

ITEM S1: The semi-structured interview guide followed during patient interviews.

CKMAPPS Patient Interview Guide

PART ONE: You and your illness – a brief biography

1. Please could you tell me briefly about your kidney disease?

Probe: When were you diagnosed?
How was your kidney disease diagnosed?
Can you tell me what you think caused your kidney disease?
What impact does your kidney disease have on your life now?
How do you think your kidney disease may impact on your life in the future?

2. Where are you now with your kidney disease in terms of its management?

Probe: CM vs. wait for RRT or on RRT.
How long since CM decision or since RRT start?

PART TWO: How decisions were made about management and views on pathway.

3. How were the options for the management of your kidney disease presented to you?

Probe: Who discussed the options with you?
How did you feel about this discussion?
When were the options discussed with you?
How did you feel about the timing of this discussion?
What information was shared with you/were you given?
How did you feel about the information you were given?
What sort of questions did you have about your options for management?
Have you discussed the option of not having dialysis?
- If yes, how was this described to you?
- If no, are you aware that some people choose not to have dialysis?
- What do you think about patients having this option?

4. Who made the decision about whether or not to have dialysis?

Probe: When was the decision made?
How much time was spent thinking about the decision?
- By you? By your doctor?
What factors influenced your final choice of management?
Have you changed your initial choice?
Do you think you will change your choice in the future?

5. [For those who chose CM] What did choosing CM mean to you?

Probe: What were the reasons you chose CM?
What did you think the benefits might be?
What other implications did you think there would be?
Have you experienced anything which you did not expect since starting on the CM pathway?
What do you think the benefits of CM are now?
Who do you think CM is most appropriate for?

[For those who chose dialysis but not yet started] What did choosing dialysis mean to you?

Probe: What were the reasons you chose to have dialysis in the future?
What do you think the benefits might be?
What other implications do you think there will be?
Who do you think dialysis is most appropriate for?

[For those already on dialysis] What did choosing dialysis mean to you?

Probe: What were the reasons you chose to have dialysis?
What did you think the benefits might be?
What other implications did you think there would be?
Have you experienced anything which you did not expect since starting dialysis?
What do you think the benefits of dialysis are now?
Who do you think dialysis is most appropriate for?

6. Can you tell me about any concerns that you had when the decision about your kidney disease management was made?

Probe: Were there any challenges that you anticipated?
Were there any opportunities that you thought you may miss out on?
Do you feel you understood fully what was being agreed?

7. Can you tell me about any concerns that you have now about the decision that was made?

Probe: How well do you feel you understood the consequences at the time?
How well do you feel you understood what was involved at the time?
Did you feel you were involved enough in the decision?
Do you feel you had enough clinical input from the doctors?

8. Overall, how do you feel about the way the decision was managed?

Probe: How did you feel about the amount of time you were given to think about the decision?
Did you feel you were able to ask questions?
Did you feel your family/significant others were able to contribute to the decision?
How do you think the decision making process could be improved?
Should anything be changed about the decision making process?

Conclusion

1. Are there any other relevant issues we haven't covered that you would like to mention?
2. Are there any questions you that would like to ask me?

Your demographic information

Gender:	Age:	Ethnicity:
Occupation prior to retirement:		Marital status:
Religion:		Living arrangements:

Thank you very much for taking the time to speak with me.