Item S1. Research ethics boards for participating sites

University of British Columbia Children's and Women's Research Ethics Board, Vancouver, Canada.

Alberta Children's Hospital, The University of Calgary Research Ethics Board, Calgary, Canada.

Baylor College of Medicine, The Institutional Review Board for Baylor College of Medicine and Affiliated Hospital, Houston, United States.

The Children's Hospital at Westmead, The Sydney Children's Hospital Network Human Research Ethics Committee, Sydney, Australia.

The Royal Children's Hospital, The Melbourne Children's Campus Research Ethics and Governance, Melbourne, Australia.

Lady Cilento Hospital, The Children's Health Queensland Hospital and Health Service Research Governance, Brisbane, Australia.

Table S1. Child question guide/Runsheet

Welcome and introduction – 10 minutes
Hi everyone. Thanks for coming along today. My name is [facilitator name] from [city/country]. We will be talking about what it is like to live with kidney problems and what sorts of things you might deal with, and what kinds of things you would want to see improve for children and young people with kidney disease. We might hear different things from different people and that's ok. There is no right or wrong answer. To save me from writing down what we talk about, I will turn the tape recorder on. But only I will listen to this afterwards. It will not be given to anyone else. Everything you say here will be private. We will not tell anyone else, we will not tell the doctors. If there are things you don't want to talk about, that's ok. Just talk about the things you feel ok talking about. If you want to stop at any time or take a break you can do that and you don't need to let us know why. **Ice-breaker** To get to know each other, can you say: Your name and your favorite thing to do on the weekends?
Focus group – 30 minutes
We would first like to hear about what it is like for you to live with kidney problems • Can you tell us a little bit about your kidney problems (age of diagnosis, past and current treatment?) • What is it like to have kidney problems? • What are the hardest things about having kidney disease?
Nominal group exercise (part 1) – 40 minutes
Now that brings us to the main activity. We just heard about all the different ways that kidney disease impacts on your life. Now we will ask you what impacts are most important to you. To decide if a treatment is good for someone with kidney problems, a researcher will study it and look at the positive and negative effects of that treatment. For example, the medications, diet and type of dialysis you are using have been tested by researchers. We want to make sure that researchers are looking at all the things that matter to you. <u>Simpler version:</u> Think about the ways that kidney disease impacts you. If you could fix, change or make anything better for children with kidney disease, what would it be? Give examples based on outcomes raised in discussion already. Write down your ideas on the paper in front of you and then we'll go around and ask you for your ideas. Remember, there is no right or wrong idea. We'll create a list on the board of all your ideas and make sure everyone knows what they mean. We will also ask you why they are important to you. We will also add some outcomes from previous groups/outcomes researchers often include in their research and ask you whether you think they are important. Now we are going to print them out and ask you to decide how important they are to you.
Rating and ranking of outcomes – 30 minutes
Here is our list of our ideas. Next to these ideas are numbers 1 (means least important) to 9 (most important). Have a look at each "outcome" or idea then you can give each one a score by drawing a circle around the number. Now we want to make this list shorter. Here are five stickers. Can you put a sticker next to the five you think are the most important from this whole list? You can use your rating to help you choose your five votes. It looks like the top 10 ideas are XYZ. Why do you think that a lot of people put a sticker on these ideas? Are there any outcomes you are surprised didn't make it into the top ten? Now, rank the list of outcomes from 10 to 1, with 1 being the most important and 10 being the least important. What did everyone put down as their number 1 and 2? What is your least important outcome?
Close
Wrap up, acknowledgements. Thank you and closing remarks

Table S2. Parent question guide/Runsheet

Welcome and introduction – 10 minutes
Hi everyone. Thanks for coming along today. My name is [facilitator name] from [city/country]. We will be talking about your experience of caring for a child with CKD and what you think research in children with kidney disease should focus on. We have invited you here because you are caring for a child with chronic kidney disease. We would like you to reflect on both good experiences and challenges with caring for a child who has kidney disease. We want you to share insights from your own personal experiences and perspectives and we encourage you to listen and consider other members' views in an open and respectful way. The goal of this session is to identify outcomes you think are important for research involving children with chronic kidneys disease, and to understand the reasons for why they are important to you. To save me from writing everything down, I will record it but this will be kept confidential. Nothing you say will be traced back to you. Only the group data will be reported. Also, what you say will not impact the care your child receives. Please note that we cannot provide clinical advice. Participation is voluntary, you are free to leave at any time without providing a reason. **Ice-breaker** To get to know each other, can you say: Your name, the first thing that comes to mind when I say "research" and something nice that has happened to you in the past month.
Focus group – 30 minutes
First, we would like to hear about your experience caring for a child with kidney disease • How did you first find out that your child had kidney disease? How did you react/feel? • How has the kidney disease changed your life? Your child's life? • What is the most challenging thing about caring for a child with kidney disease? How do you deal with this?
Nominal group exercise (part 1) – 40 minutes
Let me start by giving you some background information. Most of the treatments your child receives have been tested in studies (or trials) to determine their impacts (or outcomes). For instance, most people receive a minimum of four hours of hemodialysis, three times per week because studies tell us that receiving less than that increases the risk of hospitalization. So, "hospitalization" was the outcome for this study. However, there are a variety of outcomes that might be important to people. So the goal of the session today is to find out from you, if there was a new treatment available to your child, what types of outcomes would be most important to you. A simple definition of an "outcome" is anything that arises/changes as a result of a health condition or treatment). Give examples based on outcomes raised in discussion already. Write down your ideas and then we'll go around and put them on the board. We'll make sure everyone knows what they mean. Remember, there is no right or wrong idea. We will also ask you why they are important to you. We will add outcomes from previous groups/outcomes researchers often include in their research and ask you whether you think they are important.
Rating and ranking of outcomes - 30 minutes
Here is our list of our ideas. Next to these ideas are numbers 1 (means least important) to 9 (most important). Have a look at each "outcome" or idea then you can give each one a score by drawing a circle around the number. Now we want to make this list shorter. Here are five stickers. Can you put a sticker next to the five you think are the most important from this whole list? You can use your rating to help you choose your five votes. It looks like the top 10 ideas are XYZ. Why do you think that a lot of people put a sticker on these ideas? Are there any outcomes you are surprised didn't make it into the top ten? Now, rank the list of outcomes from 10 to 1, with 1 being the most important and 10 being the least important. What did everyone put down as their number 1 and 2? What is your least important outcome?
Close
Wrap up, acknowledgements. Thank you and closing remarks

Table S3. Top ten outcomes for patients with chronic kidney disease by treatment stage

CKD 1-5 (n = 17)		Dialysis (n = 5)		Transplant (n = 12)	
Outcome	**Importance score (SE)[a]**	**Outcome**	**Importance score (SE)**	**Outcome**	**Importance score (SE)**
Survival	0.39 (0.10)	**Lifestyle restrictions**	0.39 (0.13)	Fatigue	0.33 (0.11)
Growth	0.26 (0.05)	Graft survival	0.33 (0.18)	Hospitalization	0.27 (0.05)
Physical activity/sports*	0.25 (0.08)	**Physical activity/sports**	0.33 (0.16)	Infection	0.22 (0.09)
Kidney function*	0.25 (0.10)	Fatigue	0.29 (0.16)	**Lifestyle restrictions**	0.21 (0.08)
Medication burden	0.19 (0.03)	Hospitalization	0.26 (0.19)	**Physical activity/sports**	0.19 (0.07)
Fluid and diet restrictions	0.15 (0.05)	Survival	0.19 (0.08)	**Social functioning**	0.16 (0.03)
Social functioning*	0.14 (0.04)	Sexual function	0.17 (0.09)	Growth	0.15 (0.05)
Lifestyle restrictions*	0.13 (0.04)	**Social functioning**	0.15 (0.03)	**Kidney function**	0.15 (0.08)
Fear of surgery	0.12 (0.07)	Medication burden	0.13 (0.04)	Graft survival	0.14 (0.05)
Cognition	0.12 (0.06)	**Kidney function**	0.12 (0.05)	Ability to travel	0.12 (0.04)

*Outcomes included in the top 10 across all groups

[a]SE, standard error

Table S4. Top ten outcomes for patients with chronic kidney disease by age

8-12 years (n = 10)		13-17 years (n = 20)		18-21 years (n = 4)	
Outcome	**Importance score (SE)[a]**	**Outcome**	**Importance score (SE)**	**Outcome**	**Importance score (SE)**
Kidney function	0.32 (0.08)	Physical activity/sport	0.32 (0.04)	**Fatigue**	0.46 (0.18)
Growth	0.31 (0.07)	**Survival**	0.24 (0.11)	Hospitalization	0.44 (0.23)
Survival*	0.28 (0.06)	**Fatigue**	0.19 (0.08)	Ability to travel	0.32 (0.17)
Lifestyle restrictions*	0.25 (0.10)	Social functioning	0.18 (0.07)	Medication burden	0.28 (0.10)
Cognition	0.22 (0.08)	**Lifestyle restrictions**	0.18 (0.05)	**Survival**	0.25 (0.26)
Fear of surgery	0.20 (0.10)	Infection	0.18 (0.08)	Physical activity/sport	0.25 (0.03)
Medication burden	0.17 (0.04)	Kidney function	0.17(0.04)	Graft survival	0.18 (0.08)
School performance	0.15 (0.06)	Growth	0.16 (0.07)	**Lifestyle restrictions**	0.16 (0.01)
Fatigue *	0.11 (0.02)	Graft survival	0.15 (0.07)	Diet and fluid restrictions	0.14 (0.02)
Social functioning	0.10 (0.02)	Hospitalization	0.14 (0.06)	Sexual function	0.13 (0.06)

*Outcomes included in top 10 across all groups

[a]SE, standard error

Table S5. Top ten outcomes for caregivers by child's treatment stage

CKD 1-5 (n = 25)		Dialysis (n = 13)		Transplant (n = 22)	
Outcome	**Importance score (SE)[a]**	**Outcome**	**Importance score (SE)**	**Outcome**	**Importance score (SE)**
Kidney function*	0.69 (0.06)	**Kidney function**	0.38 (0.23)	**Survival**	0.46 (0.09)
Anemia*	0.26 (0.06)	**Anemia**	0.26 (0.13)	Infection	0.43 (0.09)
Cardiovascular disease	0.20 (0.04)	**Growth**	0.25 (0.08)	**Kidney function**	0.40 (0.08)
Survival*	0.19 (0.05)	Impact on family	0.20 (0.08)	Financial impact	0.18 (0.03)
Growth*	0.17 (0.02)	**Survival**	0.19 (0.085	**Growth**	0.14 (0.02)
Hospitalization	0.13 (0.03)	Blood pressure	0.14 (0.03)	Impact on family	0.13 (0.02)
Vascular access	0.12 (0.01)	Financial impact	0.12 (0.03)	**Graft survival**	0.13 (0.05)
Graft survival*	0.12 (0.04)	Bladder problems	0.12 (0.08)	Blood pressure	0.12 (0.02)
Bladder problems	0.11 (0.02)	**Graft survival**	0.10 (0.05)	**Anemia**	0.10 (0.04)
Infection	0.11 (0.03)	Weight	0.10 (0.02)	Weight	0.07 (0.02)

*Outcomes included in the top 10 across all groups

[a]SE, standard error

Table S6. Top ten outcomes for caregivers by child's age

0-12 years (n = 25)		**13-17 years** (n = 31)		**18-21 years** (n = 4)	
Outcome	**Importance score (SE)[a]**	**Outcome**	**Importance score (SE)**	**Outcome**	**Importance score (SE)**
Kidney function*	0.46 (0.10)	**Kidney function**	0.57 (0.08)	**Anemia**	0.54 (0.32)
Infection	0.31 (0.06)	**Survival**	0.40 (0.10)	**Kidney function**	0.50 (0.33)
Growth	0.26 (0.04)	Infection	0.18 (0.03)	School performance	0.23 (0.10)
Financial impact*	0.19 (0.03)	**Anemia**	0.17 (0.09)	**Financial impact**	0.21 (0.14)
Anemia*	0.19 (0.08)	Graft survival	0.13 (0.05)	Vascular access	0.15 (0.07)
Survival*	0.17 (0.07)	Cardiovascular disease	0.12 (0.03)	Impact on family	0.15 (0.07)
Hospitalization	0.15 (0.05)	Growth	0.11 (0.02)	**Survival**	0.14 (0.05)
Impact on family	0.14 (0.04)	Bladder problems	0.10 (0.03)	Fatigue	0.13 (0.07)
Graft survival	0.11 (0.05)	**Financial impact**	0.09 (0.03)	Appetite/diet	0.12 (0.12)
Blood pressure	0.11 (0.02)	Blood pressure	0.08 (0.02)	Cardiovascular disease	0.12 (0.10)

*Outcomes included in the top 10 across all groups

[a]SE, standard error

Table S7: Individual ranking of all outcomes– patients by treatment

Rank Position	Outcome	Importance score	N groups listing outcome	N ranking outcome	Rank position CKD (n = 17)	Rank position dialysis (n = 5)	Rank position transplant (n = 12)
1	Survival	0.25	3	17	**1**	**6**	15
2	Physical activity/Sports	0.24	3	18	**3**	**3**	**5**
3	Fatigue	0.20	2	9	15	**4**	**1**
4	Lifestyle restrictions	0.20	2	15	**8**	**1**	**4**
5	Growth	0.20	3	14	**2**	13	**7**
6	Kidney function	0.19	2	5	**4**	**10**	**8**
7	Hospitalization	0.16	5	17	18	**5**	**2**
8	Social functioning	0.15	4	21	**7**	**8**	**6**
9	Medication burden	0.14	1	9	**5**	**9**	14
10	Infection	0.13	2	6	11	29	**3**
11	Graft survival	0.13	4	14	17	**3**	**9**
12	Diet/fluid restrictions	0.11	3	17	**6**	12	18
13	Cognition	0.10	3	11	**10**	15	12
14	Family impact	0.08	2	8	13	18	16
15	School performance	0.07	3	10	14	20	17
16	Anxiety/worry	0.07	3	12	20	14	11
17	Fear of surgery	0.06	1	2	**9**	29	33
18	Employment	0.05	2	9	21	11	20
19	Blood pressure	0.05	1	9	12	29	30
20	Ability to travel	0.05	1	6	34	17	**10**
21	Fertility	0.05	1	3	22	29	13
22	Sexual functioning	0.05	1	6	34	**7**	19
23	Cardiovascular	0.04	2	7	17	21	28
24	Blood tests	0.04	2	5	20	29	21
25	Mood	0.03	2	6	28	19	22
26	Surgical recovery time	0.03	1	3	30	16	23
27	Pain	0.02	2	5	24	29	24
28	Weight	0.02	3	5	23	29	25
29	Self esteem	0.02	2	5	25	22	30
30	Appearance	0.01	1	3	28	23	31
31	Breathlessness	0.01	1	3	31	29	27
32	Time off dialysis	0.01	1	3	32	29	26
33	Catheter problems	0.01	1	2	26	29	33
34	Itchiness	0.01	1	2	29	29	33

Top ten outcomes are shaded orange

Fifty-eight outcomes were identified by children across all groups. Using stickers, each group narrowed their list of outcomes down to the top ten outcomes. Across all child groups, thirty-four outcomes were ranked.

Outcomes with the same importance score have a tie rank

Table S8: Individual ranking of all outcomes – caregivers by child's treatment

Rank Position	Outcome	Importance score	N groups listing outcome	N ranking outcome	Rank position CKD (n = 25)	Rank position dialysis (n = 13)	Rank position transplant (n = 22)
1	Kidney function	0.53	7	55	**1**	**1**	**3**
2	Survival	0.28	6	41	**4**	**5**	**1**
3	Infection	0.22	4	30	**10**	11	**2**
4	Anemia	0.20	2	20	**2**	**2**	**9**
5	Growth	0.17	6	50	**5**	**3**	**5**
6	Financial impact	0.13	5	32	11	**7**	**4**
7	Cardiovascular	0.13	3	26	**3**	12	20
8	Graft survival	0.11	3	17	**8**	**9**	**7**
9	Family impact	0.10	4	26	19	**4**	**6**
10	Blood pressure	0.09	4	30	20	**6**	**8**
11	Bladder problems	0.09	3	29	**9**	**8**	22
12	Hospitalization	0.08	3	20	**6**	23	13
13	Vascular access	0.08	2	20	**7**	16	29
14	School performance	0.08	3	25	13	14	11
15	Pain	0.06	2	15	15	15	15
16	Weight	0.06	3	24	21	**10**	**10**
17	Fatigue	0.06	2	19	12	30	18
18	Anxiety/stress	0.05	2	14	17	18	12
19	Mood	0.05	2	20	14	19	30
20	Appetite	0.04	2	15	18	21	19
21	Gastrointestinal	0.03	1	10	26	17	21
22	Self-esteem	0.03	2	12	22	20	28
23	Physical activity/sports	0.03	2	14	27	30	14
24	Cognition	0.03	1	4	25	30	16
25	Skin	0.02	1	6	34	12	32
26	Social functioning	0.02	1	9	30	24	26
27	Potassium	0.02	1	6	23	22	34
28	Cancer	0.02	1	6	33	30	17
29	Developmental delays	0.02	1	8	28	30	24
30	Employment	0.02	1	5	29	30	25
31	Depression	0.01	1	5	24	30	33
32	Fertility	0.01	1	7	32	25	27
33	Travel	0.01	1	5	31	30	31

Top ten outcomes are shaded blue

Fifty-four outcomes were identified by caregivers across all groups. Using stickers, each group narrowed their list of outcomes down to the top ten outcomes. Across all caregiver groups, 33 outcomes were ranked.

Outcomes with the same importance score have a tie rank

Table S9: Individual ranking of outcomes– patients by age

Rank Position children overall	Outcome	Rank position age 8-12 (n = 10)	Rank position age 13-17 (n = 20)	Rank position age 18-21 (n = 4)
1	Survival	**3**	**2**	**5**
2	Physical activity/Sports	15	**1**	**6**
3	Fatigue	**9**	**3**	**1**
4	Lifestyle restrictions	**4**	**5**	**8**
5	Growth	**2**	**8**	13
6	Kidney function	**1**	**7**	25
7	Hospitalization	13	**10**	**2**
8	Social functioning	**10**	**4**	11
9	Medication burden	**7**	12	**4**
10	Infection	11	**6**	25
11	Graft survival	17	**9**	**7**
12	Diet/fluid restrictions	18	11	**9**
13	Cognition	**5**	16	25
14	Family impact	14	13	25
15	School performance	**8**	20	25
16	Anxiety/worry	24	14	12
17	Fear of surgery	**6**	33	25
18	Employment	19	17	25
19	Blood pressure	20	18	14
20	Ability to travel	32	28	**3**
21	Fertility	28	15	25
22	Sexual functioning	32	19	**10**
23	Cardiovascular	16	22	25
24	Blood tests	12	25	25
25	Mood	25	23	25
26	Surgical recovery time	32	21	25
27	Pain	21	31	25
28	Weight	25	27	25
29	Self esteem	28	24	25
30	Appearance	32	26	25
31	Breathlessness	32	29	25
32	Time off dialysis	32	30	25
33	Catheter problems	22	33	25
34	Itchiness	26	33	25

Top ten outcomes are shaded orange

Fifty-eight outcomes were identified by children across all groups. Using stickers, each group narrowed their list of outcomes down to the top ten outcomes. Across all child groups, thirty-four outcomes were ranked.

Outcomes with the same importance score have a tie rank

Table S10: Individual ranking of outcomes–caregivers by child's age

Rank Position	Outcome	Rank position child age 0-12 (n = 25)[a]	Rank position child age 13-17 (n = 31)	Rank position child age 18+ (n = 4)
1	Kidney function	**1**	**1**	**2**
2	Survival	**6**	**2**	**7**
3	Infection	**2**	**3**	**28**
4	Anemia	**5**	**4**	**1**
5	Growth	**3**	**7**	**11**
6	Financial impact	**4**	**9**	**4**
7	Cardiovascular	11	**6**	**10**
8	Graft survival	**9**	**5**	20
9	Family impact	**8**	13	**6**
10	Blood pressure	**10**	**10**	15
11	Bladder problems	14	**8**	20
12	Hospitalization	**7**	18	28
13	Vascular access	16	12	**5**
14	School performance	18	11	**3**
15	Pain	13	17	28
16	Weight	12	22	16
17	Fatigue	20	16	**8**
18	Anxiety/stress	17	14	28
19	Mood	24	15	14
20	Appetite	21	20	**10**
21	Gastrointestinal	15	27	28
22	Self-esteem	25	21	28
23	Physical activity/sports	19	24	28
24	Cognition	32	19	17
25	Skin	22	33	12
26	Social functioning	27	26	28
27	Potassium	23	32	28
28	Cancer	28	25	28
29	Developmental delays	26	31	28
30	Employment	32	23	18
31	Depression	32	28	14
32	Fertility	29	30	28
33	Travel	32	29	21

Top ten outcomes are shaded blue

Fifty-four outcomes were identified by caregivers across all groups. Using stickers, each group narrowed their list of outcomes down to the top ten outcomes. There were 33 outcomes ranked across all caregivers groups.

Outcomes with the same importance score have a tie rank

[a]Two caregivers did not report their child's age

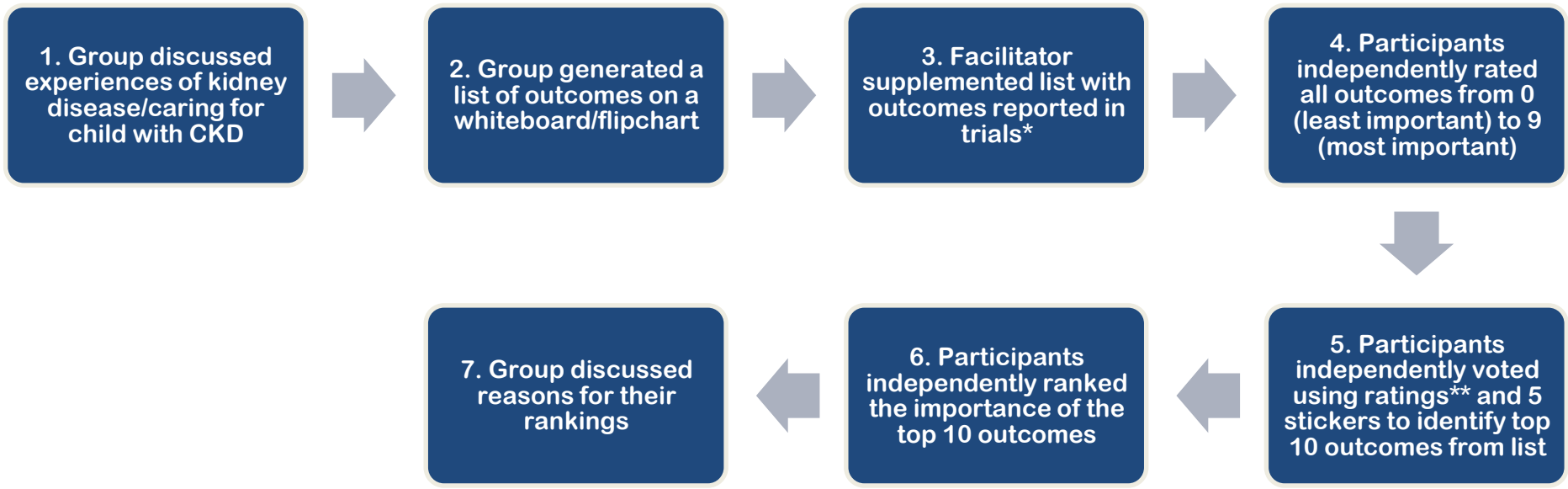

Figure S1. *The facilitator suggested other outcomes be added to the list that are frequently reported in trials in children with CKD [13] **The rating exercise was used to allow participants to identify which outcomes were the most important to them