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Patient expectations and experiences of remote monitoring for chronic diseases: Systematic review and thematic synthesis of qualitative studies



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ARTICLE INFO	A B S T R A C T
<i>Keywords:</i> Remote patient monitoring Systematic review Patient Chronic disease	Objectives: To describe the range of patients' beliefs, attitudes, expectations, and experiences of remote monitoring for chronic conditions across different healthcare contexts and populations. Design: We searched MEDLINE, Embase, PsychINFO, and CINAHL, Google Scholar, and reference lists of related studies through to July 2017. Thematic synthesis was used to analyse the findings of the primary studies. Study characteristics were examined to explain differences in findings. Setting: All healthcare settings Participants: Adults with chronic diseases Outcomes: Patient beliefs, attitudes, expectations and experiences of remote monitoring Results: We included 16 studies involving 307 participants with chronic obstructive pulmonary disease, heart failure, diabetes, hypertension, and end stage kidney disease. The studies were conducted in 8 countries. We identified four themes: gaining knowledge and triggering actions (tracking and responding to change, prompting timely and accessible care, supporting self-management and shared decision-making); reassurance and security (safety in being alone, peace of mind); concern about additional burden (reluctance to learn something new, lack of trust in technology, avoiding additional out-of-pocket costs), and jeopardising interpersonal connections (fear of being lost in data, losing face to face contact). Conclusions: For patients with chronic disease, remote monitoring increased their disease-specific knowledge, triggered earlier clinical assessment and treatment, improved self-management and shared decision-making. However, these potential benefits were balanced against concerns about losing interpersonal contact, and the additional personal responsibility of remote monitoring.

1. Introduction

Chronic diseases impose a substantial burden to patients, their families, and health systems. Patients with chronic disease are at increased risk of mortality and morbidity, and have significantly reduce quality of life compared with the general population [1,2]. The costs of treatment and loss of employment opportunities can lead to economic hardship [3]. The increasing prevalence of chronic diseases globally [4] already presents a significant challenge to the capacity of health services to provide sufficient care [5]. As chronic conditions often result in increased demand for acute management, interventions that proactively support self-management, and enable early recognition of changes in condition may help to prevent hospitalisation, reduce treatment costs, and maintain health-related quality of life [6,7].

Remote monitoring involves a tele-monitoring device in the patients' home that can link clinical data from the patient electronically to a clinical site [8]. This potential health intervention can support home or community-based care and remote settings, with the benefit of improving the patients' ability to self-manage [9,10] and increasing patient satisfaction and quality of life [11,12]. Remote monitoring has been associated with lower mortality for patients with heart failure [13], reduced hospital admissions for people with chronic disease [11]. Despite the potential benefits of remote monitoring, there is some reluctance among patient to utilise and adhere to remote monitoring because the ongoing or long-term benefits are not apparent to them [14], or they do not trust in technology [15]. A more detailed and

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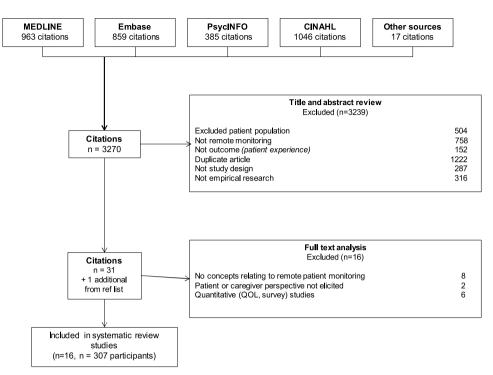


Fig. 1. Search results.

comprehensive understanding of patient experiences and perceptions of remote monitoring is still needed.

Pooling qualitative data together from multiple studies can provide more diverse and in-depth evidence about patients' experiences, perspectives, knowledge and beliefs across different healthcare contexts to inform the development and improve the uptake of remote monitoring. We aimed to describe the attitudes, beliefs and values about remote monitoring among patients with chronic conditions.

2. Methods

This thematic synthesis is reported according to the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) framework [16].

2.1. Selection criteria

Qualitative studies that reported the experiences and perspectives of remote monitoring among adult patients (over 18 years) with any chronic diseases including but not limited to cardiovascular disease, chronic obstructive pulmonary disease, diabetes, chronic kidney disease, and hypertension were eligible for inclusion. We considered remote monitoring as any telemonitoring that transferred data directly from a non-hospitalised patient to the health provider [8]. We excluded non-English articles to avoid misinterpreting cultural and linguistic nuances in translations, and studies that included structured questionnaires or surveys as the sole method for data collection or reported only quantitative data. Studies that did not elicit data directly from patients were also excluded.

2.2. Data sources and searches

We searched MEDLINE, Embase, PsychINFO, and CINAHL, from inception to July 1, 2017, and searched Google Scholar and reference lists of related studies and reviews. (Supplementary File 1) Two authors (RCW and SCP) screened all titles and abstracts independently and excluded those that did not meet the search criteria (ie.screened twice). Full texts of potentially relevant articles were then also screened independently by the same two authors. Any discrepancies were discussed with other authors.

2.3. Comprehensiveness of reporting

Evaluation of the transparency of reporting for each included qualitative study was performed independently by RCW and SCP using the COREQ framework [17]. Any discrepancies were discussed between all authors. This framework includes criteria to evaluate the research team, study methods, context of the study, analysis and interpretation of study findings.

2.4. Data analysis

We used thematic synthesis as described by Thomas and Harden [18]. We imported all participant quotations and text under the "Results/Findings' or "Discussion/Conclusion" sections of each study into HyperRESEARCH (ResearchWare, INC 2009, version 3.0.3) qualitative research software. One author (RCW) performed line-by-line coding of the findings of the primary studies, interpreted the data, and inductively identified concepts. For all remaining papers, the text was either coded into existing concepts or a new concept was created when required. Similar concepts were grouped into themes and subthemes. Conceptual links among themes were identified (by RCW) using a mind mapping approach to extend the findings offered by the primary studies and to develop an analytical thematic schema. To ensure that coding captured all relevant issues and reflected the primary data, researcher triangulation was used, in which two authors (SCP/AT) independently reviewed the preliminary themes and analytical framework and discussed the addition or revision of themes with the first reviewer (RCW). These were integrated into the final analysis which was then reviewed by all authors independently.

3. Results

3.1. Literature search

Sixteen studies involving 307 patients were included (Fig. 1). Most

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UK 20 Yes 69* Chronic obstructive pulmonary Qualitative Semi-structured	Sanders 2012 [39]	England	22	No	23-92	Diabetes, chronic obstructive pulmonary disease, heart failure	Qualitative	Semi-structured	Grounded theory
	Ure 2011 [10]	UK	20	Yes	69*	Chronic obstructive pulmonary	Qualitative	Semi-structured	Ethnography

NB: *mean age only reported. NS = not stated.

Table 2

Appraisal of Study Reporting.

Item	Studies reporting each item	Number of studies (%)
Personal Characteristics		
Interviewer / facilitator identified	(9, 10, 15, 19-22, 24, 33-37, 39)	14 (88)
Occupation of the interview of facilitator	(9, 10, 20, 21, 24, 33-35, 37)	9 (56)
Experience or training in qualitative research	(9, 20, 21, 24, 34, 35)	6 (38)
Relationship with participants		
Relationship established prior to study commencement	(9, 24, 34, 35)	4 (25)
Participant Selection		
Selection strategy (e.g. snowball, purposive, convenience, comprehensive)	(9, 10, 15, 19-24, 33-39)	16 (100)
Method of approach or recruitment	(9, 10, 15, 19-24, 34-39)	15 (94)
Sample size	(9, 10, 15, 19-24, 33-39)	16 (100)
Number and/or reasons for non-participation	(9, 19-22, 24, 33, 36, 38, 39)	10 (63)
Setting		
Venue of data collection	(9, 10, 15, 19, 20, 22-24, 34-36, 38, 39)	13 (81)
Presence of non-participants (e.g. clinical staff)	(22, 24, 34, 35, 38, 39)	6 (38)
Description of the sample	(9, 15, 19-24, 34-39)	14 (88)
Data Collection		
Questions, prompts or topic guide	(9, 10, 15, 19-24, 33-39)	16 (100)
Repeat interviews / observations		5 (31)
Audio / visual recording	(9, 10, 15, 19-24, 33-38)	15 (94)
Field notes	(15, 22, 33, 34, 37-39)	7 (44)
Duration of data collection (interview of focus group)	(10, 15, 19-22, 24, 33-37, 39)	13 (81)
Protocol for data preparation and transcription	(9, 10, 15, 19-24, 33-39)	16 (100)
Data (or theoretical) saturation	(9, 10, 15, 23, 24, 34, 35, 39)	8 (50)
Data Analysis		
Researcher/expert triangulation (multiple researchers involved in coding and analysis)	(9, 10, 15, 19-22, 24, 33-39)	15 (94)
Derivation of themes or findings (e.g. inductive, constant comparison)	(9, 10, 15, 19-24, 33-39)	16 (100)
Use of software (e.g. NVivo, HyperRESEARCH, Atlas.ti)	(9, 10, 19-24, 33-36, 39)	13 (81)
Member checking (participant feedback on findings)	(23, 24, 34)	3 (19)
Reporting		
Participant quotations or raw data provided (picture, diary entries)	(9, 10, 15, 19-24, 33-39)	16 (100)
Range and depth of insight into participant perspectives (thick description provided)	(10, 15, 19-22, 24, 33-35, 37-39)	13 (81)

studies (9, 56%) were from the United Kingdom, and the remaining studies were from Denmark, Norway, Taiwan, United States, Canada, and Australia. The participants were aged from 23 to 92 years of age (Table 1) and were diagnosed with chronic obstructive pulmonary disease (COPD) (6 studies), heart failure (HF) (3 studies), diabetes (2 studies), end stage kidney disease (2 studies), hypertension and diabetes (1 study), HF or COPD (1 study), diabetes, COPD and HF (1 study).

3.2. Comprehensiveness of reporting

The comprehensiveness of reporting varied across the included studies (Table 2) and ranged from three (12%) to all items included in the COREQ framework. All studies reported sample size, strategy and provided participant quotations. In terms of data collection, 15 (94%) studies reported the use of recording. Member checking was reported in 19% of studies. Half the studies reported data saturation.

3.3. Synthesis

We identified four themes: gaining knowledge and triggering actions; reassurance and security; concern about additional burden; and jeopardising interpersonal connections. The subthemes are described below and we have indicated the number of studies these subthemes were identified in and where possible, if the data were specific to a particular population (e.g based on country, patient demographics, diagnosis). Table 3 includes a selection of participant quotations and explanations provided by the authors to illustrate each theme. Conceptual relationships between themes and subthemes are presented in Fig. 2. Cross-tabulation of themes by chronic diseases is presented in Fig. 3.

3.3.1. Gaining knowledge and triggering actions

3.3.1.1. Tracking and responding to change. Patients with all chronic

conditions across six studies reported that remote monitoring enabled increased understanding of their condition. They gained awareness of what their "normal" clinical values and symptoms were [19], as well as clinically-significant changes in signs and symptoms. Collecting clinical data at home enabled some to obtain accurate and frequent measurements of their own health status: "if my asthma got worse I would look at the guideline which my doctor has given me and do something about it before ending up in hospital" [15].

3.3.1.2. Providing timely and accessible care. In 12 studies patients felt more frequent data collection at home validated their symptoms and prompted clinicians to take earlier action in response to these data. Patients were more certain of when it was necessary to seek medical attention. They believed "problems were picked up quickly (and) advice given on how to remedy them" [20]. Remote monitoring was observed to result in reduced need for hospitalisations and "stops me having to physically go so often to the doctors' surgery" [9].

3.3.1.3. Supporting self-management and shared decision-making. Remote monitoring promoted confidence to self-manage, including independently making changes to medication regimens. This was identified in seven studies and particularly noted in patients with heart failure who were encouraged to adjust fluid management medications based on daily data such as weight. Patients also felt being able to discuss their monitoring data made them feel empowered and a more equal partner in their care, allowing them to be "better equipped to engage with health care services" [21].

3.3.2. Reassurance and security

3.3.2.1. Safety in being alone. More frequent monitoring increased patients' sense of safety in remaining independent at home, particularly for those living alone and older adults in six included studies. Remote monitoring had "given me a sense of security....I felt encouraged because I knew that it [expert help] wasn't far away and I

Table 3

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Selected participant quotations for each th Themes/subthemes	Quotations	Contributing studies
		contributing studies
Gaining knowledge and triggering actions Tracking and responding to change	"I know a lot more about it [COPD] now than I used to, I didn't know how the illness worked" [35] "It's made it easier for me to know what's what. If you don't have the machine then you don't have any facts to talk about. So I suppose it's made me realise I have to do certain things in a certain way and when I've felt like perhaps experimenting I know I mustn't, with the medication for instance" [19] "you learn about your disease, what the causes are and how to manage them. It clarifies many questions in your mind not only that but you also learn, whether you're get better or worse." [15] "look at the machine and I can tell the exact day when I started to feel off" [21].	[15,19,22,33,35,37]
Providing timely and accessible care	"For me this is ideal, because by the time you do actually contact the doctor, who's then saying can you get to the surgery, and sometimes you couldn't, it's hospital again, whereas now, we nip it in the bud" [21] "The technology can get the information to your doctor faster than you could. How good is that to be able to instantly find out what's going on in your body, you know, so you can do something about it	[9,10,15,19–22,24,35–38]
Supporting self-management and shared decision-making	instead of waiting three or four days to get to the doctor and maybe something happening" [36] "The doctors kept saying to me that you can self-medicate with fluid tablets. And I would think 'oh no [laugh], I don't know what I'm doing here, so I'm not going to do that' But then the [telemonitoring staff] at the other end said take another fluid tablet And then gradually, I started to realise that when I felt unwell I was able to think 'oh, you know, take another tablet or half a Tablet" [34] "When I've got it bad and it's great to know that you can just take a reading and say; 'well, I do need a doctor or I do need to start these steroids" [35]	[10,15,21,22,34,35,37]
	"It's definitely helped with health management. I want to know all about my health now. I didn't do nothing before [telehealth] at all" [21] "taking medications on time and maintaining a stable lifestyle" [37]	
	"It's a good way of keeping track, on how you're progressing, and rather than going to the health centre every three months, and then found that you're slipping a bit, or your readings are going out of control again" [9] "I felt quite happy to be involved instead of just being a vegetable that sat back and swallowed	
	"After that (joining the telehealth program), I obediently monitored my blood glucose on time. I found out that I ate too much meat, so my blood glucose increased. Now, I eat more vegetable and less meat" [33]	
	"I think you're much more aware, and you can keep your eye on all the readings and if something gets high or low I'd be aware and mention it" [21]	
Reassurance and Security Safety in being alone	"I can see how it would be useful for somebody who is more elderly. or does a mistake and doesn't realise it" [23] "It gives me a lot more independence. You're using measurements which normally wouldn't be available to me as a patient that's good, it's reassuring, it's like having another person with you even though it's a machine" [21]	[15,21-23,33,35,38]
Peace of mind	"It gives a feeling of safety [when] somebody observes that everything is going as it should" [38] "Because, I live alone and I would be very happy to have something monitoring me" [15] "It's reassuring. I know my children like the fact that I've got it" [21] "Because of this device, I feel it is like a partner accompanying me; then I have a sense of security and feel at ease" [37] "I think it will make people more relaxed because they know exactly what's happening to them. If you	[10,15,19–24,34,37]
Concern about additional burden Reluctance to learn something new	are not feeling too well, you can go back on and recheck your status"[15] "The older you get the more forgetful you get, it's sometimes difficult to manage that sort of	[15,20,37,39]
	machinery, to remember how to do it" [39] "Training is important, particularly in older people like myself the person who needs to use the system should be sat down by an expert and told exactly what to do step by step, training is very important in our age" [15] 'It would rely upon my wife to input the information <i>via</i> the TV [due to blindness]. And she doesn't like	
Lack of trust in technology	technology one bit I couldn't do it myself" [39] "I think the device needs to be checked to ensure that it is working properly; if it needs to be repaired frequently, it would be a barrier to use [37] "When the system is down, how are we going to find out about our condition? A machine is a machine.	[15,37]
Avoiding additional out-of-pocket costs	Sometimes, the machine goes wrong. It's difficult to trust a machine."[15] "It would be better not to charge for it! Now most consumers using this device are elderly! The elderly usually have no income. If there is a charge for this service, it would be a problem" [37] "I would use it, but I suppose a lot of other people, would be reluctant to use this system due to the costs of this and the installation, I only worry about the price whether I can afford to buy this system."[15]	[15,33,37]
Jeopardising interpersonal connections Fear of being lost in data	"As a result of [telemonitoring], they increased the quantity of one of the drugs I'm taking, which hasn't made the slightest difference"[34] "It is difficult with the weight because sometimes I've had people phoning up and saying: "take an extra diuretic"" [19]	[19,34]
Losing face to face contact	"The only thing I miss with it [telehealth] is that I do not get the nurses coming to visit like I used to, human contact" [21] No [telehealth is not as good as in-person care], it's a bit personal, I think. With face to face you can see how people react when you tell them things"[21] "I think face-to-face communication with your doctor will solve many other problems, it is not only the examination of your heart, lungs or blood pressure. Communication is important for me." [15]	[15,21,22,39]

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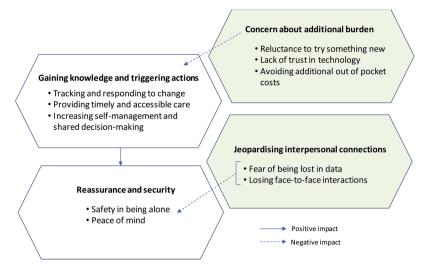


Fig. 2. Thematic schema.

Patients' reported as a result of using remote monitoring in chronic disease conditions including gaining knowledge, triggering actions, supporting self-management and enabled shared decision-making. However, despite many patients reporting that remote monitoring enhanced reassurance and safety in managing their chronic disease at home, some described initial apprehension towards using technology, based on unfamiliarity and doubts regarding its reliability. Others were concerned that their care would become dependent on technology, resulting in depersonalised care, reductions in face-to-face interaction, and increased out of pocket costs.

was able to just talk to them" [22]. Patients became less fearful of being alone, or not picking up an important clinical sign that there condition may be deteriorating, such as a high blood pressure recording. Patients, particularly those on dialysis, reported that they felt they had a "safety net" [23] provided in being monitored.

3.3.2.2. Peace of mind. Remote monitoring provided patients with peace of mind and reduced their anxiety and stress and was identified in 10 studies. "It makes you feel like somebody's looking after you. If anything goes wrong, you can get in touch with them any time you want" [24]. By "cutting down the stress, it takes their fears away" [15] and allowed a greater sense of normality. For others, remote monitoring "meant that somebody else would assume some of the responsibility" [23] alleviating some of the pressure they felt.

3.3.3. Concern about additional burden

3.3.3.1. Reluctance to learn something new. Patients in 4 included studies were reluctant to commence remote monitoring because they believed that learning how to use the technology would create an additional burden for them. Older patients particularly were concerned that they would be confused by the data and this may consequently

trigger additional anxiety. Others feared they would not understand the written instructions and could not safely operate the technology,

3.3.3.2. Lack of trust in technology. In only two of the included studies, some patients found it "difficult to trust a machine" [15]. Older patients particularly, felt they had less confidence or experience with technology. However, many patients who had used remote monitoring described that these concerns were overcome through continued exposure to the technology and individualised training and support.

3.3.3.3. Avoiding additional out-of-pocket costs. Participants in programs in which remote monitoring was initially provided at no cost to the patient voiced concern about the introduction of ongoing expenses and servicing costs after an initial period. Two studies in Taiwan and one in Australia found patients concerned that they would not be able afford the on-going costs of remote monitoring.

3.3.4. Jeopardising interpersonal connections

3.3.4.1. Fear of being lost in data. In two of the included studies patients were concerned that remote monitoring would replace the personal

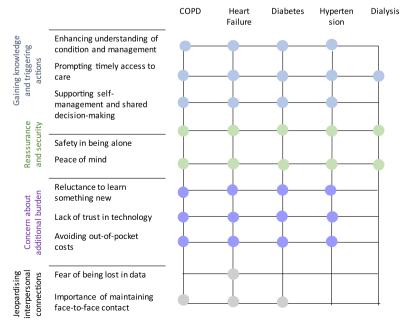


Fig. 3. Cross-tabulation of themes by chronic condition.

care and human encounters they received from clinicians. Some felt clinicians sometimes focused on the data, rather than the symptoms and concerns they were expressing.

3.3.4.2. Losing face to face contact. Patients in four studies were concerned about losing or diminishing the frequency of contact with nurses and doctors. This personal contact was important to patients as it helped to establish trust and allowed for better communication. They wanted remote monitoring to be a tool to assist in supporting them at home rather than replacing their interpersonal interactions.

4. Discussion

For patients with chronic disease, remote monitoring supported selfmanagement of their condition as it increased their confidence and sense of safety. Remote monitoring also enabled early identification of clinical exacerbations, increased shared decision-making, and prevented hospitalisations. However, some patients were initially apprehensive about using technology because they felt unfamiliar with it and doubted its reliability. Some were also concerned that their care could become more focussed on clinical data rather than personal interaction and this might lead to fewer face-to-face consultations with clinicians. Some patients also anticipated an increased personal burden of having to input data and manage the technology.

Qualitative comparisons across studies suggest older patients and those less familiar with technology were concerned about their ability to safely use remote monitoring. Studies that explored views of dialysis patients reported only the positive themes associated with remote monitoring. This may be influenced by the small number of studies for this group and by the fact that many dialysis patients are already using technology and therefore may be more familiar and confident with this aspect of care. Most themes were consistent across countries, although the concern that remote monitoring would jeopardise interpersonal connections was more common in studies undertaken in the United Kingdom.

The perceived advantages of remote monitoring highlighted in this review are consistent with results of a previous review exploring experimental and quasi-experimental studies of telemonitoring in patients with chronic conditions [25]. This earlier study also found telemonitoring was well received and accepted by patients and promoted active participation in care and improved awareness and feelings of security. In addition, our findings describe patients' concerns of added burden, fear of being lost in data or losing the interpersonal connections with health professionals. These findings may help to explain the previously reported limited adoption and long-term adherence to remote monitoring [26–28]. Our study also reports studies from a wider range of long term conditions and across a more diverse range of countries than the previous review.

We performed a comprehensive and systematic literature search and included studies across several chronic diseases, to generate diverse insights of the patient experience of remote monitoring. However, there are potential limitations. We excluded non-English articles and most studies were conducted in high-income countries. Therefore, the broader transferability of our findings is uncertain. Despite the growing popularity of e-health, and the large number of studies evaluating remote monitoring particularly in heart failure, this review shows there are only a small number of studies specifically exploring patient experiences. There was also a lack of patient perspective in conditions such as obstructive sleep apnoea where remote monitoring is utilised and has the potential to enhance patient outcomes.

To deliver the benefits of remote monitoring in chronic diseases, we recommend increased training and support, particularly for older patients to increase confidence and capability. Technology should also be designed to have minimal user burden, be user-friendly, and have mechanisms installed to provide reassurance of safety. Patients value accessible health care services [29] and this review indicates that remote monitoring may further improve access and therefore satisfaction with care. Patients therefore should be informed of this and the potential flow on benefits of remote monitoring, particularly for those more apprehensive about the management of their condition at home.

Remote monitoring devices may benefit from a user centered-design approach that incorporates the patient preferences, requirements and needs [30-32]. Enhancing patient-provider communication through a messaging system within devices may provide additional support, access and reassurance to patients that they are being closely monitored. Devices that enable patients to see that data has been successfully transferred to health care providers can also help encourage confidence. Despite potential advances in remote monitoring however, some patients may prefer personal encounters with health professionals and remote monitoring may not meet the needs of all populations. Future interventions and randomised controlled trials to evaluate the acceptability and usability of RPM technology in diverse patient populations, including varying degrees of literacy, connectivity and accessibility may help remote monitoring meet the needs of multiple types of patients. Additionally, given the lack of data on the specific aspects or components of remote patient monitoring programs that are particularly valued by patients, patient preference research could help inform the design of future technologies. Specific aspects that enhance patient experience and confidence may help improve design and uptake. The small number, and variability in reporting of studies included in this review emphasise the need for more comprehensive research into patient experiences and preferences on this topic. Future qualitative studies could also include a longitudinal component to evaluate the change in patients perceived benefits of remote monitoring over time, particularly in more vulnerable groups such as older or rural patients.

For patients with chronic disease, remote monitoring increased their disease-specific knowledge, triggered earlier clinical assessment and treatment, improved self-management and shared decision-making. However, these potential benefits were balanced against concerns about losing interpersonal contact, and the additional personal responsibility of remote monitoring. Future technology development may benefit from addressing these patient concerns, making more user-friendly technology and enhancing communication to the patient that provides them with reassurance and confidence.

Declaration of interest

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