

Patient interview guide

Exploring patient and carer perceptions and experiences of home dialysis decision making.

1. Introduction

- a. Explanation of study, obtain informed consent, demographic info
- b. Can you tell me about what happened when you first found out you had kidney disease?

2. Information and decisions about dialysis

- a. When did you first hear about dialysis – what kinds of information or education did you get? (*decision-making process, preferences*)
- b. Who else was involved in your education and decision making – how did they influence your thoughts or decisions about dialysis (their manner, shared decision making?)
- c. What sorts of things influenced your beliefs/decisions about the different types of home dialysis (PD, APD, HHD)?
- d. Can you tell me about whether you felt you received enough information to make an informed decision about home haemodialysis or peritoneal dialysis?
- e. If you had to choose again, what sorts of things would help you make decisions about dialysis?

3. Beliefs about home dialysis

- a. What were your first thoughts or reactions when you first heard about PD and home HD?
- b. What do you believe are the potential advantages of PD or HHD compared to dialysis in hospital - why?
- c. What do you believe are the potential risks of PD or HHD compared to dialysis in hospital - why?
- d. If someone asked you what dialysis they should choose, what would you tell them?

4. Living with home dialysis

- a. Have you considered changing your place or type of dialysis– why?
- b. For you, what do you think are potential reasons that would stop you having home dialysis? For others?
- c. In NZ the number of people on home dialysis has reduced over the last 15 years, why do you think that might be?

5. Socioeconomic and cultural issues impacting on home dialysis

- a. Will home dialysis have a financial impact on you or other members of your family - how? (paid work, unpaid work, benefits, expenses e.g. travel, costs, electricity, water)
- b. Do you think there are social or cultural issues that might influence decisions about home dialysis for you or your family?
- c. What are your beliefs/thoughts about financial assistance (i.e. whether adequate and/or accessible); and if it influences their thinking towards home dialysis?
- d. Are there cultural or spiritual factors which influence the place of dialysis for you? (non-medicalised environment, days of rest, whanaunatanga, wairua)
- e. How could the education and support you received about dialysis options better address your cultural or spiritual needs?

6. Conclusion

- a. What kinds of support or services would you need if you did dialysis at home – why?
- b. Is there anything else that you think is important to add?