



Getting the most out of remote care: Co-developing a Toolkit to improve the delivery of remote kidney care appointments for underserved groups

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Abstract

Background: Telephone and video appointments are still common post-pandemic, with an estimated 25%–50% of kidney appointments in the United Kingdom still conducted remotely. This is important as remote consultations may exacerbate pre-existing inequalities in those from underserved groups. Those from underserved groups are often not represented in health research and include those with learning disability, mental health needs, hearing/sight problems, young/older people, those from ethnic minority groups.

Objectives: The aim was to develop a Toolkit to improve the quality of remote kidney care appointments for people from different underserved groups.

Design: A parallel mixed methods approach with semistructured interviews/focus groups and survey. We also conducted workshops to develop and validate the Toolkit.

Participants: Seventy-five renal staff members completed the survey and 21 patients participated in the interviews and focus groups. Patients ($n = 11$) and staff ($n = 10$) took part in the Toolkit development workshop, and patients ($n = 13$) took part in the Toolkit validation workshop.

Results: Four themes from interviews/focus groups suggested areas in which remote appointments could be improved. Themes were quality of appointment, patient empowerment, patient–practitioner relationship and unique needs for underserved groups. Staff reported difficulty building rapport, confidentiality issues, confidence about diagnosis/advice given, technical difficulties and shared decision making.

Conclusion: This study is the first to explore experiences of remote appointments among both staff and those from underserved groups living with kidney disease in the United Kingdom. While remote appointments can be beneficial, our findings

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indicate that remote consultations need optimisation to meet the needs of patients. The project findings informed the development of a Toolkit which will be widely promoted and accessible in the United Kingdom during 2024.

KEYWORDS

education, patient involvement, quality improvement

INTRODUCTION

Chronic kidney disease (CKD) is a global health issue, with 697.5 million cases of all-stage CKD recorded in 2017, with a global prevalence of 9.1% (Bikbov et al., 2020). Traditionally, care of patients with CKD involves regular scheduled hospital visits (Grove et al., 2023). However, since 2019, the coronavirus disease (COVID-19) pandemic resulted in a rapid shift to remote kidney care, with the introduction of digital technologies and increased reliance on telehealth. Telehealth or remote care refers to synchronous (telephone or video) and asynchronous (patient portals or online medical records) clinical practices that allow healthcare professionals to provide patient care at a distance (Sikka et al., 2021; Wosik et al., 2020). Remote appointments have since remained a central component of healthcare delivery, as they can provide increased accessibility to care and effectively address a range of patient needs (Rohatgi et al., 2017). However, our previous scoping review (Ewart et al., 2022) found that some people struggled with remote appointments, potentially more likely to be those who are from underserved groups. Underserved groups have specific needs and characteristics such as high health-care burden and unique difference in how they can respond or engage with healthcare systems (National Institute for Health Research, 2022).

LITERATURE REVIEW

Remote appointments (telephone or video) continue to proliferate beyond the pandemic. In the United Kingdom in 2022, around 25% of all National Health Service (NHS) appointments were remote (NHS Digital 2023). In 2023, anecdotal evidence suggests up to 50% renal clinics in the United Kingdom (especially general nephrology or transplant) continue to be remote, with wide variation between hospitals.

A scoping review found that patients with CKD reported overall satisfaction with remote care services and benefits included increased convenience, involvement in their own care and increased patient safety (Ewart et al., 2022). Grove et al. (2023) found that remote follow-up of patient reported outcome measures (PROMs) may increase patient engagement and knowledge of disease, improve patient-practitioner communication and have increased convenience. From the practitioner perspective, benefits include convenience and increased family engagement in patient care (DePuccio

et al., 2022), fewer missed appointments (Lew et al., 2021), cost saving (Hull et al., 2020) and increased efficiency of appointments (Lightfoot et al., 2022).

While opportunities for remote consultations may enhance the lives of some people living with CKD, drawbacks include concerns about consultation quality due to limited physical examination and loss of social connection (Ladin et al., 2021). Ewart et al. (2022) found that technical difficulties, privacy and loss of interpersonal communication negatively impact patients' experience of remote care, while access to technology, an existing patient-practitioner relationship and a stable illness contributed to successful remote consultations. Practitioners have also reported challenges such as reduced ability for physical examination, communication difficulties (e.g., hard of hearing, non-English speakers), lack of confidentiality and delayed intervention (Kanavaki et al., 2021; Lightfoot et al., 2022).

Pitfalls of remote care may create and perpetuate existing health inequalities in underserved communities (Bonner et al., 2018; Stauss et al., 2021; Walker et al., 2019). Ladin et al. (2021) found lower satisfaction with telehealth among older patients with lower socioeconomic status and among patients identifying as Black, Hispanic and Native American. Despite reporting poorer health outcomes (Clark-Cutaia et al., 2021), underserved groups are underrepresented in health and social care research. The reasons for underrepresentation are complex, but possible barriers include language, sociocultural issues resulting in unfair access to health services and inequalities, lack of research understanding and trust and practical issues such as lack of transport and costs (Passmore et al., 2021; Shepherd, 2020). Further studies are required to understand access to and quality of care for those from underserved groups to inform the ongoing delivery of remote kidney care.

AIMS AND OBJECTIVES

The aim of this mixed-methods quality improvement project was to develop a Toolkit to highlight best practice and improve the quality of remote kidney care appointments for people from underserved groups. The specific objectives were:

- Conduct patient interviews/focus groups to understand the barriers and facilitators to remote care among different underserved groups living with kidney disease

- Conduct a survey to understand practitioners' perceptions of barriers and facilitators to remote care among different underserved groups.
- Conduct stakeholder workshops to co-design a remote care Toolkit to be disseminated in the United Kingdom.

We employed the reporting framework suggested by the Standards for Quality Improvement Reporting Excellence (SQUIRE) publication guidelines for reporting healthcare quality improvement research (Ogrinc et al., 2015).

MATERIALS AND METHODS

Our project team was diverse: one person living with kidney disease, one community leader from Healthwatch (an independent UK organisation that helps people share their views and experiences of health care), the project lead (a kidney nurse), three part-time research assistants, three kidney doctors and a kidney psychologist.

The study used a mixed methods approach with semistructured interviews and focus groups, a structured survey and Toolkit development workshops in parallel design (Creswell & Clark, 2017).

Stage one: Identifying and establishing facilitators for patient interviews and focus groups

Underserved groups are defined by National Institute for Health Research (2022), as those with lower inclusion in research, higher health care burden and differences in how groups respond to or engage with healthcare interventions compared to the general population. We sought general and kidney care voluntary and charitable organisations and influential individuals to act as facilitators for patient recruitment, as these methods have been recommended to improve recruitment of underserved groups (Morris et al., 2022).

Stage two: Patient interviews and focus groups

Over a 6-month period, we worked with community facilitators to recruit people who were:

- at risk of or living with kidney disease (CKD stage 3–5);
- living in the United Kingdom;
- aged 18 years and above;
- identified with one or more of the following underserved groups: ethnic minorities (those from a community that has different national/cultural traditions from the main UK population), had mental health needs, learning disability/difference, hearing or sight difficulties, young people (18–30 years).

Multiple recruitment strategies were used to reach participants. Study materials included a project website, Twitter page and posters. Materials were sent via social media (involving influential people who live with kidney disease), kidney charities, kidney patient associations and voluntary organisations (both general and kidney-specific organisations) who disseminated study information through their community. Participants were given the choice of participating face-to-face or online, and via an interview or focus group. No particular criteria were used during the recruitment stage of the focus groups. Due to the initial constraints in enrolment, we separately invited members of two familiar kidney patient networks to attend the focus groups. Both groups comprised men and women over the age of 18 living with kidney disease. All participants were financially compensated for taking part.

Interviews and focus groups followed a semistructured approach and were guided by a topic schedule (see Supporting Information S1: File 1). Questions focused on their experience, barriers and facilitators to remote care and recommendations to improve remote care experiences among patients. All interviews and focus groups were audio recorded with consent, transcribed verbatim and analysed independently by two members (P. T. and C. E.) of the project team (with cross comparison on 10% analysis) using the six phases of thematic analysis outlined by Braun and Clarke (2006): (i) Familiarisation with the data; (ii) Generation of initial codes; (iii) Search for themes; (iv) Review of themes; (v) Categorisation of themes and (vi) Production of the report. The final themes were agreed collectively among the project team.

Stage three: Staff survey

We investigated renal staff perspectives on the delivery of remote renal care among underserved groups in the United Kingdom using an online survey. All renal staff who had conducted remote consultations (video or telephone) in the past year in the United Kingdom were eligible to participate and all primary and secondary health care professionals working in all healthcare settings were invited, including nurses, psychologists, dietitians, therapists, pharmacists and doctors. Our aim was to rapidly recruit a large ($n = 100$) and varied sample size recruited via professional or university organisations and networks, via email and social media.

The staff survey was developed by reviewing our previous scoping review (Ewart et al., 2022) and adapting Lightfoot et al. (2022) survey which examined the views and experiences of patients and clinicians of remote kidney healthcare during the COVID-19 pandemic. The draft survey was reviewed by the wider project team and converted into an online format using Jisc (<https://www.onlinesurveys.ac.uk/>). Pilot testing was then conducted with four clinicians (one nurse, one dietitian and two kidney doctors). Survey questions were structured and concluded with open-ended questions. See Supporting Information: File 2 for staff survey. Descriptive statistics (means, frequency) were conducted.

Stage 4: Toolkit development

Stakeholder workshops were conducted with patients and staff to co-develop recommendations for the Toolkit, a robust and inclusive methodology, aligning with patient-centred principles (Tembo et al., 2021). A data-led approach was used to inform workshop discussions and Toolkit recommendations using themes identified from interviews/focus groups and staff surveys to identify potential strategies for the remote consultation Toolkit. Discussions were facilitated to evaluate Toolkit content and to consider the accessibility, feasibility, acceptability and effectiveness to implement recommendations. Workshops were facilitated by researchers, and we conducted two patient workshops, in-person at the university ($n = 5$) and online ($n = 6$) and one wider project team workshop ($n = 10$) online on Microsoft Teams. Findings from the workshop were then collated and recommendations were used to inform the draft Toolkit.

Stage 5: Toolkit validation

The draft Toolkit was circulated amongst the project team, and all those who attended the workshops via email for feedback and validation. Patients ($n = 5$) attended a final workshop online to review and refine the draft Toolkit. Feedback was then collated, and amendments were included into the final Toolkit.

ETHICAL APPROVAL

University ethical approval from London South Bank University to undertake the staff survey, patient interviews and focus groups was granted in January 2023. Health Research Authority (HRA) approval was not required as participants were not recruited via the National Health Service.

RESULTS

Patient interviews/focus groups

During the first 3 months of recruitment, participant uptake was limited ($n = 7$), so several additional recruitment strategies were adopted. First, recruitment materials were translated into Bengali and Urdu. Second, a recruitment video was created by the project team patient representative and translated into Bengali and Urdu. Third, financial incentives for participation were increased. This resulted in an additional 14 participants. The project team also attempted to arrange in-person visits to the facilitator community centres and local religious centres, but this proved unsuccessful, mostly due to limited engagement from facilitators and time constraints.

Thirty potential participants indicated their interest in participating and were invited to an interview/focus group. Recruitment

uptake was high with 21 participants taking part (70%). Non-participants were those with hearing and sight issues ($n = 1$), Caribbean heritage ($n = 1$), Asian heritage ($n = 1$), African heritage ($n = 2$), young people ($n = 1$) and unknown ($n = 3$). Reasons for not participating included poor health (22.2%), did not meet eligibility criteria (11.1%), no response (66.6%). No clear relationship was identified between demographics and nonparticipants. The final sample included 21 participants who identified their ethnicity as African ($n = 1$), Caribbean ($n = 4$), Asian ($n = 6$), Asian Indian descent ($n = 1$) those with hearing and sight issues ($n = 2$), those with mental health needs ($n = 5$), those with learning disabilities/differences ($n = 1$) and young people ($n = 1$). All interviews ($n = 11$) and focus groups ($n = 10$ people) were conducted online according to participant preference.

We identified four themes and related subthemes which are described in the following section with supporting quotations. See Supporting Information: File 3 for coding tree.

The themes were: quality of appointment (need for physical examination, delayed appointments, feeling rushed, loss of interpersonal communication), patient empowerment (health-seeking behaviour, patient choice, health literacy), patient-practitioner relationship (existing rapport, trust) and unique needs for underserved groups (health conditions, language barriers, digital literacy, ethnic minority groups). Themes and illustrative quotes are presented in Table 1.

Quality of appointment

Need for physical examination

Several patients felt the lack of physical examination during remote consultations negatively impacted the quality of their appointments, for example missed signs and symptoms, which was a particular concern given the complexity of health issues associated with kidney disease.

Delayed appointments

Most patients reported that practitioners did not call at the agreed time or failed to communicate changes, leaving patients waiting for a call. Some patients said that it was not always clear when their practitioner was calling, leaving patients feeling frustrated and subsequently affecting the perceived quality of remote consultations.

Feeling rushed

Patients felt that it was difficult to ask questions during remote appointments, often feeling rushed by their practitioner. Some participants expressed not feeling heard or understood during the appointments, preventing them from asking questions or sharing. Patients reported that having the time and space to ask questions improved the quality of their appointments.

TABLE 1 Themes, subthemes, codes and quotes.

Theme	Subtheme	Code	Quotes
Quality of appointments	Need for physical examination	Physical examination	'It's really inappropriate because you can't look at someone's ankles and see if they're swollen; you can't tell if people are telling you the truth ... You can't tell if they drink enough; you can't look at their skin and see if they're dehydrated. It's not appropriate'.
	Delayed appointments	Time of call	'It was okay but you could be waiting up to an hour before they would come and "see" you. So, if your appointment was at say eleven, you would keep your phone on or your laptop on until they allow you to enter the room'
	Feeling rushed	Difficulty asking questions	'It's hard to do that with some people because they can be very brisk. And, even though they say, "Have you got any questions?" the way they say it is not actually inviting you to say any of them'.
		Feeling heard	'...With some of them, because I didn't think they were listening or interested, then you just don't bother telling them...'
	Loss of interpersonal communication	Digital communication	'There's no replacement for face-to-face. There's a whole ... You don't get the whole empathy; you don't get the ... I'm trying to think of the words. You just don't get the whole vibes of it: of face-to-face. There's a barrier. If it's on the phone, you can't see anyone's facial expressions; you can't ask to see a copy of the scan they're talking about or anything. There are limitations. In person, you can show them things that they can't see, you can ask to see something. If there's something you don't understand, they can turn something over and draw a little scribble on the back of it or give you a note to take away. You just can't replace it'.
		Nonverbal cues	'I had a lot of questions, especially when you're virtual, if you're either not getting any straight answers or if you feel like you're taking someone's time up, if you hear any sigh, any pause, anything like that, you're not going to continue with your questions, even if they're important to you. Whereas if you're in-person and you can see the person and you can read their body language, you know you've got them in the room, I think you're more likely to have the confidence to press on, even if you can tell that there's not a huge amount of enthusiasm to be working through your list of questions'
Patient empowerment	Health seeking behaviour	Note taking	'If I don't have my notes nearby, I'll forget stuff that I wanted to say, but I write it down because I've talked to my therapist about how I can feel more in control of those things'.
		Asking questions	'I just didn't have the honesty to say, "I haven't understood a word. Can you repeat that, or can you say it more slowly?" I just pretended I could hear everything'.
		Active patient participation in consultation	'But because I want to have control, I can force it a bit because I think no, you're not doing this to me, we'll discuss it together. But it's really difficult, anything doctors can do or say can make someone feel like they're properly included'
	Patient choice	Mode of consultation	'I felt it was more compulsory and not an option, but it was okay because I didn't want to have a break in this journey, so we have to take it'.
		Patient needs and accommodations	'They were really frustrating because they wouldn't do any video appointments. They said they didn't do video appointments. And I was like, "Well, how am I going to manage them?" They know I don't do the telephone... They

(Continues)

TABLE 1 (Continued)

Theme	Subtheme	Code	Quotes
			just said they don't offer them and there didn't seem to be any exceptions'. [person with hard of hearing]
	Health literacy	Patient requests	'...I don't particularly want to be talking to a man on the phone about it...'
		Patient knowledge and experience	'Trying to educate myself on things has helped because it means I feel more on a level footing when it comes to understanding what they're saying, because otherwise they're just reading off a computer screen to me.... But because I want to have control'
		Practitioner explanations and education	'If he doesn't bring it up, it can't be that serious.' I've never had any follow-up on it. But I've looked it up so I know it needs treatment and it can be precancerous.
Patient-provider relationship	Existing rapport	Length of relationship	'I've got a good relationship with my consultant; I've known him for years now and we can talk freely and openly about anything...'
		Rapport building face-to-face	'I think there is still a need to see somebody, there is always going to be that need because that's how you build the relationship, especially if you are new to kidney failure and you are a new patient'.
		Consistent communication	'If you are perhaps going to go to transplant or whatever type of dialysis you decide, you need to keep speaking to the same consultant and developing that relationship'
	Trust	Lack of trust in patients	'Some of it might have been down to trust because I was questioned on whether I was doing the dialysis I said I was doing, which I found frustrating because I was doing it, very much so. And the fact that it wasn't working, and I wasn't feeling any better, I was just feeling worse, wasn't exactly going to make me feel great, then being accused, or hinted of an accusation, that that was going on. So maybe some of it was the lack of trust as well'.
		Lack of trust in practitioners	'And I did think, after the appointment, "He's lowered my drugs." That's based on one blood test. They wouldn't normally do that. This is a man I don't know: never come across him before.'
		Uncertainty with remote care procedures	'So, usually, I'd know it's going to be ... Even though they'd call me, they'd want me to confirm who I am, which always seems a bit daft, really. It should be me confirming who they are, really'.
	Distrust in the wider healthcare system	'I went to the GP and the receptionist was just like, I'll get someone to call you and I'm still waiting for somebody to call me. Before, you would say that and you knew it was done, it was as good as done because you had complete trust in the service but now, nah. You ring up and you are number 16 and don't even apologies or anything because it's the norm'	
Unique needs for underserved groups	Health conditions	Hearing and sight	'And there was one [place name] surgeon, who, while I can read his mouth, it's very useful and I can have a conversation with him. But, on the phone, not a chance. And I literally, spent the whole call just going, "Um hum. Yes. Uh huh"'.
		Mental health	'I don't necessarily think that was a virtual thing, but in some ways it [mental health] exacerbated it because you don't have any immediate person to talk to and it's harder to get yourself across sometimes virtually'

TABLE 1 (Continued)

Theme	Subtheme	Code	Quotes
		Mental health	'My mental health had changed dramatically. It was like I was really battling with my emotions and that was really difficult to deal with so I ended up with counselling, but I didn't mention it to my family because I didn't know what they would think of me'.
		Disabilities	'Because you haven't got that pressure of going down the hospital. You have to check that everything is working okay but at the end of the day I think this is the future, not to have to go struggling to go to the hospital. I find that very uncomfortable, you know'.
	Language barriers	Accents	'It was not hearing but, also, things like, the [name of speciality] supporter had a really thick [name of country] accent as well. So, trying to hear and work out the pronunciation at the same time: I was really lost'.
	Digital literacy	Navigating technology	'It started as virtual but as I say, the virtual only happened ... to me it was technologically a hindrance because I don't know what platform they use but there is nobody there manning the platform, so you log in...'
		Lack of guidance	'They would send me the link and there were some problems to begin with because it wouldn't work on my computer, but it would work on my phone, but I wanted to sit down at my computer and do the face-to-face call but no, it didn't happen. It wasn't working, it only worked on my phone...'
		Experience using technology	'I think, to some extent, but because in my work I'm very familiar with virtual setting that probably means that I interact with it with a bit more confidence and there's a bit less of an asymmetry between me and the doctor on that platform'.
	Ethnic minority groups	Ethnic inequalities	'I actually had a conference in 2016 for the Black community in my area and I invited the consultants and people to come and talk to people, individuals, and I was surprised at the mix that we have in our community. I didn't know that a lot of Black people think that if you are sick in hospital, they won't treat you because they want your kidney. I'd never heard that until that day. So, these are the things why I get involved, to kill all the myths so that people are cared and treated the way they should be treated'.

Loss of interpersonal communication

Several patients reported that the lack of interpersonal communication and nonverbal cues during remote consultations further negatively impacted the quality of appointment, sometimes making it difficult for patients to navigate the conversation.

Patient empowerment

Health seeking behaviour

Participants demonstrated varying levels of health literacy, empowerment and overall health seeking behaviour during their remote appointments. Health seeking behaviour is interpreted here as patients' ability to advocate for their own health during remote

consultations, with many patients using strategies such as writing their questions down to feel more in control. Having the confidence to ask questions during consultations and actively participating in decision-making about their care was varied.

Patient choice of appointment type

Patient choice was crucial to feeling empowered. Patients indicated that remote consultations often felt compulsory, taking away patients' sense of control. In some cases, even when patients expressed their needs and accommodations for remote consultations, their requests were ignored. One female participant expressed a preference for a female doctor when discussing personal matters, which she felt was not respected by her clinical team.

Health literacy

Many participants had been living with kidney disease for a long time and had significant knowledge about their condition. Patients indicated that knowledge and health literacy was essential to feeling empowered and reducing power balances between patients and practitioners. Patients also noted that it was important for practitioners to provide clear explanations and provide answers about their symptoms.

Patient–practitioner relationship

Existing rapport

The patient–practitioner relationship was a common theme among many patients, with an existing relationship being a key factor in successful remote consultations. Patients noted that previous face-to-face appointments were necessary to build a rapport with practitioners, particularly for new patients. Patients also reported that consistent communication with the same practitioner was an important factor in building relationships.

Trust

Trust was another widely reported theme and was found to intersect remote consultations in various ways. Patients reported an element of uncertainty and distrust with remote consultation procedures especially if they did not always know who they were speaking to. Patients felt that trust was an essential component of the patient–practitioner relationship, with some patients feeling that practitioners did not trust patients' own management of their condition. Conversely, some patients reported a lack of trust in practitioners' decisions, particularly with unfamiliar staff. Some patients also reported a general distrust for the wider healthcare system, including staff and NHS policies, such as inconsistencies in communications and staff failing to follow-up.

Unique needs for underserved groups

Health conditions

Health conditions can create additional challenges for patients living with kidney disease, with patients reporting unique barriers to remote consultations contributing to health inequalities. Patients with hearing and sight problems widely reported difficulties during remote consultations, such as inability to lip read during telephone appointments or difficulties understanding practitioners' accents.

Some patients shared that their mental health issues were exacerbated by remote consultations due to feeling isolated alongside the challenges of communicating and expressing themselves

remotely. However, one patient with a learning disability felt that remote consultations were more convenient and were much more comfortable at home with carer support.

Language barriers

Barriers in language were reported by patients from their practitioners, with some patients noting that that information was lost during appointments due to practitioners' accents and pronunciation.

Digital literacy

While patients in this study chose to participate in the interviews/focus groups online, indicating that patients had access to technology and were digitally literate, some patients still reported difficulties navigating technology for remote consultations. Patients also reported a lack of guidance on setting up and accessing video consultations shared, which contributed to missed appointments. Digital literacy and experience using technology among patients also contributed to their confidence to engage in remote consultations.

Ethnic minority groups

We interviewed two patients of African and Caribbean heritage who perceived disparities in their care because of their ethnicity feeling that because NHS staff (in their hospital) were primarily White British, they felt apprehensive about their engagement with the healthcare system. One patient of Black heritage expressed disparities in engagement with the healthcare system among Black communities, highlighting the need to address barriers to kidney care in general among ethnic minorities.

Renal staff survey

Seventy-five staff completed the survey: 61% were female, with a mean age of 47.2 (SD = 9.6) years. 98.7% of respondents had undertaken consultations using telephone or video. Of those, 24 (32.4%) conducted appointments by telephone 100% of the time, with 3 (4%) of staff very satisfied with telephone appointments. Only 1 appointment (1.4%) was conducted by video, with 53 (76.8%) never having used video appointments. 1 (2.9%) was very satisfied and 7 (20.6%) not satisfied at all with video appointments.

Staff reported challenges of remote appointments with specific underserved groups: young people (14.7%), patients struggling with English language (69.3%), cultural or religious issues (17.3%), people with mental health needs (46.7%), people with learning differences/difficulties (62.7%), people with hearing/sight impairment (76%), none (6.7%). Staff characteristics and survey responses of the benefits and challenges can be found in Supporting Information: File 4.

Table 2 compares answers from staff of their perceptions of how far people from underserved groups have different benefits/challenges with remote appointments, compared with the general kidney patient population.

Key recommendations identified from the workshops

Stakeholder workshops discussed key themes identified in the interviews/focus groups that needed to be addressed in remote care practice. Workshop discussions concluded that a web-based online Toolkit with printable resources was the most effective mode to disseminate the

Toolkit. Furthermore, workshop discussions indicated that two separate sections of the Toolkit: a patient and staff section would ensure more efficient access to the platform and provision of more tailored recommendations. Table 3 summarises the themes derived from the workshops and consequently formed the sections of the Toolkit.

Themes and subthemes were quality of appointment (need for physical examination, delayed appointments, feeling rushed, loss of interpersonal communication), patient empowerment (health seeking behaviour, patient choice, health literacy), patient-practitioner relationship (existing rapport, trust) and unique needs for underserved groups (comorbid health conditions, language barriers, digital literacy, ethnic minority groups).

TABLE 2 Comparison of benefits and challenges to remote care among patients living with kidney disease generally and those from underserved groups.

Question	General	Underserved groups	Comparison (%)
Benefits for staff			
Fewer missed appointments as patients are more likely to attend	57 (76%)	55 (73.3%)	+2.7
More convenient as appointments can be conducted in office (less travel to out-patient department)	50 (66.7)	41 (54.7%)	-12
Benefits for patients (perceived by staff)			
Reduced burden of travel (money and time)	72 (96%)	66 (88%)	-8
Less anxiety when attending an appointment at home	39 (52%)	32 (42.7%)	-9.3
Less waiting time to wait to be seen	43 (57.3%)	32 (42.7%)	-14.6
Challenges for staff			
Difficulty in creating rapport with patients (unable to assess nonverbal cues)	50 (66.7%)	58 (77.3%)	+10.6
Less able to communicate freely with patients because of confidentiality issues	18 (24%)	29 (38.7%)	+14.7
Less confident about diagnosis/advice given to patients	24 (32%)	38 (50.7%)	+18.7
More difficult to assess whether the patient has taken on board the discussion	52 (69.3%)	46 (61.3%)	-8
Less able to communicate with people who have difficulties with the English language	50 (66.7%)	44 (58.7%)	-8
Unable to carry out a physical examination	58 (77.3%)	50 (66.7%)	-10.6
Less able to communicate with people who have difficulties with hearing/sight problems	61 (81.3%)	52 (69.3%)	-12
Challenges for patients (perceived by staff)			
More difficult to hear the conversation	47 (62.7%)	50 (66.7%)	+4
Difficulties with equipment/technology	47 (62.7%)	52 (69.3%)	+6.6
Less able to make shared decisions about care	14 (18.7%)	21 (28%)	+9.3
More difficult to have an honest conversation	23 (30.7%)	31 (41.3%)	+10.6
Caring for fragile/vulnerable or high-risk patients when not seeing them face-to-face	48 (64%)	43 (57.3%)	-6.7
Contact made at a different time from what was expected	43 (57.3%)	36 (48%)	-9.3

Note: In Comparison (%) column + indicates that underserved groups may benefit; - indicates that underserved groups may not benefit.

TABLE 3 Workshop recommendations and the corresponding features of the Toolkit.

Results (themes) from the interviews/focus groups and the staff survey	Recommendations for renal staff Toolkit	Recommendations for patient Toolkit	Toolkit content/structure
Quality of appointment	Health care professionals need to prepare patients for a remote appointment	Patients to understand what to expect: Time and length of call, introduction and call content	A list of what to expect before a remote appointment
Patient empowerment	Ensure patients have been sent clear written instructions on how to have a good remote consultation	Preparation by the patient before the appointment will empower them to advocate for themselves	Top tips for a good remote appointment
Patient-practitioner relationship/rapport	Personalise the appointment or build a good rapport with the patients	Understand how to have a good partnership with health care professionals	A section on how to help patients and staff get the most out of the appointments. For example, what questions to ask; how to self-manage.
Health inequalities	Provide a conducive environment and extra support for those with complex needs	Toolkit tailored to specific patient needs: Learning disability, visual problems, hearing problems, care home residents	Top tips for remote appointments with people from underserved groups (with links to relevant charity webpages, such as Royal National Institute for Blind People)
Language barrier	Provide translation services for people whose first language is not English	People that do not speak or understand English need to be catered for	A section outlining how staff and patients can be supported for example, interpreter services, visual aids, extending the length of the appointment
Choice	Give the patients a chance to decide the type of appointment they prefer	Patients to decide the best type of appointment for them	A section highlighting the benefits and challenges of remote appointments including the power of choice
Technology support	Utilise resources to support patients with limited technology	Patients facing challenges with technology should have support from the staff, if they wish to have a remote appointment.	Signpost resources that provide information on setting up technology for a remote appointment

DISCUSSION

Consistent with previous studies (Ewart et al., 2022), both patients and staff highlighted the importance of relationship and rapport between patients and practitioners when conducting remote appointments. Nuances of communication are often lost in remote care, resulting in less personal care (Lunney et al., 2020), while the transition to remote care may have disrupted patient-practitioner relationships. Our study highlights the need to replicate face-to-face communication in remote appointments with particular attention paid to interpersonal communication and rapport to develop 'digital intimacy' (Piras & Miele, 2019). We also found that patient's trust in practitioners and the healthcare system was a key component to successful remote appointments, which is often established through long-term patient-practitioner relationships (Imlach et al., 2020; Varsi et al., 2021). Therefore, strategies included in the Toolkit aim to facilitate stronger patient-practitioner relationships which in turn can contribute to increased trust.

We also found that patient choice and shared decision making were central to patients' sense of patient empowerment. Consistent with previous research with people dialysing at home (Chu et al., 2023), our study suggests that a blended approach to remote care, combining face-to-face and remote care delivery would facilitate equity of care alongside efficient delivery. Patient choice and shared decision making is paramount (Perl et al., 2023), particularly for those experiencing additional burdens such as those with communication difficulties. Educating patients about how best to take part in remote care and strengthening communication can lead to increased empowerment to initiate dialogue around decisions regarding their treatment (Grove et al., 2023). Therefore, educating patients and practitioners about choice of a remote appointment and how best to conduct a remote appointment in partnership is an important component of the Toolkit.

To improve the quality of remote appointments, patients report the need to address issues of appointment length and timekeeping (Schutz et al., 2022). In our study, patients reported the need for

ample time to express themselves and communicate openly with their practitioners without feeling rushed or unheard. We also found that the perceived poor quality of appointments among participants contributed to a lack of trust in the health care professionals and the health care system. The need for physical assessments further influenced appointment quality, which is particularly important for patients with kidney disease who might have many symptoms (Kaufman-Shriqui et al., 2022). Furthermore, technological innovations, such as wearable technologies to obtain vital signs, offer promising solutions to improve remote physical examinations (Yao et al., 2022).

Despite the widespread delivery of remote care, digital inequalities and exclusion can be a prevailing barrier to remote care (Chesser et al., 2016). While most patients in the current study participated online, suggesting they had access to technology and were confident using technology, many reported challenges using remote consultation platforms and initial challenges navigating the transition to remote care during the pandemic. Ftouni et al. (2022) found that for video appointments it is necessary to provide patients with guidance on how to set up their device (Ftouni et al., 2022). Therefore, the Toolkit includes a preconsultation checklist and tips for patients to prepare for their remote appointments. Practitioners will also have a checklist to assess the appropriateness of remote care for individual patients, taking into consideration access and experience with technology.

IMPLICATIONS FOR CLINICAL PRACTICE

During the Toolkit development, we sought to address the primary barriers identified by participants, providing strategies for both patients and staff to optimise remote care delivery and experiences. Aligning with the differing needs of underserved groups, the Toolkit is available in various formats including online content, downloadable resources and video excerpts from patients, available in easy-read format and translated versions. The Toolkit can be found here <https://kidneycareuk.org/health-professionals/remote-kidney-care-toolkit/>. Next steps are to integrate the Toolkit into clinical practice include public impact and engagement activities to promote the Toolkit among patients and practitioners.

Limitations

Consistent with previous research among underrepresented groups (Passmore et al., 2021; Shepherd, 2020), and despite using various recruitment strategies, we had limited engagement from community facilitators and subsequent participant uptake for interviews and focus groups. We found that recruitment was most effective through local kidney patients associations known to the study team and individual influencers (people living with kidney disease who had a national profile). Despite

accommodating for both online and in-person, all interviews/focus groups were conducted online. Therefore, this sample is not representative of digitally excluded groups, pertinent to remote care and further refinement of the Toolkit may be necessary to meet the needs of digitally excluded groups. As many of the patients participating in the study took part online, it is likely that this sample is not representative of digitally excluded groups, pertinent to remote care. The primary language of the project team was English, although a few members of the team spoke other Asian and African languages, and translation was available. Despite some of our recruitment materials being translated into other languages, all participants spoke English, but not always as their first language. Overall, this study may have been influenced by selection bias due to the voluntary nature of participation in this study and therefore the Toolkit is likely not generalisable to all underserved groups.

CONCLUSION

This study contributes to the current evidence on the barriers and facilitators to remote kidney care experiences among patients and staff, important because 25%–50% (wide variation across different hospitals) of appointments still appear to be conducted remotely. Findings from the staff survey and qualitative interviews/focus groups demonstrate that while remote appointments were often viewed as beneficial, further optimisation of remote services are required to ensure patients from different underserved groups can have the same experience and outcome as those who do not have specific needs.

AUTHOR CONTRIBUTIONS

Patricia Tu and Catriona Ewart are research assistants, who participated in design and coordination, undertook interviews, analysed data, helped to draft manuscript, read and approved the final manuscript. Udit Mitra is a research assistant, who participated in design and coordination, helped to draft manuscript, read and approved the final manuscript. Fez Awan, Jyoti Baharani, Emma Coyne, Gavin Dreyer, Chipiliro Kalebe-Nyamomgo and Martin Wilkie are members of project team, they participated in study design, read and approved the final manuscript. Nicola Thomas is the Principal Project Leader, who conceived the study, participated in design and coordination, helped to draft manuscript, read and approved the final manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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