

Supplementary Item 1. Participating Sites and Institutional Review Boards

British Columbia Children's Hospital, The University of British Columbia Research Ethics Board, Vancouver, Canada.

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

Texas Children's Hospital, 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.

Supplementary Item 2. Child question guide

We want to know what it's like for you to have kidney problems

- Can you tell us a little bit about your kidney problems (how long, what treatment you have?)
- What is it like to have kidney problems?
- What are the hardest things about having kidney disease? (school, family, hospital)
 - How could this be better addressed?
 - How well do you think these things are understood by the health care staff?
 - In what ways do they understand? In what ways don't they understand?
- When it comes to making decisions about treatment – who makes the decisions? Do you feel you get to have a say about your treatment – why?
- Can you think of a time when you felt involved or not involved in a decision?
 - How did it go? What did you want to happen?
 - If you spoke up, what happened?
 - Knowing what you now know, how would you make the same decision?

Supplementary Item 3. Parent question guide

- How did you first find out that your child had kidney disease? How did you react/feel?
- How has the kidney disease/dialysis/kidney transplant changed your life and your child's life?
- What is the most challenging thing about caring for a child with kidney disease, and how do you deal with it?
- How well do you think these things are understood by the health care staff? In what ways do they understand/don't they understand?
- What do you think about the information you have about your child's kidney problems or treatment?
- To what degree do you feel you are involved in making decisions about your children's treatment – why?
- When it comes to making a decision about treatment, who makes the decision?
- Has there been a time when you may have not agreed with the doctor – what happened then? Was it resolved – how/why?
- Do you think your child is involved – in what way?
- Can you think of a time when you felt involved or not involved in making a decision about treatment?
- What happens when your child might disagree with what you think is best for them?
- Is there anything else that you think might be important to add about communication or decision-making?