Kidney Allocation Survey of the Informed Public

Revised March 2007

Contents

This report was revised in March 2007. In response to inquiries additional information was added to the methods and information in some of the data tables was further refined.

ACKNOWLEDGEMENTS

We wish to acknowledge and thank the many individuals who took the time to complete the survey. We are grateful they provided us with their opinions and beliefs on some of the factors that are used to allocate kidneys. We are especially thankful that they included so many of their personal stories of their own or their family member's plight with renal disease. Their stories added important content to this survey and allowed us a glimpse into their lives with renal disease.

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- **Greg Knoll MD,** Forum Chair, Organ Allocation in Canada: Phase I Kidney Medical Director, Renal Transplant Program, The Ottawa Hospital
- **Beryl Ferguson,** National Program Director, The Kidney Foundation of Canada.
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- The success of this project is the result of a team effort of the CCDT staff. **Margo Charchuk MSc**, Research Coordinator for the CCDT **and Carole Loiseau BSW, RSW, MSc,** Director of Corporate Services for the CCDT, worked with experts to design and implement the project, analyze the survey results and compile the report.

INTRODUCTION AND SUMMARY

Numerous studies have shown that kidney transplantation is the best available option for people with end-stage renal disease. Not only are there distinct quality of life benefits for the individual after transplantation, but there is also evidence of a survival advantage. However, historically, there has been a discrepancy between the number of individuals requiring organ and tissue transplants and the numbers of organs and tissues available for transplantation. For example, according to the Canadian Organ Replacement Register (CORR) recent statistics show that at the end of 2005 there were 2758[1] Canadians waiting for a kidney transplant, 1030[2] kidneys were transplanted and 66[3] individuals died while waiting for a kidney. This discrepancy is among one of the many reasons that the development of a fair, transparent and equitable kidney allocation system is needed in Canada.

Currently in Canada, there is no uniform way of establishing priorities among the many factors that determine the allocation of a deceased donor kidney. For example, some transplant programs give higher priority to time spent on the wait list while others give first priority to tissue matching to achieve the best match between donor and recipient. The development of a uniform kidney allocation system across Canada will help to maintain public trust and increase equitable access.

The Canadian Council for Donation and Transplantation (CCDT), through its Kidney Allocation Steering Committee, is working to develop recommendations for an allocation model that is acceptable, useful and adaptable within unique regions across Canada. The CCDT is a national, not-for-profit organization mandated to provide the Federal/Provincial/Territorial Conference of Deputy Ministers of Health (CDM) with advice on organ and tissue donation and transplantation in Canada.

In preparation for developing this advice, the CCDT Kidney Allocation Steering Committee has been involved in gathering detailed information which includes expert advice and opinions from health care professionals, extensive reviews of published literature, a scan of current practices from other countries, and input from the informed public. As well, a Canadian consensus forum on kidney allocation will include medical and surgical specialists, organ procurement organization staff, bioethicists and other allied health professionals.

As part of these explorations, the Kidney Allocation Steering Committee in collaboration with The Kidney Foundation of Canada (KFoC) surveyed the informed public on specific allocation factors. For the purposes of this survey and report we have classified the informed public as individuals who are affiliated with the Kidney Foundation of Canada. The goal of the survey was to capture their views and beliefs on some of the complex issues involved in the kidney allocation process. The results will be presented to forum participants for discussion and incorporation into the development of a kidney allocation model.

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[1] Canadian Organ Replacement Register, Canadian Institute for Health Information, (2005) Patients Waiting for Transplant on December 31, 2005, Canada and Provinces.

[2] Canadian Organ Replacement Register, Canadian Institute for Health Information, (2005) Transplants by Organ and Donor Type, Province of Treatment, Canada.

[3] Canadian Organ Replacement Register, Canadian Institute for Health Information, (2005) Patients Who Died While Waiting for a Transplant, Canada and Provinces, Summary Statistics, January 1 to December 31, 2005.

The specific goals of the survey were:

- To develop an understanding of the informed publics' opinions and views surrounding some specific allocation factors used in the decision to allocate a deceased donor kidney

The specific topics addressed in this survey include:

- Age of the potential kidney transplant recipient
- Length of time the potential kidney transplant recipient has spent on the waiting list
- Length of time the potential kidney transplant recipient has spent on dialysis
- The estimated chance of survival of the donated kidney
- Kidney-pancreas versus kidney transplantation
- Demographics

The CCDT hosted the English and French web-based survey from July 17, 2006 until September 1, 2006. Individuals affiliated with the Kidney Foundation of Canada (KFoC) were invited to participate in the survey via email blasts from 13 regional branches. Branch offices sent emails to all individuals affiliated with the KFoC either currently or from the past. KFoC branch offices were also provided with hard copies of the survey for those individuals lacking internet access.

The survey consisted of 3 demographic questions, 10 scenario questions with options for additional comments and a final comment option. The survey was estimated to take respondents 15 minutes to complete. A total of 545 informed individuals completed either all or parts of the survey.

The responses to this survey are based on a non-random sample of individuals affiliated with the Kidney Foundation of Canada. The report presents the survey answers in the present tense as they represent opinions in a certain time frame. Due to rounding, some responses may equal +/- 100 percent. The varied response rates of some age groups, regions and personal categories limit the generalizability of results. Caution is always required in extrapolating the findings of the survey research beyond the parameters of the survey itself. It was not the intention of the CCDT that this survey would provide data sufficient to indicate significant differences between respondents. It is important to note that this is a descriptive study and results should not be interpreted as representing statistically significant differences between any groups.

This report presents the findings of this survey and a methods section which discusses research limitations in detail. The survey questions are included in the appendices.

The major findings of the survey are:

Age of the Recipient

Survey participants were asked to consider the **age** of the patient in determining who should receive a deceased donor kidney; they were also given an option to state that age should not be used as a determining factor.

In the first scenario there was a choice between two potential recipients – an 8 year old and a 35 year old. A small majority (57%) of survey participants believe that the age of the patient should not be used to determine who receives a deceased donor kidney. More

than one third (33%) believe that the 8 year old should receive the donor kidney and 10% believe the 35 year old should receive the donor kidney.

In the second scenario both potential recipients have been on dialysis for three years. One patient is 25 years old and the other is 65 years old. Just over half (52%) of the respondents believe that the age of the patient should not be used to decide who should receive the donor kidney. Just under half (44%) believe that the 25 year old should receive the kidney and only 4% believe that the 65 year old should receive the donor kidney.

In the last scenario both potential recipients have been on dialysis for three years. One is 25 years of age and the other is 65 years of age. In this scenario the deceased donor was 20 years old and had excellent kidney function. Interestingly, when information about the deceased donor was included participants were slightly more likely (52%) to believe that the 25 year old should receive the kidney than in the above scenario. Forty-five percent (45%) of the respondents believe that the age of the patient should not be used to determine who receives the donor kidney and 3% believe the 65 year old should receive the kidney.

Participants are slightly more likely to believe that age should not be used a factor to determine who should receive an allocated kidney. However, a fair number of respondents would choose to allocate the deceased donor kidney to a younger patient - especially when the donor is of a similar age.

Length of Time on the Waiting List

Survey participants were asked to consider the **length of time on the waiting list** to determine who should receive a deceased donor kidney; they were also given an option to state that the length of time on the waiting list should not be used as a determining factor.

In the first scenario there are two potential recipients for a deceased donor kidney. Both patients are on dialysis therapy with one on the waiting list for 3 years and the other for one year. Respondents overwhelmingly (85%) believe that the patient who has been waiting for 3 years should receive the donor kidney. Fourteen percent (15%) of respondents believe that the time on the waiting list should not be used to determine who receives the kidney and only 1 (0%) person believes that the patient who waited one year should receive the donor kidney.

In the second scenario there are two potential recipients for a deceased donor kidney. Both patients are on dialysis therapy. One has been on dialysis for 2 years but was only recently put on the waiting list; the other has been on dialysis for 1 year and has been on the waiting list for 1 year. Survey respondents agree (74%) that the patient who has been on dialysis for 2 years should receive the donor kidney. Just over one quarter (26%) believe that the patient who began dialysis one year ago and has been on the waiting list for one year should receive the donor kidney.

In the last scenario there are two potential recipients for a deceased donor kidney. One patient has been on dialysis for one year and on the waiting list for 3 months. The other patient is not on dialysis but has been on the waiting list for 5 months. The majority (82%) of participants believe that the patient who has been on dialysis for 1 year and on the waiting list for 3 months should receive the donor kidney. Just less than 2 in 10 (18%) respondents believe that the patient who is not on dialysis and on the waiting list for 5 months should receive the donor kidney.

Survey participants overwhelmingly agree that time spent on dialysis should be a determining factor in allocating a deceased donor kidney. Participants also agree that time spent on dialysis is more important than time spent on the waiting list.

Estimated Chance of Kidney Survival

Survey participants were asked to consider the **estimated chance of kidney survival** to determine who should receive a deceased donor kidney.

In the first scenario there are two potential recipients of a deceased donor kidney. One patient has been on dialysis for 3 years and, because of an excellent match, it is estimated that the kidney has an 85% chance of lasting for 3 years. The other patient has been on dialysis for 7 years and it is estimated that the kidney has a 75% chance of also lasting for 3 years. Many (64%) of the respondents agree that the patient who has been on dialysis for 7 years and in which the kidney has a 75% chance of lasting 3 years should receive the donor kidney. Just over one third (36%) believe that the patient who has been on dialysis for 3 years and in which the kidney has an 85% chance of lasting for 3 years should receive the donor kidney.

In the second scenario there are two potential recipients of a deceased donor kidney. One patient has been on dialysis for 3 years and it is estimated that the kidney has an 85% chance of lasting 3 years. The other patient has been on dialysis for 4 years and it is estimated that the kidney has a 75% chance of lasting 3 years. Respondents were fairly evenly divided on this question. Half (51%) of respondents believe that the patient who has been on dialysis for 3 years and in which the kidney is estimated to have an 85% chance of lasting 3 years should receive the donor kidney. The other half (49%) believe that the patient who has been on dialysis for 4 years and in which it is estimated that the kidney has a 75% chance of lasting 3 years should receive the donor kidney.

Respondents believe that time spent on dialysis should have more weight than the tissue match of the kidney. However, this shifted slightly when there was very little difference in time spent on dialysis between potential recipients.

Kidney –Pancreas Transplantation versus Kidney Transplantation

Survey participants were asked to consider between recipients receiving a **kidney-pancreas transplant or a kidney transplant only** to determine who should receive a deceased donor kidney.

In the first scenario one potential recipient has diabetes, has been on dialysis for two years and is waiting for a combined kidney-pancreas transplant. The other potential recipient does not have diabetes, has also been on dialysis for two years and is waiting for a kidney transplant. Most (71%) of the respondents believe that the patient who has diabetes and is waiting for a combined kidney-pancreas transplant should receive the transplant. Almost 2 in 10 (20%) participants agree that the need for a combined kidney-pancreas transplant should not be used to determine who should receive the donor kidney. Just under 1 in 10 (9%) of the informed public believe that the patient who does not have diabetes and is waiting for a kidney transplant only should receive the donor kidney.

In the second scenario, one patient has diabetes and has been on dialysis for 2 years. This patient is waiting for a combined kidney-pancreas transplant. The second patient does not have diabetes and has been on dialysis for 5 years. This patient is waiting for a kidney transplant only. Half (50%) of all respondents believe that the patient who has diabetes, has been on the waiting list for 2 years and is waiting for a *kidney-pancreas* transplant should receive the transplant. The other half (50%) believe that the patient who does not have diabetes, has been on the waiting list for 5 years and is waiting for a *kidney* transplant should receive the transplant.

Respondents agree that potential recipients with diabetes should be allocated the deceased donor kidney-pancreas when time spent on dialysis is equal. This shifts slightly when one potential recipient has been on dialysis for a longer period of time.

In the above scenarios many respondents agree that the age of the potential recipient should not be used as a factor to determine who should be allocated a deceased donor kidney. However, length of time spent on dialysis appears to be the most important factor with time spent on the waiting list the next most important factor. Although many respondents understand the importance of tissue matching and how a good match will increase the survival time of the kidney graft they do not agree that it should outweigh extended amounts of time spent on dialysis. Most participants believe that potential recipients with diabetes should receive a deceased donor kidney-pancreas transplant but as above they do not believe that it should outweigh potential recipients who have spent long periods of time on dialysis.

METHODOLOGY

Survey Design

The kidney allocation survey for the informed public was designed using scenarios in order to get a snap shot of opinions and beliefs on how specific factors should be used in the decision to allocate deceased donor kidneys.

Kidney allocation is a difficult and complicated process and the intent of the progression of questions was to simulate how multiple factors are at play in allocation decisions. The kidney allocation scenarios were based on original questions copied with permission from the authors from the journal article *Allocation of deceased donor kidneys for transplantation: Opinions of patients with CKD*[4]. An iterative process took place over several months in which CCDT staff and the Kidney Allocation Steering Committee modified[5] the scenarios to address the Canadian context.

A draft of the survey was pilot tested with 9 CCDT staff members. Some of the feedback related to the complexity of the scenarios as multiple factors were introduced. Staff indicated that they rethought earlier responses and requested the ability to change their answers. As a result, the survey tool allowed for this feature.

The kidney allocation public opinion survey consisted of demographic questions that included the age of the respondent, their province or territory of residence, and the category that best describes their affiliation with renal disease. Responses to the demographic questions were neither mandatory nor limited. While survey questions did specify that respondents select only one response per question, in some cases, particularly related to the question that best described their affiliation with renal disease, some respondents selected multiple categories.

There were 10 scenario questions that addressed specific allocation factors including age of the recipient, time on dialysis, the matching of the kidney and kidney-pancreas transplant versus kidney transplant for patients with diabetes. The scenario questions also had options for additional comments as kidney allocation is complicated and multifactored and the intent was to provide space for important information. There was also an option for any final comments on the questions or the survey. The scenarios were grouped by allocation factor with questions progressing from single to multiple factors to enable analysis at each level. The scenarios also progressed in level of difficulty as multiple factors were introduced. Responses to the scenario questions were not mandatory. As such, respondents did not have to answer each question before moving on to the next question. At any time they could return to a previous screen to change their answers.

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[4] Geddes, C.C., Rodger, S.C., Smith, C., & Ganai, A. (2005). Allocation of deceased donor kidneys for transplantation: Opinions of patients with CKD. *American Journal of Kidney Diseases, 46*(5), 949-959.

[5] The CCDT and the KFoC would like to thank the authors of this article for allowing their scenarios and preamble to be copied and modified.

Sample
Demographics of the participants

The original intent was to sample members of the public who are affiliated with the Kidney Foundation of Canada and are considered informed of issues relating to end stage renal disease and transplantation. These included, but are not limited to, volunteers, board members and staff, stakeholders, individuals associated with organ procurement organizations, renal social workers, renal patients, and health care professionals. There were 545 survey respondents and it is estimated that the survey was sent to 3380 individuals affiliated with KFoC branch offices. However these individuals were able to forward the email link on to other members of the informed public that may have included dialysis patients, recipients, family members and friends and for this reason an accurate sample size and response rate is unknown.

A small group of respondents did not identify their age group (less than 5 individuals) as questions were not mandatory. Of those who answered this question, more than one quarter (27%) of survey participants are between the ages of 46 and 55 years. Twenty-one percent are 36-45 years of age, 18% are over 65 years of age, 15% are 56-65 years of age, 14% are 26-35 years of age and 4% are under 25 years of age.

An electronic copy of the survey instrument was also distributed to branch offices who could make hard copies and forward to other potential survey participants. This hard copy was widely distributed in Alberta to individuals with renal disease. While we do know that the hard copy was distributed in other regions we do not know any of the specifics. A high volume of the hard copies (167) were received at the CCDT office (163 were from Alberta).

Because of this distribution half (50%) of survey participants are from Alberta. Participants from Ontario, British Columbia, Saskatchewan and Manitoba comprise 14%, 9%, 6% and 6% respectively. Four percent (4%) are from Quebec, 3% from New Brunswick, and 2% each from Newfoundland and Labrador and Nova Scotia.

Survey respondents were asked to choose a category that best describes their affiliation with renal disease and the KFoC. One quarter (25%) are health care professionals, almost 2 in 10 (19%) are recipients and one in ten (11%) are individuals waiting for a transplant or a family member of a person with kidney disease (10%). Other survey participants are employees (9%) or volunteers (7%) of a not-for-profit organization such as the KFoC and 4% of the respondents are living donors. The majority of survey respondents who chose the 'other' category either have kidney disease or have a friend with kidney disease. A small group of respondents (approximately 10-15 individuals) selected more than one category (e.g., volunteer, family member of person with kidney disease).

Sample

Province/Territory	**Number of Respondents**	**Number Accessed***	**Response rate (%)**	**Distribution Issues**
British Columbia	51	150	34%	Branch office received an electronic hard copy version of the survey.

Alberta/Yukon	272	2351	12%	The Southern Alberta branch printed hard copies of the survey and did a mail out to its patient population.
Saskatchewan	36	228	16%	Branch office received an electronic hard copy version of the survey.
Manitoba	34	50	68%	Branch office received an electronic hard copy version of the survey.
Ontario (Eastern 25, Central 113, Greater Ontario 150)	81	288	28%	Branch office received an electronic hard copy version of the survey.
Quebec	22	77	29%	Branch office received an electronic hard copy version of the survey.
Nova Scotia	14	60	23%	Branch office received an electronic hard copy version of the survey.
New Brunswick	19	76	25%	Branch office received an electronic hard copy version of the survey.
Prince Edward Island	1	50	2%	Branch office received an electronic hard copy version of the survey.
Newfoundland and Labrador	12	50	24%	Branch office received an electronic hard copy version of the survey.

Implementation

The survey was translated into French and both versions were uploaded to the Internet using Zoomerang, an on-line survey software tool. The on-line and hard copy survey was available from July 17, 2006 until September 1, 2006.

The KFoC sent an email to its thirteen branches requesting that an email blast be sent to anyone on their email distribution list. In response to requests, the CCDT provided the KFoC with a link to a hard copy for members lacking internet access. The hard copy of the survey was widely distributed in southern Alberta to dialysis units, renal transplant recipients, pre-dialysis units, and staff in organ procurement organizations. Two weeks before the survey was closed a reminder email was sent to branch offices. Any hard copy surveys received with a postmark after the closing date of September 1, 2006 were not entered. Potentially, the survey could have been accessible to any member of the general public as access was not restricted.

Analysis

The Internet survey tool Zoomerang was used for analysis of the data. Data from the English and French surveys was combined prior to the analysis. Uncompleted surveys that resulted from visits to the survey sites, which were logged by the Internet survey tool, were excluded from the analysis.

In addition to summary responses for each question, cross tabulations of the data were performed on each scenario question the age groups of participants and the category that best described their affiliation with renal disease. Because demographic questions were neither mandatory nor limited, it was possible for a respondent's opinion to be discluded (in the case of age) or included more than once if more than one category was identified. Cross tabulations were not done by region because of the oversampling in the province of Alberta.

Comments provided after each question and at the end of the survey were thematically analysed with one or two major themes captured. The comments were reviewed independently by two researchers for content and similar themes emerged. These themes are presented according to frequency of responses and are not representative of all the respondents to this survey.

The opinions in this survey are based upon a non-random sample of members of the informed public and may not represent the opinions of all members of the public. The results of this survey are a snapshot and reflect responses and attitudes that were given in a certain period of time. It is important to note that this is a purely descriptive survey and caution is required in interpreting these results beyond the parameters of the survey itself. It must also be noted that these results are not intended to be generalized to all members of the public.

Limitations

There were several limitations to this study.

First, survey questions were not entirely uniform which reduced comparability between questions. For 5 of the questions the option to indicate that a specific factor should not be considered in the allocation of a kidney was not included. Although it is important to have choices limited it is also telling to understand which factors members of the informed public believe should not be considered. This lack of uniformity also inhibits the ability to fully analyze the data and to draw inferences about comprehension and importance of the factors.

Second, some of the complexity of kidney allocation may not have been entirely well translated into the survey instrument particularly in the case of questions that included multiple factors.

Third, the survey was not distributed uniformly. Certain branches of the KFoC mailed out hard copies of the survey to their affiliated members. The survey was then circulated among some pre-dialysis units, dialysis and transplant clinics, and may also have been photocopied and further distributed. Other offices may not have circulated beyond individuals with access to the internet. Because of this it is impossible to provide an accurate estimate of the number of individuals who may have received the survey and cross tabulations by regions were not conducted.

Fourth, Internet surveys do not ensure equal representation and over sampling may occur. As well, certain populations have easier access to computers and the Internet.

Finally, the Internet survey tool Zoomerang does not have the capacity to do cross tabulations on the comments sections. It is important to understand which questions were confusing or thought provoking for various members of the informed public.

KIDNEY ALLOCATION FACTORS

Age of the Recipient

Half of the informed public believe that the age of the patient should not be used to determine who should receive a deceased donor kidney.

Survey participants were asked to consider three scenarios in which the **age** of the potential recipient in deciding who should receive a deceased donor kidney.

Scenario 1: Participants were asked to choose between allocating a donor kidney to an 8 year old patient, a 35 year old patient or to indicate that age should not be a factor used to determine who should receive the donor kidney. Just over half (57%) of the surveyed respondents do not believe that the age of the patient should be used to decide who should be allocated a deceased donor kidney. One third (33%) of the respondents believe that the 8 year old should receive the kidney and 1 in 10 (10%) believe the 35 year old should receive the kidney.

Individuals aged 56-65 years were slightly more likely to believe that the age of the patient should not be used to decide who should receive the kidney in this case.

Age of the Recipient

Q. 4. A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 is 35 years old. Patient 2 is 8 years old. All other factors are equal. To which patient do you think the available kidney should be allocated?		**The 35 year old patient.**	**The 8 year old patient.**	**The age of the patient should not be used to make the decision in this case.**
AGE	N= 521	%	%	%
Under 25 years	19	5	32	63
26- 35 years	76	8	43	49
36- 45 years	106	9	36	55
46- 55 years	142	8	32	61
56- 65 years	81	11	22	67
Over 65 years	96	16	34	50

Health care professionals were more likely (46%) than living donors (6%) to believe that the 8 year old should receive the kidney.

**Because demographic questions were neither mandatory nor limited, the total number of respondents who answered each question does not match the number of respondents by age group or category in the cross tabulations.*

Age of the Recipient

Q. 4. A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 is 35 years old. Patient 2 is 8 years old. All other factors are equal. To which patient do you think the available kidney should be allocated?		**The 35 year old patient.**	**The 8 year old patient.**	**The age of the patient should not be used to make the decision in this case.**
CATEGORY	N= 521	%	%	%
Person waiting for transplant	59	12	39	49
Living donor	17	12	6	82
Recipient	105	13	32	54
Family member of person with kidney disease	52	19	21	60
Not-for-profit organization employee (i.e., Kidney Foundation)	49	10	20	69
Volunteer (e.g., with the Kidney Foundation)	39	15	28	56
Health care professional	133	4	46	51
Other; please specify:	85	9	29	61

Almost half (47%) of the participants provided additional comments to this question. The most common theme to emerge was the need for additional information about the potential recipients such as their health status, length of time on dialysis and whether the 35 year old has dependents. Another common theme to emerge was in relation to the match of the kidney and the importance of allocating based on tissue match.

Scenario 2: Participants were then asked to consider between a 25 year old and a 65 year old who have both been on dialysis for 3 years. They were also given the choice that age should not be used to determine who receives the deceased donor kidney. A slight majority (52%) believe that age should not be used in deciding who should receive a donor kidney. However, just under half (44%) of the respondents agree that the 25 year old should receive the kidney. A small percentage (4%) believes that the 65 year old should be the recipient.

As in the above question, all age groups seem to agree that age should not be a factor in determining who should receive the donor kidney. Interestingly, those under 25 years of age believe that the 25 year old (72%) should receive the donor kidney and do not think the 65 year old (0%) should receive the donor kidney. Whereas those survey participants over 65 years of age were much more likely to believe that the 25 year old (52%) should receive the donor kidney than those over age 65 (3%).

Age of the Recipient

**Because demographic questions were neither mandatory nor limited, the total number of respondents who answered each question does not match the number of respondents by age group or category in the cross tabulations.*

Q. 6 A deceased donor kidney becomes available for one of two patients on dialysis therapy. Both patients have been on dialysis for 3 years. Patient 1 is 25 years old and Patient 2 is 65 years old. All other factors are equal. To which patient do you think the available kidney should be allocated?		The 25 year old.	The 65 year old.	The age of the patient should not be used to make the decision in this case.
AGE	N=519	**%**	**%**	**%**
Under 25 years	18	72	0	33
26- 35 years	76	50	5	45
36- 45 years	106	43	4	45
46- 55 years	140	39	2	59
56- 65 years	81	38	6	56
Over 65 years	97	52	3	45

There were no significant opinion differences between members of the various groups affiliated with The Kidney Foundation of Canada or with renal disease.

Age of the Recipient

Q. 6. A deceased donor kidney becomes available for one of two patients on dialysis therapy. Both patients have been on dialysis for 3 years. Patient 1 is 25 years old and Patient 2 is 65 years old. All other factors are equal. To which patient do you think the available kidney should be allocated?		The 25 year old.	The 65 year old.	The age of the patient should not be used to make the decision in this case.
CATEGORY	N=519	%	%	%
Person waiting for transplant	58	36	9	57
Living donor	17	59	0	47
Recipient	104	38	4	59
Family member of person with kidney disease	51	45	4	51
Not-for-profit organization employee (i.e., Kidney Foundation)	49	43	8	51
Volunteer (e.g., with the Kidney Foundation)	38	55	5	40
Health care professional	133	46	2	53
Other; please specify:	84	49	4	49

**Because demographic questions were neither mandatory nor limited, the total number of respondents who answered each question does not match the number of respondents by age group or category in the cross tabulations.*

Just under (39%) of the surveyed informed public provided additional comments to the question of whether a 25 year old or a 65 year old should receive the deceased donor kidney. As in the first scenario the most common theme regarded the need for additional information on the health status of the potential recipients, their present quality of life and whether there would be any compliance issues. Again the importance of the tissue match between the donor and potential recipient was repeatedly stressed. There were also several comments that provided support for their decision to choose the 25 year old over the 65 year old. These mainly centered on the need for the younger patient to have a chance at life and to be free of hardships of dialysis.

Scenario 3: In the final question relating to the age of the potential recipient there was information provided about the deceased donor who is described as 20 years old with excellent kidney function. Both potential recipients have been on dialysis for 3 years with one patient being 25 years old and the other 65 years old. Respondents agree (52%) that the 25 year old should receive the donor kidney. Slightly less (45%) believe that age should not be used to determine who should receive the deceased donor kidney. Just 3% of respondents believe that the 65 year old should receive the donor kidney.

Respondents from all of the age groups were of the similar opinion as to who should receive the donor kidney.

Age of the Recipient

Q. 8 A deceased donor kidney becomes available for one of two patients on dialysis therapy. The donor was 20 years old and had excellent kidney function. Patient 1 is 25 years old. Patient 2 is 65 years old. Both patients have been on dialysis for 3 years. All other factors are equal. To which patient do you think the available kidney should be allocated?		**The 25 year old.**	**The 65 year old patient.**	**The age of the patient should not be used to make the decision in this case.**
AGE	N=513	%	%	%
Under 25 years	18	67	0	33
26- 35 years	76	57	3	41
36- 45 years	104	50	2	48
46- 55 years	137	50	2	48
56- 65 years	80	46	6	48
Over 65 years	97	57	3	40

There were no significant differences between members of the various groups affiliated with the Kidney Foundation of Canada or with renal disease as to who should receive the donor kidney.

**Because demographic questions were neither mandatory nor limited, the total number of respondents who answered each question does not match the number of respondents by age group or category in the cross tabulations.*

Age of the Recipient

Q. 8. A deceased donor kidney becomes available for one of two patients on dialysis therapy. The donor was 20 years old and had excellent kidney function. Patient 1 is 25 years old. Patient 2 is 65 years old. Both patients have been on dialysis for 3 years. All other factors are equal. To which patient do you think the available kidney should be allocated?		**The 25 year old patient.**	**The 65 year old patient.**	**The age of the patient should not be used to make the decision in this case.**
CATEGORY	N=513	%	%	%
Person waiting for transplant	59	39	10	51
Living donor	16	56	0	44
Recipient	102	45	2	53
Family member of person with kidney disease	51	49	4	47
Not-for-profit organization employee (i.e., Kidney Foundation)	46	54	4	41
Volunteer (e.g., with the Kidney Foundation)	37	60	3	38
Health care professional	132	58	0	42
Other; please specify:	83	57	4	40

Comments: One third (35%) of respondents provided additional comments to this question. Many respondents indicated that their beliefs were not different from the previous question.

It is interesting to note that in this scenario there was additional information included about the 20 year old deceased donor but this does not seem to have been an important influence in their decision making. Participants are slightly more likely to believe that age should not be used a factor to determine who should receive an allocated kidney.

**Because demographic questions were neither mandatory nor limited, the total number of respondents who answered each question does not match the number of respondents by age group or category in the cross tabulations.*

Length of Time on the Waiting List

The informed public appear to believe that the length of time on dialysis and length of time on the waiting list should be among some of the most important factors in determining who should receive a deceased donor kidney.

Survey participants were asked to consider three scenarios to determine if the **length of time a potential recipient has spent on dialysis or on the waiting list** should be a factor in the allocation of a deceased donor kidney.

Scenario 1: Members of the informed public were asked to consider between one patient who is on dialysis and has been on the waiting list for 3 years and another patient who is on dialysis but has been on the waiting list for 1 year. The vast majority (85%) of participants believe that the patient who has been on the waiting list for 3 years should receive the donor kidney. Fifteen percent of respondents agree that the time spent on the waiting list should not be used to decide who should receive the donor kidney. One respondent believed that the patient who has been on the waiting list for one year should receive the donor kidney.

Individuals over the age of 65 were considerably more likely (24%) than those aged 35 years and younger (6%) to believe that time on the waiting list should not be used to make the decision as to who should receive the donor kidney.

Length of Time on Dialysis or on the Waiting List

Q. 10 A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 has been on the waiting list for 3 years, and Patient 2 has been on the waiting list for 1 year. All other factors are equal. To which patient do you think the available kidney should be allocated?		**The patient who waited 3 years.**	**The patient who waited 1 year.**	**The time on the waiting list should not be used to make the decision in this case.**
AGE				
	N=496	%	%	%
Under 25 years	17	94	0	6
26- 35 years	70	93	1	6
36- 45 years	100	88	0	12
46- 55 years	135	86	0	14
56- 65 years	77	83	0	17
Over 65 years	96	76	0	24

**Because demographic questions were neither mandatory nor limited, the total number of respondents who answered each question does not match the number of respondents by age group or category in the cross tabulations.*

Surveyed health care professionals were slightly less (8%) likely than those waiting for a transplant (21%) to agree that time on the waiting list should not be used to determine who should receive the donor kidney.

Length of Time on Dialysis or on the Waiting List

Q. 10 A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 has been on the waiting list for 3 years, and Patient 2 has been on the waiting list for 1 year. All other factors are equal. To which patient do you think the available kidney should be allocated?		**The patient who waited 3 years.**	**The patient who waited 1 year.**	**The time on the waiting list should not be used to make the decision in this case.**
CATEGORY	N= 496	%	%	%
Person waiting for transplant	58	79	0	21
Living donor	16	88	0	13
Recipient	100	80	0	20
Family member of person with kidney disease	49	82	0	18
Not-for-profit organization employee (i.e., Kidney Foundation)	47	87	2	11
Volunteer (e.g., with the Kidney Foundation)	38	84	0	16
Health care professional	121	92	0	8
Other; please specify:	81	84	0	16

One quarter (27%) of respondents provided additional comments to this question. Many respondents argued that time spent on dialysis should be the main consideration as it is well known that morbidity and mortality rates increase with time spent waiting for a transplant. Other individuals reflected on the main purpose of the waiting list as being to move up in the queue to receive a transplant. As in the other comments respondents requested that other factors be included about the potential recipients, for example: their health status, quality of life and if there are any compliance issues.

Scenario 2: In the second scenario two potential recipients are on dialysis therapy. One began dialysis 2 years ago but was just recently put on the waiting list because of the amount of time it took to complete the medical investigations necessary to ensure they were fit for transplantation. The second patient began dialysis one year ago and went on the waiting list immediately. Almost three quarters (74%) of the respondents agree that the patient who started dialysis therapy two years ago but was just put on the waiting list should receive the donor kidney. One quarter (26%) of the respondents believe that the patient who started dialysis one year ago and was immediately put on the waiting list should receive the donor kidney.

**Because demographic questions were neither mandatory nor limited, the total number of respondents who answered each question does not match the number of respondents by age group or category in the cross tabulations.*

Respondents under the age of 25 appear more likely (45%) than those aged 36-45 years (20%) to believe that the patient who began dialysis 1 year ago and was put on the wait list immediately should receive the donor kidney.

Length of Time on Dialysis or on the Waiting List

Q. 12 A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 started dialysis therapy 2 years ago, but was just recently put on the wait list because of the length of time taken to complete the investigations to ensure they were fit for transplantation. Patient 2 started dialysis therapy 1 year ago and went on to the waiting list immediately because they needed no more investigations. All other factors are equal. To which patient do you think the available kidney should be allocated?	**The patient who started dialysis 2 years ago and was just put on the wait list because of the time it took to complete the investigations.**	**The patient who started dialysis 1 year ago and has been on the waiting list for 1 year.**
AGE N=480	%	%
Under 25 years 18	55	45
26- 35 years 71	63	37
36- 45 years 98	80	20
46- 55 years 135	79	21
56- 65 years 75	71	29
Over 65 years 91	75	25

There were no significant differences between members of the various categories as to who should receive the donor kidney.

Length of Time on Dialysis or on the Waiting List

Q. 12. A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 started dialysis therapy 2 years ago, but was just recently put on the wait list because of the length of time taken to complete the investigations to ensure they were fit for transplantation. Patient 2 started dialysis therapy 1 year ago and went on to the waiting list immediately because they needed no more investigations. All other factors are equal. To which patient do you think the available kidney should be allocated?	**The patient who started dialysis 2 years ago and was just put on the wait list because of the time it took to complete the investigations.**	**The patient who started dialysis 1 year ago and has been on the waiting list for 1 year.**
CATEGORY N=480	%	%
Person waiting for transplant 57	77	23
Living donor 16	69	31
Recipient 95	72	28
Family member of person with kidney disease 49	78	22
Not-for-profit organization employee (i.e., Kidney Foundation) 47	70	30
Volunteer (e.g., with the Kidney Foundation) 34	73	27
Health care professional 125	74	27
Other; please specify: 79	73	27

**Because demographic questions were neither mandatory nor limited, the total number of respondents who answered each question does not match the number of respondents by age group or category in the cross tabulations.*

One third (30%) of respondents provided additional comments to this question. Interestingly, many of those who chose to respond to this question wondered why the investigations of the first potential recipient took so long and argued that if it were due to the slowness of the system they should not be penalized. Others added that the waiting list time should start when the individual begins dialysis.

Scenario 3: In the third scenario there are two potential recipients for a deceased donor kidney. One patient has been on dialysis for one year and on the waiting list for 3 months. The second patient is not on dialysis yet but was put on the waiting list 5 months ago when doctors believed that this patient would need to start dialysis within the next 6 months. The majority (82%) of individuals believe that the patient who has been on dialysis for 1 year and on the wait list for 3 months should receive the donor kidney. Less than 2 in 10 (18%) of the surveyed informed public believe that the patient who is not on dialysis but has been on the waiting list for 5 months should be allocated the donor kidney.

Those aged 46-55 years are more (21%) inclined to believe that the kidney should be allocated to the patient who is not on dialysis but has been on the waiting list for 5 months than those aged under 25 years (6%).

Length of Time on Dialysis or on the Waiting List

Q. 14. A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 has been on dialysis therapy for 1 year and on the waiting list for 3 months. Patient 2 is not on dialysis therapy yet, but was put on the waiting list 5 months ago when the doctors believed he/she would need dialysis therapy within the next 6 months. All other factors are equal. To which patient do you think the available kidney should be allocated?		**The patient on dialysis for 1 year and on the waiting list for 3 months.**	**The patient on the waiting list for 5 months but not yet on dialysis**
AGE	N=482	%	%
Under 25 years	18	94	6
26- 35 years	71	80	20
36- 45 years	97	80	20
46- 55 years	132	79	21
56- 65 years	76	84	16
Over 65 years	96	84	16

Volunteers are less likely (8%) than living donors (27%) or health care professionals (26%) to indicate that the patient who is not on dialysis but has been on the waiting list for 5 months should receive the donor kidney.

**Because demographic questions were neither mandatory nor limited, the total number of respondents who answered each question does not match the number of respondents by age group or category in the cross tabulations.*

Length of Time on Dialysis or on the Waiting List

Q. 14.A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 has been on dialysis therapy for 1 year and on the waiting list for 3 months. Patient 2 is not on dialysis therapy yet, but was put on the waiting list 5 months ago when the doctors believed he/she would need dialysis therapy within the next 6 months. All other factors are equal. To which patient do you think the available kidney should be allocated?		**The patient on dialysis for 1 year and on the waiting list for 3 months.**	**The patient on the waiting list for 5 months but not yet on dialysis**
CATEGORY	N=482	%	%
Person waiting for transplant	57	86	14
Living donor	15	73	27
Recipient	97	77	23
Family member of person with kidney disease	48	88	13
Not-for-profit organization employee (i.e., Kidney Foundation)	47	91	9
Volunteer (e.g., with the Kidney Foundation)	36	92	8
Health care professional	123	74	26
Other; please specify:	78	85	15

Less than one third (28%) of participants provided additional comments to this question. The majority reiterated their belief that the patient who has been on dialysis should receive the deceased donor kidney. However, several commented on pre-emptive transplantation as affording a better outcome for renal failure patients.

Survey participants agree that time spent on dialysis should be a determining factor in allocating a deceased donor kidney. In fact, participants overwhelming agree that time spent on dialysis is more important than time spent on the waiting list.

**Because demographic questions were neither mandatory nor limited, the total number of respondents who answered each question does not match the number of respondents by age group or category in the cross tabulations.*

Estimated Chance of Kidney Survival

It appears that the estimated chance of kidney survival or the matching of the kidney are less important factors to the informed public.

In the following two scenarios survey participants were asked to consider the **estimated chance of kidney survival** as a factor in determining who should receive the deceased donor kidney.

Scenario 1: In the first scenario there are two potential recipients for a deceased donor kidney. One patient has been on dialysis for 3 years and because of the excellent match between this potential recipient and the donor kidney it is estimated that the kidney will have an 85% chance of lasting for 3 years. The second patient has been on dialysis for 7 years and because the match with the donor kidney is not as good it is estimated that the kidney will have a 75% chance of lasting for 3 years. More than half (64%) of the respondents agree that the deceased donor kidney should be allocated to the patient who has been on dialysis for 7 years and in which it is estimated that the kidney has a 75% chance of lasting for 3 years. Just over one third (36%) believe that the kidney should be allocated to the patient who has been on dialysis for 3 years and it is estimated that the kidney has an 85% chance of lasting 3 years.

Respondents under 25 years of age are more likely (47%) than those over the age of 65 years (30%) to believe that the patient who has been on dialysis for 3 years and for whom the transplant is estimated to have an 85% chance of lasting for 3 years should be allocated the donor kidney.

Estimated Chance of Kidney Survival

Q. 16. A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 has been on dialysis therapy for 3 years, and it is estimated that the transplant has an 85% chance of lasting 3 years because of an excellent match with the donor. Patient 2 has been on dialysis for 7 years, and it is estimated that the transplant has a 75% chance of lasting 3 years because the match with the donor is not as good as Patient 1. All other factors are equal. To which patient do you think the available kidney should be allocated?		**The patient on dialysis for 7 years for whom the transplant is estimated to have a 75% percent chance of lasting 3 years.**	**The patient on dialysis for 3 years for whom the transplant is estimated to have an 85% chance of lasting 3 years.**
AGE	N=472	%	%
Under 25 years	18	47	53
26- 35 years	67	61	39
36- 45 years	98	57	42
46- 55 years	134	69	31
56- 65 years	74	62	38
Over 65 years	90	70	30

There were no significant differences between members of the various categories as to who should receive the donor kidney.

**Because demographic questions were neither mandatory nor limited, the total number of respondents who answered each question does not match the number of respondents by age group or category in the cross tabulations.*

Estimated Chance of Kidney Survival

Q. 16. A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 has been on dialysis therapy for 3 years, and it is estimated that the transplant has an 85% chance of lasting 3 years because of an excellent match with the donor. Patient 2 has been on dialysis for 7 years, and it is estimated that the transplant has a 75% chance of lasting 3 years because the match with the donor is not as good as Patient 1. All other factors are equal. To which patient do you think the available kidney should be allocated?		**The patient on dialysis for 7 years for whom the transplant is estimated to have a 75% percent chance of lasting 3 years.**	**The patient on dialysis for 3 years for whom the transplant is estimated to have an 85% chance of lasting 3 years.**
CATEGORY	N=472	%	%
Person waiting for transplant	56	63	38
Living donor	15	67	33
Recipient	97	65	35
Family member of person with kidney disease	47	68	32
Not-for-profit organization employee (i.e., Kidney Foundation)	46	57	43
Volunteer (e.g., with the Kidney Foundation)	36	61	39
Health care professional	120	63	38
Other; please specify:	80	65	35

One third (32%) of participants provided additional comments to this question. Most of the respondents believe that 7 years on dialysis should be the deciding factor and argue that there is only a 10% difference in the estimated chance of kidney survival. However, there were also several comments about the closest match being an important factor in deciding who should receive the donated kidney.

Scenario 2: In the second scenario there are two potential recipients of a deceased donor kidney. One patient has been on dialysis for 3 years and it is estimated that the donor kidney has an 85% chance of lasting for 3 years because of an excellent match between the donor kidney and the potential recipient. The second patient has been on dialysis for 4 years and it is estimated that the kidney has a 75% chance of lasting for 3 years because the match is not as good. The respondents appear to be evenly divided when asked to choose between the two potential recipients. Half (50%) believe that the patient who has been on dialysis for 3 years and for whom it is expected that the kidney has an 85% estimated chance of surviving for 3 years should receive the donor kidney. Half (49%) believe that the patient who has been on dialysis for 4 years and in which it is estimated that the kidney has a 75% chance of surviving for 3 years should receive the donor kidney.

All of the age groups and members of the different categories appear to be evenly divided on this question.

**Because demographic questions were neither mandatory nor limited, the total number of respondents who answered each question does not match the number of respondents by age group or category in the cross tabulations.*

Estimated Chance of Kidney Survival

Q. 18. A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 has been on dialysis therapy for 3 years, and it is estimated that the transplant has an 85% chance of lasting 3 years because of an excellent match with the donor. Patient 2 has been on dialysis for 4 years, and it is estimated that the transplant has a 75% chance of lasting 3 years because the match with the donor is not as good as Patient 1. All other factors are equal. To which patient do you think the available kidney should be allocated?		**The patient on dialysis for 4 years for whom the transplant is estimated to have a 75% percent chance of lasting 3 years.**	**The patient on dialysis for 3 years for whom the transplant is estimated to have an 85% chance of lasting 3 years.**
AGE	N= 466	%	%
Under 25 years	18	44	56
26- 35 years	66	52	48
36- 45 years	98	42	58
46- 55 years	132	54	46
56- 65 years	71	52	48
Over 65 years	91	45	55

Estimated Chance of Kidney Survival

Q. 18. A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 has been on dialysis therapy for 3 years, and it is estimated that the transplant has an 85% chance of lasting 3 years because of an excellent match with the donor. Patient 2 has been on dialysis for 4 years, and it is estimated that the transplant has a 75% chance of lasting 3 years because the match with the donor is not as good as Patient 1. All other factors are equal. To which patient do you think the available kidney should be allocated?		**The patient on dialysis for 4 years for whom the transplant is estimated to have a 75% percent chance of lasting 3 years.**	**The patient on dialysis for 3 years for whom the transplant is estimated to have an 85% chance of lasting 3 years.**
CATEGORY	N=466	%	%
Person waiting for transplant	55	49	51
Living donor	15	60	40
Recipient	96	49	51
Family member of person with kidney disease	47	53	47
Not-for-profit organization employee (i.e., Kidney Foundation)	45	40	60
Volunteer (e.g., with the Kidney Foundation)	36	50	50
Health care professional	119	50	50
Other; please specify:	7	45	56

Less than one quarter (24%) of participants provided additional comments to this question. Most respondents who chose to provide additional comments backed up their choice of the kidney being allocated where it would have an 85% chance of lasting for 3 years. They argue that the difference in time on dialysis is not as significant and that the survival of the kidney is more important. Others argue that the time on dialysis should still be more important and that there is only a 10% difference in the estimates of kidney survival time.

In the above scenarios respondents were more likely to believe that time spent on dialysis should have more weight than the tissue match of the kidney. However, this shifted slightly when there was very little difference in time spent on dialysis between potential recipients.

**Because demographic questions were neither mandatory nor limited, the total number of respondents who answered each question does not match the number of respondents by age group or category in the cross tabulations.*

Kidney –Pancreas Transplantation versus Kidney Transplantation

The informed public believe that when all factors are equal a deceased donor kidney and pancreas should be allocated to a patient who has diabetes and needs a combined kidney-pancreas transplantation.

Survey participants were asked in the following two scenarios to consider whether the need for a **kidney or kidney-pancreas transplant** should be a factor in determining who should receive the deceased donor kidney.

Scenario 1: In the first scenario there are two potential recipients of a deceased donor kidney. One patient has diabetes and is in need of a combined kidney-pancreas transplant. The other patient does not have diabetes and is waiting for a kidney transplant only. Both patients have been on dialysis for 2 years. Almost three quarters (72%) of survey respondents believe that the patient who has diabetes and who is waiting for a combined kidney-pancreas transplant should receive the donor kidney and pancreas. One in ten (9%) participants believe that the patient who does not have diabetes and is waiting for a kidney transplant should receive the donor kidney. Two in ten (18%) respondents believe that the need for a pancreas transplant should not be used to make an allocation decision in this case.

Members of the informed public aged 46-55 years were the most likely (81%) to believe that the patient who has diabetes and is waiting for the kidney-pancreas transplant should receive the donor kidney. Surveyed respondents over 65 years of age were the most likely age group to believe that the need for a pancreas transplant should not be used to make a decision in this case.

Kidney-Pancreas versus Kidney Transplant

Q. 20. A deceased donor kidney becomes available for one of two patients on dialysis therapy. The donor pancreas is also suitable for transplantation. Patient 1 has diabetes and is on the waiting list for a combined kidney-pancreas transplant. Patient 2 does not have diabetes and is on the waiting list for a kidney transplant only. Both patients have been on dialysis for 2 years. All other factors are equal. To which patient do you think the available kidney should be allocated?		**Patient 1 who has diabetes and is on the waiting list for a combined kidney-pancreas transplant.**	**Patient 2 who does not have diabetes and is on the waiting list for a kidney transplant only.**	**The need for a pancreas transplant should not be used to make the decision in this case.**
AGE	N=480	%	%	%
Under 25 years	17	53	18	29
26- 35 years	65	66	11	23
36- 45 years	96	78	5	17
46- 55 years	135	81	7	11
56- 65 years	73	81	7	18
Over 65 years	93	56	13	31

**Because demographic questions were neither mandatory nor limited, the total number of respondents who answered each question does not match the number of respondents by age group or category in the cross tabulations.*

Individuals waiting for a transplant were more likely (34%) than health care professionals (14%) to believe that the need for a pancreas transplant should not be used to make the decision in this case.

Kidney-Pancreas versus Kidney Transplant

Q. 20. A deceased donor kidney becomes available for one of two patients on dialysis therapy. The donor pancreas is also suitable for transplantation. Patient 1 has diabetes and is on the waiting list for a combined kidney-pancreas transplant. Patient 2 does not have diabetes and is on the waiting list for a kidney transplant only. Both patients have been on dialysis for 2 years. All other factors are equal. To which patient do you think the available kidney should be allocated?		**Patient 1 who has diabetes and is on the waiting list for a combined kidney-pancreas transplant.**	**Patient 2 who does not have diabetes and is on the waiting list for a kidney transplant only.**	**The need for a pancreas transplant should not be used to make the decision in this case.**
CATEGORY	N=480	%	%	%
Person waiting for transplant	59	56	10	34
Living donor	15	80	0	20
Recipient	97	72	11	17
Family member of person with kidney disease	46	85	2	13
Not-for-profit organization employee (i.e., Kidney Foundation)	46	74	9	17
Volunteer (e.g., with the Kidney Foundation)	34	70	12	18
Health care professional	121	83	3	14
Other; please specify:	74	64	18	19

Just over one quarter (27%) of survey participants provided additional comments to this question. Respondents most commonly responded that both the kidney and the pancreas should be transplanted into the patient with diabetes to help lessen the effects of further renal disease and that it would help to maximize the use of both organs.

Scenario 2: In the second scenario one potential recipient has diabetes and has been on dialysis for two years and is waiting for a combined kidney-pancreas transplant. The second potential recipient does not have diabetes and has been on dialysis for 5 years and is waiting for a kidney transplant. The surveyed informed public are evenly divided on this question. Half (50%) believe that the potential recipient who has diabetes and has been on dialysis for 2 years should receive the donor kidney-pancreas transplant. The other half (49%) believe that the potential recipient who does not have diabetes and has been on dialysis for 5 years and is waiting for a kidney should receive the donor kidney.

Individuals aged under 25 years were more likely (79%) than those aged 36-45 years (38%) to believe that the patient who does not have diabetes and has been on dialysis for 5 years should receive the donor kidney.

**Because demographic questions were neither mandatory nor limited, the total number of respondents who answered each question does not match the number of respondents by age group or category in the cross tabulations.*

Kidney-Pancreas versus Kidney Transplant

Q. 22. A deceased donor kidney becomes available for one of two patients on dialysis therapy. The donor pancreas is also suitable for transplantation. Patient 1 has diabetes and is on the waiting list for a combined kidney-pancreas transplant. Patient 1 has been on dialysis for 2 years. Patient 2 does not have diabetes and is on the waiting list for a kidney transplant only. Patient 2 has been on dialysis for 5 years. All other factors are equal. To which patient do you think the available kidney should be allocated?		**Patient 1 who has diabetes, has been on dialysis for 2 years and is on the waiting list for a combined kidney-pancreas transplant.**	**Patient 2 who does not have diabetes, has been on dialysis 5 years and is on the waiting list for a kidney transplant only.**
	N=461	%	%
Under 25 years	19	21	79
26- 35 years	64	48	52
36- 45 years	92	63	38
46- 55 years	129	54	46
56- 65 years	73	49	51
Over 65 years	92	39	61

In this scenario health care professionals were more likely (64%) than individuals waiting for a transplant (37%) to believe that the patient with diabetes and who has been on dialysis for two should receive the combined kidney-pancreas transplant.

Kidney-Pancreas versus Kidney Transplant

Q. 22. A deceased donor kidney becomes available for one of two patients on dialysis therapy. The donor pancreas is also suitable for transplantation. Patient 1 has diabetes and is on the waiting list for a combined kidney-pancreas transplant. Patient 1 has been on dialysis for 2 years. Patient 2 does not have diabetes and is on the waiting list for a kidney transplant only. Patient 2 has been on dialysis for 5 years. All other factors are equal. To which patient do you think the available kidney should be allocated?		**Patient 1 who has diabetes, has been on dialysis for 2 years and is on the waiting list for a combined kidney-pancreas transplant.**	**Patient 2 who does not have diabetes, has been on dialysis 5 years and is on the waiting list for a kidney transplant only.**
CATEGORY	N=461	%	%
Person waiting for transplant	54	37	63
Living donor	14	57	43
Recipient	95	53	47
Family member of person with kidney disease	46	46	54
Not-for-profit organization employee (i.e., Kidney Foundation)	46	48	52
Volunteer (e.g., with the Kidney Foundation)	34	47	53
Health care professional	119	64	34
Other; please specify:	75	36	65

Just over one quarter (26%) of survey participants provided additional comments to this question. In this scenario respondents provided most of their comments on the amount of time the second patient had spent on dialysis and believe that it should be an important factor. However, there were also several comments regarding the potential waste of the donor pancreas if the first potential recipient did not receive the combined kidney-pancreas transplant.

**Because demographic questions were neither mandatory nor limited, the total number of respondents who answered each question does not match the number of respondents by age group or category in the cross tabulations.*

FINAL COMMENTS

When provided the opportunity for final comments, survey participants pointed out the importance of the survey and their new awareness of the complexity of kidney allocation.

At the end of the survey there was an opportunity for members of the informed public to provide final comments. Of the 545 individuals that participated in the survey over a third (38%) provided final comments.

The most common theme to emerge was around the importance of the survey. Many voiced their appreciation at the opportunity to be heard.

Participants commented on their new awareness of the decision making process and the complexity of kidney allocation factors. Many noted their respect for the healthcare professionals who are faced with these choices. Respondents also commented on the need for changes to kidney allocation policies and practice.

In addition, several comments were made about the controversial nature of kidney allocation and the importance of objectivity, ethics, and transparent standards and guidelines.

The opportunity to provide comments throughout the survey allowed for the development of an understanding of what factors are considered important for the informed public. Many commented on the need for additional information about the potential recipients and gave personal examples of how these factors have influenced their own lives. There were many examples given of their own or a family member's plight with renal disease and the devastation of life on dialysis. It was an important opportunity for many to have their voices heard.

CONCLUSION

The intent of the survey was to explore the beliefs and opinions of the informed public on specific factors used to allocate deceased donor kidneys.

In general, survey participants do not believe that the age of the potential recipient should be a deciding factor in determining who should be allocated a deceased donor kidney. In spite of this when participants are asked to choose they are more inclined to believe that younger recipients should receive the donor kidney.

Respondents overwhelming agree that the time spent on either dialysis or on the waiting list should be important factors in determining who should be allocated a deceased donor kidney. However, the time spent on dialysis appears to be the most important factor for surveyed individuals. Many provided additional comments on the health and lifestyle implications of living on dialysis and that the main goal of allocation should be to remove patients from dialysis as soon as possible.

A small majority of surveyed individuals do not believe that tissue matching should outweigh time spent on dialysis as a determining factor in kidney allocation. This opinion changes somewhat when length of time spent on dialysis between potential recipients is smaller.

The majority agree that potential recipients with diabetes should receive an allocated kidney-pancreas transplant when all other factors are equal. There is a shift in opinion when the length of time spent on dialysis is a mediating factor.

Many respondents chose to add additional comments to each question which generally included support for the choices they had indicated. Final comments reflect the survey participants' belief that the survey was important as it allowed them a voice in shaping decision making which impacts their lives. Participants elaborated on the controversial nature of allocating this scarce resource and their new appreciation for healthcare providers in this regard.

APPENDICES

Appendix A: Glossary and Definition of Terms

Allocation	The process of determining how organs are distributed. Allocation includes the system of policies and guidelines, which ensure that organs are distributed in an equitable, ethical and medically sound manner.
CCDT	Canadian Council for Donation and Transplantation
CORR	Canadian Organ Replacement Register a national information system that records, analyzes and reports the level of activity and outcomes of vital organ transplantation and renal dialysis activities. CORR is funded through the federal and provincial ministries of health through the Canadian Institute for Health Information (CIHI), which manages CORR.
Compliance	Adherence of patients to medical advice and instructions, especially immunosuppressive drug schedules.
Deceased Donor	An individual from whom at least one solid organ is recovered or the purpose of transplantation after suffering brain death or cardiac death.
Diabetes	A disease in which the pancreas does not manufacture an adequate amount of insulin. As a result, the level of sugar in the blood is too high. A leading factor in heart and kidney disease.
Dialysis	A mechanical process designed to partially perform kidney functions, including correcting the balance of fluids and chemicals in the body and removing wastes.
ESRD	End-stage renal disease: irreversible kidney failure.
Graft	A transplanted organ or tissue.
Kidneys	A pair of organs that remove wastes from the body through the production of urine. All of the blood in the body passes through the kidneys about 20 times every hour. Kidneys can be donated from living and deceased donors and transplanted into patients with kidney failure.
Match	The compatibility between the donor and the recipient. The more appropriate the match, the greater the chance of a successful transplant.
Organ Procurement Organization (OPO)	An organization responsible for the procurement of organs for transplantation and the promotion of organ donation. OPOs serve as the vital link between the donor and recipient and are responsible for the identification of donors, and the retrieval, preservation and transportation of organs for transplantation.

Pancreas	Irregularly shaped gland that lies behind the stomach and secretes pancreatic enzymes into the small intestines to aid in the digestion of proteins, carbohydrates and fats. Islet cells within the pancreas secrete glucagon, which regulates blood sugar levels and insulin, which lowers blood sugar levels. If the pancreas fails, the individual becomes diabetic, and may need to take insulin. The pancreas can be donated and transplanted.
Recipient	A person who receives a transplant.
Statistically Significant	Describes a mathematical measure of difference between groups. The difference is said to be statistically significant if it is greater than what might be expected to happen by chance alone.
Tissue matching	A blood test that helps evaluate how closely the tissues of the donor match those of the recipient.
Tissue Type	An individual's combination of HLA antigens. Matching for tissue type is used in the allocation system for kidney and pancreas transplantation.
Waiting Time	The amount of time a candidate is on the Wait List. Waiting times can be influenced by many factors, including: • blood type (some are rarer than others) • tissue type • height and weight of transplant candidate • size of donated organ • medical urgency • time on the waiting list

Appendix B: Top-Line Survey Results

1. Please check the box that best describes you:

Age	Number of respondents	Percentage of respondents
Under 25 years	21	4%
26- 35 years	78	14%
36- 45 years	114	21%
46- 55 years	149	27%
56- 65 years	83	15%
Over 65 years	99	18%

2. What is your province or territory of residence?

Province/Territory	Number of respondents	Percentage of respondents
British Columbia	51	9%
Alberta	272	50%
Saskatchewan	36	7%
Manitoba	34	6%
Ontario	81	15%
Quebec	22	4%
Prince Edward Island	1	0%
New Brunswick	19	3%
Newfoundland and Labrador	12	2%
Nova Scotia	14	3%
North West Territory	1	0%
Nunavut	0	0%
Yukon Territory	0	0%

3. Which category best describes you? (Please only check one.)	Number of respondents	Percentage of respondents
Person waiting for transplant	61	11%
Living donor	19	4%
Recipient	107	19%
Family member of person with kidney disease	54	10%
Not-for-profit organization employee (i.e., Kidney Foundation)	53	9%
Volunteer (e.g., with the Kidney Foundation)	41	7%
Health care professional	138	25%
Other; please specify:	90	16%

The following scenarios explore some of the factors that are used to determine how kidneys are allocated to individuals in need of a transplant. Please choose ONE response:

AGE

4. A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 is 35 years old. Patient 2 is 8 years old. All other factors are equal. To which patient do you think the available kidney should be allocated?	**Number of respondents**	**Percentage of respondents**
The 35 year old patient.	52	10%
The 8 year old patient.	173	33%
The age of the patient should not be used to make the decision in this case.	297	57%

6. A deceased donor kidney becomes available for one of two patients on dialysis therapy. Both patients have been on dialysis for 3 years. Patient 1 is 25 years old and Patient 2 is 65 years old. All other factors are equal. To which patient do you think the available kidney should be allocated?	**Number of respondents**	**Percentage of respondents**
The 25 year old.	231	44%
The 65 year old.	19	4%
The age of the patient should not be used to make the decision in this case.	272	52%

8. A deceased donor kidney becomes available for one of two patients on dialysis therapy. The donor was 20 years old and had excellent kidney function. Patient 1 is 25 years old. Patient 2 is 65 years old. Both patients have been on dialysis for 3 years. All other factors are equal. To which patient do you think the available kidney should be allocated?	**Number of respondents**	**Percentage of respondents**
The 25 year old patient.	267	52%
The 65 year old patient.	15	3%
The age of the patient should not be used to make the decision in this case.	232	45%

LENGTH OF TIME ON THE WAITING LIST

10. A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 has been on the waiting list for 3 years, and Patient 2 has been on the waiting list for 1 year. All other factors are equal. To which patient do you think the available kidney should be allocated?	**Number of respondents**	**Percentage of respondents**
The patient who waited 3 years.	422	85%
The patient who waited 1 year.	1	0%
The time on the waiting list should not be used to make the decision in this case.	73	15%

The following two questions use slight variations of the same scenarios:

12. A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 started dialysis therapy 2 years ago, but was just recently put on the wait list because of the length of time taken to complete the investigations to ensure they were fit for transplantation. Patient 2 started dialysis therapy 1 year ago and went on to the waiting list immediately because they needed no more investigations. All other factors are equal. To which patient do you think the available kidney should be allocated?	**Number of respondents**	**Percentage of respondents**
The patient who started dialysis 2 years ago and was just put on the wait list because of the time it took to complete the investigations.	361	74%
The patient who started dialysis 1 year ago and has been on the waiting list for 1 year.	130	26%

14. A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 has been on dialysis therapy for 1 year and on the waiting list for 3 months. Patient 2 is not on dialysis therapy yet, but was put on the waiting list 5 months ago when the doctors believed he/she would need dialysis therapy within the next 6 months. All other factors are equal. To which patient do you think the available kidney should be allocated?	**Number of respondents**	**Percentage of respondents**
The patient on dialysis for 1 year and on the waiting list for 3 months.	401	82%
The patient on the waiting list for 5 months but not yet on dialysis	90	18%

ESTIMATED CHANCE OF KIDNEY SURVIVAL

The following two questions use slight variations of the same scenarios:

16. A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 has been on dialysis therapy for 3 years, and it is estimated that the transplant has an 85% chance of lasting 3 years because of an excellent match with the donor. Patient 2 has been on dialysis for 7 years, and it is estimated that the transplant has a 75% chance of lasting 3 years because the match with the donor is not as good as Patient 1. All other factors are equal. To which patient do you think the available kidney should be allocated?	**Number of respondents**	**Percentage of respondents**
The patient on dialysis for 7 years for whom the transplant is estimated to have a 75% percent chance of lasting 3 years.	308	64%
The patient on dialysis for 3 years for whom the transplant is estimated to have an 85% chance of lasting 3 years.	175	36%

18. A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 has been on dialysis therapy for 3 years, and it is estimated that the transplant has an 85% chance of lasting 3 years because of an excellent match with the donor. Patient 2 has been on dialysis for 4 years, and it is estimated that the transplant has a 75% chance of lasting 3 years because the match with the donor is not as good as Patient 1. All other factors are equal. To which patient do you think the available kidney should be allocated?	**Number of respondents**	**Percentage of respondents**
The patient on dialysis for 4 years for whom the transplant is estimated to have a 75% percent chance of lasting 3 years.	232	49%
The patient on dialysis for 3 years for whom the transplant is estimated to have an 85% chance of lasting 3 years.	245	51%

KIDNEY-PANCREAS TRANSPLANTATION

20. A deceased donor kidney becomes available for one of two patients on dialysis therapy. The donor pancreas is also suitable for transplantation. Patient 1 has diabetes and is on the waiting list for a combined kidney-pancreas transplant. Patient 2 does not have diabetes and is on the waiting list for a kidney transplant only. Both patients have been on dialysis for 2 years. All other factors are equal. To which patient do you think the available kidney should be allocated?	**Number of respondents**	**Percentage of respondents**
Patient 1 who has diabetes and is on the waiting list for a combined kidney-pancreas transplant.	348	71%
Patient 2 who does not have diabetes and is on the waiting list for a kidney transplant only.	42	9%

The need for a pancreas transplant should not be used to make the decision in this case.	100	20%
22. A deceased donor kidney becomes available for one of two patients on dialysis therapy. The donor pancreas is also suitable for transplantation. Patient 1 has diabetes and is on the waiting list for a combined kidney-pancreas transplant. Patient 1 has been on dialysis for 2 years. Patient 2 does not have diabetes and is on the waiting list for a kidney transplant only. Patient 2 has been on dialysis for 5 years. All other factors are equal. To which patient do you think the available kidney should be allocated?	**Number of respondents**	**Percentage of respondents**
Patient 1 who has diabetes, has been on dialysis for 2 years and is on the waiting list for a combined kidney-pancreas transplant.	235	50%
Patient 2 who does not have diabetes, has been on dialysis 5 years and is on the waiting list for a kidney transplant only.	236	50%

Appendix C: Survey Instrument

Welcome to the Kidney Allocation Survey.

The survey has 3 demographic and 10 allocation questions with options for additional comments to each question. It takes about 15 to 20 minutes to complete.

You can return to a previous page to view and/or change your responses by using your back button.
However, once you submit the survey after the final comments box, you will not be able to change or view your responses.

Your survey participation is anonymous; that is, you will not be identified in the survey. By doing the survey, you are consenting to participation.

We thank you for taking the time to complete our on-line survey.

Kidney Allocation Public Opinion Survey

1

Please check the box that best describes you:

- Under 25 years
- 26- 35 years
- 36- 45 years
- 46- 55 years
- 56- 65 years
- Over 65 years

2

What is your province or territory of residence?

- British Columbia

- Alberta
- Saskatchewan
- Manitoba
- Ontario
- Quebec
- Prince Edward Island
- New Brunswick
- Newfoundland and Labrador
- Nova Scotia
- North West Territory
- Nunavut
- Yukon Territory

3

Which category best describes you? (Please only check one.)

- Person waiting for transplant
- Living donor
- Recipient
- Family member of person with kidney disease
- Not-for-profit organization employee (i.e., Kidney Foundation)
- Volunteer (e.g., with the Kidney Foundation)
- Health care professional
- Other; please specify:

SUBMIT

Kidney Allocation Public Opinion Survey

The following scenarios explore some of the factors that are used to determine how kidneys are allocated to individuals in need of a transplant. Please choose ONE response:

AGE

4

A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 is 35 years old. Patient 2 is 8 years old. All other factors are equal. To which patient do you think the available kidney should be allocated?

- The 35 year old patient.
- The 8 year old patient.
- The age of the patient should not be used to make the decision in this case.

5

Comments about the above question:

6

A deceased donor kidney becomes available for one of two patients on dialysis therapy. Both patients have been on dialysis for 3 years. Patient 1 is 25 years old and Patient 2 is 65 years old. All other factors are equal. To which patient do you think the available kidney should be allocated?

- The 25 year old.
- The 65 year old.
- The age of the patient should not be used to make the decision in this case.

7

Comments about the above question:

8

A deceased donor kidney becomes available for one of two patients on dialysis therapy. The donor was 20 years old and had excellent kidney function. Patient 1 is 25 years old. Patient 2 is 65 years old. Both patients have been on dialysis for 3 years. All other factors are equal. To which patient do you think the available kidney should be allocated?

- The 25 year old patient.
- The 65 year old patient.
- The age of the patient should not be used to make the decision in this case.

9

Comments about the above question:

SUBMIT

Kidney Allocation Public Opinion Survey

LENGTH OF TIME ON THE WAITING LIST

10

A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 has been on the waiting list for 3 years, and Patient 2 has been on the waiting list for 1 year. All other factors are equal. To which patient do you think the available kidney should be allocated?

- The patient who waited 3 years.
- The patient who waited 1 year.
- The time on the waiting list should not be used to make the decision in this case.

11

Comments about the above question:

The following two questions use slight variations of the same scenarios:

12

A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 started dialysis therapy 2 years ago, but was just recently put on the wait list because of the length of time taken to complete the investigations to ensure they were fit for transplantation. Patient 2 started dialysis therapy 1 year ago and went on to the waiting list immediately because they needed no more investigations. All other factors are equal. To which patient do you think the available kidney should be allocated?

- The patient who started dialysis 2 years ago and was just put on the wait list because of the time it took to complete the investigations.
- The patient who started dialysis 1 year ago and has been on the waiting list for 1 year.

13

Comments about the above question:

14

A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 has been on dialysis therapy for 1 year and on the waiting list for 3 months. Patient 2 is not on dialysis

therapy yet, but was put on the waiting list 5 months ago when the doctors believed he/she would need dialysis therapy within the next 6 months. All other factors are equal. To which patient do you think the available kidney should be allocated?

- The patient on dialysis for 1 year and on the waiting list for 3 months.
- The patient on the waiting list for 5 months but not yet on dialysis

15

Comments about the above question:

SUBMIT

Kidney Allocation Public Opinion Survey

ESTIMATED CHANCE OF KIDNEY SURVIVAL

The following two questions use slight variations of the same scenarios:

16

A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 has been on dialysis therapy for 3

years, and it is estimated that the transplant has an 85% chance of lasting 3 years because of an excellent match with the donor. Patient 2 has been on dialysis for 7 years, and it is estimated that the transplant has a 75% chance of lasting 3 years because the match with the donor is not as good as Patient 1. All other factors are equal. To which patient do you think the available kidney should be allocated?

- The patient on dialysis for 7 years for whom the transplant is estimated to have a 75% percent chance of lasting 3 years.
- The patient on dialysis for 3 years for whom the transplant is estimated to have an 85% chance of lasting 3 years.

17

Comments about the above question:

18

A deceased donor kidney becomes available for one of two patients on dialysis therapy. Patient 1 has been on dialysis therapy for 3 years, and it is estimated that the transplant has an 85% chance of lasting 3 years because of an excellent match with the donor. Patient 2 has been on dialysis for 4 years, and it is estimated that the transplant has a 75% chance of lasting 3 years because the match with the donor is not as good as Patient 1. All other factors are equal. To which patient do you think the available kidney should be allocated?

- The patient on dialysis for 4 years for whom the transplant is estimated to have a 75% percent chance of lasting 3 years.
- The patient on dialysis for 3 years for whom the transplant is estimated to have an 85% chance of lasting 3 years.

19

Comments about the above question:

SUBMIT

Kidney Allocation Public Opinion Survey

KIDNEY-PANCREAS TRANSPLANTATION

20

A deceased donor kidney becomes available for one of two patients on dialysis therapy. The donor pancreas is also suitable for transplantation. Patient 1 has diabetes and is on the waiting list for a combined kidney-pancreas transplant. Patient 2 does not have diabetes and is on the waiting list for a kidney transplant only. Both patients have been on dialysis for 2 years. All other factors are equal. To which patient do you think the available kidney should be allocated?

- Patient 1 who has diabetes and is on the waiting list for a combined kidney-pancreas transplant.
- Patient 2 who does not have diabetes and is on the waiting list for a kidney transplant only.
- The need for a pancreas transplant should not be used to make the decision in this case.

21

Comments about the above question:

22

A deceased donor kidney becomes available for one of two patients on dialysis therapy. The donor pancreas is also suitable for transplantation. Patient 1 has diabetes and is on the waiting list for a combined kidney-pancreas transplant. Patient 1 has been on dialysis for 2 years. Patient 2 does not have diabetes and is on the waiting list for a kidney transplant only. Patient 2 has been on dialysis for 5 years. All other factors are equal. To which patient do you think the available kidney should be allocated?

- Patient 1 who has diabetes, has been on dialysis for 2 years and is on the waiting list for a combined kidney-pancreas transplant.
- Patient 2 who does not have diabetes, has been on dialysis 5 years and is on the waiting list for a kidney transplant only.

23

Comments about the above question:

24

Do you have any final comments about these questions or the survey?

SUBMIT