

Improving consumer trust in digital health: A mixed methods study involving people living with chronic kidney disease

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Abstract

Aim: To explore preferences, experience and trust in digital health in people living with chronic kidney disease (CKD), and tailor these findings towards solutions that may enhance uptake of digital health services.

Methods: Mixed methods study, with cross-sectional survey and individual interviews with adults living with CKD attending specialist appointments at an Australian metropolitan hospital. Descriptive statistics and Wilcoxon matched-pairs test were used for survey responses and thematic analysis of interview transcripts, both reported on a theme-by-theme basis provided an overall understanding of trust in digital healthcare.

Results: Digital health is changing the way health services are provided, and our results demonstrate that despite limited familiarity, participants are open to learn and adapt to existing digital models of care. Limited exposure to technology may undermine trust in digital health, and telehealth can promote improvements in health literacy. Having the choice in health-care modalities can promote trust, which can arise from trustful relationships with clinicians who demonstrate genuine interest in patient care. Participants expressed more concerns about sharing identity data than health data online and worry about fragmented information among providers. They preferred public health services due to distrust generated by the perceived risk of private sector data commercialisation. Building trust requires increasing awareness of digital health benefits, promoting positive experiences, improving digital literacy and ensuring interoperability and transparency in digital healthcare systems.

Conclusion: People with CKD want to learn and benefit from digital health. Choice and open disclosure on data management and purpose are paramount to building trust.

Keywords

Digital health, telehealth, eHealth, trust, mixed methods studies

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Introduction

The global prevalence of chronic kidney disease (CKD) is over 10% and is often seen in combination with cardiovascular disease or diabetes.¹ In Australia, this number jumps to 44% of people aged 75 years and above.² CKD is a condition that compromises renal function and can eventually lead to kidney failure, requiring a transplant or dialysis treatment. People with CKD may need to self-manage up

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to 90% of their care, with only 10% done with direct clinical support.³

To meet their care needs, nearly half of the CKD population access online information and resources.⁴ While over 70% of Australians want to engage with trustworthy digital health information and systems,⁵ approximately half of the information available online is not evidence-based. This limitation has an impact on consumer confidence in engaging with digital models of care.⁶ Mistrust is reported to be one of Australia's most critical challenges for delivering effective and sustainable digital health care.⁷

Digital health is an umbrella term referring to a range of technologies that can be used to enhance patients' care, specifically to improve access to timely care, and share health information. These include mobile health applications, electronic health records, wearable devices, robotics and artificial intelligence.⁸ Telehealth falls under the umbrella term of digital health and involves consulting a clinician using either video or telephone calls.⁹ There are many advantages and opportunities in using digital health for people with CKD.¹⁰ In fact, digital health tools have been shown to improve CKD outcomes, satisfaction and self-management.^{11,12}

Trust is a complex, and often multidimensional concept.¹³ Trust is a predictor of digital health acceptance,^{14,15} adoption^{16–19} and its use.^{20–23} Trust in digital health can be understood as the belief in the reliability, honesty, and ability of a healthcare system, service or professional to provide digital health services effectively, such as video consultations and electronic health records.^{24,25} In initial surveys of people with CKD, we found a significant association between experience with telephone and video consultations and reported levels of trust,²⁶ demonstrating that exposure to telehealth modalities can influence trust.

With health service providers being the major source of data breaches in Australia,²⁷ a lot of attention to cybersecurity and data privacy has been given to the healthcare space. However, recent evidence calls for the need for additional research on consumer perceptions and trust in various digital health tools, especially amongst people living with chronic health conditions.²⁸ As CKD management entails frequent interactions with the health system and various specialists and services, the CKD population lends itself well for investigating consumer trust in digital health for chronic conditions.

We aimed to explore preferences, experience and trust in engaging with digital health in people living with CKD. These findings will help inform potential solutions to enhance uptake and enhance trust in digital health models of care.

Method

Study design

In this qualitatively driven sequential explanatory mixed methods study (quan → QUAL), a cross-sectional survey

was followed by individual interviews to provide further insight into initial survey results.²⁹ We wanted to gain a deeper understanding of how consumers' preferences, use and experience with digital health initiatives and devices are related to their trust in digital health. This approach allows us to explore both the quantitative aspects, such as patterns and trends in preferences and use of digital health, and the qualitative aspects, such as the personal experiences and perceptions that shape trust. This study received ethical approval from the Metro South Health Human Research Ethics Committee (HREC/2022/QMS/86923) and The University of Queensland Research Ethics and Integrity Office (2022/HE001817). The Mixed Methods Reporting in Rehabilitation and Health Sciences (MMR-RHS) research checklist guided the reporting of mixed methods findings (Supplemental file A).

Setting and participant recruitment

Adults living with stage 3–5 CKD (eGFR < 60 mL/min/1.73 m²), including transplant recipients, attending in-person or telehealth specialist appointments at an Australian metropolitan hospital were invited to participate in an online survey. Participants could nominate in the survey if they were willing to answer additional questions via an interview. Interview options included telephone, video or in person, according to personal preference. Here we report on the digital health component of the survey and the related interview feedback.

Data collection

Survey data was collected from December 2022 until April 2023 using the online platform Qualtrics or paper format (Supplemental file B). The details of the survey development, recruitment, individual consent and cross-sectional results measuring trust and confidence in using telehealth modalities were reported elsewhere.²⁶ De-identified survey data was exported from Qualtrics into Stata (version 17). Two experienced qualitative researchers (MT, SC) not members of the hospital team or familiar with any of the participants conducted individual interviews over the telephone and audio was recorded. Recordings were transcribed by Otter.ai, followed by a manual check to ensure completeness and accuracy. Interviews lasted on average 18 min and included questions about general trust in digital health, quality of care experienced, opinions on safety, privacy and training, as well as concerns and suggestions for the future of digital health (See Supplemental file C for full interview guide). Interview data were manually identified by attributing codes to the participants according to the analysis order (P1, P2, P3, etc). Interviews were continued until no new codes were emerging in the analysis, considering the aim of the study and the quality of the

information obtained, following principles of information power.³⁰

Data analysis

Descriptive statistics of survey data were obtained using Stata (version 17) and reported in frequencies and percentages. Wilcoxon matched-pairs testing was used to compare the means of survey responses, considering the non-normal distribution of the data, reporting only significant results integrated to the qualitative findings, including the means, standard deviations and p-values with statistical significance of $p < 0.05$.

Interview transcripts were independently coded by one investigator (SC) using thematic analysis³¹ and NVivo (version 12) to organise the data. The independent coding followed a process where each transcript was de-identified then reviewed line by line to identify concepts and themes, compared within and across individual interviews, and developed into a coding scheme. A sample of 30% of the transcripts were independently coded by a second investigator (MT) and divergences discussed until consensus. A third qualitative investigator reviewed the entire codebook (JK) for consistency. Representative quotes from participants were selected and agreed upon for each theme and sub-theme to capture the key perspectives of participants.

Data integration

Data integration started with data collection through the sampling framework, where interview participants were selected from the survey respondents.³² Mixed results from the survey and thematic analysis of the interviews were compared and integrated through narrative description by using the weaving approach.^{32,33} Both qualitative and quantitative findings are reported together under themes and subthemes providing an overall understanding of trust in digital healthcare. Participants' quotes representing overall ideas were included in the text and identified by quotation marks.

Results

Demographics

Survey ($n = 156$) and interview ($n = 24$) participant characteristics are summarised in Table 1. Full survey demographics are reported elsewhere²⁶ but collated in Table 1 to illustrate the representativeness of the interview sample. From the 24 people with CKD interviewed, the average time since diagnosis was 17 (± 13.2) years and 15.5 (± 11.7) years since starting treatment. Similar to the survey participants, most interview participants were Australians (87.5%), male (54.2%) and never had a video consultation before (58.3%) (Table 1).

Digital devices in use

A list of digital devices used for personal purposes or to communicate with clinicians (e.g. to exchange health information, to perform telehealth consultations) is collated in Table 2. Mobile phones were the top-ranked device for both purposes.

Familiarity with digital health and telehealth

Around half of interview participants were unsure what digital health was, and three had never heard this term. Other participants said digital health was related to data sharing rather than communication or interaction. Around half of people interviewed defined telehealth as talking to 'doctors on the phone' (P9), and the remainder were aware that telehealth could also be conducted via video. In response to how digital health compared to telehealth, one participant commented 'It feels scarier, I guess' (P20).

Participants listed benefits of digital health such as having prescriptions dispensed and being able to conveniently access personal (routine) test results. Digital health also made them feel safe with their own medical record and medication list available in case of an accident or for travelling. Some people trusted digital health because they believe sharing their health information online can benefit others and increase access to care and convenience. Table 3 summarises survey participants' digital health use, considering different tools and their purposes.

Survey and interview data analysis on trust in digital health resulted in five themes and 17 subthemes. Participants' quotes representing overall ideas were included in the text and extra example quotes for each theme and subtheme are listed in Table 4.

1. Trust in digital health and telehealth modalities

Online misinformation can affect trust. Over 66% of survey participants reported that they used the internet in relation to health-related questions. Some interview participants acknowledged the potential of misinformation to undermine trust considering that it's 'too easy to find things that are incorrect' (P1).

Trust and preferences in digital healthcare modalities. Email was the predominant way of communicating with clinicians using technology (44.4%), over instant messages (38.3%) and mobile apps (19.5%). However, interview participants felt that the telephone was easier, more efficient and comfortable for ongoing and routine care when compared to video. It's easier to wait for a telephone consultation than for a video consultation – you are always ready for a telephone call.

I quite like phone. The phone's fine. That way you know the phone rings and then like you did today, and then we just

Table 1. Characteristics of people with CKD surveyed (n = 156) and interviewed (n = 24).

	Survey (n = 156)	Interview (n = 24)
Gender	<i>n</i> (%)	<i>n</i> (%)
Female	57 (36.5%)	11 (45.8%)
Male	87 (55.8%)	13 (54.2%)
Transgender	1 (0.6%)	0
Did not answer	10 (6.4%)	0
Prefer not to say	1 (0.6%)	0
Age group		
18–20 years	1 (0.6%)	0
21–30 years	2 (1.28%)	0
31–40 years	10 (6.4%)	0
41–50 years	30 (19.2%)	5 (20.8%)
51–60 years	30 (19.2%)	7 (29.2%)
61–70 years	51 (32.7%)	9 (37.5%)
71–80 years	27 (17.3%)	3 (12.5%)
81–90 years	4 (2.56%)	0
Did not answer	1 (0.6%)	0
Employment		
Employed full-time	35 (22.4%)	2 (8.3%)
Employed part-time	18 (11.5%)	6 (25.0%)
Self-employed	9 (5.8%)	1 (4.2%)
Pension (e.g. age or disability pension)	59 (37.8%)	8 (33.3%)
Self-funded retiree	25 (16.0%)	6 (25.0%)
Unemployed/job-seeking	4 (2.6%)	1 (4.2%)
Other	6 (3.8%)	0
Education		
Primary school	7 (4.5%)	0

(continued)

Table 1. Continued.

	Survey (n = 156)	Interview (n = 24)
High school grade 10	28 (17.9%)	5 (20.8%)
High school grade 12	24 (15.4%)	2 (8.3%)
Technical or trade qualification	40 (25.6%)	4 (16.7%)
Undergraduate degree	29 (18.6%)	7 (29.2%)
Postgraduate degree	27 (17.3%)	6 (25.0%)
Did not answer	1 (0.6%)	0
Frequency of healthcare consultations		
At least once a week	12 (7.7%)	3 (12.5%)
At least once a month	54 (34.6%)	13 (54.2%)
Every 2 months	62 (39.7%)	4 (16.7%)
Every 3 months	17 (10.9%)	4 (16.7%)
Experience with telephone consultations		
Yes	150 (96.1%)	24 (100.0%)
No	5 (3.2%)	0
Did not answer	1 (0.6%)	0
Experience with video consultations		
Yes	44 (28.2%)	10 (41.7%)
No	108 (69.2%)	14 (58.3%)
Did not answer	4 (2.6%)	0
Total	156 (100.0%)	24 (100.0%)

talk rather than sending me a link, having to click on the link and then waiting for them to come into the office. Because sometimes it can be 40 minutes before they actually click on the link. (P24)

People living remotely appreciate telehealth more, which can be used as a triage mechanism for better arrangements for in-person appointments. Some interview participants trusted telephone and video equally, though they don't always like looking at themselves on a video saying, 'it's too distracting' (P23).

Table 2. Digital devices for personal use and for communicating with clinicians.

Digital devices	Usage	
	Personal (n = 154) n (%)	Telehealth (n = 155) n (%)
Mobile phone	151 (98.1%)	146 (94.2%)
Landline	40 (26.0%)	23 (14.8%)
Tablet	65 (42.2%)	19 (12.3%)
Laptop	85 (55.2%)	48 (20.0%)
Desktop computer	56 (36.4%)	-
Smartwatch	36 (23.4%)	-
Smart TV	62 (40.3%)	-
Smart speaker	17 (11.0%)	-
Wi-Fi/Bluetooth connected device	43 (27.9%)	-
Other	5 (3.2%)	2 (1.3%)
I don't use any of these devices	2 (1.3%)	3 (1.9%)

Others trust video more than the telephone as the visual clues allow them to check the identity of the person they are interacting with, helping to avoid scams. Also, they believed video promotes better interaction, and their clinician can see their body language and physical changes. Video was particularly preferred over the telephone for counselling.

I think a video one is better when you're trying to show some form of either a symptom or an issue you have... As I said for me, if you've got swollen ankles. Yes, in some cases if I had them it would be easier for the doctor to be able to see that. Or if they asked me questions in relation to abrasions or bruising it's easier when they can physically see what we're talking about. (P16)

For a video call to work well, interview participants said that people need to have an appropriate device with a big enough screen for people to see clearly. However, survey data (Table 2) shows that mobile phones are the top-ranked devices used to communicate with clinicians (94.2%).

Security features and reassurances like 'standards and digital security' (P4) instilled trust in digital applications. Interview participants felt overall there are good security systems in place, but features such as two-factor

authentication and encryption contribute to even better overall trust in digital activities.

I suppose there's things... I wouldn't bank with somewhere that didn't have two factor authentication and some kind of code through my phone. If it didn't have that it would be a big red flag. It's kind of an implicit standard that I would expect. (P13)

There are encryption programmes out there that can't be broken... So those same encryption programmes can be used to encrypt the medical data. (P8)

Comparing trust in telehealth to in-person appointments.

Interview participants preferred in-person consultations to check for things that could be potentially missed on the telephone, such as complications in their disease management, or after long periods without seeing the doctor. A group of consumers believed that not everything can be captured or is appropriate by video, when in-person provides a better-quality service and is a more natural way to communicate given that 'people often adopt different personalities when they're on screen' (P2).

Consumer choice of care modality can impact trust. If given a choice of modality, in-person consultations were favoured

Table 3. Digital health use and communication with clinicians.

Purpose	Device	Examples given to participants (not restrictive)	Yes n (%)	No n (%)	Unsure n (%)
Automated symptom checker	Mobile app (n = 152)	Babylon app	13 (8.5%)	137 (90.1%)	1 (1.3%)
	Website (n = 152)	None	39 (25.7%)	107 (70.4%)	6 (3.9%)
Telehealth	Email (n = 153)	None	68 (44.4%)	82 (53.6%)	3 (2.0%)
	Instant messaging (n = 154)	SMS, WhatsApp, Messenger	59 (38.3%)	93 (60.4%)	2 (1.3%)
Telehealth or to upload/access data	Mobile app (n = 154)	Better Health, Teladoc, MySugr App, Apple Health	30 (19.5%)	121 (78.6%)	3 (2.0%)
Search for health-related answers	Social media (n = 154)	Facebook, Twitter/X, Instagram	25 (16.2%)	128 (83.1%)	1 (0.6%)
	Internet search engine (n = 154)	Google, Bing, Yahoo	102 (66.2%)	50 (32.5%)	2 (1.3%)

by 25.2% of survey participants, 5.2% preferred the telephone and 0.6% would choose video. The remaining proportion of participants preferred a combination of modalities (hybrid model), depending on the complexity and nature of the problem (65.1%), or they did not have a preference (3.9%). Similarly, interview participants would trust a hybrid model ‘as long as there’s always an option to see a doctor if you think you really need to’ (P22). Sometimes the condition can get serious, and consumers need the reassurance that they will be heard if they identify something unusual.

It would be good to have as a patient the option to say what do you want for your next appointment - telehealth or face to face [in-person]? Whether that’s like I said, in my situation, I wasn’t really asked. I was pretty much just told we’ll do a telehealth. (P21)

Some interview participants said they lack choice on the care modality and ‘nobody’s ever actually said to me “oh do you want one [video consultation]?”’ (P10). Others said they would like to have the choice, but that telehealth should not be the only option available. For others, the choice is already there and ‘you can request actually to go and see them if you’d rather’ (P22).

2. The relationship between digital health literacy and trust

People are eager to learn. Interview participants who had never used video to communicate with their clinicians said they were open to learning or trying something new.

They highlighted the need for people to feel comfortable with the technology and learn new skills for telehealth to work. Information sessions, training, video tutorials, in-person onboarding or support during the appointment were thought to be helpful.

Lower exposure to technology can decrease trust. Assumptions that ‘older people are not tech-savvy’ (P13) were common among interviewees. Older people not being exposed to video technology also resulted in comments such as, ‘I’m old, I don’t trust technology’ (P20).

Telehealth can promote health literacy. Interview participants stressed the importance of knowing about their own condition to be able to have a successful telephone consultation, and that telehealth is helping to increase self-management and self-efficacy.

Telehealth sort of makes me be more organised rather than on the day answering questions, I have to have my information before ready to go because I’m going to waste time or whatever then you’re sort of fumbling around looking for information. (P16)

3. Trust and privacy concerns

Differentiating trust in sharing health data from identity data online. Overall, survey participants did not like sharing their personal data over telehealth whether it was with a new or regular clinician. However, when comparing

Table 4. Additional example quotes from interview participants for each theme and subtheme.

Theme/subtheme	Example quotes
1. Trust in digital health and telehealth modalities	
<i>Online misinformation can affect trust</i>	<p><i>Just have to look at the emergence of the anti-vaccination [...] some of the claims and how outlandish they are. Ill-informed. That comes from a position of people who've been fed information that they haven't, I suppose, critically thought through. And they're buying into a narrative that's entirely false. (P13)</i></p> <p><i>When I do go and see the doctor and they go, 'Oh, you're short this vitamin.' And I'm like, 'Oh, what is that in?' and they look at me and they go, 'Well you just take this tablet.' And I'm like, 'No, like, don't worry. I'll Google it. I'll find out'. (P5)</i></p>
<i>Trust and preferences in digital healthcare modalities</i>	<p><i>I think I trust both [telephone and video] equally I just don't particularly like looking at myself on the video call. (P5)</i></p> <p><i>There was one particular conversation where she remarked that she thought I sounded a lot better, which I'm certainly a bit better. That's true enough. But what she didn't know was that while she was talking to me, I was actually a little bit elevated, I was also very agitated. So she was unable to see on the telephone that I was pacing at the time. That information she would only have if she had asked me about that or it had been in person." (P18)</i></p>
<i>Comparing trust in telehealth to in-person appointments</i>	<p><i>"Sometimes, like as a result of a telehealth appointment then they'll say 'Yeah, I probably should see you, how about you come in'. (P22)</i></p> <p><i>People often adopt different personalities when they're on screen. [...] People don't feel at ease with technology, not 100% at ease. (P2)</i></p>
<i>Consumer choice of care modality can impact trust</i>	<p><i>They might make you a telehealth appointment, but you can request actually to go and see them if you'd rather. Like sometimes, you think, no I really need them to look at something or whatever, well, then you can go in, get an appointment. There is [a choice on the modality of care], it's not absolute." (P22)</i></p> <p><i>"I'm absolutely fine with having telephone or the Zoom calls. As long as there's always an option to see a doctor if you think you really need to. (P22)</i></p>
2. The relationship between digital health literacy and trust	
<i>People are eager to learn</i>	<i>I think if their doctors or hospital or a district, whatever it may be, said we're going to try and use this more, which is convenient to a patient and they were going to hold information sessions, I would imagine a majority of people would be happy to do that. Most people don't like having to public transport or drive and find somewhere to park or walk up the hill. I think if the education was there, I think most people would pick it up on it. (P16)</i>
<i>Lower exposure to technology can decrease trust</i>	<p><i>My parents, they really don't trust computers because they don't know how they work. So, the general idea that they use to their more face to face [in-person] people they always have, as you get younger, you've had less and less face to face [in-person] contact. (P8)</i></p> <p><i>I'm old, I don't trust technology. (P20)</i></p>
<i>Telehealth can promote health literacy</i>	<i>I've been a patient at the [hospital] for the best part of 10 years, I understand the routine on what they're going to request from me and what I should be</i>

(continued)

Table 4. Continued.

Theme/subtheme	Example quotes
	<p><i>preparing to have ready for them. So, telehealth sort of makes me be more organised. Rather than on the day answering questions, I have to have my information before ready to go because I'm going to waste time or whatever then you're sort of fumbling around looking for information. (P16)</i></p> <p><i>Information is exchanged digitally either through text messages with blood test results and things. I think a lot of people wouldn't be savvy enough to understand and look at a blood test result. And so therefore a lot of people it wouldn't suit. There are a lot of people I'm sure like myself that would be comfortable with that. (P21)</i></p>
3. Trust and privacy concerns	
<i>Differentiating trust in sharing health data from identity data online</i>	<p><i>What are they gonna do with it? They can't, there's nothing... I wouldn't be concerned if other people found out. (P23)</i></p> <p><i>Even if it were to sort of be leaked out or whatever I know when people were concerned about allowing any medical professional or the police at times to access your medical records. And I was never worried about that. (P24)</i></p>
<i>Trust can be undermined by commercialisation intent</i>	<p><i>It's [data protection procedures] a government thing, that's all as protected as it's ever going to get. And once again, you know, I don't really care if people know I've got a wart on my little toe or something [laughs]. (P10)</i></p> <p><i>I think there is privacy in the public sector because I do I get just about everything done in the public system. And I think in that system probably, okay, yes. But in the private system, I think money plays to bigger part. And it is a big concern of mine were around, you know, there's too much privatisation in the health system. (P2)</i></p>
<i>Sharing health information across clinicians can promote trust</i>	<p><i>My biggest concern is when it's [health data] not transferred between healthcare providers! (P13)</i></p> <p><i>There are great advances in the digital health and especially the ability for me to go to a separate doctor who then has access to all my medical records. For me, personally, I don't care if I could print it in the newspaper. I wouldn't care about my mess. (P8)</i></p> <p><i>Basically, you have to, if you're going to let them do their job, and heal you, you have to have full faith in them. (P20)</i></p>
4. Trust in provider can be extended to trust in digital health	
<i>Aligned interests can promote trust</i>	<i>I really think it's [telehealth] something that should always be there. It's really good, and I just feel really spoiled in a way when you get these calls, and you think, "Oh, they care about me!" So it is really good. (P19)</i>
<i>Trust in a known provider can be transferred to digital health</i>	<p><i>I like telehealth. I've used telehealth during COVID. I know my doctors very well because I've been going to my doctors a long time. So, it works well for them and for me. (P16)</i></p> <p><i>I trust that the doctors [act] in everybody's interests to keep up with... like in every profession, you have to keep up with latest trends and more knowledge and all the rest of it. (P24)</i></p>

(continued)

Table 4. Continued.

Theme/subtheme	Example quotes
5. Increasing trust in telehealth and digital health in the future	
Consumer digital health literacy and awareness of telehealth benefits need to be improved	<p>At the moment you've got that much out there that I don't understand. (P15)</p> <p>If you try to teach my neighbour [how to connect via video], he'll kind of look at you and go: 'I have no idea what you're talking about' (laughs). Same age as me, he's never been interested in computers so far. If it became necessary, so you'd have to put it in basic terms. And why this is as secure as going to see somebody face to face [in-person]. And I find you would have greater acceptance of it. [...] Yeah, people would be more trust-minded and would allow them to transition to it. With that trust, they would then use it more and more because they have more reliance on it. (P8)</p>
Embracing hybrid models of care	<p>I think most of your appointments could be via video conferencing, type idea. But I think about once a year, as I've said before, you need to visit, see them. (P12)</p> <p>They tend to tell me rather than ask me whether 'Are you happy to do your next phone appointment or would you like to come in?'. They tend to make that decision for me. I guess it gets back to, the doctors probably do that because they probably feel that most patients don't really know enough about their own medical condition to make a decision. (P21)</p>
Promote video consultations	Possibly some worthwhile advertising but more sort of letting people know what telehealth does for you. (P1)
Interoperability could promote trust and integrated care	<p>The Australian Government is absolutely disgustingly bad at linking the various systems that we have across Australia. It's like coming to a different country called Queensland. And I lived in a country called Victoria, yet we all live in Australia. (P21)</p> <p>I like the notion of having apps connected to your provider. The way you know, a lot of information should be shared across different providers through whatever it's called, My Health [...] Some kind of trusted platform, I mean, I use an iPhone so if there was some kind of app that was secure and trusted that my health provider can get access to that [...]. And I think that's probably more of a role in the future. Because if there's a way that somebody could actually enter your Apple Watch and tell you if you're having some irregular ECG. (P13)</p>
Regulation and transparency on digital health appropriateness	<p>I guess they just have to make sure there's like, checks in place or passwords and you know what I mean? They've just got to have a decent IT team and system to make sure it, like people trust the banking. So you know, why wouldn't they trust as long as the correct things are in place? (P5)</p> <p>Being transparent in the way digital health is managed, and what it is used for and the restrictions around disease. (P7)</p>

telehealth modalities, people significantly ($p < 0.001$) prefer to share personal data over the telephone (regular clinician: mean 3.88, SD 0.07; new clinician: 3.49, SD 0.09) rather than video (regular clinician: mean 3.78, SD 0.08; new clinician: 3.37, SD 0.09), with both new and regular clinicians.

Interviews provided further insights, differentiating between health data and personal identity data. Mostly,

participants are not worried about sharing their health data online and did not see great harm in data leaks as they would not be the only ones affected. They did not feel that their health data was particularly confidential. As one participant said, 'I think if anyone looked at my records, they'd go, "Oh God, leave her alone" [laughs]'. (P20) What interview participants fear is identity fraud if their identification data gets leaked.

Trust can be undermined by commercialisation intent. Some interviewees expressed a strong preference for controlling their data sharing, fearing unauthorised access and commercial exploitation by private companies. They trust public healthcare providers more than private ones with their data.

You don't know what's ahead with a private company. I just, I just wouldn't be quite confident with that. (P6)

Sharing health information across clinicians can promote trust. Interview participants were more concerned if their health data did not get shared between the clinicians involved in their care. They also would like to have access to their health data at any time and choose who they share that information with. Participants trusted electronic medical records and felt the benefits of digital health are worth the risks.

I take a list of all my medications, a brief medical history everywhere I go. So, anything, if there was some sort of data leak, honestly, like that wouldn't be ideal, but I think the threat of that versus me being able to easily access that information, I'd rather. I think it's worth the risk. (P22)

4. Trust in provider can be extended to trust in digital health

Aligned interests can promote trust. Interview participants trust telehealth when they feel that clinicians show genuine interest in their health. Many participants highlighted that they trust clinicians that provide quality care, whether they see them in person or via telehealth.

Trust in a known provider can be transferred to digital health.

Interview participants wanted to see the same clinician rather than a new staff member every appointment. Participants stressed that having a regular clinician or team who knows their medical history and their latest tests before a telehealth appointment can promote trust. They would trust telehealth or other digital health modalities if their doctor recommended them. Participants believe that their doctor would act in their best interest and keep up to date about safe and effective technological tools.

If it's your regular doctor that you see all the time that already knows your medical history, then you can do much more by telehealth, than if you were to call a doctor that you had never seen before. You really want to go and meet them in person first, so that they know you and they know your medical history before you even begin. (P10)

Interview participants felt this prior knowledge enabled clinicians to prescribe confidently over the telephone and

made them feel safe to share their data. Survey results showed that participants significantly ($p < 0.001$) preferred to share their data over the telephone with their regular clinician (mean 3.88, SD 0.07) over a new clinician (3.49, SD 0.09). A similar preference for sharing personal data over video consultations with a regular clinician (3.78, SD 0.08) instead of a new clinician (3.37, SD 0.09) was also found ($p < 0.001$).

Some interview participants would prefer video instead of telephone for better trust in the initial telehealth appointment with a new clinician. Other participants trust telehealth with an unknown doctor since 'it's a trusted number [calling] anyway, you're picking up. And it's an appointment that's prior made so you know exactly what's going on. It's not as if it's out of the blue' (P16). Checks in place such as knowing the appointment time and the number calling promoted trust.

5. Increasing trust in telehealth and digital health in the future

Consumer digital health literacy and awareness of telehealth benefits need to be improved. Participants highlighted the importance of increasing their digital literacy, commenting, 'at the moment you've got that much out there that I don't understand' (P15). They wanted adequate technical support for current technologies and services rather than new technology development. Marketing strategies to raise awareness of telehealth benefits can increase trust and reduce resistance to use telehealth.

'I think you've absolutely got to use marketing skills. Just like advertising marketing skills because you can convince people of the need for something that they didn't want in the first place. (P12)

Embracing hybrid models of care. Around half of interviewees and 65.1% of survey participants would like to have the right balance of in-person and telephone consultations, according to their needs and wishes. Keeping appointments over the telephone when the condition is stable would be an option, but there is a fear that the telephone may become too prevalent.

I think we're heading towards the right balance of being able to, like get a quickie repeat prescription on your phone, which is good and still being able to go and visit a doctor in person which is good. And you know, so we're sort of heading there but things...you do kind of wonder at the moment whether things are going too far the other way. (P10)

Promote video consultations. Interview participants emphasised the need to increase awareness and prevalence of

video consultations as an alternative to some in-person appointments.

I think a primary face to face [in-person] is great. But I think as an alternative in most cases, teleconferencing is an absolute must. (P16)

I'd hate to have a talk over the phone. Like a little iPhone or something. The iPad is good. But people with phones, it'd be hard. (P14)

Survey responses showed a significant difference in understanding what types of healthcare they could receive through a telephone (3.79 ± 0.99) versus a video (3.57 ± 0.99) consultation ($p < 0.001$). Survey results also showed 20% of participants would select a new clinician if they did not offer telehealth consultations, whereas 21.9% said they were unsure. The remainder (50.1%) would avoid picking a clinician that did not offer telehealth.

Interoperability could promote trust and integrated care.

Interview participants mentioned the need for a national unique digital health platform to overcome fragmented care by centralising all health data, hosting telehealth consultations and digitising processes such as appointment bookings and confirmations.

The only thing that comes to mind is perhaps having a single trusted platform that everyone dials in and dials out of. [...] Everyone uses different ones. So perhaps if it was one Australian healthcare digital platform that everyone dialled in and dialled out of. Maybe that would be helpful. (P23)

Regulation and transparency on digital health appropriateness.

Participants believed that transparency in health data management processes increases trust in digital health, with data security issues solved, and regulations and clarity around appropriateness of digital health. Also, having a human component to any AI-driven digital health can promote trust.

From a data governance perspective to make sure that there's smooth stewardship all over the place, that data are put to the best use, and protected, and private, similarly if there's a data governance model, engagement, emerging technologies, such as artificial intelligence, that they have a level of regulation, supervision so decisions aren't made solely on the basis of an algorithm. There's some human component to it. (P13)

Participants expressed their hope for telehealth systems to adopt similar security system as banks, as participants tended to trust Internet banking.

Discussion

This study investigated preferences, experience and trust in digital health among individuals with CKD. The primary findings demonstrate that despite limited familiarity with video consultations and other digital health modalities (e.g. online symptom checker or mobile app) compared to telephone consultations, participants were open to learning and adapting to digital health, prioritising existing models over new developments. Participants recognised that limited exposure to technology may undermine trust in digital health, and they highlighted the role of telehealth in improving health literacy. The importance of having the choice in healthcare modalities to promote trust in telehealth was stressed. While most participants communicate with clinicians via mobile devices, they favour larger screens for video consultations. Trust in telehealth was seen to arise from trustful relationships with clinicians who demonstrate genuine interest in the patients' care. Participants expressed more concerns about sharing identity data than health data online and worried about fragmented health information among providers. They preferred public health services due to distrust generated by the fear of commercial exploitation of health data by private companies. Our results provide insights to enhance uptake and develop trustful digital models of care; showing that building trust requires increasing awareness of telehealth benefits, improving digital literacy and ensuring interoperability and transparency in digital healthcare systems.

Sharing personal information online

Study participants are largely unconcerned about sharing their health data online, viewing identity fraud from leaked identification data as the primary risk. A global survey with over 6000 participants from six countries had similar findings where people were not concerned about sharing their health information online, especially if it leads to better care.³⁴ Our study is commensurate with these findings, however, our participants did report concerns about sharing identity data due to potential leaks and identity fraud. A different scenario might arise with priority populations, including those who have stigmatised conditions (e.g. HIV) or criminalised behaviours (e.g. drug use), who might not trust in sharing their health information online.³⁵ Transparency in detailing what information is collected, who can access it and the intended use can be helpful in fostering trust.³⁵

Privacy and data security appear to be less of a concern for people with CKD when it comes to digital health. In contrast to some literature, people in this study were more concerned if their health data did not get shared between different clinicians involved in their care. Lack of communication and fragmented care has caused problems for one in seven Australians who see three or more clinicians for

the same condition.³⁶ Increasing integrated care is a likely benefit of digital health, however, concrete evidence is only just now emerging as integrated digital chronic care systems in Europe have had different maturity levels and evaluation strategies.³⁷

Trust is undermined by fear of commercial exploitation of health data and boosted by giving consumers choice

Another important finding of our study is the consensus among participants that trust can be undermined by fear of commercial exploitation of health data. People with CKD in our study tended to trust public healthcare services more than those provided by the private sector. A national survey reporting public attitudes towards sharing health data with private companies revealed that Australians are concerned about the private sector corporate interests, corruption and profit above health agendas.³⁸ Conversely, it seems that freedom of choice offered by the Australian private sector increases the trust people have in their services.³⁹ Unfortunately, our study could not assess this phenomenon as our participants were public hospital patients. However, we did learn that giving consumers the option to choose between in-person or telehealth appointments can boost trust in telehealth services. And we recognise the critical importance of empowering consumers to sustain telehealth services.⁴⁰ Future investigations could explore how to integrate shared decision-making processes into clinical workflows to address the lack of consumer choice in the modality of care, not yet present in Australia,⁴¹ despite consumers having the right to participate in the decision on the best modality for their care.⁴² This shared decision should also account for variations in telehealth effectiveness and clinical suitability to offer high-quality and safe care.⁴³

Previous research conducted in Australia has found that consumers prefer telehealth for brief consultations, while favouring in-person visits for more complex issues, with familiarity driving a preference for telephone calls.⁴⁴ Our findings are similar, with consumers preferring in-person consultation to check for things potentially missed over the telephone and a belief that video would not capture everything compared to an in-person consultation. That is expected considering the lack of exposure to video according to the results of a cross-sectional study with the same population.²⁶ Neural and behavioural differences between video and in-person interactions have already been reported,⁴⁵ with the latter considered superior. However, the post-COVID healthcare model in Australia relies heavily on telephone consultations to complement in-person care,⁴⁶ and it is known that positive experience predicts trust.²⁶ Further, a recent systematic review found video consultations may be more effective than phone

under certain circumstances,⁴³ which supports a recommendation from participants of this study to promote video consultations.

Positive experience with digital health builds cognitive trust

The rapid advancement yet unequal access opportunities to healthcare technology has widened the gap between those comfortable with digital tools and those who are not. The digital divide is exacerbated by lack of experience and low digital literacy levels, leading to decreased trust and reluctance to adopt telehealth in the future.^{47–49} Our findings suggest a broad range of experiences and feelings towards digital health. But overall, people are open to learning and adapting, and they believe that promoting existing models, such as video consultations, is more beneficial than constantly developing and introducing new technologies.

This study also highlighted that people are more apprehensive about digital health than telehealth, due to their unfamiliarity with digital health tools. One possible explanation for this finding is the difference between cognitive trust, which is based on observed performance, and affective trust, which is influenced by emotions and irrational feelings.⁵⁰ While people may have similar levels of affective trust in both digital health and telehealth, their cognitive trust in digital health is notably lower given the lack of knowledge and exposure. A similar explanation can be adopted for higher trust in telephone consultations compared to video, reported elsewhere.²⁶ This difference could be a factor in why people are hesitant to fully adopt digital healthcare options, particularly video consultations. The longer this lack of familiarity persists, the greater the digital divide can become.

Factors that influence trust in digital health

Authors from other fields, such as preventive health or business, have differentiated personal to contextual factors that influence the decision to trust.^{51,52} Hurley's Decision to Trust Model⁵¹ identifies personal factors – risk tolerance, level of adjustment, and power imbalances – from contextual factors – security, alignment of interests and similarities, perceptions around capability, integrity and benevolence, and levels of communication – which collectively shape individuals' trust decisions.⁵¹ In an attempt to classify our results into Hurley's two domains,⁵³ the themes that hinder trust are mostly related to contextual factors. Personal factors found in this study, such as individual risk tolerance and transferable trust from clinician to the technology, seem to be favourable to the decision to trust digital health. Our participants believed that the benefits of telehealth are worth the risks. They seem to be keen to try and learn new digital health approaches, and although

the power imbalance in the patient-clinician relationship is acknowledged,⁵⁴ consumers trusted that clinicians would act in their best interest. This high trust in clinicians also overlaps some contextual factors, such as perceptions around clinicians' capability, integrity and benevolence. That might explain the transferable trust consumers have in the digital health solution recommended by the clinician reported in this study, reinforcing previous literature on how important the role of the clinician is in digital health adoption.⁵⁵

On the other hand, contextual factors with the potential to influence the decision not to trust, such as concerns around identity data security, online misinformation and the need for regulation and transparency on digital health appropriateness, are issues that should be tackled from the healthcare providers' and decision-makers' perspectives.⁵⁵ Promoting consumer trust in digital health and telehealth models of care widely will continue to generate greater utility,^{56,57} adoption,^{58,59} and acceptance,⁶⁰ optimising the benefits that these modalities of care can provide. Technological solutions such as multi-factor authentication and encryption can be applied to healthcare.⁶¹ These solutions, suggested by our study findings, may increase individuals' trust in digital health modalities.

Implications for practice

To enhance the uptake and sustain the use of digital models of care, building trust among consumers is crucial.^{57,62–64} Our results show that this can be potentially achieved by increasing awareness of the benefits of digital health, improving digital literacy and ensuring transparency in the use and sharing of individual's health data. Giving consumers the choice between digital and in-person care, and integrating shared decision-making processes into clinical workflows, can also promote trust. Addressing concerns about data privacy, particularly regarding identity data, and ensuring seamless communication among healthcare providers are important steps to mitigate fears of fragmented care and data misuse. Additionally, leveraging the trust consumers already have in their clinicians by involving them in promoting digital health options can help bridge the digital divide and foster greater confidence in these technologies.

Strengths and limitations

A strength of this research is the mixed methods design which used both quantitative and qualitative data to explore the topic, overcoming weaknesses of each methodology that would have been present otherwise. A limitation may be that the participants were from a single metropolitan site, with a specific chronic condition and so generalisation of the results about digital health trust may be limited to this patient cohort. However, our participant group was

purposively selected due to the added potential value of digital health interventions to their care (e.g. care is ongoing, involves many test results, and multiple specialists are involved), similar to other chronic conditions such as type 2 diabetes and cardiovascular diseases. Therefore, similar results would be expected from these cohorts. On the other hand, our findings may not be broadly applicable to rural and remote healthcare settings, because the study focused primarily on frequent users of metropolitan health services, who mostly found digital health models convenient and did not seem to face notable access issues. There may also have been a recruitment bias, with high prevalence of people that tend to trust more, as it was requested from them to volunteer and share their personal experiences in a research study, and less trusting or private people may not have volunteered and provided their details. That said, interview participants had varying digital health experiences levels and demographics, and some openly critiqued the government and admitted to not trusting private-for-profit entities, so we are confident our analysis did indeed include a variety of perspectives. Lastly, digital health user fatigue can increase over time, often leading to the abandonment of digital healthcare platforms.⁶⁵ This highlights the need for future research to focus on trust-building interventions that reduce the burden on users, promoting long-term engagement with digital health services.

Conclusion

This study found that people living with CKD have a willingness to embrace digital health despite initial unfamiliarity and lack of experience. Trust in digital health hinges on knowledge, established and even relationships with clinicians, and transparent and interoperable systems. Educating patients on digital health benefits, improving digital literacy, and addressing privacy concerns, especially in relation to fear of commercial exploitation of health data and protecting identity data are key to fostering trust and advancing digital healthcare adoption. Future research should focus on effective and safe hybrid models of care, integrating consumers' choice of modalities into clinical and administrative workflows. Strategies to enhance consumers' digital health literacy and improve consumer experience are essential to build and sustain trust and confidence in using these hybrid models.

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