

Supplementary File 3. SONG-Kids Interview guide

Introduction

1. Could you briefly tell me about your experience growing up with kidney problems/kidney disease?
2. How does CKD impact on your life at the moment? How is it different now, compared to when you were a child living with kidney disease? What are things you missed out on?

Meaning of life participation

3. Life participation, or being able participate in life, has been found to be an important thing to focus on in research in children with CKD. Caregivers, young patients and health care providers told us this was important.
 - What do you think of when I say "life participation," what does it mean to you?
 - How would you define 'life participation'?
4. Life participation is about being able to do the things that are meaningful and important to you. What things/activities are important to you or other young adults with kidney disease - Why? (work/career, income, family/having children, education, travel, intimate relationships, social life, physical activity, freedom/flexibility, independence)
5. Do you think the meaning (or the types of activities) of life participation is different between young adults with kidney disease, and young adults without kidney disease – why?

Experience of life participation during childhood

6. As a child, what areas of your life were most impacted or limited? (school, travel, social life, quality of life, physical activity, freedom and flexibility)
7. Has your ability to participate in life changed over time, throughout your journey with CKD? How?

Impact of (childhood) CKD on life participation in young adulthood

8. Has your ability to participate in life been shaped (or impacted) by having childhood CKD? How?
9. What areas of your life have been most impacted or limited? How/Why? (work/career, income, family/having children, education, travel, intimate relationships, social life, physical activity, freedom and flexibility, independence)
10. What about your future? Are there areas of your life that you believe will be impacted or limited due to CKD?

Improving life participation

11. Do you think life participation should be discussed/or addressed by health care providers – why/how?
12. Has anything helped to improve your ability to participate in life - how? What about when you were a child?
13. Can you suggest things that may be helpful to improve life participation for young adults? What about for children with kidney disease?