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TITLE: Who should be prioritized for renal transplantation?: Analysis of stakeholder group and altruistic preferences.

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Abstract.

Introduction / Aims: To ascertain preferences of different stakeholders about who should be prioritized for renal transplantation. Taking into account preferences of patients, donors, healthcare workers, carers, ethnic minorities, and altruistic respondents.

Methods: Elicit preferences using discrete choice experiments (DCE's). The original design was piloted on 60 individuals, who completed a questionnaire (and had been asked to suggest other possible attributes) and then ranked attributes in order of priority. Following on from this a decision was taken about which attributes and levels should be included. Our final selection included the amount of time a person waited for a transplant; tissue type match; how many dependents (either adults or children recipients have); recipient age; diseases affecting life expectancy; and other recipient illnesses.

Data: Responses from 908 patients (including 96 ethnic minorities); 48 donors (or relatives of deceased donors); 41 carers; and 113 healthcare workers.

Results: Using interaction dummy variables we established that preferences differed comparing healthcare workers, donors, carers, and ethnic minorities to the patient group. There was also a statistically significant difference in preferences between patients who claimed to be altruistic "considering only what is best for others" and the rest of the sample.

Conclusions: Preferences expressed via DCEs may differ according to the stakeholder groups included, and altruistic vs. non-altruistic respondents.

Introduction / Aims.

Available statistics (UK Transplant 2006) suggest that in 2005 / 2006, 5,863 patients awaited a renal transplant (8% up on 2004 / 2005). However over that period only 1,203 received cadaveric transplants, and 590 received living donor transplants. Currently 13.1 million people are on the UK organ donor register. Despite this the numbers awaiting a renal transplant are increasing. This recently led the UKs Chief Medical Officer, Sir Liam Donaldson to call for reform. He wanted a policy whereby everyone would be placed on the organ donor register unless they opted out. However, even if such a reform was introduced it would take time to clear the backlog of patients

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awaiting transplantation. So a need remains to have an efficient system in place for organ allocation.

This research was initiated to determine the preferences of stakeholders in kidney transplantation using discrete choice experiments (DCEs). Stakeholder groups included patients, carers, donors / relatives of deceased donors, and healthcare professionals. Information on age, gender, ethnicity, and number of dependents respondents have, was gathered. Patient preferences are also analyzed in terms of transplant status (i.e. whether successfully transplanted or whether patients are still awaiting a transplant), age, and quality of life. We also wanted to establish whether preferences varied according to whether or not patients claimed to have altruistic preferences.

Equity in cadaveric transplantation has recently been raised to a high level of interest by several factors, including:

a) Recognition that current UK kidney allocation policy disadvantages those with less common tissue types and blood groups, creating a systematic disadvantage for ethnic minorities (Higgins et al. 1997).

b) A reduction in the importance of HLA matching in determining transplant outcomes (largely due to the development of anti-rejection drugs), providing the opportunity to develop the current matching system (Koene 2002).

c) External criticism of the current matching scheme (Sassi et al 2001).

Although there is some previous work in this area (Zenios et al 1999; Yuan et al 1994; Ubel et al 1993; Neuberger et al 1998; Wilmot et al 2004), only a minority is from the UK; little compares views from a full range of different stakeholder groups; and none includes the views or preferences of the families of cadaveric donors. There has been some good work involving the application of DCEs in transplantation, but this related to liver not kidney transplantation (Ratcliffe et al 2000).

Methods.

Key stages included:

1) Identifying choice dimensions and levels (for pilot questionnaire).

For the pilot DCE we held interviews with clinicians, to establish which attributes to include. We then selected 7 attributes, including:

a) Amount of time a person has waited: With levels of 1 month, 2 years, and 10 years.

b) Tissue type matching: With levels of non-favourable tissue type match; favourable tissue type match, and perfect tissue type match (with associated kidney survival rates of 86%, 89%, and 90% respectively).

c) Recipients employment status: With levels of not employed, part-time, and full-time.

d) How many dependent children recipients have: With levels of none, 1, or 4 children.

e) Extra years of life expectancy gained due to a transplant: With levels of 1, 5, or 12 years.

f) Recipient age: With levels of 20 years, 45 years, and 70 years.

g) Other recipient illnesses: With levels of healthy except for kidney disease; kidney disease with a condition sometimes affecting activities (asthma); or kidney disease with a condition that affects their activities on a daily basis (severe arthritis).

2) Design of the pilot questionnaire: We used SPEED v. 2.1 to generate a DCE design.

3) Interviews / administration of the pilot questionnaire: We conducted 60 interviews (41 patients, 16 healthcare workers, 1 carer, 1 donor, and a renal secretary). During interviews respondents were invited to suggest other potential attributes, and rank attributes in order of priority. Finally respondents filled in a DCE questionnaire.

4) Analysis of responses for the pilot exercise: Findings from interviews indicated that 31 / 60 of respondents thought that employment status shouldn't be considered (it was also the only insignificant attribute in the regression), therefore it was dropped; those with dependent children might be a priority, but respondents suggested those with adult dependents might also, so the attribute was changed to dependents (children or adults); the ceiling on recipient age was revised down to 65 years; finally the inclusion of an attribute relating to life expectancy resulted in unreal scenarios (70 year olds with severe arthritis expected to live for an extra 12 years, when 45 year olds without co-morbidities had shorter life expectancy). Therefore we changed this attribute to refer to diseases affecting life expectancy. Candidates for additional attributes included whether recipients would be likely to comply or lead a healthy lifestyle, and whether the illness was self-inflicted. However, the Renal Consultant on the project argued against the inclusion of these, since those considered unlikely to comply would not be transplanted anyway, and unlike liver problems renal problems are rarely self inflicted.

5) Selection of final attributes and levels: Attributes and levels included:

a) Amount of time a person has waited for a transplant (difwait): This had levels of 1 month, 2 years, and 10 years. Coding was such that the coefficient on the amount of time a person has waited for a transplant, related to how much respondents valued a 1 year reduction in waiting times.

b) Tissue type matching (diftiss): Attribute levels corresponded with figures from UK Transplant on transplant survival. Scenarios included 3 categories of tissue match, and respondents were presented with the information that:

- Non-favourable tissue match implies an 86% average kidney survival rate, 1 year post transplant.
- Favourable tissue match implies an 89% average kidney survival rate, 1 year post transplant.
- Perfect tissue type match implies a 90% average kidney survival rate, 1 year post transplant.

Coding of variables was such that coefficients on tissue type matching related to respondent valuation of transplanting to patients with a 1% increase transplant success. It follows that for a basic regression model, a difference between prioritising a perfect match rather than a non-favourable one is equivalent to $(90 - 86) \times \beta_2$ (β_2 is the coefficient on diftiss).

c) How many dependents (either children or adult) recipients have (difdep): This attribute had levels of No dependents, 1, or 4 dependents. Data was coded so the coefficient indicates the average value per extra dependent, of prioritizing people with dependents (either adults or children).

d) Recipient age (difage): This had levels of 20 years, 45 years, and 65 years. The coding was such that coefficients on recipient age indicated how much respondents valued prioritizing those who are younger (per year).

e) Diseases affecting life expectancy: These included (in addition to kidney disease): no disease; moderate diseases (uncontrolled hypertension or obesity); and severe disease (heart attack, stroke, or diabetes with complications). This discrete attribute was modelled using 2 discrete variables:

- **No disease affecting life expectancy (except kidney disease) rather than moderate disease (dif_Dis_n_to_m):** Looks at how much people value prioritizing people with no diseases affecting life expectancy (other than kidney disease), rather than moderate diseases (uncontrolled hypertension or obesity).
- **Moderate disease affecting life expectancy rather than severe disease (dif_Dis_m_to_s):** Looks at how much people value prioritizing people with moderate diseases affecting life expectancy in addition to kidney disease (such as uncontrolled hypertension or obesity), rather than severe diseases (heart attack, stroke, or diabetes with complications).
- **No disease rather than severe disease affecting life expectancy:** Established by summing the significant coefficients upon Dif_Dis_n_to_m and Dif_Dis_m_to_s.

f) Other recipient illnesses: These relate to non-life threatening diseases which affect quality of life. Levels included: healthy accept for kidney disease; kidney disease with a condition sometimes affecting activities (mild asthma); or kidney disease with a condition affecting daily activities (severe arthritis). Differences were modelled using 2 discrete variables:

- **No other recipient illnesses (accept kidney disease) rather than a moderate disease affecting quality of life(dif_ill_n_to_m):** Looks at how much respondents value prioritizing people without diseases affecting quality of life (other than kidney disease) rather than a moderate condition (mild asthma) affecting quality of life.
- **Moderate diseases affecting quality of life rather than a severe disease (dif_ill_m_to_s):** Looks at how much respondents value prioritizing people with a moderate disease affecting quality of life (mild asthma) rather than a severe disease (severe arthritis).
- **No disease rather than severe disease affecting quality of life:** This can be established by summing significant coefficients upon dif_ill_n_to_m and dif_ill_m_to_s.

The DCE questionnaires elicited other information. Patients were asked about their age; gender, whether they had dependents; their ethnicity; the perspective they adopted when answering the questionnaire (whether it was: what is best for me; what is best for me and others; or disregarding what is best for me and only considering others); their transplant status (i.e. successful, failed, on dialysis not transplanted, on waiting list etc); and Eq-5d quality of life questions were posed, and a Visual Analogue Scale (VAS) was included.

Questionnaires for carers, donors / relatives of deceased donors, and healthcare workers differed because information on transplant status and quality of life for these respondents was not requested. Donor versions asked whether respondents were relatives of deceased donors or live donors, whilst healthcare worker versions sought job descriptions.

6) Development of the final DCE questionnaire design: Dr Julie Ratcliffe (Consultant for the DCE questionnaire design) sourced a DCE design template from the design team working for Prof. Jordan Louvierre, which was used for the final DCE. It was a main effects design without a constant comparator with 18 pairwise choices. Half of these choices went into version A, and the other half into version B (we distributed equal numbers of each version).

7) Questionnaire distribution: 20,000 flyers and freepost reply envelopes were included in Kidney Life inviting patients, carers, donors, or healthcare workers to request a questionnaire. All renal patients from the British Organ Donor Society (BODY) had a questionnaire sent to them, and we targeted healthcare workers via a mailout to NHS trusts.

8) Data analysis: This was conducted using STATA v. 7. For the econometric analysis we ran model A for the overall sample, and sub-groups:

$$Y_i = \beta_0 + \beta_1 difwait + \beta_2 diftiss + \beta_3 difdep + \beta_4 difage + \beta_5 dif\_Dis\_n\_to\_m + \beta_6 dif\_Dis\_m\_to\_s$$

$$+\beta_7 dif\_ill\_n\_to\_m + \beta_8 dif\_ill\_m\_to\_s + \mu + \varepsilon \qquad \text{(Model A)}$$

Y_i is the binary dependent variable, μ is the random effects error term (which allows for multiple responses from each respondent) and ξ is the other Probit error term. We ran model A for the following groups of respondents:

Model 1: Pooled sample of all respondents (Patients, carers, donors / relatives of deceased donors, and healthcare workers).
Model 2: Patients
Model 3: Carers
Model 4: Donors
Model 5: Healthcare workers
Model 6: Non-white ethnic minority patients
Model 7: Asian patients.

<u>Models including interaction dummy variables.</u>

These models allow for comparison of the main body of the respondent sample with a defined sub-group, to establish whether there is evidence of statistically significant difference in preferences between the main sample and the subgroup. Therefore when comparing preferences between those respondents who indicated they disregarded what is best for them and only considered what is best for others (altruists), and those answering otherwise, we use a series of interaction dummy variables, using a model with the following functional form:

$$Y_i = \beta_0 + \beta_1 difwait + \beta_2 diftiss + \beta_3 difdep + \beta_4 difage + \beta_5 dif\_Dis\_n\_to\_m + \beta_6 dif\_Dis\_m\_to\_s$$

$$+\beta_7 dif\_ill\_n\_to\_m + \beta_8 dif\_ill\_m\_to\_s + \beta_9 Ddifwait + \beta_{10} Ddiftiss + \beta_{11} Ddifdep + \beta_{12} Ddifage$$

$$+\beta_{13} Ddif\_Dis\_n\_to\_m + \beta_{14} Ddif\_Dis\_m\_to\_s + \beta_{15} Ddif\_ill\_n\_to\_m + \beta_{16} Ddif\_ill\_m\_to\_s$$

$$+\mu + \varepsilon \qquad \text{(Model B)}$$

Variables with associated coefficients numbered 9-16 involve use of interaction dummy variables (indicated by an upper case ‘D’ prefix). Here:

D = 1 for all responses coming from those respondents indicating they are altruistic

D = 0 otherwise.

We also adopted this functional form to establish differences in preferences for the following:

Model 8: Patients generally vs. patients who have altruistic preferences.
Model 9: Patients generally vs. patients already successfully transplanted.
Model 10: Patients generally vs. patients currently awaiting a transplant.
Model 11: Patients generally vs. patients with Eq-5d scores in the lowest 1st quartile.
Model 12: Patients generally vs. patients with Eq-5d scores in the highest 4th quartile.
Model 13: Patients generally vs. patients with below average Eq-5d scores.
Model 14: Patients generally vs. patients with above average Eq-5d scores.
Model 15: Patients generally vs. patients with a VAS score in the lowest 1st quartile of quality of life.
Model 16: Patients generally vs. patients with a VAS score in the highest 4th quartile of quality of life.
Model 17: Patients generally vs. younger patients (1st quartile of the age distribution).
Model 18: Patients generally vs. older patients (4th quartile of the age distribution).
Model 19: Patients vs. carers.
Model 20: Patients vs. donor respondents (live donors or relatives of deceased donors).
Model 21: Patients vs. healthcare workers.
Model 22: Patients vs. non-white ethnic minorities.
Model 23: Patients vs. Asian ethnic minorities.

Presentation of results.

Significance of coefficients and predictive power of models: We indicate the significance or otherwise of coefficients as follows: ** Denotes significance at the 1% level; * Denotes significance at the 5% but not 1% level; the absence of an asterix indicates there is not a significant difference at the 5% level. Details of the percentage of actual values predicted by the model are indicated, and Mc Faddens R^2.

Marginal rate of substitution (MRS) in basic models: MRS relates to respondents average trade-offs, and the rate at which respondents would allow a deterioration in one attribute for an improvement in another (all things being equal). We assume a linearly additive main effects indirect utility function, so MRS is simply the ratio of two attributes (Lancsar et al 2007). For the purposes of this analysis we have expressed all the attribute difference coefficients as a ratio relative to how much people value a 1 year improvement in transplant waiting times (i.e. difwait). This was because difwait was significant in every econometric model, unlike some other attributes like diftiss. When a given coefficient is not statistically significant at the 5% level, we have assumed there is no difference, and MRS = 0.

Marginal rates of substitution (MRS) for models using interaction dummy variables: Interaction dummy variables can be used to establish whether there is evidence of a statistically significant difference in preferences between a sub-group and the wider sample. If there is a statistically significant difference for a specific dummy difference variable, then MRS for that attribute varies for that sub-group. However, if the coefficient on a given dummy difference variable is insignificant, we assume MRS doesn't differ compared to the wider sample.

Results.

Sample characteristics.

Key information on the sample (by stakeholder group) is tabulated below:

	Patients	**Carers**	**Donor**	**Healthcare workers**
AGE				
Mean age	54.88 years	52.37 years	54.67 years	43.23 years
GENDER				
Male	508 (56.1%)	10 (24.4%)	14 (29.2%)	51 (45.5%)
Female	397 (43.9%)	31 (75.6%)	34 (70.8%)	61 (54.4%)
ETHNICITY				
White (British)	812 (89.6%)	38 (92.7%)	44 (91.7%)	89 (78.8%)
White ethnic minorities	27 (2.9%)	1 (2.4%)	1 (2.1%)	9 (8%)
Non-white ethnic minorities	69 (7.6%)	2 (4.9%)	1 (2.1%)	11 (9.7%)
Asian groups	50 (5.5%)	1 (2.4%)	1 (2.1%)	9 (8%)
Not indicated	13 (1.4%)	0 (0%)	2 (4.2%)	3 (2.6%)
DEPENDENT CHILDREN				
0	755 (84.4%)	33 (80.5%)	36 (76.6%)	51 (45.9%)
1	72 (8%)	2 (4.9%)	5 (10.6%)	22 (19.8%)
2	49 (5.5%)	5 (12.2%)	2 (4.3%)	26 (23.4%)
3	12 (1.3%)	0 (0%)	3 (6.4%)	9 (8.1%)
> 3	7 (0.7%)	1 (2.4%)	1 (2.1%)	3 (2.7%)
DEPENDENT ADULTS				
0	750 (83.7%)	16 (40%)	39 (83%)	98 (87.5%)
1	121 (13.5%)	17 (42.5%)	6 (12.8%)	11 (9.8%)
2	17 (1.9%)	6 (15%)	2 (4.3%)	3 (2.7%)
> 2	8 (0.9%)	1 (2.5%)	0 (0%)	0 (0%)

The patient sample comprised of 586 / 908 patients (64.5%) who had transplants, and 118 failed (20.1%), but 468 (79.9%) had been successful; 279 / 908 patients claimed to be waiting for a renal transplant (average wait of 22.6 months); 237 / 908 patients (26.1%) had been on dialysis without transplantation; and 57 / 908 (6.3%) reported they had kidney disease but not dialysis.

There are 48 responses to the donor questionnaire (21 from living donors, and 27 from relatives of deceased donors). The healthcare worker sample comprised of 9 renal surgeons; 37 renal physicians; 17 transplant co-ordinators; 31 nurses; 9 clinical scientists; 1 GP; 1 dietician; 1 network manager; 1 transplant scientist; 1 medical student; 1 transplant immunologist; 1 tissue typer; 1 clinical audit manager; 1 renal technologist; and 1 renal pathologist.

Basic econometric models (model type A).

Whole sample.

Findings from model 1 (Table 1) suggest 7 / 8 of the difference variables are significant at the 1% level, but one difference variable (dif_Dis_n_to_m) is insignificant.

The coefficient on diftiss indicates respondents average valuations of a 1% improvement in kidney survival rates due to improved tissue match, it has an MRS of 1.32. Since the difference in transplant survival between a transplant involving a less favourable match rather than a favourable one is 3%, this implies that the MRS of transplanting to someone with a favourable rather than non-favourable match is equivalent to 1.32 x 3 (i.e. 3.96). Therefore if you had two patients available for transplantation of one organ (when transplantation for one would involve a non-favourable match, but for the other it would be favourable match), then all other things being equal, you would expect the patient with the less favourable match to have waited 3.96 years longer than the other patient to be considered of equal priority, and more than 3.96 years to be considered a higher priority. Similarly if the comparison was between those same 2 patients but one had a non-favourable match, and the other a perfect match then it would require the non-favourable match to have waited 5.28 years for them to be regarded as of equal priority. Whereas if the difference between them was a favourable vs. a perfect match, it would require the non-favourable match to have waited 1.32 years longer, for them to be of equal priority.

The variable difdep has an MRS of 1.38. This implies that those on the transplant list with dependents are rated as a higher priority. Therefore someone with no dependents (all other things being equal) would be expected to wait an extra 1.38 years for a kidney transplant, to be considered an equal priority relative to someone with 1 dependent. If the alternative candidate for transplantation had 4 dependents, then other things being equal, someone without any dependents would need to be on the waiting list for 5.52 years (1.38 x 4 = 5.52) to be of equal priority.

MRS on age indicates how much respondents value prioritising younger rather than older patients (i.e. for each year younger). At 0.19, it implies that if you had two patients in competition for one organ, and the older one had waited one year longer than the younger one, then all other things being equal the younger one would have to have be 5.26 years younger (i.e. 1 / 0.19 = 5.26) to be considered as of equal priority, and more than 5.26 years younger to be of greater priority.

Respondents do not overall prioritize people without a disease affecting life expectancy more than someone with a moderate disease affecting life expectancy (the difference variable pertaining to this is not significant). They would however prioritize those with a moderate disease affecting life expectancy, rather than a severe disease, and the MRS is 15.56. This implies all other things being equal, a person with a severe disease affecting life expectancy rather than a moderate one, would have to have waited 15.56 years longer to be considered of equal priority to a person with a moderate disease affecting life expectancy. Moreover, since a difference between having no diseases affecting life expectancy and a moderate disease affecting life expectancy is insignificant, a difference between prioritizing someone with no disease affecting life expectancy not a severe disease, has an MRS of 15.56.

The coefficient on dif_ill_n_to_m is negative. This suggests respondents would prioritize someone with a moderate disease affecting quality of life in preference to a person with no disease (other than kidney disease) affecting quality of life, and the associated MRS is -2.53. Thus if 2 patients were competing for one kidney, and one had a moderate disease affecting quality of life, and the other had no disease (other than kidney disease), then all other things being

equal, the person without a disease affecting quality of life would be expected to have waited for 2.53 years longer, to be considered of equal priority. This result may seem counter-intuitive, but may be due to the fact that respondents may feel those already suffering from impaired quality of life from a moderate illness, ought to be prioritized for surgery, enabling them to get off renal dialysis (so quality of life is not further impaired).

However, in contrast the coefficient on dif_ill_m_to_s is positive, suggesting people would prioritize a person with a moderate disease affecting quality of life more highly than someone with a severe disease affecting quality of life, perhaps because extending the life of someone with a severe disease affecting quality of life is considered a low priority. With an MRS of 4.74, this suggests that if there are 2 patients available for transplantation of one organ (differing only in terms of how long they had waited for a transplant and the fact that one of them had a severe illness affecting quality of life, whilst the other had a moderate one) then the person with a severe disease affecting quality of life would have to have waited 4.74 years longer to be considered of equal priority, and more than 4.74 years to be of greater priority.

Table 1: Whole sample (Patients, carers, healthcare workers, & donors).

Attribute	**Model 1: Whole sample – all groups**	**Implied MRS – relative to waiting time**	**Model 2: Patient group**	**Implied MRS – relative to waiting time**
Difwait	.0427**	1	.0443**	1
Diftiss	.0565**	1.32	.0624**	1.41
Difdep	.0589**	1.38	.0634**	1.43
Difage	.0080**	0.19	.0069**	0.16
dif_Dis_n_to_m	.0290	0	-.0004	0
dif_Dis_m_to_s	.6646**	15.56	.6789**	15.33
dif_ill_n_to_m	-.108**	-2.53	-.1207**	-2.73
dif_ill_m_to_s	.2022**	4.74	.1850**	4.18
Constant	.1226**		.1208**	
Number of respondents	1110		908	
% of actual values predicted	58.58%		64.03%	
Mc Faddens R^2	0.103		0.110	

Patient group.

The patient group comprised 81.8% of the sample overall, so it is unsurprising that the coefficients and MRS, are broadly similar for model 2 (table 1) compared to model 1 (table 1). The same 7 / 8 coefficients are significant, MRS figures change a little but changes are small. Therefore the findings from model 2 can be subjected to broadly similar interpretation to those for model 1, when the model 1 MRS figures are substituted in.

Carers donors and healthcare workers.

We ran the same basic econometric model (model type A) for carers (model 3 –table A1), donors (model 4 – table A1), and healthcare workers (model 5 –table A2), see appendix A. In the interests of brevity we do not provide any interpretation of these findings. We consider the more meaningful results for these groups arise when we use interaction dummy variables to compare preferences for them to patients.

Analysis of patient responses by ethnicity of respondent.

It was important to establish whether the preferences of ethnic minority patients differ from other patients. Some ethnic minority groups (especially Asians and Blacks) are both more likely to suffer from kidney disease (UK Transplant 2006), and more likely to be a poor tissue match. It is therefore likely their preferences might differ. This is why we have conducted separate analyses for non-white ethnic minority patients (model 6) and Asian patients (model 7). For details of the results of these analyses refer to appendix A (tables A2, and A3). We consider that examining differences in preferences comparing ethnic minority groups to the patient sample using interaction dummy variables provides more meaningful results, so we concentrate on these.

Interaction dummy variable models (model type B).

Analysis of preferences by the perspective adopted by respondents (altruistic vs. non-altruistic responses).

Respondents are asked "What perspective did you adopt when answering this questionnaire?." They were given 3 response options:

- Answering the questions in terms of what would be best for me.
- Answering the questions in terms of what would be best for me and others.
- Disregarding what is best for me and only considering what is best for others.

Overall 895 / 908 patients responded, 3.3% considered only what was best for them, 35.5% claimed they considered what was best for them and others, and 59.7% considered what was best only for others (altruistic responders). We used an interaction dummy variable model to establish whether preferences varied for those claiming to have altruistic preferences vs. other patients (model 8, table 2). Findings suggested that for 7 / 8 of the difference variables results did not differ between the groups. However those who identify themselves as altruistic responders attach a lower valuation to prioritising patients with more child / adult dependents (MRS = 1.06 vs. 1.74).

Table 2 - Model 8: Patients values vs. those purely for altruistic patients.

Attribute	Coefficient for patients in general	Implied MRS for patients in general (non-altruistic group)	Coefficient for dummy variable for patients who are 'altruistic.'	Implied MRS for patients in general – altruistics.[4]
Difwait	.0475**	1	-.0054	1
Diftiss	.0569**	1.20	.0096	1.20
Difdep	.0825**	1.74	-.0321**	**1.06**
Difage	.0081**	0.17	-.0019	0.17
dif_Dis_n_to_m	.0452	0	-.0739	0
dif_Dis_m_to_s	.6151**	12.95	.1097	12.95
dif_ill_n_to_m	-.0959*	-2.02	-.0410	-2.02
dif_ill_m_to_s	.2104**	4.43	-.0431	4.43
Constant	.1210**			
% of actual values predicted:	62.03%	**Sample:** 908 patients - 492 are altruistic	**Mc Faddens R^2:**	0.111

[4] When there is a difference in MRS for the group represented by an interaction dummy variable this is always indicated in **bold.**

Patient sample, with interaction dummy variables for those who are successfully transplanted.

Model 9 (table 3) establishes whether preferences differ amongst patients reporting they have been successfully transplanted (compared to patients overall). There is evidence of a statistically significant difference with respect to 2 difference variables (dif_Dis_m_to_s, and dif_ill_m_to_s). In both cases the findings suggest a higher MRS amongst the successfully transplanted respondents. Successfully transplanted patients place more emphasis upon prioritizing those with moderate rather than severe co-morbidities affecting length of life (MRS = 18.84 vs. 14.72); and place more emphasis upon prioritizing those with moderate rather than severe illnesses affecting quality of life (MRS = 6.04 vs. 3.17). Perhaps those who have been transplanted may have been less susceptible to co-morbidities, and may thus prefer to prioritize those like themselves.

Table 3 - Model 9: Patients values with interaction dummy variables for those who are successfully transplanted.

Attribute	**Coefficient for patients in general**	**Implied MRS for patients in general**	**Coefficient for dummy variable for the patients who are 'Successfully transplanted patients'**	**Implied MRS for the successfully transplanted group**
Difwait	.0404**	1	.0082	1
Diftiss	.0578**	1.43	.0079	1.43
Difdep	.0653**	1.62	-.0026	1.62
Difage	.0061**	0.15	.0011	0.15
dif_Dis_n_to_m	.0151	0	-.0386	0
dif_Dis_m_to_s	.5947**	14.72	.1666**	**18.84**
dif_ill_n_to_m	-.0880*	-2.18	-.0715	-2.18
dif_ill_m_to_s	.1281**	3.17	.1157*	**6.04**
Constant				
% of actual values predicted:	64.05	**Sample:** 896 patients	**Mc Faddens R^2:**	0.124

Patient sample, with interaction dummy variables for those who are currently waiting for a transplant.

Model 10 provided no evidence of a statistically significant difference in patient preferences for any attribute for those waiting for a transplant, compared to other patients (all interaction dummy variables proved insignificant). Therefore results are not presented.

Quality of life and patient responses.

We considered whether patient responses are affected by their quality of life. We ran econometric models with interaction dummy variables (model B). Using patient responses to Eq-5d we ran regression analyses for a sample of those in the lowest quartile in terms of Eq-5d scores (model 11), and then the highest quartile in terms of Eq-5d scores (model 12). These models suggested none of the interaction variables are significant, so we ran a model with an interaction dummy

variable for below average Eq-5d scores (model 13) and above average scores (model 14). Once again none of the interaction dummy variables proved to be significant.

We also used data from the Visual Analogue Scale (VAS), and found some evidence of statistically significant differences in preferences for 1 attribute in those within the lowest 1st quartile in terms of quality of life (see model 15, table 4). They regard prioritising those with moderate rather than severe disease as a lower priority (MRS for dif_Dis_m_to_s was lower). However, there was no evidence of a relationship between VAS and preferences for those in the 4th quality of life quartile (model 16). In the interests of brevity results from models 11, 12, 13, 14, and 16 are not presented.

Table 4 - Model 15: Patients values with interaction dummy variables for those in the lowest quartile (1st quartile) of quality of life as measured by a Visual Analogue Scale .

Attribute	**Coefficient for patients in general**	**Implied MRS for patients in general**	**Coefficient for dummy variable for the patients who are 'Successfully transplanted patients'**	**Implied MRS for the successfully transplanted group**
Difwait	.043**	1	.004	1
Diftiss	.065**	1.50	-.016	1.50
Difdep	.063**	1.44	.004	1.44
Difage	.007**	0.16	-.001	0.16
dif_Dis_n_to_m	-.014	0	.041	0
dif_Dis_m_to_s	.731**	16.84	-.236**	**11.41**
dif_ill_n_to_m	-.133**	-3.06	.051	-3.06
dif_ill_m_to_s	.195**	4.49	-.040	4.49
Constant	.122**			
% of actual values predicted:	62.96%	**Sample:** 895 patients	**Mc Faddens R^2:**	0.111

Respondent age and preferences.

Model 17 (table 5) uses interaction dummy variables to establish whether younger respondents (lowest quartile - aged 19-46) have different preferences to other patients. They value 1 attribute differently (dif_Dis_m_to_s [MRS = 3.86]), it is insignificant in the rest of the sample. Findings for the 4th quartile of the age distribution (model 18, table 6) show those aged 64 – 89 have a different MRS for all attributes compared to other patients. The coefficient on Ddifwait is significant and negative, so the denominator for MRS scores falls for all calculations.

Table 5 – Model 17: Patients values with interaction dummy variables for younger patients (in the 1st quartile of the age distribution).

Attribute	Coefficient for patients in general	Implied MRS for patients in general	Coefficient for dummy variable for the patients who are 'Successfully transplanted patients'	Implied MRS for the successfully transplanted group
Difwait	.0422**	1	.0101	1
Diftiss	.0611**	1.45	.0062	1.45
Difdep	.0660**	1.56	-.0064	1.56
Difage	.0067**	0.16	.0006	0.16
dif_Dis_n_to_m	-.0386	0	.1630*	**3.86**
dif_Dis_m_to_s	.6776**	16.05	0055	16.06
dif_ill_n_to_m	-.1147**	-2.72	-.0464	-2.72
dif_ill_m_to_s	.1679**	3.98	.0920	3.98
Constant	.1196**			
% of actual values predicted:	60.48%	**Sample:** 889 patients	**Mc Faddens R^2:**	0.112

Table 6 - Model 18: Patients values with interaction dummy variables for older patients (in the 4th quartile of the age distribution).

Attribute	Coefficient for patients in general	Implied MRS for patients in general	Coefficient for dummy variable for the patients who are 'Successfully transplanted patients'	Implied MRS for the successfully transplanted group
Difwait	.0483**	1	-.0147*	**1**
Diftiss	.0638**	1.13	-.0035	**1.90**
Difdep	.0652**	1.35	-.0035	**1.94**
Difage	.0073**	0.15	-.0016	**0.22**
Dif_Dis_n_to_m	.0291**	0	-.1130*	**-2.50**
Dif_Dis_m_to_s	.6920**	14.33	-.0490	**20.63**
Dif_ill_n_to_m	-.1510**	-3.13	.1004	**-4.50**
Dif_ill_m_to_s	.2326**	4.82	-.1713**	**1.83**
Constant	.1197**			
% of actual values predicted:	64.17%	**Sample:** 889 patients	**Mc Faddens R^2:**	0.112

Patient and carer sample, with interaction dummy variables for those who are carers.

For 1 / 8 of the difference variables, preferences are statistically significantly different between patients and carers (Model 19, table 7). It would appear that carers prioritize those with dependents (i.e. either adults or children) less than patients (MRS = 0.11 vs. 1.43). However findings are based on only 41 carer responses (in addition to 908 patients), and thus should be treated with caution.

Table 7 - Model 19: Patients values vs. those who are carers.

Attribute	Coefficient for patients in general	Implied MRS for patients in general	Coefficient for dummy variable for the patients who are 'Carers.'	Implied MRS for the carer group
Difwait	.0443**	1	-.0155	1
Diftiss	.0624**	1.41	-.0406	1.41
Difdep	.0634**	1.43	-.0584*	**0.11**
Difage	.0069**	0.15	-.0006	0.15
Dif_Dis_n_to_m	-.0004	0	.1209	0
Dif_Dis_m_to_s	.6789**	15.32	-.1966	15.32
Dif_ill_n_to_m	-.1206**	-2.72	.1109	-2.72
Dif_ill_m_to_s	.1849**	4.17	-.0319	4.17
Constant	.1207**			
% of actual values predicted:	63.44%	**Sample:** 908 patients and 41 carers	**Mc Faddens R^2:**	0.108

Patient and donor sample, with interaction dummy variables for those who are donors.

Model 20 (table 8), suggests that the preferences of the donor group vary in two respects. Relative to patients they value prioritising those with better tissue matches negatively not positively (MRS = -0.18 vs. 1.41). Moreover the donor sample value prioritising recipients with dependents negatively rather than positively (MRS = -0.13 vs. 1.43). Care should be taken in relation to these findings which are based on only 48 donor responses (plus 908 patient responses).

Table 8 - Model 20: Patients values vs. those who are donors.

Attribute	Coefficient for patients in general	Implied MRS for patients in general.	Coefficient for dummy variable for the patients who are 'Donors.'	Implied MRS for the donor group
Difwait	.0442**	1	-.0111	1
Diftiss	.0623**	1.41	-.0701*	**-0.18**
Difdep	.0632**	1.43	-.0689**	**-0.13**
Difage	.0069**	0.16	-.0024	0.16
Dif_Dis_n_to_m	-.0012	0	.1360	0
Dif_Dis_m_to_s	.6780**	15.34	-.2328	15.34
Dif_ill_n_to_m	-.1165**	-2.64	-.0277	-2.64
Dif_ill_m_to_s	.1820**	4.12	.0469	4.12
Constant	.1145**			
% of actual values predicted:	63.54%	**Sample:** 908 patients and 48 donors	**Mc Faddens R^2:**	0.108

Patient sample, with interaction dummy variables for those who are healthcare workers.

Model 21 (table 9) shows healthcare workers have statistically significant differences in preferences for 2 / 8 of the variables. They value prioritizing the young rather than the old more

highly (MRS = 0.44 vs. 0.16), and in contrast to patients, they place a value on prioritising those with moderate rather than no other diseases (apart from kidney disease) affecting life expectancy (MRS = 3.90 vs. 0).

Table 9 - Model 21: Patients values vs. those who are healthcare workers.

Attribute	**Coefficient for patients in general**	**Implied MRS for patients in general.**	**Coefficient for dummy variable for the patients who are 'healthcare workers.'**	**Implied MRS for the healthcare worker group.**
Difwait	.0444**	1	-.0057	1
Diftiss	.0625**	1.41	-.0133	1.41
Difdep	.0638**	1.44	-.0037	1.44
Difage	.0069**	0.16	.0124**	**0.44**
Dif_Dis_n_to_m	.0006	0	.1730*	**3.90**
Dif_Dis_m_to_s	.6803**	15.32	.0819	15.32
Dif_ill_n_to_m	-.1269**	-2.86	.0992	-2.86
Dif_ill_m_to_s	.1893**	4.26	.1381	4.26
Constant	.1301**			
% of actual values predicted:	63.52%	**Sample:** 908 patients and 113 healthcare workers	**Mc Faddens R^2:**	0.112

Patient sample, with interaction dummy variables for those who are non-white ethnic minorities.

Model 22 (table 10) indicates there are statistically significant differences between non-white ethnic minority groups, and patients overall with respect to 2 difference variables. For diftiss (differences in tissue match), 'non-white ethnic minorities' had a negative rather than a positive MRS (-0.06 vs. 1.54) suggesting they may prefer to prioritise people with poorer tissue match. Note many 'non-white ethnic minorities' are likely to have poorer tissue match because of a paucity of ethnic minority donors. They also place less emphasis upon prioritising those with moderate (uncontrolled hypertension or obesity) as opposed to severe co-morbidities (heart attack, stroke, or diabetes with complications), affecting life expectancy (MRS = 8.01 vs. 15.96). This may be partly attributable to the higher prevalence of diabetes and heart disease in this group.

Patient sample, with interaction dummy variables for those who are Asian minority groups.

Model 23 (table 11) indicates there are statistically significant differences between Asian ethnic minority groups and patients overall for the 2 same difference variables as 'non-white ethnic minorities.' This time the MRS for diftiss does not change sign, but is much lower than for the patient sample overall (MRS = 0.32 vs. 1.52). The Asian sample also places much less emphasis upon prioritising those with moderate rather than severe diseases affecting life expectancy (MRS = 3.42 vs. 15.80). This again may be due to the higher prevalence of severe co-morbidities affecting life expectancy amongst Asians (particularly diabetes, and heart attacks).

Table 10 - Model 22: Patient values vs. those who are non-white ethnic minorities.

Attribute	Coefficient for patients in general	Implied MRS for patients in general	Coefficient for dummy variable for the patients who are 'non-white ethnic minority patients.'	Implied MRS for non-white ethnic minority groups.
Difwait	.0445**	1	-.0011	1
Diftiss	.0687**	1.54	-.0714**	**-0.06**
Difdep	.0600**	1.35	.0389	1.35
Difage	.0074**	0.17	-.0047	0.17
dif_Dis_n_to_m	.0060	0	-.0681	0
dif_Dis_m_to_s	.7101**	15.96	-.3542**	**8.01**
dif_ill_n_to_m	-.1059**	-2.38	-.1644	-2.38
dif_ill_m_to_s	.1788**	4.02	.0709	4.02
Constant	.1216**			
% of actual values predicted:	63.78%	**Sample:** 908 patients – 69 are non-white ethnic minorities	**Mc Faddens R^2:**	0.112

Table 11 - Model 23: Patient values vs. those who are Asian ethnic minorities.

Attribute	Coefficient for patients in general	Implied MRS for patients in general	Coefficient for dummy variable for the patients who are 'Asian ethnic minority patients.'	Implied MRS for Asian patient groups overall.
Difwait	.0447**	1	-.0054	1
Diftiss	.0678**	1.52	-.0823**	**0.32**
Difdep	.0605**	1.35	.0424	1.35
Difage	.0073**	0.16	-.0057	0.16
dif_Dis_n_to_m	.0018	0.04	-.0156	0.04
dif_Dis_m_to_s	.7062**	15.80	-.4121**	**3.42**
dif_ill_n_to_m	-.1080**	-2.42	-.1944	-2.42
dif_ill_m_to_s	.1775**	3.97	.1207	3.97
Constant	.1217**			
% of actual values predicted:	63.91%	**Sample:** 908 patients (50 are Asian ethnic minorities)	**Mc Faddens R^2:**	0.112

Conclusions.

This paper presents evidence (model 2) suggesting patients generally value a range of criteria that can be used to prioritize patients for renal transplantation. They include the amount of time patients have waited; how good a tissue match recipients are; how many dependents (adults or children patients have); respondents age; whether patients have a moderate rather than a severe disease affecting life expectancy; whether patients have no disease (other than kidney disease)

affecting quality of life; and whether patients have a moderate not a severe disease affecting quality of life. However patients generally do not value a difference between whether patients have no disease affecting length of life vs. a moderate disease affecting length of life.

There is evidence of a difference in preferences between those who claim to have altruistic preferences rather than those who do not with respect to 1 attribute (model 8). Successfully transplanted patients also appear to have different preferences to patients who have not been successfully transplanted (model 9) for 2 variables. However there is no evidence of a difference in preferences comparing those who are currently waiting for a transplant vs. those who are not (model 10). Evidence of a relationship between patient respondent quality of life and preferences is weak. There is no evidence of any relationship between Eq-5d scores and preferences (models 11, 12, 13, and 14), There is evidence of a relationship between quality of life (as measured by VAS) and preferences for those in the lowest quartile with respect to quality of life, but for only 1 attribute (model 15), but no evidence of an association between DCE preferences and VAS scores for those in the highest quartile of VAS scores (model 16). The link between respondent age and preferences is stronger. Those in the lowest quartile of the age distribution (aged 19-46) have a different MRS with respect to 1 variable (model 17). However those in the highest quartile of the age distribution have a different MRS with respect to every variable (model 18).

Preferences also vary by stakeholder group. Compared to the patient sample carers have statistically significant differences in preferences for 1 / 8 of the variables (model 19); for donors there are differences relative to the patient group for 2 / 8 variables (model 20); and for healthcare workers with respect to 2 / 8 variables (model 21). There is also evidence that preferences differ according to the ethnicity of respondents. Non-white ethnic minorities have statistically significant differences in preferences for 2 / 8 variables compared to patients overall (model 22); and Asian ethnic minorities for to 2 / 8 variables (model 23).

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Appendix A.

Table A1: Carer group and Donor group

Attribute	Model 3: Carer group	Implied MRS – relative to waiting time	Model 4: Donor group	Implied MRS – relative to waiting time
Difwait	.0287**	1	.0357**	1
Diftiss	.0218	0	-.0043	0
Difdep	.0049	0	.0167	0
Difage	.0075*	0.26	.0046	0
dif_Dis_n_to_m	.1201	0	.1503	0
dif_Dis_m_to_s	.4818**	16.79	.4113**	11.52
dif_ill_n_to_m	-.0078	0	-.0688	0
dif_ill_m_to_s	.1516	0	.2095	0
Constant	.1174		.0085	
Number of respondents	41		48	
% of actual values predicted	50.54%		54.63%	
Mc Faddens R^2	0.061		0.070	

Table A2: Healthcare worker group, and non-white ethnic minority groups.

Attribute	Model 5: Healthcare worker group	Implied MRS – relative to waiting time	Model 6: Non-white ethnic minority patient groups	Implied MRS – relative to waiting time
Difwait	.0404**	1	.0421**	1
Diftiss	.0514**	1.27	-.0027	0
Difdep	.0631**	1.56	.0952**	2.26
Difage	.0196**	0.49	.0028	0
dif_Dis_n_to_m	.1818**	4.50	-.0705	0
dif_Dis_m_to_s	.7845**	19.42	.3480**	8.27
dif_ill_n_to_m	-.0707	0	-.2157*	-5.12
dif_ill_m_to_s	-.3640**	-9.01	.2081*	4.94
Constant	.2052**		.0366	
Number of respondents	113		69	
% of actual values predicted	59.43%		56.73%	
Mc Faddens R^2	0.129		0.075	

Table A3: Asian patients.

Attribute	Model 7: Asian patients groups	Implied MRS – relative to waiting time
Difwait	.0379**	1
Diftiss	-.0140	0
Difdep	.0992**	2.62
Difage	.0018	0
dif_Dis_n_to_m	-.0219	0
dif_Dis_m_to_s	.2874*	7.58
dif_ill_n_to_m	-.2482*	-6.59
dif_ill_m_to_s	.2578*	6.80
Constant	.0367*	
Number of respondents	50	
% of actual values predicted	57.14%	
Mc Faddens R^2	0.066	