National Attitudes Toward Living Kidney Donation in the United States: Results of a Public Opinion Survey

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Rationale & Objective: Understanding national attitudes about living kidney donation will enable us to identify and address existing disincentives to living kidney donation. We performed a national survey to describe living kidney donation perceptions, perceived factors that affect the willingness to donate, and analyzed differences by demographic subgroups.

Study Design: The survey items captured living kidney donation awareness, living kidney donation knowledge, willingness to donate, and barriers and facilitators to living kidney donation.

Setting & Population: We surveyed 802 US adults (aged 25-65 years) in June 2021, randomly selected from an online platform with diverse representation.

Analytical Approach: We developed summed, scaled indices to assess the association between the living kidney donation knowledge (9 items) and the willingness to donate (8 items) to self-reported demographic characteristics and other variables of interest using analysis of variance. All other associations for categorical questions were calculated using Pearson's χ^2 and Fisher exact tests. We inductively evaluated free-text responses to identify additional barriers and facilitators to living kidney donation.

Results: Most (86.6%) of the respondents reported that they might or would definitely consider donating a kidney while they were still living. Barriers to living kidney donation included concerns about the risk of the surgery, paying for medical expenses, and potential health effects. Facilitators to living kidney donation included having information on the donation surgery's safety, knowing that the donor would not have to pay for medical expenses related to the donation, and hearing living kidney donation success stories. Awareness of the ability to participate in kidney-paired donation was associated with a higher willingness to donate.

Limitations: Potential for selection bias resulting from the use of survey panels and varied incentive amounts, and measurement error related to respondents' attention level.

Conclusions: Most people would consider becoming a living kidney donor. Increased rates of living kidney donation may be possible with investment in culturally competent educational interventions that address risks associated with donating, policies that reduce financial disincentives, and communication campaigns that raise awareness of kidney-paired donation and living kidney donation.

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Living kidney donation is promoted as the best treatment option available for people living with kidney failure.[1] Public attitudes about living kidney donation are subject to change and can be affected by legislation, scientific innovation, media campaigns, and individual experiences.

In recent years, legislative efforts and national-level organizations have worked to facilitate living kidney donation by reducing financial disincentives and expanding opportunities to donate.[2] For example, the National Living Donor Assistance Center (NLDAC) was established in 2006 by the Health Resources and Services Administration to remove travel costs related to living donations and was later revised to cover lost wages and dependent care costs.[3] In addition, there are patient-centric organizations, such as the National Kidney Registry (NKR) and the National Kidney Foundation (NKF), that have dedicated programs aimed at reducing barriers to donation.[4,5] The NKR's donor shield program provides protections such as lost wages, travel and dependent care reimbursement, kidney prioritization, and complication protection.[5] Another piece of legislation consistently re-introduced to Congress is the Living Donor Protection Act (LDPA).[6] If passed, this act would reduce barriers prohibiting insurance companies from denying coverage, limiting coverage, or charging higher premiums for living donors.[6] In 2007, federal legislation was clarified to establish the legality of kidney-paired donation, a practice in which patients with incompatible donors swap kidneys with another incompatible pair to receive a compatible kidney.[7]

Several studies have explored attitudes toward both living kidney donation and living organ donation as a whole.[8-11] A study from 2012 evaluating racial and ethnic differences in living kidney donation found that African American participants were less willing to donate to relatives when compared with White participants, with differences mediated by socioeconomic status, medical trust, and concerns about burial after death.[8] Another study from 2012 found that 82.5% of the public were extremely willing or very willing to participate in kidney-paired donation.[9] Research in 2019 studying individuals who offered to donate without first knowing someone in need of a transplant shows that media sources sharing personal

PLAIN-LANGUAGE SUMMARY

Understanding what the general public thinks about living kidney donation will help to develop better education and increase the number of living kidney donors. We surveyed the public to find out: (1) how aware they are about the opportunity to donate a kidney while alive; (2) how much they know about living kidney donation; (3) whether they would be willing to donate; and (4) what would affect their willingness to donate. We found that teaching people about the risks of donating, decreasing costs related to donation, and raising awareness about it could increase the number of people willing to donate.

living kidney donation narratives can motivate the public.[10] The Health Resources and Services Administration conducted a survey of 10,000 US adults in 2019 to assess changing public opinions about organ donation and transplantation.[11] The study found that 86% said they would participate in living donation for a family member, 76% for a close friend, 55% for an acquaintance, and 46% for a stranger.[11] The study also found that the willingness toward living donation for all 4 categories had declined since 2012.[11] These studies have helped the transplant community understand the public sentiments about living donation, but there remains a paucity of recent, national data to inform policy initiatives and tailored educational interventions specific to living kidney donation.

Therefore, we conducted a national survey to understand the public's: (1) awareness of opportunities for living kidney donation; (2) attitudes toward donating a kidney while alive; (3) knowledge related to living kidney donation; and (4) barriers and facilitators that affect willingness to donate.

METHODS

Survey Design

Experts in living kidney donation from the NKR and Johns Hopkins University partnered with a professional survey developer to design and iteratively refine a 64-item survey (Item S1) measuring 5 domains, as follows: (1) respondent demographics; (2) living kidney donation-related knowledge; (3) awareness of the opportunity to become a living kidney donor and organizations that facilitate living kidney donation and kidney-paired donation; (4) willingness to donate; and (5) factors that might affect willingness to donate a kidney while alive. The New York University Langone health institutional review board classified this study as not human subject research.

Sampling Strategy

The study sample was drawn from national-level panels of demographically diverse groups who were randomly routed to complete surveys by a market research firm. Eligible participants resided in the US and were aged 25-66 years old. Purposive sampling on the variables gender and age was used to ensure sufficient sample sizes to explore associations. Gender was defined as the social, psychological, cultural, and behavioral aspects of being a man, women, or other gender identity. Respondents provided their written consent when they enrolled in a panel and then completed the web-based survey using CMIX, the firm's internal scripting tool. Respondents were given incentives (eg, hotel points or airline miles) through the firm per their indicated preference.

If we consider the target population as adults aged 25-66 years in the United States potentially eligible for living kidney donation, then selection bias (by design) likely affects our inferences. To reduce sources of selection bias, potential respondents were blinded to the topic until the survey was presented to them, and demographic results were assessed in post hoc analyses. To address potential measurement errors, the marketing firm used digital fingerprints for each participant and removed respondents from their platform if they appeared unengaged across multiple surveys (eg, not spending sufficient time on the survey).

Survey Administration

Surveys were administered in June 2021. The sample size was selected to ensure a sufficiently low margin of error (±3.3%) at a 95% confidence level. A total of 2,149 people were solicited once, either by email or mobile application, to participate; 1,223 agreed to participate (56.9% response rate). Responses from 323 respondents were removed from analyses because they did not provide answers to the free-text response questions, indicating that they were likely unengaged. Responses from an additional 98 respondents were removed because at least 1 quality control question was answered incorrectly. Respondents were asked to select somewhat agree for the 2 quality control questions, and respondents who did not select somewhat agree were removed from the analysis. The final sample included 802 (37.3%) responses.

Statistical Analysis

All quantitative analyses were conducted using Stata/MP 17.0 for Linux (College Station). Survey weights were developed using age and sex data from the 2020 American Community Survey to adjust study results to better reflect US population demographics.[12] For analyses, we categorized states of residence into the West Coast, West, Midwest, Northeast, and Southeast regions. We categorized responses on racial or ethnic identities into White, Black, Asian, Hispanic, and Other.

Living Kidney Donation Knowledge Score

A living kidney donation knowledge scale was developed by summing scores on the 9 questions related to knowledge (Table S1). Respondents' knowledge score increased

by 3 points for every question answered correctly. Range and mean scores were calculated to describe knowledge scores. Scores were then standard normalized for analysis for easier interpretation: normalized scores had a mean value of 0 and a standard deviation of 1.

Living Kidney Donation Willingness Score

A living kidney donation willingness scale was developed by summing scores on the 8 questions related to willingness to donate a kidney while alive (Table S1). Respondents' willingness score increased by 1 if they were somewhat willing and 2 if they were very willing. For the questions on willingness based on relationship to recipient, scores increased by 1 for somewhat willing, 2 for very willing, and 3 if they had already donated. Range and mean scores were calculated to describe willingness scores. Scores were then standard normalized for analysis for easier interpretation.

Analytical Approach

Descriptive statistics such as percentages, means, and standard deviations in living kidney donation knowledge and willingness scores were calculated. Associations for categorical questions were calculated using Pearson's χ^2 tests. Differences in knowledge and willingness scores across measures of awareness, perceived barriers, perceived facilitators, and demographic groups were calculated using analysis of variance. Fisher exact tests were used for outcomes with expected cell counts under 5.

Because many categories of religion had a small number of respondents, the assumptions of a χ^2 test were not met. Therefore, we collapsed all religion categories with cell counts under 20 (Mormonism, Judaism, Islam, Hinduism, and Buddhism) and those who reported other into a single other category before performing a Fisher exact test. However, because these categories of religion are not necessarily similar, we performed an additional Fisher exact test among these categories only to assess potential differences within the other subgroup.

Free-text response questions assessing additional barriers and facilitators to living kidney donation were analyzed using inductive categorization.[13] The first coder (KK) inductively categorized the free-text response questions using Microsoft Excel version 16.63.1 and met regularly with the second coder (HS) to reach a consensus and ensure reliability.

Table 1. Characteristics of the National Sample

Characteristic	N (%)
Gender	
Male	364 (45.4)
Female	438 (54.6)
Age	
25-34	209 (26.1)
35-44	202 (25.2)
45-54	189 (23.6)
55-65	202 (25.2)
Educational attainment	
High school or less	189 (23.6)
Some college	252 (31.4)
Bachelor's degree	221 (27.6)
Post-graduate degree	140 (17.5)
Race or ethnicity	
White	639 (79.7)
Black	56 (7.0)
Asian	50 (6.2)
Hispanic	25 (3.1)
Other	32 (4.0)
Religion	
Protestant	298 (37.2)
Catholic	166 (20.7)
Mormonism	10 (1.2)
Judaism	16 (2.0)
Islam	17 (2.1)
Hinduism	4 (0.5)
Buddhism	12 (1.5)
Spiritual	133 (16.6)
Atheist	57 (7.1)
Other	89 (11.1)
Income	
<50K	339 (42.3)
50K-<75K	149 (18.6)
75K-<100K	109 (13.6)
100K-<150K	119 (14.8)
150K-<250K	74 (9.2)
≥250K	12 (1.5)
Region	
Midwest	247 (30.8)
Northeast	242 (30.2)
Southeast	171 (21.3)
West	57 (7.1)
West Coast	85 (10.6)

Note: n = 802.

RESULTS

Study Population

The study population included 802 US adults (aged 25-65 years), who were predominantly female 438 (54.6%); White 639 (79.7%); protestant 298 (37.2%) or catholic 166 (20.7%); living in the Midwest 247 (30.8%) or Northeast 242 (30.2%) regions of the United States; with household incomes below $50,000 per year 339 (42.3%); and with education levels ranging from high school or less 189 (23.6%) to having post-graduate degrees 140 (17.5%) (Table 1).

Awareness of the Opportunity for Living Donation

Recent exposure to content about living kidney donation was reported by 178 (22.2%) respondents. News stories and social media were the most commonly reported sources (Table 2). Sources of living kidney donation content varied by age; 23 (71.8%) respondents aged 55-65 years old reported seeing this content by means of news stories ($P = 0.02$), whereas 32 (66.7%) respondents aged 35-44 years old reported seeing this content by means of social media ($P < 0.001$).

Table 2. Differences in Knowledge of and Willingness Toward Living Kidney Donation Across Responses to Awareness Questions

Question	N (%)	Mean ± SD Knowledge Scale	*P* Value	Mean ± SD Willingness Scale	*P* Value
Past year exposure to living donation content			0.3		0.04
Yes	178 (22.2)	0.01 ± 0.93		0.22 ± 1.02	
No	560 (69.8)	–0.00 ± 1.01		–0.09 ± 0.99	
Not Sure	64 (8.0)	–0.20 ± 1.18		0.12 ± 0.92	
Previously heard of NKF			< 0.01		< 0.001
No	471 (58.7)	–0.10 ± 1.03		–0.16 ± 1.01	
Yes	331 (41.3)	0.10 ± 0.98		0.22 ± 0.95	
Previously heard of NKR			0.03		< 0.001
No	622 (77.6)	–0.06 ± 1.02		–0.11 ± 0.99	
Yes	180 (22.4)	0.12 ± 0.97		0.36 ± 0.97	
Awareness that NKR has a national registry of people in need of a kidney donation			< 0.01		< 0.001
No	51 (28.3)	–0.24 ± 0.99		–0.08 ± 1.03	
Yes	129 (71.7)	0.27 ± 0.94		0.54 ± 0.89	
Awareness that NKR has a national registry of people wishing to donate one Of their kidneys			0.1		0.08
No	75 (41.7)	–0.01 ± 0.97		0.20 ± 0.98	
Yes	105 (58.3)	0.21 ± 0.98		0.47 ± 0.95	
Awareness that NKR helps people through kidney-paired donation			0.2		0.04
No	81 (45.0)	0.03 ± 0.98		0.20 ± 0.96	
Yes	99 (55.0)	0.21 ± 0.97		0.50 ± 0.96	
Awareness that NKR conducts medical research on kidney donation			0.2		0.2
No	117 (65.0)	0.05 ± 1.00		0.30 ± 0.93	
Yes	63 (35.0)	0.26 ± 0.92		0.49 ± 1.04	
Unaware of NKR's functions			0.5		0.04
No	170 (94.4)	0.14 ± 0.95		0.40 ± 0.97	
Yes	10 (5.6)	–0.14 ± 1.30		–0.21 ± 0.94	

Note: Positive scores indicate greater knowledge/willingness compared with the mean response; negative scores indicate less knowledge/willingness (mean = 0 and SD = 1). P-values test the null hypothesis that the mean responses across all levels of the variable are the same.
Abbreviation: SD, standard deviation.

Of all respondents, 331 (41.3%) had previously heard of the NKF and 180 (22.4%) had previously heard of the NKR (Table 2). Having heard of the NKR varied by region ($P = 0.04$) and income ($P = 0.02$); respondents living in the Southeast region of the United States. and those with an annual income between $150,000-$250,000 were more likely to report having previously heard of the NKR. Not having heard of either organization was reported by 277 (34.5%) and varied by race or ethnicity ($P = 0.005$); respondents who reported Asian race were more likely to not have heard of either the NKF or NKR. Religion was also associated with not having previously heard of either organization in both versions of the Fisher exact tests (within smaller religion categories $P < 0.01$; collapsed religion categories $P = 0.01$).

A total of 129 (71.7%) respondents who had previously heard of the NKR knew that the organization has a national registry of potential kidney recipients, 105 (58.3%) knew that NKR has a national registry of potential living kidney donors, and 99 (55%) knew that NKR helps people through kidney-paired donation (Table 2). However, only 63 (35%) knew that NKR supports medical research on kidney donation (Table 2). Knowing that NKR has a national registry of potential kidney recipients and potential living kidney donors varied by age ($P = 0.04$); those aged 45-54 years old were more likely to know both to be true.

A total of 249 (31.1%) respondents were currently registered to be an organ or tissue donor on death, 88 (11%) were or knew someone who was a living

donor, 125 (15.6%) thought about donating 1 of their kidneys while still alive, and 104 (13%) reported that they knew someone who has needed a kidney donation.

Individuals with recent exposure to living kidney donation content had a higher mean willingness scale (mean = 0.22) than respondents with no recent exposure (mean = −0.09) ($P = 0.04$). By contrast, we observed no association between recent exposure to living kidney donation content and knowledge scores. Compared with those unaware of the NKF, having previously heard about the NKF was associated with higher scores on both the knowledge (mean = 0.10 vs −0.10; $P < 0.01$) and willingness (mean = 0.22 vs −0.16; $P < 0.001$) scales. Similar results were observed for NKR awareness: knowledge (mean = 0.12 vs −0.06; $P = 0.03$) and willingness (mean = 0.36 vs −0.11; $P < 0.001$) (Table 2).

Compared with unaware respondents, awareness that the NKR has a national registry of potential kidney recipients was associated with greater knowledge (mean = 0.27 vs −0.24; $P < 0.01$) and willingness scores (mean = 0.54 vs −0.08; $P < 0.001$). In addition, willingness scores were higher for respondents aware that NKR helps people through kidney-paired donation (mean = 0.50 vs 0.20; $P = 0.04$) (Table 2).

Knowing someone who has needed a kidney donation in the past (knowledge $P = 0.02$; willingness $P < 0.001$), being currently registered to be an organ or tissue donor on death (knowledge $P < 0.001$; willingness $P < 0.001$), and having thought about donating a kidney while still alive (knowledge $P = 0.04$; willingness $P < 0.001$) were associated with greater scores on the knowledge and willingness scales; respondents with these connections to organ donation had higher scores on both scales.

Knowledge Related to Living Kidney Donation

Raw scores on the knowledge scale ranged from 0-21, with an overall mean score of 13.2. The mean living kidney donation knowledge scores varied significantly by race or ethnicity ($P < 0.01$), gender ($P = 0.03$), and age ($P < 0.001$). Those with greater knowledge about living kidney donation tended to be White (mean = 0.08 vs below average scores for the other groups), to identify as female (mean = 0.06 vs −0.10), and to be older (mean scores increasing monotonically by age, from −0.17 to 0.19) (Table 3).

Willingness to Donate

A total of 694 (86.6%) respondents reported that they might (n=472 [58.9%]) or would definitely (n=222 [27.7%]) consider donating a kidney while still alive. When asked, "assuming the coronavirus was not a concern and you were medically able, how likely would you agree today to donate a kidney to the following people if they needed a kidney within the next 2 months?", 664 (95.7%) said they were somewhat or very likely to donate to a biological family member, 624 (89.9%) to a nonbiological family member, 622 (89.6%) to a close friend, 421 (60.7%) to an acquaintance, 383 (55.2%) to a stranger for whom they had background information on, and 335 (48.3%) to a stranger whom they had no background information on.

Raw willingness scores ranged from 0-20, with an overall mean score of 9.9. Scores on the living kidney donation willingness scale varied by age ($P = 0.02$); those aged 45-54 years old were most willing (mean = 0.12), whereas the oldest group (aged 55-65 years old) were least willing (mean = −0.22) (Table 4).

Willingness toward living kidney donation was positively associated with scores on the knowledge scale ($P < 0.001$). Those who would not consider donating tended to have lower knowledge scores (mean = −0.50) compared with those who might (mean = 0.04) or would definitely (mean = 0.09) consider it.

Potential Barriers that Affect Willingness Toward Living Kidney Donation

The most frequently cited barriers to living kidney donation included (n [% somewhat or strongly agree]): concerns that donating a kidney would negatively affect their health (612 [76.3%]); concerns around the risks of the living kidney donation surgery (582 [72.6%]); general aversion to any kind of surgery (580 [72.3%]); concerns that the idea of donation sounds scary (572 [71.3%]); and concerns about medical expenses related to donation (527 [65.8%]) (Table 5). Worrying about having to pay for medical expenses related to living kidney donation was associated with age ($P = 0.02$); younger respondents were more concerned about this barrier than older respondents.

Respondents strongly agreeing that they have concerns about the risk of the surgery had lower living kidney donation knowledge scores (mean = −0.15) compared with those only somewhat agreeing (mean = 0.01) or having no such concern (mean = 0.07) ($P = 0.04$). Similarly, those most averse to any type of surgery also tended to have lower knowledge scores ($P < 0.01$) and lower willingness to donate scores ($P < 0.001$). Similarly, respondents with the strongest concerns about needing to pay for medical expenses had the lowest knowledge ($P = 0.03$) and willingness ($P < 0.01$) scores. Those with the greatest concern that donating a kidney would negatively affect their health status had the lowest willingness scores ($P < 0.001$), but knowledge score did not differ statistically according to this concern (Table 5).

In addition to answering questions about specific perceived barriers to donation, respondents reported these barriers using the free-text response question: not trusting the medical system; having concerns about pain, recovery, and future illness; not knowing anything about the recipient; having concerns about the physical ability to donate because of health or age; having concerns about

Table 3. Differences in Knowledge About Living Kidney Donation Across Demographic Groups

Variable	N	Mean Knowledge ± SD	*P* Value
Overall	802 (100.0)	−0.02 ± 1.01	
Gender			0.03
Male	364 (45.4)	−0.10 ± 1.05	
Female	438 (54.6)	0.06 ± 0.95	
Age			< 0.001
25-34	209 (26.1)	−0.17 ± 1.02	
35-44	202 (25.2)	−0.14 ± 1.05	
45-54	189 (23.6)	0.08 ± 0.94	
55-65	202 (25.2)	0.19 ± 0.98	
Educational Attainment			0.2
High school or less	189 (23.6)	−0.14 ± 1.00	
Some college	252 (31.4)	0.06 ± 1.10	
Bachelor's degree	221 (27.6)	−0.02 ± 0.95	
Post-graduate degree	140 (17.5)	0.03 ± 0.96	
Race or ethnicity			< 0.01
White	639 (79.7)	0.08 ± 0.95	
Black	56 (7.0)	−0.56 ± 1.11	
Asian	50 (6.2)	−0.34 ± 1.17	
Hispanic	25 (3.1)	−0.12 ± 1.09	
Other	32 (4.0)	−0.32 ± 1.24	
Religion			0.05
Protestant	298 (37.2)	0.11 ± 1.00	
Catholic	166 (20.7)	−0.07 ± 0.90	
Mormonism	10 (1.2)	−0.44 ± 0.66	
Judaism	16 (2.0)	0.14 ± 0.89	
Islam	17 (2.1)	−0.19 ± 0.77	
Hinduism	4 (0.5)	−1.45 ± 1.18	
Buddhism	12 (1.5)	−0.62 ± 1.16	
Spiritual	133 (16.6)	−0.01 ± 1.05	
Atheist	57 (7.1)	0.29 ± 0.97	
Other	89 (11.1)	−0.34 ± 1.08	
Income			0.3
<50K	339 (42.3)	−0.03 ± 1.01	
50K-<75K	149 (18.6)	−0.08 ± 1.04	
75K-<100K	109 (13.6)	0.06 ± 0.93	
100K-<150K	119 (14.8)	−0.13 ± 1.03	
150K-<250K	74 (9.2)	0.21 ± 1.04	
≥250K	12 (1.5)	0.06 ± 0.68	
Region			0.3
Midwest	247 (30.8)	−0.08 ± 1.02	
Northeast	242 (30.2)	−0.03 ± 1.01	
Southeast	171 (21.3)	0.02 ± 1.00	
West	57 (7.1)	0.39 ± 0.83	
West Coast	85 (10.6)	−0.12 ± 1.07	

Note: Positive scores indicate greater knowledge compared to the mean response; negative scores indicate less knowledge (mean = 0 and SD = 1). P-values test the null hypothesis that the mean responses across all levels of the variable are the same.
Abbreviation: SD, standard deviation.

needing to change current lifestyle behaviors; or wanting to save their kidney for a loved one (Table 6).

Potential Facilitators that Motivate Willingness Toward Living Kidney Donation

The most commonly cited facilitators to living kidney donation included (n [% somewhat or strongly agree]): knowing that the donor or their family could get another kidney if they needed one (631 [78.7%]); information on the safety of the donation surgery (631 [78.6%]); information that would make donors less worried about their health after donation (615 [76.7%]); knowing that the donor would not have to pay for donation-related medical expenses (612 [76.3%]); and information on how donated kidneys successfully helped recipients (603 [75.2%]) (Table 7).

Table 4. Differences in Willingness Toward Living Kidney Donation Across Demographic Groups

Characteristic	N (%)	Mean Willingness ± SD	*P* Value
Overall	802 (100.0)	0.00 ± 1.00	
Gender			0.1
Male	364 (45.4)	−0.05 ± 0.94	
Female	438 (54.6)	0.05 ± 1.06	
Age			0.02
25-34	209 (26.1)	0.06 ± 0.94	
35-44	202 (25.2)	0.04 ± 0.98	
45-54	189 (23.6)	0.12 ± 1.02	
55-65	202 (25.2)	−0.22 ± 1.05	
Educational attainment			0.5
High school or less	189 (23.6)	0.02 ± 0.98	
Some college	252 (31.4)	0.01 ± 1.10	
Bachelor's degree	221 (27.6)	−0.01 ± 0.92	
Post-graduate degree	140 (17.5)	−0.04 ± 0.97	
Race or ethnicity			0.4
White	639 (79.7)	0.02 ± 1.00	
Black	56 (7.0)	0.05 ± 0.93	
Asian	50 (6.2)	−0.22 ± 0.95	
Hispanic	25 (3.1)	−0.11 ± 0.95	
Other	32 (4.0)	−0.00 ± 1.21	
Religion			0.1
Protestant	298 (37.2)	0.04 ± 0.97	
Catholic	166 (20.7)	0.03 ± 1.00	
Mormonism	10 (1.2)	−0.26 ± 0.94	
Judaism	16 (2.0)	−0.02 ± 1.24	
Islam	17 (2.1)	−0.01 ± 0.99	
Hinduism	4 (0.5)	−0.15 ± 1.05	
Buddhism	12 (1.5)	0.29 ± 0.72	
Spiritual	133 (16.6)	0.15 ± 1.02	
Atheist	57 (7.1)	−0.27 ± 1.00	
Other	89 (11.1)	−0.25 ± 1.01	
Income			0.4
<50K	339 (42.3)	−0.01 ± 1.03	
50K-<75K	149 (18.6)	0.10 ± 0.99	
75K-<100K	109 (13.6)	0.06 ± 1.04	
100K-<150K	119 (14.8)	−0.08 ± 0.95	
150K-<250K	74 (9.2)	−0.10 ± 0.96	
≥250K	12 (1.5)	−0.05 ± 0.45	
Region			0.5
Midwest	247 (30.8)	0.02 ± 0.95	
Northeast	242 (30.2)	−0.06 ± 1.04	
Southeast	171 (21.3)	0.14 ± 0.99	
West	57 (7.1)	0.11 ± 0.92	
West Coast	85 (10.6)	−0.21 ± 1.05	

Note: Positive scores indicate greater willingness compared with the mean response; negative scores indicate less willingness (mean = 0 and SD = 1). P-values test the null hypothesis that the mean responses across all levels of the variable are the same.
Abbreviation: SD, standard deviation.

Respondents who strongly agreed that information on the safety of the donation surgery; knowing that they would not have to pay for any medical expenses related to the donation; and information on how donated kidneys successfully helped recipients would cause them to be more likely to donate tended to have higher knowledge and willingness scores (all $P < 0.01$). Those who strongly or somewhat agreed that they would be more likely to donate with an assurance that the donor or their family members could get another kidney if needed had much higher willingness scores ($P < 0.001$) than those unmotivated by this assurance. Similarly, respondents believing that information alleviating concerns about after donation health would make them more likely to donate tended to

Table 5. Differences in Knowledge of and Willingness Toward living kidney donation by Presence of the Top 5 Barriers to Living Kidney Donation Reported by Participants

Barriers	N (%)	Strongly or Somewhat Agree, n (%)	Mean ± SD Knowledge Scale	*P* Value	Mean ± SD Willingness Scale	*P* Value
The whole idea sounds scary		572 (71.3)		0.03		< 0.001
Strongly agree	232 (28.9)		−0.17 ± 0.95		−0.39 ± 1.06	
Somewhat agree	340 (42.4)		0.05 ± 0.89		0.00 ± 0.87	
No impact	230 (28.7)		0.05 ± 1.21		0.39 ± 0.99	
The surgery sounds risky		582 (72.6)		0.04		< 0.001
Strongly agree	215 (26.8)		−0.15 ± 0.99		−0.41 ± 1.06	
Somewhat agree	367 (45.8)		0.01 ± 0.94		−0.01 ± 0.87	
No impact	220 (27.4)		0.07 ± 1.13		0.41 ± 0.98	
I worry that donating a kidney would negatively affect my health		612 (76.3)		0.5		< 0.001
Strongly agree	257 (32.0)		−0.07 ± 0.95		−0.35 ± 1.02	
Somewhat agree	355 (44.3)		0.02 ± 1.01		0.05 ± 0.88	
No impact	190 (23.7)		−0.00 ± 1.09		0.38 ± 1.04	
I worry that I would have to pay my medical expenses		527 (65.8)		0.03		< 0.01
Strongly agree	245 (30.6)		−0.15 ± 1.03		−0.13 ± 1.01	
Somewhat agree	282 (35.2)		0.03 ± 0.94		−0.02 ± 0.92	
No impact	275 (34.3)		0.06 ± 1.05		0.13 ± 1.06	
I don't like any surgery		580 (72.3)		< 0.01		< 0.001
Strongly agree	337 (42.0)		−0.10 ± 0.93		−0.36 ± 1.00	
Somewhat agree	243 (30.3)		−0.06 ± 1.01		0.05 ± 0.89	
No impact	222 (27.7)		0.16 ± 1.11		0.49 ± 0.90	

Note: Response options for the closed-ended question, "Which of the following, if any, are things that make you, personally, less likely to donate a kidney while you are still living?" were strongly agree, somewhat agree, and does not apply or not a concern (ie, no impact). Positive scores indicate greater knowledge or willingness compared with the mean response; negative scores indicate less knowledge or willingness (mean = 0 and SD = 1). The barriers included in this table were the barriers that had the top 5 highest combined percentages of strongly agree and somewhat agree. P-values test the null hypothesis that the mean responses across all levels of the variable are the same.
Abbreviation: SD, standard deviation.

have much higher willingness scores ($P < 0.001$) than respondents less interested in this information (Table 7).

Knowing that the donor or their family could get another kidney if they needed one ($P = 0.01$) and information on the safety of the donation surgery ($P = 0.03$) were associated with income. Information on the safety of the donation surgery was also associated with race or ethnicity ($P = 0.01$).

In addition to answering questions about specific perceived facilitators to donation, respondents reported these facilitators using the free-text response question: being compensated; having a terminal illness; having fewer health concerns; having more information on the procedure, the recovery process, and life after transplant; having more information on the recipient; having reasons related to religion or God; wanting to help loved ones; and wanting to help someone they do not know (Table 8).

DISCUSSION

In this national survey assessing public opinions on living kidney donation, we found that 694 (86.6%) respondents would consider donating a kidney while still living. Those who were more willing to donate had recent exposure to content about living kidney donation, were aware of the opportunity to participate in kidney-paired donation through the NKR, had greater knowledge about living kidney donation, and were less concerned about undergoing surgery or covering out-of-pocket costs associated with living kidney donation. Respondents reported that hearing success stories of how living kidney donation helped transplant recipients would make them more likely to donate. Our survey revealed the need for educational programs that address knowledge-related and awareness-related barriers and policy initiatives that support the removal of systematic barriers to living kidney donation.

Over 600 (75%) respondents reported that receiving information on the health and financial risks of living kidney donation would increase their willingness to donate. Wanting more information on living kidney donation was also a facilitator identified from free-text responses. The results are consistent with the work of Waterman et al,[14] who recommended consensus-driven, evidence-based national campaigns to raise awareness of the risks and benefits of living kidney donation. We also found that those who know someone who has needed a kidney in the past reported more willingness toward living kidney donation. This aligns with results from Segev et al,[9]

Table 6. Free-Text Responses to the Question, "What else makes you, personally, less likely to donate a kidney while you are still living?"

Themes	Example Response 1	Example Response 2
Not trusting the medical system or providers	Do not trust health care workers	Bad doctors
Having concerns about pain, recovery, and future illness	Painful and if I run into a kidney problem down the road, I won't be able to rely on the other kidney	I'm mostly concerned about [the] effects on my own health. It doesn't make much sense to donate an organ just to later have health problems of my own.
Not having enough information	Being unsure how the whole process works	Don't have enough information
Not knowing anything about the recipient	Depends who it's for	I would never donate a kidney to a bad individual
Having concerns about personal responsibilities related to finances or caring for loved ones	Lack of child care and medical expenses	I do not have the time nor do I have a financial stand point where I can take time off work
Having concerns about physical ability to donate because of health or age	Not sure if my kidney is healthy enough and if my age will be able to take it	I am in poor health and have a family history of kidney disease
Having concerns related to religious beliefs	[I] wonder about what God thinks about us giving away our body part while we are living... Our body is a temple and we are supposed to build on our temple not break it down	Besides religious considerations, not much
Having concerns about lifestyle changes	I'm afraid whether I can continue my life normally as before	Not being able to drink what I want
Wanting to save their kidney for a loved one	I'm saving my kidneys for my children or sister	If I had a loved one who doesn't quite need one now but may need one in the future

who found that knowing someone who donated or received an organ, is associated with increased willingness toward kidney-paired donation. In addition, our finding that knowledge about living kidney donation is associated with higher living kidney donation willingness supports research by Rodrigue et al,[15] who found that living kidney donation education efforts that directly engage potential recipients' social networks increase living donor inquiries and evaluations for Black patients on the waiting list. Educational interventions around living kidney donation, especially those tailored to suit specific population groups, have also been successful in increasing living kidney donation knowledge and should be expanded to suit other groups.[16-20]

We found that donation-related expenses were barriers to living kidney donation for 527 (66%) respondents and that being compensated was a living kidney donation facilitator identified from the free-text responses. This underscores that despite ongoing efforts, potential living kidney donors still face financial disincentives. The following initiatives have the potential to address current systemic barriers to living kidney donation: (1) efforts to expand the NLDAC by increasing the total amount allocated from federal funding, increasing the poverty rate for eligibility, and removing recipient finances for eligibility[21]; (2) efforts to modify the National Organ Transplant Act to allow the government to compensate donors without exploitation or coercion[22]; (3) Health Resources and Services Administration's announcement of an organ procurement and transplantation network modernization initiative focused on improving accountability and transparency[23]; (4) efforts by the Centers for Medicare and Medicaid services to solicit public comments around how to improve the transplant ecosystem in the United States, including living donation[24]; and (5) the reintroduction of the LDPA, which prohibits insurance companies from discriminating against donors.[6] These national-level efforts represent opportunities to further progress toward reduced costs for donors and increased rates of living kidney donation.[6,21-24]

This survey study has limitations associated with its use of survey panels. People who participate in surveys through panels tend to have more access to technology and are of higher socioeconomic status, potentially limiting the generalizability of results.[25] We addressed this by recruiting respondents with a range of income and education levels (Table 1). In addition, survey panels are prone to data quality concerns related to respondents' attention level.[26] To address this, we used quality control questions to screen out inattentive respondents. This survey also employed different recruitment modalities and incentives. Information on recruitment and incentives was not available at the participant level, limiting our ability to identify resulting biases. Despite these limitations, we were able to recruit a large, demographically diverse sample of the US population.

Table 7. Differences in Knowledge of and Willingness Toward Living Kidney Donation by Presence of the Top 5 Facilitators to Living Kidney Donation Reported by Respondents

Facilitators	N (%)	Strongly or Somewhat Agree, n (%)	Mean ± SD Knowledge Scale	*P*	Mean ± SD Willingness Scale	*P* Value
Information that would make me less worried about my health after donating		615 (76.7)		0.09		< 0.001
Strongly agree	251 (31.3)		0.02 ± 1.00		0.48 ± 0.94	
Somewhat agree	364 (45.4)		0.05 ± 0.93		−0.01 ± 0.80	
No impact	187 (23.3)		−0.18 ± 1.16		−0.64 ± 1.09	
Knowing that I or a family member could get another kidney if we needed one		631 (78.7)		0.08		< 0.001
Strongly agree	283 (35.3)		−0.00 ± 0.97		0.39 ± 0.94	
Somewhat agree	348 (43.4)		0.07 ± 0.96		0.02 ± 0.81	
No impact	171 (21.3)		−0.22 ± 1.14		−0.69 ± 1.08	
Information that would tell me about the safety of such surgeries		631 (78.7)		< 0.001		< 0.001
Strongly agree	293 (36.5)		0.12 ± 0.99		0.49 ± 0.92	
Somewhat agree	338 (42.1)		0.02 ± 0.91		−0.05 ± 0.78	
No impact	171 (21.3)		−0.33 ± 1.17		−0.74 ± 1.04	
Knowing that I would not have to pay for any medical expenses		612 (76.3)		< 0.001		< 0.001
Strongly agree	327 (40.8)		0.14 ± 0.95		0.43 ± 0.88	
Somewhat agree	285 (35.5)		−0.01 ± 0.97		−0.10 ± 0.82	
No impact	190 (23.7)		−0.29 ± 1.11		−0.60 ± 1.09	
Information that would tell me about the success of donated kidneys to help people		603 (75.2)		0.01		< 0.001
Strongly agree	270 (33.7)		0.07 ± 0.979		0.50 ± 0.93	
Somewhat agree	333 (41.5)		0.02 ± 0.934		0.00 ± 0.79	
No impact	199 (24.8)		−0.20 ± 1.16		−0.69 ± 1.01	

Note: Response options for the closed-ended question, "Which of the following, if any, would make you more likely to donate a kidney while you are still living?" were strongly agree, somewhat agree, and "Would Not make me More Likely to Donate" (ie, no impact). Positive scores indicate greater knowledge or willingness compared with the mean response; negative scores indicate less knowledge or willingness (mean = 0 and SD = 1). The facilitators included in this table were the facilitators that had the top 5 highest combined percentages of strongly agree and somewhat agree. P-values test the null hypothesis that the mean responses across all levels of the variable are the same.
Abbreviation: SD, standard deviation.

Table 8. Free-Text Responses to the Question, "What else makes you, personally, more likely to donate a kidney while you are still living?"

Themes	Example Response 1	Example Response 2
Being compensated	A cash incentive and free follow-up medical treatment	If I would be financially compensated
Having a terminal illness	If I were dying of an illness that doesn't affect my kidneys	If I had cancer
Having fewer health concerns	If I was in better health	If my kidneys were healthy
Having more information on the procedure, the recovery process, and life after transplant	If I had more information about living with one kidney	Information on recovery time after donating a kidney
Having more information on the recipient	As long as I was aware of the reason behind why another needed a kidney. If it isn't self-inflicted…I would be more likely to donate.	How the person has lived their life up till needing a kidney
Having reasons related to religion or God	Because I feel like the Good Lord is telling me to do the right thing	An epiphany from God
Wanting to help loved ones	Knowing and caring about the person in need	Someone I cared about needed it
Wanting to help someone	Knowing I was saving someone's life	Just knowing that donating my kidney would save another's life would be all I would need to donate

In summary, the majority of the US public surveyed would consider donating a kidney while still alive. This suggests that there are potential living kidney donors who have not yet presented to transplant centers and that further growth of living kidney donation is possible. Culturally competent educational campaigns, outreach initiatives around the opportunity for kidney-paired donation, and national-level policies that reduce financial disincentives to living kidney donation are important next steps.

SUPPLEMENTARY MATERIALS

Supplementary File (PDF)

Item S1: Survey Instrument

Table S1: Living Kidney Donation Knowledge and Willingness Scale Breakdown

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