble act that will help save or improve people's lives.

Factor 3, The hallmark of this factor is the need for a cue for action suggesting that interventions based on Immediacy Theory may be most effective for this group. For this factor, behavioural campaigns should focus on providing information about allocation system and the laws that prevents unethical management of organs, this also includes highlighting if there are financial rewards for the donors, the nationality and race of the donors if possible. Complete transparency in the organ donation data on both ends; donation and transplantation are essential for this factor (S2/+2 and S34/+1). Other medical information regarding brain death definition is important too (S14/+2, S47/+1 and S30/+1).

The campaigns message for this group should maintain the organ donation is a selfless act (S7/+5) offering the gift of life (NHS, 2020) and improving the life of people in need, picturing donors as hero and asserting organ donation as the ultimate charitable act especially at certain holidays like Christmas and Eid (NHS, 2019a) [16]. this suggests that Self-Affirmation Theory by emphasising their roles as givers and their values such as selflessness to be effective for this group. Campaigns however should avoid religiously motivated messages and avoid awareness about the need for the organs as well (S13/+3 and S36/–3).

CONCLUSION

There is a chronic and severe shortage of donated organs in UK (NHS, 2018) [19] and a valid argument to a continuously increased demand (Cheetham et al., 2016; Jox, Assadi, & Marckmann, 2015) [20, 21]. There is a complex net of social, religious, and psychological barriers against organ donation, in addition to a potential lack of knowledge and awareness and a history of mistrust in the medical profession. Designing more effective interventions is crucial to increase donated organs.

We examined viewpoints on organ donation using Q methodology. Our results show four distinctive viewpoints. We make no claim to generalise the results for general population, instead, Q methodology examine the variations of views in the population. Our research suggests that people with different viewpoints are influenced by different behavioural change strategies, and we predict that interventions designed with these factors in mind will produce better outcomes than «one-size-fits-all» strategy.

Our data suggests that busting myths and improving knowledge level about organ donation is more effective for people loading on Factor 1, people loading on all other factors may benefit from different strategies that are seldom applied in focused and strategic ways. Moreover, the consensus statement on family agreement on rank zero implies that participants do not consider family disagreement as a barrier which contradicts the fundamental theoretical idea of theory of planned behaviour that is commonly used in the organ donation field. Taken together, the results indicate that there are many folds on the viewpoints about organ donation that we need to unfold. Further research should be conducted to assess the prevalence of each factor and experiments to validate the conclusions on the effective behavioural intervention designs.

The authors declare no conflict of interest.

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The article was submitted to the journal on 12.10.2021