

## **Supplemental material contents**

**Appendix 1:** Survey provided to participants to rate each key term

**Appendix 2:** Survey provided to participants to rate each process indicator

**Appendix 3:** Survey provided to participants to rate each outcome indicator

**Appendix 4:** Participant ratings for each key term and quality indicator

**Appendix 5:** The final definitions of key terms after participant ratings and comments were reviewed.

**Appendix 6:** The final process indicators after participant ratings and comments were reviewed.

**Appendix 7:** The final process indicators after participant ratings and comments were reviewed.

## 2. Definition of Key Terms Survey

There are several key terms that need to have a clear definition that everyone can agree on. This is important because we have to speak the same language when measuring and comparing the living donor evaluation process across transplant programs. In this survey, we present a series of key terms and propose definitions.

Please read each definition and indicate how strongly you agree or disagree with the statements provided (1 = strongly disagree; 9 = strongly agree). If you disagree, please indicate why you disagree so we can modify/clarify the definition accordingly.

All definitions apply to a donor candidate for a unique recipient. For example, if a donor candidate is evaluated to donate to a brother, withdraws from the evaluation because another candidate is preferred, and then later is evaluated to donate to a child, they would have two separate records.

Some candidates are evaluated at more than one transplant centre (evaluation team). In such cases communication with the first transplant centre is counted for measures such as the first contact, testing start date etc.

Communication with the transplant centre where the donation will occur is counted as the approval date etc.

Thank you!

If you have any questions, please contact [steven.habbous@lhsc.on.ca](mailto:steven.habbous@lhsc.on.ca)

You may save and continue your progress at a later time.

### Living donor candidate

**Any person with who contacts a living donor program with an interest of being evaluated as a living kidney donor or learning more about the living kidney donor process.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Is this definition clear and unambiguous?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you agree with this definition?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this definition:

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**First contact date**

**This is the date the donor candidate first reached out to the living donor program (i.e., phoned, emailed, in-person, interacted with an on-line web-based intake system). The donor candidate may have contacted the program to get more information about kidney donation, or they may have contacted the program to begin their testing; both reasons count as a first contact date.**

**Note: if a person called on behalf of someone else (e.g. called on behalf of donor candidate A), that would still count as the first contact date for donor candidate A.**

	1	2	3	4	5	6	7	8	9
	(strongly disagree)				(neutral)				(strongly agree)
Is this definition clear and unambiguous?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you agree with this definition?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this definition:

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**Testing start date**

**This is the date the evaluation team reviewed a medical-social questionnaire completed by the candidate, and has determined the candidate is eligible to proceed with further evaluation. They will now ask the candidate to do further tests beyond the questionnaire (e.g. laboratory tests).**

**\*Note: this is the date the evaluation team decided the candidate is eligible to proceed (versus the time they communicated this to the candidate, in cases where they are unable to reach the candidate right away).**

**\*Note: If the candidate had some testing ordered and/or completed before the evaluation team reviewed their complete medical-social questionnaire, still use questionnaire approval as the testing start date.**

**\*Note: if candidate provided information on their medical-social questionnaire that made them ineligible to be a donor and proceed with the evaluation, they would not have a testing start date.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Is this definition clear and unambiguous?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you agree with this definition?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this definition:

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**Evaluation start date**

**This is the first contact date (defined above).**

**\* Note: Sometimes a person contacts a donor evaluation team to obtain more information, rather than any intent to start their evaluation. However, becoming informed about donation means someone is interested in the process, and this will count as the evaluation start date.**

**\*Note: The medical-social questionnaire is part of the living donor evaluation. Some candidates do not complete the questionnaire immediately for a variety of reasons (much like any other test in the evaluation). In addition, some programs may provide the medical-social questionnaire on their website (readily accessible), and so the testing start date may not be a valid measure of the evaluation start date for all programs.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Is this definition clear and unambiguous?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you agree with this definition?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this definition:

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**Approval date(s)**

**This is the date the candidate was approved to donate by a given specialist involved in the candidate's evaluation who is responsible for rendering a decision on donor eligibility. Following the approval date, the specialist does not require any further testing beyond the standard tests that are routinely done in the weeks prior to surgery (e.g. pre-admission labs, infectious disease and pregnancy testing 2 weeks prior to nephrectomy).**

**\*Note: Many donors will have at least three approval dates (one from a nephrologist, one from a surgeon, and one from a psychosocial specialist). Other donors may require additional approvals from other specialists or from specialists from different centres.**

**\*Note: Sometimes eligibility is decided through group discussion, in which case several specialists may have the same approval date.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Is this definition clear and unambiguous?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you agree with this definition?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this definition:

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**Donor candidate withdrawal date**

**This is the date that the donor indicated to the evaluation team that they no longer wish to proceed with the evaluation and are no longer interested in becoming a living kidney donor (to a given recipient).**

**\*Note: This measure is only completed for candidates who indicate to the evaluation team that they wish to withdraw from further evaluation. If a candidate simply does not follow up with the evaluation team and does not explicitly express their intent to withdraw, do NOT complete this measure (refer to "donor lost to follow-up").**

**\*Note: If a candidate indicates they wish to withdraw but then changes their mind, the period between withdrawal and evaluation re-start can be considered a hold period (described below) or the candidate can be considered a new record. This will depend on whether the evaluation team decides to start the evaluation from the beginning or resume where it was left off.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Is this definition clear and unambiguous?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you agree with this definition?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this definition:

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**Donor candidate declined from ever donating date**

**This is the date the evaluation team rendered a decision that the donor candidate will never be eligible to donate.**

**\*Note: This is the date the evaluation team decided the candidate is ineligible to proceed (versus the time they communicated this to the candidate, in cases where they are unable to reach the candidate right away).**

**\*Note: If the candidate needs to do something to be evaluated further (e.g. lose weight, reduce smoking, secure a primary care physician etc.) then they will be placed on hold instead (see "hold start date" described below).**

**\*Note: If the candidate becomes ineligible to donate because of a change in the status of the intended recipient, then this is the date the donor evaluation team became aware of this status change rather than the date they communicated this with the donor candidate. This may occur if the recipient is no longer eligible for transplant or received a kidney from another donor (living or deceased).**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Is this definition clear and unambiguous?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you agree with this definition?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this definition:

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**Donor lost to follow-up**

Sometimes a donor candidate simply does not follow-up, and has no further communication with the evaluation team. In this case, the evaluation team can assign the date of last contact with the candidate as the date of loss to follow-up. This includes settings where candidates are given instructions on what they need to do to be considered eligible (e.g. lose a certain amount of weight), but the team fails to receive any update from the candidate after a reasonable amount of time (3 months). The living donor evaluation cannot progress until the candidate is engaged.

**\*Note:** Sometimes a donor candidate loses contact with the evaluation team for a prolonged period of time (i.e., 3 months), is given a loss to follow-up date, but then re-initiates contact; in such cases the period between last contact and evaluation resumption can be considered a hold period (described below) or the candidate can be considered a new record. This will depend on whether the evaluation team decides to start the evaluation from the beginning or resume where it was left off.

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Is this definition clear and unambiguous?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you agree with this definition?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this definition:

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**Evaluation end date**

**This is the date of approval (the last approval date), date of withdrawal, date of decline, or date of loss to follow-up.**

**\*Note: Any tests after this date (i.e., tests 2 weeks prior to surgery) are not considered.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Is this definition clear and unambiguous?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you agree with this definition?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this definition:

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**Potential pre-emptive living kidney donor transplant****All of the following must be true on the donor's testing start date:**

- intended recipient currently not on dialysis; AND
- intended recipient did not receive dialysis or a deceased donor kidney transplant in the 3 months following the testing start date (to give the donor candidate enough time to complete the evaluation); AND
- intended recipient is approved for transplant within the 3 months following the testing start date

	1	2	3	4	5	6	7	8	9
	(strongly disagree)				(neutral)				(strongly agree)
Is this definition clear and unambiguous?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you agree with this definition?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this definition:

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**Hold start date**

**This is the date that no further testing on the donor candidate is performed for at least 2 months because the evaluation team must wait to receive some information or action from the donor candidate or their intended recipient in order to proceed. This may include weight loss, smoking cessation, recipient referral, other donor candidates will be assessed first, etc. A given candidate may have multiple holds dates in their evaluation.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Is this definition clear and unambiguous?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you agree with this definition?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this definition:

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**Hold end date**

**This measure is only completed for candidates who were given a hold start date, where this is the end date for that start date. This is the date that the reason the donor evaluation was placed on hold is no longer valid (e.g., weight reduced, smoking reduced, intended recipient has been assessed by the transplant team, etc.).**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Is this definition clear and unambiguous?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you agree with this definition?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this definition:

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### 3. Process Indicators Survey

Process indicators are things we can measure that can tell us something about the efficiency (or inefficiency) of the living donor evaluation process. This is often the time needed to complete certain tasks. In this survey, we present a series of process indicators that we can use to measure the living donor evaluation process.

Please read each process indicator and indicate how strongly you agree or disagree with the statements provided (1 = strongly disagree; 9 = strongly agree). The underlined terms were defined in the previous survey (attached here for reference). When you provide your opinion on whether a process indicator should be measured, please keep in mind both how important and how easy it would be to accurately measure it.

Thank you!

If you have any questions, please contact [steven.habbous@lhsc.on.ca](mailto:steven.habbous@lhsc.on.ca)

You may save and continue your progress at a later time.

[Attachment: "Appendix 3 - Definitions - 06Dec2017.docx"]

#### 1. Total donor evaluation time

**This is the time from evaluation start date until evaluation end date**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If during the donor's evaluation, the process was put on hold, that should be recorded at the time of the evaluation end (as a simple yes/no), along with the reason(s) for being put on hold.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this indicator?

**2. Time until donation**

**This is the time from evaluation start date until donation. This is only completed for candidates who do go on to donate a kidney.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this time	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this indicator?

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**3. Time until testing start****This is the time from evaluation start until testing start.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this time	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Comments/suggestions about this indicator?

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**4. Time to review the medical-social questionnaire within the program**

**This is the time from when the medical-social questionnaire is received by the program until it is reviewed (internally) by the program. This includes any time the program takes to clarify responses or complete missing responses with the candidate.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this time	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Comments/suggestions about this indicator?

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**5. Time until first blood or urine test**

**This is the time from evaluation start date until the next blood or urine test was completed by the donor candidate. Blood or urine tests completed before the evaluation start date are not included.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this time	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this indicator?

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**6. Time until first 24-hour urine test**

**This measure is only available / completed for programs that require at least one 24-hour urine test as part of the donor candidate evaluation. This is the time from evaluation start date until the first 24-hour urine test. It is only provided for candidates who complete at least one 24-hour urine test for creatinine clearance as part of their evaluation.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this time	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this indicator?

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**7. Time until first diagnostic test is performed**

**This is the time from evaluation start date until a given diagnostic test is performed. There will be multiple of these (i.e., time until first ultrasound, first chest x-ray, first electrocardiogram, first CT angiogram, etc.)**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this time	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this indicator?

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**8. Time from CT until evaluation end**

**This is the time from the date the CT angiogram was completed until evaluation end date (for those donor candidates who had a CT angiogram and an evaluation end).**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this time	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Comments/suggestions about this indicator?

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**9. Time to consultation**

**This is the time from evaluation start date until a given consultation is performed (i.e., time until nephrology consult, time until surgery consult, time until social work consult, etc.). The time to consultation with each specialist will be a separate process indicator. If there are multiple consults with a given specialist, the first consultation will be counted.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this time	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this indicator?

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**10. Time to initial compatibility (crossmatch) test**

**To determine whether the donor and recipient tissues are compatible, donor and recipient samples are mixed. This is the time from evaluation start date until the donor's blood sample is provided for the initial crossmatch. This is not the time the cross-match is performed.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this time	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this indicator?

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**11. Time until potential initial compatibility (crossmatch) test**

**This indicator is the time from evaluation start date until the earliest possible crossmatch date, which is one month after the first recipient serum sample is frozen. As a minimum of two recipient samples collected at least one month apart are required to perform the initial crossmatch test, this indicator may suggest delays on the recipient side.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this time	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this indicator?

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**12. Time from evaluation start date until recipient referral**

**This is the time between the donor candidate's evaluation start date and the date the transplant centre received a referral for the intended recipient for evaluation. Sometimes the donor candidate comes forward before the intended recipient has even been considered for transplantation. If this happens, the donors' evaluation process is often placed on hold until the transplant program confirms they have received a referral for the intended recipient to begin their evaluation. If the intended recipient was referred before the donor candidate's evaluation start date, then the value for this measure would be negative.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this time	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this indicator?

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**13. Time until recipient referral received by donor evaluation team**

**This is the time from when the dialysis centre or clinic sends the recipient referral package to the transplant centre's recipient team until the living donor program is notified by the recipient team that they have received the package**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this time	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions about this indicator?

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**Other process indicator #1****Please describe this below**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

Please describe this indicator

---

**Other process indicator #2****Please describe this below**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Please describe this indicator

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## 4. Outcome Indicators Survey

Outcome indicators are things we can measure that can tell us something about the effectiveness of the living donor evaluation process for a living kidney donor program. In this survey, we present a series of outcome indicators that we can use to measure how well a transplant centre is performing in living kidney donation.

Please read each outcome indicator and indicate how strongly you agree or disagree with the statements provided (1 = strongly disagree; 9 = strongly agree). The underlined terms were defined in the previous survey (attached here for your reference).

Thank you!

If you have any questions, please contact [steven.habbous@lhsc.on.ca](mailto:steven.habbous@lhsc.on.ca)

You may save and continue your progress at a later time.

[Attachment: "Appendix 3 - Definitions - 06Dec2017.docx"]

### 1. Annual number of living donor kidney transplants

**A kidney transplant occurring from a living donor every calendar year (January through December).**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to increase this	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions for this indicator:

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**2. Annual number of pre-emptive living donor kidney transplants**

**A preemptive transplant is one that occurs before the recipient starts dialysis. This is the number this occurs every calendar year.**

**\*Note: this measure would also require a yes/no indicator for having a prior transplant:**

**- NO if the recipient is a first-time kidney transplant**

**- YES if the recipient is currently living with a failing kidney from a prior transplant.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to increase this	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions for this indicator:

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**3. Annual number of living donor kidney transplants done in the first year of dialysis**

**In most regions, it is very unlikely an intended recipient would receive a deceased donor kidney in their first year on dialysis.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to increase this	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions for this indicator:

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**4. Annual number of potential pre-emptive transplants lost**

**This is the number of times that a recipient started dialysis despite having a living kidney donor. The transplant must be considered a potential pre-emptive living kidney donor transplant and the donor must be in active evaluation for at least 3 months.**

**\*Note: This is irrespective of whether the donor candidate is/was approved for donation or not, as they may not have had their tests completed. We also do not know if the intended recipient was referred for transplant evaluation, or was eligible to receive a transplant when the donor candidate contacted the program. This is also irrespective of whether or not the intended recipient receives a transplant.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The date the intended recipient started dialysis should also be documented	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions for this indicator:

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**5. Annual number of recipient deaths (instead of living donor transplant)**

**This is the number of times the intended recipient died before receiving a transplant despite having a living donor candidate whose evaluation was at least 3 months long and was still being evaluated at the time the recipient died.**

**\*Note: This is irrespective of whether the donor candidate is/was approved for donation or not, as they may not have had their tests completed. We also do not know if the intended recipient was referred for transplant evaluation, or was eligible to receive a transplant when the donor candidate contacted the program.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The date the intended recipient died should also be documented	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions for this indicator:

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## 6. Annual number of intended recipient deceased donor transplants (instead of living donor transplants)

This is the number of times the intended recipient received a deceased donor transplant despite having a living donor candidate whose evaluation was at least 3 months long and was still being evaluated at the time the recipient was transplanted.

**\*Note: This is irrespective of whether or not the deceased donor graft failed and the donor candidate resumed the evaluation**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The date the intended recipient received the deceased donor transplant should also be documented	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions for this indicator:

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**7. Annual number of intended recipients rendered ineligible**

**This is the number of times the intended recipient developed a new event that made them no longer eligible for transplant, despite having a living donor candidate whose evaluation was at least 3 months long and was still being evaluated.**

**\*Note: if the cause of the recipient's ineligibility directly precipitated in the recipient's death, then this is considered an intended recipient's death before transplant (defined above) rather than recipient ineligibility.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If during the donor's evaluation, the process was put on hold, that should be recorded at the time of the evaluation end (as a simple yes/no), along with the reason(s) for being put on hold.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions for this indicator:

**8. Total healthcare cost of the living donor candidate's evaluation**

The total cost of the living donor evaluation may be higher if the evaluation was longer (i.e., repeated testing), more tests were being performed, or if a centre schedules tests in a certain way. This indicator is the total cost of the living donor candidate's evaluation to the healthcare system (regardless of donation). This indicator does not count any costs to the recipient's care (i.e. if a shorter evaluation time resulted in savings from averted dialysis).

**\*Note: this outcome will include a variable to indicate whether the candidate donated or not:**

- 1 = donated

- 0 = did not donate

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions for this indicator:

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**9. The number of times a medical test is repeated**

**This is restricted to tests that are only usually measured once during a donor candidate's evaluation (i.e., nuclear GFR, split renal function, CT scan, renal ultrasound). A test may be repeated because the results were inconclusive, unreliable, abnormal, or out-of-date. This indicator documents the number of times (and reasons) this occurred for each given repeated test.**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments/suggestions for this indicator:

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**10. The number of visits to the transplant centre****This is the number of times the donor candidate is required to come to the hospital to complete testing**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Comments/suggestions for this indicator:  

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**Other outcome indicator #1****Please describe this below**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

Please describe this indicator

---

**Other outcome indicator #2****Please describe this below**

	1 (strongly disagree)	2	3	4	5 (neutral)	6	7	8	9 (strongly agree)
Efforts should be made to reduce this	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This should be measured and compared across transplant programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Please describe this indicator

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## Appendix 4: Ratings for original key terms and indicators

<b>Key terms (Appendix 1 for definitions)</b>	<b>Clear and unambiguous*</b>	<b>Agree with definition*</b>
Potential living donor candidate	8.5 (8, 9) Agree	8 (8, 9) Agree
First contact date	9 (8, 9) Agree	9 (8, 9) Agree
Testing start date	9 (8, 9) Agree	9 (8, 9) Agree
Approval date(s)	9 (8, 9) Agree	9 (8, 9) Agree
Withdrawal date	9 (8, 9) Agree	9 (8, 9) Agree
Decline date	8.5 (8, 9) Agree	8 (8, 9) Agree
Lost to follow-up date	9 (8, 9) Agree	9 (8, 9) Agree
Evaluation end date	9 (8, 9) Agree	8.5 (8, 9) Agree
Hold start date	9 (8, 9) Agree	8.5 (8, 9) Agree
Hold end date	9 (8, 9) Agree	9 (8, 9) Agree
Potential pre-emptive living kidney donor transplant	8 (6, 9) Disagree	8 (5, 9) Disagree
Reasonable amount of time [to complete the evaluation if the goal is a pre-emptive transplant]	Not rated	Not rated
Reasonably long period of time [to be considered lost to follow-up]	Not rated	Not rated
<b>Process indicators (Appendix 2 for description)</b>	<b>Efforts to improve*</b>	<b>Used for comparisons*</b>
Time from decision to start testing until donation	8 (7, 9) Agree	8 (7, 9) Agree
Time from decision to start testing until evaluation end	8 (7, 9) Agree	8 (7, 9) Agree
Time from decision to start testing until first diagnostic test is performed	8 (6, 9) Disagree	8 (7, 9) Agree
Time from decision to start testing to consultation	8 (7, 9) Agree	8 (7, 9) Agree
Time from decision to start testing to initial compatibility (crossmatch) test	8 (6, 9) Disagree	8 (6, 9) Disagree
Time from first contact date until recipient referral	7 (5, 8) Agree	7 (5, 9) Disagree
Time from when the recipient referral sent to transplant program until it is received by the donor evaluation team	8 (5, 9) Disagree	8 (5, 9) Disagree
Time from first contact until testing start (decision to start testing)	8 (6, 9) Disagree	8 (7, 9) Agree
Time to review the medical-social questionnaire within the program	8 (6, 9) Disagree	8 (6, 9) Disagree
Time from decision to start testing until first blood or urine test	8 (6, 9) Disagree	8 (5, 9) Disagree
Time from decision to start testing until first 24-hour urine test	7 (5, 8) Agree	7 (5, 9) Disagree
Time from CT until evaluation end	7 (6, 9) Disagree	7.5 (6, 9) Disagree
Time from decision to start testing until potential initial compatibility (crossmatch) test	7 (5, 8) Agree	7 (5, 8) Agree
Time from initial crossmatch until results received	Not rated	Not rated
Time from approval until the operating room booking	Not rated	Not rated
Time from approval until donation	Not rated	Not rated
Diagnostic testing done on the same visit	Not rated	Not rated

<b>Outcome indicators (Appendix 3)</b>	<b>Efforts to improve*</b>	<b>Used for comparisons*</b>
Total healthcare cost of the living donor candidates' evaluation	7.5 (6, 9) Disagree	8 (7, 9) Agree
The number of visits to the transplant centre	8 (7, 9) Agree	8 (7, 9) Agree
Annual number of living donor kidney transplants	9 (8, 9) Agree	9 (8, 9) Agree
Annual number of pre-emptive living donor kidney transplants	9 (8, 9) Agree	8 (7, 9) Agree
Annual number of living donor kidney transplants done in the first year of dialysis	9 (7, 9) Agree	8 (7, 9) Agree
Annual number of potential pre-emptive transplants lost	8.5 (7, 9) Agree	8 (6, 9) Disagree
Annual number of deaths of the intended recipient (instead of living donor transplant)	9 (8, 9) Agree	8 (6, 9) Disagree
Annual number of deceased donor transplants received by the intended recipient (instead of living donor transplants)	8 (6, 9) Disagree	7 (6, 9) Disagree
Annual number of times the intended recipient was rendered ineligible (instead of living donor transplants)	7.5 (6, 9) Disagree	8 (6, 9) Disagree
The number of times a medical test is repeated	8 (6, 9) Disagree	8 (5, 9) Disagree

\*Median (interpercentile range: 30<sup>th</sup>, 70<sup>th</sup>) percentile presented. Disagreement was assigned if the interpercentile range was greater than the interpercentile range adjusted for symmetry (see Box 1). Participants rated each key term, process indicator, and outcome indicator on a 9-point Likert scale (1 = most unimportant; 9=most important).

## Appendix 5: Final definitions of key terms

**Definitions with consensus, high rating, and minimal (or no) changes to the definition. These were not discussed with the Working Group.**

### **Potential living donor candidate**

Any person who contacts a living donor program with an interest of being evaluated as a living kidney donor.

### **First contact date**

The date the **potential living donor candidate** first reached out to the transplant program (i.e., phoned, emailed, in-person, interacted with an on-line web-based intake system).

*\*Note:* if a person called on behalf of someone else (e.g. called on behalf of donor candidate A), that would not count as the first contact date for donor candidate A.

### **Decision to start testing date** (*formerly the testing start date*)

The date the evaluation team reviewed a medical-social questionnaire completed by the **potential living donor candidate**, and has determined the candidate is eligible to proceed with further evaluation. They will now ask the candidate to do further tests beyond the questionnaire (e.g. laboratory tests).

*\*Note:* this is the date the evaluation team decided the candidate is eligible to proceed (versus the time they communicated this to the candidate, in cases where they are unable to reach the candidate right away).

*\*Note:* if the candidate provided information on their medical-social questionnaire that made them ineligible to be a donor and proceed with the evaluation, they would not have a decision to start testing date. Rather, they would have a **decline date**.

### **Approval date(s)**

This is the date the **potential living donor candidate** was approved to donate by a given specialist involved in the candidate's evaluation who is responsible for rendering a decision on donor eligibility. Following the approval date, the specialist does not require any further testing beyond the standard tests that are routinely done in the weeks prior to surgery (e.g. pre-admission labs, infectious disease and pregnancy testing 2 weeks prior to nephrectomy).

*\*Note:* Many donors will have at least three approval dates (one from a nephrologist, one from a surgeon, and one from a psychosocial specialist). Other donors may require additional approvals from other specialists or from specialists from different centres.

*\*Note:* Sometimes eligibility is decided through group discussion, in which case several specialists may have the same approval date.

### **Withdrawal date**

This is the date that the **potential living donor candidate** indicated to the evaluation team that they no longer wish to proceed with the evaluation or are no longer interested in becoming a living kidney donor.

*\*Note:* This measure is only completed for candidates who indicate to the evaluation team that they wish to withdraw from further evaluation. If a candidate simply does not follow up with the evaluation team and does not explicitly express their intent to withdraw, do NOT complete this measure (refer to **lost to follow-up**).

*\*Note:* If the **potential living donor candidate** indicates they wish to withdraw but then changes their mind, the period between withdrawal and evaluation re-start can be considered a hold period (**hold start** until **hold end**, described below) or the candidate can be considered a new record. This will depend on whether the evaluation team decides to start the evaluation from the beginning or resume where it was left off.

### Decline date

This is the date the **potential living donor candidate's** evaluation team rendered a decision that the **potential living donor candidate** is ineligible to donate and the evaluation will stop.

*\*Note:* This is the date the evaluation team decided the **potential living donor candidate** is ineligible to proceed (versus the time they communicated this to the candidate, in cases where they are unable to reach the candidate right away).

*\*Note:* If the **potential living donor candidate** needs to do something to be evaluated further (e.g. lose weight, reduce smoking, secure a primary care physician etc.) then they may be placed on hold instead (see "**hold start date**" described below). Alternatively, the candidate can be considered a new record. This will depend on whether the evaluation team decides to start the evaluation from the beginning or resume where it was left off.

### Lost to follow-up date

Sometimes a **potential living donor candidate** simply has no further communication with the evaluation team. In this case, the evaluation team can assign the date of last contact with the candidate as the date of loss to follow-up. This includes settings where **potential living donor candidates** are given instructions on what they need to do to be considered eligible (e.g. lose a certain amount of weight), but the team fails to receive any update from the candidate after a **reasonably long period of time**. The living donor evaluation cannot progress until the candidate is engaged.

*\*Note:* Sometimes a donor candidate loses contact with the evaluation team for a prolonged period of time (i.e., 3 months), is given a loss to follow-up date, but then re-initiates contact; in such cases the period between last contact and evaluation resumption can be considered a hold period (described above) or the candidate can be considered a new record. This will depend on whether the evaluation team decides to start the evaluation from the beginning or resume where it was left off.

*\*Note:* Sometimes the evaluation team is able to connect with the donor candidate (e.g. a phone call). If the candidate provides a reason for withdrawing from the evaluation, the date of last contact may be used as the **withdraw date**.

### Evaluation end date [derived]

This is the latest of the approval date(s), withdrawal date, decline date, or lost to follow-up date.

*\*Note:* Any tests after this date (i.e., pre-operative testing, donation) are not considered. This omission is necessary, otherwise the evaluation end date would equal the donation date minus 2 weeks (would not provide any additional information for donors).

### Hold start date

This is the date that no further testing on the **potential living donor candidate** is performed because the evaluation team must wait to receive some information or action from this candidate or their intended recipient (if there is one) in order to proceed. Some reasons include the need for weight loss, smoking cessation, intended recipient referral, or other **potential living donor candidates** to be assessed first. A given **potential living donor candidate** may have multiple holds dates (or reasons for the hold) in their evaluation.

### Hold end date

This measure is only completed for candidates who were given a **hold start date**. This is the date that the reason the **potential living donor candidates'** evaluation was placed on hold is no longer valid (e.g., weight reduced, smoking reduced, intended recipient has been assessed by the transplant team, etc.) and the evaluation will resume.

As per comments, definition was revised. These were discussed with the Working Group.

#### Potential pre-emptive living kidney donor transplant

All of the following must be true:

- the **donation date**, **declined date**, **withdrawal date**, or **lost to follow-up date** [described below] is not before the date the intended recipient starts dialysis (these are not “potential” pre-emptive living kidney donor transplants).
- intended recipient is free from dialysis for a **reasonable amount of time** after the **decision to start testing date** or the date the intended recipient is approved for transplant, whichever occurs later. This is necessary to ensure the **potential living donor candidate** has enough time to complete a thorough evaluation.
- intended recipient starts dialysis after a **reasonable amount of time** after the **decision to start testing date** or the date the intended recipient is approved for transplant, whichever occurs later. If the intended recipient never starts dialysis then transplant may never be required (not relevant for quality improvement).
- the intended recipient has a **potential living donor candidate** (e.g. not an anonymous donor).
- the potential living donor candidate ultimately donates.

Definitions that were proposed during the revision of the definition above. These were discussed with the Working Group.

#### Reasonable amount of time [to complete the evaluation if the goal is a pre-emptive transplant]

The minimum time to complete the living donor evaluation if the goal is a pre-emptive transplant

*\*Note:* This proposed definition arose while revising the definition for “potential pre-emptive living kidney donor transplant”. After discussing this with the Working Group, consensus was that this could not be defined at the present time and is therefore left to the discretion of the measurer.

#### Reasonably long period of time [to be considered lost to follow-up]

The minimum time of absence (e.g. no contact) between the **potential living donor candidate** and the evaluation team is X months

*\*Note:* This proposed definition arose while revising the definition for “lost to follow-up date”, as this was necessary to measure the potential pre-emptive transplant. After discussing this with the Working Group, consensus was that this could not be defined at the present time and is therefore left to the discretion of the measurer.

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Any **bolded text** refers to a definition of a key term

## Appendix 6: Final process indicators

**Process indicators with consensus, high rating, and minimal (or no) changes to the definition. These were not discussed with the Working Group.**

### **Time until donation (B-Z)<sup>a</sup>**

This is the time from **decision to start testing date** until the donation date (donors only)

### **Total evaluation time (B-F)**

The time from **decision to start testing date** until **evaluation end date**.

### **Time until first diagnostic test is performed (B-D<sub>n</sub>)**

This is the time from **decision to start testing date** until a given diagnostic test is performed. There will be multiple of these (i.e., time until first ultrasound, first chest x-ray, first electrocardiogram, first CT angiogram, etc.)

### **Time to consultation (B-E<sub>n</sub>)**

This is the time from **decision to start testing date** until a given consultation is performed (i.e., time until nephrology consult, time until surgery consult, time until social work consult, etc.). The time to consultation with each specialist will be a separate process indicator. If there are multiple consults with a given specialist, only the first consultation will be counted.

### **Time to initial compatibility (crossmatch) test (B-C)**

To determine whether the donor and recipient tissues are compatible, donor and recipient samples are mixed. This is the time from **decision to start testing date** until the **potential living donor candidates'** blood sample is drawn for the initial crossmatch. This is *not* the time the cross-match is performed.

### **Time from first contact date until recipient referral (A-R<sub>2</sub>)**

This is the time between the **first contact date** and the date the transplant centre received a referral for the intended recipient for evaluation. Sometimes the **potential living donor candidate** comes forward before the intended recipient has even been considered for transplantation. If this happens, the candidates' evaluation process is often placed on hold until the transplant program confirms they have received a referral for the intended recipient to begin their evaluation. If the intended recipient was referred before the **potential living donor candidate's first contact date**, then the value for this measure would be negative.

### **Time until recipient referral received by donor evaluation team (R<sub>2</sub>-R<sub>1</sub>)**

This is the time from when the dialysis centre or clinic sends the recipient referral package to the transplant centre's recipient team until the living donor program is notified by the recipient team that they have received the package.

*\*Note:* this should be measured regardless of whether or not the potential recipient has a living donor candidate

**Process indicators with comments or rating scores suggesting lower strength for agreement. These were discussed with the Working Group.**

### **Time until first blood or urine test (B-D<sub>n</sub>)**

This is the time from **decision to start testing date** until the next blood or urine test was completed by the donor candidate. Blood or urine tests completed before the **decision to start testing date** are not included.

*\*Note:* this was brought to the Working Group to decide whether or not to retain this metric.

### Time until first 24-hour urine test (B-D<sub>n</sub>)

This measure is only available / completed for programs that require at least one 24-hour urine test as part of the **potential living donor candidate** evaluation. This is the time from **decision to start testing date** until the first 24-hour urine test. It is only provided for candidates who complete at least one 24-hour urine test for creatinine clearance as part of their evaluation.

*\*Note:* this was brought to the Working Group to decide whether or not to retain this metric.

### Time from CT until evaluation end (D<sub>n</sub>-F, where D<sub>n</sub> is the CT)

This is the time from the date the CT angiogram was completed until the **evaluation end date**. **Evaluation end date** must occur after the CT angiogram date.

*\*Note:* this was brought to the Working Group to clarify that the denominator would exclude candidates who were lost to follow-up (presumed rare at this stage) or withdrew from the evaluation because this wait-time would be influenced by candidate-driven factors.

## Process indicators that were revised and discussed with Working Group

### Time until *potential* initial compatibility (crossmatch) test (B-R3)

Time from **decision to start testing date** until date the first recipient serum is prepared (drawn, frozen) for crossmatching

*\*Note:* this was brought to the Working Group to clarify the wording of the description. Through this discussion additional metrics emerged relating to the initial crossmatch test (below)

## Process indicators that were added and discussed with the Working Group

### Time from initial crossmatch until results received

This is the time from the **initial crossmatch date** until the results of this test are received. This was broken down into 3 separate indicators according to who received the results:

1. By the donor candidate
2. By the living donor coordinators
3. By the transplant coordinator

### Time from approval until operating room (OR) booking (F-G)

This is the time from the last **approval date** until the OR was booked.

*\*Note:* if the OR is rescheduled this is still the date the OR was booked the first time.

*\*Example:* I put in the request to book the OR on Jan 15th, where the surgical date will take place Feb 20th. The date the OR was booked is Jan 15th.

### Time from approval until donation (G-Z)

This is the time from the last **approval date** until donation (donors only).

### Diagnostic testing done on the same visit

What proportion of candidates who completed the following tests, did so on the same day (e.g. during the same visit):

- Consultation with psychosocial specialist
- Nuclear GFR (if required)
- Consultation with nephrologist
- CT angiogram
- Consultation with a surgeon/urologist

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*\*Note:* the list of tests above can change over time, or multiple metrics can be reported to accommodate differences in protocols between transplant centres.

*\*Note:* This indicator aligns with the desire to conduct same-day testing. No additional data collection is needed since each is measured above as “Time until first diagnostic test is performed (B-D<sub>n</sub>)”

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## Process indicators that were removed, as per participant comments.

### Time until testing start

This is the time from first contact until testing start.

Belief is that this is highly candidate-driven and not easily improved. It is also difficult to determine the testing start date. The added effort to collect this date with the little gain makes this indicator not worth the effort.

*\*\*Note:* This can be replaced by the time from **first contact date** until **decision to start testing date** with no additional data collection.

### Time to review the medical-social questionnaire within the program

This is the time from when the medical-social questionnaire is received by the program until it is reviewed (internally) by the program. This includes any time the program takes to clarify responses or complete missing responses with the candidate.

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Any **bolded text** refers to a definition

CT – computed tomography; GFR – glomerular filtration rate

<sup>a</sup> include hold period in estimation [median 8 (7, 9)]



## Appendix 7: Final outcome indicators

**Outcome indicators with consensus, high rating, and minimal (or no) changes to the definition. These were not discussed with the Working Group.**

### **Total healthcare cost of the living donor candidates' evaluation**

The total cost of the living donor evaluation may be higher if the evaluation was longer (i.e., repeated testing), more tests were being performed, or if a centre schedules tests in a certain way. This indicator is the total cost of the **potential living donor candidate's** evaluation to the healthcare system (regardless of donation). This indicator does not count any costs to the recipient's care (i.e. if a shorter evaluation time resulted in savings from averted dialysis).

*\*Note:* can easily restrict this to donors and non-donors without additional data collection

### **The number of visits to the transplant centre**

This is the number of times the **potential living donor candidate** is required to come to the hospital to complete testing

### **Annual number of living donor kidney transplants**

A kidney transplant occurring from a living donor every calendar year (January through December).

### **Annual number of pre-emptive living donor kidney transplants**

A pre-emptive transplant is one that occurs before the recipient starts dialysis. This is the number every calendar year.

*\*Note:* this measure would also require a yes/no indicator for having a prior transplant:

- NO if the recipient is a first-time kidney transplant
- YES if the recipient is currently living with a failing kidney from a prior transplant.

### **Annual number of living donor kidney transplants done in the first year of dialysis**

In most regions, it is very unlikely an intended recipient would receive a deceased donor kidney in their first year on dialysis.

### **Annual number of potential pre-emptive transplants lost<sup>a</sup>**

This is the number of potential pre-emptive living kidney donor transplant.

Under the lower-limit scenario, restrict only to **potential living donor candidates** who ultimately donated. Under the upper limit scenario, restrict to **potential living donor candidates** who donated, were declined, or withdrew (the reason for decline or withdrawal may be due to the fact that the recipient started dialysis).

### **Annual number of deaths of the intended recipient (instead of living donor transplant)<sup>b</sup>**

This is the number of times the intended recipient died before receiving a transplant despite having a living donor candidate whose evaluation was at least a **reasonable amount of time** and was still being evaluated at the time the recipient was transplanted (e.g. **decline date** or **withdrawal date** did not precede the date the recipient died).

*\*Note:* This is irrespective of whether or not the deceased donor graft failed and the donor candidate resumed the evaluation.

### **Annual number of deceased donor transplants received by the intended recipient (instead of living donor transplants)<sup>c</sup>**

This is the number of times the intended recipient received a deceased donor transplant before receiving a transplant despite having a living donor candidate whose evaluation was at least a **reasonable amount of time** and was still being evaluated at the time the recipient died (e.g. **decline date** or **withdrawal date** did not precede the date the recipient died).

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*\*Note:* This is irrespective of whether the donor candidate is/was approved for donation or not, as they may not have had their tests completed. We also do not know if the intended recipient was referred for transplant evaluation, or was eligible to receive a transplant when the donor candidate contacted the program.

#### **Annual number the intended recipient was rendered ineligible (instead of living donor transplants)<sup>d</sup>**

This is the number of times the intended recipient developed a new event that made them no longer eligible for transplant, despite having a **potential living donor candidate** whose evaluation was at least a **reasonable amount of time** and was still being evaluated at the time the recipient became ineligible (e.g. **decline date** or **withdrawal date** did not precede the date the recipient died).

*\*Note:* if the cause of the recipient's ineligibility directly precipitated in the recipient's death, then this is considered an intended recipient's death before transplant (defined above) rather than recipient ineligibility.

#### **Outcome indicators that were removed as per discussion with Working Group**

##### **The number of times a medical test is repeated**

This is restricted to tests that are only usually measured once during a **potential living donor candidate's** evaluation (i.e., nuclear GFR, split renal function, CT scan, renal ultrasound). A test may be repeated because the results were inconclusive, unreliable, abnormal, or out-of-date. This indicator documents the number of times (and reasons) this occurred for each given repeated test.

The reason to omit is because this is difficult to operationalize. Usually repeated tests are done because they're necessary. Restricting this to situations where a more efficient healthcare system could have avoided these repetitions (e.g. the quality of the scan was poor, contrast agent was used incorrectly, the transplant centre cannot obtain the original image performed elsewhere, etc.) is unlikely to result in efficiency gains because these occurrences are uncommon. The reason for the repeat would also to be collected as well.

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Any **bolded text** refers to a definition;

CKD – chronic kidney disease; eGFR – estimated glomerular filtration rate; CT – computed tomography

<sup>a</sup> the date the intended recipient started dialysis should also be documented [median 8 (7, 9), agreement]

<sup>b</sup> the date the intended recipient died should also be documented [median 8 (7, 9) agreement]

<sup>c</sup> the date the intended recipient received the deceased donor transplant should also be documented [median 8 (7, 9) agreement]

<sup>d</sup> if during the donor's evaluation, the process was put on hold, that should be recorded at the time of the evaluation end (as a simple yes/no), along with the reason(s) for being put on hold [median 8 (6, 9) disagreement]