



Patients' perspectives on digital health tools

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ABSTRACT

Objective: Digital technology has changed the way healthcare is delivered and accessed. However, the focus is mostly on technology and clinical aspects. This review aimed to integrate and critically analyse the available knowledge regarding patients' perspectives on digital health tools and identify facilitators and barriers to their uptake.

Methods: A narrative review was conducted using the Scopus and Google Scholar databases. Information related to facilitators and barriers to uptake was synthesised and interpreted using thematic and content analyses, respectively.

Results: Seventy-one out of 1722 articles identified were eligible for inclusion. Patient empowerment, self-management, and personalisation were identified as the main factors that contributed to patient uptake in using digital health tools. Digital literacy, health literacy, and privacy concerns were identified as barriers to the uptake of digital health technology.

Conclusion: Digital health technologies have changed the way healthcare is experienced by patients. Research highlights the disconnect between the development and implementation of digital health tools and the patients they are created for. This review may serve as the foundation for future research incorporating patients' perspectives to help increase patients' engagement with emerging technologies.

Innovation: Participatory design approaches have the potential to support the creation of patient-centred digital health tools.

1. Introduction

The international healthcare industry has been under increasing strain due to several factors, including the increasing global population age and a shortage of clinical specialists [1]. These lead to an imbalance between demand and available services. Healthcare organizations are continuously looking for approaches to address this imbalance and minimize the pressure on health systems. In this regard, digital technologies such as smart devices, portable devices, and wearables, have changed how healthcare is delivered and accessed. More recently, these technologies have been designed and integrated with Artificial Intelligence (AI) to inform public health policy [2], improve healthcare systems [3], boost productivity, and optimize procedure workflow. Often, these technologies have aimed to enhance patients' empowerment and engagement in their healthcare. However, most digital technologies have been mainly designed with a technical mindset and based on a technology perspective. Recently, there has been a shift in this top-down model to involve pharmaceutical companies and clinicians in the development of digital health technologies. This helps narrow the gap between health technology specialists and clinicians and is a step toward having more acceptable technologies in healthcare.

Technological advancements have enabled online health services, such as remote monitoring and consultations. These technologies and services have allowed greater access to services irrespective of geographical location while helping patients have a more active role in their clinical treatment. This active role can be interpreted as patient engagement, patient involvement, patient adherence, and compliance [4]. Despite this, few studies, have focussed attention on consumers' or patients' perspectives with respect to digital health solutions, despite the low uptake and acceptance by patients [5]. Digital tools, such as patient portals, mobile applications, and wearable technologies bring convenience [6], provide patients with easier access to their health records and clinical expertise, and make collecting health data less intrusive. This could lead to better patient experiences [7] and could potentially shift the patient-provider relationship from a paternalistic model to a patient-centred model [8,9]. Despite digital health tools being designed for patients' perceived needs, it appears that they have rarely involved patients in the design process from the early stages [10], and there is a lack of attention to their perspectives [11].

Many studies recommend involving patients from the beginning of the development process [12-22] and highlight the need to incorporate the

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patient's voice into the design of digital health technologies. Originating in Scandinavia, participatory design is an approach to supporting the involvement of users in the design of products or services [23]. Designing digital health tools with the intended users—patients and clinicians—could help increase patient uptake and better support continued use. For example, Andersen, et al. [24] explored the challenges of collaborating with patients and healthcare providers to design a mobile health (mHealth application) for remote monitoring of patients' cardiac devices. Design researchers tested prototypes with actual users, which allowed them to develop and refine their products to better support the intended user's [24]. The close collaboration of both patients and clinicians provided insight into how both groups may use certain features. For example, the research explored a 'symptom tracking' feature and found that patients would record symptoms irrelevant to their specific condition. Consequently, this led to clinicians disliking this feature [24]. This study surmised that the different perspectives of patients and clinicians needed to be addressed so that the design could be meaningful for the respective groups.

Many studies recommend a participatory approach in the design of future digital health technologies [14,21,22,25,26]. However, studies report different factors and criteria of patients' views of digital health tools. In this research, we aim to review and integrate the available knowledge regarding patients' perspectives on digital health tools and applications. This helped us to extract and understand the current research trends, identify gap(s) and explore future directions. This study also aimed to identify barriers and recognise factors that support the uptake of digital health tools.

2. Methods

In this research, a critical review method was chosen to explore the literature, not only to aggregate research findings but to critically analyse them and provide a new interpretation of the existing data [27].

The review was undertaken on English articles published from January 2010 to November 2021 in Scopus and Google Scholar databases. To narrow our focus and be able to identify the most relevant research articles, we used Boolean operators to create our search strings. These strings were constructed with the following keywords and their combinations: 'patient', 'perspective', 'technology', 'telemedicine', 'patient engagement' and 'eHealth'. In addition to the searched databases, the reference lists within the articles selected were searched for additional articles regarding patients' perspectives on digital health technologies.

We examined articles published from 2010 to 2021, and only studies on digital health tools that included the patient's perspective over various geographical locations. The search results yielded 1722 potentially relevant articles. The title and abstract of the retrieved articles were then scanned, and we further limited our focus to only those articles focusing on patients who used digital health technologies. This reduced the number of potentially relevant articles to 319. Finally, after skimming the full text, 71 articles were included for our data analysis. This procedure is illustrated in Fig. 1.

2.1. Data analysis

The data analysis in this research was a continuous and iterative mechanism used to transform and interpret data. In the first screening, all results

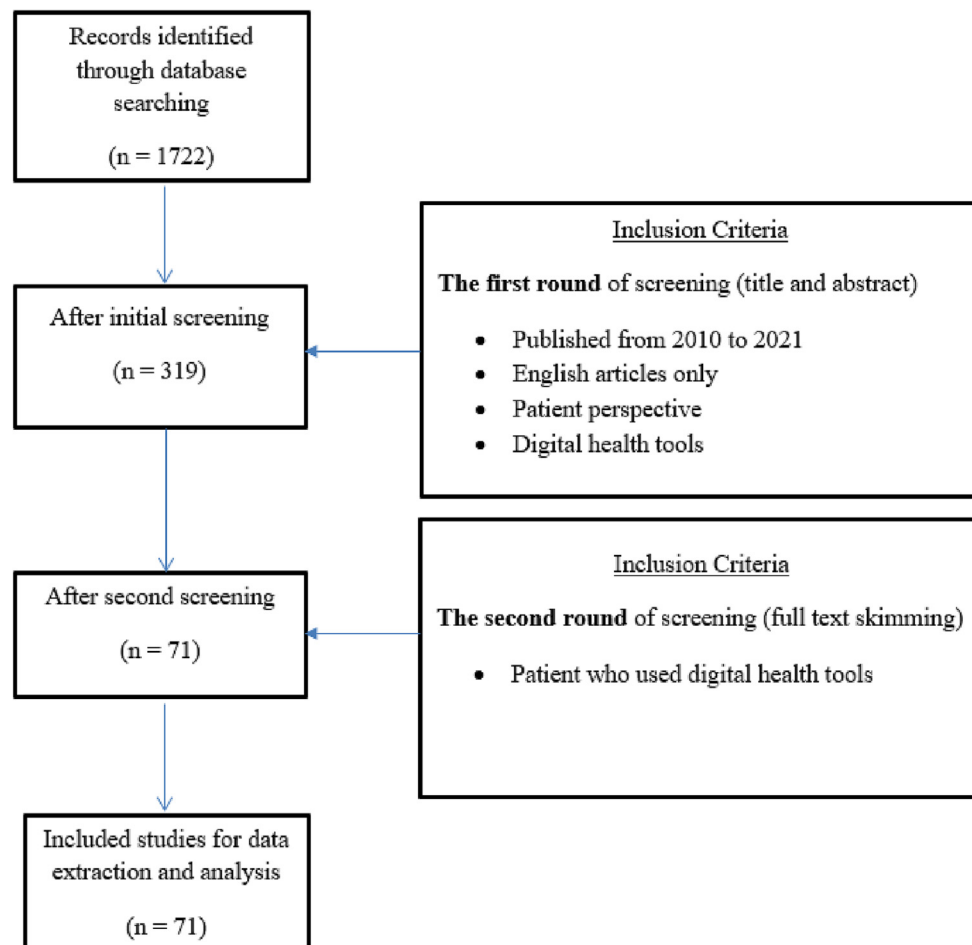


Fig. 1. Study selection procedure.

of the electronic search were examined for relevant titles and abstracts. Articles were reviewed and included or excluded based on the relevancy of the findings and the pre-defined inclusion and exclusion criteria by the research team.

After identifying relevant articles ($n = 71$), the full text of these articles was extracted and prepared for data analysis.

Thematic and qualitative content analyses were used. By using thematic analysis we tried to identify, analyse and report themes or patterns within data and find some agreement across them, and then categorise them by labels and codes [28,29]. Then to make the findings clearer for readers, as Myers [30] and Mayring [31] suggested, content analysis was used to interpret the qualitative data.

3. Results

Our data analysis yielded two major categories for the patients' perspectives on using digital health tools. The 'Facilitator' category included those perceptions that promote or facilitate patients' uptake of digital health tools. The 'Barrier' category was used to describe the factors that contributed to patients' decreased willingness to use digital health technologies for their healthcare purposes. The categories derived from the data analysis and their major sub-categories are illustrated below (Fig. 2).

3.1. Facilitators

Our thematic analysis revealed patient empowerment, self-management, and personalisation as the factors that contributed most to patient uptake in the use of digital health tools. In the following subsections, these factors are explained in more detail.

3.1.1. Patient empowerment

As defined by World Health Organisation, patient empowerment is a procedure that gives patients the information and abilities so that they can have more influence over choices and behaviours that have an impact on their health [32]. Different studies have attributed patient portals as a factor in facilitating patient control, empowerment, and

engagement [33-37]. Patient experiences with technology-enabled care is explored in a systematic review [33] and found that patient empowerment was linked to a patient's participation in decision making, achieving control, and learning about their health. Furthermore, patients feeling empowered was linked to reduced frustration with technology.

ElKefi and Asan [38] explored the impact of digital technology on cancer patient communication with healthcare providers. They found empowered patients were well-informed of their condition, which enhanced their relationship with their healthcare provider. This was also found to be linked to patient's being more involved in decision-making processes [38]. In a research study [36], it was found that patients could self-manage their health more easily with access to their medical records. It was identified that access to medical records meant patients could read through their consultation notes supporting them to better understand their medical condition, identify mistakes, and address misunderstandings between themselves and their clinicians.

In contrast, semi-structured interviews conducted with patients showed that the use of digital health technologies could help to perpetuate patients feeling that they were in a powerless position [39]. This was more evident when patients perceived their doctors as experts and consequently, patients were reluctant to assert their interests or opinions during consultations [37,39]. Likewise, in [40], the researchers discovered that patients using a telehealth service for video consultations did not feel comfortable asserting their perspectives. Compared to an in-person consultation, patients felt they had less control.

Traditionally, healthcare professionals were the main decision-makers regarding their patients' health [41]. This restricts the opportunity for partnership and shared decision-making processes between patients and healthcare providers [39]. However, research suggested that the patient and healthcare provider dynamic has changed due to the use of digital technology [22]. The use of these technologies has meant that relationships between patients and providers have become more collaborative, with patients able to share their opinions about their treatment more easily [37,42-46].

mHealth technologies, such as mobile applications, have successfully increased patient engagement by fostering patient motivation [47].

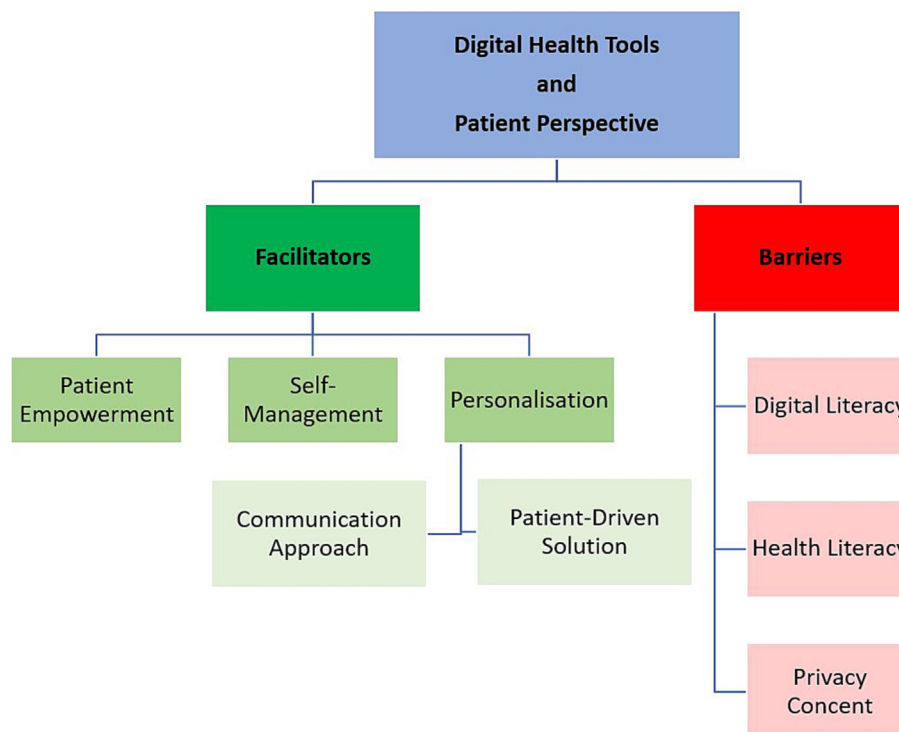


Fig. 2. Facilitators and barriers of digital health tools use by patients.

For example, Morrissey, Casey, Glynn, Walsh and Molloy [47] found that participants had increased motivation and engagement with a mobile app to monitor their blood pressure because they could view their data as a graph. In the same study, patients felt empowered during doctor visits because they could track and follow their blood pressure readings. Similarly, patients in a study by Rief et al. [45] found that tracking their health made them feel like they were working with their healthcare provider to improve their health outcomes. This finding is congruent with other studies that show visual representations of health data help to legitimize patient experiences [48,49].

3.1.2. Self-management

Patient self-management originates from patients having a better understanding of their condition. It is defined as a systematic delivery of information and encouraging interventions by healthcare professionals to improve patients' abilities and confidence in managing their health issues [50]. Ideally, patients are sufficiently self-assured to manage their problems on a medical, social, and emotional level. Digital technology in healthcare has become a catalyst for preventive medicine and more engaged patients. Through semi-structured group discussions, participants in a study by Du et al. [51] described how they benefitted from using technology to manage their diabetes, as they were able to visualise and be more aware of their calorie intake. The incorporation of digital technology into patients' lives has been shown to increase their awareness of lifestyle behaviours, which has helped them understand how to better manage their health [51]. Likewise, Ng, et al. [52], found that veterans who could visualise their health data showed increased motivation when managing their health.

In a focus group research study, the use of technology by patients was found to increase their independence, autonomy, and control over their health (Babbage et al., 2020), which was achieved through a combination of education and self-management.

A good patient-clinician relationship could be the key to effective self-management [37]. Previous studies have noted that more engaged patients have better relationships with their healthcare providers [42,53]. However, neglecting some factors might create challenges for patients. For example, Nahm et al. [54] found, that a more prevalent issue among the older patient population is remembering login details across multiple patient portals. In their research, the authors found that older patients often manage more than one chronic condition and, therefore, may use multiple patient portals across different healthcare providers. In Australia, Hanna et al. [21] found that patients preferred one patient portal that integrated health records from different health services (e.g., in-patient stays, outpatient services, radiology, etc.). The patients believed this would maximise the benefit of patient portals, as different healthcare providers would have access to the same information [21].

To address this issue, Widenbos et al. [55] highlighted how an integrated online patient system may be beneficial for chronically ill patients who needed to manage their health data across different healthcare systems. Creating a user-friendly system was suggested to be an important factor to increase patient uptake and engagement with patient portals [55]. Access to medical records resulted in patients feeling strong ownership of their health data [56]. This strong sense of ownership is associated with well-informed patients, which places them in a stronger position to better manage their health conditions [36,56].

3.1.3. Personalisation

Personalised Care strives for patients to have choice and control over how their care is planned and delivered. This is based on 'what matters' to patients and their individual strengths and needs [57]. It is believed that personalised medical services have also been linked to increased patient engagement [58]. In a study observing patient engagement in the context of rehabilitation, King et al., [58] found that patient engagement increased when there was an element of personalised care. The shift toward personalisation in the digital health environment enables patients to be part of the decision-making process regarding their health and have a more active role in their treatment. In the context of digital technology,

personalisation refers to the process of tailoring the user experience of a digital platform, product, or service to an individual's specific needs, preferences, behaviours, and characteristics. It involves the use of data and algorithms to create personalised content, recommendations, and interactions that are relevant and useful to the user. This helps shift the power balance from health providers making patient decisions to a shared decision-making process where the patient's needs are considered [8]. This is sometimes referred to as personalised medicine. Different studies have shown that a personalised approach to digital technologies can increase patient engagement [45,47,59]. Creating an online interface that appeals to patients could be vital to increasing patient engagement with their health.

Personalisation is becoming increasingly important in the digital age as users are inundated with an overwhelming amount of information and content. By tailoring user experiences to their specific needs and preferences, digital platforms can enhance user engagement, satisfaction, and loyalty.

3.1.4. Personalisation through communication

Using semi-structured interviews, Piras and Miele [60] explored the digital intimacy relationship between clinicians and patients. In the past, clinicians were often found to be emotionally detached from patients so that they could adequately treat them [60]. However, with the emergence of a patient-centered paradigm and the concept of personalization, it was found to be more difficult to treat patients solely based on the interpretation of clinical data [60]. Understanding a patient's lifestyle and behaviours can support the interpretation of clinical data. This may be demonstrated through an example of a patient monitoring their diabetes, where personalised communication between the clinician and patient helped provide the context for a low glucose reading [60].

Furthermore, Akbar et al., [35] and Kern et al., [61] illustrated that better patient outcomes are linked to more effective communication between patients and their healthcare providers. Patients had increased motivation to engage in activities that lowered their blood pressure via text messaging when there was an element of personalisation that helped patients feel they were listened to [62]. Similar findings were reported by Dawson et al. [63], who explored using mobile text messaging to improve diet in haemodialysis patients. The researchers observed patients' declining attention and motivation due to a lack of personalisation. Participants felt that the text message reminders were too generic, and they demanded more personalised messages that they could better relate to.

How patients value patient portal functionalities was analysed by Wildenbos et al. [55] who discovered that older patients preferred communicating with their healthcare provider about their medical notes. Subsequently, this was linked to increased patient engagement. Although patients had access to their clinicians, Wildenbos et al. [55] noted that communication through patient portals could be ineffective due to late responses from healthcare providers. General Practitioners (GPs) in Wells et al. [64] research believed that implementing patient portals could negatively impact their workload by having to deal with more questions from patients outside consultation times. In contrast, patients in [45] study received prompt responses from their healthcare provider, which increased their comfort and feelings of ease of use.

Interestingly, patients in Wells et al. [64] study preferred a phone conversation or in-person communication, as they felt it was inappropriate to electronically communicate with their healthcare provider. These patients were also aware of the increased workload with online communication by their healthcare providers [64]. In contrast, older patients in [54] study, preferred online communication as they struggled to reach their clinicians on the phone. As indicated by [65], patients perceived the purpose of patient portals as a tool to communicate with their clinicians. However, the reason why patients wanted an online portal was not explored in depth.

In this regard, and to improve portals' uptake by patients it is recommended that patients should be included in the design process, specifically in the development and refining stages [66]. Generally, patients seem aware of their clinician's workload and, as a result, are considerate of the ways they contact their clinicians. This highlights the need for patient portals to be better integrated into clinicians' work systems.

3.1.5. Personalising through patient-driven solutions

There have been case studies of patients creating digital health tools to better manage their health [67,68], as opposed to tools designed by researchers, clinicians, and industry professionals (traditionally believed to be the experts) [67]. One example of a user-driven tool is the Nightscout project [67]. The Nightscout project involved uploading glucose data to the cloud, which allowed a parent to monitor their child's glucose levels remotely. The project demonstrated how patient needs and experience are vital to creating digital health tools [67]. More effective collaboration between patients, clinicians, and designers could lead to digital health tools that are better tailored to their users.

3.2. Barriers

Digital literacy, health literacy, and privacy concerns were identified as the most reported barriers to the uptake of digital health technology among patients.

3.2.1. Digital literacy

The use of digital technology for health purposes is dependent on the patient. In this regard, digital literacy is a strong barrier to adopting digital health tools and online patient portal services [69-71]. Research conducted by [69] highlighted that digital tools for healthcare often fail to meet the needs of most people. These researchers emphasised needing more research to understand better how people with low literacy search and read health information so that digital tools may be designed to be more accessible and usable for a wider group population. Different methods were used to measure digital literacy, including quantitative surveys, qualitative methods such as focus groups and analytical tools such as Interpretative phenomenological analysis methods [72] and semi-structured interviews [73] to examine older adults' experiences of technology.

A barrier to the uptake of digital technology among older adults was patients feeling uncomfortable using technology [74]. Older adults reported being worried about breaking digital devices and about the security of their data [72]. In particular, the language and complexity of the technology impacted patient engagement as it affected the confidence and interest of participants [72]. Although digital technology was perceived as a barrier among older adults, Hill et al. [72] found it to be a facilitator once patients' fears were overcome. Once this happened, digital technology enabled patients to have more enjoyment and better support, as the technology allowed them to overcome the physical barriers of mobility, distance, and the limitations of time and, consequently, enabled them to continue to participate in their communities [72].

Interestingly, several participants in [47] study showed little interest in engaging with technology and did not have the desire to become digitally competent to manage their hypertension. This reluctance to embrace new technologies was attributed to these patients already having a system to monitor their hypertension [47]. A generational influence on the acceptance of digital health tools is describe in [75]. The older population views technology as a barrier due to their low digital literacy, whereas younger people are more comfortable using technology [75]. However, this digital literacy barrier can be overcome through support and education. For example, simple to use interfaces made it easier for patients to develop technical skills in the context of their in-home telerehabilitation [76].

3.2.2. Health literacy

Health literacy refers to a patient's ability to understand medical information and terminology. Many studies have raised concerns about health literacy when enabling patients to access their electronic medical records [20,46,66,69,77,78]. Health literacy was evaluated using different approaches such as validated questionnaire [79], self-reported health literacy in surveys or using open-ended questions [80] or eye-tracking techniques [69].

Bernaerdt, Moerenhout and Devisch [39] identified that vulnerable patients, who may benefit the most from accessing their medical records, are at risk of being disadvantaged due to their low health literacy preventing

them from understanding their information. These researchers noted that patients with low health literacy were less likely to use online patient portals.

Like the digital literacy barrier, the health literacy barrier could be overcome with access to extra support [39]. concluded that older adults preferred their medical notes to be presented to them in laymen's terms [55] so that it is easier for them to understand. However, a research by Wells et, al., [64] identified that GPs often document their medical consultations in terms more accessible to patients because their patients often find this information easier to understand. In one study, some participants were reluctant to engage with the mobile application for managing hypertension due to not knowing what to do if a high blood pressure reading was recorded [47]. This led to participants perceiving the mobile application as a potential source of anxiety, which consequently led to unnecessary concern and doctor visits [47]. This was congruent with findings in Pillemer et al. [56] mixed-method study in which the researchers explored the perspectives of clinicians and patients and the impact of patients having access to their laboratory results via a patient portal. Both clinicians and patients shared similar concerns regarding test results becoming a source of anxiety due to not understanding what the results might mean [56]. This emphasises the need to create systems that present information in an easy to understand way and without increasing clinician workload. It was suggested that digital tools need to be tested with the intended users, with a focus on creating accessible systems that ensure health information is comprehensible by all users [66,69]. In their literature review, Househ, Borycki and Kushniruk [81] found that using videos to communicate health information was beneficial for people with low health literacy skills. Presenting information within a video was shown to be easier to understand compared with written information [81]. However, the authors noted that by finding health information online, there was a chance of spreading misinformation which could mislead patients and result in risking patient safety [81].

3.2.3. Privacy concerns

Many studies revealed that privacy can be a barrier to the use of digital tools in healthcare [14,53,71,72,82-89]. In these studies, patients resisted using digital technologies and sharing their health data with their clinicians. The main reason for their resistance was associated with the fear of sharing their data and potential misuse by third parties. To measure privacy concerns, the Antecedent Privacy Concern Outcomes Macro-model (APCO) and Concern For Information Privacy scale (CFIP) models were used [82], along with quantitative analysis of participant's reported privacy concerns.

Various studies found that participants were concerned about their data being misused, especially by insurance companies [82,86-88]. Patients were concerned about facing discrimination if their health information was available to third parties or government agencies [82,83,87-89]. This issue was highlighted for patients with psychiatric conditions. This group feared that if their medical records were hacked, their medical information may be negatively perceived by employers [89]. Reinhardt, Schwarz and Harst [90], conducted a scoping review on the non-use of telemedicine and found that privacy and security of data was a barrier to use. In another study, however, participants were found to be more concerned about the security of their financial information than they were about their health information [91].

In contrast, Guo, Zhang and Sun [92] found that when using online patient portals, participants were willing to relinquish their privacy for personalised medicine. Consequently, they suggested that creating personalised services would increase the adoption and retention of electronic medical records. Added personalisation may help to create trust between patients and healthcare providers, and this would also help to minimize privacy concerns [92].

Most patients are aware that free mHealth applications make private data easily accessible [59]. However, patients using mHealth applications may be willing to risk the security of their private data if they can benefit from its use [59]. This illustrates that in some instances, patients may be willing to sacrifice privacy if they can benefit from the use of digital health tools.

4. Discussion and conclusion

4.1. Discussion

Technology has now infiltrated all spheres of our daily lives - from grocery shopping to learning and communicating online. This has accelerated but also become largely normalised (especially in the context of healthcare) through the COVID-19 pandemic.

From the literature, it was suggested that patients that were more engaged with digital health tools benefited the most from the management of their health condition.

The identified facilitators of patient uptake of digital health tools, such as patient empowerment, self-management, and personalization, can help to shift more paternalistic healthcare models to those that are more patient-centered, where relationships between clinicians and patients are more collaborative.

Although increased self-management is a facilitator of the use of digital health tools, such as patient portals, it does highlight the issue of managing multiple chronic conditions across various patient portals. Personalisation results from moving to digital platforms, yet patients reported they did not want to lose the human contact experienced during more traditional consultations. However, access to digital platforms for communication may result in an increase in clinician workload.

One of the challenges to ensuring the success of digital health tools, therefore, is how to simultaneously meet the seemingly opposing needs of patients and clinicians.

The studies identified through this literature review, especially regarding the barriers to the uptake of digital health tools, point to the need for a modified approach to designing digital health tools – where patients work alongside clinicians and technicians to ensure end products meet their needs and abilities.

So far, research highlights the disconnect between the development and implementation of digital health tools and the patients they are created for. Some researchers have noted the possibility of discontinued use as patient motivation seems to decrease over time [49,75,90]. However, the reasons for this drop in motivation were not explored in-depth in these studies (nor was overcoming barriers to the uptake of digital health tools explored). Exploring patient perspectives in-depth, through qualitative methods, will be useful when developing future digital health tools. For example, some studies indicated that both digital literacy and health literacy could be overcome with support. Further research is needed to develop a better understanding of these issues, as well as patients' health information privacy fears regarding and devising ways to overcome them.

Studies also highlight that employing participatory design could help avoid these issues altogether by working with patients to design the content of digital health tools. In this regard, healthcare and digital health technology developers must shift their development strategies to become more patient-centred, where patients as end-users have a more active role in designing digital health solutions. This would more likely result in patients' requirements being addressed, which could ultimately improve patients' uptake and usage of digital health tools. Participatory design is not new to either healthcare or information systems design [93]. However, it has been used inconsistently, at least in the healthcare context. Despite health services becoming more complex, traditionally, healthcare systems have been slow to embrace change and innovate [94]. More recently, there has been a paradigm shift toward a more human-centred approach to designing services and technologies to improve patients' experiences of healthcare [95]. This approach often involves designers working together with clinicians and patients to enhance mutual communication and understanding in order to improve the efficiency and experience of healthcare.

4.2. Innovation

Digital health tools offer huge potential for healthcare organizations and patients. In addition to providing health services to anyone, anytime, and anywhere, to harness the full benefits of these technologies, patients

- as end users in most cases - should be considered at the core of the solution or service. Patient acceptance plays a major role in the success of these technologies, and their involvement becomes even more important when digital health tools are designed for specific groups such as older adults [1] or vulnerable populations such as people with mental health support requirements [3].

Consequently, more recently, there has been an emphasis on a modified approach to designing digital health tools – where patients work alongside clinicians and technicians to ensure the end product meets their needs and abilities. This approach was used in [96,97] research studies where a care coordination platform for patients with dementia was designed with dementia care experts, caregivers and patients.

Patient-focused, participatory qualitative research may provide insight into patients' needs so that digital health technology can be better designed – *with* the users, rather than *for* them [98]. The key to continuous use and uptake of digital health tools will be understanding and empathising with the experience of those using and those providing health services, products, and interventions [99].

4.3. Conclusion

This review aimed to explore and integrate the available knowledge on patients' perspectives on using digital health tools. Six themes were identified as either facilitators or barriers to use. Further research should use participatory design methods to create patient-centred digital tools.

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Declaration of Competing Interest

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