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Personal Viewpoint

When Good Intentions Are Not Enough: Obtaining Follow-Up Data in Living Kidney Donors

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The Organ Procurement Transplant Network/United Network for Organ Sharing (OPTN/UNOS) has increased the amount of data collected before and after donation and increased the duration of donor follow-up to 2 years, yet there is evidence that reporting is incomplete. We examined the frequency of missing data in the OPTN/UNOS donor follow-up registry and found that reporting rates were low, particularly for donors who may have limited access to health care. We argue that a national donor follow-up registry is essential to ensure transparency in ascertaining long-term health outcomes among all living donors and in providing assessments of quality assurance within transplant programs. We have suggested approaches to strengthen the donor follow-up registry system. These include setting clear and high standards for follow-up reporting, a system of incentives and penalties that would motivate transplant centers to comply with these standards and would encourage donors to follow-up and lifelong follow-up reporting by primary care providers. We argue that the US government must provide funding to support a donor follow-up registry that can allow for meaningful and valid conclusions, in recognition of donors' public service and to maintain trust in the system of living organ donation.

Key words: Donor follow-up, live donor transplantation, renal transplantation, UNOS database analysis

Abbreviations: ESRD, end-stage renal disease; HHS, Department of Health and Human Services; LKD, living kidney donor; OPTN, Organ Procurement Transplant Network; PCP, primary care provider; UNOS, United Network for Organ Sharing.

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Introduction

Living kidney donation has become increasingly prevalent, with a disproportionate increase in donors emotionally unrelated to their recipients (1) and in donors with medical problems such as obesity (2). In recognition of the growing population of living donors as well as the decreasing direct benefit and potential risk to living donors, the Organ Procurement Transplant Network/United Network for Organ Sharing (OPTN/UNOS) has increased the amount of data collected before and after donation and increased the duration of donor follow-up to 2 years. In this Viewpoint, we detail deficiencies in the OPTN/UNOS follow-up registry, discuss why a living donor registry that provides meaningful follow-up data is essential to the field of living donor transplantation and suggest approaches to strengthening the registry.

UNOS Living Donor Data Collection

OPTN/UNOS has collected follow-up data on living kidney donors (LKDs) from transplant centers at 6 weeks, 6 months and 1 year since 1999, but in 2008 increased the duration of follow-up to 2 years. Though short-term (6-week) reporting to UNOS is fairly complete, there is incidental data indicating that longer term reporting is incomplete (3,4). Moreover, the most recent OPTN report revealed that more than 30% of living donors in 2006 were declared "lost to follow-up" and therefore had no follow-up data (5).

There has been no detailed exploration of the completeness of longer term data reported to OPTN/UNOS. We therefore examined the frequency of missing data for medically important questions on the living donor follow-up form for LKDs between 2000 and 2008 (for detailed methods, see Supporting Documents). Results are shown in Table 1 and illustrate that rates of form submission and reporting for all follow-up questions decreased with increasing duration of follow-up. Reporting rates were higher for questions that could be answered without a visit to a health care provider (e.g. antihypertensive medication use, kidney complications) than for questions that would typically require a visit (e.g. blood pressure, serum creatinine). For example, in 2008 the 6-month reporting on use of antihypertensive medication was 83% whereas the 6-month reporting of systolic blood pressure was 56%.

We further analyzed the summary data to determine how baseline characteristics were associated with the likelihood of unreported data. For this analysis, serum creatinine was chosen as representative of a question that would require a

Table 1: Reporting rates by year of donation and duration of follow-up

Year of organ donation	2000	2001	2002	2003	2004	2005	2006	2007	2008
Number of donors	5500	6045	6240	6473	6647	6571	6435	6043	5968
Percentage of forms submitted									
At 6 months	99.7	99.7	99.9	96.1	74.0	77.2	82.9	84.8	88.8
At 1 year	66.0	74.2	82.7	73.2	50.5	54.2	52.9	64.9	76.1
At 2 years[1]	–	–	–	–	–	–	–	–	72.9
Percentage reported									
At 6 months	–	–	–	–	–	–	–	–	–
At 1 year	–	–	–	–	–	–	–	–	–
At 2 Years[1]	–	–	–	–	–	–	–	–	–
Current weight	36.9	38.6	41.7	41.4	46.3	48.8	50.2	54.6	60.3
	26.1	28.0	30.0	34.4	28.5	29.5	30.6	38.0	48.7
	–	–	–	–	–	–	–	–	40.9
Creatinine	40.6	46.6	50.1	54.1	56.0	60.3	62.5	63.2	65.5
	27.4	32.2	35.0	42.1	32.8	35.2	33.8	38.3	46.8
	–	–	–	–	–	–	–	–	36.5
SBP	33.8	35.9	39.8	40.4	43.0	43.7	46.8	49.3	55.7
	24.4	26.7	29.8	33.5	26.3	25.5	26.1	32.9	41.1
	–	–	–	–	–	–	–	–	35.1
DBP	33.7	35.8	39.8	40.4	43.0	43.7	46.7	49.3	55.7
	24.4	26.6	29.8	33.5	26.3	25.5	26.1	32.8	41.0
	–	–	–	–	–	–	–	–	35.0
HTN meds[2]	–	–	–	–	68.5	67.8	74.3	78.9	83.1
	–	–	–	–	43.9	46.2	46.7	59.4	70.4
	–	–	–	–	–	–	–	–	60.2
Urine analysis[2]	–	–	–	–	49.6	50.1	49.9	55.4	60.6
	–	–	–	–	35.7	36.1	37.4	47.8	56.3
	–	–	–	–	–	–	–	–	47.2
Maintenance dialysis	99.6	99.7	100.0	96.1	74.0	77.2	81.4	84.8	88.8
	66.0	74.2	82.7	73.2	50.5	54.2	52.9	64.8	76.1
	–	–	–	–	–	–	–	–	63.5
Diabetes[2]	–	–	–	–	68.6	74.0	79.4	82.3	86.7
	–	–	–	–	48.1	51.3	50.4	62.7	74.3
	–	–	–	–	–	–	–	–	20.2
Readmission[2]	–	–	–	–	74.1	77.2	80.4	84.5	88.7
	–	–	–	–	50.1	52.4	51.3	64.9	75.9
	–	–	–	–	–	–	–	–	63.4
Kidney complications	99.7	99.8	100.0	96.1s	73.6	75.0	80.4	84.1	88.1
	66.0	74.2	82.7	73.2	48.9	51.8	50.9	64.5	75.5
	–	–	–	–	–	–	–	–	63.4

Based on OPTN data as of August 25, 2010. SBP = systolic blood pressure; DBP = diastolic blood pressure; HTN = hypertension.
[1]Only donors from March 2008 to June 2008 (N = 1908) were considered as the denominator for 2 years form submission.
[2]These questions were added to the form in 2004.

visit with a health care provider and antihypertensive medication use was chosen as representative of a question that could be answered by phone. The impact of LKD characteristics on likelihood of reporting is shown using odds ratios in Table 2. LKDs who may have limited access to healthcare, such as non-Whites, younger donors, non-US citizens and the uninsured, had lower rates of follow-up reporting. LKD characteristics that may be associated with greater overall long-term health risks had a variable impact on follow-up reporting: older LKDs and hypertensives had higher rates of reporting whereas obese LKDs and smokers had similar or lower rates compared to their lower risk reference groups.

These data indicate that UNOS follow-up of LKDs is inadequate to form valid conclusions regarding longer term outcomes, particularly in LKDs from groups with less access to healthcare. Indeed, the OPTN/UNOS living donor data task force concluded that, "As currently collected, the OPTN/UNOS data are incomplete beyond the point when the discharge form is submitted. . .and therefore useless for research or making conclusions about living donor safety" (6).

Rationale for a Living Donor Follow-up Registry

There is general agreement within the literature that long-term medical outcomes after kidney donation are not fully understood and that continued efforts at data collection are required (7,8). The ultimate question is whether living donation impacts the course and consequences of future health

Table 2: Association of donor characteristics with data reporting for creatinine and HTN medication variables (all years combined)

	Creatinine[1]		HTN meds[2]	
	At 6 months OR (95% CI)	At 1 year OR (95% CI)	At 6 months OR (95% CI)	At 1 year OR (95% CI)
Age group				
18–34	Ref	Ref	Ref	Ref
35–49	***1.06 (1.02–1.1)***	***1.09 (1.05–1.14)***	***1.10 (1.04–1.17)***	***1.17 (1.11–1.22)***
50–64	***1.18 (1.12–1.23)***	***1.30 (1.23–1.36)***	***1.24 (1.16–1.34)***	***1.28 (1.20–1.36)***
≥65	***1.21 (1.02–1.42)***	***1.75 (1.49–2.07)***	1.30 (0.99–1.70)	***1.75 (1.38–2.20)***
Sex				
Male	Ref	Ref	Ref	Ref
Female	***1.09 (1.05–1.12)***	***1.09 (1.05–1.13)***	***1.16 (1.10–1.22)***	***1.15 (1.10–1.20)***
Race				
White	Ref	Ref	Ref	Ref
Black	*0.79 (0.75–0.83)*	*0.80 (0.76–0.85)*	*0.72 (0.67–0.78)*	*0.70 (0.66–0.75)*
Hispanic	*0.91 (0.87–0.96)*	0.95 (0.90–1.01)	*0.78 (0.73–0.85)*	*0.90 (0.84–0.96)*
Other	*0.71 (0.66–0.77)*	*0.66 (0.61–0.72)*	*0.52 (0.47–0.59)*	*0.65 (0.58–0.72)*
Donor type				
Biological	Ref	Ref	Ref	Ref
Nonbiological	***1.17 (1.13–1.22)***	***1.20 (1.15–1.24)***	***1.08 (1.03–1.15)***	1.02 (0.98–1.07)
Health insurance				
Yes	Ref	Ref	Ref	Ref
No	1.03 (0.95–1.11)	*0.88 (0.82–0.95)*	*0.84 (0.78–0.91)*	*0.75 (0.70–0.80)*
Immigration status				
US citizen	Ref	Ref	Ref	Ref
Resident alien	*0.72 (0.64–0.81)*	*0.72 (0.63–0.81)*	*0.57 (0.47–0.68)*	*0.66 (0.55–0.79)*
Nonres alien	1.08 (0.98–1.20)	*0.84 (0.76–0.93)*	*0.70 (0.62–0.80)*	*0.80 (0.71–0.91)*
Predonation BMI				
<30	Ref	Ref	Ref	Ref
≥30	0.96 (0.92–1.00)	0.96 (0.92–1.01)	0.44 (0.42–0.47)	0.96 (0.91–1.02)
Cigarette use				
No	Ref	Ref	Ref	Ref
Yes	1.02 (0.96–1.09)	*0.88 (0.83–0.93)*	1.01 (0.94–1.08)	*0.90 (0.85–0.96)*
History of HTN				
No	Ref	Ref	Ref	Ref
Yes	***1.27 (1.06–1.54)***	***1.36 (1.14–1.62)***	1.08 (0.88–1.33)	***1.24 (1.04–1.48)***

Based on aggregate OPTN data as of August 25, 2010. Cells with OR significantly greater than reference are bolded and italicized, those with OR significantly less than reference are italicized.
[1]Data from 2000 to 2008.
[2]Data from 2004 to 2008. BMI = body mass index; HTN = hypertension.

problems and whether there may be a differential impact according to predonation characteristics. The urgency of this question has been heightened by (1) recognition of limitations in existing literature (9), (2) data confirming increased blood pressure and proteinuria in LKDs (10,11), (3) growing numbers of LKDs with underlying health risks such as obesity (2) and (4) rising numbers of altruistic LKDs (1). An improved understanding of the impact of donation in LKDs with varying characteristics is required to appropriately evaluate LKD candidates and improve the informed consent process.

In theory, the most scientifically valid approach to answering these questions is longitudinal prospective cohort studies. These would evaluate clinical outcomes in donors and nondonor controls, allowing comparison to a control group that has undergone similar screening and an examination of the impact of donation itself on incidence of these outcomes. Longitudinal follow-up would permit assessment of whether subclinical findings such as increase in proteinuria or blood pressure translate into clinically important problems such as progressive renal dysfunction or hypertension. However, event rates in LKDs are low and power to detect important differences in clinical outcomes would require a study of impossible size, duration and expense. Moreover, though prospective studies are ongoing, they have not yet demonstrated the ability to recruit and retain sufficient numbers of appropriate control subjects.

Retrospective cohort studies are a more time- and cost-efficient way to examine risk in donors and they are the major source of our current knowledge of LKD outcomes. However, all retrospective cohort studies to date suffer from low rates of inclusion that make these studies vulnerable to selection bias and invalid conclusions. For example, the deservedly hailed study by Ibrahim et al. included a follow-up examination of 255 LKDs; this represents an impressive recruitment effort by the researchers but fewer than 12% of all invited participants (12). These low inclusion rates reflect difficulties in locating donors, the absence of an ongoing relationship with the transplant center and the contradictory message inherent in the lack of routine

follow-up coupled with a request many years later to undergo a thorough medical evaluation.

Importantly, even multicentered cohort studies will have inadequate numbers of LKDs from subgroups who may be at increased risk of future health problems. This includes Black and Hispanic LKDs, who have higher rates of hypertension, diabetes, chronic kidney disease and end-stage renal disease (ESRD) compared to White LKDs (13,14). In general, the rates of these problems are similar to those seen in nondonor minority populations and there is no evidence that donation itself increases health risks in these populations. Nonetheless, these studies illustrate that, among non-White populations, current donor eligibility screening criteria are inadequate to select LKDs who are at lower risk for future health problems.

Many experts have recommended linking UNOS donor registration forms to large database such as the US Renal Data System or health insurance database. This type of linkage analysis is extremely efficient and has provided us with important data (13,14). If baseline data are properly and rigorously recorded going forward, data linkage could offer insights into risks in obese, hypertensive or other high-risk LKDs. However, outcomes are necessarily limited to major events tracked in registries (such as death and ESRD) or to specific groups who may not represent all LKDs (such as the insured).

A national donor follow-up registry can provide a more comprehensive assessment of possible risks to LKDs than either cohort studies or database linkage. A registry would establish at the outset that donor follow-up is expected and that follow-up and registry reporting are important and thereby achieve a greater degree of follow-up than retrospective cohort studies. A registry would obtain outcome data on a much larger and more diverse population of LKDs than either retrospective or prospective cohort studies, providing sufficient power to determine if particular baseline characteristics predict worsened long-term health outcomes in subgroups of LKDs. In contrast to data linkage studies, a registry would not be limited to a small number of hard outcomes but could examine the broader scope of important health outcomes.

A further reason to favor a national follow-up registry over other approaches to study is the need for quality assurance assessments at all transplant centers. A registry can provide the transparency in quality assurance that is necessary to maintain public trust in the system of living organ donation.

We believe that only a national donor follow-up registry can serve the vital tasks of (1) ascertaining long-term health outcomes among all living donors and in particular subgroups of donors, (2) providing assessments of quality assurance within transplant programs and (3) maintaining transparency in the performance of these tasks.

Approach to a Living Donor Follow-up Registry

A number of other countries have national donor registries that we may look to for guidance, but their data reporting is incomplete as well (15). The EULID project by the European Commission was designed to establish consensus on living donor practices and stated that, "Any registry proposal must be realistic and, therefore simple; its implementation must be feasible" (15). Certainly creation of a registry with unachievable standards will not improve upon the current OPTN/UNOS data. However, the European Union nations have national health care systems that ensure health care for all living donors and protection of donors on an individual level. The same is not true for US donors, 18% of whom are uninsured, with higher rates among groups of donors who face greater long-term health risks including Blacks and Hispanics (16). Moreover, we believe that living donation is an extraordinary situation—LKDs undergo a surgery with no medical benefit to themselves—and demands extraordinary measures to ensure that a living donor follow-up registry is feasible and realistic. We therefore propose the following:

(1) Requirement that transplant centers provide meaningful data for 75% of all donor follow-up forms for 2 years, with escalating penalties for center noncompliance.
UNOS currently requires 100% compliance with follow-up reporting, but this duty can be met by answering a single element on the follow-up form or by declaring a donor lost to follow-up, without any documentation of efforts to contact the donor. The OPTN/UNOS Living Donor Committee has recommended enforcement of a minimum standard for reporting, but there is not yet consensus as to what this minimum standard should be or even as to what constitutes form completion. We believe a completed form should answer all questions that can be obtained by phone contact with the donor or his/her surrogate (e.g. history of hypertension). Requiring that centers complete 75% of mandated follow-up forms and have data for questions that require a visit to a health care provider data (e.g. serum creatinine) for 50% of all mandated forms sets a bar that will provide meaningful data.
Once standards are set, compliance could be carefully monitored and centers that do not meet these standards would then have an opportunity to formulate an action plan to improve their compliance, as has been suggested by the OPTN/UNOS Living Donor Committee. Levels of compliance should be publicly available and readily comparable to centers of similar volume, as an incentive to compliance. Review of compliance data will enable identification of systematic barriers to follow-up reporting nationwide and according to categories of transplant centers. To this point there has been no penalty for nonadherence to required follow-up, even for centers that report 100% of their donors

as lost to follow-up. Eventual penalties for noncompliance should include loss of OPTN designation for living donor transplantation.

(2) Enforcement of measures to encourage follow-up and limit disincentives on the part of living donors.

The responsibility for incomplete donor follow-up lies not only with transplant centers, but with the LKDs themselves. In a recent survey of US transplant centers, the most common barrier to LKD follow-up was donor inconvenience. The impact of donor inconvenience is augmented by donors' perception of risks to their health: 63% of centers state LKDs do not follow-up because they believe their health is good and there is no need (22). Only 48% of centers include information regarding follow-up in their consent forms and between 3% and 10% do not discuss important medical risks thought to be relevant to kidney donation (17), in violation of UNOS requirements (18). Though LKDs' confidence in their future health may be justified in most cases, informed consent demands that transplant centers discuss with applicable LKDs the limits in knowledge regarding long-term outcomes in Blacks and Hispanics and in those with underlying medical problems, including obesity and existing data indicating increased health risks in future pregnancies. Education as to potential risks as well as the importance of long-term health maintenance should not end with donation but should be reinforced at all postdonation follow-up visits.

The second and third most commonly cited barriers to donor follow-up are direct and indirect costs to donors. A full 25% of LKDs pay out-of-pocket for the cost of their mandated follow-up (18). Even LKDs with health insurance are likely to face copays for these visits. We consider it to be unacceptable for donors to pay to meet transplant center requirements to follow donor health. Unfortunately, the UNOS mandate for donor follow-up was not accompanied by funding to do so or recommendations for obtaining reimbursement, forcing transplant centers to absorb costs not covered by recipient or donor insurance or the Medicare cost report. Indirect costs such as missed work days could be avoided if the transplant center has incentive to provide flexible scheduling for donor follow-up appointments. Ultimately, governmental agencies must allocate funding for a unified and centralized system for compensating direct and indirect costs of mandated donor follow-up.

We believe that pre- and postdonation education regarding the importance of follow-up evaluation, in combination with an elimination of expenses incurred by donors will serve, over time, to increase donor follow-up.

(3) Lifelong reporting of donor follow-up data by primary care providers (PCPs).

It is clear that health risks for LKDs do not end at 2 years postdonation. However, it would be unrealistic for transplant centers to collect LKD follow-up data for a longer interval postdonation, given that about 45% of Americans will move to a new address within a 5-year period (19). Moreover, while adverse outcomes in the first 2 years could conceivably reflect problems within a transplant center and therefore should be collected by transplant centers and reported to UNOS, longer term health outcomes will reflect characteristics of the LKDs themselves and do not necessarily require involvement of transplant centers and a transplant-specific agency. Follow-up data beyond 2 years is essential to meet the goals of a donor follow-up registry and the only way to achieve this follow-up is to create a system for donors' PCPs to submit this data.

The immediate and largest obstacle to this proposal is economic: who will pay for many years of follow-up evaluation and maintenance of the registry? We believe that this should be the government's recompense for the national service living donors provide. The US Department of Health and Human Services (HHS) states that their mission is, as follows: "To enhance the health and well-being of Americans by providing for effective health and human services . . . " (20). There is no question that LKDs improve the quality and quantity of life for Americans with ESRD beyond any other treatment available and advance the mission of HHS. The federal government must provide funds to HHS to ensure that long-term health is followed in all donors and reported to a registry that will allow a thorough analysis. We propose that HHS pay for yearly follow-up evaluations to enable follow-up form completion in all donors without health insurance. Although, it may seem naïve to expect the federal government to add this cost to its budget in this time of budget cuts, there is evidence to suggest that concern over future health care costs has prevented potential donors from donating (21). If the government were to demonstrate their commitment to living donor transplantation in this way, the reward could well be an increase in the currently stagnant number of LKDs.

Collection of lifelong donor follow-up data should be overseen by an agency under HHS, such as the Health Resources and Service Administration, that has a more general role in healthcare and not specifically with transplantation, because this data would be reported by PCPs. Newly adopted requirements for electronic medical records could simplify the reporting process enormously: if a PCP codes for a donor nephrectomy for a patient, a submission form could be automatically generated and much of it could be automatically populated; all that would be left would be for the PCP to electronically submit the form to the designated agency.

Some authors have suggested mandated long-term follow-up that is limited to LKDs from subgroups for whom there is little existing data, such as minority populations and those with underlying health problems such as hypertension and hematuria (22). This strategy acknowledges the logistic and economic difficulties of attempting to follow all LKDs and ensures that efforts

would be targeted to answer the most urgent questions. Although we would support such an approach, it assumes that we have identified all gaps in LKD outcomes and would impede recognition of risk factors that might be uncovered with broader donor follow-up.

Conclusions

All parties involved in living organ donation want to do what is "right" for living donors, but current efforts to establish the long-term safety of living donation are thwarted by a lack of consensus on what is "right". We present our examination of incomplete follow-up data in the OPTN/UNOS living donor registry and the demographic disparities in follow-up reporting to spur the progression from discussion and debate toward active measures. We have argued that only a national registry can answer our duty to ensure safety of all living donors and to provide transparency in that process. We have suggested approaches to ensure a registry that can allow for meaningful and valid conclusions. These include setting clear and high standards for follow-up reporting, a system of incentives and penalties that would motivate transplant centers to comply with these standards and would encourage donors to follow-up and lifelong follow-up reporting by PCPs to a separate federal agency that would be responsible for maintaining the registry and for any costs of follow-up that would otherwise be incurred by donors. As Winston Churchill said, "The era of procrastination, of half-measures, of soothing and baffling expedients, of delays, is coming to its close. In its place we are entering a period of consequences".

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Disclosure

The authors of this manuscript have no conflicts of interest to disclose as described by the *American Journal of Transplantation*.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Detailed Methods

Aggregate data from the LDF were obtained from the OPTN/UNOS database for the 6-month, 1-year and 2-year time points for living kidney donors with donation years 2000–2008. The starting year of 2000 was chosen because this was the first full year of mandated donor follow-up reporting and the final year of 2008 was chosen because this was the latest year with full follow-up. Certain questions were added to the follow-up form in 2004, so data for these questions is reported only for 2004–2008. Two-year follow-up reporting was required for donors who donated as of March 2008, therefore our 2-year follow-up data from UNOS covers only donors with donation dates between March 1 and June 30, 2008. For each question examined, we categorized data as either having a meaningful value reported or being unreported (which included such categories as reported unknown, validated lost to follow-up and donors with unsubmitted forms). Total number of forms represents those forms submitted with any follow-up data. This was determined by identifying the question with the highest number of combined responses within that subgroup with the exception of missing; therefore, the total number of forms does not include forms submitted for donors declared by the center to be lost to follow-up. Data was then examined for years 2000–2008 combined according to summary data of particular donor demographic and health risk characteristics as reported in the Living Donor Registration (LDR). Certain questions (health insurance, predonation weight, cigarette use and history of hypertension) were added to the LDR in 2004; for those questions our examination was limited to 2004–2008. Baseline BMI was calculated as (weight in kg)/(height in m)^2. When particular baseline characteristics were reported as unknown, those donors were excluded from examination of the impact of those characteristics. In addition, there were 332 donors who were identified as multiracial who were excluded from the examination of the impact of race.

Statistical analysis was performed using SAS 9.1.3 (SAS Institute Inc., Carey, NC, USA). We excluded 2-year follow-up from analysis, given the short duration of data collection for this time point. We used logistic regression to determine the association of summary data of donor baseline characteristics with unreported data and to generate an odds ratio. All tests were two-tailed and alpha was set at 0.05.

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