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Healthcare professional and community preferences in deceased donor kidney allocation: a best-worst scaling survey.

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Abbreviations

ABS – Australian Bureau of Statistics

ANZDATA – Australian and New Zealand Dialysis and Transplant Registry

ANZSN – Australian and New Zealand Society of Nephrology

BWMNL - Best-worst multinomial logit

BWS – Best-worst scaling

KAS – Kidney Allocation System

KDPI – Kidney Donor Performance Index

PS – Preference score

QoL – Quality of life

RSA – Renal Society of Australia

SBWMNL – Sequential best-worst multinomial logit

TNA – Transplant Nurses Association

TSANZ – Transplant Society of Australia and New Zealand

Abstract

Deceased donor kidneys are a scarce community resource, therefore the principles underpinning organ allocation should reflect societal values. This study aimed to elicit community and healthcare professional preferences for principles guiding the allocation of kidneys from deceased donors and compare how these differed across the populations. A best-worst scaling survey including 29 principles in a balanced incomplete block design was conducted among a representative sample of the general community (n=1237) and

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healthcare professionals working in transplantation (n=206). Sequential best-worst multinomial logistic regression was used to derive scaled preference scores (PS) (range 0-100). Thematic analysis of free text responses was performed. Five of the six most valued principles among members of the community related to equity, including priority for the longest waiting (PS 100), difficult to transplant (PS 94.5) and sickest (PS 93.9), and equitable access for men and women (PS 94.0) whereas the top four principles for healthcare professional focused on maximizing utility (PS 89.9-100). Latent class analysis identified unmeasured class membership among community members. There are discordant views between community members and healthcare professionals. These should be considered in the design, evaluation and implementation of deceased donor kidney allocation protocols.

Background

Deceased donor kidney transplantation relies on the altruism of donors and families in providing an organ to benefit an individual with whom they have no personal connection. As such, the general community who comprise the pool of organ donors are key stakeholders in organ allocation policy. The need for kidneys exceeds availability, therefore deceased donor organs are a scarce resource and ethical principles underpinning utilisation should reflect the values of all stakeholders[1]. Algorithms that determine organs allocation are typically designed by healthcare professionals expert in clinical aspects of transplantation. It is not clear that the principles valued by this group necessarily reflect the priorities of the broader community.

Scarcity produces a situation where ethical principles underpinning decisions must be balanced [2]. This has been brought into focus during the COVID-19 pandemic[3]. Principles of equity (defined as *"the absence of unfair and avoidable or remediable differences in health among population groups defined socially, economically, demographically or geographically*")[4] and justice should be considered to ensure that those most in need or most deserving have access to donor organs, and that access is not arbitrarily contingent on gender, ethnicity, socioeconomic situation, or age. Nonetheless, the overall benefit derived

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from the scarce resource should be maximized. These principles are often in conflict and the effect of prioritizing one often compromises the other.

Expertise is essential to developing an allocation system. This expertise may, however result in priorities distinct from the population providing or receiving the resource. In recent years, there has been an increased focus on ensuring that researchers and healthcare professionals partner with patients and community to ensure resource allocation aligns with the broad range of stakeholder priorities [5, 6]. Transplantation relies on a unique personal act of generosity in providing a precious resource. It is vital that the views of the community in determining how that gift should be used are respected.

Previous studies on community preferences for allocating solid organs highlight the complex balance between ethical principles that underpin attitudes to this challenging issue in the broader population. In a review of qualitative and quantitative studies, Tong et al (2010) [7] identified seven themes describing community preferences including maximum benefit, social valuation, moral deservingness, prejudice, 'fair innings', 'first come, first served' and medical urgency. A more recent systematic review by Oedingen et al (2019)[8] applied a distributive justice framework. They found that while a rational utilitarian ethical model was preferred, this was contradicted by simultaneous priority to treat the most in need and concluded that "data on public preferences regarding clear trade-offs in donor organ allocation are still lacking". Similarly, in a qualitative study into perspectives of nephrologists on deceased donor kidney wait listing and allocation, Tong et al (2011)[9] explored the theme of reconciling tensions between equity and maximizing benefit.

In this online best worst scaling (BWS) study we examine the relative priorities of competing preferences in the general community and healthcare professionals for the allocation of kidneys from deceased donors to determine overlap and differences.

Methods

Study population

Adults were recruited from the community using an Australian online research panel (Survey Sampling International, Shelton, CT, USA). Quota sampling on age, sex, ethnicity and

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State/Territory of residence was used to obtain a respondent population broadly representative of Australian adults (target sample size of 1,000). To enable comparison with the Australian adult population estimated from the 2016 Australian population census from the Australian Bureau of Statistics (ABS) [10] , ethnicity was grouped according to the following criteria Indigenous Australians, and non-Indigenous Australians of varied descent (British/Irish, European, Asian, North American, South American, New Zealander, Pacific Islander, African and Middle Eastern). Data was collected during March 2018.
Healthcare professionals working in Australia in organ donation or kidney transplantation were recruited by email and advertising in professional society newsletters. Emails were sent to all registered contributors to the Australia and New Zealand Dialysis and Transplant Registry, all members of the Renal Society of Australia (RSA) and Transplant Nurses Association (TNA). Invitations were sent to all renal unit department heads requesting circulation among unit staff. Advertisements were placed in newsletters of the Australian and New Zealand Society of Nephrology), the Transplant Society of Australia and New Zealand, RSA and TNA. Data was collected between October 2018 and January 2019.

Best-Worst Scaling

An object case BWS survey, a type of discrete choice experiment, was conducted [11]. BWS surveys and discrete choice experiments have been widely used to address an extensive range of health and clinical research questions[12-14]. Best-worst scaling surveys are particularly suited to eliciting the relative preference or importance of a large number of attributes, items, statements or health related outcomes including the recently developed COVID-19 core outcomes set [15]. Other approaches such as the Likert scale rate the individual items on a scale from not important to critically important giving an individual rating for each item i.e. with no trade-off between them. This results in little differentiation between most, or all items and it is not possible to determine relative importance. The design and analysis of BWS surveys are underpinned by long established random utility theory [16, 17]. In a BWS participants are shown a list of items and asked to choose the best and the worst item. They are then shown a series of lists each with a different subset of items and preferences are estimated for all of the items based on the choices [13, 18].

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Allocation Principles:

Based on findings of qualitative and quantitative studies in the Australian community, literature review and expert panel, 29 principles for allocation were identified [19-21]. To assist with interpretation, principles were grouped into five broad topics adapted from Persad, Wertheimer and Emanuel (2009) [2, 3]: 1) equity in access, 2) prioritizing the worst off 3) prioritizing those who will benefit most, 4) maximizing total benefit, and 5) promoting and rewarding usefulness. Maximizing benefit was divided into principles in which utility maximization was explicitly stated or implied. Topics were used for reporting and were not shown to survey respondents. As principles could fit multiple topics categorization was based on investigator consensus. The 29 principles are provided in supplementary Table S1.

Survey design:

Details of survey design and analysis which is underpinned by random utility theory [22,23] are provided in Supplementary Appendix S1.

The surveys were programmed into Qualtrics *(Qualtrics Software, Provo, UT, United States)*. An example of a single best-worst task (choice set) from the community study is shown in **Error! Reference source not found.**. In the community survey, each participant was shown 10 tasks and, in the healthcare professional survey they were shown 15. Each BWS task contained a different selection of principles (see Appendix S1 for design methods) and participants were asked to nominate the most important and the least important principles from the list. Relative preference for all 29 principles were then determined based on the choices made. Participants were provided the opportunity to nominate principles additional to the predetermined principles included in the BWS via a free-text response question included at the end of the survey.

Background on deceased donor organ allocation and instructions on completing the survey preceded the best-worst tasks (see Supplementary Appendix S2). Simple language was used however, no additional information was provided as to meaning or implications. Self-reported demographic details were collected. For the community these included: State/Territory of residence, rural/metropolitan location, gender, age, education, marital status, ethnicity, first language spoken at home and knowledge/experience of end stage kidney disease and transplants. For healthcare professionals these included: State/Territory

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of practice, rural/ metropolitan, gender, age, professional role, years practicing and whether they had practiced overseas.

Statistical Analysis

The relative importance of the 29 allocation principles was determined using a sequential best worst multinomial logit (SBWMNL) regression model [13] using a conditional logistic regression model to capture information on choices. Further detail of analysis is provided in Supplementary Appendix S1. Regression coefficients of the utility function for the best/worst selections provide the relative importance scores for each outcome [18]. As these have the same scale, preference scores were scaled to 0-100 (least to most important).

Preference heterogeneity was evaluated using a panel specification of a latent class regression model to identify classes of preference structures [24] and to link probability of class membership to respondent characteristics. An iterative process based on model fit and ability to predict composition of classes was used to define the optimal number of classes (for the community survey, 3 classes were specified; for healthcare professionals , latent class analysis did not provide meaningful insights and is not reported).

The block design was undertaken using SAS V9.4, SBWMNL analysis using Stata V15.0 (*Stata Corp, Texas, USA*) and latent class analysis using NLOGIT V6 *(Econometric Software Inc.)*.

Analysis of free text

To identify allocation principles not covered by the BWS survey, all free-text responses were extracted and compiled. Individual principles were grouped under broad ethical categories by ED and MS and reviewed by the investigator group and refined accordingly. The authors recognize that some principles may fit within multiple ethical categories. Categorization of principles were used for reporting to aid in the description and interpretation of the primary survey responses. Analysis involved coding comments according to the pre-defined principles covered in the survey and any additional concepts identified by participant

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comments. Initial codes and concepts were developed by author ED and reviewed by all investigators and refined accordingly. Thematic analysis was limited to principles that were not addressed in the BWS survey. Reporting of qualitative data from free text analysis has, where applicable, followed the consolidated criteria for reporting qualitative research (COREQ) checklist (Appendix S3). [25]

The University of Sydney Human Research Ethics Committee (HREC:2017/869) approved the study.

Results

Participants

A total of 1,237 were recruited for the community survey. Of these, 115 (9%) did not consent to proceed with the survey, 40 (3%) started but did not complete the survey and 1,082 (87%) completed the survey. Characteristics of those completing the survey are shown in Table 1 with comparison to the Australian adult population as estimated from the 2016 Australian population census from the Australian Bureau of Statistics (ABS) [10]. A few respondents had end stage kidney disease (32 (3%) on dialysis and 16(1%) with a transplant). Almost half (48%) of all respondents were registered organ donors. The majority reported to be 'slightly' or 'not at all' knowledgeable about chronic kidney disease (68%), transplant (70%) and organ donation (50%).

In total, 206 healthcare professionals consented to the study, completed at least one question and were included in the analysis (169 (82%) completed all questions), with characteristics shown in Table 1. Almost half (48%) were doctors. Women were over-represented in the healthcare professional survey (68%) compared to both the general population (51%) and the community survey (50%).

Preferences for allocation principles:

Regression coefficients and 95% confidence intervals for the SBWMNL model are presented in Table 2. Scaled preference scores represent the relative importance of each principle for each study population and are shown in Table 2 and **Error! Reference source not found.**.

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Of 6 principles with preference scores (PS) greater than 90 in the community survey, 5 of related to equity in allocation. These included principles of needs-based equity with priority for those who had been waiting the longest (PS 100.0), are difficult to transplant (PS 94.5) and for the sickest patients (PS 94.0). Community members also valued equity in access regardless of gender (PS 94.0) or socioeconomic circumstances (PS 91.9). Of principles related to maximizing benefit, maximizing quality of life (PS 93.2) was a key priority in the community study, followed by maximizing survival (PS 89.3) and the number of transplants (PS 85.6).

In contrast, 5 of the 6 top priorities for healthcare professionals related to maximizing overall benefit. Allocating kidneys with the best predicted survival to recipients with the best predicted survival (PS 100.0) or to the young (PS 90.1) were key priorities, as were maximizing survival (PS 93.0) and quality of life (PS 87.0) and minimizing total waiting time across the waiting list (PS 89.9). The highest ranked equity principle was ensuring equity in access for Indigenous candidates (PS 87.0).

Principles that promoted or rewarded social usefulness were of lower priority for both groups. For example, priority for prior kidney donors or for those registered as organ donors had preference scores ≤50 for both community and healthcare professionals. Other principles that were not prioritized by either group included priority for older recipients or for allocation of local donor organs to local recipients.

Latent Class Analysis:

Latent class analysis of the community study identified 3 classes with average class probabilities of 0.29, 0.42, and 0.30. Coefficients of principles for each latent class are shown in Supplementary Table S2. Class 1 preference profile is dominated by principles reflecting treating people equitably. The most valued principle being equity for socially disadvantaged groups followed by priority the longest waiting times, equity in access between genders and for Indigenous Australians, maximizing transplants and priority to the sickest. Class 2 is dominated by principles that reflect consideration for helping the worst-off. The most highly valued being priority to the sickest, longest waiting, difficult to

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transplant, first transplant and poorest quality of life. The class 3 profile is dominated by principles favoring the young and maximizing survival particularly for children, followed by organs with best predicted survival to the young, greatest improvement in quality of life, organs with best predicted survival to individuals with best predicted survival and young donors to young.

Five predictors of membership of classes 1 and 2 relative to 3 were identified (Table 3). Class 1 (*treating people equitably*) is less likely to include men (odds ratio[95%CI]; 0.49 [0.28-0.87]), and registered donors (0.61 [0.35-1.04]) and more likely to be younger than 50 years (2.84 [1.55-5.19]. Class 2 (*helping the worst off*) is less likely to be a registered donor (0.35[0.21-0.55]) or have little or no knowledge of kidney disease (0.59 [0.36-0.95]), more likely to live in a metropolitan area (2.03 [1.17-3.51]) and to be younger than 50 years (1.68 [1.02-2.74]). Consequently, class 3 (*age and survival*) are more likely to be older than 50 and to be registered donors compared to classes 1 and 2.

Latent class analysis of the healthcare professions study did not add to the interpretation of the SBWMNL analysis and is not reported.

Free text:

Free text comments were provided by 300 (23%).

Free text comments commenting on principles included in the BWS survey were not included in the thematic analysis as they did not contribute additional insights beyond the quantitative analysis. Illustrative comments of themes are shown in Table 4.

Thematic analysis of community free text revealed three additional themes: *considering health behaviors, penalizing antisocial behavior* and *decisional burden*. A prominent theme in responses was those with past or current *lifestyle behaviors* deemed to be unhealthy (e.g. alcohol consumption, smoking, “bad lifestyle”) should be penalized or given lower priority, particularly if behaviors contributed to their illness. Conversely, respondents commented that patients who adhered to a healthy lifestyle should be prioritized. Some respondents commented that candidates with *anti-social behaviors* such as criminal activity, illicit drug use or having tattoos, should be given lower priority or excluded from organ allocation. Many described *decisional burden* in completing the survey, reporting they felt poorly equipped to make such decisions and that these should be deferred to expert doctors.

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Respondents commented on the burden of "playing God" and expressed relief that others made the decisions.

Analysis of free text by healthcare professionals revealed a prominent theme focused on recipient health, *lifestyle behaviors and adherence*. Additional themes included considering *contribution to society*, *patient choice* to accept higher risk organs, *simplicity and transparency* and a focus on *highly sensitized patients*. A broader range of themes in by healthcare professionals and the length of many free text comments likely represents pre-existing opinions in this group.

Discussion

This BWS study demonstrates important differences between priorities held by community members and healthcare professionals working in the transplant field regarding allocation of deceased donor kidneys. While principles relating to equity are most valued by members of the general community, higher priority for utility is seen among healthcare professionals. This highlights the need for policy makers and those developing allocation protocols to be aware of differences between their own priorities and those of the range of stakeholders. Furthermore, we identified preference heterogeneity among community respondents. This shows the need to consider multiple viewpoints as preferences and values may vary depending on characteristics such as age, gender and personal experience.

Among the broader community we found that while principles that explicitly described maximizing utility were prioritized the strongest preference was for principles of equitable access to transplantation and helping those most in need. This indicates that while there may be general support for policies designed to maximize utility, the broader community may nonetheless favor policies that ensure justice and fairness over maximizing efficiency at the cost of inequality. This finding is similar to an earlier study in solid organ transplantation, in which Howard et al (2015)[21] found that for the general community "lower pre-transplant life expectancy (need) was more important that higher post-transplant life expectancy (utility)". They concluded that implementing allocation algorithms favoring utility may be

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misaligned with community preferences. In contrast, among health care professionals there was a clear preference to maximize efficiency.

Since introduction of longevity matching in the US Kidney Allocation System (KAS) in 2014, there has been interest in the Australian transplant community on the role of survival indices in the Australian context [26, 27]. Although not yet used in kidney allocation, the Kidney Donor Profile Index (KDPI) is reported with all kidneys offered [28, 29]. Of the top 3 principles for healthcare professionals, 2 related explicitly to survival-based matching (allocating the organs with best predicted survival to recipients with best predicted survival or to younger recipients), and the third to maximization of patient survival. This finding indicates support for longevity-based matching among transplant clinicians in Australia with prominence reflecting policy debate. In contrast, among the general community, survival-based matching had a preference score of 74.9 and 13 of 29 principles were rated more highly. This highlights the need to consider unintended consequences of implementing survival based matching to ensure that changes in policies align with broader community priorities.

Deceased donor kidney transplantation is specialized and despite the provision of uniform background information to both groups, prior knowledge likely influenced participants' responses. For example, we found that community members prioritized principles in which maximizing benefit was explicitly stated (e.g. "Overall patient survival should be maximized") higher than principles where increased utility was implied, but specialized knowledge may be required to appreciate this (e.g. "Organs with best predicted survival should be given preferentially to those who have the best predicted survival"). The theme *decisional burden* in free text from community affirms difficultly in weighing complex priorities. The structure for consumer input into kidney allocation policy in Australia, where 1-2 members of the community participate in the Renal Transplant Advisory Committee comprising up to 22 healthcare professionals[30], places excessive decisional burden on individuals and alternative strategies for consultation should be considered [31]. For healthcare professionals, a high degree of knowledge of the current allocation system may have resulted in responses that reflect current deficiencies, such as the need to prioritize the highly sensitized. Only a small number of people with personal experience of end stage

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kidney disease were included in our community study and further studies into the preferences of this population are needed, as well as into the preferences of family and friends of previous organ donors.

A key limitation of the BWS survey is that whilst the BWS survey provides relative preferences for many principles, it does not allow assessment of the trade-offs between principles. In short, the BWS cannot address the implication of varying each principle on the outcomes of allocation. For example, favoring children and young adults will result in fewer transplants being available for older adults and the elderly. The BWS may indicate a preference for younger over older recipients, but it does not suggest that older candidates should not be considered for transplantation.

The preference scores indicate the relative priority for principles within each population, however those with low scores may still be supported, albeit with lower importance. Insights can be gained from examining those principles not prioritized strongly by either population. Giving priority to registered donors had a low preference score among the general community and health care professionals, suggesting that introducing an incentive (as has been implemented in Israel [32]) is not a key priority in Australia. Noting the lower priority seen across both groups for certain principles, such as the allocation of kidneys to a recipient within the same region as the donor or priority for registered donors, may help inform which components of the current or proposed allocation algorithm could be omitted or weighted differently.

In line with good practice[33], the 29 principles used were based on qualitative studies, literature and expert panel review, however, there may be important principles omitted and the way a principle was framed in the survey may have influenced preference scores [34, 35]. For example, lifestyle behavior was framed to align with the Australian National Health and Medical Research Council's Ethical Guidelines for Organ Transplantation from Deceased Donors [36] and phrased as *"Access to transplantation should be equal regardless of whether or not past lifestyle behaviors contributed to the cause of their kidney disease"* and received low community and healthcare professionals preference scores. . Alternate framing e.g.,

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"Priority should be given people for whom past lifestyle behaviors has not contributed to the cause of their kidney disease" may have received a different preference.

Comments on penalizing poor health behaviors and rewarding positive lifestyle choices were provided by both groups. Health behaviors are commonly considered in eligibility for transplant wait listing and therefore may be less relevant to allocation policy, a concept that may be underappreciated by members of the community. The contradiction of some views expressed in free text responses with current ethical guidelines demonstrates that while considering stakeholder preferences is important this does not replace the need for a vigorous ethical critique. It is important to note, that free text responses were voluntary and provide the views of a minority of individuals motivated to include a comment. These cannot be considered as being saturated with respect to the diversity of views.

Our study provides two key advances that are relevant to allocation policies for deceased donor organs. Firstly, we were able to determine the relative priority of many principles and values using the BWS survey and extend current understanding of what the general community considers to be important. This is key to defining which principles should guide the trade-off between equity and efficiency when considering allocation policies. Secondly, our methods have allowed us to draw direct comparisons between the community on whose generosity organ donation relies, and health care professionals who largely dictate the usage of this resource. It is particularly valuable for healthcare professionals to recognize that their views, inherently informed by their knowledge and experience, may not always align with the views and preferences of the broader community.

Our findings highlight the need for policy makers to recognize that the priorities held by healthcare professionals do not necessarily reflect those of the broader community and other stakeholders. Policy debates among healthcare professionals in deceased donor kidney allocation that focus on optimizing organ and recipient survival and maximizing utility should not ignore community preference for equitable access. While public opinion should not dictate health policy, recognizing the general public as legitimate stakeholders with views that may diverge from those held by health care professionals will help ensure that the use of organs reflects the priorities of the community on whose altruism the deceased donor transplant system depends. Appreciating differences in community and professional

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views may assist in developing targeted public education programs to accompany policy changes. Further studies exploring acceptable trade-offs including discrete choice experiments, focus groups, and consultation with people with kidney disease are important steps in a comprehensive approach to stakeholder engagement in developing kidney allocation systems.

Disclosures:

The authors declare no conflicts of interest

Data Availability Statement:

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Legends

Table 1:

Demographics of survey respondents compared with the Australian population from the Australian Bureau of Statistics Census 2016. CKD – Chronic Kidney Disease

Table 2:

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Relative preferences for principles guiding deceased donor kidney allocation among community members and healthcare professionals. Regression coefficients and 95 % confidence intervals for the sequential best worst multinomial logit (SBWMNL) regression model are shown. These have been scaled to preference scores that represent the relative importance of each principle for each study population ranging from 0 to 100 where 0 is the lowest preference and 100 is the top preference. QoL – quality of Life

Table 3:
Predictors of class membership in the latent class analysis of the sequential best worst multinomial logit model of community preferences in deceased donor kidney allocation.

Table 4:
Illustrative quotations from the general community and healthcare professionals in response to the question "Are there any values or principles that you would like to nominate as being important when considering allocating kidneys from deceased donors?"

Figure 1:
Example of a best worst choice set from the community study. Participants are requested to select what they view as the most important principle related to deceased donor kidney allocation followed by the least important principle.

Figure 2:
Relative preferences for principles guiding deceased donor kidney allocation among community members and healthcare professionals. Preference scores are scaled coefficients from the sequential best worst conditional logistic regression model and represent the relative importance of each principle for each study population ranging from 0 to 100 where 0 is the lowest preference and 100 is the top preference. QoL – quality of Life

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Supporting Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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Table 1.

		Community Study	Healthcare Study	Australian Population
Characteristic	**Levels**	**N (%)**	**N (%)**	**%**
N		1082	206	
Age group:	18-30	146 (14)	12 (6)	22
	31-40	158 (15)	30 (15)	18
	41-50	168 (16)	51 (25)	17
	51-60	240 (22)	53 (26)	16
	61-70	212 (20)	11 (5)	13
	>70	95 (9)	4 (2)	12
	Missing	63 (6)	45 (22)	-
Gender:	Female	540 (50)	141 (68)	51
	Male	542 (50)	64 (31)	49
	Non-Binary	n/a	1 (1)	n/a
State/Territory:	Australian Capital Territory	11 (1)	7 (3)	2
	New South Wales	322 (30)	52 (25)	32
	Northern Territory	7 (1)	2 (1)	2
	Queensland	218 (20)	40 (19)	20
	South Australia	115 (11)	8 (4)	7
	Tasmania	33 (3)	8 (4)	1
	Victoria	265 (25)	71 (35)	26
	Western Australia	111 (10)	18 (9)	10
Location:	Metropolitan	812 (75)	165 (80)	71
	Regional/Rural	270 (25)	41 (20)	29
Ethnicity[1]	Indigenous Australian	18 (2)		3
	Non-Indigenous Australian	789 (73)		67
	Other Ethnicity	275 (25)		30
Main language:	English	1004 (93)		90

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	Other	78 (7)	10
Relationship status:	Married /defacto	647 (60)	58
	Single	250 (23)	18
	Separated/Divorced	142 (13)	9
	Widowed	36 (3)	5
	Other	7 (1)	10
Highest education:	University/Technical College	732 (68)	55
	High School	191 (18)	47
	Primary School	158 (15)	6
	Not Stated	-	9
Annual household income (pre-tax):	Not Stated	126 (12)	10
	Up to $35,000	224 (21)	18
	$35,000- $65,000	255 (24)	29
	$65,001- $95,000	169 (16)	11
	$95,001 - $125,000	131 (12)	10
	$125,001 - $150,000	84 (8)	6
	>$150,000	93 (9)	15
End Stage Kidney Disease	Dialysis	32 (3)	
	Transplantation	16 (2)	
Registered Donor	Yes	498 (46)	
CKD Knowledge:	Not knowledgeable at all	276 (26)	
	Slightly knowledgeable	457 (42)	
	Moderately knowledgeable	246 (23)	

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	Very knowledgeable	78 (7)	
	Extremely knowledgeable	25 (2)	
Transplant Knowledge	Not knowledgeable at all	323 (30)	
	Slightly knowledgeable	430 (40)	
	Moderately knowledgeable	241 (22)	
	Very knowledgeable	69 (6)	
	Extremely knowledgeable	19 (2	
Organ Donation Knowledge	Not knowledgeable at all	156 (14)	
	Slightly knowledgeable	386 (36)	
	Moderately knowledgeable	371 (34)	
	Very knowledgeable	118 (11)	
	Extremely knowledgeable	51 (5)	
Healthcare professional role:	Nephrologist		87 (42)
	Transplant Surgeon		6 (3)
	Doctor in Training		7 (3)
	Nurse/Transplant Coordinator		73 (35)
	Donation		12 (6)

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	Coordinator	
	Allied Health	6 (3)
	Other	15 (7)
Practice years:	Less than 2 years	27 (13)
	2 to 5 years	26 (13)
	5 to 10 years	33 (16)
	More than 10 years	119 (58)
Previously worked overseas:	Yes	47 (23)
	No	158 (77)

[1]. Ethnicity is defined by ancestry and includes British/Irish, European, North American, Southern and Central American, SE Asian, NE Asian, South and Central Asia, New Zealander and other.

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Table 2

Table 2	**Community**			**Healthcare Professionals**			
Summary of Principle	Coefficient	95% CI	Preference Score	Coefficient	95% CI	Preference Score	
Priority for Longest Waiting	1.58	1.45 1.72	100.0	2.62	2.26 2.99	81.4	
Priority for Difficult to Transplant	1.49	1.36 1.63	94.5	2.63	2.30 2.97	81.7	
Gender Equality	1.49	1.35 1.63	94.0	2.42	2.05 2.78	75.0	
Priority for Sickest	1.48	1.34 1.63	93.9	1.42	1.12 1.72	44.1	
Maximise QoL	1.47	1.34 1.60	93.2	2.74	2.43 3.05	85.2	
Socioeconomic Equality	1.45	1.30 1.60	91.9	2.66	2.25 3.07	82.7	
Maximise Survival	1.41	1.28 1.54	89.3	3.00	2.68 3.31	93.0	
Maximise Transplants	1.35	1.21 1.49	85.6	1.92	1.51 2.34	59.7	
Priority for Greatest Improvement in QoL	1.33	1.20 1.47	84.4	2.24	1.90 2.58	69.5	
Minimize Waiting Time	1.29	1.15 1.42	81.6	2.89	2.54 3.25	89.9	
Priority for Children	1.26	1.12 1.40	79.9	2.60	2.23 2.97	80.8	
Equality for Indigenous Persons	1.25	1.11 1.40	79.7	2.80	2.44 3.17	87.0	
Priority for Poorest QoL	1.19	1.06 1.31	75.6	1.32	1.03 1.61	41.0	
Best Kidney to Best Survival	1.18	1.04 1.31	74.9	3.22	2.86 3.58	100.0	
Best Kidneys to Young	1.12	0.98 1.25	71.1	2.90	2.56 3.25	90.1	
Priority for First Transplant	0.92	0.79 1.04	58.9	0.94	0.66 1.22	29.2	

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Priority to Prior Donors	0.87	0.73	1.01	56.0	1.62	1.22	2.02	50.3
Young Donors to Young Recipients	0.78	0.65	0.91	50.4	2.47	2.10	2.83	76.6
Priority for Young Adults	0.78	0.65	0.91	50.1	1.93	1.60	2.26	59.9
Age Equality	0.77	0.65	0.90	49.9	0.89	0.64	1.14	27.7
Consider Future Transplant Opportunities	0.49	0.37	0.60	32.1	1.78	1.42	2.14	55.3
Equality Regardless of Adherence	0.39	0.26	0.52	26.0	0.61	0.31	0.91	18.9
Choice to Accept Poorer Kidney	0.38	0.26	0.50	25.5	1.57	1.27	1.87	48.8
Equality Regardless of Past Lifestyle	0.38	0.25	0.51	25.5	1.37	1.05	1.68	42.4
Poorer Kidneys to Older Patients	0.30	0.19	0.42	20.7	1.30	1.01	1.59	40.5
Poorer Kidneys to Poorer Survival	0.26	0.15	0.38	18.3	1.71	1.37	2.05	53.1
Priority to Registered Donors	0.17	0.04	0.29	12.4	0.01	-0.29	0.31	0.2
Priority for Older Adults	Reference			2.0	Reference			0.0
Priority to Same State	-0.03	-0.17	0.10	0.0	0.69	0.36	1.03	21.5

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Table 3:

	Latent Class								
	1			**2**			**3**		
Descriptive theme	**"Treating people equitably"**			**"Helping the worst off"**			**"Favouring the young"**		
Predictor	**Odds ratio**	**95% Confidence interval**	**P**	**Odds ratio**	**95% Confidence interval**	**P**	**Odds ratio**	**95% Confidence interval**	**P**
Male	0.49	0.28-0.87	0.01	0.81	0.50-1.30	0.37			
Metropolitan resident	0.87	0.50-1.51	0.62	2.03	1.17-3.51	0.01			
Registered donor	0.61	0.35-1.04	0.07	0.35	0.21-0.55	<0.01		Reference	
Younger than 50 years	2.84	1.55-5.19	<0.01	1.68	1.02-2.74	0.04			
Little or no knowledge of kidney disease	1.02	0.57-1.84	0.94	0.59	0.36-0.95	0.03			

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Table 4: illustrative quotations from the general community and healthcare professionals in response to the question "Are there any values or principles that you would like to nominate as being important when considering allocating kidneys from deceased donors?"

Theme	Quotation
Illustrative Quotations from Community Members	
Considering health behaviours	*"The current system is most ethical, but if you are going to prioritise, preference should be given to those whose organ failure is not their fault e.g. those with self-inflicted liver failure from alcohol, lung failure from smoking and kidney/ pancreas failure from type 2 diabetes from poor diet should be a lesser priority."*
	"People who live a lifestyle that gives them a poorer chance of surviving the transplant should be lower down the list than those who take care of their health."
Anti-social behaviour	*"Those with a criminal history should not be considered for a kidney transplant...eg those in jail or have been released"*
	"Person who has history of using drugs (illegal drugs) should not be given the new kidneys."
Decisional burden	*"Not something I feel qualified to comment on. Medical practitioners are best to decide."*
	"I do not envy the team making these allocation decisions."
	"It is a very difficult area to attempt to bring such black and white decision processes to bear. I certainly don't envy the people who have to do it."
Illustrative Quotations from Health Care Professionals	
Lifestyle behaviours and adherence	*"Behaviour: Potential adult recipients should demonstrate their intention to respect the gift of a transplant by their conduct in their pre-transplant life (keeping appointments, taking medications as prescribed, accepting advice from health professionals)"*
	"I believe there should be emphasise on behaviours epically life style, compliance to medication and diet mental health as the organs are valuable commodity and we don't want them to be wasted."

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Contribution of society	*"Single parents whose children's lives will be improved because of a parent who can care for them because of a kidney transplant should be given some priority."*
	"Priority to get workers back to work - supporting families and improving quality of life for their spouses and children. Priority to get children and young adults back to education and life, to improve their long term outcomes in contributing to society"
Patient choice to accept risk	*"Patients should be able to choose if they wish to take donor kidneys at higher risk than average, eg due to infection risk or young age"*
	"Patient choice in receiving kidneys with poorer predicted outcome."
Simplicity and transparency	*"Values and principles vary from person to person and it can make things more complicated than they should be."*
	"The balance between equity and utility should always be a transparent. The process should be inclusive not exclusive,"
Highly sensitized patients	*"In those potential recipients that are highly sensitized - they should preferentially receive a deceased donor kidney if crossmatch negative and minimal or no DSA."*
	"Priority to be given to those that are highly sensitized and to children, after that time wait or best HLA matching."

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