

Transplant Candidate Patient Interview Guide

Question Guide, Version 2.0

1. Interviewer Name	
2. Participant ID#	
3. Interview Date (mm/dd/yyyy)	_ _ _ / _ _ _ / _ _ _ _ _ _
4. Participant agrees for interview to be audio recorded	Yes..... <input type="checkbox"/> No <input type="checkbox"/>
5. Time Interview Began (hh:mm)	_ _ _ : _ _ _
6. Time Interview Ended (hh:mm)	_ _ _ : _ _ _

Step 1: Complete Q1-3 above before the interview.

Step 2: Introduce yourself at the beginning of the interview. Thank the participant for taking part in the interview.

Step 3: Read “information about the study” below to the participant.

Step 4: Ask for participant permission to record interview; tick appropriate box in Q4 above.

Step 5: Turn on audio recorder if acceptable. Document the time the interview begins in Q5 above. Conduct the interview.

Step 6: At the end of the interview, thank the participant and ask if she/he has any further questions. Document the time the interview ended in Q6 above.

Step 7: Provide reimbursement and document appropriately.

Step 8: Ask if acceptable to receive a summary of the interview results. If so, document response and record preferred contact information (e-mail address or mail address) separate from the interview notes.

I. Information about the study

As you know, the wait-list for kidney transplantation is very long. Nearly 20% of donated kidneys are not transplanted and discarded. Many of these discarded kidneys might be usable for transplantation in an appropriate patient. Little is known about how transplant patients make decisions about accepting kidneys. The purpose of our interview is to learn about how you have decided or how you would decide whether to accept an offered kidney. There are no right or wrong answers to the questions I will ask, and if you do not know the answer to every question, that is ok. We just want to know your honest thoughts and opinions.

ABOUT YOUR TRANSPLANT EXPERIENCE

A1. What year/month were you put on the waitlist for a kidney transplant?

A2. Are you on dialysis?

A3. If yes: How long have you been on dialysis?

Objective 1 – Characterize transplant recipients' kidney acceptance decision process

The goal of the first set of questions is to learn more about your decision-making process to accept a kidney.

1. In your opinion, what is a successful kidney transplant?
2. What information about kidney quality did the transplant team give you when you were waitlisted?

Probe: How about at interval clinic?

Probe: Have you ever heard the term kidney donor profile index or KDPI?

Probe: (if yes) What is your understanding of KDPI?

Probe: What is a good KDPI number? What is a bad KDPI number?

3. When you were waitlisted did your transplant team ever talk to you about the option of accepting a kidney that was of lower quality (KDPI>85)?
 Yes → Continue with next questions:
 No
 Don't remember

Probe: What makes a kidney lower quality?

Probe: What did your transplant team say about lower quality (high KDPI) kidneys¹?

¹ Use term patient is familiar with- KDPI if they know it, low vs high quality if they don't.

Probe: What could happen if you accepted a lower quality kidney (high KDPI) kidney?

Probe: What did they tell you about your chances of being transplanted if you accepted a lower quality kidney?

4. Did you consent to receive offers of lower quality (high KDPI) kidneys?

Probe: (If yes) What motivated you to consider accepting these kidneys?

5. Have you received any kidney offers?

Yes

No (If No skip to 7)

6. Have you turned down a kidney that was offered to you?

Yes → If YES, all Probes

No → If No, probe kidney information

If YES:

Probe: What information about the kidney did you get when they called you with the offer?

Probe: What motivated you to turn it down?

Probe: What were the advantages of turning it down?

Probe: What were the disadvantages of turning it down?

Objective 3 – Characterize patients' perceptions of waiting on dialysis verses receiving a kidney of certain quality

The next questions are about your perceptions of the trade-offs about receiving a lower quality kidney or staying on the waiting list longer.

7. Which treatment for kidney disease helps patients to live longer?

Transplant

Dialysis

Patients live just as long on either treatment

8. Kidney transplant and dialysis both have risks. What are the risks of staying on dialysis instead of getting a transplant?

9. What are the risks of getting a transplant instead of continuing on dialysis?

10. In your experience, what makes waiting for a kidney challenging?

Next I'm going to ask you to think about what you would do in a couple of hypothetical scenarios. Before we start, I'm going to go review a little bit of information about KDPI with you. If you have questions just let me know. Go over information script about average graft survival by KDPI, sleepy kidney, kidneys that never function completely, and transplant vs dialysis.

11. Scenario: Imagine that you have been on the wait-list for 3 years. You are offered a kidney with KDPI >85. It is going to take 2 more years before an average kidney became available. If you waited for 2 more years for a kidney, your chances of dying would increase because you would still be on dialysis. If you accepted the kidney with, then your chances of dying would decrease because you would no longer be on dialysis.

Probe: How would you decide what to do?

Probe: What information would help you make a decision?

12. Imagine that you were offered a high quality kidney that was expected to last for about 11 years. Your transplant team has recommended that you accept the kidney. What, if any, additional information would you need to make a decision about accepting this kidney?

13. Imagine that you were offered a lower quality kidney that was expected to last for about 5 years. Your transplant team has recommended that you accept this kidney. What, if any, additional information would you need to make a decision about accepting this kidney?

14. Northwestern University has developed a computer program to help patients like you make decisions about whether to accept kidney offers of varying quality. You can enter information about the donor as well as your own health information. The program then predicts your health outcomes if you accept the kidney, and compares this with the predicted outcomes if you decline the kidney.

Would you be willing to use this program?

Probe What would make you willing to use it?

Probe: What information would you like it to provide? (eg what health outcomes would you like it to predict?)

Probe: Currently the program focuses on predicting how long a patient will live. What other outcomes would you like to see?

Probe: (if quality of life) What does quality of life mean to you?

15. What, if anything, else do you think is important for us to know about your experiences with decision making about accepting a kidney offer?

ABOUT YOU

B1. What is your gender?

- Female
- Male
- Nonbinary

B2. What is your age?

B3. What is your marital status?

- Single / never married
- Married / living as married
- Divorced or separated
- Widowed / surviving partner
- Other

ABOUT YOU

B4. Which of the following racial groups best describes you?

- White
- African American or Black
- Asian
- American Indian or Alaskan Native
- Native Hawaiian or Other Pacific Islander
- Mixed or Multiple Races
- Other

B5. Which of the following describes your ethnicity?

- Hispanic or Latino
- Not Hispanic or Latino

ABOUT YOU

B6. What is the highest level of education you have completed?

- Less than high school
- Some high school
- High school or equivalent (e.g., GED)
- Some college but no degree
- Technical school
- Associate's degree (2-year college degree)
- 4-year college degree (e.g., BA, BS)
- Some graduate school but no degree
- Graduate or professional degree (e.g., MBA, MS, MD, PhD)

B7. Which of the following best describes your employment status?

- Employed full-time (40 or more hours per week)
- Employed part-time (less than 40 hours per week)
- Self-employed
- Homemaker
- Student
- Retired
- Disabled/Unable to work
- Unemployed but looking for work
- Unemployed and not looking for work

B7. Which of the following is your primary type of health insurance?

- Medicare
- Medicaid
- Private
- Other _____

That's the end of the questions that we have for you today.

I want to thank you for your time and for the helpful information that you provided.

Transplant Recipient Patient Interview Guide

Question Guide, Version 2.0

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2. Participant ID#	
3. Interview Date (mm/dd/yyyy)	_ _ _ / _ _ _ / _ _ _ _ _ _
4. Participant agrees for interview to be audio recorded	Yes..... <input type="checkbox"/> No <input type="checkbox"/>
5. Time Interview Began (hh:mm)	_ _ _ : _ _ _
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Step 1: Complete Q1-3 above before the interview.

Step 2: Introduce yourself at the beginning of the interview. Thank the participant for taking part in the interview.

Step 3: Read “information about the study” below to the participant.

Step 4: Ask for participant permission to record interview; tick appropriate box in Q4 above.

Step 5: Turn on audio recorder if acceptable. Document the time the interview begins in Q5 above. Conduct the interview.

Step 6: At the end of the interview, thank the participant and ask if she/he has any further questions. Document the time the interview ended in Q6 above.

Step 7: Provide reimbursement and document appropriately.

Step 8: Ask if acceptable to receive a summary of the interview results. If so, document response and record preferred contact information (e-mail address or mail address) separate from the interview notes.

I. Information about the study

As you know, the wait-list for kidney transplantation is very long. Nearly 20% of donated kidneys are not transplanted and discarded. Many of these discarded kidneys might be usable for transplantation in an appropriate patient. Little is known about how transplant patients make decisions about accepting kidneys. The purpose of our interview is to learn about how you have decided or how you would decide to accept an offered kidney. There are no right or wrong answers to the questions I will ask, and if you do not know the answer to every question, that is ok. We just want to know your honest thoughts and opinions.

ABOUT YOUR TRANSPLANT EXPERIENCE

- A1. What year/month did you receive your transplant?
- A2. How long did you wait for your transplant from the time of listing?
- A3. How long were you on dialysis before receiving a transplant?

Objective 1 – Characterize transplant recipients' kidney acceptance decision process and understanding of post-transplant complications

The goal of the first set of questions is to learn more about your decision-making process to accept a kidney.

1. In your opinion, what is a kidney successful transplant?
2. What information about kidney quality did the transplant team give you when you were waitlisted?

Probe: How about at interval clinic?

Probe: Have you ever heard the term kidney donor profile index or KDPI?

Probe: (if yes) What is your understanding of KDPI?

Probe: What is a good KDPI number? What is a bad KDPI number?

3. When you were waitlisted did your transplant team ever talk to you about the option of accepting a kidney that was of lower quality (KDPI>85)?
 Yes → Continue with next questions:
 No

Probe: What makes a kidney lower quality?

Probe: What did your transplant team say about low quality kidneys (high KDPI)?

Probe: What could happen if you got a low quality kidney (high KDPI)?

Probe: What did they tell you about your chances of being transplanted if you accepted a lower quality kidney?

4. Did you consent to receive offers of lower quality (high KDPI) kidneys?
(If yes) What motivated you to consider accepting these (high KDPI) kidneys?
5. What information about your kidney did they provide when they called you about the offer?

Probe: What information did they provide about the donor?
Probe: What was the KDPI?
Probe: (if known) What did you think about your kidney's KDPI?

6. How did you decide to accept the kidney that you received?

Probe: What information was most important in making this decision?

Probe: Who did you speak with from the transplant team to help you make the decision?

7. Have you ever previously turned down a kidney that was offered to you?

Yes → If YES, go to Question 3a
 No → If YES, go to Question 3d.

If YES:

- 3a. Probe: What motivated you to turn it down?
3b. Probe: What were the advantages of turning it down?
3c. Probe: What were the disadvantages of turning it down?

If NO:

- 3d. Probe: Would you have accepted any kidney offer?
3e. Probe: What would have made you turn down a kidney offer?

Objective 3 – Characterize patients' understanding of waiting time benefits/consequences of receiving a kidney of certain quality
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The next questions are about your perceptions of the trade-offs about receiving a lower quality kidney or staying on the waiting list longer.

8. Which treatment for kidney disease helps patients to live longer?

Transplant
 Dialysis

___ Patients live just as long on either treatment

9. What are the risks of staying on dialysis instead of getting a transplant?
10. What are the risks of getting a transplant instead of continuing on dialysis?
11. In your experience, what made waiting for a kidney challenging?

Next I'm going to ask you to think about what you would do in a couple of hypothetical scenarios. Before we start, I'm going to go review a little bit of information about KDPI with you. If you have questions just let me know. Go over information script about average graft survival by KDPI, sleepy kidney, kidneys that never function completely, and transplant vs dialysis.

12. Scenario: Imagine that you have been on the wait-list for 3 years. You are offered a kidney with KDPI >85. It is going to take 2 more years before an average kidney became available. If you waited for 2 more years for a kidney, your chances of dying would increase because you would still be on dialysis. If you accepted the kidney, then your chances of dying would decrease because you would no longer be on dialysis.

Probe: How would you decide what to do?

Probe: What information would help you make a decision?

13. Imagine that you were offered a high quality kidney that was expected to last for about 11 years. Your transplant team has recommended that you accept the kidney. What, if any, additional information would you need to make a decision about accepting this kidney?
14. Imagine that you were offered a lower quality kidney that was expected to last for about 5 years. Your transplant team has recommended that you accept this kidney. What, if any, additional information would you need to make a decision about accepting this kidney?

15. Northwestern University has developed a computer program to help patients like you make decisions about whether to accept kidney offers of varying quality. You can enter information about the donor as well as your own health information. The program then predicts your health outcomes if you accept the kidney, and compares this with the predicted outcomes if you decline the kidney.

Would you be willing to use this program?

Probe: What would make you willing to use it?

Probe: What information would you like it to provide? (eg what health outcomes would you like it to predict?)

Probe: Currently the program focuses on predicting how long a patient will live. What other outcomes would you like to see?

Probe: (if quality of life) What does quality of life mean to you?

16. What, if anything, else do you think is important for us to know about your experiences with decision making about accepting a kidney offer?

ABOUT YOU

B1. What is your gender?

- Female
- Male
- Nonbinary

B2. How old are you?

B3. What is your marital status?

- Single / never married
- Married / living as married
- Divorced or separated
- Widowed / surviving partner
- Other

ABOUT YOU

B4. Which of the following racial groups best describes you?

(Select all that apply)

- White
- African American or Black
- Asian
- American Indian or Alaskan Native
- Native Hawaiian or Other Pacific Islander
- Mixed or Multiple Races
- Other

B5. Which of the following describes your ethnicity?

(Click only one answer.)

- Hispanic or Latino
- Not Hispanic or Latino

ABOUT YOU

B6. What is the highest level of education you have completed?

(Click only one answer.)

- Less than high school
- Some high school
- High school or equivalent (e.g., GED)
- Some college but no degree
- Technical school
- Associate's degree (2-year college degree)
- 4-year college degree (e.g., BA, BS)
- Some graduate school but no degree
- Graduate or professional degree (e.g., MBA, MS, MD, PhD)

B7. Which of the following best describes your employment status?

(Click only one answer.)

- Employed full-time (40 or more hours per week)
- Employed part-time (less than 40 hours per week)
- Self-employed
- Homemaker
- Student
- Retired
- Disabled/Unable to work
- Unemployed but looking for work
- Unemployed and not looking for work

B7. Which of the following is your primary type of health insurance?

- Medicare
- Medicaid
- Private
- Other _____

That's the end of the questions that we have for you today.

I want to thank you for your time and for the helpful information that you provided.

Transplant Nurse Coordinator Interview Guide

Question Guide, Version 2.0

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2. Participant ID#	
3. Interview Date (mm/dd/yyyy)	_ _ _ / _ _ _ / _ _ _ _ _ _
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Step 7: Provide reimbursement and document appropriately.

Step 8: Ask if acceptable to receive a summary of the interview results. If so, document response and record preferred contact information (e-mail address or mail address) separate from the interview notes.

I. Information about the study

As you know, the waitlist for kidney transplantation is very long. Nearly 20% of donated kidneys are not transplanted and get discarded. Many of these discarded kidneys might be usable for transplantation in an appropriate patient.

The purpose of our interview is to learn your opinions about how and why kidneys get discarded. There are no right or wrong answers. If there are any questions you don't know the answer to or that are not applicable to your role just let me know.

ABOUT YOUR TRANSPLANT EXPERIENCE

A1. What's your role?

A1b. How long have you been working in this role?

A2. What was your transplant center (kidney) volume in 2019?

0-49

50-99

100-199

200+

1. In your opinion, what is a successful kidney transplant?

2. How does your center manage your waitlisted patients?

Probe: How do you determine when to start requesting blood samples from patients waitlisted at your center?

Probe: How, if at all, does your transplant program facilitate the collection of samples?

Probe: How, if at all, does cost affect waitlist management?

3. How do you educate your patients about kidney quality?

Probe: What information do you provide them before they start getting offers?

4. When patients are waitlisted, do members of the transplant team tell patients that they might wait less time if they accepted a KDPI >85 kidney?

Yes → If YES, go to Question 12a.
 No → If NO, go to Question 12b.

Probe: What do you tell them about their waiting time?

5. Could you describe the process for contacting patients on the match run?

6. What information do you provide to patients when an organ offer is made?

7. How do you know when to code out for a kidney offer?

Probe: What is the role of KDPI in this decision?

8. Does your center use virtual cross-matching?

5a. (If yes) How does your center use virtual cross-matching?

Probe: When, if at all, does your center use only the virtual cross-match to accept kidneys for transplant?

Only ask 9 if they are also involved in the coordination of post-transplant care:

9. How is post-transplant care managed for the patients transplanted at your center?

Probe: In your experience, how do post-transplant care needs differ for patients who received high KDPI kidneys vs patients who got average kidneys?

Probe: How do you manage care for patients with delayed graft function?

10. In your experience, what, if any, role do your center's outcomes play in decisions about which kidneys to transplant?

11. What strategies does your center have in place to increase the transplantation of high KDPI kidneys?

Probe: Does your transplant center maintain a list of patients considered appropriate for transplanting high KDPI kidneys?

(If yes) How does your center decide which candidates are appropriate for a high KDPI kidney?

Probe: What additional strategies do you think could help to increase the transplantation of high KDPI kidneys at your center?

12. In your experience, what factors usually lead to your center turning down a kidney offer?

Probe: Could you give me an example of a kidney offer that your center turned down?

13. In your experience, what are the benefits of transplanting more high KDPI kidneys?

14. What are the risks of transplanting more high KDPI kidneys?

15. In your opinion, what should be done to reduce kidney discard at the national level?

Probe: What national policies could help to reduce discard?

16. Is there anything else you'd like to share about your experiences with your transplant center's decision making about accepting high KDPI kidneys?

17. What, if any, additional factors should we consider when studying policy solutions to reduce kidney discard?

ABOUT YOU

B1. What is your gender?

- Female
- Male
- Nonbinary

B2. Which of the following racial groups best describes you?

(Select all that apply)

- White
- African American or Black
- Asian
- American Indian or Alaskan Native
- Native Hawaiian or Other Pacific Islander
- Mixed or Multiple Races
- Other

B3. Which of the following describes your ethnicity?

(Click only one answer.)

- Hispanic or Latino
- Not Hispanic or Latino

That's the end of the questions that we have for you today.

I want to thank you for your time and for the helpful information that you provided.

Transplant Physician Interview Guide

Question Guide, Version 2.0

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2. Participant ID#	
3. Interview Date (mm/dd/yyyy)	_ _ _ / _ _ _ / _ _ _ _ _ _
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Step 5: Turn on audio recorder if acceptable. Document the time the interview begins in Q5 above. Conduct the interview.

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Step 7: Provide reimbursement and document appropriately.

Step 8: Ask if acceptable to receive a summary of the interview results. If so, document response and record preferred contact information (e-mail address or mail address) separate from the interview notes.

I. Information about the study

As you know, the waitlist for kidney transplantation is very long. Nearly 20% of donated kidneys are not transplanted and get discarded. Many of these discarded kidneys might be usable for transplantation in an appropriate patient.

The purpose of our interview is to learn about how you make decisions about what kidneys you would transplant. There are no right or wrong answers to the questions I will ask, and if you do not know the answer to every question, that is ok. We just want to know your honest thoughts and opinions.

The goal of the first set of questions is to learn more about your decision-making process to accept a kidney for a particular patient.

1. Are you a transplant nephrologist or a transplant surgeon?

2. How many years have you been a transplant nephrologist or transplant surgeon?

3. What was your transplant center (kidney) volume in 2019?
 - 0-49
 - 50-99
 - 100-199
 - 200+

4. What is your role in making decisions about accepting primary organ offers?

5. In your opinion, what is a successful kidney transplant?

6. How do you decide if a patient is a candidate for kidney transplant?

Probe: When do you delist patients?
Probe: When do you make patients temporarily inactive?

7. How do you educate your patients about kidney quality?

Probe: What information do you provide them?
Probe: When is this information provided?

8. When patients are waitlisted, do members of the transplant team tell patients that they might wait less time if they accepted a KDPI >85 kidney?

___ Yes

___ No

4a. Probe: What does the transplant team tell patients about the waiting time?

9. What recipient characteristics do you consider when deciding whether or not someone is a good candidate for a KDPI >85 kidney?

Probe: In general, what types of patients do you think would benefit from KDPI >85 kidneys?

Probe: What types of patients would you not recommend accept KDPI >85 kidneys?

Probe: How do you consider the patient's preferences when deciding if they are a good candidate for a high KDPI kidney?

10. Are you involved in discussing organ offers with patients?

If Yes: What information do you provide to patients when an organ offer is made?

11. If Yes: What factors have influenced you to decline a kidney offer for your patient?

12. If Yes: What factors have caused patients of yours to turn down offers?

Probe: Could you give me an example of a kidney offer you thought was a good fit but your patient decided to decline?

The goal of this set of questions is to understand how you evaluate kidney quality in general.

Ask only if they make decisions about offers:

13. In what situations do you place a provisional yes for a kidney?

14. How do you know when to code out?

Probe: What is the role of KDPI in this decision?

Probe: What is the role of creatinine in this decision?

Probe: What about cold ischemia time?

15. How does your center use biopsy information when deciding whether or not to transplant a kidney?

Probe: In what situations do you rely on biopsy information the most?

Probe: In what situations is biopsy information not necessary?

16. What is the role of kidney pumping in your center's decision making about whether or not to transplant a kidney?

Probe: What is the role of pump parameters when making a decision about whether or not to transplant a kidney?

Probe: In what situations is it most important for a kidney to be on pump?

Probe: When is putting the kidney on pump not necessary?

The next questions are about practices and strategies to increase transplantation of high KDPI kidneys.

17. How, if at all, does the way transplant outcomes are evaluated affect decisions about what kidneys to transplant?

18. What strategies does your center have in place to increase the transplantation of high KDPI kidneys?

Probe: In addition to giving patients the option to consent for high KDPI kidney offers, does your transplant center maintain a list of patients considered most appropriate for transplanting high KDPI kidneys? (ie a target list)

(If yes) How does your center decide which candidates go on this list?

Probe: What additional strategies do you think could help to increase the transplantation of high KDPI kidneys at your center?

19. Imagine that a computer program is developed to help providers like yourself make decisions about whether to transplant kidneys. To use the program, you would enter information about the patient and the donor kidney, and the program statistically evaluates expected patient health outcomes if you transplant the kidney verses if you do not transplant the kidney.

Probe: Would you be willing to use this program

Probe: What would make you willing to use this program?

Probe: We've said broadly that this program will evaluate expected patient health outcomes. Currently, the program has the ability to predict patient survival with and without the transplant. What other outcomes would you want the program to predict? That is, what information would be most helpful to you in making a decision about whether to transplant?

20. In your opinion, what should be done to reduce kidney discard at the national level?

Probe: What national policies could help to reduce discard?

21. Is there anything else you'd like to share about your experiences with decision making about accepting high KDPI kidneys for transplant?

ABOUT YOU

B1. What is your gender?

- Female
- Male
- Nonbinary

B2. Which of the following racial groups best describes you?
(Select all that apply)

- White
- African American or Black
- Asian
- American Indian or Alaskan Native
- Native Hawaiian or Other Pacific Islander
- Mixed or Multiple Races
- Other

B3. Which of the following describes your ethnicity?
(Select only one answer.)

- Hispanic or Latino
- Not Hispanic or Latino

B4. What experience do you have in contributing to transplant policy-making?

- ___ Institution-level policy-making
- ___ work with SRTR
- ___ UNOS Committee participation
- ___ UNOS Regional Committees
- ___ AST/ASTS Committee / Workgroup participation
- National Other Committees: _____
- ___ No policy-making experience

That's the end of the questions that we have for you today.

I want to thank you for your time and for the helpful information that you provided.

Map of OPTN Regions

