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#### Abstract

We elicit time and risk preferences for kidney transplantation from the entire population of patients of the largest Italian transplant centre using a discrete choice experiment (DCE). We measure patients' willingness-to-wait (WTW), expressed in months, for receiving a kidney with one-year longer expected graft survival, or low risk of complication. Using a mixed logit in WTW-space model, we find heterogeneity in patients' preferences. Our model allows WTW to vary with the patient's age and duration of dialysis. The results suggest that WTW correlates with age and duration of dialysis. The implication for transplant practice is that including individual preferences in kidney allocation protocols that assign "non-ideal" (expanded donor criteria) organs may not only increase the expected survival rates of patients with transplanted organs but also improve patients' satisfaction.

#### Keywords

Stated preferences, Mixed logit, Willingness to wait, Marginal kidney

**JEL Codes** I18, I14, C90, D61

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# The role of heterogeneity of patients' preferences in kidney transplantation

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#### Abstract

We elicit time and risk preferences for kidney transplantation from the entire population of patients of the largest Italian transplant centre using a discrete choice experiment (DCE). We measure patients' willingness-to-wait (WTW), expressed in months, for receiving a kidney with one-year longer expected graft survival, or low risk of complication. Using a mixed logit in WTW-space model, we find heterogeneity in patients' preferences. Our model allows WTW to vary with the patient's age and duration of dialysis. The results suggest that WTW correlates with age and duration of dialysis. The implication for transplant practice is that including individual preferences' in kidney allocation protocols that assign "non-ideal" (expanded donor criteria) organs may not only increase the expected survival rates of patients with transplanted organs but also improve patients' satisfaction.

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# 1 Introduction

Kidney transplantation carries several advantages over dialysis treatment for patients with end-stage renal disease (ESRD) in terms of long-term mortality risk, improved survival rates and quality of life (Merion et al. 2005; Held et al. 2016). Nevertheless, the disparity between the large number of transplant candidates and the scarcity of organs available continues to increase. There are currently 94,754 patients<sup>1</sup> waiting for a kidney transplant in the US, and more than 33,000 of them have been waiting for more than three years. Recent data in both the US and Europe confirm that the demand for kidneys far outpaces supply (Hart et al., 2018), prompting physicians to push the limits of donor suitability to utilise organs from donors with characteristics different from the "ideal" situation. Selection criteria for donor appropriateness have been widened significantly in recent years to include older persons and those with co-morbidities such as hypertension, diabetes, suboptimal renal function, or risky behaviours that could potentially increase the risk of infectious disease transmission (the so-called Expanded Criteria Donors, ECD).<sup>2</sup> As a consequence, an increasing number of transplants are now performed by expanding the pool of donors to include those who would have been considered unsuitable before. The ECD program implemented since 2002 in the US and the Eurotransplant Seniors Program (ESP) implemented since 1999 in Europe are two examples of such policies.

The result of kidney transplantation from marginal donors is one of the most topical issues in the transplant literature (examples include Ojo et al. 2001, Metzger et al. 2003, Merion et al. 2005 and more recently Sunjae Bae et al. 2019). From a clinical point of view, ECD or "marginal" kidneys, while inferior to standard criteria donor (SCD) kidneys, may prolong the life of the recipient compared to dialysis treatment. Moreover, transplantation with a marginal donor kidney is more cost-effective than dialysis as a means of treating ESRD (Held et al. 2016; Eggers 1992; Eggers and Kucken 1994).

The functional recovery following a transplant crucially depends on the length of the cold ischemia time, defined as the interval between the procurement of the organ and its reperfusion during the recipient operation. Since kidneys begin to degrade during this

 $<sup>^1\</sup>mathrm{Based}$  on OPTN data as of March 7, 2019

<sup>&</sup>lt;sup>2</sup>Being precise, ECD are deceased donor kidneys conveying a 70% or higher risk for a graft loss for transplant recipients relative to the ideal donation and are characterised by a donor age older than 60 years or older than 50 years and accompanied by two additional risk factors, including a history of hypertension, elevated terminal donor creatinine, and cerebrovascular cause of death (Metzger et al., 2003).

cold ischemia time, surgeons typically transplant them within 24 hours. If the preferences of patients were known in advance and ECD organs were offered only to patients who are willing to accept them, the number of organs discarded could be substantially reduced. Recipients' preferences, however, are largely ignored in kidney allocation algorithms. This is true for any organ transplant, but, while in the case of other organs (e.g., liver, heart, and lung), alternative options are considerably limited, dialysis could be a reasonable option against which patients on the waitlist can balance costs and benefits. As a result, different patients may have heterogeneous preferences regarding the proposed treatment: they may prefer to wait longer with the prospect of receiving an "ideal" kidney, or they may be willing to accept an organ of inferior quality with the advantage of shorter waiting time. Preferences may or may not correlate with recipients' social, cultural, or economic status and psychological predispositions.

There is a limited but growing body of literature on ESRD patients' preferences. A recent paper by Agarwal et al. (2019) establishes an empirical framework to analyse how tradeoffs embedded in waitlist systems map into individual preferences and applies it to the allocation of deceased donor kidneys. The researchers develop a method for estimating patient preferences using administrative data and apply it to the kidney waitlist data from New York to estimate payoffs from various types of transplants. Reese et al. (2010) assessed patients' willingness to accept a kidney from a donor with an increased risk of blood-borne viral infection (DIRVI) in the USA, and Kamran et al. (2017) employed a discrete choice experiment (DCE) to evaluate patients' willingness to accept a marginal graft.<sup>3</sup> We contribute to this literature applying a DCE to investigate patients' preferences for the time and risk attributes of kidney transplantation and examine trade-offs for these attributes based on a willingness-to-wait (WTW) approach. We elicit preferences of the entire population of patients waiting for a transplant at the largest transplant centre in Italy, the Pancreas and Kidney Transplant Unit of the School of Medicine of the University of Padova. By using real patients waiting for a transplant rather than a sample from the general population, we minimise the chances a poor understanding of the alternatives from which respondents have to choose in the experiment. We find a significant WTW heterogeneity for all the attributes in the experiment. Moreover, WTW correlates with patients' age and duration of dialysis. Since reducing cold ischemia time and reducing or-

<sup>&</sup>lt;sup>3</sup>For a systematic review of discrete choice experiments and conjoint analysis studies measuring tradeoffs in nephrology, look at Clark et al. (2018).

gan waste are important design objectives for every kidney allocation scheme, our findings have important implications for the design of efficient kidney allocation algorithms.

The remainder of this article is organised as follows. Section 2 provides some background information about the Italian Transplant Network, the Pancreas and Kidney Transplant Unit of the School of Medicine of the University of Padova, where we run our experiment, and the subjects involved in the study. Section 3 describes the design of the experiment, Section 4 illustrates our modelling approach, Section 5 presents the results, and finally, Section 6 provides some discussion.

# 2 The Italian Transplant Network

In Italy, transplantation is an intervention that falls within the essential levels of assistance (LEA), i.e., those medical treatments that the Italian National Healthcare System (NHS) is required to provide free of charge to every citizen. For citizens who suffer from ESRD, all medical treatments, including dialysis and kidney transplant, are provided free of charge. There are 42 kidney transplant centres in Italy. A transplant centre is suggested to each ESRD patient who is declared suitable for a kidney transplant, which typically is the centre nearest to the patient's residence. A transplant candidate can also choose to enrol at any other centre provided there is an available slot: each transplant centre can have a maximum of 250 patients enrolled in its waiting list. There is no age limit for kidney transplant eligibility. All transplant activities in Italy are coordinated by the 'Centro Nazionale Trapianti' (Transplant National Centre) and three multi-region coordination programs - Nord Italia Transplant program (NITp), Associazione Interregionale Trapianti (AIRT), Organizzazione Centro-Sud Trapianti (OCST) - that cover the entire territory. The Pancreas and Kidney Transplant Unit of the School of Medicine of the University of Padova belongs to the NITp, which coordinates the transplant activities in five Italian regions in the north of the country. The allocation scheme for kidney transplants in these regions is managed by the NITp, which is responsible for the assignments of available organs from deceased donors to the single transplant centre.<sup>4</sup>

<sup>&</sup>lt;sup>4</sup>Patients who suffer end-stage renal disease can also receive an organ from a living compatible donor. Typically, this living donor is a relative of the patient. Patients who have an incompatible willing donor can also participate to Kidney Paired Exchange programs, which are designed to increase the number of transplants from living donors by exchanging donors among incompatible pairs. In this paper, we do not mention the option of living donations because none of the patients involved in our study had a compatible or incompatible donor. For further information visit www.trapianti.sanita.it

We administered a survey that included a few questions regarding socioeconomic status and 16 questions that constituted the actual Discrete Choice Experiment to all the 250 patients included on the waiting list for a kidney transplant at the Kidney and Pancreas Transplantation Unit of the University of Padova in April 2015.<sup>5</sup> The key advantage of interviewing this population was that respondents knew the precise nature of the problem and understood the proposed transplant attributes. A psychologist conducted face-to-face interviews using a Paper Assisted Personal Interview (PAPI) methodology. The interviewer explained the experiment and obtained informed consent from each participant. Two participants were discarded due to their psychological condition. The remaining 248 patients completed the questionnaire. Interviews took place on the day in which patients visited the transplant centre for their routine annual check-up. The first interviews took place on  $14^{th}$  April, 2015; the last took place on  $6^{th}$  June, 2017. Ethical approval for the study was obtained from the Ethical Committee of the University of Padova.

# **3** Design of the experiment

Discrete choice experiments (DCEs) are used to elicit individuals' stated preference parameters among alternative medical treatments (de Bekker-Grob et al. 2012; Ryan and Gerard 2003; Lancsar et al. 2011; Meenakshi et al. 2012; Fischer et al. 2018). Treatments are described by their underlying attributes, consistent with the Lancasterian theory of demand (Lancaster, 1966), and the alternatives are formed by varying the values taken by a set of attributes. Typically, each individual is asked to choose their preferred alternative from a list of choice sets, thus contributing multiple observations (Lancsar et al., 2017). The opportunity to include continuous variables, such as cost or waiting time attributes, allows researchers to estimate willingness to pay (WTP) (Hole 2008; Nieboer et al. 2010) or willingness to wait (WTW) (Brown et al. 2015; Rousseau and Rousseau 2012; Hagemi et al. 2017; Marshall et al. 2018) for variations in attributes' levels. Those measures constitute meaningful preference parameters if the results of the DCE are interpreted within a random utility framework (McFadden 1974; McFadden and Train 2000).

A crucial feature of this study is that we interviewed patients waiting for a transplant, as opposed to merely a sample from the general population, to reduce the possibility of poor understanding of the DCE. Following the same logic, we determined the attributes

<sup>&</sup>lt;sup>5</sup>A copy of the survey instrument in Italian and its translation to English is in the appendix.

and levels in consultation with the surgeons from the same transplant centre as the patients. Qualitative methods are increasingly used to determine attributes and levels in the design of discrete choice experiments (Coast and Horrocks, 2007), but consulting with the surgeons on the kidney transplant unit of Padova allowed us to use exactly the same wording that patients are accustomed to using when discussing the attributes included in the DCE. As an example, surgeons describe the infectious and neoplastic risks of a kidney as either standard or augmented to patients. This is an explicit choice made to emphasise to patients that a zero-risk kidney does not exist. Attributes and levels are reported in Table 1.

Attributes	Definition	Levels
Waiting time	The number of months one has to wait to obtain the proposed transplant	6, 12, 36, 60 months
Graft survival	The expected length of time the kidney functions well enough to keep recipients from either needing initiation (or return to) dialysis, or another transplant	10, 15, 20 years
Infectious risk	The risk of contracting infectious disease through the transplanted organ	Standard Augmented
Neoplastic risk	The risk of contracting a tumour through the transplanted organ	Standard Augmented

Table 1: Attributes and levels used to define the kidney transplant choices

Two attributes are enumerable (i.e., waiting time and expected graft survival). Waiting time is the number of months that patients can expect to wait to undergo the proposed transplant. This is our "numeraire", i.e. the attribute that allows us to compute WTW for changes in other attributes. The expected graft survival is the expected number of years of functioning of the transplanted organ. In the case of organ failure, patients return to dialysis and can be re-transplanted.

Infectious and neoplastic risk are qualitative attributes, but the levels are ordinal: augmented risk is higher than standard. A standard-risk kidney is an organ for which the evaluation process did not identify any risk factors for transmittable disease. Standard risk is the most frequent condition in the assessment of donors and grafts. Surgeons speak of standard-risk, and not zero-risk, kidneys since infectious or neoplastic diseases can be transmitted even if guidelines and good clinical practices are followed. An organ is labelled as augmented risk if certain medical tests could not be performed or the donor engaged in certain risky behaviours prior to death (e.g., use of drugs) that increase the probability of infections that cannot be detected immediately after contraction (Venettoni et al., 2006).

A full factorial design using the attributes and levels hitherto-defined would have resulted in 48 possible profiles (4 \* 3 \* 2 \* 2), leading to 1128 possible choice sets, which is clearly too many to be implemented in a DCE. We designed the experiment to be consistent with economic theory: since McFadden and Train (2000) demonstrated that a necessary precondition for the interpretation of parameters' estimates obtained from a DCE as preference parameters is the assumption of complete, monotone and transitive preferences, we selected choice sets that respect these axioms. Therefore, we restricted the design to 16 choice sets using a D-efficient algorithm that searches for a list of choice sets in which dominant alternatives do not appear, choice sets are not repeated, and the number of choice sets for which the answer can be inferred from the previous one is minimised (assuming transitivity and monotonicity).<sup>6</sup> The number of choice sets to be included was determined by a pilot study conducted by taking students as subjects, wherein we found no evidence of any fatigue effect with 16 choice sets.

Table 2 reports an example of a choice task. Patients were asked which of the two alternatives (A or B) they would prefer in each choice task. The four attributes taking specific levels described each alternative. We did not include an opt-out option in the choice tasks: in our context, an opt-out choice would mean remaining on dialysis. Since respondents were all patients enrolled in a waiting list for kidney transplantation, they already revealed to prefer receiving a transplant over remaining in dialysis.<sup>7</sup>

<sup>&</sup>lt;sup>6</sup>When a full factorial design is not feasible, the most common metric in design construction is Doptimality (Johnson et al., 2013). We then modified the AlgDesign Package in R (Aizaki and Nishimura, 2008) to be theory-consistent as explained.

<sup>&</sup>lt;sup>7</sup>Sometimes opt-out options in DCE are interpreted as indifference between the proposed treatments. The four attributes we chose are thought to be continuous, and the levels are realisations of (random) characteristics defining each "good" (Lancaster, 1966). As a result, completeness implies that the probability that a respondent is indifferent between any couple of alternatives is zero.

	Treatment A	Treatment B
Waiting Time	6 Months	6 Months
Expected Graft Survival	20 Years	15 Years
Infectious Risk	Standard	Standard
Neoplastic Risk	Augmented	Standard
Your Choice ?		

Table 2: Illustration of a choice task (Original in Italian): Which of the two treatments would you prefer? Put an X below the chosen treatment.

# 4 Econometric analysis

Response data from DCEs are modelled within a random utility maximisation framework (McFadden, 1974). The utility obtained by patient m from choosing kidney transplant alternative t in a choice set s is specified as a function of waiting time,  $time_{mts}$ , other attributes of the transplant (namely graft survival and infectious and neoplastic risk) included in the vector  $\boldsymbol{x}_{mts}$ , an alternative specific constant (ASC), and a random term,  $\varepsilon_{mts}$ , Extreme Value distributed with variance  $\mu_m^2(\pi^2/6)$ .

$$U_{mts} = V(time_{mts}, \boldsymbol{x}_{mts}, ASC_t) + \varepsilon_{mts}$$
  
=  $-\alpha_m time_{mts} + \boldsymbol{\beta}'_m \boldsymbol{x}_{mts} + ASC_t + \varepsilon_{mts}$  (1)

 $ASC_t$  controls for the 'residual' mean influence of unobservable sources of marginal utility (Berry et al., 1995). Since in the DCE at hand alternatives are randomly assigned label A or B in each choice set, this term controls for left-to-right (reading) bias (Ryan et al., 2018).

The probability patient m chooses treatment A in choice set s is defined as

$$P_{mAs} = Prob(U_{mAs} - U_{mBs} > 0) = 1 - Prob(U_{mAs} - U_{mBs} \le 0)$$
$$1 - Prob(\varepsilon_{maAs} - \varepsilon_{mBs} \le V(time_{mAs}, \boldsymbol{x}_{mAs}, ASC_A) - V(time_{mBs}, \boldsymbol{x}_{mBs}, ASC_B) \quad (2)$$

If patients' preferences are complete, monotone, and transitive, assuming a distribution for the taste coefficients  $\alpha_m$  and  $\beta_m$ ,  $P_{mAs}$  defines a latent variable model that can be estimated with a mixed multinomial logit (McFadden and Train, 2000).

The coefficients  $\alpha_m$  and  $\beta_m$  represent the preferences of patient m. Alternatively, an easier way to interpret heterogeneity in preferences is to resort to Willingness to Wait (WTW). The WTW for attribute k is the number of months patient m is willing to wait for an extra level of attribute k, that is, the marginal rate of substitution between attribute kand *time*:

$$WTW_{km} = -\frac{\partial U/\partial x_{k,m}}{\partial U/\partial time_m} = -\frac{\beta_{k,m}}{\alpha_m}$$
(3)

The distributional assumptions on the preference coefficients determine the distribution of  $WTW_{km}$ . The standard approach to ensuring a well defined distribution for  $WTW_{km}$ is to assume that the coefficient  $\alpha_m$  is not random, implying each vector  $WTW_m$  has the same distribution of  $\beta_m$ . This approach is problematic since  $\varepsilon_{mts}$  variance depends on  $\mu_m$ , a patient–specific scale-parameter. If  $\alpha_m$  is not random, then for all k,  $WTW_{km}$  are not scale free, and variation in  $\mu_m$  can induce variation in  $WTW_{km}$ , holding taste coefficients constant. In other words, variation in scale will be confounded with the variation in WTW for transplant attributes (Train and Weeks, 2005). An alternative approach is to assume  $\alpha_m$  to be log-normally distributed. Still, this would result in unrealistic estimates of the means and standard deviation of WTW values and heavily skewed distributions (Hole and Kolstad, 2012). To overcome these problems, we follow Hensher and Greene (2011), re-parametrise the model, and estimate the multinomial mixed logit in WTW space. The individual utility function (1) can be rewritten as follows:

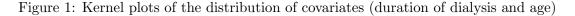
$$U_{mts} = -\alpha_m \left[ time_{mts} - \left(\frac{1}{\alpha_m}\right) \boldsymbol{\beta}'_m \boldsymbol{x}_{mts} \right] + ASC_t + \varepsilon_{mts}$$

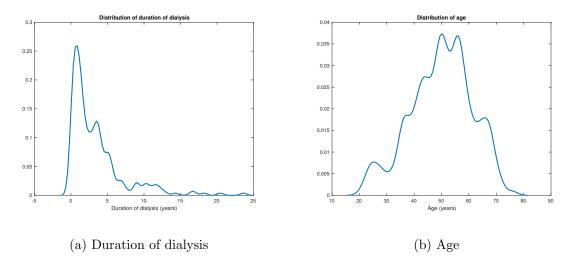
$$= -\alpha_m \left[ time_{mts} - \boldsymbol{WTW}'_m \boldsymbol{x}_{mts} \right] + ASC_t + \varepsilon_{mts}$$
(4)

The time attribute parameter  $\alpha_m$  becomes the normalising constant in the WTW space representation. We can now directly assume a distribution of  $WTW_m$  rather than of the original preference coefficients. We assume each  $WTW_{km}$  to be normally distributed and, following Hole and Kolstad (2012),  $\alpha_m$  to be log-normally distributed. The model hitherto-outlined allows for heterogeneity in unobservable characteristics. Nevertheless, preferences in kidney transplantation may also differ along observable dimensions (Roth et al., 2004). Whether or not  $WTW_m$  correlates with patients' observable characteristics constitutes an important question from a policy perspective: observable characteristics can easily be included in kidney allocation protocols.

We focus on age and duration of dialysis. Age has been found to affect time and risk preferences in many domains (Morin and Suarez, 1983; Bishai, 2004), while patients who have spent longer periods in dialysis are typically given priority in allocation protocols.

Figure 1 presents the kernel density plots of the distributions of duration of dialysis and age, respectively. Duration of dialysis is left-skewed, with a larger part of the mass between zero and five years but a long right tail (figure 1a) accounting for patients for whom it is more difficult to find a compatible kidney. Conversely, the age distribution is fairly symmetric (figure 1b). The difference in skewness of the two distributions, and therefore the low correlation between age and duration of dialysis, can be explained by the fact that the probability of a patient finding a compatible organ depends primarily on the tissue type, regardless of age.





To account for age and duration of dialysis, we assume that the mean of each  $WTW_{km}$ and of  $\lambda_m$  depend on the socioeconomic variables:

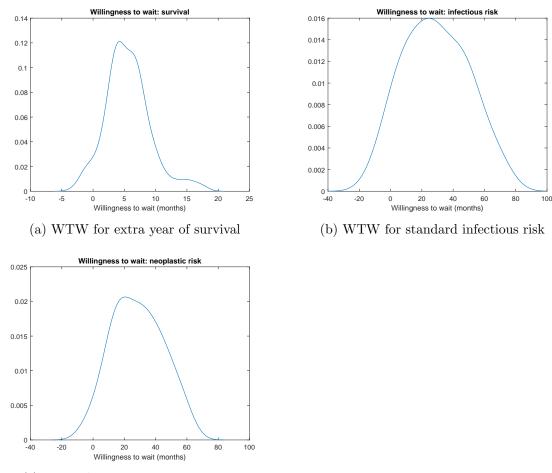
$$WTW_{mk} = \delta_{okm} + \delta_{1km}age + \delta_{2km}dialysisduration, \quad \forall k = 1, 2, 3$$
 (5)

$$\alpha_m = exp(\gamma_{om} + \gamma_{1m}age + \gamma_{2m}dialysisduration) \tag{6}$$

In other words, we allow  $WTW_{mk}$  to vary across individuals both randomly and systematically with age and duration of dialysis. We refer to this model as the 'mean heterogeneity in WTW-space' model. Detailed discussion on how to account for heterogeneity around the mean of the distribution in the mixed logit framework can be found in Greene et al. (2006) and Bhat (2000).

# 5 Results

Figure 2 reports the kernel density plots of the WTW estimates. The plots immediately highlight a substantial dispersion in the distributions, pointing to significant preference heterogeneity across patients.



(c) WTW for standard neoplastic risk

Figure 2: Kernel density plots of the distribution of individual WTW

The WTW for an extra year of graft survival, presented in panel 2a, is concentrated at about five months, with a long right tail implying the presence of a small number of patients who are willing to wait longer than the average WTW. The mean and median of the distribution are, in fact, close to each other: 50% (125) of the patients are willing to wait more than five months for a transplant that will offer an extra year of survival. In figure 2b and 2c, the distributions are less concentrated than the one shown in figure 2a, suggesting even more heterogeneity in WTW for changes in the risk attributes. The left tails of the distributions are in the negative domain, implying that some respondents prefer shorter graft survival or higher infections and neoplastic risk. This is becasuse we assumed **WTW**<sub>m</sub> to be normally distributed, i.e., we did not impose any restriction on

the sign of WTW estimates. In Table 3, we report the first and second moments of the empirical distribution of each parameter estimate. The means are all significantly different from zero and have the expected sign. The standard deviations (SD, column 2) are also significant and sizeable, supporting the evidence in favour of preference heterogeneity.

(1)	(2)
(Mean)	(SD)
-2.714***	0.932***
(0.089)	(0.117)
5.315***	4.694***
(0.476)	(0.412)
27.968***	24.619***
(1.994)	(1.963)
27.670***	21.017***
(2.143)	(2.121)
3.477 ***	-
(0.699)	
7936	
248	
-2134.741	
0.193	
4350.294	
	$(Mean)$ $-2.714^{***}$ $(0.089)$ $5.315^{***}$ $(0.476)$ $27.968^{***}$ $(1.994)$ $27.670^{***}$ $(2.143)$ $3.477^{***}$ $(0.699)$ $7936$ $248$ $-2134.741$ $0.193$

Table 3: Baseline multinomial mixed logit, empirical distributions first and second moment

Standard errors in parentheses, \* p < 0.1, \*\* p < 0.05, \*\*\* p < 0.01

Abbreviations: BIC Bayesian Information Criterion, ASC: Alternative Specific Constant, SD: standard deviation.

The mean WTW for a kidney that will offer an additional year of graft survival is about five months.<sup>8</sup> On average, patients are willing to wait, *ceteris paribus*, 27 to 28 months longer for a kidney of standard risk as compared to one of augmented risk.

The mean of ASC is statistically significant indicating the presence of left-to-right biases in our data, a result common to many other DCEs in the health domain (see e.g. Determann et al., 2017).

<sup>&</sup>lt;sup>8</sup>We estimated an alternative version of the model to estimate WTW for a 5-year graft survival differences, the same time span as in the proposed levels of the graft survival attributes. Results are reported in Appendix A.1 and are in line with those reported here.

Estimates in Table 3 do not account for systematic differences driven by observable characteristics. As we explained in section 4, there are good reasons to investigate whether at least part of the heterogeneity can be associated to differences in age and duration of dialysis. We now discuss the estimates of the model accounting for mean heterogeneity reported in Table 4.

## 5.1 Age

Time and risk preferences have been found to vary with age in several domains. We expect that differences in life expectancy cause WTW in attributes of kidney transplantation to vary according to patients' ages. Column 3 of Table 4 shows the mean of the empirical distribution of the marginal effect of age on  $WTW_m$ : all the coefficients are statistically significant at the conventional level. All else equal, every additional year of age reduces WTW for an extra year of graft survival by 0.1 months (3 days). Similarly, an extra year of age reduces the WTW for a standard infectious risk by 0.3 months (9 days) and the WTW for a standard neoplastic risk by about 0.4 months (12 days).

	(1)	(2)	(3)	(4)
	(Mean)	(SD)	(Age)	(Duration of dialysis)
Waiting time $(\alpha)$	-3.433***	0.982 ***	0.017 **	-0.046 *
	(0.427)	(0.124)	(0.008)	(0.025)
$WTW_{survival}$	$9.198^{***}$	4.273***	-0.101***	0.428***
	(1.771)	(0.326)	(0.033)	(0.087)
$WTW_{standard infectious risk}$	36.599***	24.234***	-0.260**	1.585***
·	(7.223)	(1.875)	(0.130)	(0.281)
$WTW_{standard\ neoplasticrisk}$	42.584***	21.240***	-0.359**	1.019 ***
-	(9.272)	(1.934)	(0.164)	(0.382)
ASC	3.363 ***			
	(0.652)			
Number of observations	7936			
Number of respondents	248			
Log-likelihood	-2124.516			
$McFadden-R^2$	0.197			
BIC	4401.67			

Table 4: Mean heterogeneity in WTW-space model results

Standard errors in parentheses, \* p < 0.1, \*\* p < 0.05, \*\*\* p < 0.01

Abbreviations: BIC Bayesian Information Criterion, ASC: Alternative Specific Constant, SD: standard deviation.

Observable differences in age account for a significant proportion of heterogeneity in WTW: Table 5 shows the WTW for each attribute at different values of age using the coefficient estimates from Table 4 of equation 5. In each line of the table, we assign specific values for age (21-80) and fix duration of dialysis at its mean (3.4 years). A patient with an age of 21 years (the lowest value observed in our data) and with 3.4 years of dialysis is willing to wait 8.5 months for a kidney that will offer an expected additional year of functioning. WTW drops substantially with age: a 65 years old patient with the same duration of dialysis (3.4 years) is willing to wait only 4 months longer for an additional year of graft survival.

	(1)	(2)	(3)
Age (years)	$WTW_{survival}$	$WTW_{infectious}$	$WTW_{neoplastic}$
21	8.52	36.49	38.49
25	8.11	35.45	37.05
30	7.61	34.15	35.25
35	7.10	32.85	33.45
40	6.59	31.55	31.66
45	6.09	30.25	29.86
50	5.58	28.95	28.06
55	5.08	27.64	26.27
60	4.57	26.34	24.47
65	4.07	25.04	22.67
70	3.56	23.74	20.87
75	3.05	22.44	19.08
80	2.55	21.14	17.28

Table 5: WTW for different age levels and for an average duration of dialysis (3.4 years)

The WTW values are obtained using Equation 5 and the coefficient estimates from Table 4. To use Equation 5, we assign specific values for age (21-80) and take the mean of duration of dialysis (3.4 years).

Our findings complement previous studies that have used administrative data. For instance, using data from the Scientific Registry of Transplant Recipient database and based on survival models, Schold and Meier-Kriesche (2006) showed that older patients (those 65 years and above) had longer life expectancy when they accepted an ECD after two years of dialysis (5.6 years) compared with waiting for a standard kidney (5.3 years) or a living donation (5.5 years) after four years of dialysis. The same study also indicated that younger patients (18-39 years old) had longer life expectancy with a living donation (27.6 years) or standard kidney (26.4 years) after four years on dialysis compared with an ECD after two years of dialysis (17.6 years). In the study by Jay et al. (2017), pre-emptive transplantation of "non-ideal" kidneys on recipients over the age of 60 reduces mortality hazard compared with the waitlist, including transplant recipients of standard quality kidneys. In other words, patients in our experiment are "rational": they are willing to accept "worse" kidneys as they age, and previous literature shows that this choice would increase their life expectancy.

We provide evidence that younger patients are willing to wait longer for a kidney transplant characterised by better levels of the attributes (i.e., an extra year of graft survival, standard infectious risk, and standard neoplastic risk) compared to older patients. In Appendix B.1, we report evidence that the full distribution is shifted to the left for older individuals, suggesting that keeping patients on the waiting list as they age may change their preferences. However, accounting for the dynamics in preferences and WTW as age increases would necessitate observing a patient at two points in time, which is beyond the scope of this study.

## 5.2 Duration of dialysis

Patients who are diagnosed with irreversible chronic kidney failure and lack access to pre-emptive transplantation need to undergo dialysis treatment whilst waiting for kidney transplantation. The length of stay on dialysis depends, among other factors, on initial health condition and on the probability of finding a compatible organ, which depends not only on their blood type but also, even more importantly, on their tissue type. Every individual has some donor-specific anti-HLA (Human Leukocyte Antigen) antibodies that prevent the patient from receiving a kidney from certain donors. Roughly speaking, the more of these antibodies a patient has, the less likely the patient is to find a compatible organ because the patient has to wait for an HLA-compatible kidney. This means that transplant candidates with longer dialysis history are often those with a large number of anti-HLA antibodies. As a consequence, almost all allocation mechanisms prioritise individuals that have spent a long period of time on dialysis for reasons of fairness. This allocation rule may not be optimal, however, if preferences change with the duration of dialysis. This is precisely what we want to investigate in this section: how  $WTW_m$  differs according to the duration of dialysis.

Results are presented in column 4 of Table 4. The coefficients of 'Duration of dialysis'

on all the attributes are positive and significant, indicating that the longer the duration of dialysis, the longer patients are willing to wait for a kidney with a better-expected outcome.<sup>9</sup> To be more specific, on average, a patient with an extra year of time spent in dialysis is willing to wait an additional 0.4 months (12 days) for a kidney that will offer an extra year of graft survival. Similarly, every additional year spent in dialysis increases WTW for a kidney with standard, rather than augmented, infectious risk by 1.6 months and increases WTW for a kidney with standard neoplastic risk by one month. As for age, the mean heterogeneity in the WTW-space model highlights that preference heterogeneity is associated with a key observable patients' characteristic, namely time spent in dialysis.

Duration of	(1)	(2)	(3)
dialysis (years)	WTW <sub>survival</sub>	$WTW_{infectious}$	$WTW_{neoplastic}$
0.5	4.35	24.38	25.12
1	4.57	25.17	25.63
2	4.99	26.75	26.65
3	5.42	28.34	27.67
4	5.85	29.92	28.69
5	6.28	31.51	29.71
6	6.70	33.09	30.73
7	7.13	34.68	31.75
8	7.56	36.26	32.77
9	7.99	37.85	33.79
10	8.42	39.43	34.81
11	8.84	41.02	35.83
12	9.27	42.60	36.85
15	10.56	47.36	39.91
20	12.69	55.28	45.00

Table 6: WTW for different duration of dialysis and for an average age (50 years)

The WTW values are obtained using Equation 5 and the coefficient estimates from Table 4. To use Equation 5, we assign specific values for the duration of dialysis (0.5-20) and keeping age at its mean value (50 years).

In Table 6, we show how WTW for changes in each kidney transplantation attribute varies for different values of duration of dialysis, holding age fixed at its mean value (50 years). The model indicates that for a patient with an average age of 50 years and dialysis duration of six months (0.5 years), the WTW for a kidney that will offer one additional year of graft survival is about 4.4 months. A 50-year old patient with 6 years on dialysis

 $<sup>^{9}</sup>$ The duration of dialysis was obtained by taking the difference between the date of interview and the starting date of dialysis.

is willing to wait about 7 months for a kidney that will provide an additional year of graft survival. As we did for age, we report in Appendix B.2 some further analysis on how the shape of the distribution of WTW changes with the duration of dialysis. We show that the distribution is shifted to the left and the shape changes substantially for patients with longer duration of dialysis. In other words, the degree of preference heterogeneity increases with dialysis duration.

# 6 Discussion and conclusions

In this paper, we elicit the preferences from a population of patients waiting for a kidney transplant by using a DCE. We estimate individual WTW parameters for changes in the expected graft survival and risk attributes of deceased donors' organs. Experimental design and econometric specification of the model used to analyse the data control as much as possible for restrictions imposed by the underlying utility maximisation framework in order to reduce confounding effects in preference parameters estimation. The baseline results point to heterogeneity in the patients' time and risk preferences. We then devise a model that accounts for systematic differences in preference parameters due to age and duration of dialysis, both observable characteristics of the patients. Both patients' age and their duration of dialysis are significant predictors of WTW for changes in the attributes of kidney transplantation. Younger patients are willing to wait longer compared to older patients for a better kidney, and patients with longer duration of dialysis are willing to wait longer for a better organ.

Almost half of the patients aged 60 and above are projected to die before receiving a kidney transplant due to organ shortages and prolonged waiting times (see Schold et al., 2009). "Non-ideal" kidneys, or extended criteria donor (ECD) kidneys, represent an opportunity for increasing access to earlier transplantation for older patients, as already acknowledged in the medical literature (see Jay et al., 2017).

Assigning "marginal", or ECD, organs to older patients would increase the number of transplants and reduce the number of wasted organs. Our results suggest that a large proportion of older patients waiting for a transplant would be willing to accept an ECD kidney to reduce waiting time. Moreover, we demonstrate that age is inversely related to WTW for a better organ, and could, therefore, be used in kidney allocation algorithms to reduce cold ischemia time by assigning ECD organs to patients willing to accept them. Currently in Italy, the possibility of a preemptive kidney transplant, performed before the

patient begins dialysis, from a deceased donor organ is almost excluded from consideration (except for paediatric patients). There is considerable evidence, however, that preemptive transplantation has several clinical advantages. One of the main reasons for the failure to consider the possibility of a pre-emptive kidney transplant from a deceased donor organ pertains to the ethical concern around the unintended harmful effects on waiting list patients on dialysis. Our study suggests that older patients may even be willing to accept lower-quality kidneys that would be discarded if not allocated immediately.

Our study also provides evidence that patients with a longer duration of dialysis are willing to wait for longer than patients with similar demographic characteristics but a shorter duration of dialysis. This result needs further investigation. The amount of time that a given patient can expect to spend on the waiting list, which depends on blood type and HLA antibodies, is predictable. Therefore, it may be the case that such patients develop different time preferences compared to other patients because they have been aware since their time of enrolment on the waiting list that they have less chance of finding a compatible organ.

#### **Competing interests**

None.

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# A Appendix

# A.1 5-year graft survival differences

The results are presented in Table 7 and Figure 3. The variable ' $WTW_{SURVIVAL (15 YEARS)}$ ' relates to the average WTW for a kidney that offers 15 years of survival rather than 10 years. The benchmark for comparison is an organ which will offer 10 years of survival. On average, patients are willing to wait, *ceteris paribus*, 13.7 months longer for a kidney that will offer 15 years of survival rather than 10 years.

	(1)	(2)
	(Mean)	(SD)
Waiting time $(\lambda)$	-2.759***	1.398***
	(0.118)	(0.170)
$WTW_{survival (15 years)}$	13.783***	4.207***
	(1.484)	(1.373)
$WTW_{survival (20 years)}$	38.861***	14.199***
	(2.239)	(1.824)
$WTW_{standard\ infectious\ risk}$	28.202***	21.689***
	(0.971)	(1.655)
$WTW_{standard\ neoplastic\ risk}$	24.767***	-18.038***
	(1.406)	(1.686)
ASC	1.686 ***	-
	(0.519)	-
Number of observations	7936	
Number of respondents	248	
Log-likelihood	-2139.54	
$McFadden-R^2$	0.269	
BIC	4377.851	

Table 7: Multinomial mixed logit in WTW-space model, empirical distributions first and second moment (normal, waiting time-log-normal)

Standard errors in parentheses, \* p < 0.1, \*\* p < 0.05, \*\*\* p < 0.01

Abbreviations: BIC Bayesian Information Criterion, ASC: Alternative Specific Constant, SD: standard deviation.

The WTW for a kidney that will offer 20 years of graft survival compared to 10 years of survival is about 40 months longer. The WTW increases by 25 months when the expected graft survival changes from 15 to 20 years, which is consistent with the WTW of 5 months for an additional year of graft survival.

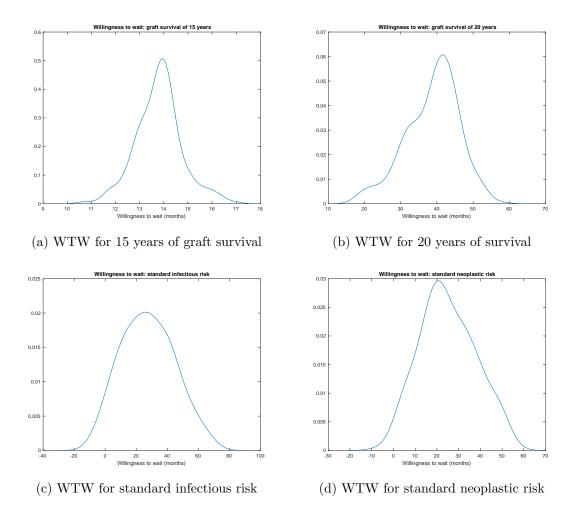


Figure 3: Kernel density plots of the distribution of individual WTW

In the model recalibrated for a 5-year difference in the expected graft survival (Table 7), we find that patients are willing to wait 28 months longer for a kidney of standard infectious risk rather than an augmented risk, keeping all other factors constant. Further, patients are willing to wait 24.8 months longer for a kidney of standard neoplastic risk rather than a kidney of augmented neoplastic risk.

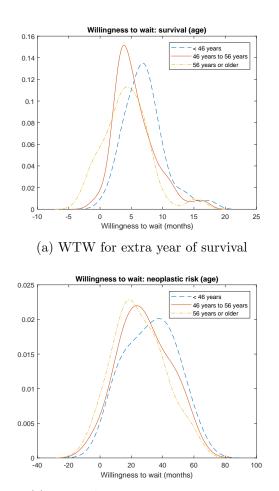
The distribution of WTW for 15 years of expected graft survival presented in panel 3a, indicates heterogeneity in WTW: the distribution is concentrated around 14 months. In figure 3b, the distributions are more dispersed compared to figure 3a, indicating that there is more heterogeneity in the WTW for 20 years of graft survival than for 15 years.

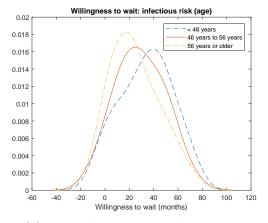
# **B** Appendix

In this section, we employ kernel density plots to display the heterogeneity in WTW for changes in the lvels of each transplant attribute and to examine how WTW varies with observable characteristics. We also present the cumulative density functions (CDF) of WTW estimates to describe variations in the WTW in terms of the first-order and second-order stochastic dominance approach.

# B.1 WTW distributions across age groups

Figure 4 presents the distributions of the WTW for each of the three attributes.





(b) WTW for standard infectious risk

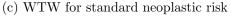
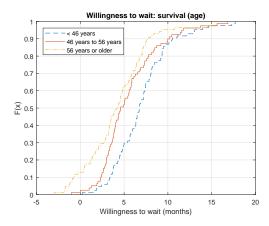
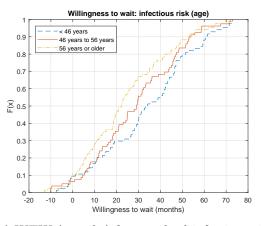


Figure 4: Kernel density plots of the distribution of WTW: effect of age

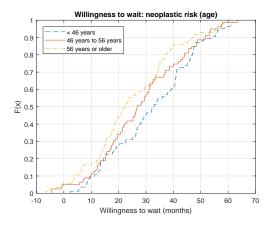
The plots are generated for three age groups: younger than 46, 46-56, and 56+ years of age. In fig 4a, the distributions of WTW for changes in each attribute across the three age groups differ, and for patients aged 56 years and above, the entire distribution is shifted to the left. For a kidney transplant that will offer an extra year of graft survival, the distribution of WTW is more dispersed among older patients (56+ years) than the other age groups. In figures 4b and 4c, the entire distribution of WTW for a transplant with standard risk attributes among patients of 56 years and above is shifted to the left and becomes more concentrated, implying less variability in WTW among older patients.



(a) WTW (months) for extra year of survival



(b) WTW (months) for standard infectious risk



(c) WTW (months) for standard neoplastic risk

Figure 5: Visual representations of the CDF of WTW values: effect of age

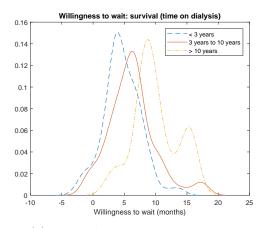
In Figure 5, we show the cumulative density functions (CDFs) of the WTW for changes

in each of the three attributes. The plots demonstrate that the WTW for each attribute among patients in the first two age groups (younger than 46 and 46-56 years of age) firstorder stochastically dominates the older groups (+56 years). The first-order stochastic dominance provides evidence that for a given initial level of WTW, the probability that WTW exceeds the initial WTW is higher among the younger patients than the older ones. For example, given an average WTW for standard infectious risk of 28 months, the probability that WTW exceeds 28 months is higher among the younger patients than the older ones, suggesting that an increase in age is expected to shift the distribution of WTW to the left, thus producing a lower WTW. This implies that keeping a patient on the waiting list as age increases may alter preferences and, hence, the WTW. Accounting for the dynamics in preferences and WTW as age increases, however, would necessitate observing a patient at two points in time.

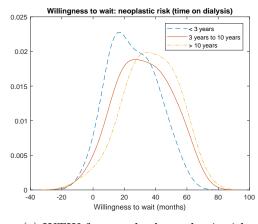
#### B.2 WTW distribution and duration of dialysis

We also present the differences in the shape of the distribution of WTW across three groups of patients according to the duration of dialysis: those who have spent less than 3 years on dialysis, those who have spent 3 to 10 years on dialysis, and those who have spent over 10 years on dialysis. The data reveals that 58.87% (146 patients) had spent less than 3 years, 33.47% (83 patients) had spent 3-10 years, and the remaining 7.66% (19 patients) had spent above 10 years on dialysis.<sup>10</sup> The shapes of the distributions of the WTW are different across patients with a different duration of dialysis (Figure 6). The distributions of WTW for changes in each of the attributes are shifted to the left among patients with a duration of dialysis of over ten years. For patients with over 10 years of dialysis, there is a lower frequency at the mean but a wider distribution elsewhere, implying more heterogeneity in the WTW values. While the dispersions are roughly the same for standard infectious risk and standard neoplastic risk, the distribution of WTW for a kidney that will offer an extra year of graft survival is more concentrated. For patients with less than three years on dialysis, however, the distributions are shifted to the left for all the attributes, suggesting the presence of impatience (time-discounting) predominantly in the early stages of dialysis.

<sup>&</sup>lt;sup>10</sup>We repeated the analysis dividing the population in tertiles of the distribution of time in dialysis, and result are consistent with what we present here.



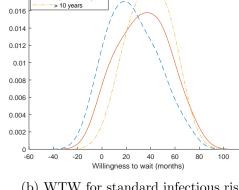
(a) WTW for extra year of survival



(c) WTW for standard neoplastic risk

Figure 6: Kernel density plots of the distribution of WTW: effect of dialysis duration

In Figure 7, we show the CDF of WTW for changes in each of the three attributes. The CDF of WTW for changes in each attribute among patients with duration of dialysis of over three years first-order stochastically dominates patients with less than three years. At any initial level of WTW, the probability that WTW exceeds the initial level of WTW is higher among patients with over three years of dialysis. For example, panel 7a of Figure 7 suggests that given the WTW of 5 months for a kidney that will offer an additional year of functioning, the probability that the WTW exceeds 5 months is higher among patients with duration of dialysis of 3-10 years and over ten years compared to patients with less than three years on dialysis.



Willingness to wait: infectious risk (time on dialysis)

0.02

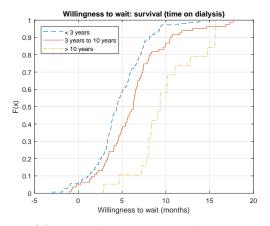
0.018

< 3 years

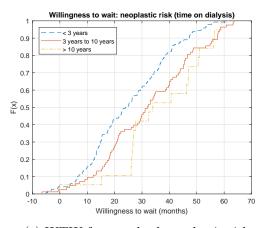
3 years to 10 year

(b) WTW for standard infectious risk

120

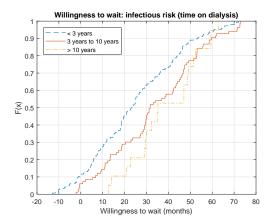


(a) WTW for extra year of survival



(c) WTW for standard neoplastic risk

Figure 7: Visual representations of the CDF of WTW values: effect of dialysis duration



(b) WTW for standard infectious risk

# C Appendix

In what follows, the English translation of instructions and the questionnaire are presented.

# C.1 Kidney transplant survey (Original in Italian)

I am part of a group of researchers from the University of Padua and the Ca' Foscari University of Venice carrying out a study that aims to assess whether it is possible to increase the well-being of patients who need a kidney transplant, naturally maintaining or by improving the clinical results of transplants. This research project, considered of strategic importance by the University of Padua, provides a survey on the characteristics and preferences of patients awaiting kidney transplantation. Your participation in this investigation is vital for scientific research. We will ask you about the preferences for alternative pairs of medical treatments, some demographic information, and your general state of health.

The results of this study will be published in specialised scientific journals and presented in scientific conferences. The information collected in this questionnaire will be linked to the information already held by the Regional Transplant Centre, but no publication or presentation will ever contain your name or any information that could identify you. All data collected will be archived and analysed in a strictly anonymous manner, pursuant to art. 7 and of the art. 13 of the Legislative Decree n. 196/03 in force since 1 January 2004 on the protection of individuals concerning the processing of personal data. Furthermore, the use of your data for commercial purposes is strictly prohibited. If you do not have any further questions or requests for clarification, we can start the interview.

# Patients' preferences for the different transplant options

#### Instructions:

In this section sixteen alternative treatment pairs will be presented. You will be asked to express your preference between treatment A and treatment B by placing an X in the box below them. We remind you again that the answers will have no influence on how the future kidney transplant will be conducted. A transplant (treatment) is characterised by the following factors:

- Waiting time is the time one will have to wait in order to obtain the proposed transplant. The waiting time depends on the characteristics of the recipient and the frequency with which donors of a particular type are available.
- Graft survival is determined by the characteristics of the transplanted graft, the characteristics of the recipient, and the compatibility between donor and recipient.
- Infectious risk (standard or augmented) is the risk of contracting an infectious disease through the graft. If it is standard, the organ has undergone all the possible checks, even if complete safety cannot be guaranteed. If it is augmented, some of the controls have not been performed, or the donor had some risky behaviours in the days before his or her death, but an infection may still not result from clinical diagnostics (even if it is possible).
- Neoplastic risk (standard or augmented) is the risk of contracting a tumour through the transplanted organ. If it is standard, the donor was not affected by a tumour, almost surely, even if a minimum level of risk does exist (for example, if the donor was not aware of the problem and it did not emerge from checks). It is augmented if the donor had some kinds of neoplastic disease. Still, it is not high in terms of probability, because the due checks have been performed.

Below are proposed 16 pairs of treatments (transplants) described by different attributes. Please, indicate the preferred one for each pair, by crossing (X) in the square below it.

	Treatment A	Treatment B
Waiting Time	6 Months	6 Months
Expected Graft Survival	20 Years	15 Years
Infectious Risk	Standard	Standard
Neoplastic Risk	Augmented	Standard
Your Choice ?		

	Treatment A	Treatment B
Waiting Time	12 Months	36 Months
Expected Graft Survival	15 Years	20 Years
Infectious Risk	Standard	Augmented
Neoplastic Risk	Standard	Augmented
Your Choice ?		

2. Which of the two treatments would you prefer? Put an X below the chosen treatment

	Treatment A	Treatment B
Waiting Time	60 Months	6 Months
Expected Graft Survival	20 Years	15 Years
Infectious Risk	Standard	Augmented
Neoplastic Risk	Augmented	Standard
Your Choice ?		

	Treatment A	Treatment B
Waiting Time	6 Months	12 Months
Expected Graft Survival	10 Years	10 Years
Infectious Risk	Augmented	Standard
Neoplastic Risk	Augmented	Augmented
Your Choice ?		

	Treatment A	Treatment B
Waiting Time	36 Months	60 Months
Expected Graft Survival	10 Years	10 Years
Infectious Risk	Augmented	Standard
Neoplastic Risk	Standard	Standard
Your Choice ?		

5. Which of the two treatments would you prefer? Put an X below the chosen treatment

	Treatment A	Treatment B	
Waiting Time	60 Months	36 Months	
Expected Graft Survival	15 Years	10 Years	
Infectious Risk	Augmented	Augmented	
Neoplastic Risk	Augmented	Standard	
Your Choice ?			

	Treatment A	Treatment B
Waiting Time	60 Months	60 Months
Expected Graft Survival	20 Years 20 Years	
Infectious Risk	Augmented Standard	
Neoplastic Risk	Standard	Augmented
Your Choice ?		

	Treatment A	Treatment B
Waiting Time	36 Months	6 Months
Expected Graft Survival	15 Years	10 Years
Infectious Risk	Standard	Augmented
Neoplastic Risk	Augmented	Augmented
Your Choice ?		

8. Which of the two treatments would you prefer? Put an X below the chosen treatment

	Treatment A	Treatment B
Waiting Time	6 Months 12 Months	
Expected Graft Survival	15 Years	20 Years
Infectious Risk	Standard	Augmented
Neoplastic Risk	Standard	Standard
Your Choice ?		

	Treatment A	Treatment B
Waiting Time	12 Months	60 Months
Expected Graft Survival	10 Years 15 Years	
Infectious Risk	Standard	Augmented
Neoplastic Risk	Augmented	Augmented
Your Choice ?		

	Treatment A	Treatment B
Waiting Time	12 Months	36 Months
Expected Graft Survival	20 Years	20 Years
Infectious Risk	Augmented	Standard
Neoplastic Risk	Standard	Standard
Your Choice ?		

11. Which of the two treatments would you prefer? Put an X below the chosen treatment

	Treatment A	Treatment B
Waiting Time	6 Months	12 Months
Expected Graft Survival	15 Years	15 Years
Infectious Risk	Augmented Standard	
Neoplastic Risk	Standard	Standard
Your Choice ?		

	Treatment A Treatment B			
Waiting Time	60 Months	12 Months		
Expected Graft Survival	10 Years	15 Years		
Infectious Risk	Standard	Augmented		
Neoplastic Risk	Standard	Augmented		
Your Choice ?				

	Treatment A	Treatment B
Waiting Time	36 Months	60 Months
Expected Graft Survival	20 Years	20 Years
Infectious Risk	Augmented	Augmented
Neoplastic Risk	Augmented	Standard
Your Choice ?		

14. Which of the two treatments would you prefer? Put an X below the chosen treatment

	Treatment A	Treatment B	
Waiting Time	36 Months	6 Months	
Expected Graft Survival	20 Years	20 Years	
Infectious Risk	Standard	Standard	
Neoplastic Risk	Standard	Augmented	
Your Choice ?			

16. Which of the two treatments would you prefer? Put an X below the chosen treatment

	Treatment A	Treatment B
Waiting Time	12 Months	36 Months
Expected Graft Survival	15 Years	15 Years
Infectious Risk	Augmented	Standard
Neoplastic Risk	Augmented	Augmented
Your Choice ?		

We thank you for your precious time and collaboration. Next are a few questions about the logical abilities of patients about different combinations of choices.

# **SHARE** Numeracy Questions

Now I would like to ask you some questions that are needed to evaluate how people use numbers in everyday life.

- 1. The probability of contracting an illness is 10 percent, how many people out of one thousand would be expected to get the disease?
- 2. In a sale, a shop is selling all items at half price. Before the sale the sofa costs 300 Euros. How much will it cost in the sale?
- 3. A second hand car dealer is selling a car for 6,000 Euro. This is two-thirds of what it costs new. How much did the car cost new?

# Personal information:

#### 1. Education:

 $\Box$ Elementary $\Box$ Lower middle $\Box$ Higher middle  $\Box$ Degree

#### 2. Family composition (not just the people living with you)

#### 3. What is your current profession?

 $\Box$ Manager $\Box$ Self–<br/>employed $\Box$ Employee $\Box$ Housewif<br/>e $\Box$ Retired $\Box$ Student $\Box$ Other——

4. Do you currently have a disability pension?

 $\Box$  Yes  $\Box$  No

## Medical information:

- 1. First year diagnosis/age of onset of the pathology------
- 2. Dialysis start date: month/year-----
- 3. Dialysis type

 $\Box$ Haemodialysis  $\Box$  Peritoneal dialysis

4. Presence of diabetes mellitus  $\Box$  yes  $\Box$  no

5. Date listed for renal transplantation: \_\_\_\_/\_\_\_/ \_\_\_\_/

# Dialysis:

		Absolutely True	True	I don't know	False	Absolutely False
1	Dialysis affects my life too much	1	2	3	4	5
2	Dialysis makes me lose too much time	1	2	3	4	5
3	I find it frustrating to live with dialysis	1	2	3	4	5
4	I feel dialysis a burden to my family	1	2	3	4	5

In your opinion, how true or false are the following statements?

# General health status:

 $\Box$  Excellent

 $\Box$  Very good  $\Box$  Good  $\Box$  Passable

 $\Box$  Poor