Nephrol Dial Transplant (2021) 36: 1742–1753
doi: 10.1093/ndt/gfab035
Advance Access publication 15 February 2021

ORIGINAL ARTICLE

Long-term risks after kidney donation: how do we inform potential donors? A survey from DESCARTES and EKITA transplantation working groups

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ABSTRACT

Background. Publications from the last decade have increased knowledge regarding long-term risks after kidney donation. We wanted to perform a survey to assess how transplant professionals in Europe inform potential kidney donors regarding long-term risks. The objectives of the survey were to determine how they inform donors and to what extent, and to evaluate the degree of variation.

Methods. All transplant professionals involved in the evaluation process were considered eligible, regardless of the type of profession. The survey was dispatched as a link to a web-based survey. The subjects included questions on demographics, the information policy of the respondent and the use of risk calculators, including the difference of relative and absolute risks and how the respondents themselves understood these risks.

Results. The main finding was a large variation in how often different long-term risks were discussed with the potential donors, i.e. from always to never. Eighty percent of respondents stated that they always discuss the risk of end-stage renal disease, while 56% of respondents stated that they always discuss the risk of preeclampsia. Twenty percent of respondents answered correctly regarding the relationship between absolute and relative risks for rare outcomes.

KEY LEARNING POINTS

What is already known about this subject?

- very little is known regarding how transplant professionals inform donors about long-term risks after donation; and
- previous studies were performed before the publication of recent papers finding increased long-term risks for hypertension, end-stage renal disease, preeclampsia and death after kidney donation.

What this study adds?

- this study is the largest ever on the subject, and no other such study has been performed during the last decade;
- this study is the only study that describes the current practice of how transplant professionals in Europe inform potential donors regarding long-term risks; and
- there is currently a large variation and no uniform standards regarding how transplant professionals inform potential kidney donors about long-term risks.

What impact this may have on practice or policy?

- there is a need for education and information among health professionals counselling potential donors regarding long-term risks; and
- this study will hopefully inspire more focus on how donors receive information about long-term risks, and help improve and standardize the counselling of potential kidney donors regarding these risks.

Conclusions. The use of written information and checklists should be encouraged. This may improve standardization regarding the information provided to potential living kidney donors in Europe. There is a need for information and education among European transplant professionals regarding long-term risks after kidney donation and how to interpret and present these risks.

Keywords: kidney donors, long-term risks, transplant professionals

INTRODUCTION

Kidney transplantation from a living donor has been performed for over six decades. Early studies on long-term follow-up of donors were reassuring [1]. However, during the last decade our understanding of long-term risks in donors has changed. Studies have indicated increased risks of hypertension, proteinuria, end-stage renal disease (ESRD), preeclampsia and death [2–7].

Before starting the donor evaluation process, a potential donor will receive some type of presentation of potential risks related to the evaluation, the nephrectomy and life after donation. This includes information regarding long-term risks related to kidney donation. With recent studies, this is more complicated than before. Previous surveys on this subject were performed before newer data on long-term risks were published. The DESCARTES (Developing Education Science and Care for Renal Transplantation in European States) working group previously published a review and position article about the long-term risks of kidney donation [8]. Here, we surveyed transplant professionals in Europe about what they consider to be potential long-term risks after kidney donation, and how they would present these risks. The objectives of the survey were: to determine (i) what transplant professionals perceive as quantitative long-term risks, (ii) how they inform donors and (iii) to what extent they inform donors, and to evaluate (iv) the degree of variation that could exist between physicians from different countries. Ultimately, the results of the survey will be used to create guidelines for providing information to potential donors.

MATERIALS AND METHODS

The survey was intended to include transplant professionals in Europe involved in evaluation of potential living kidney donors. All transplant professionals involved in the evaluation process were considered eligible, regardless of the type of profession. However, we were aware that most respondents were likely to be nephrologists or transplant surgeons. The survey was supposed to take no more than five minutes to fill out. The survey questions were inspired by previous surveys [9, 10], but took also into account recently published studies in the field of living kidney donation [3–5, 7, 11]. The questions for a preliminary draft of the survey were suggested by three of the authors (G.M, D.A. and U.M). This draft was then circulated among other co-authors. Questions were entered and removed through discussion and with the objective of the survey in mind. After agreement on a set of questions, the survey was then circulated to other authors for their opinion on the choice of questions, and for assessment of the precision of the questions and choice of answers. After reaching agreement within the author group, the survey was tested on a group of physicians to get feedback and to ensure internal validity of the survey form. The survey was converted from a regular document to an online survey using Survey monkey. Additional testing of the functionality of multiple choices options was done, and this resulted in the present

survey. Questions were of different categories. The first part of the survey dealt with demographic characteristics of the respondent and the affiliated transplant centre. The second part consisted of questions regarding the information policy of the respondent in general, and regarding some long-term risks, namely hypertension, ESRD, death and preeclampsia in particular. We did not ask respondents whether they personally believed these risks were increased, but only whether they discussed these risks with the potential donor. However, it is more likely that physicians will discuss a risk if they actually think that the concerning outcome could occur.

The last part of the survey concerned the use of risk calculators, including the difference of relative and absolute risks and how the respondents themselves understood these risks. Survey questions are listed in the Supplementary Appendix. A link to the survey, accompanied by a short letter, was dispatched by e-mail to members of DESCARTES ($N = 535$), a working group of the European Renal Association – European Dialysis and Transplant Association. A link was also sent out as a newsletter to all members of the European Society of Organ Transplantation. The newsletter was successfully delivered to 8588 members, and registered as opened by 2969 members. This yielded 112 responses, resulting in a response rate of 3.8%. This was deemed as unsatisfactory. Therefore, in addition to the aforementioned strategy, co-authors used their personal networks and targeted individuals from each European country, whom they knew were involved in the evaluation of living kidney donors. These individuals were then responsible for the dissemination of the survey in their respective countries. In some countries, invitations to the survey were subsequently carried out through national associations to all of their members, while in other countries only selected individuals received the survey. Some of those who received the survey were asked to forward the link to other suitable respondents. Due to this strategy, it is not possible to precisely calculate the final response rate. We crudely estimate the final response rate to be around 10%. The link to the survey was dispatched only once, but some of those who were asked to pass on the link may have sent reminders to their contacts. All respondents could choose to be a collaborator in the final publication of the survey.

RESULTS

A total of 392 transplant professionals responded to the survey (Table 1). Mean age was 49 years, with a mean of 13 years of experience with donor evaluation. Centres surveyed performed on average 30 living-donor transplantations per year, although the number varied widely. Almost all respondents were directly involved in the work-up of potential kidney donors. Sixty-eight percent of respondents labelled their centre's living donor policy as liberal, while 32% labelled it as restrictive, although it was up to the respondent to define these terms. Seventy-six percent of respondents stated that their centres provide donors with life-long follow-up after donation. Seventy-five percent of respondents were nephrologists, 19% were surgeons and 5% were coordinators. Survey respondents were from 30 different countries (Table 1 and Figure 1). The countries with the highest contribution of respondents were Spain (16%), Italy (11%), France (11%), the UK (10%), the Netherlands (9%) and Germany (9%), so that the majority of the respondents (66%) were from these six countries.

Table 2 and Figure 2 report on the type of risk disclosed and on the use of written information. Ninety-seven percent of respondents stated that they routinely inform donors about long-term risks. Regarding the risk of hypertension after donation, 76% of respondents stated that they always discuss this risk and 11% stated that they discuss this risk often. Seventy percent of respondents informed about the risk of hypertension in writing.

Regarding the risk of developing ESRD after donation, 80% of respondents stated that they always discuss this risk and 8% stated that they discuss this risk often. Sixty-two percent of respondents informed about the risk of developing ESRD in writing.

Regarding the risk of death after donation, 63% of respondents stated that they always discuss this risk and 7% stated that they discuss this risk often. Fifty-seven percent of respondents inform about risk of death in writing.

Regarding the risk of preeclampsia after donation, 56% of respondents stated that they always discuss this risk and 11% stated that they discuss this risk often. Forty-six percent of respondents informed about the risk of preeclampsia in writing.

Respondents were asked if they test whether the donor understood the information about possible long-term risks. Fifty-two percent stated that they always test this, 21% often test this, 14% test this occasionally, 7% rarely and 6% never. When asked how they test whether the donor understood the information, only 2% used a written test. Thirty-six percent used specific verbal questions. Fifty-six percent stated that they ask only if the donor fully understood the information, and 4% do not test this at all.

Table 3 and Figure 3 report on the risk quantification. Respondents were surveyed regarding differences between relative and absolute risks for rare outcomes, and if they used this when informing donors. Sixty-eight percent stated that they differentiate between absolute and relative risks when informing donors about increased risk of rare outcomes. Thirty-seven percent responded that they tailor numerical long-term risk predictions of ESRD to the individual risk profile rather than reporting an average estimate. Respondents were asked to estimate the increase in the relative risk of ESRD during the remaining lifespan of a 50-year-old male Caucasian donor as compared with no donation. Thirteen percent responded that the relative risk was increased by 5–10-fold, 34% responded 3–5-fold and 53% 1.5-fold. Finally, respondents were asked to estimate the absolute risk of ESRD during the remaining lifespan of the same 50-year-old male Caucasian donor. Forty-one percent responded that the absolute risk was 1%. Thirty-nine percent responded that the risk was 0.1%. Eighteen percent responded 2%, and 2% responded that the absolute risk was 10%. Out of a total of 359 respondents, 73 respondents (20%) answered what was deemed as the correct combination of answers, namely a relative risk of 3–5- or 5–10-fold, and a corresponding absolute risk of 1%.

Survey results are also presented separately for nephrologists, surgeons and coordinators/others in Supplementary data, Tables S1 and S2. There were no major differences between groups.

DISCUSSION

The current survey is the largest survey ever performed on this subject. During the last decade no similar survey has been published. The main finding was a large variation in how often different long-term risks were discussed with the potential donors, i.e. from always to never. In Table 4, we have summarized the currently known long-term risks after kidney donation, including those mentioned in this survey. In Table 5 we have summarized the recommendations from current guidelines regarding how to inform about long-term risks. Housawi *et al.* also investigated whether there were practice variations in communicating risks to the potential donor [10]. They surveyed 203 transplant professionals and found that there was a large variation in the risks communicated to potential kidney donors. The specific long-term medical risks evaluated in the study were hypertension, proteinuria, chronic kidney disease, renal failure requiring dialysis, premature cardiovascular disease and death. Another study by Parekh *et al.* from 2008 surveyed 223 transplant professionals [9]. Most of the respondents stated that they provided donors with information regarding potential long-term risks. However, there was a large variation among respondents whether these risks were conveyed as 'increased' or 'not increased'. In a more recent study from the USA by Thiessen *et al.* [15], health professionals were asked to submit the forms they used for obtaining informed consent from donors. The authors received 148 consent forms. The contents were compared against a list of required elements for informed consent, as stated by the Organ Procurement and Transplantation Network. There were large variations between centres regarding which long-term risks were disclosed in the informed consent forms. For example, potentially increased risks for ESRD were only mentioned in half of the consent forms.

The four studies cited above need to be understood in light of the scientific knowledge that was available at the time they were performed. Several important papers on donor risk have been published since [5–7]. Consequently, time of publication is relevant when interpreting studies on how risk is conveyed to donors. A more recent survey published in 2016 found that 25% of surgeons never informed the donor about the risk of ESRD and that 53% never informed the donor about the risk for hypertension and other cardiovascular complications [16]. The current survey is the first one implementing the latest knowledge on donor risk published during the last decade [5–7].

In the current survey, a long-term risk commonly discussed with potential donors was hypertension. This was also the case in two of the above-mentioned surveys. In the survey by Housawi *et al.*, 92% of respondents discussed this risk with potential donors [10]. In the survey by Parekh *et al.*, 96% discussed this risk with donors [9], and a majority of respondents was of the impression that the risk for hypertension was increased after donation. The transplant community has been aware of this risk for more than a decade, after Boudville *et al.* published their landmark paper in 2006 with a meta-analysis of available studies [4], and both of these surveys were published after this meta-analysis.

On the other hand, only half of the respondents stated that they always discussed the risk for preeclampsia with potential donors. No previous surveys have evaluated this, probably

Table 1. Respondent characteristics

	n	Finding (range, %)
Age (years)	391	49 (27–81)
Experience donor evaluation (years)	392	13 (0–42)
Living donor transplants per year	392	30 (0–500)
Are you directly involved in the living donor work-up?	392	• Yes 362 (92) • Occasionally 27 (8) • Never 3 (1)
What is your specialty?	392	• Nephrologist 295 (75) • Surgeon 73 (19) • Coordinator 21 (5) • Other 3 (1)
Do you have mandatory follow-up for donors?	359	• Life-long 275 (76) • Some years 42 (12) • Recommend it 42 (12)
Centre attitude towards living donation	392	• Liberal 267 (68) • Restrictive 125 (32)
Country	392	1. Spain 62 (16) 2. Italy 46 (11) 3. France 43 (11) 4. UK 41 (10) 5. The Netherlands 36 (9) 6. Germany 35 (9) 7. Turkey 21 (5) 8. Belgium 18 (5) 9. Austria 12 (3) 10. Denmark 9 (2) 11. Hungary 7 (1.7) 12. Norway 6 (1.5) 13. Romania 6 (1.5) 14. Poland 5 (1.3) 15. Czech Republic 5 (1.3) 16. Macedonia 5 (1.3) 17. Slovakia 5 (1.3) 18. Switzerland 4 (1) 19. Sweden 3 (0.7) 20. Albania 2 (0.5) 21. Bosnia 1 (0.3) 22. Croatia 2 (0.5) 23. Cyprus 2 (0.5) 24. Estonia 3 (0.7) 25. Finland 3 (0.7) 26. Greece 2 (0.5) 27. Ireland 1 (0.3) 28. Lithuania 1 (0.3) 29. Montenegro 1 (0.3) 30. Portugal 2 (0.5) 31. Israel 1 (0.3) 32. Serbia 1 (0.3) 33. Slovenia 1 (0.3)

Continuous data are reported as mean (range), categorical data as number (percentage).

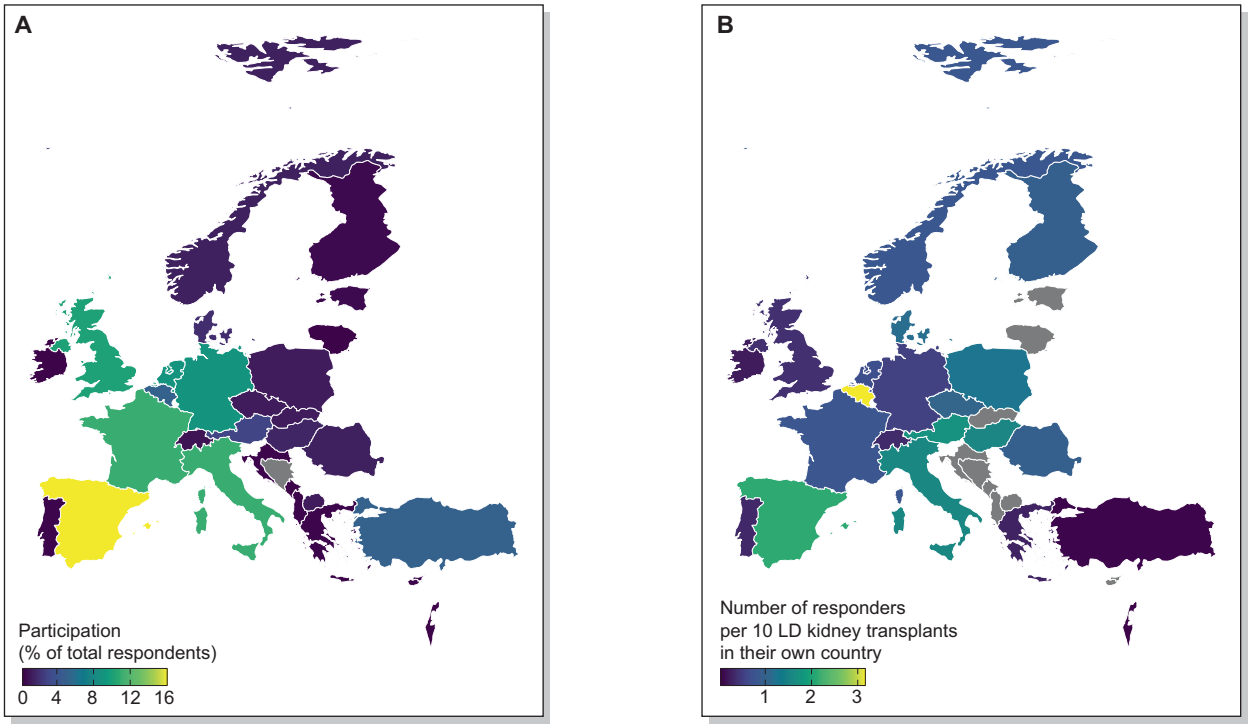

FIGURE 1: Origin of the respondents to the survey, reported as proportion of the total (A) and as number of respondents per 10 living donor kidney transplants in their own country (B). The number of living donor kidney transplants was based on data from the Global Observatory on Donation and Transplantation for the year 2018 (http://www.transplant-observatory.org/); in (B), countries with <20 living donor kidney transplants in 2018 are reported in grey. Colour scale (legend on the right) reflects the numbers in the plot.

because the knowledge regarding these risks has emerged only during the last decade. Three previous studies have reported an increased incidence of preeclampsia or gestational hypertension after kidney donation [7, 17, 18]. Garg *et al.* found a combined endpoint of gestational hypertension and preeclampsia in 11% of donor pregnancies, compared twith 5% in controls [7].

In the current survey, providing written information was less common than discussing risks. For different risks written information was provided by 40–73% of respondents, although this does not exclude that respondents used written materials or visual aids for other aspects of informing donors. In a study by Beasley *et al.* from 1997, 28% of respondents reported that they did not use any written material when providing the donor with information [19]. In 2008, Parekh *et al.* reported that 12% of the potential donors did not receive any written material [9], indicating that providing written information is becoming more common during recent years. Providing written information regarding long-term risks is important for the potential donor. In a survey performed after living donation, only 52% had understood the long-term risks of donation [20]. The authors concluded that it is likely that donors need to be more fully informed. Lennerling and Nyberg performed a study of written information for potential donors and found that many important subjects were lacking in these materials [21]. Written information is also important for equal access to care across institutions and countries, so that donors make their choice based on standardized information. Without providing a potential kidney donor with neutral written information regarding the known risks and benefits of living kidney donation, time to reflect upon this information and transplant professionals available for answering questions and addressing the donor's concerns, obtaining informed consent becomes difficult. When prospective donors are faced with an unknown risk, they may be unable to rationally decide and the transplant team has a difficult task in balancing the risks and benefits of living donation [8]. The increased focus on shared decision-making in medicine is also a strong argument for the importance of written information. An example of the written consent is provided along with the previously published DESCARTES position paper [8]. It is also important how the information is written, as it is often at an unnecessarily high reading level that potential donors may find hard to comprehend [22].

Only 2% of respondents stated that they used a written test to test whether the donor understood the information regarding long-term risks, while one-third stated that they asked specific questions. Current Kidney Disease: Improving Global Outcomes (KDIGO) guidelines recommend assuring that the donor has understood the given information regarding the risks and benefits, e.g. by asking the donor to 'teach back' [23]. Gordon *et al.* evaluated a comprehension assessment tool in living liver donors with 49 questions intended to test the comprehension of important aspects of informed consent [24]. As a supplement to a signed informed consent form, some type of testing of information transfer could be useful as documentation of the donor education process. In a survey performed at the day of admission, Timmerman *et al.* found large variations in the knowledge among the donors [25]. A systematic review

Table 2. Type of risk disclosed and writing material

	n	Answers (%)
Do you routinely inform about long-term risks?	385	• Yes 373 (97) • No 12 (3)
Do you discuss risk of hypertension?	360	• Always 272 (76) • Often 41 (11) • Occasionally 36 (10) • Rarely 8 (2) • Never 3 (1)
Do you inform about risk of hypertension in writing?	359	• Yes 252 (70) • No 107 (30)
Do you discuss risk of ESRD?	361	• Always 288 (80) • Often 30 (8) • Occasionally 18 (5) • Rarely 23 (6) • Never 2 (0.5)
Do you inform about risk of ESRD in writing?	361	• Yes 223 (62) • No 133 (38)
Do you discuss risk of death?	361	• Always 228 (63) • Often 24 (7) • Occasionally 25 (7) • Rarely 54 (15) • Never 30 (8)
Do you inform about risk of death in writing?	356	• Yes 223 (57) • No 133 (34)
Do you discuss risk of preeclampsia?	361	• Always 203 (56) • Often 44 (12) • Occasionally 45 (12) • Rarely 45 (12) • Never 24 (6)
Do you inform about risk of preeclampsia in writing?	356	• Yes 163 (46) • No 193 (54)
Do you test whether the donor understood the information about possible long-term risks?	361	• Always 189 (52) • Often 75 (21) • Occasionally 49 (14) • Rarely 27 (7) • Never 21 (6)
How do you test this?	361	• Ask if they fully understood the information 203 (56) • Specific verbal questions 131 (36) • Written test 9 (2) • Do not test 18 (4)

Answers are reported as number (percentage).

by Kortram *et al.* in 2014 stated the need for a guideline on how to provide information and obtain informed consent [26].

A considerable proportion of respondents stated that they differentiate between absolute and relative risks when providing information regarding rare outcomes. Furthermore, 37% stated that they tailor individual risks using risk calculators that are available online. The most common risk calculator estimates the baseline risk before donating a kidney [11]. However, it has been criticized for lack of long-term data to base estimations on [8, 27, 28]. As a consequence, it could underestimate the long-term risks of kidney disease attributable to future diabetes mellitus that has yet to occur [28]. This makes it less useful for young donors with a long remaining life span. From current studies on ESRD after kidney donation, we know that ESRD does not occur until after several decades, and that most cases occur after middle age. Consequently, the cohorts that the calculator is based on do not have enough observation time to make it relevant for estimating lifetime risks in young potential donors, as it is likely to underestimate these. The risk calculator could potentially be useful in estimating future risks of ESRD in middle-aged and older donors. With the exception of young donors in mind, such risk calculators represent a progress in the sense that they may facilitate discussions of baseline and future risks between transplant professionals and potential donors. Two other calculators have also been published, estimating impact of donor characteristics on the risk of ESRD or low renal function [29, 30].

The responses regarding absolute and baseline risks showed that transplant professionals in our survey did not have a clear grasp of the difference between absolute and relative risks for

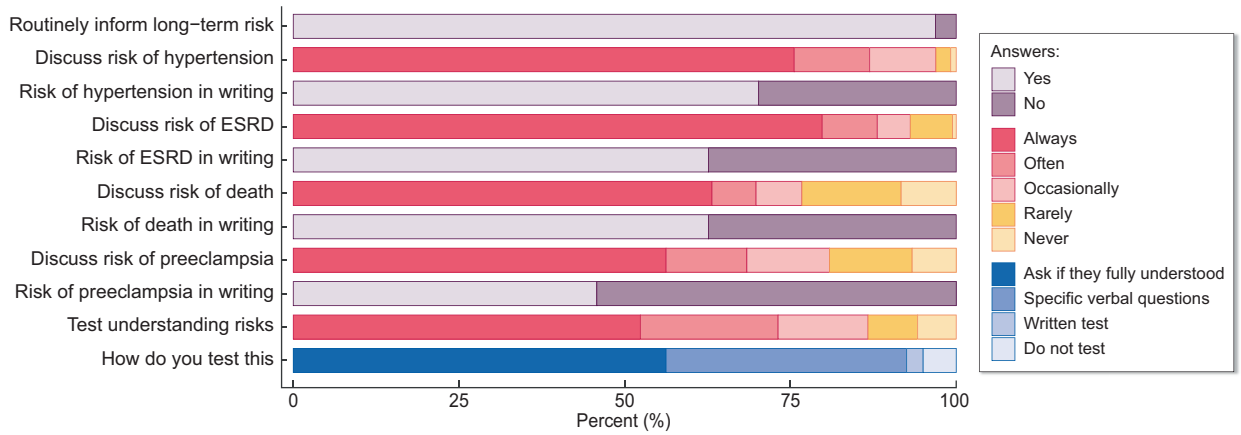

FIGURE 2: Findings from Table 2 are reported as stacked bar chart to facilitate the comparison across the different survey items.

Table 3. Risk quantification

	n	Answers
Do you differentiate between absolute and relative risks when informing potential donors about increased risk of rare outcomes?	359	• Yes 244 (68) • No 115 (32)
Do you tailor numerical long-term ESRD risk predictions to the individual donor (based on the proposed ESRD risk calculators available on the Web)?	359	• Yes 134 (37) • No 225 (63)
What is your estimation of the increase in the relative risk of ESRD during the remaining lifespan of a 50 years old male Caucasian donor as compared to no donation?	359	• 1.5-fold 190 (53) • 3–5-fold 122 (34) • 5–10-fold 47 (13)
What is your estimation of the absolute risk of ESRD in the case mentioned above?	359	• 0.1% 139 (39) • 1% 148 (41) • 2% 63 (18) • 10% 9 (2)

Answers are reported as number (percentage).

rare outcomes such as ESRD. After the publication of papers showing increased risks of ESRD in kidney donors [5, 6], there was a need for understanding and interpreting these risks. The message for potential donors was now more difficult to communicate than before [31]. Part of the solution in communicating these risks to donors and to those counselling them is knowledge about baseline risks for different outcomes, and how donation could increase this risk. The risk of getting any type of kidney disease is not likely to be increased in donors. However, if they get kidney disease later in life, they will have less reserve capacity as they are starting out with only one kidney. This will increase the risk of ESRD as compared with if they had still had two kidneys [31]. When discussing the specific outcome of ESRD, it is important to have a good understanding of the difference between absolute and relative risks. Relative risk refers to the multiplicative change in the baseline risk for ESRD, e.g. 10 times increased risk. The addition of absolute risk is relevant since ESRD is usually a rare outcome. For rare outcomes, a high relative risk will translate into a low absolute risk. An appropriate example is the 50-year-old male donor in our survey. The relative risk of ESRD after donating a kidney is likely to be around 6–10 times [5, 6] the baseline risk without donation. The absolute risk for developing end-stage renal failure during the remaining lifetime (or any other disease) will depend mostly on age. Now the 50-year-old male healthy donor has passed the period of life where most kidney diseases are likely to occur [32], and has fewer remaining life years than a corresponding younger donor. The baseline risk of future ESRD is therefore likely to be low, around 0.1%. When this is multiplied by the relative risk, the resulting absolute risk for ESRD is ∼1%, which may seem like a more reassuring risk estimate. However, the interpretation of whether this number is an acceptable risk is most of all up to the donor. This relationship between a high relative risk translating into a low absolute risk is only true when the baseline risk is very low, e.g. for rare outcomes. In a young donor with longer remaining life span, the risk of future ESRD will be higher than in a middle-aged donor. Multiplied by the same relative risk, this makes the absolute risk correspondingly higher. Young potential kidney donors are challenging for several reasons. First, since they are often very healthy, most of them will easily pass the donor evaluation. Accordingly, the donor evaluation will not select the healthiest or most suitable young donors. Second, since their remaining lifespan may be 60 or even 70 years, a large part of their risk for future kidney disease or other diseases will be unknown and impossible to quantify. For the same reason, the risks for different outcomes such as ESRD or other outcomes during their remaining lifespan will be unacceptably high when adding the risk of having only one kidney. In a 25-year-old healthy potential donor the lifetime risk of ESRD could be 1%. Multiplied with a relative risk of 5–10 this equals an absolute risk of 5–10%. In such an example one can no longer say that a high relative risk translates into a low absolute risk, since the baseline risk has now increased. The same holds true for other more common outcomes

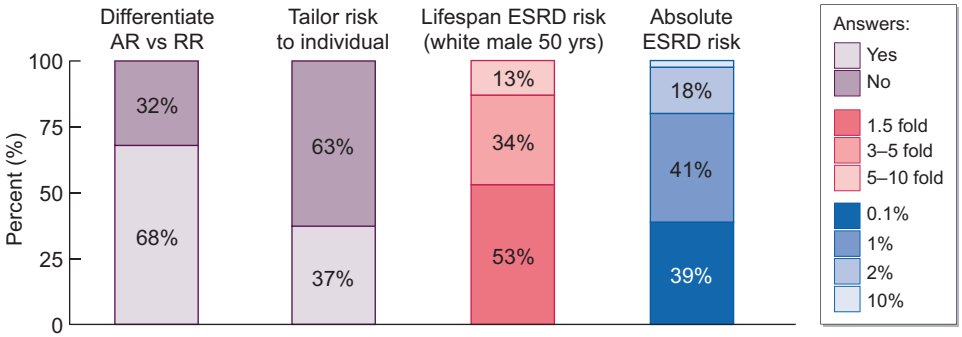

FIGURE 3: Findings from Table 3 are reported as stacked bar chart to facilitate the comparison across the different survey items. AR, absolute risk; RR, relative risk.

Table 4. Known long-term risks after kidney donation

Type of risk	Known estimates	References	Control group
Hypertension	OR 1.25 (1.12–1.39)	Haugen *et al.* [12]	HUNT cohort
	HR 1.19 (1.01–1.41)	Holscher *et al.* [2]	ARIC and CARDIA cohorts
	Systolic BP mean increase of 5 mmHg	Boudville *et al.* [4]	Meta-analysis of several studies
ESRD	HR 11.4 (4.4–29.3)	Mjøen *et al.* [5]	HUNT cohort
	90/10 000 years versus 14/10 000 years	Muzaale *et al.* [6]	NHANES III cohort
Gout	HR 1.6 (1.5–6.7)	Lam *et al.* [13]	Selected from general population using health administrative data
Preeclampsia	OR 2.4 (1.2–5.0)	Garg *et al.* [7]	Selected from general population using health administrative data
Proteinuria	147 mg/day versus 83 mg/day	Garg *et al.* [3]	Meta-analysis of several studies
Left ventricular mass increase	+7 g ± 10 versus −3 g ± 8 at 1 year	Moody *et al.* [14]	Family members, donors who did not proceed to donation, community care facilities.
All-cause mortality	HR 1.3 (1.1–1.5)	Mjøen *et al.* [5]	HUNT cohort
Cardiovascular mortality	HR 1.4 (1.03–1.91)	Mjøen *et al.* [5]	HUNT cohort

OR, odds ratio; HR, hazard ratio; BP, blood pressure; ARIC, Atherosclerosis Risk in Communities; CARDIA, Coronary Artery Risk Development in Young Adulthood; NHANES, National Health and Nutrition Examination Surveys.

such as hypertension, preeclampsia or death. Robert Steiner has previously published a method of showing the donor an absolute estimate of risk using a simple stick figure [33]. This method encourages the donor's own interpretation of risks and improves shared decision-making regarding donation. Some donors may be willing to accept very high risks, but the transplant centre also has to consider the risk, and make an independent decision.

There are some limitations in interpreting the results of this survey. Since the survey was focused on the knowledge and attitudes of individual transplant professionals, we did not evaluate visual aids, written patient materials or consent forms. Consequently, we cannot exclude discrepancies between survey responses and written information available to patients. Second, although we tried to identify and target transplant professionals involved in kidney donor evaluation in Europe, it is hard to estimate to what degree our sample is representative of the situation in Europe as a whole. We had no means to assess and handle potential selection bias. Third, we cannot exclude the possibility that respondents reported their 'ideal' behaviour, instead of reporting how they usually behave. This is a problem inherent to any self-reported survey. Fourth, donor evaluation is often a team effort. The survey did not differ between individual or group behaviour. This could partly explain some of the observed results for providing oral and written information on risks.

Finally, if we want to improve the counselling of potential donors regarding long-term risks, targeting individual transplant professionals may not be sufficient. Perhaps organizational changes need to happen to improve the situation. Transplant centres are left to themselves to assess their own practice of living donation. Since there are many different transplant centres, this may lead to different levels of quality in how the risk in relation to kidney donation is managed and communicated. Currently, there is to our knowledge no structured oversight or quality control regarding the counselling of donors in Europe. Consequently, there are may be a lack of incentives for transplant centres for improving their organizational structures. A possible solution could be increased regulatory oversight concerning the donor evaluation process, and increased use of independent assessors.

In conclusion, there seems to be a large variation in the knowledge and attitudes of transplant professionals in Europe regarding which possible long-term risks should be discussed with potential kidney donors, how these risks should be disclosed and how the written information should be used. It is

Table 5. What do current guidelines recommend?

	Statement	Reference
KDIGO	'When possible, transplant programs should provide each donor candidate with individualized quantitative estimates of short-term and long-term risks from donation, including recognition of associated uncertainty, in a manner that is easily understood by donor candidates. Protocols should be followed to provide each donor candidate with information on: Individualized risks, benefits and expected outcomes of the donor evaluation, donation, and postdonation health, including a discussion of the uncertainty in some outcomes.'	KDIGO Clinical Practice Guideline on the evaluation and care of living kidney donors. Lentine *et al.*, Transplantation 2017; 101 (8S Suppl 1): S1–S109
European Renal Best Practice (ERBP)	'We recommend that the individual risk of donation should be carefully discussed with the donor, taking into account the situation of both donor and recipient. Ideally, this should be done using standardized check lists to ensure all items are discussed.' (Ungraded Statement)	European Renal Best Practice Guideline on kidney donor and recipient evaluation and perioperative care. Abramowicz *et al.*, *Nephrol Dial Transplant* 2015; 30: 1790
UK	'The living donor must be offered the best possible environment for making a voluntary and informed choice about donation. The transplant team must provide generic information that is relevant to all donors as well as specific information that is material to the person intending to donate. This includes information about the assessment process and the benefits and risks of donation to the individual donor.' (B1)	https://renal.org/sites/renal.org/files/Living-Donor.pdf (accessed 29 October 2020)
United Network for Organ Sharing (UNOS)	'There are surgical, medical, psychosocial, and financial risks associated with living donation, which may be temporary or permanent and include, but are not limited to, *all* of the following: Potential medical or surgical risks: (i) Death (ii) Scars, hernia, wound infection, blood clots, pneumonia, nerve injury, pain, fatigue, and other consequences typical of any surgical procedure (iii) Abdominal symptoms such as bloating, nausea, and developing bowel obstruction (iv) That the morbidity and mortality of the living donor may be impacted by age, obesity, hypertension, or other donor-specific preexisting conditions'	https://optn.transplant.hrsa.gov/media/2162/living_donor_consent_checklist.pdf (accessed 29 October 2020)
EDQM (European Union)	'Information must extend to potential complications in the short and long term, both medical and psychosocial, including individual risk for the donor. Information must be culturally appropriate to and understandable by the person giving consent.'	Guide to the quality and safety of Organs for Transplantation 7th edition Chapter 13.3 https://www.edqm.eu/sites/default/files/leaflet_-transplantation-organs-7th_edition_-_november_2018.pdf

likely that potential living donors would like to receive detailed information regarding potential future risks [34]. Providing information to potential donors is complicated and often demands an individual approach and adequate time and resources. It may be hard to identify a 'one-size-fits-all' approach. However, from the results of this survey, we conclude that there is a requirement for standardization regarding the information provided to potential living kidney donors in Europe. There is already available a standardized informed consent that may be used for counselling patients [8]. However, there may be need for more written information describing potential long-term risks after donation, written at an appropriate reading level. The use of written information and checklists should be encouraged. There is also a need for information and education among European transplant professionals counselling potential living donors, especially regarding how to interpret and present risks. It is our view that it is necessary to inform potential donors regarding potential long-term risks before starting the evaluation.

SUPPLEMENTARY DATA

Supplementary data are available at ndt online.

FUNDING

No external funding received.

AUTHORS'CONTRIBUTIONS

All authors have contributed to collection of data, provided comments regarding the questionnaire, and have critically reviewed the paper and approved the final version. L.H., G.O., D.A., U.M., N.K., D.K., B.W., C.M., M.S.S., M.C., S.S.S., U.H., O.V. and R.O. participated in designing the study. G.M. created the first draft along with U.M. and D.A. U.M. created figures. G.M. performed descriptive analyses.

CONFLICT OF INTEREST STATEMENT

None declared.

(See related article by Morales-Buenrostro *et al*. Is it time to homogenize the living kidney donation informed consent?Is it time to homogenize the living kidney donation informed consent? *Nephrol Dial Transplant* 2021; 36: 1557–1558)

APPENDIX

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Received: 25.8.2020; Editorial decision: 1.2.2021