

Supplementary Material

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Item S1

PREVENT-ADPKD Clinical Trial Participation Evaluation Questionnaire

Date of Assessment _____ Study Site: _____

1. Is this your first time participating in a clinical research trial related to PKD?

- Yes
- No

2. Would you recommend joining a research study to your family or friends?

- Definitely no
- Probably no
- Probably yes
- Definitely yes

3. Did the informed consent form prepare you for what to expect during the study?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely

4. Did the information and discussions you had before participating in the research study prepare you for your experience in the study?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely

5. How easy was it for you to complete the following tasks for the study?

	Very easy	Somewhat easy	Neither easy nor hard	Somewhat difficult	Very difficult
24-hour urine collections	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Blood tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MRI scans	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Study visits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Questionnaires	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Very easy	Somewhat easy	Neither easy nor hard	Somewhat difficult	Very difficult
24-hour urine collections	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Blood tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MRI scans	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Study visits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Questionnaires	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. Did the research team members listen carefully to you?

- Never
- Sometimes
- Usually
- Always

7. Did the research team members treat you with courtesy and respect?

- Never
- Sometimes
- Usually
- Always

8. During your discussion about the study, did you feel pressure from the research staff to join the study?

- Never
- Sometimes
- Usually
- Always

9. Below is a list of possible reasons for joining a research study. When you considered joining the study, how important were these reasons to you?

Very important
 Somewhat important
 Not very important
 Not important at all

To find out more about my disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because no other medical options were available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To gain access to new treatment/therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To obtain free healthcare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To help others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of the Research/Health Center's reputation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because I am concerned about the topic of study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To obtain education and learning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of a positive experience in another study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of family influence/involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To earn money/payment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because my caregiver encouraged me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other reasons	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10. When you were not at the research site did you know how to reach the research team if you had a question?

- Never
 Sometimes
 Usually
 Always

11. When you were not at the research site and you needed to reach a member of the research team, were you able to reach him/her as soon as you wanted?

- Never

- Sometimes
- Usually
- Always
- Did not have to reach research team

12. Did you feel you were a valued partner in the research process?

- Never
- Sometimes
- Usually
- Always

13. If you considered leaving the study, did you feel pressure from the Research Team to stay?

- Never
- Sometimes
- Usually
- Always
- Did not consider leaving the study

14. Although our research team is based in Westmead (Sydney), our staff travel to other various study sites across Sydney and interstate for face-to-face study visits. How satisfied were you with this study arrangement?

- Very unsatisfied
- Somewhat unsatisfied
- Neutral
- Somewhat satisfied
- Very satisfied
- Very unsatisfied
- Somewhat unsatisfied
- Neutral
- Somewhat satisfied
- Very satisfied

15. Below is a list of possible reasons for leaving a research study. How important were the reasons for you in considering leaving the study?

	Very important	Somewhat important	Not very important	Not important at all
Pain or discomfort related to participation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worried about risks of treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Side effects that occurred during the study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Invasion of privacy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Too much time spent waiting around	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family/work issues unrelated to the study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interactions with research team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not getting test results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Under pressure to stay in study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Problems with study payments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unexpected tests and procedures that occurred during the study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because my caregiver encouraged me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation/parking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other reasons	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. Please circle the number that best describes your overall experience in the research study, where 0 is the worst possible experience, and 10 is the best possible experience.

1 2 3 4 5 6 7 8 9 10

17. Please provide any other comments regarding your participation in the study?

Thank you for completing this questionnaire

Item S2

PREVENT-ADPKD Clinical Trial Participation Interview Guide

Introduction

Hello, my name is _____ and I am calling on behalf of the PREVENT-ADPKD study from Westmead Hospital. Am I speaking to [participant name]? {If no, ask to speak to participant}

Thank you for agreeing to take part in this evaluation interview. Is now still a good time to proceed with the interview?

(if no)

That's okay, do you have another date and time in mind that we could reschedule the interview to?

(if yes)

The purpose of today's call is to find out about your experiences as a participant of the PREVENT-ADPKD study, and your feedback will help improve the design of future research studies. This interview will take approximately 20 minutes. We will be audio recording the interview to help us with data analysis but your responses will remain confidential. I will de-identify your transcript so that the other regular staff in the team will not be able to track your answers to you. We hope that in doing so, you can feel comfortable in answering the questions as honestly as you can. Just a reminder that your participation is completely voluntary. I have a list of questions prepared but how the interview flows will also largely depend on your responses too. Feel free to let me know if you have any questions or if anything is unclear, or for questions to be repeated at any time. Are you happy to continue?

Topic	Main Question	Follow-Up Questions/Prompts
Expectations and motivations for participation	<i>How did you become involved in the trial?</i>	<ul style="list-style-type: none"> • Have you participated in a research trial before? If yes, did your experience in past trials give you any expectations about this one? • If not, what ideas did you have around being part of a research trial? • Why did you choose to participate in the trial? • What risks or benefits of participating did you expect from participation? • Did you receive support you received from your doctors, family and friends about joining the trial. Why?
Informed consent	<i>Did you feel that you were given a enough information about what is to be involved in the study before consent?</i>	<ul style="list-style-type: none"> • If not, why? And how has this impacted your experience in the trial? • Were there any parts of the study that were a surprise to you because they were not explained to you clearly at the start? (e.g. frequency and description of tasks to be completed, randomisation to intervention group, costs and benefits of participation, the potential risks, ethics process, privacy of collected data and samples)
Experience of participating in a research trial	<i>How was your overall experience as a participant in the study?</i>	<ul style="list-style-type: none"> • What did you enjoy most about the study? • What did you enjoy least about the study and why? • Did you gain anything personally from participating in the trial? What/why?
Perceived adherence and acceptability	<i>How well do you think you followed the study procedures?</i>	<ul style="list-style-type: none"> • Have you been consistent with following the study procedures in this way over the three-year duration of the study. [Prompt: did you find yourself to be more compliant at the beginning, middle, or nearing the end of the trial for example?] • How acceptable did you find the study procedures? • Which parts of the study were the least acceptable? • What do you feel about the time commitment required for the study? • Can you suggest anything to improve the study?
Enablers and barriers	<i>What things or situations made it easy or hard to follow the study protocol?</i>	<ul style="list-style-type: none"> • Is there anything you or we can do to help reduce the barriers? • Did you ever think about withdrawing during the study, and if so, could you describe your thoughts and reasoning during that time?
Study staff	<i>Describe the support you received from the staff</i>	<ul style="list-style-type: none"> • How flexible were the study staff in negotiating your study commitments? • What other feedback do you have about the study staff? • We are a mobile team who are based in Westmead and travel to all the study sites for your study visits. Did this affect your participation and experience in the study?
Future	<i>Would you consider participating in a similar trial in the future?</i>	<ul style="list-style-type: none"> • If not, what aspects of the clinical trial would you change to make it more appealing for you to consider participation?

That's all the questions I have. Thank you very much for taking the time to participate in the interview. Did you have any further comments or questions before we finish off – is there anything else that you

would like to add that might be relevant? Would you be interested in receiving a summary of the findings from this evaluation study?

Thank you, have a good day.

Item S3
Coding Framework

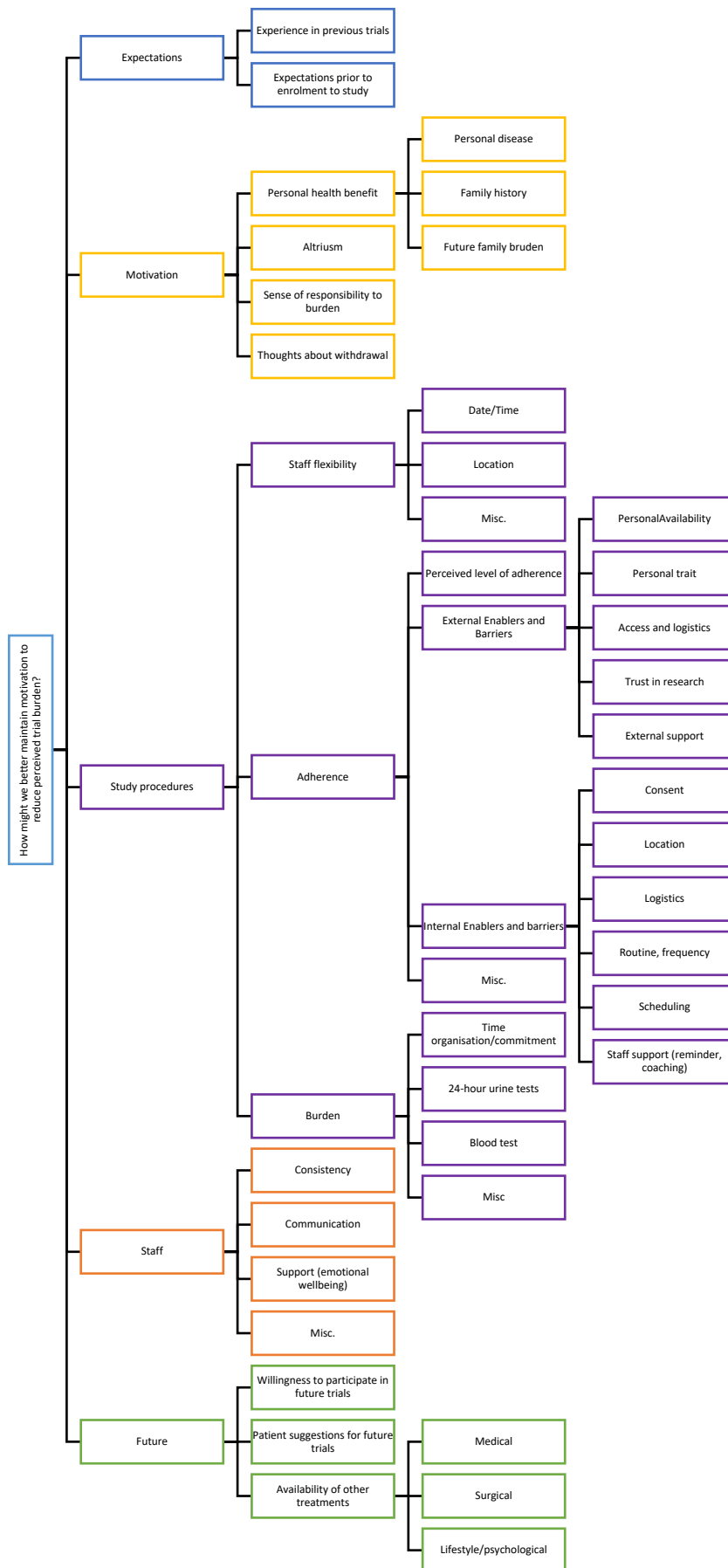


Table S1: Question 16 Additional Comments from Questionnaire		
Participant Number	Demographics	Additional comments
2	Female, 30s	Thanks to the team for their dedication. Keep up with the good work!
3	Male, 60s	thanks to the team for their dedication. keep up the good work
4	Female, 50s	Happy to help out on future research :)
6	Male, 60s	Dr xxx always considerate and compassionate
7	Female, 30s	My involvement wasn't too demanding so it was easy to take part in study. The hardest was probably the 24hour collection as I had to be home the whole day and ensure I was available the next day to drop off at collection centre but that was really only a problem when I was working. Staff have been great and flexible with organising appointments at convenient locations. Thanks!
11	Male, 30s	The 24 hr urine collection was probably the hardest part only because I had to do mine only on weekends with limited collection centres open on Sunday. Apart from that, I think everyone/everything was well prepared and organised.
13	Female, 50s	Trying to help the next generation!
19	Female, 60s	I was happy to participate in the hope that more research could result in better treatments in the future in view of my children having the disease
27	Female, 20s	24 hr urine analysis burdensome. Staff great.
29	Female, 40s	Will be great if I can get more information about the polycystic kidney disease by email
33	Female, 70s	Happy to have the opportunity to contribute to research and possible treatment options. Very positive experience overall.
36	Female, 50s	My GP would have liked more correspondence with him regarding regular blood tests and results
42	Male, 40s	I have been grateful to undertake this opportunity and would like to thank the research team for the care, attention and commitment they have put into this study. Special thanks to Annette.
50	Female, 30s	I only considered leaving because I was moving overseas. I'm glad the research team were flexible and could accommodate for this and that I could still stay and contribute as much as I did despite being away for some study visits.
63	Female, 50s	I joined the study to assist in the understanding of PKD. I didn't receive any direct benefit from the study, however I was happy to do it.
66	Male, 60s	Thank you for the opportunity to attend
69	Male, 50s	Hopefully study outcomes will produce usable data to improve the lives of people with PKD.
70	Female, 20s	To see the results of the three years would be good after it is finished.
71	Female, 70s	It went well and I was happy to be part of it. The travel to Sydney from Bathurst and return and COVID 19 worry is the only reason for delaying or half doing the last session.

72	Female, 40s	Happy to be finished until the end.
75	Male, 50s	Very worth while study staff were a pleasure to deal with right through out the study.
76	Female, 40s	I would just like to say how amazing Alex has been. She was always polite, helpful and caring. I am glad and have been part of this study along with my son. Hopefully one day there will be something to cure this disease.
78	Male, 20s	Team was always nice and courteous.
80	Female, 50s	Glad to be able to help with research.
81	Male, 40s	Everything was explained well and no question was ever not answered. The study was run well and the researchers were a pleasure.
91	Male, 60s	Suggestion: Provide parking or reimburse car park payments
92	Male, 40s	- Found the 24-hr urine test difficult to perform (working Mon-Fri, the activities on weekend) - Would have liked the test results to be more available to my renal specialist (unless they are Pathwest, my renal specialist never plots them on his charts/trends at my appointments) - Pathology I went to (branch in Perth CBD) always struggled with the requests and coding in their system (e.g. osmolality was rare for them)
95	Female, 30s	The team was very accomodating and supportive. Thank you.
96	Male, 20s	Staff were extremely helpful.
102	Males, 40s	Staff was friendly and answered all questions asked. Would happily work with them again.
106	Female, 40s	The staff and involved health professionals were amazing. Very thoughtful, considerate and supportive. Thank you.
110	Female, 50s	I have found the study to be fairly easy. My only negative is that due to the long timeframe somedays were hard with the water intake. Mainly due to illness or weather. Maybe more interaction by way of messages or check-in calls now and again would help people to stay connected. Also, water filter bottles were supplied at the beginning but needed to be replaced or receive more filter replacements.
112	Male, 50s	Thanks for doing the work!
115	Male, 50s	Time has flown by so quickly it really has been painless and easy.
117	Male, 60s	At the start of the study my diet was reviewed and I have been able to make some positive changes because of this discussion.
118	Male, 60s	I hope to have good news
121	Female, 40s	Happy to do study. Always able to contact Annette when needed to and get a quick reply
125	Male, 40s	Lots of effort and hard work done by research team which includes regular follow-up with me on my visits, tests and thank you all research team for your valuable time. I trust this clinical trial brings positive outcome for people with PKD. All the very best and I really appreciate dedication for research team.
127	Female, 50s	The awful experience with the rude blood collection staff at xxx on a few occasions, especially one

129	Female, 20s	That it's been a great educational experience! thank you
133	Male, 60s	The study team were always supportive and willing to arrange alternative options due to living most of the time in Thailand. I really appreciated that. Thanks!
134	Male, 30s	Please continue to pay for parking
135	Male, 50s	Thank you for your support and encouragement during this research. It has been a positive experience.
136	Male, 60s	Amazing care provided
139	Female, 40s	Xxx was the best
140	Female, 60s	I found it an interesting process to be part of. I look forward to seeing the results published and see if the fluid management makes any difference to disease progression.
141	Male, 40s	It has been an easy study to be involved in end I hope it help with preventing PKD
142	Female, 50s	I hope/would like to see some of the results or outcomes of the study and any conclusions or recommendations
144	Female, 50s	I'm grateful that you are researching this area
146	Male, 50s	The study was conducted very professionally and I felt there were many benefits to me and others who have PKD, and the nature of the study meant there was very little downside to me.
147	Female, 50s	thank you
148	Male, 60s	xxx was fantastic. Treated me more like a friend than a patient. She was always happy to listen to my life problems and concerns. She was amazing and I wish her the very best for her future
150	Male, 60s	I would like to thank xxx and all the research team for their caring and friendly approach to the PKD Survey. If in the future you require another volunteer for further studies I'd be happy to help.
158	Female, 50s	I have been in other studies for other health issues. This one was great from start to finish. My home environment changed during this study and made the 24hour collection a concern for others. I will miss the research team.
161	Female, 30s	I considered leaving the study because I was having too much trouble drinking the required amount but the staff were really reassuring that my participation was still valuable. overall everyone was so lovely to deal with!
165	Female, 40s	Fantastic team. miss you already :)
168	Female, 30s	I'm sorry I was very slack with doing all the required tests! Otherwise, no issues - very easy study to be a part of.
176	Male, 60s	I trust it helps PKD patients in the future and helps towards a cure
180	Female, 20s	The only challenge for me was having to travel to xxx for study visits. However the research team were wonderful in arranging flights for me and luckily work was flexible. I was provided dates of travel well in advance so I could arrange time off work. Overall a fantastic experience and wonderful team

185	Female, 20s	I believe this study has and will help me greatly managing my adpkd and adopting a healthier lifestyle where I can. Water drinking has become effortless and not inconvenient. If given the opportunity again, I would definitely participate in the study.
186	Male, 40s	study was clear. team conducting it have been great.

Table S2: Selected Participant Quotations of Expectations Prior to Enrolment

Theme	Frequency* (n=31)	Quotations (Demographics, Participant number)
PKD Knowledge	10	<i>“Really to find out more about, get better education on the disease, and also, as I said in the form, the hope that by being a participant, treatments in the future would be better, because my children both have the disease as well. That was the main reasons.”</i> (Female 50s; Participant #11)
Water Intervention	9	<i>“I thought you guys would give me a bunch of water to drink. That’s what I thought. That’s it.”</i> (Male, 30s; Participant #17).
Professionalism	1	<i>“I guess just that it would be run professionally and that there would be certain things expected of me, but that they won’t be particular onerous.”</i> (Female, 30s; Participant #2)

**Frequency refers to the number of participants who were coded to the theme*

Table S3: Selected Participant Quotations of Motivations and Benefits

Theme	Frequency* (n=31)	Quotations (Demographics, Participant number)
Altruism	26	<i>"I'm happy to participate in anything that can benefit the future for research or better treatments."</i> (Female, 60s; Participant #19)
Conscientious & Organisation	16 5	<i>"I'm responsible of what should be done because I'm part of the study. It means that I made the commitment, therefore I have to do my responsibility."</i> (Female, 50s; Participant #23)
Personal Health Benefit	28	<i>"Benefit is that I'm a lot more educated now and I've got a better knowledge of what I need to be doing and what are the right things to do in terms of my fluid intake and diet, etc, exercising, just in general wellbeing, so definitely benefits here."</i> (Male, 40s; Participant #42)
Family History	11	<i>"Grandmother was diagnosed. She was on dialysis and she had a kidney transplant and then mother got diagnosed and then just filtered on down from that."</i> (Male, 30s; Participant #16)
Future Family Burden	13	<i>"The hope that by being a participant, treatments in the future would be better, because my children both have the disease as well."</i> (Female, 60s; Participant #19)
Trust in Research	11	<i>"I believe in evidence based practice, therefore I have to believe in research. Therefore why not participate in research...It's important for the research that it's been down well, so there's no point in participating in it and stuffing it up."</i> (Female, 70s; Participant #33)

**Frequency refers to the number of participants who were coded to the theme*

Table S4: Selected Participant Quotations of Participant Enablers and Barriers for Completion of Study Procedures

Theme	Frequency* (n=31)	Quotation (Demographics, Participant number)
External Support	N/A**	<p><i>"My family was very supportive. My work place wasn't particularly able to be flexible with my participation, so I had to sometimes use personal leave to get medical appointments done."</i> (Female, 20s; Participant #27)</p> <p><i>"It wasn't that easy actually. Yeah, because it kind of disrupted others a bit more because we had the changed diet. So obviously the other kind of eat the same...it was a bit disruptive to the family but they were willing to help as much as they can. But yeah, for the whole length of time obviously it was a bit hard."</i> (Males, 50s; Participant #44)</p>
Personal Availability	17	<p><i>"Yeah, just situations. I mean I've got a disabled son...I spent the most of last year in hospital having back surgeries. So that was unexpected."</i> (Female, 50s; Participant #4)</p> <p><i>"The last couple of years I had been working part time and studying, so I had extra time. So I didn't have to do a lot in terms of rescheduling."</i> (Female, 30s; Participant #50)</p> <p><i>"There was a couple of time it was inconvenient because I travel a lot of work."</i> (Female, 50s; Participant #36)</p>
Time Requirement	N/A**	<p><i>"Initially I though three years seemed like forever, but now it just went so quick."</i> (Female, 50s; Participant #36)</p> <p><i>"Just with the busyness of life there were sometimes where it was tricky to complete some aspects of it, but not insurmountable. Just needed a bit of coordination from myself and a bit of manoeuvring."</i>(Male, 40s; Participants #42)</p>
Situation Thoughts of Withdrawal	4	<p><i>"Only because I was going overseas, yeah."</i> (Female, 30s; Participant #50)</p> <p><i>"No, only that one time when there was a new drug that was available, it made me sit and think for a moment."</i> (Female, 50s; Participant #43)</p>

* Frequency refers to the number of participants who were coded to the theme
**Not applicable, all participants were asked about external support and time commitment

Table S5: Selected Participant Quotations Regarding Logistics of Study Procedures

Theme	Frequency* (n=31)	Quotation (Demographics, Participant number)
Access & Logistics	9	<i>"I suppose there are a lot of pathology locations."</i> (Female, 30s; Participant #27) <i>"The travel part is probably the worst bit."</i> (Male, 40s; Participant #30)
Multiple Locations	13	<i>"It was all good... when I had to have appointments closer to home, she was happy to do them at xxx Hospital which is closer to home for me, so that was all good."</i> (Female, 60s; Participant #19)
Flexible Schedules	27	<i>"There was plenty of flexibility in terms of appointment times and recently some flexibility in terms of location of appointments as well, which has been great."</i> (Female, 30s; Participant #27)
Routine and Frequency of Procedures	9	<i>"It was only every six months there was a thing, urine, blood test, catch up meeting within a two month period. There's only three MRIs, which over three years, you just turn up."</i> (Male. 50s; Participant #20)
Clarity of Consent Information	23	<i>"I was aware of everything that I had to do. It was explained really well actually."</i> (Female, 60s; Participant #19)
Staff Support	19	<i>"What made it easier was the instructions that you got at each study visit in the envelope and everything pre-packaged for you and do it in the week of this day"</i> (Male, 40s; Participant #42).

**Frequency refers to the number of participants who were coded to the theme*

Table S6: Selected Participant Quotations Regarding Clinical Trial Staff

Theme	Frequency* (n =31)	Quotation (Demographics, Participant number)
Support	8	<p><i>"Yeah. I felt like everyone was supportive. If I felt like something was a barrier, people would try to help me overcome it."</i> (Male, 30s; Participant #17)</p> <p><i>"I needed the support of the team behind the study. Just for reminders and stuff. Because they did that a lot in the beginning and it seemed to fade out so I kind of drifted."</i> (Male, 50s; Participant #44)</p>
Informative	5	<p><i>"They were just very professional and explained everything well."</i> (Male, 30s; Participant #31)</p>
Communication	5	<p><i>"So, the support's been great. As I say, notifying of meetings, notifying the MRIs, text messaging, and emails, and being available. Not that I've had to contact them, but sending them through the 24 hour stuff and making sure they say thank you."</i> (Male, 50s; Participant #12)</p> <p><i>"Well in terms of support, I think they're very good in communicating. For example if there is any change, they either use SMS or email and also near the visit day they will send reminders and all that. Yeah they take care of the as I mentioned the booking for parking spots and all that."</i> (Male, 60s; Participant #3)</p>

**Frequency refers to the number of participants who were coded to the theme*

Table S7: Selected Participant Quotations Regarding Clinical Trial Procedures

Theme	Frequency* (n =31)	Quotation (Demographics, Participant number)
24hour Urine	25	<p><i>"Yeah, I didn't love the 24 hour urine currently, but I wouldn't say it was unreasonable."</i> (Female, 30s; Participant #2)</p> <p><i>"Well, I guess just trying to keep on top of a large intake of water, as well as the 24 hour urine collection. Got a bit annoying at times, but it wasn't too bad."</i> (Male, 30s; Participant #31)</p>
MRI	4	<p><i>"It is quite difficult to actually be in that confined space. I'm not really a claustrophobic person, but it is difficult to actually... and I feel a little bit dizzy I think at various points."</i> (Female, 60s; Participant #24)</p> <p><i>"I just don't like them. I'm just claustrophobic so I struggled going in those machines."</i> (Male, 40s; Participant #30)</p>
Blood Test	3	<p><i>"Not really, but psychologically, you know Chinese 'oh, it's another blood test'...seems like I'm taking a lot of blood because it's not only this study because I see other specialists... so what is the cumulative effect? Oh, it seems that I'm going to the pathology lab and then having bloods all the time."</i> (Male, 60s; Participant #3)</p> <p><i>"Blood tests are very quick and easy to complete."</i> (Female, 30s; Participant #27)</p>
Questionnaire - Complicated	1	<p><i>"Yeah. I don't know just maybe the questionnaires could be little simpler...the pain one, seemed to be complicated."</i> (Male, 30s; Participant #17)</p>
Questionnaire - Too Long	4	<p><i>"I found probably the questionnaires...that you've got to repeat them all the time. They were sometimes a bit cumbersome, like having to do them all again and thinking, oh, there was a lot of questions to answer."</i> (Female, 60s; Participant #19)</p>

**Frequency refers to the number of participants who were coded to the theme*

Table S8: Selected Participant Quotations Regarding Opportunities for Improvement

Theme	Frequency* (n =31)	Quotation (Demographics, Participant number)
Improved Information Sharing	17	<i>"The sharing of information. I realize it's a study, but the tests, the blood tests and scans and that sort of things are not made available to me or my ... well they are sometimes, but they're not readily available to my GP or me."</i> (Male, 20s; Participant #28)
Reduced Time Commitments	5	<i>"I suppose have long visits shorter, shorter appointment times for the face to face or perhaps having them over the phone or kind of technology so that you could do it, you don't have to travel to the location would help."</i> (Female, 30s; Participant #27)
Money Incentives	5	<i>"If we pay someone, of course it'll become appealing. But look, I don't mind."</i> (Male, 30s; Participant #26)
Increased Education	3	<i>"Oh no, just personally, I guess that little bit of feedback and yeah, your creatinine levels are all good and ... because you're always wondering and you think well, just that personal, that little feedback would be great and maybe teaming up with the specialists, so having double up."</i> (Female, 50s; Participant #43)
24hour Urine	1	<i>"But honestly, I don't know If it's for me from a patients point of view, I would really rather read a whole page of 'these are logistics of the 24-hour urine collection', 'here's some tips to make it easier' rather than three pages around privacy and all that. Like, yeah, I get it but from our point of view it's like.... More of the helpful stuff."</i> (Female, 30s; Participant #2)
Questionnaires	4	<i>"The only thing, as I said before, was maybe the questionnaires could be not so long and cumbersome, or not as much repetitiveness in their questionnaires."</i> (Female, 60s; Participant #19)

**Frequency refers to the number of participants who were coded to the theme*

Table S9: Selected Participant Quotations Regarding Future Direction of ADPKD Research

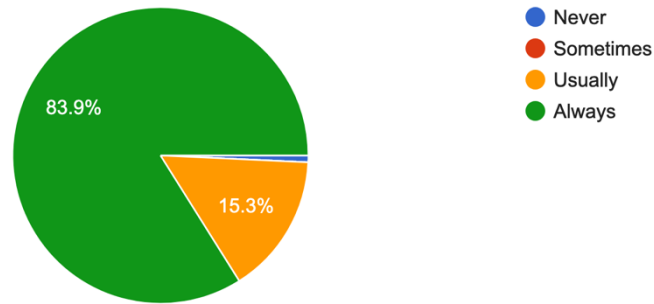
Theme	Frequency* (n =31)	Quotation (Demographics, Participant number)
Medical	16	<p>“My nephrologist that mentioned it, there's a new tablet that is coming out. That would be my first step to try reduce the cysts obviously. Surgery would probably want to be my last step. Actually dialysis would be my last step. I'd do surgery before dialysis. But yeah. I'm happy to try whatever I can to prevent getting onto that dialysis in any way shape or form.” (Female, 50; Participant #4)</p> <p>“A tablet does seem like a good idea to stop my cyst growth.” (Male, 30; Participant #17)</p> <p>“I don't know... gene therapy further down the way.” (Male, 60s, Participant #3)</p>
Lifestyle	11	<p>“Ideal treatment. I think looking at diet, looking at exercise and stress, the impact on the kidneys may be the thing for me.” (Female 50, Participant #43)</p>
Surgical	9	<p>“The cyst getting bigger, is impairing the function, so there's a way to reduce the size of the cyst, which we haven't got to yet. Like a keyhole-type surgery, I meant.” (Male 50; Participant #12)</p> <p>“If the professionals haven't got a cure for it other than so that may be other than, whether an operation to remove large ones would be of any benefit or whether it'd be dangerous or not.” (Male, 50s; Participant #32)</p>
Other	4	<p>“One woman talking about dialysis being a thing of the past in about 30 years and that they're looking at 3D kidneys.” (Female, 70s Participant #33).</p> <p>“Maybe how we can regrow our own kidneys.” (Female, 30s; Participant #50)</p>

*Frequency refers to the number of participants who were coded to the theme. ADPKD, Autosomal Dominant Polycystic Kidney Disease

Figure S1: Participant responses to whether they felt valued as research partners and if they would recommend joining the study to others

Did you feel you were a valued partner in the research process?

137 responses



Would you recommend joining a research study to your family or friends?

138 responses

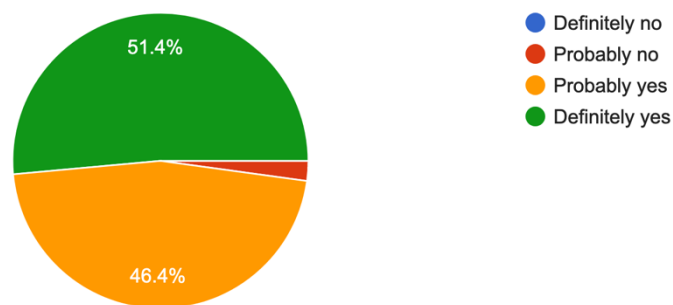
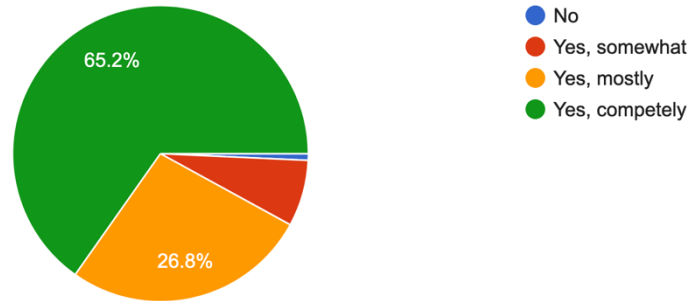


Figure S2: Participant responses regarding factors influencing recruitment (information and discussions, informed consent process and pressure from research staff)

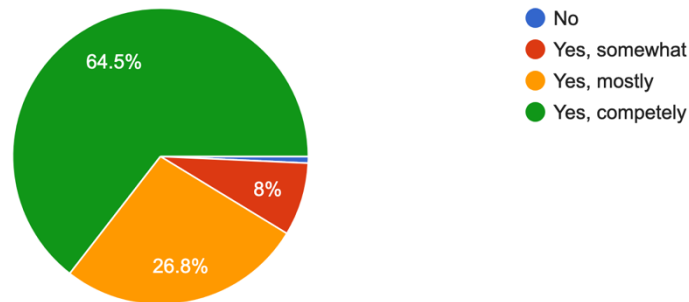
Did the information and discussions you had before participating in the research study prepare you for your experience in the study?

138 responses



Did the informed consent form prepare you for what to expect during the study?

138 responses



During your discussion about the study, did you feel pressure from the research staff to join the study?

138 responses

