

Supplementary File 1. Focus group run sheet

Time	Details	Notes
Phase 1 – Welcome and introductions, ice-breaker and objectives (10 minutes)		
15 mins	<p>Welcome</p> <p>Good [morning/afternoon] everyone. Thank you for attending this focus group to discuss your experiences and perspectives of living kidney donation. My name is _____ from the University of Sydney.</p> <p>Introduction</p> <p>We have invited you here because you have experience with living kidney donation. For this session, we would like you to reflect on your experiences after living kidney donation. This will help us to understand how donating a kidney has impacted on you, and what aspects of your experience may be more important, and those that may be less important to you. We want you to share insights from your own personal experiences and we encourage you to listen and consider other members' views, and engage in a conversation with each other.</p> <p>The goal of this session is to identify outcomes that are important to you, and to understand the reasons why they are important to you. We want future research to focus on outcomes that are most important to you, as well as information and support that is provided to donors.</p> <p>Confidentiality and voluntary participation</p> <p>What you tell us will be recorded but will be kept confidential. Nothing you say will be traced back to you or your name. Also, what you say will not impact the level or type of care you receive. Please note that we are unable to provide clinical advice about your health. You are free to leave at any time without providing a reason. We would also appreciate it if you could please keep this discussion confidential, to respect the other members in the group.</p> <p>Ice breaker</p> <p>To get to know you a bit better, could you introduce yourself by telling us:</p> <ol style="list-style-type: none"> Your name The first thing that comes to your mind when I say “kidney donor” 	
Phase 2 – Focus group discussion (30 minutes)		
30 mins	<p>Experiences/impact of living donation</p> <p>We would now like to invite you to share your ideas and experiences of donating a kidney:</p> <ul style="list-style-type: none"> • Has donating a kidney impacted on your life - in what ways? • Did anything happen to you after kidney donation that was unexpected? • What outcomes are most challenging to deal with - why and how do you cope with it? 	
Phase 3 – Nominal group Technique (Part 1) (40 minutes)		
40 mins	<p>Now we are going to have a more focused discussion and an activity to find out what outcomes of kidney donation matter to you most and why.</p> <p>Let me give you a bit of context. There are a variety of outcomes that might be experienced by kidney donors. That is, anything that arises or changes, directly as a result of donating a kidney, be it a positive or negative impact. There are research studies being conducted worldwide that are looking to determine the impacts of donating a kidney. For example, they might look at whether kidney donation impacts on the long-term kidney function of donors. We want to know what outcomes matter most to you, so that we can ensure that research focuses on those outcomes.</p> <p>I am going to ask you a question and get you to write down three ideas: <i>What outcomes do you suggest that researchers should include in their study, if they are</i></p>	

	<p><i>looking to explore the impact of donating a kidney?</i></p> <p>Please write down your 3 ideas now and then we will share them with each other.</p> <p>Now, I would like you to share your ideas. I am going to go around the table and ask each of you to give me one or two ideas from your worksheet. After the entire list is on the board, we will discuss and clarify the ideas.</p> <p>We are now going to include some outcomes [impacts] that other patients told us in the past, or outcomes that have been included in recent research studies. [write on whiteboard, read them out, and clarify]</p> <p>Are any of the outcomes unclear to anyone? If not, we will take a short break while we print out the list of outcomes. We will then rank these items from most important to least important.</p>	
<p>Break (10 minutes)</p>		
10 mins	<p>Break <i>Print list of outcomes for ranking.</i></p>	
<p>Phase 3 – Nominal group Technique (Part 2) (30 minutes)</p>		
30 mins	<p>Now we are going to look at all the ideas raised by the group and I will ask you to rank them in order of most important to least important to you. If you find it difficult to rank the whole list, please try to rank the top 20.</p> <p>Now we will have a discussion to discuss any similarities and differences in ranking. What did everyone put as: number 1, number 2, number 3, least important?</p> <p>Would anyone like to explain why they ranked (23) or how they made their decisions about ranking?</p> <p>Why do you think most people ranked (23) high/low?</p> <p>Why do you think there are differences in ranking of (23)?</p>	
<p>Wrap up (1 minute)</p>		
1 min	<p>Wrap up <i>Wrap up, acknowledgement.</i> <i>Thank you and closing remarks.</i></p>	

Supplemental Table 1: Individual ranking of all outcomes

Rank Position	Outcome	Importance score	N groups listing outcome	N donors ranking outcome	Rank position Australia	Importance score Australia	Rank position Canada	Importance score Canada
1	Kidney function	0.40	14	120	4	0.26	1	0.57
2	Time to recovery	0.27	14	115	2	0.34	5	0.19
3	Surgical complications	0.24	14	120	6	0.20	2	0.29
4	Impact on family	0.22	11	87	1	0.35	19	0.07
5	Donor-recipient relationship	0.21	14	112	3	0.27	8	0.15
6	Life satisfaction	0.18	13	102	7	0.17	4	0.20
7	Lifestyle restrictions	0.18	12	97	5	0.21	6	0.15
8	Kidney failure	0.14	10	81	19	0.07	3	0.22
9	Mortality/long-term survival	0.13	12	97	11	0.12	7	0.15
10	Acute pain/discomfort	0.12	12	99	9	0.15	16	0.10
11	Blood pressure	0.12	14	111	13	0.11	9	0.14
12	Physical function	0.12	9	83	8	0.16	18	0.08
13	Surgical mortality	0.11	13	101	12	0.12	14	0.10
14	Fatigue	0.11	12	94	18	0.08	10	0.14
15	Diabetes	0.10	13	107	15	0.09	11	0.12
16	Financial impact	0.10	14	107	10	0.13	20	0.07
17	Cardiovascular disease	0.20	14	112	14	0.09	13	0.10
18	Depression	0.09	12	94	16	0.09	15	0.10
19	Anxiety	0.09	13	91	17	0.09	17	0.09
20	Chronic pain/discomfort	0.08	11	84	22	0.06	12	0.11
21	Pregnancy	0.06	14	97	23	0.06	21	0.06
22	Weight	0.05	9	64	25	0.05	22	0.05
23	Caregiver responsibilities	0.05	3	27	21	0.09	23	0.03
24	Cholesterol	0.04	5	45	20	0.07	28	0.00
25	Fertility	0.03	7	58	24	0.06	-	-
26	Career impact	0.02	3	27	32	0.02	24	0.03
27	Insurance	0.02	4	35	26	0.04	-	-
28	Gout	0.02	5	43	27	0.03	-	-
29	Self-esteem/body image	0.02	3	24	28	0.03	-	-
30	Anemia	0.02	1	15	29	0.03	-	-
31	Bone issues	0.02	4	31	30	0.03	-	-
32	Intimacy/sex drive	0.01	2	19	31	0.02	-	-
33	Kidney stones	0.01	1	7	-	-	25	0.02
34	Urinary tract infection	0.01	1	7	-	-	26	0.01
35	Length of stay	0.01	1	8	-	-	27	0.01

Supplemental material is neither peer-reviewed nor thoroughly edited by CJASN. The authors alone are responsible for the accuracy and presentation of the material.

Supplemental Table 2. Location and number of participants in each nominal group

Group ID	City	Participants (n = 123)
1	Melbourne	7
2	Melbourne	9
3	Melbourne	9
4	Melbourne	10
5	Sydney	5
6	Sydney	10
7	Sydney	8
8	Sydney	9
9	Vancouver	12
10	Vancouver	9
11	Vancouver	11
12	Vancouver	9
13	Vancouver	9
14	Vancouver	6