

Supplementary Material

Interview guide for caregivers

Perspectives of caregivers of children and adolescents with CKD on access to healthcare

Diagnosis and impact of disease

1. Could you briefly describe what happened when you first found out your child had kidney disease, and how you sought/received care?
2. Which aspects of your life/your child's life did you feel were impacted? (e.g. financial, employment changes, family stress).
3. How were they impacted and how did you deal with it? (e.g. took extended leave from work, sought help from family and friends).

Access to care and quality of care

4. What sorts of healthcare services have you used – what prompted you to access, or how did you come to use these services? (e.g. GP, nephrology, dietitians, pathology, pharmacy, biopsy, dialysis equipment and services, psychology, social work, nursing, physiotherapy, etc.)
5. What were the most challenging aspects of or barriers to accessing care? (e.g. arranging appointments, attending clinics, transport, childcare, financial)

Suggestions to improve access

6. What sorts of things might help overcome these barriers?
7. What do you think are the critical aspects for “good” quality care for children with CKD/families - why? (e.g., ease of access, continuity of care, information and education, shared decision-making, multidisciplinary support?)?
8. If you had the power to make changes in the healthcare system, how would you have done things differently to provide the best quality care to children with CKD and their families?

Close

Is there something that you think might be relevant to mention that we have not already covered, and you would like to share?

Figure S1. Levesque's conceptual framework of access to health care.²⁵

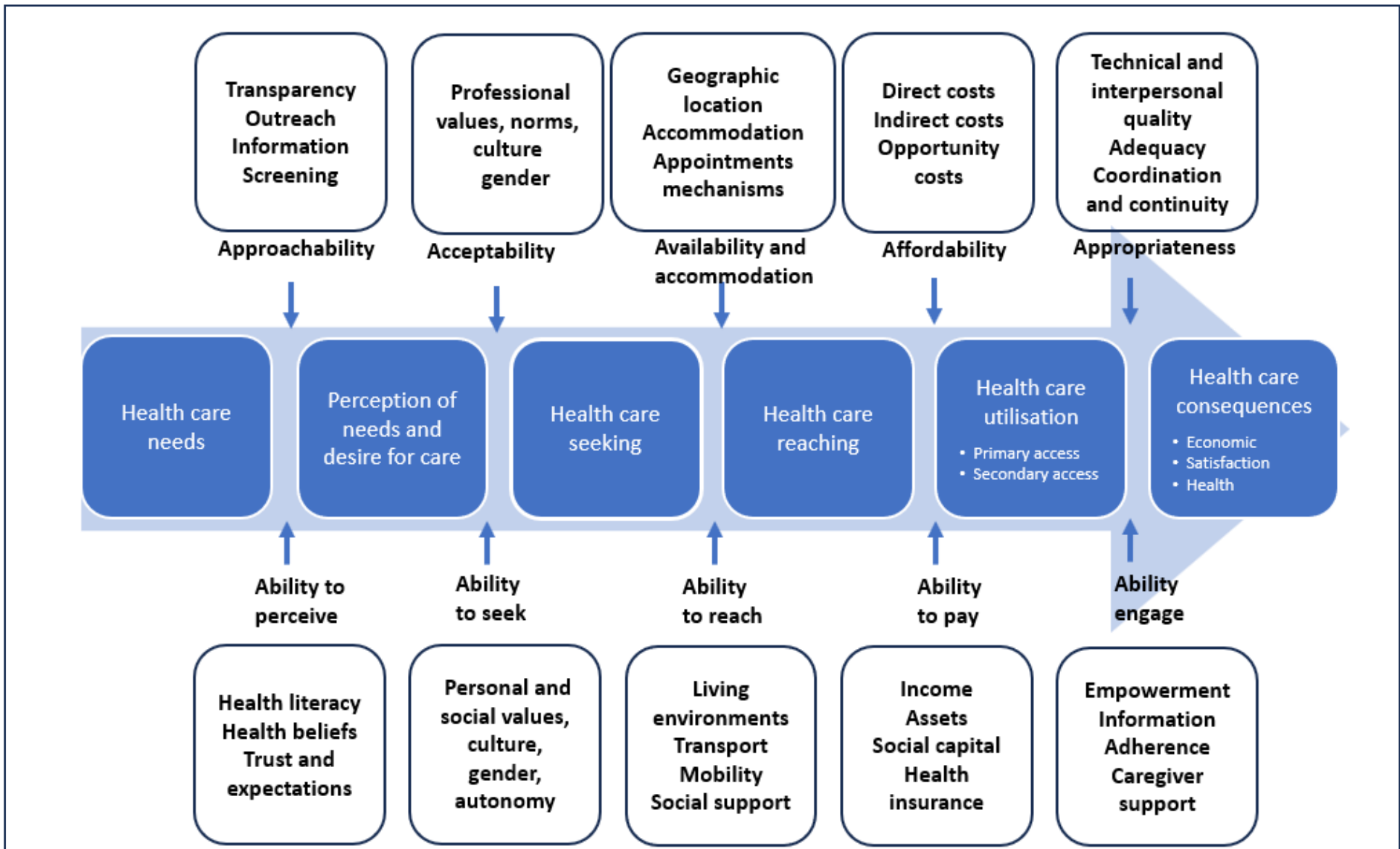


Figure S2. Mapping themes to Levesque’s conceptual framework of access to care.

