



# Follow-up Care of Living Kidney Donors in Alberta, Canada

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## Abstract

**Background:** Previous guidelines recommend that living kidney donors receive lifelong annual follow-up care to assess renal health.

**Objective:** To determine whether these best practice recommendations are currently being followed.

**Design:** Retrospective cohort study using linked health care databases.

**Setting:** Alberta, Canada (2002-2014).

**Patients:** Living kidney donors.

**Measurements:** We determined the proportion of donors who had annual outpatient physician visits and laboratory measurements for serum creatinine and albuminuria.

**Results:** There were 534 living kidney donors with a median follow-up of 7 years (maximum 13 years). The median age at the time of donation was 41 years and 62% were women. Overall, 25% of donors had all 3 markers of care (physician visit, serum creatinine, albuminuria measurement) in each year of follow-up. Adherence to physician visits was higher than serum creatinine or albuminuria measurements (67% vs 31% vs 28% of donors, respectively). Donors with guideline-concordant care were more likely to be older, reside closer to the transplant center, and receive their nephrectomy in more recent years.

**Limitations:** Our results may not be generalizable to other countries that do not have a similar universal health care system.

**Conclusions:** These findings suggest significant evidence-practice gaps, in that the majority of donors saw a physician, but the minority had measurements of kidney function or albuminuria. Future interventions should target improving follow-up care for all donors.

## Abrégé

**Contexte:** Des recommandations émises antérieurement préconisaient de faire le suivi médical à vie, sur une base annuelle, des donneurs de rein vivants afin d'évaluer leur santé rénale.

**Objectif de l'étude:** L'étude visait à vérifier si ces recommandations de bonnes pratiques étaient suivies.

**Type d'étude:** Une étude de cohorte rétrospective pour laquelle on a utilisé les bases de données interreliées en soins de santé.

**Cadre de l'étude:** L'étude concerne des patients de la province de l'Alberta, au Canada, et couvre la période allant de 2002 à 2014.

**Patients:** Des donneurs de rein vivants.

**Mesures:** Nous avons établi la proportion de donneurs qui avaient été vus par un médecin en consultation externe et pour qui des mesures de la créatinine et de l'albuminurie avaient été faites.

**Résultats:** Nous avons répertorié 534 donneurs de rein vivants dont la durée médiane du suivi médical était de sept ans (treize ans maximum). L'âge médian au moment du don d'organe était de 41 ans et la cohorte était constituée à 62 % de donneuses. Dans l'ensemble, 25 % des donneurs montraient les trois indicateurs recherchés (visite chez le médecin, mesure de la créatinine et de l'albuminurie) pour chaque année de suivi. La proportion des donneurs qui voyaient un médecin annuellement s'est avérée nettement supérieure (67 %) à celle des donneurs présentant des mesures de la créatinine (31 %) et de l'albuminurie (28 %). Enfin, on a observé que les donneurs qui suivaient les recommandations étaient plus susceptibles d'être plus âgés, de résider près du centre de greffe et d'avoir subi leur néphrectomie plus récemment.

**Limites de l'étude:** Nos résultats pourraient ne pas être généralisables aux pays n'ayant pas un système universel des soins de santé similaire à celui du Canada.



**Conclusion:** Ces constatations laissent entrevoir des écarts significatifs entre les données probantes et la pratique, en ce sens que la majorité des donneurs avaient consulté un médecin, mais que peu d'entre eux présentaient des mesures de la fonction rénale ou de l'albuminurie. Dès lors, les prochaines interventions devraient cibler l'amélioration du suivi médical de tous les donneurs.

### Keywords

administrative data, albuminuria, estimated glomerular filtration rate, health services delivery, living kidney donation

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### What was known before

Recommended care for living kidney donors includes lifelong annual blood pressure measurement, serum creatinine measurement with glomerular filtration rate (GFR) estimation, and albuminuria measurement. Currently, it is unclear what proportion of living kidney donors are receiving follow-up care and how frequently the follow-up is occurring.

### What this adds

Only one-quarter of donors are currently receiving the post-donation follow-up care recommended by best practice guidelines. Reassuringly, the majority of donors continued to see a physician on an annual basis.

### Introduction

More than 27 000 living donor kidney transplants are performed worldwide every year.<sup>1</sup> Generally, long-term clinical outcomes for living kidney donors are comparable to that of nondonors of similar baseline health.<sup>2-4</sup> However, for certain outcomes, such as end-stage renal disease (ESRD), the risk in donors may be higher than that of healthy nondonors.<sup>5-10</sup> Despite a higher relative risk, the absolute risks for these outcomes in living kidney donors remain low with a 15-year incidence of ESRD of less than 1%.<sup>5,7,8</sup> To mitigate potential risks to the donor and ensure overall good health, a suggested practice is for living kidney donors to receive lifelong annual postdonation follow-up care.<sup>11</sup> This recommendation was supported in the Kidney Disease: Improving Global Outcomes (KDIGO) clinical practice guidelines on the evaluation and care of living kidney donors.<sup>12</sup> Recommended

care includes lifelong annual blood pressure measurement, serum creatinine measurement with glomerular filtration rate (GFR) estimation, and albuminuria measurement.

Currently, it is unclear what proportion of living kidney donors are receiving follow-up care and how frequently the follow-up is occurring. A 2007 survey of 91 transplant centers in the United States found that while all centers provided early postoperative care within 3 months of donor nephrectomy, only 30% of centers recommended follow-up at 2 years.<sup>13</sup> In these centers, only 26% of donors were actually seen, meaning that <8% of all donors were followed at 2 years after donation. In 2013, United Network for Organ Sharing (UNOS) implemented mandatory reporting of clinical and laboratory data for living kidney donors to the national transplant registry at 6 months, 1 year, and 2 years after donation.<sup>14</sup> This mandate led to an increase in the rates of early follow-up data collection across the nation, from 33% preimplementation to 54% postimplementation.<sup>15,16</sup> Currently, donor follow-up beyond 2 years, when medical conditions are more likely to develop, is not currently mandated in the United States.<sup>6,8</sup> In a 2004 survey of Canadian transplant centers, only 25% of programs provided follow-up for living kidney donors beyond the first year for medical and nonmedical issues, despite almost half of donors expressing that ongoing follow-up should be provided by the transplant program.<sup>11</sup>

Long-term surveillance and monitoring can either be provided by the transplant center, local nephrologists, or family doctors.<sup>17</sup> While many transplant programs rely on family doctors to continue annual surveillance of donor health, it is unclear whether continued assessments are actually being performed.<sup>13</sup> In a 2010 survey of 276 living kidney donors

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from a single US center, 88% of donors reported seeing a physician in the previous year.<sup>17</sup> These survey studies have limitations, including response bias (only ~40% response rates from transplant centers and donors),<sup>17,18</sup> selection bias (responders tend to be different from nonresponders), and external validity (results may not be generalizable to a Canadian population with a universal health care system).<sup>13,17</sup>

To better understand the current state of follow-up care of living kidney donors, we performed a retrospective cohort study using health care administrative databases in Alberta, Canada. We examined the proportion of living kidney donors who had evidence of annual outpatient physician visits, serum creatinine measurements, and albuminuria measurements. We also examined what factors were associated with recommended follow-up care.

## Methods

### Design and Setting

We conducted a population-based, retrospective cohort study using linked health care databases within the Alberta Kidney Disease Network (AKDN).<sup>19</sup> More than 99% of Alberta residents are registered with Alberta Health and have universal access to hospital care and physician services. This study followed guidelines for observational studies (Table S1) and was approved by the research ethics boards at the Universities of Alberta and Calgary. A waiver of patient consent was granted.

### Data Sources

We ascertained baseline characteristics, covariate information, and outcome data from the AKDN records (Table S2). The Alberta Health database contains information on demographics, vital statistics, and diagnostic and procedural information for inpatient and outpatient physician services. These data sources were linked to a provincial laboratory repository via unique, encoded, patient identifiers held by the AKDN. These databases have been previously used for research on health outcomes and services.<sup>20-22</sup>

### Population

We identified all adult living kidney donors ( $\geq 18$  years old) who underwent donor nephrectomy between May 1, 2002, and March 31, 2014, in Alberta, Canada (Figure S1). Living kidney donors were identified using an algorithm of 1 diagnostic code for kidney donation (*International Statistical Classification of Diseases, Tenth Revision, ICD-10: Z52.4*) and 1 procedural code for kidney procurement or excision (*Canadian Classification of Health Interventions, CCI: 1.PC.58, 1.PC.89, or 1.PC.91*) (Table S2). Similar codes have been used in previous studies to identify living kidney donors and assess for perioperative events.<sup>23,24</sup> We have validated this algorithm and found it to have a sensitivity of 97%

and a positive predictive value of 90% compared with the gold standard of living kidney donor identification by the provincial tissue and organ agency and verification through manual perioperative chart review.<sup>25</sup> The date of nephrectomy served as the start date for follow-up (index date). We excluded out-of-province donors and a small proportion of donors (<3%) with errors in their records (eg, missing sex or date of birth, date of death prior to nephrectomy).

### Baseline Characteristics

Baseline demographics, including age and sex, were determined from Alberta Health administrative data files. Indigenous race/ethnicity was retrieved from the registry file. It was not possible to identify other race/ethnic groups, although more than 85% of the Alberta population is white. Postal codes were linked to the Canadian Census using the Postal Code Conversion file to determine median neighborhood household income quintile (level 5 being the highest) as well as rural versus urban location of residence and distance from the transplant center, as previously described.<sup>26,27</sup> The presence of 1 or more diagnostic codes in the 3 years prior to the index date was used to identify comorbidities using validated *International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM)* and ICD-10 coding algorithms applied to physician claims and hospitalization data.<sup>28,29</sup> Hypertension was identified from hospital discharge records and physician claims based on a validated algorithm.<sup>30,31</sup> Demographic data were complete except for income quintile (0.4% missing).

### Outcomes

The primary outcome was evidence of KDIGO guideline-concordant care as defined by annual outpatient physician visits, serum creatinine measurements, and albuminuria measurements in every year ( $\pm 6$  months of the anniversary date) following kidney donation.<sup>12</sup> We did not consider physician visits or laboratory values in the first 6 months after donation, as these are usually related to postoperative monitoring. Urinalysis, urine protein-creatinine ratio (PCR) measurement, or urine albumin-creatinine ratio (ACR) measurement qualified as albuminuria measurements in any given year. We also assessed the proportion of donors who met all 3 criteria in  $\geq 75\%$  of years of their observed follow-up,  $\geq 50\%$  of years of follow-up, and in no years of follow-up. We assessed trends in follow-up care over the first decade following donation. In additional analyses, we examined the components of the primary outcome (physician visits, serum creatinine measurements, albuminuria measurements) individually.

### Statistical Analyses

Donors were followed from their index date (date of donor nephrectomy) until the first of death, development of ESRD

(defined as chronic dialysis or transplantation), emigration from the province, end of last full year of available follow-up, or end of study period (March 31, 2015). We compared baseline characteristics of donors with guideline-concordant follow-up care versus donors without using  $\chi^2$  or Fisher exact tests and Kruskal-Wallis tests. Associations of guideline-concordant follow-up care with donor demographic, socioeconomic, and comorbidity covariates were assessed using multivariable logistic regression (adjusted odds ratio). Statistical analyses were performed using Stata MP 13.1 (Stata Corporation, College Station, TX). A value of  $P < .05$  was used to define statistical significance.

## Results

### Baseline Characteristics

There were 534 living kidney donors in Alberta between 2002 and 2014 who were included in the study (Figure S1). The median age at the time of donation was 41 years (interquartile range [IQR], 33-50) and 62% of donors were women (Table 1). Most donors resided in urban areas (88%) and within 50 km of the transplant center (59%). As expected, in the year prior to donation, donors had multiple physician visits (median, 7; IQR, 4-9), serum creatinine measurements (median, 3; IQR, 2-4), and albuminuria measurements (median, 5; IQR, 3-7). The median predonation estimated glomerular filtration rate (eGFR) was 100 mL/min/1.73 m<sup>2</sup> (IQR, 88-113) and 90% of donors had none or very mild predonation proteinuria. At the time of donation, 12% of donors had a history of hypertension and 15% had a history of depression.

### Guideline-Concordant Care

During the study period, 0.8% of donors died, 0.2% developed ESRD, and 4% of donors emigrated from the province. Over a median follow-up of 7 years (IQR, 3-10, maximum 13 years), 25% ( $n = 132$ ) of living kidney donors had complete follow-up care, defined as a physician visit, serum creatinine measurement, and albuminuria measurement in each year of available follow-up. Donors with complete follow-up care were more likely to be older, have higher income status, resided closer to the transplant center, have a history of predonation hypertension, and receive their nephrectomy in more recent years compared with donors without complete follow-up (Table 1). Donors with complete postdonation follow-up also had more predonation physician visits and less missing predonation serum creatinine and albuminuria measurements in the year prior.

There were 31% of donors who met all 3 criteria in  $\geq 75\%$  of their years of follow-up and 53% in  $\geq 50\%$  of their years of follow-up (Table 2). Sixty-seven percent of donors saw a physician in each year of follow-up, and the majority of these visits were to primary care physicians. A total of 31% of

donors had serum creatinine measurements annually, whereas only 28% had an albuminuria measurement annually. Interestingly, almost 20% of donors never had guideline-concordant care, and a small, but sizable proportions of patients had no evidence of an outpatient physician visit (6%), never had a serum creatinine measurement (12%), or never had a measure of urine albumin excretion (15%) after donation.

In the years following donation, the proportion of donors achieving guideline-concordant follow-up steadily declined due to the decrease in serum creatinine and albuminuria monitoring (Figure 1), whereas the proportion of donors seeing an outpatient physician remained constant. At 2 years, 50% of donors had all 3 markers of care (87% had a physician visit, 61% had a serum creatinine measurement done, and 55% had an albuminuria measurement performed).

For the 98 donors who had at least 10 years of follow-up, 35% had all 3 markers of care performed in their 10th year after donation (83% had a physician visit, 54% had a serum creatinine measurement done, and 38% had an albuminuria measurement performed).

### Predictors of Guideline-Concordant Care

After multivariable adjustment for predonation baseline characteristics, each increase in year of donor age at the time of donation was associated with a 7% higher likelihood of guideline-concordant care (Table 3). Every 10 km increase in distance to the transplant center was associated with a 2% lower likelihood of guideline-concordant care. We also observed a center effect as donors who underwent nephrectomy in the Northern Alberta program were 3 times more likely to achieve complete follow-up care, compared with donors who underwent nephrectomy in the Southern Alberta program. Compared with donors who underwent nephrectomy earlier in the study, donors from more recent years were more likely to achieve complete follow-up. For example, 23% of persons who donated in the year 2007-2010 had guideline-concordant care 5 years after donation, compared with 8% of persons who donated in the year 2002-2006. After adjustment, there was no significant correlation between sex, income status, predonation eGFR, or history of hypertension and guideline-concordant care.

## Discussion

Alberta, Canada, has the third highest living donor rate in the country (~20 per million population).<sup>35</sup> In this population-based study of living kidney donors, we found that only 25% of donors in Alberta received guideline-concordant care and that, in adjusted analyses, complete and consistent follow-up was associated with older age, closer proximity to the transplant center, and more recent date of nephrectomy.

Previous guideline recommendations on postdonation follow-up care are ungraded and based on expert opinion, as

**Table 1.** Baseline Characteristics of All Living Kidney Donors at the Time of Donor Nephrectomy and a Comparison Between Those With and Without Guideline-Concordant Follow-up Care.<sup>a</sup>

Characteristic	Total (n = 534)	Donors with guideline- concordant care (n = 132)	Donors without guideline- concordant care (n = 402)	P value
Age, y	41.5 (33.2-50.4)	49.8 (40.4-55.5)	40.1 (31.2-48.2)	<.001
18-30	108 (20.2)	12 (9.1)	96 (23.9)	<.001
31-40	151 (28.3)	25 (18.9)	126 (31.3)	
41-50	152 (28.5)	40 (30.3)	112 (27.9)	
51-60	97 (18.2)	39 (29.6)	58 (14.4)	
>60	26 (4.9)	16 (12.1)	10 (2.5)	
Sex				
Men	203 (38.0)	51 (38.6)	152 (37.8)	.87
Women	331 (62.0)	81 (61.4)	250 (62.2)	
Race				
Nonindigenous race	510 (95.5)	128 (97.0)	382 (95.0)	.47
Indigenous race	24 (4.5)	4 (3.0)	20 (5.0)	
SES <sup>b</sup>				
Lowest (level = 1)	100 (18.7)	15 (11.4)	85 (21.1)	.047
Middle (level = 3)	115 (21.5)	28 (21.2)	87 (21.6)	
Highest (level = 5)	108 (20.2)	36 (27.3)	72 (17.9)	
Missing	2 (0.4)	1 (0.8)	1 (0.3)	
Residence <sup>c</sup>				
Rural	64 (12.0)	11 (8.3)	53 (13.2)	.14
Urban	470 (88.0)	121 (91.7)	349 (86.8)	
Distance to transplant center, km <sup>d</sup>	35.0 (20.0-220.0)	30.0 (20.0-107.5)	40.0 (20.0-230.0)	.047
<50	313 (58.6)	94 (71.2)	219 (54.5)	.004
50.1-150	67 (12.6)	14 (10.6)	53 (13.2)	
150.1-300	88 (16.5)	11 (8.3)	77 (19.2)	
>300	66 (12.4)	13 (9.9)	53 (13.2)	
Year of cohort entry				
2002-2006	204 (38.2)	10 (7.6)	194 (48.3)	<.001
2007-2010	170 (31.8)	42 (31.8)	128 (31.8)	
2011-2014	160 (30.0)	80 (61.6)	80 (19.9)	
Site of nephrectomy				
Southern Alberta	225 (42.1)	41 (31.1)	184 (45.8)	.003
Northern Alberta	309 (57.9)	91 (68.9)	218 (54.2)	
Number of physician visits in the year prior <sup>e</sup>	7.0 (4.0-9.0)	7.0 (6.0-11.0)	6.0 (4.0-9.0)	<.001
Number of serum creatinine measurements in the year prior <sup>e</sup>	3.0 (2.0-4.0)	3.0 (2.0-4.0)	3.0 (2.0-4.0)	<.001
Predonation eGFR, <sup>f</sup> mL/min/1.73 m <sup>2</sup>	99.5 (87.8-113.0)	95.2 (82.8-105.2)	103.6 (90.3-115.7)	<.001
≥90	351 (65.7)	79 (59.9)	272 (67.7)	<.001
80-89	82 (15.4)	23 (17.4)	59 (14.7)	
70-79	45 (8.4)	21 (15.9)	24 (6.0)	
<70	13 (2.4)	7 (5.3)	6 (1.5)	
Missing <sup>g</sup>	43 (8.1)	2 (1.5)	41 (10.2)	
Number of albuminuria measurements in the year prior <sup>e</sup>	5.0 (3.0-7.0)	6.0 (4.0-9.0)	4.0 (3.0-6.0)	<.001
Predonation albuminuria <sup>f</sup>				
None/Mild	478 (89.5)	125 (94.7)	353 (87.7)	<.001
Moderate	11 (2.1)	5 (3.8)	6 (1.5)	
Severe/Nephrotic	0 (0)	0 (0)	0 (0)	
Missing <sup>g</sup>	45 (8.4)	2 (1.5)	43 (10.7)	

(continued)

**Table 1. (continued)**

Characteristic	Total (n = 534)	Donors with guideline- concordant care (n = 132)	Donors without guideline- concordant care (n = 402)	P value
Predonation hemoglobin A1c, % <sup>f</sup>				
<5.5	70 (13.1)	20 (15.2)	50 (12.4)	<.001
5.5-5.9	82 (15.4)	36 (27.3)	46 (11.4)	
6.0-6.4	9 (1.7)	3 (2.3)	6 (1.5)	
≥6.5	0 (0)	0 (0)	0 (0)	
Missing <sup>g</sup>	373 (69.9)	73 (55.3)	300 (74.6)	
Predonation LDL, mmol/L <sup>f</sup>				
<2	53 (9.9)	12 (9.1)	41 (10.2)	<.001
2.0-3.4	235 (44.0)	71 (53.8)	164 (40.8)	
3.5-4.9	94 (17.6)	31 (23.5)	63 (15.7)	
≥5	8 (1.5)	4 (3.0)	4 (1.0)	
Missing <sup>g</sup>	144 (27.0)	14 (10.6)	130 (32.3)	
Predonation kidney biopsy <sup>h</sup>	8 (1.5)	1 (0.8)	7 (1.7)	.69
Comorbid conditions <sup>h</sup>				
Hypertension	65 (12.2)	25 (18.9)	40 (10.0)	.006
Atrial fibrillation	0 (0)	0 (0)	0 (0)	N/A
Asthma	10 (1.9)	2 (1.5)	8 (2.0)	.99
Chronic pulmonary disease	11 (2.1)	5 (3.8)	6 (1.5)	.15
Depression	79 (14.8)	17 (12.9)	62 (15.4)	.48
Gestational hypertension	2 (0.6)	0 (0)	2 (0.8)	.99

Note. Data are presented as median (interquartile range) or as count (percent). ACR = albumin-creatinine ratio; CKD-EPI = Chronic Kidney Disease-Epidemiology Collaboration; eGFR = estimated glomerular filtration rate; KDIGO = Kidney Disease: Improving Global Outcomes; LDL = low-density lipoprotein; N/A = not applicable; PCR = protein-creatinine ratio; SES = socioeconomic status.

<sup>a</sup>Complete follow-up was defined as evidence of an outpatient physician visit, an outpatient serum creatinine measurement, and an outpatient albuminuria measurement in every year of available follow-up.

<sup>b</sup>Income was categorized according to fifths of average neighborhood income (1 = low, 5 = high).

<sup>c</sup>Urban location indicates a population >10 000 or a population >1000 with population density >400/km<sup>2</sup>.

<sup>d</sup>For the mean distance from the transplant center, >500 km was imputed as 500 km.

<sup>e</sup>All visits and measurements were used, including if multiple events occurred on the same day.

<sup>f</sup>Laboratory values were based on the most recent reading in the 1 year prior to donation. eGFR was calculated using the CKD-EPI equation.<sup>32,33</sup>

Albuminuria was defined using ACR, PCR, or dipstick and categorized based on KDIGO.<sup>19,34</sup>

<sup>g</sup>Laboratory data were available from May 1, 2002, onward; thus, living kidney donors in 2002 may not have available laboratory data in the 1 year prior to donation.

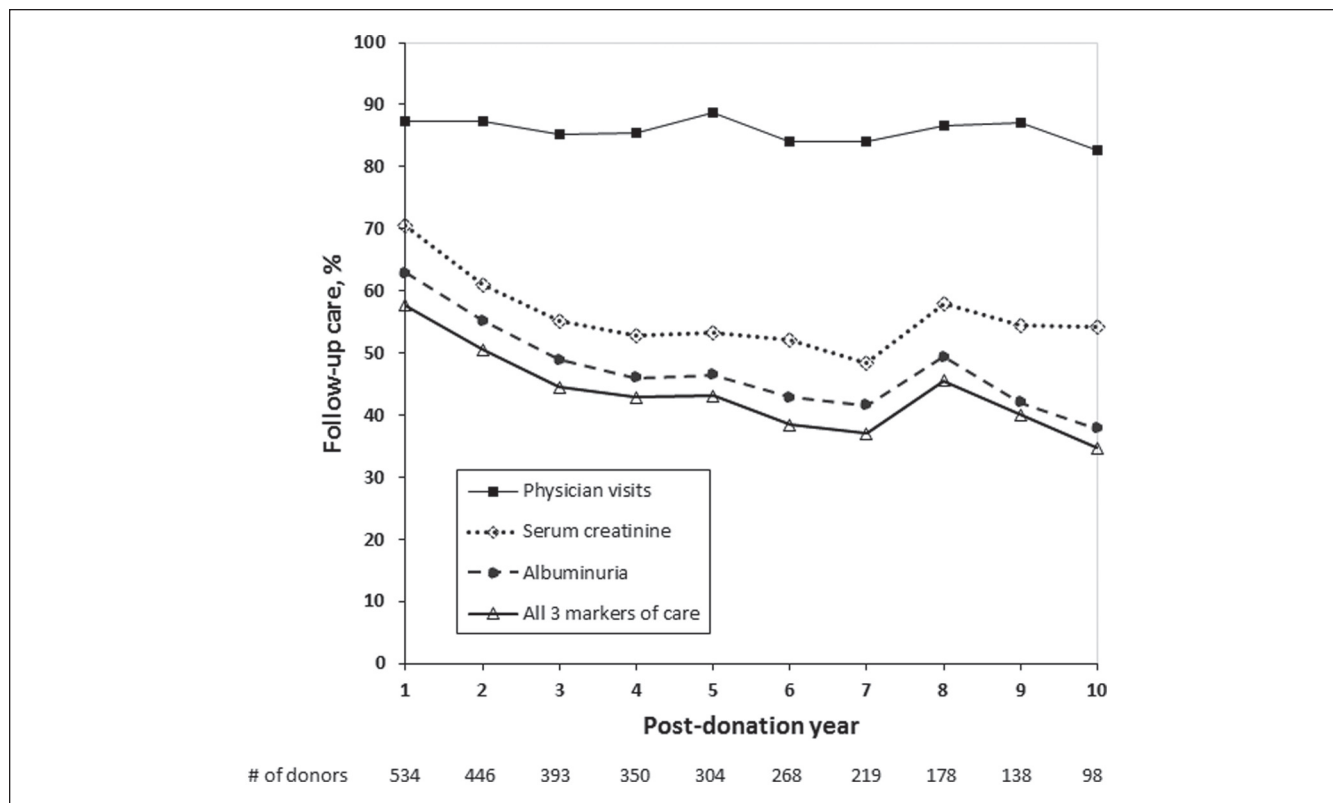
<sup>h</sup>Comorbid conditions were based on algorithms of diagnostic or procedural codes in the 3 years prior to donation (Table S2). Kidney biopsy was assessed in the 1 year prior to donation.

**Table 2. Proportion of Donors (n = 534) Who Have Evidence of Guideline-Concordant Follow-up Care.**

Outcome	Each year (100% of years)	≥75% of years	≥50% of years	No years (0% of years)
All 3 markers of care	132 (24.7)	166 (31.1)	283 (53.0)	103 (19.3)
All physician visits	359 (67.2)	426 (79.8)	478 (89.5)	33 (6.2)
Primary care physician visit	323 (60.5)	394 (73.8)	455 (85.2)	45 (8.4)
Nephrologist visit	57 (10.7)	70 (13.1)	103 (19.3)	345 (64.6)
Serum creatinine	168 (31.5)	229 (42.9)	367 (68.7)	66 (12.4)
All albuminuria measurements	152 (28.5)	195 (36.5)	310 (58.1)	80 (15.0)
Urinalysis	145 (27.2)	189 (35.4)	293 (54.9)	84 (15.7)
Protein-creatinine ratio	32 (6.0)	41 (7.7)	82 (15.4)	325 (60.9)
Albumin-creatinine ratio	65 (12.2)	79 (14.8)	131 (24.5)	247 (46.3)

there was insufficient evidence available to ground evidence-based recommendations.<sup>11,12</sup> Our study reports that only one-quarter of donors are receiving guideline-concordant care.

The majority of donors appear to have regular follow-up with a physician, but recommended testing is only being done in a minority. To meet the best practice of care recommendations,



**Figure 1.** Proportion of donors who have evidence of follow-up care during each postdonation year.

**Table 3.** Adjusted Associations of Baseline Characteristics With Guideline-Concordant Follow-up Care.<sup>a</sup>

Characteristic	Guideline-concordant care <sup>b</sup>	P value
Age, per year	1.07 (1.04-1.10)	<.001
Sex		
Men	1.00 (Referent)	
Women	0.84 (0.50-1.41)	.52
Race		
Nonindigenous race	1.00 (Referent)	
Indigenous race	0.81 (0.23-2.87)	.74
SES <sup>c</sup>		
Lowest (level = 1)	0.55 (0.23-1.31)	.18
Middle (level = 3)	1.00 (Referent)	
Highest (level = 5)	1.19 (0.57-2.48)	.64
Residence		
Rural	1.00 (Referent)	
Urban	1.61 (0.64-4.02)	.31
Distance to transplant center, per 10 km	0.97 (0.96-0.99)	.01
Year of cohort entry		
2002-2006	1.00 (Referent)	
2007-2010	6.55 (2.97-14.45)	<.001
2011-2014	26.94 (11.63-62.42)	<.001
Site of nephrectomy		
Southern Alberta	1.00 (Referent)	
Northern Alberta	3.11 (1.64-5.89)	<.001

(continued)

**Table 3. (continued)**

Characteristic	Guideline-concordant care <sup>b</sup>	P value
Predonation eGFR, mL/min/1.73 m <sup>2</sup>		
≥90	1.00 (Referent)	
80-89	0.78 (0.39-1.56)	.48
70-79	0.88 (0.38-2.05)	.77
<70	1.06 (0.26-4.24)	.94
Missing	0.47 (0.02-11.06)	.64
Predonation albuminuria		
None/Mild	1.00 (Referent)	
Moderate	2.70 (0.62-11.79)	.19
Missing	0.51 (0.02-11.66)	.67
Predonation hemoglobin A1c, %		
<5.5	1.00 (Referent)	
5.5-5.9	1.85 (0.81-4.23)	.15
6.0-6.4	0.58 (0.10-3.42)	.55
Missing	1.46 (0.62-3.41)	.38
Comorbid conditions		
Hypertension	1.75 (0.84-3.61)	.13
Asthma	0.34 (0.05-2.40)	.28
Chronic pulmonary disease	1.16 (0.26-5.23)	.85
Depression	0.71 (0.34-1.50)	.37

Note. CI = confidence interval; eGFR = estimated glomerular filtration rate; SES = socioeconomic status.

<sup>a</sup>Guideline-concordant follow-up care was defined as evidence of an outpatient physician visit, an outpatient serum creatinine measurement, and an outpatient albuminuria measurement (urine dipstick, albumin-creatinine ratio, or protein-creatinine ratio) in every year of available follow-up.

<sup>b</sup>Data are presented as adjusted odds ratio (95% CI). Adjusted for age, sex, indigenous race, SES, residence, distance to transplant center, year of cohort entry, site of nephrectomy, predonation eGFR, predonation albuminuria, predonation hemoglobin, hypertension, asthma, chronic pulmonary disease, and depression.

<sup>c</sup>Donors with missing income data (n = 2) were reclassified in the middle quintile for these analyses.

our study highlights that we should focus on improving renal function monitoring.

Follow-up care may result in the prevention, early detection, and management of diseases. One systematic review reported that in the general population, annual preventive examinations had a consistently beneficial association with delivery of recommended preventive services and reductions in patient uncertainty and worry.<sup>36</sup> More recently, the Canadian Task Force on Preventive Health Care has challenged the utility of annual physical examination in the general population.<sup>37,38</sup> In living kidney donors, early detection and treatment of conditions that are known to affect kidney function may protect them from further loss of kidney function and other complications related to low GFR.

Ongoing follow-up care also provides an opportunity to inform and educate living kidney donors on new research on long-term outcomes and complications. Recent evidence suggests that compared with healthy nondonor controls, the relative risk of ESRD may be higher in living kidney donors (adjusted hazard ratio, 11.4).<sup>5,7,8</sup> However, the 15-year absolute risk of ESRD is low (15-year incidence 0.2%-0.5%).<sup>5,6,39-41</sup> Living kidney donors may have a higher risk of gout compared with healthy matched nondonors, and female donors may have a higher risk of gestational hypertension or

preeclampsia compared with matched nondonors, although the vast majority of women have normal healthy pregnancies after donation.<sup>9,10,42</sup>

Follow-up care also allows for continued monitoring of the overall health status and psychosocial well-being of living kidney donors. While the donor evaluation process can involve frequent testing and appointments with the transplant center, the postdonation care involves minimal, if any, contact. This can leave donors with a sense of abandonment after undergoing an altruistic procedure to save the life of another without any medical benefit to themselves. In interviews with living kidney donors on their follow-up experiences, 1 donor said, "Nobody cared for me any longer. Before the operation everybody was on his toes for me."<sup>43</sup>

Unfortunately, there are barriers to follow-up for living kidney donors, including sociodemographic and geographic factors, perception of unnecessary need for follow-up due to excellent donor health, unreimbursed costs, and limited resources and personnel.<sup>13,44-46</sup> In our study, after adjustment for various factors, we found that donors who were older, resided closer to the transplant center, and donated more recently were more likely to achieve complete and consistent postdonation follow-up. We also found a center effect, as donors who underwent nephrectomy in 1 program were 3



times more likely to achieve complete follow-up care, compared with donors in another program. A better understanding of the barriers and facilitators that affect local practices regarding donor follow-up may help transplant centers develop strategies and policies to improve follow-up rates for their donors.

A few countries have instituted systematic approaches to long-term living donor follow-up that may serve as models. The European Living Donation and Public Health project mandates living donor registration and follow-up data collection through a centralized database and performs regulatory audits at the national and center level.<sup>47</sup> Similarly, the Swiss Living Donor Health Registry coordinates distribution of a health questionnaire and tubes for blood and urine samples and asks donor to make an appointment with the family physician at 1 year and then biennially thereafter.<sup>48</sup> In 2017, the US Scientific Registry of Transplant Recipients began a “Living Donor Collective” pilot project that seeks to achieve lifelong living donor follow-up through direct contacts by staff and novel data linkages.<sup>49</sup> Center-based initiatives to provide long-term donor follow-up and support through integrated clinical and laboratory monitoring, expansion of preventive health strategies, and fostering of peer education through social support networks between past, current, and future donors are also being tested.<sup>50</sup>

Our findings fill an important knowledge gap in the existing literature.<sup>12</sup> To date, this is one of the largest, most comprehensive studies of real-world living kidney donor follow-up care that reports rates of physician visits, serum creatinine testing, and albuminuria testing.<sup>51</sup> Our results may not be generalizable to other countries or regions that do not have a similar universal health care system. Given its observational nature, the possibility of residual confounding must also be considered. We lacked data on certain baseline characteristics such as smoking, blood pressure control, and body mass index, as well as transplant-related characteristics, such as donor-recipient relationship. However, we were able to identify and control for important demographics and comorbidities commonly associated with follow-up care. We also looked at outpatient physician visits as a surrogate for blood pressure measurements, and other markers of care, including assessment of body weight and preventive health delivery. We are unable to confirm that these services were delivered and whether the lack of serum creatinine and albuminuria measurement was due to physician or patient decisions.

Although our study found that only one-quarter of donors are currently receiving the postdonation follow-up care recommended by best practice guidelines, we are reassured that the majority of donors continued to see a physician on an annual basis. This suggests that donors and their physicians should be counseled on the importance of renal health surveillance and that a framework of contact for such surveillance is in place. Further research is needed to determine whether routine follow-up of living kidney donors, who are generally of excellent health at donation, actually mitigates

long-term risks and complications. Ensuring timely and adequate follow-up for living kidney donors is an internationally recognized priority aimed at protecting donors and ensuring the integrity, quality, and safety of organ donation.<sup>12</sup>

### List of Abbreviations

ACR, albumin-creatinine ratio; AKDN, Alberta Kidney Disease Network; CCI, Canadian Classification of Health Interventions; eGFR, estimated glomerular filtration rate; ESRD, end-stage renal disease; GFR, glomerular filtration rate; ICD-9-CM, International Classification of Diseases, Ninth Revision, Clinical Modification; ICD-10, International Statistical Classification of Diseases, Tenth Revision; IQR, interquartile range; KDIGO, Kidney Disease: Improving Global Outcomes; PCR, protein-creatinine ratio; UNOS, United Network for Organ Sharing.

### Ethics Approval and Consent to Participate

This study was approved by the institutional review board at the University of Alberta and the University of Calgary.

### Consent for Publication

All authors consent for publication.

### Availability of Data and Materials

Additional data is available in the Appendix.

### Authors' Note

This study is based in part on data provided by Alberta Health and Alberta Health Services. The interpretation and conclusions contained herein are those of the researchers and do not necessarily represent the views of the Government of Alberta or Alberta Health Services. Neither the Government of Alberta nor Alberta Health or Alberta Health Services express any opinion in relation to this study.

### Author Contributions

N.N.L. conceived the study and drafted the manuscript. A.L. performed the statistical analyses and created the figure. All authors interpreted the results, revised the manuscript, and approved the final version of the manuscript.

### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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