Living Donor Follow-up Practices: Transplant Center Data

A joint project of the OPTN/UNOS Living Donor and Transplant Administrators Committees

The OPTN/UNOS Living Donor Committee and the Transplant Administrators Committee are surveying transplant centers to learn more about how individual programs conduct followup with their living donors after donation surgery. Our goal is to learn what programs see as their strengths and weaknesses in monitoring living donors over time. Each program is organized differently, and we are interested in how your program runs its follow-up program.

You are not required to identify your transplant center to complete this survey. If you choose to identify your center, everything you tell us will be kept completely confidential, and any information associated with your center’s name will be used only by UNOS Research Department staff for the purposes of this survey project. In our report, no program or center will be identified or linked with any specific survey responses.

Results of the survey will be reviewed by the Living Donor and Transplant Administrators Committees and will be reported to the OPTN/UNOS Board of Directors. Results of the survey could lead to changes or improvements in living donor follow-up.

We estimate that this survey will take approximately 20 minutes to complete. If you cannot complete the survey in one session, you may exit the survey and return to complete it at a later time.

Thank you for your participation.

What is your job title?

☐ Transplant Program Director
☐ Transplant Program Administrator/Manager
☐ Clinical Coordinator
☐ Transplant Coordinator
☐ Data Coordinator
☐ Social Worker
☒ Independent Donor Advocate
☐ Administrative assistant (non clinical)
☐ Other: ____________________________
GENERAL KNOWLEDGE & ATTITUDES ABOUT LIVING DONOR FOLLOW-UP

In your opinion, what information should be tracked by the OPTN to assess living donors' well-being? (Check all that apply)

- Physical health status
- Donor’s ability to return to work
- Psychological well-being
- Job loss
- Difficulty obtaining health insurance
- Loss of insurance
- Difficulty obtaining life insurance
- Insurance not covering donor expenses as expected
- Unanticipated change in the relationship between donor and recipient
- New temporary or permanent disability
- Donation regret by the donor
- Unexpected out-of-pocket costs from donation
- Other __________________________________

How much do you agree or disagree with each of these statements? (Please check the category which best represents your opinion)

Collecting post-donation data on donors’ health will result in:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Somewhat Agree</th>
<th>Somewhat Disagree</th>
<th>Strongly Disagree</th>
<th>Don’t Know</th>
<th>NA</th>
</tr>
</thead>
<tbody>
<tr>
<td>…improved knowledge about the health of living donors in your program.</td>
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<td>…improved health for living donors nationally.</td>
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<td>…reduction of medical risks associated with kidney donation</td>
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<td>…reduction of medical risks associated with liver donation</td>
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<td>…improved national trust in the process of living donation</td>
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<tr>
<td>…improved information that can be provided to prospective living donors about the risks of donation.</td>
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<td>…improvement in the donation outcomes for future living donors.</td>
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</tbody>
</table>

Does your program perform living KIDNEY donor transplants?

- Yes → continue below
- No → skip to Living Liver Donor Follow-up Section
LIVING KIDNEY DONOR FOLLOW-UP: ATTITUDES AND CURRENT PRACTICES

In your opinion, what is the minimum length of time a living KIDNEY donor’s health should be monitored post-donation?
- 90 days
- 6 months
- 1 year
- 2 years
- 5 years
- For the rest of the donor’s life

Under current policy, living KIDNEY donor follow-up reporting is required at 6 month, one-year and two years post donation. In your opinion, should the first reporting period occur earlier?
- Yes
- No

In your program, how much of a priority is it to achieve a full two years of follow-up of living KIDNEY donors?
- An extremely high priority
- A high priority
- A moderately high priority
- A low priority

What health parameters should be tracked at multiple time points to evaluate the health status of a living KIDNEY donor? (Check all that apply)
- Blood pressure
- Fasting blood glucose
- Urinalysis
- Weight
- Urine protein
- Waist circumference
- Serum creatinine
- Development of hypertension
- Urine protein-creatinine
- Fasting lipid profile
- New medications
- Other __________________________

During the evaluation or consent process, does your program tell potential living KIDNEY donors that two years of medical follow-up will be required after donating?
- Yes
- No
- Don’t know

If your program informs potential living KIDNEY donors that two years of medical follow-up will be required after donating, does your program (check all that apply)
- Determine a plan with the potential donor to achieve follow-up
- Explain who will be responsible for the cost of follow-up
- Explain why it is important for the donor to participate in follow-up

At what time points does your program attempt to contact living KIDNEY donors? (check all that apply)
- < 1 month post-donation
- 3-4 months post-donation
- 6 months post-donation (continued on next page)
- 1 year post-donation
- 2 years post-donation
- Do not attempt any contact
- Other ___________________________

What type(s) of contact do you have with living KIDNEY donors? (Check all that apply)
- In-person (return to center)
- Telephone
- Email
- Letter
- Don’t know
- Other ____________________________

Please provide your best estimate to answer the following question. For KIDNEY donors who donated at your program during the past two years, what percentage do you contact at each of the following time points?

<table>
<thead>
<tr>
<th></th>
<th>1 – 25%</th>
<th>26 – 50%</th>
<th>51 – 75%</th>
<th>76 – 100%</th>
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</thead>
<tbody>
<tr>
<td>Within 1 month post-donation?</td>
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<tr>
<td>At 3-4 months post-donation?</td>
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<tr>
<td>At points beyond 2 years post—donation?</td>
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</table>

When collecting living KIDNEY donor follow-up data, what direct costs are incurred by your center? (check all that apply) Costs of:
- Staff time to follow-up with or locate living donors by telephone
- Staff time to conduct ongoing medical assessments of donors
- Staff time to complete UNOS living donor follow-up forms
- Living donor medical tests
- Housing costs for the living donors returning for medical tests
- Transportation costs for living donors returning for medical tests
- Other ____________________________

Would your center approve a potential living KIDNEY donor who is suitable with regards to all clinical and psychosocial evaluations, but who does not have private health insurance?
- Yes, always
- No
- Don’t know
- Yes but only under some circumstances (what: _________________________________)

Does your program perform living LIVER donor transplants?
- Yes → continue below
- No → skip to Completion of Living Donor Follow-up Forms Section
LIVING LIVER DONOR FOLLOW-UP: ATTITUDES AND CURRENT PRACTICES

In your opinion, what is the minimum length of time a living LIVER donor’s health should be monitored post-donation?
- 90 days
- 6 months
- 1 year
- 2 years
- 5 years
- For the rest of the donor’s life

Under current policy, living LIVER donor follow-up reporting is required at 6 month, one-year and two years post donation. In your opinion, should the first reporting period occur earlier?
- Yes
- No

In your program, how much of a priority is it to achieve a full two years of follow-up of living LIVER donors?
- An extremely high priority
- A high priority
- A moderately high priority
- A low priority

What health parameters should be tracked at multiple time points to evaluate the health status of a living LIVER donor? (Check all that apply)
- Blood pressure
- Total bilirubin
- SGPT/ALT
- SGOT/AST
- Fasting blood glucose
- SGOT/AST serum albumin
- Lipid profile
- INR
- Serum creatinine
- Other ___________________________

During the evaluation or consent process, does your program tell potential living LIVER donors that two years of medical follow-up will be required after donating?
- Yes
- No
- Don’t know

If your program informs potential living LIVER donors that two years of medical follow-up will be required after donating, does your program (check all that apply)
- Determine a plan with the potential donor to achieve follow-up
- Explain who will be responsible for the cost of follow-up
- Explain why it is important for the donor to participate in follow-up

At what time points does your program attempt to contact living LIVER donors? (check all that apply)
- < 1 month post-donation
- 3-4 months post-donation
- 6 months post-donation
- 1 year post-donation
- 2 years post-donation
- Do not attempt any contact
- Other ___________________________
What type(s) of contact do you have with living LIVER donors? (Check all that apply)

- In-person (return to center)
- Telephone
- Email
- Letter
- Other __________________________

Please provide your best estimate to answer the following question. For KIDNEY donors who donated at your program during the past two years, what percentage do you contact at each of the following time points?

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When collecting living LIVER donor follow-up data, what direct costs are incurred by your center? (check all that apply) Costs of:

- Staff time to follow-up with or locate living donors by telephone
- Staff time to conduct ongoing medical assessments of donors
- Staff time to complete UNOS living donor follow-up forms
- Living donor medical tests
- Housing costs for the living donors returning for medical tests
- Transportation costs for living donors returning for medical tests
- Other __________________________

Would your center approve a potential living LIVER donor who is suitable with regards to all clinical and psychosocial evaluations, but who does not have private health insurance?

- Yes, always
- No
- Don’t know
- Yes but only under some circumstances (what: __________________________)

COMPLETION OF LIVING DONOR FOLLOW-UP FORMS

If you contact donors after donation, do you collect psychosocial information (e.g., resumption of normal life activities)?

- Yes
- No

Does your program have a designated independent donor advocate or advocate team?

- Yes
- No

If yes, does the advocate or a member of the advocate team contact previous donors for any follow-up post operatively?

- Yes
- No
**How is contact provided to donors?**
- In-person (return to center)
- Telephone
- Email
- Do not know
- Other ________________________________

**How were you informed about the current UNOS policy for living donor follow-up? (Check all that apply)**
- By the transplant administrator
- Through a UNOS email/communication
- Through the UNOS website
- Regional meetings
- Through a transplant organization
- At a medical conference
- Do not know
- Other ________________________________

**How many people are responsible for completing and/or submitting the living donor follow-up forms in your program?**
- 1
- 1-2
- 3-4
- >5

**What are the job titles or positions of all of those responsible for completing the living donor follow-up forms? (Check all that apply)**
- Transplant Program Director
- Transplant Program Administrator/Manager
- Clinical Coordinator
- Transplant Coordinator
- Data Coordinator
- Social Worker
- Independent Donor Advocate
- Administrative assistant (non clinical)
- Other: ________________________________

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**ENSURING LIVING DONOR CARE**

**How often are each of the following activities completed to help ensure that medical information recorded on living donor follow-up forms is accurate? (Indicate the answer most applicable for your center)**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Never</th>
<th>Rarely</th>
<th>Occasionally</th>
<th>Often</th>
<th>Constantly</th>
</tr>
</thead>
<tbody>
<tr>
<td>A review of medical records is conducted by a second person to ensure accuracy.</td>
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<tr>
<td>A review of the forms is conducted by a second person to ensure that all fields are complete.</td>
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</tr>
<tr>
<td>A review of living donor lab values recorded on the data collection forms occurs to ensure that all values are within normal range and confirmed by a second person.</td>
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</tbody>
</table>
Living donor data collection forms with out-of-range (abnormal) lab values trigger a request for donors to return to the transplant center for reevaluation.

Information is reviewed with the donor or donor’s physician.

In general, if a living donor experienced post operative complications, for example, an abscess, would your center provide care for this problem?

☐ Yes, always
☐ No
☐ Don’t know

If care was necessary and was provided at your center, would the care be provided at no cost to the donor?

☐ Yes, always
☐ No
☐ Would depend on the circumstances of the case

DONORS WHO ARE LOST TO FOLLOW-UP

Under what circumstances does your center classify a living donor as lost to follow-up? (Check all that apply)

☐ If donor is called multiple times and does not respond
☐ If donor phone number on file is incorrect
☐ If the donor cannot be located through any information the donor originally provided (e.g., other family or the recipient)
☐ If the donor cannot be located using internet phone databases or other resources
☐ Other ______________________________________

If a donor is reported as lost to follow-up at one time point, do you make any additional efforts to locate them at any point after that?

☐ No
☐ Yes, for one more time point after that
☐ Yes, at each time point thereafter
☐ Yes, other _________________________________

What laboratory values are recorded on the forms when a donor is lost to follow-up?

☐ Last laboratory values available in the donor’s medical record
☐ Nothing, leave the space blank
☐ Other _________________________________

POTENTIAL BARRIERS TO LIVING DONOR FOLLOW-UP

What difficulties or barriers does your transplant center have with achieving living donor follow-up? (Check all that apply)

☐ Lack of staff time to follow-up with or locate living donors by telephone
☐ Lack of staff time to conduct ongoing medical assessments of living donors
☐ Lack of staff time to complete OPTN living donor follow-up forms
☐ Cost of additional medical testing for living donors
☐ Lack of reimbursement to centers for living donor follow-up costs
☐ Lack of reimbursement to donors for costs associated with participating in follow-up
☐ Living donors do not want to return to the transplant center for medical tests as time passes
☐ Living donors’ contact information becomes outdated as time passes (e.g., lost to follow-up)
☐ Living donors say that they do not want to be contacted
☐ Other _________________________________
Some programs report a significant burden associated with collecting required living donor follow-up data, and have suggested that a third party should be responsible for collecting and reporting living donor follow-up. Would your program be willing to pay a third party to collect and submit living donor follow-up data?

☐ Definitely would be willing
☐ Might be willing
☐ Not likely to be willing
☐ Very unlikely to be willing

Do you have any suggestions on how to increase the accuracy of living donor follow-up data reported to the OPTN?

[space expanded as respondents recorded answers]

Do you have any suggestions on how to track living donors’ health status over a two year period more easily?

[space expanded as respondents recorded answers]

Do you have any suggestions on how to simplify the reporting of living donor follow-up to the OPTN?

[space expanded as respondents recorded answers]

Do you have any suggestions on how to reduce transplant center costs associated with living donor follow-up?

[space expanded as respondents recorded answers]

Do you have any suggestions on how to increase the reimbursement rates associated with living donor follow-up?

[space expanded as respondents recorded answers]

Do you have any suggestions on how to identify other sources (e.g., local, national) of funding for costs associated with living donor follow-up?

[space expanded as respondents recorded answers]

Is there anything else about living donor follow-up at your center that you think would be important for us to know?

[space expanded as respondents recorded answers]

OPTIONAL: Please provide your institution's name or four letter UNOS code. Your center's responses will be kept confidential and used only by Research staff at UNOS to analyze survey results. Providing your center's name or UNOS code will allow us to look at patterns of living donor follow-up practices that might vary by center size, region, etc. Information that identifies your center will be deleted after analyses are complete.

_________________________________