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Abstract #2751

# Partnering With Living Donors in the Development of Long-term Follow-up Data Collection Instruments

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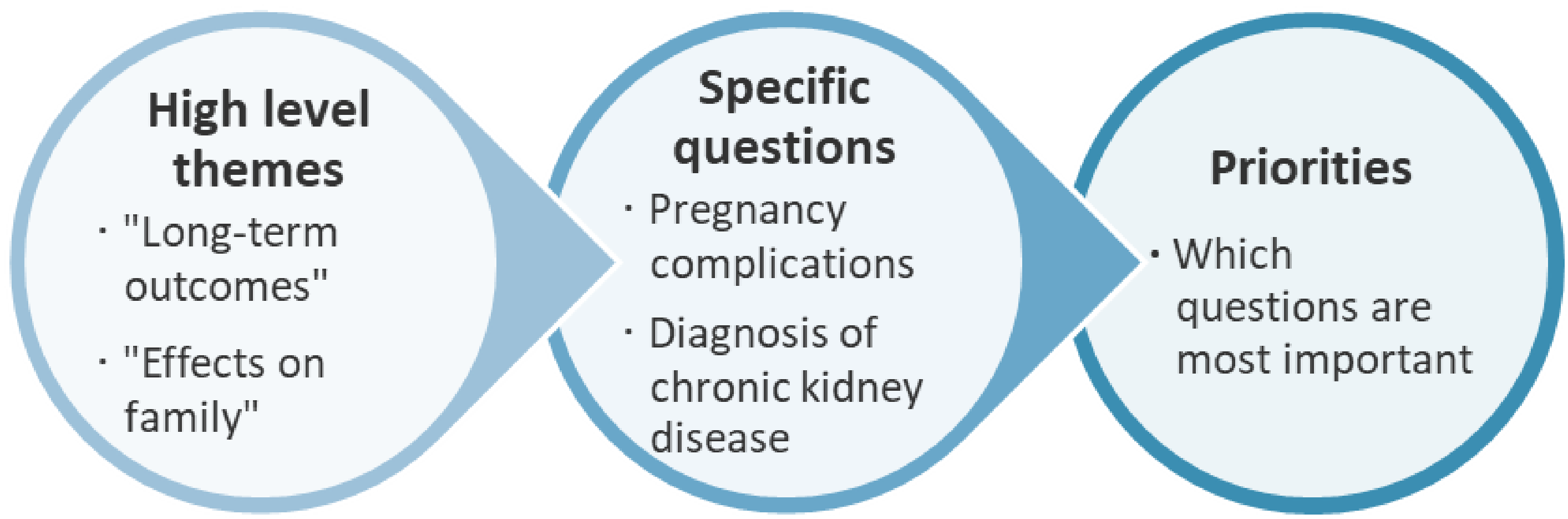
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## Introduction

- More than 200,000 living donor organs have been donated since 1987, but systematic data on outcomes are inconsistently collected.
- SRTR’s Living Donor Collective (LDC) is a voluntary lifetime registry following living donor candidates, guided by the Living Donor Steering Committee (LDSC) made up of 15 living kidney and liver donors.
- The Organ Procurement and Transplantation Network (OPTN) is considering systematic collection of potential living donor data with long-term follow-up by SRTR through voluntary annual surveys and registry linkages.
- Living donors must be active partners in determining what data would help potential donors make informed decisions about living donation.

## Methods

- Between October 2023 and May 2024, two 90-minute LDSC meetings were convened to brainstorm and prioritize data elements.
- Design-thinking principles were applied to brainstorm 50 specific data elements within 10 themes derived from prior research:



- 10 LDSC members individually completed an online prioritization exercise of the 50 data elements (April-May 2024).
  - Data elements rated as “critically important” by at least 50% were identified as top priorities.
  - Elements rated “important” and “critically important” by at least 60% were identified as second-level priorities.
  - 5 additional data elements were included for consideration in future surveys due to clinical or scientific priority by transplant professionals.

## Conclusion

Future surveys of a larger sample of living donors would help determine which of these are most important to a broader sample of donors, and how best to engage donors and donor candidates in follow up efforts.

## Results:

Thematic Area	Data Element
Clinical / scientific priority	<b>Short-term recovery and return to normal life</b>
	Short-term lab values
	Time to resume usual activities after donation
	Experienced any acute pain or discomfort
	Location of acute pain
	Time to resume usual activities longer, shorter, or as anticipated
	Feeling knowledgeable about your expected lab values immediately after donation
Clinical / scientific priority	<b>Long-term health and other consequences of donation</b>
	Long-term lab values
	Whether any candidate/living donor had been diagnosed with chronic kidney or liver disease after donor evaluation/donation
	Experienced any chronic pain or discomfort
	Location of chronic pain
Second priority	<b>Financial issues</b>
	Overall cost of donation
	Report of physical limitations due to donation impacting paid employment
	Life insurance status
	Experience of not qualifying for financial assistance due to recipient making too much money
	Difficulty obtaining insurance
	Utilization of organ donor assistance programs
Top priority	Health insurance status
	<b>Changes in relationship with the person needing an organ</b>
	Report of experience of the recipient experiencing a good or bad outcome, and the emotional impact of that outcome on the donor or potential donor
	Report of whether decision to donate or not donate negatively or positively impacted relationship between donor and recipient
	<b>Changes in lifestyle and life satisfaction afterwards</b>
	Any difficulty being able to perform normal activities or work after donation
	Report of time it took to return to predonation activities
	Report of how donating impacts satisfaction with life
	Report of negative feelings about physical or life restrictions
	Employment status before and after donor evaluation and over time
Top priority	Report of motivation to take steps to remain healthy
	If employed prior to donor evaluation, how supportive were employers of donation/potential donation
	Report of whether not donating impacts satisfaction with life
	<b>Overall experience with donor evaluation and donation</b>
	Whether a donor would make the same decision to donate again
	Expenses related to donation
	Overall satisfaction with donation experience
	Report of lack of consideration given to the donor (timing, costs, etc)
	Satisfaction of donor evaluation experience
	<b>Clinical outcomes that would be collected and reported by transplant professionals</b>
Top priority	Whether any living donor deaths were related to donation
	Whether a donated kidney or liver resulted in organ failure, including the need for dialysis or transplant
	Comparison of mortality between donors and non-donors
	Hospital readmission rates related to donation
	Cause of death
	Hospital length of stay related to donation
	Type of surgical procedure performed (open, laparoscopic, etc)
	Time from in-person donor evaluation to donation