

Evaluation and Improvement from a Human-Centered Design Perspective

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Evaluation and Improvement from a Human-Centered Design Perspective



Tingting Wang

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DISSERTATION

for the purpose of obtaining the degree of doctor at Delft University of Technology by the authority of the Rector Magnificus, prof.dr.ir. T.H.J.J. van der Hagen chair of the Board for Doctorates to be defended publicly on Tuesday 25 February 2025 at 15:00 o'clock

by

Tingting WANG

Master of Art in Design Science, Jiangnan University, China born in Anhui, China This dissertation has been approved by the promotors.

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Keywords: Digital health; User experience; Healthcare design; eHealth; mHealth;

User-Centered Design; Human-Computer Interaction

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Summary

A positive digital patient experience can improve health and care outcomes, but a positive digital patient experience does not just happen; it refers to understanding, evaluating, and improving the entire patient journey through digital health. Human-centered design is often applied to understand patients' needs and improve patient experiences when designing digital health solutions. However, human-centered design for digital health is demanding. It often involves multiple stakeholders with different values and requires evidence for implementation. Patient perspectives routinely differ from those of other stakeholders. Even within the same patient group, individual situations are also often different from each other. Yet, it is not always apparent that patients were engaged in the design process and were empowered enough to voice their opinions. Listen to the patients' voices and uncover their unique needs; designers are expected to speak for patients. This thesis aims to support designers in improving the quality of care in digital health by defining, evaluating, and designing digital patient experiences. This thesis is divided into three parts to achieve this goal.

Part A: defining digital patient experiences

To build a common understanding of digital patient experiences among design, technology, and healthcare communities and to facilitate transdisciplinary knowledge exchange and learning between these different fields for driving digital health innovation, this part contains one chapter and focuses on defining digital patient experiences. In chapter 2, we proposed the term "digital patient experience" as a common phrase to describe the patient experience in digital health and defined "digital patient experience" by synthesizing the reported patient experience or user experience of varied digital health interventions from multiple reviews. Specifically, the concept of the digital patient experience was defined as "the sum of all interactions affected by a patient's behavioral determinants, framed by digital technologies, and shaped by organizational culture, that influence patient perceptions across the continuum of care channelling digital health." In addition, we identified information on influencing factors and summarized them into 9 categories (i.e., patient capability, patient opportunity, patient motivation, intervention technology, intervention functionality, intervention interaction design, organizational environment, physical environment, and social environment). These categories were classified into positive, negative, and double-edged factors based on their positive, negative, or dynamic impacts on digital patient experiences. Furthermore, we uncovered 4 design constructs (i.e., personalized, information, navigation, and visual design) and 3 common design methods (i.e., user-centered design or humancentered design, co-design, and inclusive design) as design considerations for addressing digital patient experiences. Finally, we proposed a framework and 9 design guidelines to help digital health designers and developers improve digital patient experiences throughout the entire design process.

Part B: evaluating digital patient experiences

In the second part, we discussed the importance of evaluating digital patient experiences, developed an evaluation guide to help digital health researchers, designers, and developers further evaluate digital patient experiences, and conducted a case study to evaluate digital patient experiences in a clinical setting. Following the research findings of Chapter 2 on defining the digital patient experience, in Chapter 3, we first identified five typical evaluation objectives and related stakeholder groups. We then described potential evaluation timing considerations in terms of 4 intervention maturity stages and 3 evaluation timings. We also collected knowledge on evaluation indicators of digital patient experiences and grouped them into 3 categories: intervention outputs, patient outcomes, and health care system impact. These were then classified into 9 themes (i.e., intervention functionality, usability, care quality, patient emotional outcomes, perceptual outcomes, capability outcomes, behavioral outcomes, clinical outcomes, and system economic outcomes) and 22 subthemes. Furthermore, we noted a set of common study designs, data collection methods, and instruments, as well as data analysis methods, that can be used or adapted to evaluate digital patient experiences. To facilitate the standard evaluation of digital patient experiences, we recommend 6 directions for further research on digital patient experience evaluation. In Chapter 4, we conducted a prospective observational study to evaluate digital patient experiences of using virtual reality distraction in wound care for pain management. This chapter can be used as an example for guiding digital health designers and developers to evaluate digital patient experiences in clinical settings. It also offers inspiration to improve the design, development, and implementation of the virtual reality distraction in wound care for better digital patient experiences. For example, We found that patients who had high levels of technology acceptance, pain during previous wound care, or previously used VR distraction in wound care were more willing to use VR distraction in wound care. These findings indicate patient behavioral determinants have an influence on their intention to use digital health solutions, which supports our findings in Chapter 2 that patients' behavioral determinants influence patient perceptions of using digital health. In addition, in Chapter 4, no evidence was found on the effectiveness of virtual reality distraction in significantly reducing pain or anxiety during wound care. Although many studies have indicated the effectiveness of using virtual reality distraction in wound care for pain management, our research results do not support this argument. To avoid ineffective digital health implementation, we encourage more rigorous research on investigating the effectiveness of virtual reality distraction in wound care or how to improve its effectiveness through design. Besides, on average, the digital patient experience and patient satisfaction with using virtual reality distraction in wound care were positive, which reveals that although digital health solutions do not always lead to a significant better health outcome, they can contribute to a better treatment experience, which is also very valuable.

Part C: designing digital patient experiences

In the final part, we focus on guiding the design of digital patient experiences. We investigated the general human-centered design process in digital health and synthesized all research findings to generate a web-based design guide to support the understanding, evaluation, and improvement of digital patient experiences. In chapter 5, we mapped the (re)design and continuous improvement processes in digital health into 8 stages and grouped them into 4 phases: preparation, problem-thinking, problem-solving, and implementation. We also identified 12 challenges and classified them into 4 categories: contextual, practical, managerial, and commercial challenges. Furthermore, we outlined 8 corresponding strategies. recommended by the participating designers, to address each challenge type. Finally, we created a framework including design deliverables, activities, involved stakeholders, design challenges, and related design strategies for each design stage. The framework not only aids designers in understanding the design practices in the healthcare industry but also guides them when managing their digital health design processes towards the improvements of digital patient experiences. In chapter 6, we presented a web-based digital patient experience design guide that synthesized the previous research findings, and we further evaluated the design guide. We show that our digital patient experience design guide was evaluated as usable with good content quality, but that it needs further improvement in providing relevant, detailed, and resourceful content, intuitive and interactive interfaces, as well as simple and ready-to-use templates. We believe these improvement insights are relevant for developing and evaluating design guides in general. In addition, participants reported conflicting tensions in the guide's design, requiring a balance between specific and general, less and more, as well as fixed and flexible. These tensions reveal the diversity and conflicts in students' needs for useful and effective design guides. On the one hand, users want design guides to hold relevant, detailed information and content, provide a systematic overview, include complete conceptual explanations, detailed design cases, and integrated design resources, enabling them to use the design guide as a resource library for flexible exploration. On the other hand, they want a design guide to be simple and easy to use, offering concise and clear information with low learning and usage costs, enabling them to effortlessly complete efficient designs. We believe this study serves as an example, inspiring future design researchers to develop and evaluate their own design guides.

In conclusion, this thesis contributes theoretically (via new knowledge) and practically (via the design guide) to facilitate a scientific impact on the definition, evaluation, and design of digital patient experiences from a human-centered design perspective, thus, supporting the improvement of the quality of care in digital health solutions.

Preface

"What is design?" This is a question that I have been thinking about since 2013, when I started my Bachelor of Engineering in Industrial Design at Anhui University in China. At that time, all my understanding of design was making something that was tangible, visualized, and creative. In my daily life, I commented on every design product based on how I understood design. Although I did not have a set of clear criteria about what was good design, "user-friendly" was intuitively used. Indeed, since I was a fresh design student, I have been unconsciously considering "experience" as a core element of evaluating daily "good" design. "Experience design" has captured my attention.

In 2017, I went to Jiangnan University to do my Master of Art in design science. Due to my interest in "experience design," I chose "interaction and experience design" as my master's program. From there, I started knowing that the design discipline is a broad and interdisciplinary field that focuses on more than creating tangible, visualized, and creative products, services, or systems. Design can manipulate user experiences, empower social innovation, and contribute to human wellbeing. I was educated to use inclusive design methods when designing for vulnerable user groups, such as designing for healthy aging. I was taught to map the entire user journey to uncover the unique user needs and empathize with their feelings. I learned how to use well-known design frameworks, methods, and tools, such as the double-diamond framework, the human-centered design method, and the patient journey map, to manage design processes, communicate design requirements, and meet user needs. But most of the time, I used them because they were part of a common design routine that I was taught to follow. I realized there were some important but complicated connections behind these design frameworks, methods, and tools that I had missed in my understanding of design. I wasn't clear about where these design methods came from or what exactly I could get from using them. I was a bit doubtful about the time I spent learning and using new methods and whether they could guarantee what I wanted to achieve as a designer. I was motivated to figure out these blurry areas.

Therefore, I started my PhD journey at Delft University of Technology in October 2020. I got a nice research project that was part of the Consultation Room 2030, and it was formulated as "Digital patient experience: evaluation and improvement from a human-centered design perspective". Within this PhD project, I act as a design researcher, a design communicator, and a designer. I conduct design research, collaborate across disciplines, communicate with multiple stakeholders, facilitate knowledge transfer, supervise design students, and develop design guides. These different roles and activities not only help me extend my knowledge in defining, evaluating, and designing digital patient experiences but also deepen my understanding of doing design and designing design. I also became more aware of the relationships between design research, design education, and design practice; they are in a big loop that influences each other and supports each other. My promotors always told me

that doing a PhD is a learning process. In the past four years, I have grown a lot by doing self-reflection in the learning process, which helped me learn from failures and correct research directions. I believe the target readers of this doctoral thesis, those from the design, technology, and healthcare communities, are not only interested in my research findings on defining, evaluating, and designing digital patient experiences but also in my reflections through the whole learning process and the lessons that I learned from doing a PhD in design. Therefore, I'll present both in this doctoral thesis. Research findings will be written in each chapter, and after each chapter, I'll write my reflection as a lesson from doing a PhD in design that may link to my working experiences in each study.

Abbreviations

CT: Computed Tomography

DH: Digital Health

DHI: Digital Health Intervention

DHD: Digital Health Design

DRM: Design Research Methodology

EMC: Erasmus Medical Center

HCD: Human-Centered Design

HCI: Human-Computer Interaction

HCP: Health Care Provider

HIS: Health Information System

HIT: Health Information Technology

ICU: Intensive Care Unit

ISO: International Organization for Standardization

MVP: Minimum Viable Product

NHS: National Health Service

PCC: Patient-Centered Care

PEx: Patient Experience

PREM: Patient-Reported Experience Measure

PRISM: Performance of Routine Information System Management

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PROM: Patient-Reported Outcome Measure

QoC: Quality of Care

RCT: Randomized Controlled Trial

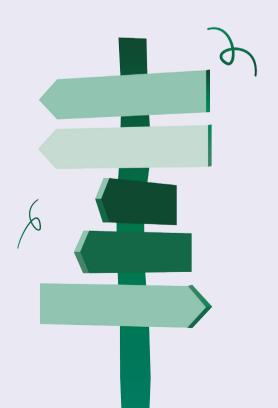
RQ: Research Question

RtD: Research-through-Design

UCD: User-Centered Design

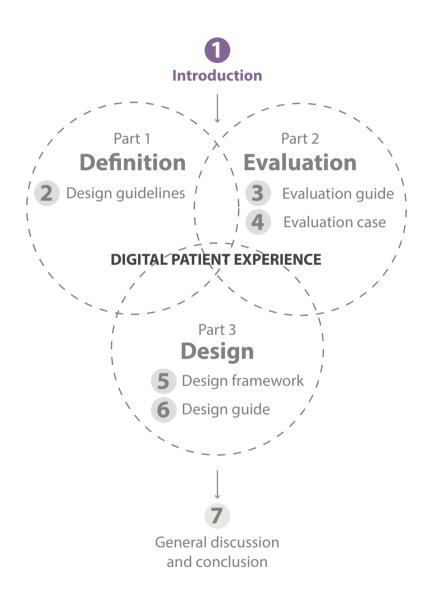
UX: User Experience

VR: Virtual Reality



Chapter 1

Introduction



1.1. Background

Have you ever been a patient? What are the feelings of being a patient? Vulnerability, fear, anxiety, frustration, impatience, isolation, loneliness, sadness, depression, resentment, anger, guilt, shame, empowerment, relief, gratitude, hope, or optimism... according to a query on ChatGPT (ChatGPT, 2024). Apparently, more negative emotion vocabularies were used, which reveals the challenges facing a patient. A human being can have nearly thousands of known diseases. We are all people, and we are all patients at some points in our life course.

Six years ago, I broke my left leg while practicing my skateboarding skills in a very early morning, suddenly, I changed from being a "healthy and energetic" person to needing to lie in bed while awaiting surgery (see Figure 1-1). I remembered clearly when I fell off my skateboard. A crisp sound of a bone breaking as the pain hit me hard made me sweat and cry. Fear, anxiety, worry, concern, sadness, regret, even shame and guilt—all emotions came to me. I tried to calm down, picking up my mobile phone. With shaky hands, I searched "how to tell if a bone is broken" and "what to do if you break a bone". I did some selfdiagnosis following the online information and tried to figure out what to do next: inform my family members and friends, get a referral letter, go to the hospital, do a Computed Tomography (CT) scan, pay the diagnosis and treatment fee, enrol in an in-patient clinic or not... Unfortunately, I was informed of a bone fracture and suggested having surgery as soon as possible. "No way...", I did not trust the doctor that much and doubted if the surgery was the best option. To make a quick and right decision, I immersed myself in the online sea of ankle surgery information and bone-broken patients' stories to seek evidence on what was good for me. Reading more information did not release my stress but made me feel even more overwhelmed. I couldn't even figure out which information was trustworthy and suitable for me, and which was incredible and irrelevant. What I got was the impression that having surgery seemed like a common choice, and I did so. I thought the surgery would be a turning point; everything would get better afterward. However, another type of pain came to me, and more concerns related to recovery and future quality of life were raised: when can the pain completely go away? when can I walk again? how can I pick up my studies and exercise after lying on the bed over three months? can I run and jump as well as I did before? I was looking for any signals that proved my situation was better or worse... That was a sensitive period; my parents had to be very careful not to make me emotional. Until today, I still couldn't tell if there were any side effects on my life due to the injury or surgery. But what I can tell is that I am more aware of the feelings of being a patient, not only concerning the physical pain or discomfort but also other thoughts about long-term wellbeing and quality of life-the overall experiences in a patient journey.

Although we have discovered more than thousands medical and surgical procedures and drugs for treatment, we can't cure all diseases, and we can't guarantee that everyone will live a long and healthy life. What we can do is increase the likelihood of desired health outcomes,

enhanced patient experiences (PEx), and improved quality of care (QoC), which provides more effective, safe, people-centered care (PCC) that is timely, equitable, integrated, and efficient (World Health Organization & World Bank Group, 2018). Digital health (DH) technologies have the potential to achieve this goal, which can help "make health systems more efficient and sustainable, enabling them to deliver good quality, affordable, and equitable care (World Health Organization, 2021a)" and "reduce inefficiencies, improve access, reduce costs, increase quality and make medicine more personalized for patients (The US Food and Drug Administration, 2020)".

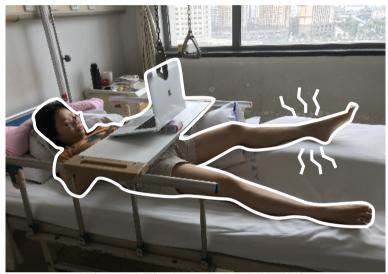


Figure 1-1. Tingting at the hospital in 2018

1.2. Digital Health Solutions

Digital health (DH) is an emerging field of study and has been expanded as an umbrella term that encompasses a broader set of scientific concepts and technologies (Tecco, 2017) since it was first introduced by Frank in 2000 (Frank, 2000). (The US Food and Drug Administration, 2020) describes DH as having "a wide range of uses, from applications in general wellness to applications as a medical device", and its broad scope includes "mobile health (mHealth), health information technology (HIT), wearable devices, telehealth and telemedicine, and personalized medicine". A review study identified 95 unique definitions of DH and inferred it as "the proper use of technology for improving the health and wellbeing of people at individual and population levels, as well as enhancing the care of patients through intelligent processing of clinical and genetic data" (Fatehi et al., 2020). For convenience, we use eHealth, mHealth, telemedicine, telehealth, virtual health, remote health, electronic consultations and health information systems (HIS) as interchangeable terms for DH in this thesis.

The COVID-19 pandemic accelerated the adoption of DH technologies (Golinelli et al., 2020),

which have been promoted, applied, or evaluated worldwide, from developing countries to developed countries, in varied clinical settings, from in-home monitoring to intensive care unit (ICU) management, to deliver high-quality health services that patients need for varied healthcare purposes, including promotive, preventive, curative, rehabilitative, or palliative. For example, in 2019, Germany passed the Digital Healthcare Act to improve healthcare provision for the good of patients through digitalisation and innovation (Fatchi et al., 2020; Federal Ministry of Health, 2019). In a multisite observational study of 129,400 patients within England's National Health Service (NHS) services, a study evaluated a personalized artificial intelligence-enabled self-referral chatbot and found it can help overcome the pervasive inequality in mental healthcare (Habicht et al., 2024). A scientometric study that analysed more than 16,000 articles found that DH technologies in cardiovascular care were growing exponentially, which received most interest from researchers from North America, Austria, and parts of Western Europe (Zwack et al., 2023). DH solutions, such as mobile health with a focus on education and behaviour change for patients in urban areas with chronic diseases (Yang & Kovarik, 2021) and Internet hospitals that represent internet medical platforms combining online and offline access for medical institutions to provide a variety of telehealth services directly to patients (Han et al., 2020) are booming in China as well. DH also shows great potential to improve healthcare in Africa as well as other underserved and epidemic areas (Xue et al., 2015). DH has been routinely used in some parts of the world to extend access to specialized healthcare knowledge across geographic boundaries, increase patient adherence to medication regimes, reduce referral wait times, leverage intensivist coverage over more ICU beds, decrease hospital readmissions and mortality, etc (Kvedar et al., 2014; Lowery et al., 2014; Xue & Liang, 2007). DH technologies show potentials to strengthen health systems and improve health outcomes (Martin et al., 2019; World Health Organization, 2021a), reduce costs (Cadili et al., 2022; Eze et al., 2020), enhance patient care pathway (Awad et al., 2021), and improve the effectiveness and efficiency of healthcare delivery (Kvedar et al., 2014; Lingg & Lütschg, 2020). The digitalization of healthcare enables us to get a deeper understanding of patients at the individual level by collecting, connecting, and analysing patient data across large populations; therefore, we are able to explore how to treat a particular patient or patient group more appropriately (Cancela et al., 2021).

1.3. Patient Experience in Digital Health

Although digital technologies are shaping the future of global health (World Health Organization, 2021a), Digital health (DH) solutions should not be discussed and planned, let alone implemented, without a focus on patients, who are the intended beneficiaries in most situations. Patients are unique because of their differing conditions and mindsets. To be clear, in this thesis, using the term "patient" is not restrictive or intended to reduce the person to a patient due to illness, but to bring attention to people who are struggling with certain health issues or are looking for a healthier life (Lalanda et al., 2017; Popa et al., 2024).

The values of quality of care (QoC) and patient-centered care (PCC) are widely accepted

(Epstein & Street, 2011). Patient experience (PEx) as an important component of PCC and OoC (Ahmed et al., 2014; Debra de Silva, 2013; Larson et al., 2019), has been considered as a key element of the triple aim (i.e., population health, experience of care, and per capita costs) and quadruple aim (i.e., better outcomes, improved patient experience, improved clinician experience, and lower cost) of the health care system and is widely used by healthcare researchers and practitioners for health and care improvement (Berwick et al., 2008; Bodenheimer & Sinsky, 2014). The concept of PEx has many definitions (Wolf & Jason, 2014). Access to appropriate care, patients' active participation in care, a good patientphysician relationship, reliable evidence-based care, comprehensible information, physical comfort, emotional support, involvement of family and friends, individualized approaches, responsiveness of services, and continuity of care were considered as the core elements of PEx (Kneeland, 2016; NHS National Quality Board, 2011; Shandley et al., 2020; Staniszewska et al., 2014). Besides, patient satisfaction, patient perception, and patient reports are sometimes used interchangeably with the term PEx as well (Ahmed et al., 2014). In this thesis, we follow the widely accepted definition given by the Beryl Institute, which is "the sum of all interactions, shaped by an organization's culture, that influence patient perceptions, across the continuum of care" (The Beryl Institute, 2024). Compared to the term PEx, which is a familiar concept for practitioners and researchers who are working in the healthcare world, "user experience (UX)" is a common terminology often adopted by people from the Human-Computer Interaction (HCI) and design communities in terms of utilizing digital technologies to improve healthcare services (Bate & Robert, 2023). UX is about technology that addresses human needs beyond the instrumental, with a focus on the affective and emotional aspects of the interaction under certain context and temporality (Hassenzahl & Tractinsky, 2006). It refers to "a person's perceptions and responses that result from the use and/or anticipated use of a product, system or service" (Bolton et al., 2018; Jokela et al., 2003).

We found both terms "patient experience" and "user experience" were used to investigate how people experience DH (Boissy, 2020; Brunton et al., 2015), but they were often used and preferred by different communities. We recognized that research on DH often involves two central study domains: health, which refers to biomedical sciences and psychology, and technology, which represents human-computer interaction and software engineering (Blandford et al., 2018). However, non-shared concepts and language between these two domains may lead to related researchers and practitioners working in 'parallel universes' (Pagliari, 2007). Not to mention if "patient experience" or "user experience" can allow researchers and practitioners to adequately understand, evaluate, and improve how people, particularly patients, experience certain DH solutions. Therefore, in this thesis, we argue that building a common understanding of these concepts is necessary and suggest using a unified term, digital patient experience, which is defined as "the sum of all interactions affected by a patient's behavioral determinants, framed by digital technologies, and shaped by organizational culture, that influence patient perceptions across the continuum of care channelling digital health", to converge the worlds of healthcare, technology, and design

for communicating, evaluating, and improving how patients experience DH solutions. More details about the definition of the digital PEx can be found in Chapter 2.

1.4. Human-Centered Design in Healthcare

Although digital health (DH) has the potential to improve or at least provide comparable patients' overall healthcare experience and satisfaction as traditional face-to-face healthcare services (Alkire et al., 2020; Bolton et al., 2018; Hamiel et al., 2024; Kneeland, 2016), the adoption of DH solutions routinely in large-scale clinical practice by patients remains challenging (Cancela et al., 2021; Choi et al., 2019; Greenhalgh & Shaw, 2017). It is still unclear how DH technologies influence the patient experience (PEx) or user experience (UX) (Mobasheri et al., 2014), whether patients experience more benefits (e.g., perceived convenience) or risks (e.g., privacy concerns) of using DH solutions (Golinelli et al., 2020; Kamillah et al., 2022; Perakslis et al., 2023; Thiyagarajan et al., 2020). More research is needed to understand, evaluate, and improve PEx in certain DH solutions (Farrell et al., 2022).

The need for improved PEx is unfulfilled (World Health Organization, 2018). Delivering the DH solutions that patients need to ensure outcomes and experiences of care that are valued by them is a call to action (Popa et al., 2024). User-Centered Design (UCD) and Human-Centered Design (HCD) has been suggested and applied to improve the relevance, uptake, and impact of DH solutions on the target user groups, support the development of innovative, effective, and patient-centered care, as well as optimize the PEx (Bhattacharyya et al., 2019; Cancela et al., 2021; Chadalavada et al., 2024; Göttgens & Oertelt-Prigione, 2021; Solomon & Rudin, 2020; Vagal et al., 2020). UCD was coined by Donald Norman in the 1980s (Harte et al., 2017; Norman & Draper, 1986). UCD and HCD were often used interchangeably, the former often referred to human factors to increase the usability or user friendliness of the solution, the latter often focused on human values and a multistakeholder or systems perspective (Göttgens & Oertelt-Prigione, 2021). DH design often involves to multiple stakeholders (Tingting Wang, Shuxian Qian, et al., 2022). To address "impacts on a number of stakeholders, not just those typically considered as users", the International Organization for Standardization (ISO) extends UCD to HCD and describes HCD as "an approach to interactive systems development that aims to make systems usable and useful by focusing on the users, their needs and requirements, and by applying human factors/ ergonomics, and usability knowledge and techniques" (The International Organization for Standardization, 2019). For convenience, in this thesis, we will refer to user-centered design as part of human-centered design. Although some studies pointed out the key elements and phases of applying HCD to healthcare innovation, a narrative review study suggested that developing a detailed design guideline engaging stakeholders, especially vulnerable patients, with consideration of their roles, experiences, expertise, agency, and power dimensions is needed (Göttgens & Oertelt-Prigione, 2021).

1.5. Research Aim

Digital health (DH) solutions are emerging to tackle varied health system challenges, such as deliver convenient, personalized, and accessible healthcare services (Gopal et al., 2019; World Health Organization, 2018). However, current patient adoption and adherence to DH solutions remain low partially due to poor design and negative experiences (Tingting Wang, Guido Giunti, et al., 2022b; Wang, Giunti, et al., 2024). Although human-centered design (HCD) (Carayon et al., 2020; Melles et al., 2021) has the potential to meet user needs and further improve patient experience (PEx) in DH. There is still very little rigorous practical guidance on how to improve DH design so that technologies have a positive impact on PEx. Along with the fact that design researchers and designers increasingly contribute to shaping future healthcare (Groeneveld et al., 2018), neither learning nor educating new DH design knowledge and skills would just happen themselves; they had to be researched, designed, and improved. Design knowledge transformation in this area is required. To further improve the quality of care in digital health, it is vital to understand, evaluate, and improve the digital patient experience from a human-centered design perspective (Alkire et al., 2020; Kellermann & Jones, 2013; Larivière et al., 2017). Recognizing the above research gaps, this thesis aims to provide a design guide that facilitates defining, evaluating, and designing digital patient experiences from a human-centered design perspective, thus improving the quality of care in digital health.

1.6. Research Questions and Methods

To achieve the above research aim, we came up with five main research questions. Following the Design Research Methodology (DRM) (Blessing & Chakrabarti, 2009), five studies were conducted to answer five research questions (ROs), see Figure 1-2.

- RQ 1. What is the state-of-the-art of patient experience in digital health in the literature?
 - Study I. An umbrella systematic review was conducted to identify the influencing factors and design considerations of the digital patient experience in the literature. A definition and nine design guidelines for understanding and improving the digital patient experience were generated.
- RQ 2. How to identify the gap from the state-of-the-art towards improved digital patient experience?
 - Study II. An umbrella systematic review was performed to investigate the evaluation objectives, timing considerations, indicators, and approaches of the digital patient experience in the literature. An evaluation guide was generated to support digital health designers and developers in evaluating the digital patient experience and seeking insights for further improvements.
- RQ3. What are the expectations and perceptions of patients about digital patient experience?
 - Study III. A prospective observational study was conducted to investigate the digital patient experience of using virtual reality distraction in wound care treatment.
- · RQ4. What are the perspectives and experiences of designers on the human-

centered design of digital patient experience?

Study IV. An interview study was performed to investigate human-centered design design practitioners' views, experiences, and values on digital patient experience.

• RQ5. What design guidelines can be formulated for the human-centered design of improved digital patient experience?

Study V. A design intervention study (i.e., iterative prototyping and user test workshops) was conducted to generate and evaluate a design guide for improving digital patient experience based on the previous studies.

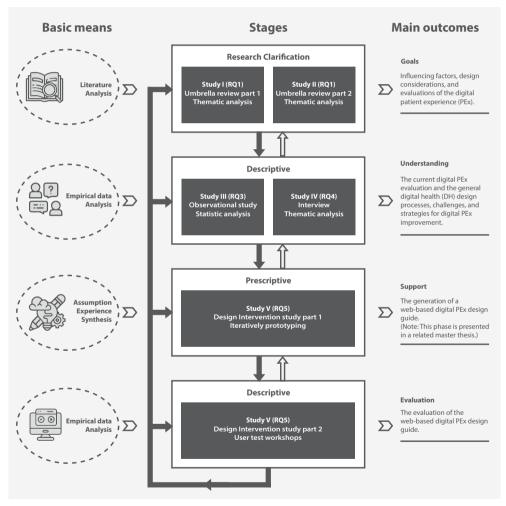


Figure 1-2. Research approach, adapted from the Design Research Methodology framework (Blessing & Chakrabarti, 2009)

1.7. Thesis Outline

This thesis is divided into three parts that contains seven chapters, as Figure 1-3 presents. Chapter 1 provides an overview of this thesis, Chapters 2-6 represent five studies that describes the definition, evaluation, and design of the digital patient experience from a human-centered design perspective, then Chapters 7-8 discuss and conclude the contributions, limitations, and future research directions of this PhD study.

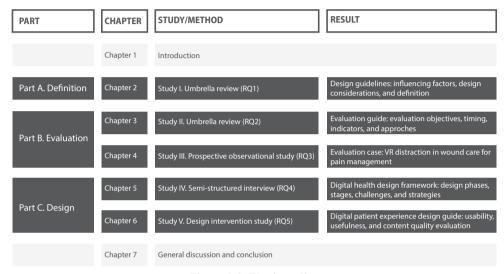


Figure 1-3. Thesis outline

Part A-Defining digital patient experiences

In Chapter 2, the state-of-the-art of the patient experience in digital health in the literature is described. An umbrella review was performed to systematically review the influencing factors and design considerations of patient experience in digital health. The term "digital patient experience" is proposed to describe patient experience in digital health and defined as "the sum of all interactions affected by a patient's behavioral determinants, framed by digital technologies, and shaped by organizational culture, that influence patient perceptions across the continuum of care channeling digital health." A framework and 9 design guidelines for digital patient experience improvement were generated.

Part B-Evaluating digital patient experiences

The second part contains Chapters 3-4. In Chapter 3, a review of reviews was conducted to systematically identify the evaluation objectives, evaluation timing considerations (i.e., when to measure), evaluation indicators (i.e., what to measure), and evaluation approaches (i.e., how to measure) regarding the digital patient experience. An evaluation guide was generated to support the digital patient experience evaluation research and practice. In Chapter 4, a prospective observational study in a clinical setting was performed as a case study

exemplifying the evaluation of digital patient experience of using virtual reality distraction for pain management during wound care.

Part C-Designing digital patient experiences

In the final part, Chapter 5 is a semi-structured interview study that obtained insights into current human-centered design practices in the digital health area. A digital health design framework was proposed to improve the digital patient experience in the design process. It provides an overview of design deliverables, activities, stakeholders, challenges, and corresponding strategies for each design stage. In Chapter 6, a design intervention study, which contains iterative prototyping and user test workshops, was performed to generate and evaluate a web-based design guide that transfer all research findings into more practical design knowledge and guidelines, which can be used for improvement by everyone interested in improving the digital patient experience.

In the last Chapter of this thesis, the general discussion and conclusion are provided. In Chapter 7, the implications, limitations, and future research directions are discussed.

This thesis is primarily intended for digital health designers, researchers, and design students who want to evaluate and improve digital patient experiences in their human-centered design process. People from broader design, technology, and healthcare communities may find useful information herein as well.

Lessons for doing a PhD 01

How to Cross the Doctoral "River"?

Once, I read a Chinese story called "The Little Horse Crosses the River (小马过河)(崇文, 2009)." The story is about a little horse that needs to cross a swift river. Unsure of the river's depth, the little horse encounters an old ox. The ox tells him, "The water is shallow, just reaching your calves. You can cross it." Encouraged, the little horse is about to cross when a squirrel stops him, saying, "The river is very deep. One of my friends drowned in it." After hearing both the ox and the squirrel, the little horse becomes even more hesitant and goes home to ask his mother. His mother tells him, "You will know whether the river is deep or shallow if you try it yourself." Encouraged by his mother, the little horse carefully crosses the river and successfully reaches the other side. He finds that the river is neither as shallow as the ox said nor as deep as the squirrel claimed.

I often think of this simple story. Four years ago, facing the same situation as the little horse, I was hesitant about pursuing a PhD in design. I consulted many people for advice and received various suggestions—some encouraged me, and some discouraged me. Now, as I am about to finish my PhD journey, I realize that, like the little horse, pursuing a PhD in design is neither as easy as some people say nor as difficult as others claim. However, I am grateful to all those mentors, friends, and even strangers who shared their experiences with me. Although most of them have unique experiences with their PhD journeys, their stories provided me with multiple perspectives to form a more systematic view of pursuing my PhD, which helped me avoid becoming too complacent to make mistakes or too anxious to be hesitant. Recently, many juniors also came to me for suggestions on pursuing a PhD in design. I did have a lot of experiences and thoughts to share with them, but I think the best answer was, "You will know it till you try it yourself". I do not know if my way of crossing the doctoral river is more like the ox's or the squirrel's. I hope the lessons that I learned through my PhD journey can help some junior PhDs prepare for their journeys in design.

If I could run my PhD again, I think I would prepare my PhD journey with a more systematic view by communicating with senior researchers more frequently, making more actionable plans, and doing regular self-reflections.

First, communication builds common understandings and creates learning spaces. My promotors have been very supportive in the past four years. In the first two years, we met each other almost every week. I had weekly meetings with each promotor and monthly group meetings with the whole supervision team, which helped us align with each other and progress the research smoothly. Even in the last two years, we still kept meeting each other biweekly. I would suggest junior PhDs communicate with your supervision team more often; in case they are too busy to be available, scheduling a series of meetings in advance is a good way. In addition, meeting peers and senior PhDs or postdocs is also very helpful. I started my

PhD in October 2020, when people had to keep social distance due to COVID-19. Therefore, I missed many chances to communicate with other PhDs, which was a bit of a pity. Lucky for me, I still received many suggestions from others, such as my officemates, on how to do a literature review, how to prepare a Go/No-Go meeting, how to arrange doctoral education, how to write a doctoral thesis, etc. These shares opened my mind and saved me time.

Second, planning is essential, as the book "Mastering Your PhD" (Gosling & Noordam, 2011) said. Although, compared to planning, there are often changes and delays in reality, having plans not only makes me feel a sense of certainty and keeps the timeline in mind, but also helps me communicate with others more effectively. Even small plans, like an agenda for a meeting, can already increase the transparency of communication and help everyone who joins the meeting prepare. As an old saying in China: "Sharpening the knife does not delay the chopping of wood (磨刀不误砍柴工)". Spending time on making plans, for example, how to manage your references and your data, will increase your work efficiency a lot in the coming years.

Last, I like doing self-reflection, which has played an important role in my self-growth. My promotors always tell me that doing a PhD is a learning process, which not only helps me avoid too much self-doubt when making mistakes but also encourages me to face challenges. Self-reflection is an important step in this learning process, where I can learn from my own failures, correct my research direction, and share my lessons with others.

































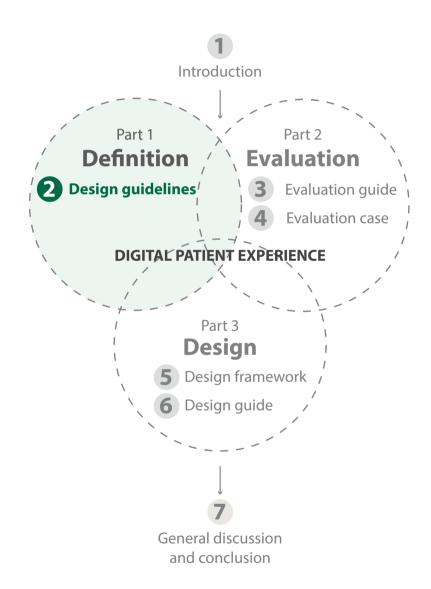




PART A
DEFINING DIGITAL
PATIENT EXPERIENCES

Chapter 2

Design Guidelines: Influencing Factors, Design Considerations, and Definition.



The content of this chapter was published in:

Wang, T., Giunti, G., Melles, M., & Goossens, R. (2022). Digital patient experience: umbrella systematic review. *Journal of Medical Internet Research*, 24(8), e37952. doi:10.2196/37952.

Abstract

Background:

The adoption and use of technology have significantly changed health care delivery. Patient experience has become a significant factor in the entire spectrum of patient-centered health care delivery. Digital health facilitates further improvement and empowerment of patient experiences. Therefore, the design of digital health is served by insights into the barriers to and facilitators of digital patient experience (PEx).

Objectives:

This study aimed to systematically review the influencing factors and design considerations of PEx in digital health from the literature and generate design guidelines for further improvement of PEx in digital health.

Methods:

We performed an umbrella systematic review following the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) methodology. We searched Scopus, PubMed, and Web of Science databases. Two rounds of small random sampling (20%) were independently reviewed by 2 reviewers who evaluated the eligibility of the articles against the selection criteria. Two-round interrater reliability was assessed using the Fleiss-Cohen coefficient (k1=0.88 and k2=0.80). Thematic analysis was applied to analyze the extracted data based on a small set of a priori categories.

Results:

The search yielded 173 records, of which 45 (26%) were selected for data analysis. Findings and conclusions showed a great diversity; most studies presented a set of themes (19/45, 42%) or descriptive information only (16/45, 36%). The digital PEx–related influencing factors were classified into 9 categories: patient capability, patient opportunity, patient motivation, intervention technology, intervention functionality, intervention interaction design, organizational environment, physical environment, and social environment. These can have three types of impacts: positive, negative, or double edged. We captured 4 design constructs (personalization, information, navigation, and visualization) and 3 design methods (human-centered or user-centered design, co-design or participatory design, and inclusive design) as design considerations.

Conclusions:

We propose the following definition for digital PEx: "Digital patient experience is the sum of all interactions affected by a patient's behavioral determinants, framed by digital technologies, and shaped by organizational culture, that influence patient perceptions across the continuum of care channeling digital health." In this study, we constructed a design and evaluation framework that contains 4 phases—define design, define evaluation, design

ideation, and design evaluation—and 9 design guidelines to help digital health designers and developers address digital PEx throughout the entire design process. Finally, our review suggests 6 directions for future digital PEx—related research.

Keywords:

digital health; eHealth; telemedicine; telehealth; mobile health; mHealth; patient experience; user experience; influencing factors; user-centered design; human-computer interaction

2.1. Introduction

Recently, there has been a significant increase in the use of digital health technologies. In addition, many countries currently use digital health technologies to support health care service delivery to overcome the disruptions caused by the COVID-19 pandemic. These include web-based patient consultations and requesting pharmacy and medication refills (World Health Organization, 2021b). Digital health offers care without the risk of exposure to the virus, especially for vulnerable patients such as older adults and patients with chronic diseases (Mehrotra et al., 2020). Before the COVID-19 pandemic, there was increasing recognition of the potential of digital health to improve the accessibility of health care in different clinical settings (eg. ambulatory care, acute care, and inpatient care) (Marcin et al., 2016). Digital health provides an opportunity to both reduce the costs of care and improve patient affordability (Davis & Oakley-Girvan, 2015; World Health Organization, 2016a), and previous research suggests that digital health has the potential to provide health prevention, consultation, treatment, and management (Arnberg et al., 2014; Bender et al., 2013; Davis & Oakley-Girvan, 2015; Escriva Boulley et al., 2018; McLean et al., 2016; Pal et al., 2018). With digital health solutions continuing to grow in both number and functionality, patient interest in digital health has rapidly increased, leading to an expanding reliance on digital health technologies (Jared, 2020).

As DH became a more familiar term, it has generated many definitions and the concept has been expanded to encompass a much broader set of scientific concepts and technologies (Tecco, 2017). These include digital health applications, ecosystems and platforms (World Health Organization, 2020), patient portals (Irizarry et al., 2015), mobile health apps (Free et al., 2013), eHealth records, and appointment scheduling applications (Ammenwerth et al., 2012). For the purposes of this study, we will use eHealth, mobile health, telemedicine, telehealth, virtual health, remote health, electronic consultations, and health information systems (HISs) as interchangeable terms for digital health.

2.1.1. Patient Experience in Digital Health

Digital health (DH) has the potential to improve patients' overall health care experience (Alkire et al., 2020; Bolton et al., 2018; Kneeland, 2016). However, there is currently no common concept for describing patient experience (PEx) in digital health. Neither the general PEx nor user experience (UX) adequately reflects the experience of a patient using a digital service. For example, in a hospital setting, the environment's cleanliness, background noise, and even food provision could affect PEx (Reeves et al., 2002); however, these factors would not be expected to influence the experience of a patient using a digital service. Similarly, the fact that the system passes usability heuristics does not necessarily mean that the overall experience of a patient using digital health services is positive (Richardson et al., 2021). Therefore, it is vital to understand the experiences of individuals using digital health and how the design of new technologies can affect them (Alkire et al., 2020; Kellermann & Jones,

2013; Larivière et al., 2017).

The concept of (non-digital) PEx has many definitions in general health care practice and research. The Beryl Institute defines PEx as "the sum of all interactions, shaped by an organization's culture, that influence patient perceptions, across the continuum of care" (The Beryl Institute, 2024). Other definitions and studies note that the core elements of optimized PEx include access to appropriate care, patients' active participation in care, a good patientphysician relationship, reliable evidence-based care, comprehensible information, physical comfort, emotional support, involvement of family and friends, individualized approaches, responsiveness of services, and continuity of care (Kneeland, 2016; NHS National Quality Board, 2011; Shandley et al., 2020; Staniszewska et al., 2014). These core elements of PEx help to recognize patients' priorities when receiving care and in providing patient-centered care. However, patients' priorities may differ for digital health, in which traditional face-toface interaction is replaced by human to digital interface interaction. Therefore, to address patient priorities in digital health, it is essential to consider UX in the design of digital health (Brunton et al., 2015). In this study, we define UX as a person's perceptions and responses that result from the use or anticipated use of a product, system, or service (Bolton et al., 2018; Jokela et al., 2003). Usable, useful, findable, accessible, credible, valuable, and desirable products are more likely to succeed in delivering a positive UX (Morville, 2005). However, the full impact of digital health technologies on PEx or UX still remains unclear (Mobasheri et al., 2014); some products even result in negative effects such as increased patient anxiety (Foley et al., 2016). Therefore, more insights into the barriers to and facilitators of individuals' experiences with digital health are required (Wolf & Jason, 2014).

2.1.2. Objectives

The objectives of this paper were to systematically review (1) the factors that influence PEx in digital health and (2) the design considerations of PEx that are in digital health. The overall aim was to generate a design framework and guidelines for further improving PEx in digital health.

2.2. Methods

We performed an umbrella systematic review compiling evidence from multiple systematic reviews (Grant & Booth, 2009) on PEx and UX in digital health. This review was conducted according to the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) methodology, which is an evidence-based minimum set of items for reporting in systematic reviews and meta-analyses (Liberati et al., 2009).

2.2.1. Digital PEx Working Definition

Throughout this study, we use the term digital PEx as a working definition to describe people's experiences in various digital health contexts. As the study progressed, the definition underwent several revisions, which resulted in a more inclusive final definition.

2.2.2. Search Strategy

We searched Scopus, PubMed, and Web of Science for studies published between January 1, 2000, and December 16, 2020. The search time window was limited to 2000 as the term digital health was first introduced by Frank (Frank, 2000) in 2000. To be inclusive, we used broad interchangeable search terms with varying combinations of digital health, PEx, and UX:

- Category 1: "patient experience" OR "health experience" OR "user experience" OR "customer experience" OR "client experience"
- Category 2: "ehealth" OR "e-health" OR "mhealth" OR "m-health" OR "telehealth" OR "telehealth" OR "digital health" OR "virtual health" OR "remote health" OR "telemedicine" OR "telemonitoring" OR "teleconsultation"
- Category 3: "patient digital experience" OR "patient experience in digital health" OR "e-patient experience" OR "epatient experience" OR "online patient experience"

After combining categories 1, 2, and 3, limits were set to restrict studies to English-language literature reviews published in journals after 2000. The final search strategy was ([category 1 AND category 2] OR category 3) AND (DOCTYPE [review]) AND (PUBYEAR>2000) AND (LIMIT-TO [SRCTYPE, "journal"]) AND (LIMIT-TO [LANGUAGE, "English"]). Google Scholar was used as an additional database to manually search for additional related references based on the snowballing method during the review process.

2.2.3. Selection Criteria

Eligibility criteria were developed for title and abstract screening and refined for full-text screening. The following inclusion criteria were proposed by TW and GG and adjusted by MM and RG:

- No duplicated articles
- Full text available
- English language
- Only completed peer-reviewed journal articles
- Only review articles
- Related to digital health (ie, use of information and communication technology in health) and PEx, UX, or health care experience

2.2.4. Screening Process

The collected articles were included in the final analysis if they met all the inclusion criteria after a 2-stage screening process: first, a title and abstract review, followed by a full-text review. In the screening process, 2-round, small random samples (20%) were independently reviewed by 2 reviewers (TW and GG) who evaluated the eligibility of the articles against the selection criteria. The interrater reliability and clarity of the selection criteria were assessed using the Fleiss-Cohen coefficient until it reached the required strength (≥0.60). Uncertainties around paper inclusion and exclusion were resolved by discussions with the research team (TW, GG, MM, and RG) when necessary.

2.2.5. Data Extraction and Thematic Analysis

Articles meeting the eligibility criteria were imported into ATLAS.ti (Scientific Software Development GmbH; version 9.0.7; 1857) for data extraction. Data were extracted for the following aspects: (1) study characteristics, including authors, year of publication, research aims, review methods, target users, and digital health intervention (DHI) characteristics; (2) the overall impression of digital PEx (eg, the foci or types of findings regarding digital PEx); (3) influencing factors of digital PEx; and (4) design considerations for improving digital PEx.

We used the Braun and Clarke 6-phase thematic analysis method (Braun & Clarke, 2006) to analyze the extracted data; these include (1) familiarization with the data, (2) generation of initial codes, (3) searching for themes among codes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the final report (analytical themes). A total of 4 researchers participated in the review process. After data familiarization, a set of a priori categories was defined by TW and refined by all the coauthors (Table 2-1). The coding was based on the Performance of Routine Information System Management (PRISM) framework (Aqil et al., 2009), which states that routine HIS performance is affected by the system's inputs (ie, technical, behavioral (Michie et al., 2011), and organizational determinants) and progress. Please note that other elements of the framework (outputs, outcomes, and impact) are discussed in another study addressing the evaluation of digital PEx (see Chapter 3).

Group discussions among the authors were used to reach an agreement on the produced a priori categories. TW quoted the relevant data across the included reviews, generated initial codes based on a priori categories, and then searched for themes among codes. Frequently used terms in the included reviews were used as inspiration to generate subsequent codes and themes. The latter process was independently and randomly validated by GG, MM, and RG.

Table 2-1. A Priori Categories of Influencing Factors of Digital Patient Experience based on the Performance of Routine Information System Management framework (Aqil et al., 2009)

The individual's psychological and physical capacity to engage in the concerned digital health activity
The individual's internal conditions that enable or disrupt patients to engage in digital health
The reflective and automatic brain processes that energize and direct patients' goal setting and decision-making and their behaviors regarding using digital health

Table 2-1. A Priori Categories of Influencing Factors of Digital Patient Experience based on the Performance of Routine Information System Management framework (Aqil et al., 2009) (continued).

Determinants and a priori categories	Description
Intervention Technology	The integration of telecommunications and computers, as well as necessary enterprise software, middleware, and storage and audiovisual software, which enables users to access, store, transmit, understand, and manipulate health information
Intervention Functionality	The ability of digital health to work as expected to help users meet their health goals and needs
Intervention Interaction Design	The process of moving digital health from its existing state to a preferred state to optimize interactions between patients and digital health interventions
Organizational Determinants	
Organizational Environment	The management of the health service system, as affected by the rules, values, and practices of the involved people or community
Physical Environment	The tangible surroundings (such as space, light, or sound) around patients, which affects their interactions with digital health
Social Environment	The cultural environment (such as policy, business, or customs) that affect patients' interactions with digital health

2.3. Results

Figure 2-1 shows the flow diagram of the systematic search. A total of 173 records were generated after the computer search; 58 (33.5%) duplicates were removed, and the titles and abstracts of 115 (66.5%) articles were reviewed. Subsequently, 53.9% (62/115) of full-text articles (including 4 additional records collected through snowballing) were reviewed for inclusion. Ultimately, 45 studies were included in the review for data extraction.

2.3.1. Study Characteristics

Embase, MEDLINE, PubMed, PsycINFO, CINAHL, and the Cochrane Library were the most common databases for the included reviews. Of these, 62% (28/45) were systematic review articles. The remainder included scoping reviews (6/45, 13%), literature reviews (3/45, 7%), integrative reviews (3/45, 7%), narrative reviews (2/45, 4%), comprehensive overviews (1/45, 2%), review of systematic reviews (1/45, 2%), and umbrella reviews (1/45, 2%). More than half of the included reviews (24/45, 53%) conducted quality assessments. The reviews included >1400 studies, which mainly or partially reported qualitative and quantitative analyses of PEx in digital health. The data analysis methods varied and included thematic analysis (8/45, 18%), meta-synthesis (5/45, 11%), meta-ethnography synthesis (2/45, 4%), taxonomy (1/45, 2%), hermeneutic synthesis (1/45, 2%), qualitative evidence synthesis (1/45, 2%), and state-of-the-art survey analysis (1/45, 2%).

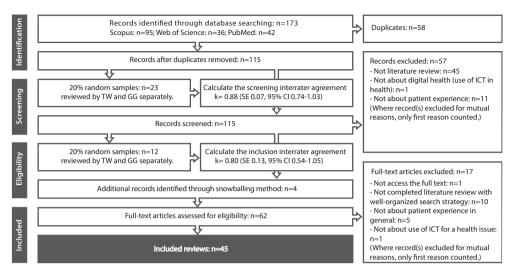


Figure 2-1. Study flow diagram. (ICT: information and communications technology)

Among the included reviews, some focused on specific populations, such as children (3/45, 7%), college students (1/45, 2%), younger people (1/45, 2%), adults (7/45, 16%), or older adults (4/45, 9%). Others either focused on the general population or did not mention the target population. The most common health issues across the included articles were chronic diseases (17/45, 38%), including chronic obstructive pulmonary disease, heart failure, cardiovascular disease, cancer, diabetes, and hypertension. Mental health problems (7/45, 16%), including depression, anxiety, psychological well-being, psychotic disorders, and schizophrenia, were the second most common health issues. The remainder either focused on other issues (8/45, 18%), including audiology, asthma, reproductive health, maternal health, newborn health, child health, adolescent health, surgery, postpartum, somatic diseases, or palliative care, or did not mention any specific health issues (14/45, 31%). Some papers (8/45, 18%) also provided multistakeholder perspectives, including health care professionals, providers, surgeons, clinicians, staff and organizations, implementers (such as health policy makers, clinicians, and researchers), and the participation of information technology.

The degree of detail provided about the interventions varied greatly across the studies. Phone-based apps, websites, handheld sensing devices, and ambient assisted living health care systems were common digital health deliveries. Interaction techniques included synchronous, asynchronous, and hybrid models. Diverse intervention platforms, systems, or functions were used to deliver various health care services, including supporting disease management (14/45, 31%); patient-to-physician communication or consultation (9/45, 20%); symptom monitoring (9/45, 20%); information transmission (4/45, 9%); health promotion activities (3/45, 7%); screening, diagnosis, or self-assessment (2/45, 4%); behavior changes (2/45, 4%); self-education (1/45, 2%); and decision-making (1/45, 2%). Multimedia Appendix 1

(see in our publication online) (Ames et al., 2019; Barello et al., 2016; Barken et al., 2019; Bashi et al., 2020; Baumel et al., 2017; Brigden et al., 2020; Brunton et al., 2015; Chaudhry et al., 2021; Cheung et al., 2019; Choi et al., 2020; Cox et al., 2017; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Eze et al., 2020; Feather et al., 2016; Firth & Torous, 2015; Fouquet & Miranda, 2020; Greenhalgh & Shaw, 2017; Ingemann et al., 2020; Jalil et al., 2015; Jones & Grech, 2016; Kuijpers et al., 2013; Lattie et al., 2019; Lemon et al., 2020; Leonardsen et al., 2020; Liddy et al., 2016; Lim et al., 2019; Memon et al., 2014; Molina-Recio et al., 2020; Morrison et al., 2014; Morton et al., 2017; O'Keefe et al., 2021; Palacholla et al., 2019; Rincon et al., 2017; Rising et al., 2018; Sakaguchi-Tang et al., 2017; Slater et al., 2017; Søgaard Neilsen & Wilson, 2019; Simen A Steindal et al., 2020; Stokke, 2016; Swanepoel & Hall III, 2010; Rachael C Walker et al., 2019; Yanxia Wei et al., 2020; Werder, 2015; Wesselman et al., 2019; Wildenbos et al., 2018) provides detailed information regarding the characteristics of the included studies.

2.3.2. Overall Impression of Digital PEx

Our study revealed great diversity in the perspectives and definitions describing patients' experiences and characteristics when using digital health, presenting a variety of influencing factors and design considerations for digital PEx. The included studies showed different foci regarding digital PEx, including influencing factors (21/45, 47%) (Ames et al., 2019; Brigden et al., 2020; Brunton et al., 2015; Cheung et al., 2019; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Eze et al., 2020; Greenhalgh & Shaw, 2017; Ingemann et al., 2020; Jalil et al., 2015; Jones & Grech, 2016; Kuijpers et al., 2013; Lim et al., 2019; Morrison et al., 2014; Palacholla et al., 2019; Sakaguchi-Tang et al., 2017; Slater et al., 2017; Stokke, 2016; Swanepoel & Hall III, 2010; Yanxia Wei et al., 2020; Werder, 2015; Wildenbos et al., 2018), digital health performance (19/45, 42%) (Brigden et al., 2020; Choi et al., 2020; Eze et al., 2020; Firth & Torous, 2015; Jalil et al., 2015; Kuijpers et al., 2013; Lattie et al., 2019; Liddy et al., 2016; Memon et al., 2014; Morrison et al., 2014; Morton et al., 2017; O'Keefe et al., 2021; Rincon et al., 2017; Sakaguchi-Tang et al., 2017; Slater et al., 2017; Stokke, 2016; Swanepoel & Hall III, 2010; Yanxia Wei et al., 2020; Wesselman et al., 2019), patient perceptions (9/45, 20%) (Barken et al., 2019; Brunton et al., 2015; Cox et al., 2017; Greenhalgh & Shaw, 2017; Jones & Grech, 2016; Leonardsen et al., 2020; Slater et al., 2017; Simen A Steindal et al., 2020; Rachael C Walker et al., 2019), evaluation methods of digital health or digital PEx (8/45, 18%) (Barello et al., 2016; Bashi et al., 2020; Baumel et al., 2017; Feather et al., 2016; Jalil et al., 2015; Lemon et al., 2020; Rincon et al., 2017; Rising et al., 2018), and design considerations (9/45, 20%) (M. F. De La Cruz Monroy & A. Mosahebi, 2019; Fouquet & Miranda, 2020; Lim et al., 2019; Molina-Recio et al., 2020; Sakaguchi-Tang et al., 2017; Slater et al., 2017; Søgaard Neilsen & Wilson, 2019; Yanxia Wei et al., 2020; Wildenbos et al., 2018). The findings and conclusions of the 45 reviews showed a great diversity. Most studies presented a set of themes (19/45, 42%) (Ames et al., 2019; Barken et al., 2019; Baumel et al., 2017; Brigden et al., 2020; Brunton et al., 2015; Cox et al., 2017; Eze et al., 2020; Jones & Grech, 2016; Lemon et al., 2020; Leonardsen et al., 2020; Liddy et al., 2016; Lim et al., 2019; Palacholla et al., 2019; Sakaguchi-Tang et al., 2017; Slater et al., 2017; Simen A Steindal et al., 2020; Rachael C Walker et al., 2019; Yanxia Wei et al., 2020; Werder, 2015) or descriptions only (16/45, 36%) (Barello et al., 2016; Chaudhry et al., 2021; Choi et al., 2020; Feather et al., 2016; Firth & Torous, 2015; Greenhalgh & Shaw, 2017; Ingemann et al., 2020; Kuijpers et al., 2013; Lattie et al., 2019; Memon et al., 2014; Morrison et al., 2014; Morton et al., 2017; Rincon et al., 2017; Stokke, 2016; Swanepoel & Hall III, 2010; Wesselman et al., 2019). Other studies concluded with a theory-based description (5/45, 11%) (Bashi et al., 2020; Cheung et al., 2019; O'Keefe et al., 2021; Rising et al., 2018; Søgaard Neilsen & Wilson, 2019), framework (4/45, 9%) (Brunton et al., 2015; Fouquet & Miranda, 2020; Slater et al., 2017; Wildenbos et al., 2018), model (2/45, 4%) (Cox et al., 2017; M. F. De La Cruz Monroy & A. Mosahebi, 2019), method (2/45, 4%) (Jalil et al., 2015; Molina-Recio et al., 2020), or checklist (1/45, 2%) (Yanxia Wei et al., 2020). Only a few studies transformed findings into design considerations (9/45, 20%) or visualized or structured their results into frameworks, models, checklists, or methods (9/45, 20%). Limited information was found on participant dropout reasons during the interventions (Ames et al., 2019; Brunton et al., 2015; Cox et al., 2017; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Jalil et al., 2015; Kuijpers et al., 2013; Morton et al., 2017; Rachael C Walker et al., 2019). The overall impression of the researchers on the DHIs was positive. In 51% (23/45) of reviews (Cheung et al., 2019; Choi et al., 2020; Cox et al., 2017; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Eze et al., 2020; Firth & Torous, 2015; Jalil et al., 2015; Kuijpers et al., 2013; Lattie et al., 2019; Leonardsen et al., 2020; Liddy et al., 2016; Lim et al., 2019; Morrison et al., 2014; Morton et al., 2017; O'Keefe et al., 2021; Rising et al., 2018; Sakaguchi-Tang et al., 2017; Slater et al., 2017; Søgaard Neilsen & Wilson, 2019; Simen A Steindal et al., 2020; Yanxia Wei et al., 2020; Werder, 2015; Wesselman et al., 2019), the DHIs either showed promising results or at least results comparable with face-to-face health care services. Only 4% (2/45) of reviews (Greenhalgh & Shaw, 2017; Memon et al., 2014) reported concrete evidence of the negative impact of current DHIs on digital PEx. In general, digital PEx was addressed because of the interactions between the DHIs and the patients involved and how the service was organized and carried out.

2.3.3. Influencing Factors of Digital PEx

An influencing factor is an aspect of the existing situation that influences other aspects of the situation, and it is formulated as an attribute of an element that is considered relevant and can be observed, measured, or assessed (Blessing & Chakrabarti, 2009). In this study, influencing factors refer to specific factors that lead to a positive or negative experience (digital PEx). Some factors have either positive or negative consistent and concrete impacts, whereas others have double-edged impacts; that is, impacts that are different per individual or change over time. Among the included papers, a common understanding of the potential influencing factors was captured from 3 aspects—behavioral, technical, and organizational determinants—following the categorization of the PRISM framework. These determinants were each classified into 3 categories, resulting in nine categories: patient capability,

patient opportunity, patient motivation, intervention technology, intervention functionality, intervention interaction design, organizational environment, physical environment, and social environment. Multimedia Appendix 2 (see in our publication online) presents an overview of the themes identified for each category, the influencing factors per theme (positive, negative, and double-edged), and references. Most factors appear to be related to technical determinants, followed by behavioral and organizational determinants. For technical determinants, we summarized 3 categories with 13 themes, containing 58 positive, 35 negative, and 13 doubleedged factors. For example, DHIs with multiple behavioral change techniques appeared to be more effective (Brigden et al., 2020; Morrison et al., 2014; Søgaard Neilsen & Wilson, 2019) and reported higher patient satisfaction (Eze et al., 2020; Lim et al., 2019). Behavioral determinants included 3 categories with 9 themes containing 11 positive, 21 negative, and 5 double-edged factors. For instance, some studies mentioned a lack of confidence in patients' own ability to use the technology (Greenhalgh & Shaw, 2017; Jalil et al., 2015; Jones & Grech, 2016; Molina-Recio et al., 2020; Sakaguchi-Tang et al., 2017; Rachael C Walker et al., 2019), leading to a negative digital PEx. Organizational determinants were classified into 3 categories with 5 themes, including 13 positive and 23 negative factors. For example, unrealistic financial reimbursement and higher costs related to the internet or equipment were practical challenges of using digital health (Ames et al., 2019; Brigden et al., 2020; Greenhalgh & Shaw, 2017; Palacholla et al., 2019; Sakaguchi-Tang et al., 2017). For the behavioral and organizational determinants, we collected more negative factors than positive factors. This is in contrast to the technical determinants, in which more positive factors were identified. Double-edged factors were less than both positive and negative factors for all the 3 determinants. Multimedia Appendix 3 (see in our publication online) provides detailed information and examples.

2.3.4. Design Considerations of Digital Patient Experience

Table 2-2 provides an overview of the identified themes for each design construct or method, related considerations, and references. To address the abovementioned influencing factors, several the included articles referred to design constructs (personalization, information, navigation, and visualization) (M. F. De La Cruz Monroy & A. Mosahebi, 2019; Lim et al., 2019; Sakaguchi-Tang et al., 2017; Slater et al., 2017; Søgaard Neilsen & Wilson, 2019; Yanxia Wei et al., 2020) and design methods (ie, human-centered design [HCD] or user-centered design [UCD], co-design or participatory design, and inclusive design) (Fouquet & Miranda, 2020; Lim et al., 2019; Molina-Recio et al., 2020; Sakaguchi-Tang et al., 2017; Slater et al., 2017; Søgaard Neilsen & Wilson, 2019; Wildenbos et al., 2018), either as recommendations or implications for improving digital PEx from a design perspective. Notably, there was an overlap between design considerations and influencing factors. The former focuses on concluding possible design suggestions, recommendations, and implications proposed by the reviewed articles. The latter involves mapping the impacts of interaction design on digital PEx in different contexts; therefore, they refer to different themes and references. Generally, the personalization construct identifies patient profiles and

tailors digital health according to patients' needs and preferences. The information construct addresses the source, language, presentation, content, and architecture of delivered health information. The navigation construct considers the interactive, delivered, and instructional elements of digital health to guide users to different areas of content within digital health. The visualization construct focuses on the aesthetics, attractiveness, visibility, and consistency of digital health appearance and interface. Furthermore, co-design and UCD or HCD were recommended as the most common methods for designing digital health, which involve multi-stakeholders and multi-disciplinaries in the design process to facilitate the designers' work, as designers need to understand end user needs and be aware of potential barriers to engaging in DHIs. Finally, inclusive design provides flexible design and is usable for a broader population. Notably, the design considerations identified in the included papers are not meant to be applied to every project; the implementation depends on the project's focus. Designers always need to balance project requirements (such as profits), user needs (such as privacy concerns), and policy regulations (such as data security). For example, peer-to-peer patient communication may not be appropriate for more sensitive health issues.

Table 2-2. Design considerations of digital patient experience.

Themes	ပိ	onsiderations	References
Design constructs			
Personalization			
Profiling	•	Careful patient selection for digital health use	(M. F. De La Cruz
	•	Assess specific metrics (eg, sociodemographic characteristics, basic health status,	Monroy & A. Mosahebi,
		individual preferences, and habits)	2019; Yanxia Wei et al.,
	•	Create an accurate patient profile	2020)
Tailoring	•	Provide personalized information, tailored intervention content, and customized	(Lim et al., 2019; Slater
		feedback (eg, predicted possible causes and consequences of a health problem and	et al., 2017; Søgaard
		advice on the behavior under investigation)	Neilsen & Wilson,
	•	Tailor the content to the user's needs and preferences	2019; Yanxia Wei et al.,
	•	Tailor images, colors, text quantity, and font size and color to what users find	2020)
		appealing	
	•	Tailor multiple variables rather than a single variable	
	•	Align with end users' habitual routines	
Autonomy	•	Choose desirable and accessible forms of delivery	(Søgaard Neilsen &
	•	Choose when and how to receive reminders	Wilson, 2019; Yanxia
	•	Select or change personalized goals for future use throughout the time span of	Wei et al., 2020)
		intervention	
	•	Select preferred styles (eg, color and font)	
Information			

Table 2-2. Design considerations of digital patient experience (continued).

Themes	ŭ	Considerations	References
Content	•	Provide comprehensive health information (eg, medical history, test results, and	(M. F. De La Cruz
		medication information)	Monroy & A. Mosahebi,
	•	Provide appropriate education and training on a health condition	2019; Lim et al., 2019;
	•	Provide concise information (not overwhelm)	Sakaguchi-Tang et al.,
	•	Provide evidence-based information from a credible source (eg, no advertisements	2017; Yanxia Wei et al.,
		and validated advice)	2020)
	•	Appropriate encryption and digital health security (eg, password setting and privacy	
		policy)	
\circ	•	Provide peer-to-peer communication through web-based forums and communities	(M. F. De La Cruz
		using instant messages	Monroy & A. Mosahebi,
	•	Access to professionals directly via email, SMS text message, or live chat	2019; Lim et al., 2019;
	•	Share duties between health care staff	Søgaard Neilsen &
			Wilson, 2019; Yanxia
			Wei et al., 2020)
Functionality	•	Rewards (eg, material incentives, intangible rewards, and messages of	(M. F. De La Cruz
		congratulations when a task is completed)	Monroy & A. Mosahebi,
	•	Reminders (eg, email messages, SMS text messages, words of the day, and pop-ups)	2019; Lim et al., 2019;
		for task completion	Sakaguchi-Tang et al.,
	•	Reflective feedback, persuasive features, and gaming features (eg, knowledge	2017; Slater et al., 2017;
		quizzes and games)	Søgaard Neilsen &
	•	Functional characteristics enable accurate and continuous self-management (eg,	Wilson, 2019; Yanxia
		activity planning, activity tracking, self-monitoring, and diaries), person-centered	Wei et al., 2020)
		care, and sustained behavior change	
	•	Appropriate dose of treatment	
Navigation			

Table 2-2. Design considerations of digital patient experience (continued).

Themes	Co	onsiderations	References
Forms of delivery	•	Readily accessible and downloadable	(Lim et al., 2019; Slater
	•	Improve DHIa delivery (eg, change from a website to a mobile phone app)	et al., 2017)
	•	Ability to print and email the information	
User flows	•	Minimum input (eg, voice commands)	(Sakaguchi-Tang et al.,
	•	Efficient access to information	2017; Yanxia Wei et al.,
	•	Clarify what to do next	2020)
	•	Provide search bar and menu bar	
	•	Tools and aids to help understand health information and complete health tasks	
Instruction and	•	Guide users to a greater extent if the design is not self-explanatory	(Lim et al., 2019;
tutorials	•	Provide more concrete, explicit, and context-sensitive instructions (eg, a virtual	Søgaard Neilsen &
		guided tour and extra internal links)	Wilson, 2019)
	•	Adopt features from common (ie, familiarized) user interfaces (eg, the iPhone	
		interface)	
	•	Provide appropriate education and training on digital health use	
Visualization			
Message	•	Visualize continuous monitoring data (eg, present data as graphs and tables)	(Yanxia Wei et al.,
presentation	•	Provide a coherent presentation in terms of colors, pictures, and themes	2020)
	•	Simple nontechnical language	
	•	Straightforward and concise text	
	•	Comprehensive descriptions of actionable message	
	•	Provide positive, nonauthoritarian, friendly, and nonjudgmental tone of voice	
	•	Multimedia messages (eg, text combined with relevant pictures or video)	
	•	Highlight information using various font styles, sizes, and colors	

Table 2-2. Design considerations of digital patient experience (continued).

Themes	Cc	onsiderations	References
Interface aesthetic	•	Show graphics (ie, visual aids) rather than (too much) text	(Lim et al., 2019;
	•	Provide a pleasing color scheme (eg, bright colors)	Søgaard Neilsen &
	•	Simple interface	Wilson, 2019; Yanxia
			Wei et al., 2020)
Design methods			
Co-design and partic	ipato	Co-design and participatory design approaches	
Multistakeholder	•	Involve end users and other stakeholders	(Lim et al., 2019;
	•	Include the user at the beginning of the design process	Sakaguchi-Tang et
			al., 2017; Slater et al.,
			2017)
Interdisciplinary	•	An interdisciplinary approach to the development and implementation	(Molina-Recio et al.,
			2020; Sakaguchi-Tang
			et al., 2017; Søgaard
			Neilsen & Wilson,
			2019)
User-centered design and		human-centered design approaches	
Needs assessment	•	Know the needs, capabilities, and environment of users through focus groups,	(Fouquet & Miranda,
		surveys, interviews, and personas	2020; Molina-Recio et
	•	Composing, preparing, and organizing content	al., 2020; Sakaguchi-
			Tang et al., 2017)
Usability testing	•	Gain early feedback from users through prototypes; benchmark testing, user testing,	(Fouquet & Miranda,
		heuristic analysis, failure modes and effects analysis, and observations in other health	2020; Molina-Recio et
		care settings	al., 2020; Sakaguchi-
			Tang et al., 2017)

Table 2-2. Design considerations of digital patient experience (continued).

Themes	Considerations	References
Implementation	Fit the technology to the person, not the person to the technology; pilot testing, task	(Fouquet & Miranda,
	analysis, and reporting mechanism	2020; Molina-Recio et
	al., 2020)	al., 2020)
• Monitor and		(Fouquet & Miranda,
sustain	posttesting, contextual inquiry, and safety and hazard reporting	2020)
Inclusive design approache	thes	
Inclusive •	Provide a flexible design that is usable by people with no limitations, as well as by	(Sakaguchi-Tang et al.,
	people with functional limitations related to disabilities or old age	2017; Wildenbos et al.,
		2018)

^aDHI: digital health intervention

2.4. Design Implications

On the basis of our findings regarding influencing factors and design considerations for digital PEx, in this section, we define digital PEx and present design guidelines for the implementation of improving PEx in digital services.

2.4.1. Definition of Digital PEx

Our review reveals the absence of a commonly used concept for PEx in digital health. An increasing number of studies have been conducted on surveying PEx, satisfaction with, and expectations in varied digital health. With the growing academic interest in this topic and increasing efforts to address PEx in digital health design practice, a common concept with a concise definition will strengthen and align efforts overall. After reviewing the alignment of widely accepted concepts of PEx, UX, and DHIs with our generated influencing factors, we observed that many of our findings are included in the PEx definition offered by The Beryl Institute. Therefore, by including the sum of all interactions shaped by an organization's culture, which influence patient perceptions across the continuum of care (Wolf & Jason, 2014) along with the constructs of UX (people's perceptions and responses (Bolton et al., 2018)), DHIs (digital health technologies (World Health Organization, 2020)), and the determinants (ie, technical, behavioral, and organizational determinants) identified in this review, we propose a concise, practical definition of digital PEx to guide the future design of digital health: "Digital patient experience is the sum of all interactions, affected by a patient's behavioral determinants, framed by digital technologies, and shaped by organizational culture, that influence patient perceptions across the continuum of care channeling digital health." Compared with the original definition of general PEx, this new definition underlines the digital part of health care delivery and includes 2 new determinants (technical and behavioral) that go beyond the organization's culture to clarify what can influence patient perceptions while traveling along a digital care pathway.

2.4.2. Design Guidelines for Improving Digital PEx

We developed a design and evaluation framework to help digital health designers or developers improve digital PEx in the design process (Figure 2-2). This framework was based on the findings of this umbrella review and was inspired by the double diamond model (Design Council, 2015, 2023). Our framework shows four phases: define design, define evaluation, design ideation, and designevaluation. The first and third phases focus on the design itself, and the second and fourth phases focus on design evaluation. In this study, we focus on explaining the first and third phases. In the first phase, designers must define the design goals by considering the factors that affect digital PEx. In this phase, we provided 3 determinants referring to 9 categories of influencing factors that have 3 types of impact on digital PEx (positive, negative, and double-edged) for designers to discover and explore. Designers can frame their design goals based on the intervention purposes and the selection of influencing factors. For example, if the purpose of the intervention is to improve patient eHealth literacy,

designers need to pay more attention to patient capability and frame a design goal to develop suitable intervention functionality for improving patient capability. After defining the design goals, designers can move to the second phase, which is the define evaluation phase. In this phase, designers need to consider evaluation indicators (patient emotional, behavioral, and health outcomes) and evaluation methods (surveys and interviews) that are used to assess digital PEx. Detailed information regarding this phase will be discussed in a parallel study. Following this, we provide 4 design constructs (personalization, information, navigation, and visualization) and 3 design methods (ie, HCD or UCD, co-design, and inclusive design) for the design ideation phase. Personalization (Brigden et al., 2020; Cox et al., 2017; Eze et al., 2020; Kuijpers et al., 2013; Lim et al., 2019; Molina-Recio et al., 2020; Slater et al., 2017; Y. Wei et al., 2020) refers to ascertaining user needs with design goals. It encompasses the design of intervention technology and functionality needs that meet the patients' ability, opportunity, and motivation to trigger behavior changes and promote health outcomes. UCD/HCD and inclusive design are valuable at this stage for the inclusion of patient perspectives. Driven by user needs and intervention goals, information includes content, communication, and functionality (Lim et al., 2019; Molina-Recio et al., 2020; Y. Wei et al., 2020), and navigation comprises forms of delivery, user flows, instructions, and tutorials (Lim et al., 2019; Molina-Recio et al., 2020; Søgaard Neilsen & Wilson, 2019; Y. Wei et al., 2020). This relates to how relevant content presented in multimedia with a clear information architecture can attract patient attention and help them understand and complete tasks efficiently (Dekkers, 2020). Co-design and participatory design are multidisciplinary collaborations that are necessary at these 2 stages. Finally, designers need to consider visualization (Eze et al., 2020; Lim et al., 2019; Molina-Recio et al., 2020; Søgaard Neilsen & Wilson, 2019; Y. Wei et al., 2020), which determines the product look. The digital health interface can affect patients' first impressions when using DHIs. An attention-grabbing, simple, and consistent interface (Y. Wei et al., 2020), layout (colors and images) (Søgaard Neilsen & Wilson, 2019), and message presentation (Y. Wei et al., 2020) can all lead to positive UX. The design guidelines (Textbox 1) can be used at this stage to produce design concepts. In addition, this phase contains the digital health design workflow, challenges, and tips from a design practice perspective (which will be presented in an ongoing interview study). Finally, we ended up with this framework by introducing the design evaluation phase, in which designers need to develop tests (based on evaluation metrics) to evaluate design concepts. If the evaluation outcomes do not meet the evaluation standards, designers can return to the design ideation phase to adjust the design concepts or return to the first phase to reconsider the design goals.

Compared with the original double diamond model, our framework separates the evaluation part from the design part. This aligns with the design research methodology framework (Blessing & Chakrabarti, 2009), which suggests generating success criteria after clarifying design research goals and before producing design support, formulating criteria for success is essential to be able to determine whether the results help achieve this aim. Therefore, we paid equal attention to design and evaluation. In addition, our framework provides detailed

reference materials (such as 3 determinants) for each phase to provide designers with more practical support. Notably, in our framework, we retain some typical features of the double diamond model: the first 2 phases are research related, the last 2 phases are practice related, and each phase starts from divergence and ends at convergence.

On the basis of our findings on influencing factors and design considerations, we mapped the combinations of design constructs and design methods into 9 design guidelines to address different influencing factors (Textbox 2-1), which can be used to guide the design ideation process. Some of the design guidelines uncovered in this study have already been implemented, resulting in a positive digital PEx, such as the digital platform PatientsLikeMe, which aims to empower patients to navigate their health journeys together through peer support, personalized health insights, tailored digital health services, and patient-friendly clinical education (PatientsLikeMe). One of the studies pointed out that patients can greatly benefit from using this platform as it improves patient health literacy, and its condition-specific customization may still further improve PEx (Wicks et al., 2018), which aligns with our design guidelines on improving "patient capability" and providing "personalized information."

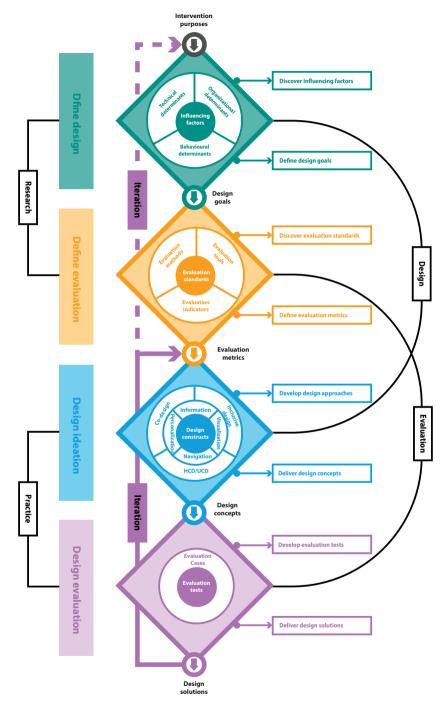


Figure 2-2. Digital patient experience design and evaluation framework. (HCD: human-centered design; UCD: user-centered design)

Textbox 2-1. Design guidelines for improving digital patient experience.

Categories and design guidelines

Patient capability

Identify patients' knowledge and skill levels by understanding their technology, language, and health literacy; consider their previous experience and current confidence level in using digital health; improve their actual literacy and correct their perceived inability; tailor design to their ability

Patient opportunity

Profile patients' identity (eg, age, gender, economic status, and daily routines) and health status (eg, illness complexity, severity, and stability); consider patients' accessibility and affordance to digital health; tailor design to their individual opportunity

Patient motivation

Recognize patients' mindset and perceived advantages and disadvantages; inform them of the potential benefits of using digital health; address their concerns and worries; understand their expectations and needs; tailor design to their preferences to trigger their motivation

Intervention technology

Increase technical usability; ensure ease of use, ready to use, and timely feedback on digital health; select technical features (eg, data accessibility) and delivery media or devices (eg, device ownership) to meet patients' preferences and needs

Intervention functionality

Strengthen theory-based interventions (eg, behavior change techniques and evidence-based interventions); improve intervention quality, considering privacy, security, and accuracy issues; provide regular and continuous social support combining both remote communication and real human contact; tailor health promotion and intervention structure to patients' needs and preferences

Intervention interaction design

Provide personalized and consistent information, clear tutorials or technical support, and visualized data; allow patients to choose personalized interactive elements; follow human or user-centered design, co-design, and inclusive design methods; involve multi-stakeholders and multi-disciplines in the design process

Organizational environment

Reduce equipment or service cost and time; improve health care providers' professional ability, communication skills, and service attitudes across the use of digital health; increase workflow transparency and clarify accountability; improve system integration and compatibility

Physical environment

Provide a familiar, warm, and comfortable environment rather than cold and unfamiliar settings; reduce environmental distractions (eg, background noise or lighting)

2.5. Discussion

2.5.1. Principle Findings

We systematically reviewed review articles on factors that influence digital PEx and considerations regarding how best to design digital PEx. The reviews varied greatly in type, including studies and data analysis methods, as well as in HIS, health issues, target patient groups, intervention content, and structure. Of the selected reviews, 62% (28/45) were systematic reviews, the rest were other types. These included qualitative, quantitative, and mixed methods studies. Thematic analysis and meta-analysis were the most common data analysis methods used in the reviews. We note that the studies described in the selected reviews were extremely heterogeneous, and information about interventions and digital PEx were often mixed and complex, making comparison difficult.

Our results are in line with the findings reported by previous authors (Aqil et al., 2009; Morville, 2005; Staniszewska et al., 2014) on the factors that affect PEx, UX, or the implementation of digital health. On the basis of the identified influencing factors and design considerations, we developed 9 design guidelines for improving digital PEx. Our findings reveal that among the selected reviews, only a few formulated design strategies or guidelines. This lack of design knowledge transformation makes it difficult for designers or developers to apply the findings directly. This aligns with the studies by Sakaguchi-Tang et al (Sakaguchi-Tang et al., 2017) and Søgaard Neilsen and Wilson (Søgaard Neilsen & Wilson, 2019); the former indicated that the absence of specific design recommendations impairs the design of digital health, with the latter suggesting that there was a lack of understanding of the most beneficial design aspects for some specific digital health and how design principles can best be applied. Moreover, the use of UCD has been recommended in many studies to address UX-relevant issues in digital health (Marcin et al., 2016; Søgaard Neilsen & Wilson, 2019; Vagal et al., 2020), which also supports our findings.

2.5.2. Digital PEx Versus General PEx and UX

We found a lack of a common term to describe PEx in digital health; UX (25/45, 56%) and PEx (17/45, 38%) were the most commonly used terms. Patient UX, patient perceptions, client experiences, patient empowerment, and user engagement were also used to describe similar concepts. Many reviews indicated that there was limited information about UX or PEx in varied digital health and underlined the need for a more holistic view of patient needs and priorities to better shape digital health design strategies and provide tailored digital health (Barello et al., 2016; Brunton et al., 2015; Jones & Grech, 2016; Memon et al., 2014; Morrison et al., 2014; Swanepoel & Hall III, 2010).

2.5.3. Influencing Factors Are More Complex Than Facilitators and Barriers

The information provided about digital PEx-influencing factors was complex and

heterogeneous. Digital health is often treated as a whole, whereas digital PEx is affected by the additive effect of varying digital health factors. A single change in a factor may affect everything else. We found that without a concrete interaction context, factors could be regarded concurrently with facilitators or barriers. For example, regular contact with health care providers (HCPs) could be perceived to increase a sense of reassurance or perceived as a burden to patients' daily lives (Brunton et al., 2015); some patients experienced digital health as time consuming or an additional burden, whereas others experienced it as time saving or convenient (Cox et al., 2017). Some influencing factors may have a soft or indirect influence on digital PEx (Baumel et al., 2017; Werder, 2015). For instance, users who are completely unaware of privacy or security risks may have excellent experience with digital health that fails to meet privacy or security requirements (Baumel et al., 2017). A lack of concrete solutions to address these barriers was mentioned (Sakaguchi-Tang et al., 2017). It is likely that digital health cannot serve all populations equally well (R. C. Walker et al., 2019), which aligns with the results of a scoping review that investigated the inequities caused by the adoption of digital health technologies (Yao et al., 2022). Some researchers indicated that older adults can also experience benefits by using digital health (M. F. I. De La Cruz Monroy & A. Mosahebi, 2019), whereas others suggested that telehealth is, at best, a partial solution for younger and fitter subpopulations (Greenhalgh & Shaw, 2017; R. C. Walker et al., 2019). Again, although some mentioned that patients preferred using personal devices (Firth & Torous, 2015; Palacholla et al., 2019; Rincon et al., 2017; Slater et al., 2017), others noted the opposite (Rincon et al., 2017).

2.5.4. Unclear benefit from the different elements in digital health.

It is likely that some patient groups benefit more than others from specific DHIs. For example, one of the reviews suggested that in telemedicine treatment for type 2 diabetes, behavioral change and continuous management were the keys to success (Jalil et al., 2015). However, it was unclear precisely which elements of digital health resulted in patients' satisfaction or dissatisfaction and how they could be addressed (Chaudhry et al., 2021). Moreover, we found limited data and even contradictory results on which factors affect digital PEx the most, which elements should be considered first when developing DHIs, and who benefits more from them. The latter is commonly mentioned (Barken et al., 2019; M. F. I. De La Cruz Monroy & A. Mosahebi, 2019) (Sakaguchi-Tang et al., 2017), with some authors suggesting that patients with unstable chronic diseases might benefit the most (Greenhalgh & Shaw, 2017; Zanaboni et al., 2018). However, another review indicated that even if patients are provided with the latest state-of-the-art technology at home, the intervention will not be beneficial if it remains unused (Jalil et al., 2015). Patients who are less activated are likely to have less positive experiences than those who are highly engaged (Barello et al., 2016).

2.5.5. Lack of multiple perspectives during the design of digital PEx

Clear communication between experts, designers, and patients regarding their understanding of digital PEx is required. Some reviews acknowledged the need for a multistakeholder

perspective on digital PEx (Cox et al., 2017; Palacholla et al., 2019). However, we found circumstances in which this was not possible. For example, in some cases, UCD for DHIs was conducted on nonpatient users either because of ethical reasons or relevant regulations (Jalil et al., 2015), and in others, apps that are not specifically designed for patients with cancer were being used for this patient (Rincon et al., 2017). HCPs are often isolated from the decision-making process to incorporate digital health into their current service provision (Brunton et al., 2015). Moreover, a lack of clinician perceptions of digital health use was also reported (Lim et al., 2019; Swanepoel & Hall III, 2010). Furthermore, no studies focused on exploring designers' views, opinions, experiences, or values in addressing PEx or UX in the design of digital health. There was little information on whether experienced designers had worked with patients in their design process.

2.5.6. Over- or under-estimated results

Some studies suggested that a lack of interest was the main reason for patients' refusal of digital health and that reasons for patient withdrawal were patients not wanting to use equipment, deteriorating health, and technical problems (Gorst et al., 2013; Sanders et al., 2012). We need to gain better insights into the reasons for patients choosing not to engage in or withdraw from digital health, as these will significantly inform future DHI development and design (Cox et al., 2017; M. F. I. De La Cruz Monroy & A. Mosahebi, 2019; Jalil et al., 2015). However, it is likely that most studies only included patients who had already agreed to or were using digital health technologies; those who refused to use, withdrew from, or had no accessibility were excluded (Ames et al., 2019; Brunton et al., 2015; Cox et al., 2017; Morton et al., 2017). One of the reviews suggested that this would result in over- or underestimated results of DHIs' effects on digital PEx, as participants who completed the intervention may differ from those who did not (Kuijpers et al., 2013). Another review found that patients only reported positive themes associated with remote monitoring, which may indicate a selection bias (R. C. Walker et al., 2019).

2.5.7. Conflicts between benefits and cost for developing DHIs

The provision of digital health can reduce the treatment burden and better integrate care into patients' daily routines (Cox et al., 2017), which is consistent with our findings; we found that most reviews had a positive perspective of DHIs. However, in one of the reviews, it was suggested that although there was agreement among most professionals that health information technology can have a positive impact on PEx, when weighing the benefits against the potential cost, demonstrating this will be challenging (Greenhalgh & Shaw, 2017; Werder, 2015). Moreover, unnecessary high-frequency monitoring could result in a waste of health resources and an increased workload for HCPs (Cheung et al., 2019). Compared with existing health care services, the application of new technology needs to demonstrate clinical evidence of improved health conditions (Jalil et al., 2015). However, there were discordant findings in terms of the benefits of using DHIs. For example, there was no concrete evidence that telemedicine consultations were quicker than face-to-face consultations (Chaudhry et al.,

2021; Eze et al., 2020; O'Keefe et al., 2021; Swanepoel & Hall III, 2010). In another case, the impact of DHIs on health care use was not examined (Eze et al., 2020). In conclusion, only user-friendly and quality-certified DHIs should be provided to patients (Rincon et al., 2017); health care organizations should not shift their focus from the basic and inexpensive strategies that affect patient care. Care is needed: new technology should not overwhelm the patient or ignore patient needs (Werder, 2015).

2.5.8. Limitations

First, when undertaking a review of review articles, some important details included in the original studies may have been lost, which increases the possibility of reporting bias. We also noted differences in the interpretation of terms and methods between the reviews. There is a lack of consistency in the terminology used to describe the functions of DHIs, HISs, or digital PEx itself. For example, in some cases, "eHealth" and "mHealth" were used as interchangeable terms (Feather et al., 2016), "persuasive technology" and "behavior change techniques" were presented as having a similar meaning (Jalil et al., 2015), and "patient engagement" and "patient activation" were also regarded as being the same (Feather et al., 2016). This inconsistent use of terms may impede knowledge translation and dissemination (Eze et al., 2020). To counter this, we summarized the varied factors with unified descriptions to build a common understanding of the digital PEx–influencing factors.

Second, the intervention types and patient groups varied widely among the reviews, limiting meaningful comparisons between different studies. In addition, the digital health landscape is rapidly evolving, and the technology infrastructure is constantly shifting (Kuijpers et al., 2013), as are the continuous updates of the UX design area. It is important to keep the influencing factors updated or adapted as the technology develops. Possibly, relevant original studies may have been excluded because of our focus on review papers. However, our approach to conducting an overarching review provides readers with a quick overview of the relevant digital PEx studies and a basis for further research.

Third, our umbrella review did not account for the multimodal relationships between subthemes or the potential overlap between subthemes within different domains. For example, different subthemes, such as "personalized design" in "interventions' interaction design" also interconnect with "interventions' technology" and "interventions' functionality." Moreover, our review process did not aim to address the question of whether some influencing factors are more important than others or how different aspects of DHIs influence them. This warrants further investigation as we suspect that differences may exist between the influencing factors, as some elements in digital health are more likely to increase or inhibit a positive digital PEx.

Finally, as we used qualitative thematic analysis to synthesize the findings and generate themes, the generated themes could have been influenced by the authors' previous research experiences and personal understanding. By asking other researchers to repeat the coding

process, the resulting themes are likely to be different. However, to minimize the potential coding bias, the generation of categories was based on the PRISM framework; 4 researchers with different backgrounds, including design, medical, and human factors, were involved in the iterative coding process, group discussion, and independent and random validation, and existing theories were used.

2.5.9. Further Research

The goals of this umbrella review were to systematically review the influencing factors that affect digital PEx and the design considerations for improving digital PEx that are summarized in the existing literature. We must conclude that, currently, much remains unknown, and the topic of digital PEx is relatively new. We propose 6 directions that require further research. The first direction is to develop frameworks or models that translate digital PEx-related research findings into design practices or implications. For example, in this study, we used design guidelines and a design framework to summarize the findings. The second direction is to identify those who will benefit more from which elements in DHIs and which influencing factors could be addressed by combining design constructs and design methods. The third direction is to further examine how designers understand and address digital PEx in the digital health design process. To address this, we conducted a qualitative study on how designers address digital PEx in design practice. The fourth direction is to standardize evaluation indicators, methods, or tools for assessing digital PEx; we are currently evaluating digital PEx in a parallel study. The fifth direction is to quantify the balance between the benefits and costs of developing user-friendly and validated DHIs. The sixth direction is to identify participants' reasons for dropping out and their impact on the reported digital PEx-related results.

2.6. Conclusion

To the best of our knowledge, this is the first study to propose the term "digital patient experience" as a common phrase to describe PEx in digital health and define digital PEx by synthesizing the reported PEx or UX of varied DHIs from multiple reviews. Multimedia Appendix 4 (see in our publication online) shows more details about the structure of this study. In this review, information on influencing factors was identified and summarized into 9 categories (ie, patient capability, opportunity, motivation, intervention technology, functionality, interaction design, organizational, physical environment, and social environment). These categories were classified into positive, negative, and double-edged factors based on their positive, negative, and diverse impacts on digital PEx. Our review uncovered 4 design constructs (personalized, information, navigation, and visual design) and 3 common design methods (UCD or HCD, co-design, and inclusive design) as design considerations for addressing digital PEx. Finally, we proposed a design and evaluation framework and design guidelines to help digital health designers and developers address digital PEx throughout the entire design process.

Lessons for doing a PhD 02 Learn by doing.

Indeed, doing a PhD in design is far more than communicating, planning, and reflecting. Your stakeholders may speak different languages because of different cultural or educational backgrounds; research time may be out of your plan because of strict ethical review procedures; you may be lost in countless research data and do not know where to reflect. Especially, being a PhD candidate means you are expected not only to learn how to do scientific research but also to have scientific contributions in your research area. Through your research journey, you may be challenged by your supervisors on your research questions; you may be doubted by your reviewers on your research methods; you may be questioned by your peers on your research results, etc.

Reflecting on my research progress, I want to share my lesson on doing a PhD in design, which is "learning by doing". Before my PhD journey, I was educated to become a designer instead of a researcher. Therefore, I had limited research knowledge and skills, which made me quite confused and feel lost when I was required to do design research instead of design in the first year of my PhD.

At the beginning, I either totally ignored the "scientific" considerations, such as using validated research methods, or was stuck on the progress due to the required "rigors", such as providing evidence. When I used to do design work, much of the data analysis and design ideas came from design intuition and personal experience. But, doing design research requires ensuring the rigor of the research. Even when dealing with qualitative data, it's necessary to ensure the objectivity and reproducibility of the data analysis, which is quite challenging. To address this, what I did was read others' similar research articles and learn from them. Learning from others can provide us with inspiration, especially when we have no idea what to do.

However, this resulted in another problem. I was anxious about "should I first read all similar research articles and then conduct a research study, or conduct a research study first and then learn the required research knowledge?" It was like the question, "Which came first, the chicken or the egg?". I wanted to exhaustively read all the research literature and learn all the research methods before making a decision. But I was also eager to start my own research as soon as possible due to the limited time. Therefore, I frequently jumped across learning new research knowledge and conducting research studies. At the beginning, I thought it would result in a loss of focus and patience. However, now that I am reflecting on my research progress, I realize this is a "learning by doing" process: starting from where I know and stopping to learn from where I do not know. This is probably not the best way to do research in design, but at least it is a doable way. If you are facing the same problem as I was, do not hesitate to start doing your research. I believe you can solve the puzzle through "learning by doing".

In addition, being realistic, recognizing your limitations, and paying attention to the finer details that truly matter is equally important. As we say in China, "刀要用在刀刃上" (the knife should be used on the blade). As PhD candidates, what we often embrace is learning, and we are eager to acquire knowledge. However, the vast expanse of knowledge can overwhelm us. We must approach this with intelligence—focusing not on learning everything, but on learning what truly matters. For everything else, collaboration with other experts is key.

It's essential not to get lost in a cycle of blind learning, but to channel our energy into the areas that will truly make a difference. Likewise, we should avoid rushing into tasks without proper reflection, which can lead to constant revisions and inefficiency. The key is to find a balance between learning and doing, using thoughtful reflection to discover the best work methods.











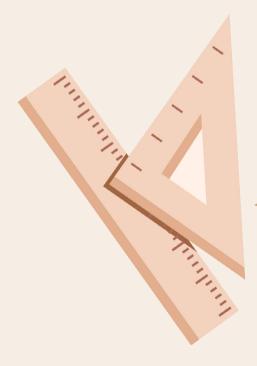








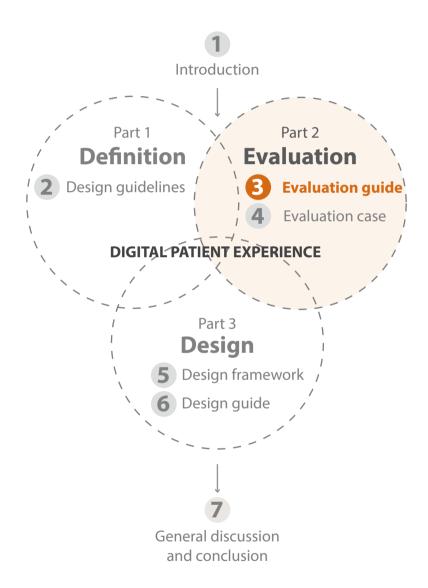




PART BEVALUATING DIGITAL
PATIENT EXPERIENCES

Chapter 3

Evaluation Guide: Timing, Indicators, and Approaches



The content of this chapter was published in:

Wang, T., Giunti, G., Goossens, R., & Melles, M. (2024). Timing, Indicators, and Approaches to Digital Patient Experience Evaluation: Umbrella Systematic Review. *Journal of Medical Internet Research*, 26, e46308. doi: 10.2196/46308.

Abstract

Background:

The increasing prevalence of DH applications has outpaced research and practice in digital health (DH) evaluations. Patient experience (PEx) was reported as one of the challenges facing the health system by the World Health Organization. To generate evidence on DH and promote the appropriate integration and use of technologies, a standard evaluation of PEx in DH is required.

Objectives:

This study aims to systematically identify evaluation timing considerations (ie, when to measure), evaluation indicators (ie, what to measure), and evaluation approaches (ie, how to measure) with regard to digital PEx. The overall aim of this study is to generate an evaluation guide for further improving digital PEx evaluation.

Methods:

This is a 2-phase study parallel to our previous study. In phase 1, literature reviews related to PEx in DH were systematically searched from Scopus, PubMed, and Web of Science databases. Two independent raters conducted 2 rounds of paper screening, including title and abstract screening and full-text screening, and assessed the interrater reliability for 20% (round 1: 23/115 and round 2: 12/58) random samples using the Fleiss-Cohen coefficient (round 1: k1=0.88 and round 2: k2=0.80). When reaching interrater reliability (k>0.60), TW conducted the rest of the screening process, leaving any uncertainties for group discussions. Overall, 38% (45/119) of the articles were considered eligible for further thematic analysis. In phase 2, to check if there were any meaningful novel insights that would change our conclusions, we performed an updated literature search in which we collected 294 newly published reviews, of which 102 (34.7%) were identified as eligible articles. We considered them to have no important changes to our original results on the research objectives. Therefore, they were not integrated into the synthesis of this review and were used as supplementary materials.

Results:

Our review highlights 5 typical evaluation objectives that serve 5 stakeholder groups separately. We identified a set of key evaluation timing considerations and classified them into 3 categories: intervention maturity stages, timing of the evaluation, and timing of data collection. Information on evaluation indicators of digital PEx was identified and summarized into 3 categories (intervention outputs, patient outcomes, and health care system impact), 9 themes, and 22 subthemes. A set of evaluation theories, common study designs, data collection methods and instruments, and data analysis approaches was captured, which can be used or adapted to evaluate digital PEx.

Conclusions:

Our findings enabled us to generate an evaluation guide to help DH intervention researchers, designers, developers, and program evaluators evaluate digital PEx. Finally, we propose 6 directions for encouraging further digital PEx evaluation research and practice to address the challenge of poor PEx.

Keywords:

digital health; eHealth; telemedicine; mobile health; mHealth; patient experience; user experience; evaluation timing; evaluation indicators; evaluation approaches; user-centered design; patient-centered care; human-computer interaction; mobile phone

3.1. Introduction

Emerging digital technologies promise to shape the future health care industry (Jandoo, 2020; Kellermann & Jones, 2013). According to our previous review (Tingting Wang, Guido Giunti, et al., 2022b), most researchers had a positive impression of digital health interventions (DHIs). The number of DHIs is proliferating (Asadzadeh & Kalankesh, 2021; Gordon et al., 2020; IOVIA Institute, 2017), which is affecting the way patients receive their health care services compared with face-to-face health care services and ultimately influencing the patient journey and overall patient experience (PEx) (Alkire et al., 2020; Shaw et al., 2018). Good PEx is a key intent of patient-centered care (Constand et al., 2014) and a core measure of care quality in digital health (DH) (Hollander et al., 2017; Philpot et al., 2019), Digital technologies have the potential to enhance or provide comparable PEx compared with some face-to-face health care services (Altinisik Ergur et al., 2022; Riley et al., 2021; Shaw et al., 2018; Whitten & Love, 2005). However, the uptake of digital technologies in health care is not as rapid as it has been in many other industries (Keown et al., 2014), and their potential in health care remains unfulfilled (Desveaux et al., 2017). According to a report by the World Health Organization (WHO) on the classification of DHIs, the health system is not responding adequately to the need for improved PEx (World Health Organization, 2018).

Despite the growing number of DHIs, evaluations that are timely, cost-effective, and robust have not kept pace with this growth (Alkire et al., 2020; Guo et al., 2020; World Health Organization, 2022a). PExs in the wide range of DHIs are mixed (Kamillah et al., 2022; Thiyagarajan et al., 2020). Few published DHIs have resulted in high download numbers and active users (Research2Guidance, 2017); most are released with minimal or no evaluation and require patients to assess the quality for themselves and take responsibility for any consequences (Koh et al., 2021). Low-quality DH may disrupt user experience (UX) (Eysenbach et al., 2002), resulting in low acceptance, and some may even be harmful (Bindhim et al., 2014). In addition, a DHI may be popular with patients but not valued by clinicians (Singh et al., 2019). To generate evidence and promote the appropriate integration and use of digital technologies in health care, an overview of how to evaluate PEx or UX in varied DHIs is needed (Fraser et al., 2011; Tingting Wang, Guido Giunti, et al., 2022b).

3.1.1. Evaluating the Digital PEx

In this study, we used the definition of digital PEx from our previous review (Tingting Wang, Guido Giunti, et al., 2022b): "the sum of all interactions affected by a patient's behavioral determinants, framed by digital technologies, and shaped by organizational culture, that influence patient perceptions across the continuum of care channeling digital health." This incorporates influencing factors of digital PEx (Tingting Wang, Guido Giunti, et al., 2022b) and the existing definitions of DHIs (World Health Organization, 2016b, 2020), PEx (Wolf & Jason, 2014), and UX (Jokela et al., 2003). Compared with the general PEx and UX, it highlights patient perceptions that are affected by technical, behavioral, and organizational

determinants when interacting with a DHI. DHI has become an umbrella term that often encompasses broad concepts and technologies (Tecco, 2017), such as DH applications, ecosystems, and platforms (World Health Organization, 2020). In this study, we followed the WHO's definition of DHIs (World Health Organization, 2016b), that is, the use of digital, mobile, and wireless technologies to support the achievement of health objectives. It refers to the use of information and communication technologies for health care, encompassing both mobile health and eHealth (World Health Organization, 2016b, 2021a). Compared with evaluating DHIs, PEx, and UX, little is known about evaluating digital PEx. However, combining the definition of digital PEx with the extensively explored measurement of PEx, UX, and DHIs can lead to an improved understanding of and enable the development of evaluation approaches for measuring digital PEx. Therefore, the evaluations of PEx, UX, and DHIs will be used as a starting point in this study to clarify when to measure, what to measure, and how to measure digital PEx.

3.1.2. When to measure

First, the timing of measuring and evaluating digital PEx is an important consideration and must align with the contextual situation, such as evaluation objectives and stakeholders, to ensure practicality and purposefulness (Greenhalgh et al., 2005; LaVela & Gallan, 2014). According to the European Union (Former Capacity4dev Member, 2022) and the Department of Health of The King's Fund (Coulter et al., 2009), an evaluation can be scheduled during the design phase or during or after the implementation phase. Similarly, the WHO (World Health Organization, 2016b) introduced 3 DHI evaluation stages: efficacy, effectiveness, and implementation. The evaluation of efficacy refers to where the intervention is under highly controlled conditions, the evaluation of effectiveness is carried out in a real world context, and the evaluation of implementation occurs after efficacy and effectiveness have been established. Furthermore, an evaluation can be performed before, during, or after the evaluated intervention in both research and nonresearch settings (Former Capacity4dev Member, 2022). However, decision-making on when to collect PEx data can be more complicated. As argued in earlier studies (Coulter et al., 2009; LaVela & Gallan, 2014), immediate feedback has the benefit of gaining real-time insights, but patients may be too unwell, stressed, or distracted to provide detailed opinions. In contrast, when the feedback is related to medical outcomes or quality of life, it often requires a lengthy period after the intervention to observe any changes. However, responses gathered long after a care episode may be inferior because of recall bias.

3.1.3. What to measure

Second, there is a need for a decision on what is required to measure to assess digital PEx. The frequently mentioned UX evaluation concepts, such as usability, functionality, and reliability, from studies (Bolton et al., 2018; Norman & Nielsen, 2016; Richardson et al., 2021) investigating UX can be applied to evaluate the intervention outputs to anticipate digital PEx at a service level. Moreover, according to the existing constructs and frameworks

of understanding or evaluating PEx (America, 2001; NHS National Quality Board, 2011; Reeves et al., 2002; Shandley et al., 2020; Staniszewska et al., 2014), such as emotional support, relieving fear and anxiety, patients as active participants in care, and continuity of care and relationships, they can be adjusted to evaluate digital PEx by understanding patient outcomes at an individual level. In addition, the National Quality Forum (Hollander et al., 2017) proposed a set of measurable concepts to be used to evaluate PEx in telehealth, for example, patients' increased confidence in, understanding of, and compliance with their care plan; reduction in diagnostic errors and avoidance of adverse outcomes; and decrease in waiting times and eliminated travel. Some of these concepts can be used to understand digital PEx at an organizational level by assessing the impact of the health care system.

3.1.4. How to measure

The third consideration is how to choose evaluation approaches appropriate for evaluating the digital PEx (LaVela & Gallan, 2014), starting from widely used theories, study designs, methods, and tools for evaluating DHIs and the related PEx or UX. There is rapidly evolving guidance for guiding DH innovators (Guo et al., 2020), such as the National Institute for Health and Care Excellence Evidence Standards Framework for Digital Health Technologies (National Institute for Health and Care Excellence, 2018). The strength of the evidence in the evaluation of DHIs often depends on the study design (Guo et al., 2020). However, the high bar for evidence in health care usually requires a longer time for evidence generation, such as prospective randomized controlled trials (RCTs) and observational studies, which often conflicts with the fast-innovation reality of the technology industry (Desveaux et al., 2017; Guo et al., 2020). In addition, many traditional approaches, such as qualitative and quantitative methods, can be used to collect experience-related data to evaluate the DHIs (Guo et al., 2020; World Health Organization, 2016b), Qualitative methods such as focus groups, interviews, and observations are often used to obtain an in-depth understanding of PEx (Coulter et al., 2009) in the early intervention development stages (World Health Organization, 2016b). Surveys using structured questionnaires, such as patient satisfaction ratings (Coulter et al., 2009; Rockville, 2016), patient-reported experience measures (PREMs) (Kingsley & Patel, 2017; LaVela & Gallan, 2014), and patient-reported outcome measures (PROMs) (Coulter et al., 2009; Kingsley & Patel, 2017; LaVela & Gallan, 2014), are often used to examine patterns and trends from a large sample. Hodgson (Hodgson, 2017) believed that strong evidence results from UX data that are valid and reliable, such as formative and summative usability tests, and stated that behavioral data are strong, but opinion data are weak.

3.1.5. Objectives

This study aims to systematically identify (1) evaluation timing considerations (ie, when to measure), (2) evaluation indicators (ie, what to measure), and (3) evaluation approaches (ie, how to measure) with regard to digital PEx. The overall aim of this study is to generate an evaluation guide for further improving digital PEx evaluation research and practice.

3.2. Methods

3.2.1. Overview

This study consists of 2 phases. In phase 1, we followed the same study search and selection process as our previous research (Tingting Wang, Guido Giunti, et al., 2022b) but focused on a different data extraction and analysis process to achieve our objectives in this study. In the previous study (Tingting Wang, Guido Giunti, et al., 2022b), we identified the influencing factors and design considerations of digital PEx, provided a definition, constructed a design and evaluation framework, and generated 9 design guidelines to help DH designers and developers improve digital PEx. To highlight the connections between "design" and "evaluation" works in the development of DH and provide readers with a clear road map, we included some evaluation-related information in the previous paper as well. However, it was limited and described at a very abstract level. In this study, detailed information on the evaluation was provided, including evaluation timing considerations, evaluation indicators, and evaluation approaches, and we aimed to generate an evaluation guide for improving the measurement of digital PEx. Given that this is an evolving area, after we finished phase 1, we conducted an updated literature search as a subsequent investigation to determine whether an update of a review was needed in this study.

3.2.2. Phase 1: The Original Review

Study Search and Selection

Following the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (Liberati et al., 2009), we conducted an umbrella systematic review (Grant & Booth, 2009) on literature reviews related to PEx and UX in DH. The term DH was first introduced in 2000 by Frank (Frank, 2000). Therefore, Scopus, PubMed, and Web of Science databases were used for searching related articles that were published between January 1, 2000, and December 16, 2020. Furthermore, Google Scholar was used to search for additional studies that were identified during the review process through the snowballing method. The computer search resulted in 173 articles, of which 58 (33.5%) were duplicates. After removing the duplicates, the titles and abstracts of a small random sampling (23/115, 20%) were reviewed by 2 independent raters to assess the interrater reliability by using the Fleiss-Cohen coefficient, which resulted in k1=0.88 (SE 0.07; 95% CI 0.74-1.03). This was followed by a group discussion to reach an agreement on the selection criteria. Subsequently, the remaining titles and abstracts (92/115, 80%) were reviewed by TW individually. After screening the titles and abstracts, half of the articles (58/115, 50.4%) remained for the fulltext review. Meanwhile, 4 additional articles were identified through snowballing and were included in the full-text screening. Another small random sample (12/62, 19%) was reviewed by the 2 raters to screen the full texts. After achieving interrater reliability, k2=0.80 (SE 0.13; 95% CI 0.54-1.05) and reaching a consensus on the inclusion criteria through another group discussion, TW reviewed the full texts of the remaining papers (50/62, 80%). Google Sheets was used for performing the screening process and assessments. Finally, as shown in Figure 3-1 (Tingting Wang, Guido Giunti, et al., 2022b), a total of 45 articles were included for data extraction. A detailed search strategy, selection criteria, and screening process can be found in our previously published study (Tingting Wang, Guido Giunti, et al., 2022b). Multimedia Appendix 1 (see in our publication online) presents the included papers and excluded articles.

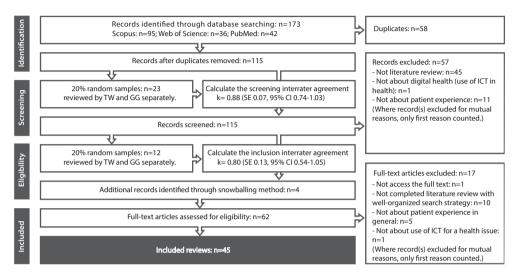


Figure 3-1. Study flow diagram. (ICT: information and communications technology)

Data Extraction and Thematic Analysis

We used ATLAS.ti (Scientific Software Development GmbH; version 9.0.7) for data extraction. Data were extracted for the three predefined objectives: (1) evaluation timing considerations, (2) evaluation indicators, and (3) evaluation approaches of the digital PEx. In addition, We collected data related to evaluation objectives among the included studies. Data analysis followed the 6-phase thematic analysis method proposed by Braun and Clarke (Braun & Clarke, 2006; Jack Caulfield, 2019): familiarization, coding, generating themes, reviewing themes, defining and naming themes, and writing up. First, we became familiar with the 45 articles included in the study. Second, after a thorough review, TW started iteratively coding the data related to the predefined objectives based on existing frameworks, including the Performance of Routine Information System Management framework (Aqil et al., 2009), monitoring and evaluation guide (World Health Organization, 2016b), measures of PEx in hospitals (Coulter et al., 2009), and an overview of research methodology (Arora, 2011). This resulted in 25 initial codes. After no additional new codes were identified, TW proposed a coding scheme to summarize the recurring points throughout the data. Then, GG, RG, and MM reviewed and discussed the coding scheme until they reached an agreement. Third, TW followed the coding scheme to code the data more precisely and completely and searched for themes among the generated codes. Fourth, TW, GG, RG, and MM reviewed and discussed these codes and themes to address any uncertainties. Fifth, the definitions and names of the generated themes were adjusted through team discussions. Finally, the analytical themes related to the evaluation timing, indicators, and approaches were produced and reported. Both deductive and inductive approaches (Jack Caulfield, 2019) were used to identify and generate themes. Four researchers were involved in the review process.

We first highlighted the evaluation timing considerations in terms of intervention maturity stages, the timing of evaluation, and the timing of datacollection, which were adopted from the description of the WHO and European Union (Table 3-1) (Coulter et al., 2009; Former Capacity4dev Member, 2022).

We then determined the evaluation indicators and classified them into 3 categories (Table 3-2). Intervention outputs are the direct products or deliverables of process activities and refer to the different stages of evaluation that correspond to the various stages of maturity of the DHI. Patient outcomes describe the intermediate changes in patients, including patients' emotions, perceptions, capabilities, behaviors, and health conditions as determined by DHIs in terms of influencing factors and interaction processes. Health care system impact is the medium- to long-term, large-scale financial (intended and unintended) effects produced by a DHI.

Finally, we concluded evaluation approaches in terms of study designs, data collection methods and instruments, and data analysis approaches (Table 3-3). According to the WHO (World Health Organization, 2016b), study designs are intended to assist in decision-making on evidence generation and clarify the scope of evaluation activities. Data collection and analysis are designed through an iterative process that involves strategies for collecting and analyzing data and a series of specifically designed tools (Former Capacity4dev Member, 2022).

Table 3-1. Initial codes of evaluation timing considerations of the digital patient experience.

Categories and initial codes	Description
Intervention matu	rity stages (Coulter et al., 2009; Former Capacity4dev Member, 2022;
World Health Organ	nization, 2016b)
Efficacy	Assess whether the DHI ^a achieves the intended results in research or controlled setting
Effectiveness	Assess whether the DHI achieves the intended results in nonresearch or uncontrolled setting
Implementation	Assess the uptake, institutionalization, and sustainability of evidence- based DHIs in a given context, including policies and practices
Timing of the eval	uation (Former Capacity4dev Member, 2022)
Before intervention	A baseline test is performed before individuals adopt or implement the intervention. It assesses individuals' initial status and their anticipated perception of the intervention
During intervention	An evaluation performed during intervention's use aims to monitor individuals' real-time feedback and reactions
After intervention	An evaluation that is performed right after or a long time after the completion of the interventions by individuals. It assesses individuals' changes regarding using the intervention
Timing of data coll	lection (Coulter et al., 2009; LaVela & Gallan, 2014)
Immediate evaluation	Aims to collect real-time data on patients' experiences during or immediately after their treatment
Delayed evaluation	Aims to obtain more substantial responses after the intervention's completion over a long period
Momentary evaluation	Aims to collect transient information from individuals at a specific moment
Continuous evaluation	Aims to gather feedback from individuals at different points along the care pathway

^aDHI: digital health intervention.

Table 3-2. Initial codes of evaluation indicators of the digital patient experience.

Categories and initial codes	Description
Intervention outp	outs (Bolton et al., 2018; Norman & Nielsen, 2016; Richardson et al., 2021;
-	anization, 2016b, 2022b)
Functionality	Assess whether the DHI ^a works as intended. It refers to the ability of the
•	DHb system to support the desired intervention.
Usability	Assess whether the DHI is used as intended. It refers to the degree to
	which the intervention is understandable and easy to use.
Quality of care	Assess whether the DHI delivers effective, safe, people-centered, timely,
	accessible, equitable, integrated, and efficient care services. It refers
	to the degree to which health services for individuals and populations
	increase the likelihood of desired health outcomes.
Patient outcomes	(America, 2001; Hollander et al., 2017; NHS National Quality Board,
2011; Reeves et al	., 2002; Shandley et al., 2020; Staniszewska et al., 2014)
Emotional	Assess whether patients' feelings and well-being change positively or
outcomes	negatively because of the use or anticipated use of DHIs. It refers to what
	the patients feels.
Perceptual	Assess whether the informed state of mind that patients achieve as
outcomes	intended before, during, or after using the DHIs. It refers to what the
	patient thinks and believes.
Capability	Assess whether patients' health literacy, communication skills, or
outcomes	computer confidence in managing diseases, communicating with health
	care providers, or operating digital devices increased as expected. It refers
	what the patient knows and acquires.
Behavior	Assess whether patients engage in activities to cope with the disease and
outcomes	treatments through DHIs. It refers to what the patient acts and does.
Clinical	Assess whether patients' health improvements meet the intentions of the
outcomes	DHIs. It refers to what medical condition the patient is in and aims to
	maintain.
Health care system	m impact (World Health Organization, 2016b)
Economic	Assess whether the DHIs are cost-effective, whether the organization
outcomes	and DH users can afford the DHI system, and whether there is a probable
	return on investment. It refers to the use of health care resources.

^aDHI: digital health intervention.

Table 3-3. Initial codes of evaluation approaches of the digital patient experience.

Categories	Description
and initial	
codes	
Study designs (World Health Organization, 2016b)
Descriptive	Aims to define the "who, what, when, and where" of the observed
study	phenomena and include qualitative research concerning both individuals and populations.
Analytical	Aims to quantify the relationship between the intervention and the outcomes
study	of interest, usually with the specific aim of demonstrating a causative link
	between the 2, including experimental and observational studies.
Data collection	methods and instruments (Streefkerk)
Qualitative	Qualitative research is expressed in words. It is used to understand
methods	concepts, thoughts, or experiences. Common qualitative methods include
	interviews with open-ended questions, observations described in words, and
	literature reviews that explore concepts and theories.
Quantitative	Quantitative research is expressed in numbers and graphs. It is used to test
methods	or confirm theories and assumptions. Common quantitative methods include
	experiments, observations recorded as numbers, and surveys with closed- ended questions.
Qualitative	Qualitative data consist of text, images, or videos instead of numbers.
analysis	Content analysis, thematic analysis, and discourse analysis are the common
	approaches used to analyze these types of data.
Quantitative	Quantitative data are based on numbers. Simple math or more advanced
analysis	statistical analysis is used to discover commonalities or patterns in the data.

3.2.3. Phase 2: The Updated Scoping Search

The decision to undertake an update of a review requires several considerations. Review authors should consider whether an update for a review is necessary and when it will be more appropriate (Cumpston & Chandler, 2020). In light of the "decision framework to assess systematic reviews for updating, with standard terms to report such decisions" (Allen, 2019), we consider that research on PEx in DH remains important and evolves rapidly. In case we missed some newly published articles that would bring significant changes to our initial findings, we conducted a rapid scoping search for articles published after our last search. we reran the search strategy as specified before with the addition of date (from December 16, 2020, to August 18, 2023) limits set to the period following the most recent search. After removing duplicates (73/367, 19.8%), we collected 294 articles in total. Following the same screening process and selection criteria, we finally identified 102 new eligible articles. The excluded articles were either not a literature review with systematic search (74/294, 25.2%),

not about DH (87/294, 29.6%), not about PEx (26/294, 8.8%), our own parallel publications (2/294, 0.7%), or not accessible in full text (3/294, 1%). The eligible and ineligible articles in this phase are available in Multimedia Appendix 2 (see in our publication online). We found that the outcomes in the new studies were almost consistent with the existing data. For example, these articles either aimed to investigate what factors influence the feasibility, efficacy, effectiveness, design, and implementation of DH; examine how patients expect, perceive, and experience the DHIs; or intend to compare the DHIs with conventional face-toface health care services. The research objectives of these new eligible articles are available in Multimedia Appendix 3 (see in our publication online) (Ames et al., 2019; Barello et al., 2016; Barken et al., 2019; Bashi et al., 2020; Baumel et al., 2017; Brigden et al., 2020; Brunton et al., 2015; Chaudhry et al., 2021; Cheung et al., 2019; Choi et al., 2020; Cox et al., 2017; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Eze et al., 2020; Feather et al., 2016; Firth & Torous, 2015; Fouquet & Miranda, 2020; Greenhalgh & Shaw, 2017; Ingemann et al., 2020; Jalil et al., 2015; Jones & Grech, 2016; Kuijpers et al., 2013; Lattie et al., 2019; Lemon et al., 2020; Leonardsen et al., 2020; Liddy et al., 2016; Lim et al., 2019; Memon et al., 2014; Molina-Recio et al., 2020; Morrison et al., 2014; Morton et al., 2017; O'Keefe et al., 2021; Palacholla et al., 2019; Rincon et al., 2017; Rising et al., 2018; Sakaguchi-Tang et al., 2017; Slater et al., 2017; Søgaard Neilsen & Wilson, 2019; Simen A Steindal et al., 2020; Stokke, 2016; Swanepoel & Hall III, 2010; Rachael C Walker et al., 2019; Yanxia Wei et al., 2020; Werder, 2015; Wesselman et al., 2019; Wildenbos et al., 2018). We considered that their findings were unlikely to meaningfully impact our findings on when to measure, what to measure, and how to measure digital PEx. As suggested by Cumpston and Chandler (Cumpston & Chandler, 2020), review authors should decide whether and when to update the review based on their expertise and individual assessment of the subject matter. We decided to use these new articles as supplementary materials (Multimedia Appendices 2 and 3, see in our publication online) but did not integrate them into the synthesis of this review.

3.3. Results

3.3.1. General Findings

This paper is a part of a larger study, and we have presented results related to study characteristics in a previous publication (Tingting Wang, Guido Giunti, et al., 2022b). Multimedia Appendix 4 (see in our publication online) provides detailed information regarding the characteristics of the included reviews, including research questions or aims, review types, analysis methods, number of included studies, target populations, health issues, and DHIs reported in each review. In this study, to achieve our research objectives, we identified reviews that reported different intervention maturity stages, timing of the evaluation, and timing of data collection. In addition, we identified a set of evaluation indicators of digital PEx and classified them into 3 predefined categories (ie, intervention outputs, patient outcomes, and health care system impact), which in turn included 9 themes and 22 subthemes. Furthermore, we highlighted evaluation approaches in terms of evaluation theories, study designs, data collection methods and instruments, and data analysis methods. we found that it was valuable to compare the

evaluation objectives of the included studies. Therefore, we captured 5 typical evaluation objectives and the stakeholders involved, which clarified why and for whom DH evaluators carried out the evaluation tasks. The detailed findings are presented in the Evaluation Objectives section.

3.3.2. Evaluation Objectives

Our review findings highlighted 5 typical evaluation objectives.

The first objective was to broaden the general understanding of the digital PEx and guide evaluation research and practice (11/45, 24%) (Bashi et al., 2020; Baumel et al., 2017; Brigden et al., 2020; Choi et al., 2020; Feather et al., 2016; Lemon et al., 2020; Leonardsen et al., 2020; O'Keefe et al., 2021; Sakaguchi-Tang et al., 2017; Slater et al., 2017; Wildenbos et al., 2018). For instance, 1 review (Lemon et al., 2020) aimed to identify implications for future evaluation research and practice on mental health smartphone interventions by investigating UX evaluation approaches.

The second was to improve the design, development, and implementation of the DHI in terms of a better digital PEx (15/45, 33%) (Bashi et al., 2020; Baumel et al., 2017; Brigden et al., 2020; Choi et al., 2020; Feather et al., 2016; Ingemann et al., 2020; Lemon et al., 2020; Leonardsen et al., 2020; Molina-Recio et al., 2020; Palacholla et al., 2019; Sakaguchi-Tang et al., 2017; Slater et al., 2017; Yanxia Wei et al., 2020; Wesselman et al., 2019; Wildenbos et al., 2018). As demonstrated in an included review (Bashi et al., 2020), the evaluation of DHIs is critical to assess progress, identify problems, and facilitate changes to improve health service delivery and achieve the desired outcomes.

The third was to achieve evidence-based clinical use and increase DHIs' adoption and uptake (14/45, 31%) (Bashi et al., 2020; Brigden et al., 2020; Choi et al., 2020; Eze et al., 2020; Feather et al., 2016; Jalil et al., 2015; Lemon et al., 2020; Leonardsen et al., 2020; Molina-Recio et al., 2020; Palacholla et al., 2019; Sakaguchi-Tang et al., 2017; Simen A Steindal et al., 2020; Wesselman et al., 2019).

The fourth was to drive ongoing investment (3/45, 7%) (Eze et al., 2020; Feather et al., 2016; Simen A Steindal et al., 2020); without compelling economic supporting evidence, the proliferation of DHIs will not occur. Therefore, ensuring the sustained clinical use, successful implementation, and adoption of and continued investment in DHIs require more evaluative information. This helps ensure that resources are not wasted on ineffective interventions (Feather et al., 2016).

The fifth was to inform health policy practice (3/45, 7%) (Lemon et al., 2020; Sakaguchi-Tang et al., 2017; Slater et al., 2017). As the 2 included articles stated (Sakaguchi-Tang et al., 2017; Slater et al., 2017), ongoing evaluation and monitoring of DHIs is critical to

inform health policy and practice. In addition, in terms of the varied evaluation objectives, the evaluation activities serve different stakeholder groups, including program investigators, evaluators, and researchers; designers, developers, and implementers; end users, patients, and health care providers (HCPs); clients and investors; and governments and policymakers.

3.3.3. Evaluation Timing Considerations

Among the included studies, evaluations were carried out at various stages of the intervention to fulfill the 5 evaluation objectives. Our findings showed that most reviews reported feasibility, efficacy, and pilot studies (32/45, 71%) (Ames et al., 2019; Barello et al., 2016; Bashi et al., 2020; Baumel et al., 2017; Brigden et al., 2020; Brunton et al., 2015; Choi et al., 2020; Cox et al., 2017; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Eze et al., 2020; Feather et al., 2016; Firth & Torous, 2015; Fouquet & Miranda, 2020; Greenhalgh & Shaw, 2017; Jalil et al., 2015; Jones & Grech, 2016; Kuijpers et al., 2013; Lattie et al., 2019; Lemon et al., 2020; Leonardsen et al., 2020; Lim et al., 2019; Memon et al., 2014; Molina-Recio et al., 2020; Morton et al., 2017; O'Keefe et al., 2021; Palacholla et al., 2019; Rincon et al., 2017; Rising et al., 2018; Slater et al., 2017; Søgaard Neilsen & Wilson, 2019; Simen A Steindal et al., 2020; Swanepoel & Hall III, 2010) and then investigated effectiveness (20/45, 44%) (Ames et al., 2019; Barello et al., 2016; Barken et al., 2019; Bashi et al., 2020; Cheung et al., 2019; Choi et al., 2020; Eze et al., 2020; Feather et al., 2016; Jalil et al., 2015; Kuijpers et al., 2013; Lattie et al., 2019; Lemon et al., 2020; Liddy et al., 2016; Lim et al., 2019; Morrison et al., 2014; O'Keefe et al., 2021; Rising et al., 2018; Søgaard Neilsen & Wilson, 2019; Swanepoel & Hall III, 2010; Wesselman et al., 2019) and implementation studies (20/45, 44%) (Barello et al., 2016; Bashi et al., 2020; Baumel et al., 2017; Brunton et al., 2015; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Eze et al., 2020; Fouquet & Miranda, 2020; Greenhalgh & Shaw, 2017; Lattie et al., 2019; Lemon et al., 2020; Leonardsen et al., 2020; Liddy et al., 2016; Memon et al., 2014; Morrison et al., 2014; Morton et al., 2017; Palacholla et al., 2019; Slater et al., 2017; Søgaard Neilsen & Wilson, 2019; Yanxia Wei et al., 2020; Werder, 2015). Notably, some reviews included >1 type of study. Our findings show that the timing of evaluation can be directly at pre- or postintervention (Brigden et al., 2020; Brunton et al., 2015; Choi et al., 2020; Cox et al., 2017; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Eze et al., 2020; Feather et al., 2016; Fouquet & Miranda, 2020; Greenhalgh & Shaw, 2017; Jalil et al., 2015; Kuijpers et al., 2013; Lattie et al., 2019; Leonardsen et al., 2020; Liddy et al., 2016; Morrison et al., 2014; Morton et al., 2017; O'Keefe et al., 2021; Palacholla et al., 2019; Slater et al., 2017; Simen A Steindal et al., 2020; Swanepoel & Hall III, 2010; Wesselman et al., 2019), at the baseline point or after a short- or long-term followup intervention (Bashi et al., 2020; Brigden et al., 2020; Brunton et al., 2015; Chaudhry et al., 2021; Cox et al., 2017; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Eze et al., 2020; Greenhalgh & Shaw, 2017; Jones & Grech, 2016; Kuijpers et al., 2013; Lattie et al., 2019; Leonardsen et al., 2020; Liddy et al., 2016; Molina-Recio et al., 2020; Rising et al., 2018; Simen A Steindal et al., 2020; Stokke, 2016; Swanepoel & Hall III, 2010; Wesselman et al., 2019), during intervention use (Brunton et al., 2015; Jones & Grech, 2016), continued monitoring (Barello et al., 2016; Slater et al., 2017), and even at dropout (Feather et al., 2016). One study (Kuijpers et al., 2013) suggested providing a period of technical training and conducting a baseline test to reduce the evaluation bias caused by individual technology familiarity and novelty. As demonstrated by another study (Feather et al., 2016), pre- and postintervention assessments using clinical trials can measure intervention effectiveness (eg, patients' blood glucose levels). In terms of the timing of data collection, 1 included study (Feather et al., 2016) suggested that evaluations directly after the intervention are appropriate so that the users retain fresh memories of the experience. To sustain intervention outcomes over a longer period, longitudinal evaluations and long-term follow-up evaluations were recommended in 2 studies (Kuijpers et al., 2013; Sakaguchi-Tang et al., 2017).

3.3.4. Evaluation Indicators

Overview

Evaluation indicators relate to the goal to which the research project or commercial program intends to contribute. Indicators are defined as "a quantitative or qualitative factor or variable that provides a simple and reliable means to measure achievement, to reflect the changes connected to an intervention, or to help assess the performance of a development actor" (World Health Organization, 2013). On the basis of our initial codes, we grouped the evaluation indicators into 3 main categories: intervention outputs, patient outcomes, and health care system impact. Each category contains several themes and subthemes (Tables 3-4, 3-5, and 3-6) and is discussed in detail in the below 3 sections: Intervention Outputs, Patient Outcomes, and Health Care System Impact.

Table 3-4. Themes, subthemes, and evaluation indicators of the intervention outputs of the digital patient experience.

Themes and	Studies	Evaluation indicators	References
subthemes	(n=45), n (%)		
Functionality (n=36, 80%	36, 80%)		
Intended values 21 (47	21 (47)	 Ability to either change or maintain the user's health state in a beneficial way: support selfmanagement, shared decision-making, trigger actions, and track and respond to changes Ability to collect clinical metrics: the number of monitored variables and the frequency, accuracy, concordance, timeliness, and visibility of monitoring 	(Baumel et al., 2017; Chaudhry et al., 2021; Cheung et al., 2019; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Feather et al., 2016; Firth & Torous, 2015; Greenhalgh & Shaw, 2017; Ingemann et al., 2020; Jalil et al., 2015; Lattie et al., 2019; Lemon et al., 2020; Leonardsen et al., 2020; Liddy et al., 2016; Molina-Recio et al., 2020; O'Keefe et al., 2021; Rising et al., 2018; Slater et al., 2017; Søgaard Neilsen & Wilson, 2019; Rachael C Walker et al., 2019; Yanxia Wei et al., 2020; Wesselman et al., 2019)
Content and information	20 (44)	 Quality of the content: evidence based, tailored, relevance, practicality, consistency, and clarity Amount of the information: comprehensible, completeness, glanceability (understandability), and conciseness Language of the information: simple nontechnical language; actionable message; and a nonauthoritarian, friendly, and nonjudgmental tone of voice 	(Ames et al., 2019; Baumel et al., 2017; Brigden et al., 2020; Cheung et al., 2019; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Jones & Grech, 2016; Kuijpers et al., 2013; Lemon et al., 2020; Lim et al., 2019; Molina-Recio et al., 2020; Morrison et al., 2014; Palacholla et al., 2019; Rincon et al., 2017; Sakaguchi-Tang et al., 2017; Slater et al., 2017; Sogaard Neilsen & Wilson, 2019; Simen A Steindal et al., 2020; Stokke, 2016; Yanxia Wei et al., 2020; Wesselman et al., 2019)

Table 3-4. Themes, subthemes, and evaluation indicators of the intervention outputs of the digital patient experience (continued).

Themes and	Studies	Evaluation indicators	References	
subthemes	(n=45), n (%)			
Intervention	20 (44)	Appropriate features that meet the intended		(Ames et al., 2019; Baumel et al., 2017; Choi
features		values: activity planning, activity scheduling,		et al., 2020; M. F. De La Cruz Monroy & A.
		activity tracking, diary, alerts, journal,		Mosahebi, 2019; Feather et al., 2016; Jalil et
		feedback, and reminders	al., 2015; Jones &	al., 2015; Jones & Grech, 2016; Lemon et al.,
		• Degree of setup, maintenance, and training:		2020; Leonardsen et al., 2020; Lim et al., 2019;
		ready to use, initial training, and ongoing		Molina-Recio et al., 2020; O'Keefe et al., 2021;
		education	Palacholla et al., 2	Palacholla et al., 2019; Rincon et al., 2017;
		 Channel or mode of delivery: phone calls, 		Sakaguchi-Tang et al., 2017; Slater et al., 2017;
		social media, mobile apps, web, video,		Søgaard Neilsen & Wilson, 2019; Yanxia Wei et
		devices, and wearable kit	al., 2020; Werder,	al., 2020; Werder, 2015; Wesselman et al., 2019)
Theory-based	11 (24)	Presence or absence of an underlying	(Barken et al., 201	(Barken et al., 2019; Baumel et al., 2017;
interventions		theoretical basis: behavior change theory,		Brigden et al., 2020; Greenhalgh & Shaw, 2017;
		social presence, and a quality certification		Lim et al., 2019; Morrison et al., 2014; Morton
			et al., 2017; Rinco	et al., 2017; Rincon et al., 2017; Søgaard Neilsen
			& Wilson, 2019; S	& Wilson, 2019; Simen A Steindal et al., 2020;
			Yanxia Wei et al., 2020)	2020)

Table 3-4. Themes, subthemes, and evaluation indicators of the intervention outputs of the digital patient experience (continued).

Themes and	Studies	Evaluation indicators	References
subthemes	(n=45), n (%)		
Technology	24 (53)	• Technology operability: the ease of use,	(Barello et al., 2016; Baumel et al., 2017;
quality attributes		learnability, memorability, readability,	Brigden et al., 2020; Chaudhry et al., 2021;
		efficiency, system errors, product, or service	Cheung et al., 2019; Choi et al., 2020; Feather
		 Technology standards and specifications: 	et al., 2016; Greenhalgh & Shaw, 2017; Jones
		interoperability, integration, scalability,	& Grech, 2016; Lattie et al., 2019; Lemon et
		ergonomics, connectivity, adaptability,	al., 2020; Leonardsen et al., 2020; Liddy et al.,
		flexibility, accuracy, and reliability	2016; Lim et al., 2019; Memon et al., 2014;
			Molina-Recio et al., 2020; Palacholla et al.,
			2019; Sakaguchi-Tang et al., 2017; Slater et al.,
			2017; Simen A Steindal et al., 2020; Stokke,
			2016; Yanxia Wei et al., 2020; Wesselman et al.,
			2019; Wildenbos et al., 2018)
Interaction	17 (38)	 Use of human-centered design methodologies 	(Baumel et al., 2017; Brigden et al., 2020; Choi
design		during the development process: co-design,	et al., 2020; Feather et al., 2016; Greenhalgh &
		user-centered design, and inclusive design	Shaw, 2017; Lemon et al., 2020; Leonardsen
		 Design quality of system architecture, 	et al., 2020; Lim et al., 2019; Memon et al.,
		layout, and interface: intuitive, interactive,	2014; Molina-Recio et al., 2020; Sakaguchi-
		personalized, and esthetic	Tang et al., 2017; Slater et al., 2017; Søgaard
			Neilsen & Wilson, 2019; Simen A Steindal et
			al., 2020; Yanxia Wei et al., 2020; Werder, 2015;
			Wildenbos et al., 2018)
Care quality (n=30, 67%	0, 67%)		

Table 3-4. Themes, subthemes, and evaluation indicators of the intervention outputs of the digital patient experience (continued).

Themes and	Studies	Ev	Evaluation indicators	References
subthemes	(n=45), n (%)			
Accessible care	27 (60)	•	Accessibility of care services: data,	(Ames et al., 2019; Barello et al., 2016; Barken
			information, and HCPsa	et al., 2019; Baumel et al., 2017; Brigden et
		•	Involvement of related stakeholders: family,	al., 2020; Cox et al., 2017; M. F. De La Cruz
			friends, and peer-to-peer communication	Monroy & A. Mosahebi, 2019; Feather et al.,
		•	Accessibility to high-quality care: timely,	2016; Greenhalgh & Shaw, 2017; Ingemann et
			integrated, continuous, improved (more	al., 2020; Jalil et al., 2015; Jones & Grech, 2016;
			predictable daily life), convenient (fits into	Kuijpers et al., 2013; Leonardsen et al., 2020;
			daily routines), and personalized care	Liddy et al., 2016; Lim et al., 2019; Molina-
				Recio et al., 2020; Morton et al., 2017; O'Keefe
				et al., 2021; Palacholla et al., 2019; Rising et
				al., 2018; Sakaguchi-Tang et al., 2017; Slater et
				al., 2017; Simen A Steindal et al., 2020; Stokke,
				2016; Rachael C Walker et al., 2019; Yanxia Wei
				et al., 2020)
Safe and	14 (31)	•	Credibility and accountability of care: the	(Ames et al., 2019; Barken et al., 2019; Baumel
credible care			owners' credibility and third-party verification	et al., 2017; Cheung et al., 2019; Feather et al.,
		•	Security of care: the number of medical errors	2016; Memon et al., 2014; Molina-Recio et al.,
		•	Privacy of care: the presence of general	2020; Rising et al., 2018; Sakaguchi-Tang et al.,
			privacy notifications, the documentation of	2017; Slater et al., 2017; Simen A Steindal et al.,
			individual access to user private data, and	2020; Swanepoel & Hall III, 2010; Yanxia Wei et
			regulation compliance	al., 2020; Werder, 2015)

^aHCP: health care provider.

Table 3-5. Themes, subthemes, and evaluation indicators of patient outcomes of the digital patient experience.

Positive emotions 11 (69) Patient satisfaction	Themes and	Studies	Eva	Evaluation indicators	References
Patient satisfaction Patient satisfaction Patient satisfaction	subthemes	(n=45), n (%)			
Positive emotions 31 (69) A sense of reassurance 2015; Chaudhry et al., 2021; Cox et al., 2017; M. F. D. La Cruz Monroy & A. Mosahebi, 2019; Feather et al., 2015; Chaudhry et al., 2021; Cox et al., 2017; M. F. D. La Cruz Monroy & A. Mosahebi, 2019; Feather et al., 2016; Firth & Torous, 2015; Greenhalgh & Shaw, 2017 Ingernann et al., 2020; Jalli et al., 2015; Jones & Greet Digermann et al., 2020; Jalli et al., 2015; Jones & Greet Digermann et al., 2020; Jalli et al., 2015; Jones & Greet Digermann et al., 2020; Jalli et al., 2015; Jones & Greet Digermann et al., 2020; Jalli et al., 2015; Jones & Greet Digermann et al., 2020; Jalli et al., 2015; Jones & Greet Digermann et al., 2020; Jones & Greet Digermann et al., 2015; Jones & Greet Digermann et al., 2020; Jones & Greet Dig	Emotional outcomes	s (n=32, 71%)			
Negative emotions 16 (36) Perceptual outcomes (n=32, 71%) Nell-being Nell-being Nell-being A sense of reassurance Nell-being A sense of reasurity A sense of pelonging A sense of insecurity A sense of insecurit	Positive emotions	31 (69)	•	Patient satisfaction	(Barello et al., 2016; Barken et al., 2019; Brunton et al.,
 Well-being A sense of security Peace of mind A sense of belonging Peace of mind A sense of belonging A sense of belonging Peace of mind A sense of belonging Peace of mind A sense of belonging Peace of mind Posses of pelonging Peace of mind Peace of minectainties Peace of			•	A sense of reassurance	2015; Chaudhry et al., 2021; Cox et al., 2017; M. F. De
 A sense of security Peace of mind A sense of belonging C Concerns A sense of belonging C Concerns Barker et al., 2021; Palacholla et al., 2019; Racid et al., 2017; Simen A Steindal et al., 2017; Simen A Steindal et al., 2019; Racid et al., 2017; Simen A Steindal et al., 2019; Racid et al., 2017; Simen A Steindal et al., 2019; Racid et al., 2019; Brunton et al., 2019; Racid et al., 2019; Brunton et al., 2019; Racid et al., 2019; Brunton et al., 2015; Greenhalgh Shaw, 2017; Ingemann et al., 2020; Liddy et al., 2019; Brunton et al., 2020; Liddy et al., 2010; Brunton et al., 2020; Stokke, 2016; Racid et al., 2019; Brunton et al., 2020; Stokke, 2016; Racid et al., 2019; Brunton et al., 2020; Stokke, 2016; Racid et al., 2019; Brunton et al., 2020; Stokke, 2016; Racid et al., 2019; Brunton et al., 2020; Stokke, 2016; Racid et al., 2019; Brunton et al., 2020; Stokke, 2016; Racid et al., 2019; Brunton et al., 2020; Stokke, 2016; Racid et al., 2019; Brunton et al., 2020; Stokke, 2016; Racid et al., 2019; Brunton et al., 2020; Stokke, 2016; Racid et al., 2019; Brunton et al., 2020; Stokke, 2016; Racid et al., 2019; Brunton et al., 2020; Brunton et al.,			•	Well-being	La Cruz Monroy & A. Mosahebi, 2019; Feather et al.,
• Peace of mind Ingemann et al., 2020; Jalil et al., 2015; Jones & Greet 2016; Kuijpers et al., 2013; Lattie et al., 2019; Lemon 2020; Leconardsen et al., 2014; Morton et al., 2020; Liddy et al., 2016; Moli Recio et al., 2020; Morrison et al., 2019; Rincon et al., 2017; Sakaguchi-Tang et al., 2019; Rincon et 2017; Sakaguchi-Tang et al., 2017; Simen A Steindal et 2020; Stokke, 2016; Swanepoel & Hall III, 2019; Rach Walker et al., 2019; Werder, 2017; Simen A Steindal et al., 2019; Brunton et al., 2019; Recenhalgh Shaw, 2017; Ingemann et al., 2015; Greenhalgh Shaw, 2017; Ingemann et al., 2019; Greenhalgh Shaw, 2017; Ingemann et al., 2019; Greenhalgh Shaw, 2017; Ingemann et al., 2020; Liddy et a., 2020; Stokke, 2016; Raw, Worries Perceptual outcomes (n=32, 71%) Worries Walker et al., 2019; Molima-Recio et al., 2020; Stokke, 2016; Raw, Walker et al., 2019)			•	A sense of security	2016; Firth & Torous, 2015; Greenhalgh & Shaw, 2017;
o A sense of belonging 2016; Kuijpers et al., 2013; Lattie et al., 2019; Lemon 2020; Liddy et al., 2016; Moli Recio et al., 2020; Morrison et al., 2014; Morton et al., O'Keefe et al., 2021; Palacholla et al., 2019; Rincon et 2017; Sakaguchi-Tang et al., 2017; Simen A Steindal et 2020; Stokke, 2016; Swanepoel & Hall III, 2019; Rincon et 2020; Stokke, 2016; Swanepoel & Hall III, 2019; Rincon et 2020; Stokke, 2016; Swanepoel & Hall III, 2019; Racindal et al., 2017; Simen A Steindal et al., 2017; Simen A Steindal et al., 2015; Greenhalgh Shaw, 2017; Ingernann et al., 2020; Liddy et al., 2020; Lones & Grech, 20 Lennon et al., 2020; Liddy et al., 2020; Liddy et al., 2020; Moi A sense of frustration et al., 2017; Palacholla et al., 2020; Stokke, 2016; Racindal outcomes (n=32,71%) Perceptual outcomes (n=32,71%)			•	Peace of mind	Ingemann et al., 2020; Jalil et al., 2015; Jones & Grech,
2020; Leonardsen et al., 2020; Liddy et al., 2016; Moli Recio et al., 2020; Morrison et al., 2014; Morton et al., 2020; Morrison et al., 2017; Sakaguchi-Tang et al., 2019; Rincon et 2017; Sakaguchi-Tang et al., 2019; Rincon et 2020; Stokke, 2016; Swanepoel & Hall III, 2010; Rach Walker et al., 2016; Swanepoel & Hall III, 2010; Rach Walker et al., 2016; Werder, 2015; Wesselman et al., 2019; Werder, 2015; Greenhalgh Shaw, 2017; Ingemann et al., 2015; Greenhalgh Shaw, 2017; Ingemann et al., 2015; Greenhalgh Shaw, 2017; Ingemann et al., 2020; Liddy et al., 2016; Lim et al., 2019; Molina-Recio et al., 2020; Mon et al., 2017; Palacholla et al., 2020; Stokke, 2016; Rach Worries Worries Walker et al., 2019) Perceptual outcomes (n=32,71%)			•	A sense of belonging	2016; Kuijpers et al., 2013; Lattie et al., 2019; Lemon et al.,
Recio et al., 2020; Morrison et al., 2014; Morton et al., 2017; Sakaguchi-Tang et al., 2017; Simen A Steindal et al., 2017; Sakaguchi-Tang et al., 2017; Simen A Steindal et al., 2017; Sakaguchi-Tang et al., 2017; Simen A Steindal et al., 2019; Rincon et al., 2019; Walker et al., 2019; Werder, 2015; Wesselman et al., 2019; Walker et al., 2019; Werder, 2015; Wesselman et al., 2019; Raenhalgh Negative emotions					2020; Leonardsen et al., 2020; Liddy et al., 2016; Molina-
O'Keefe et al., 2021; Palacholla et al., 2019; Rincon et 2017; Sakaguchi-Tang et al., 2017; Simen A Steindal e 2020; Stokke, 2016; Swanepoel & Hall III, 2010; Rach Walker et al., 2019; Werder, 2015; Wesselman et al., 2019; Werder, 2015; Wesselman et al., 2019; Werder, 2015; Wesselman et al., 2010; Rach Walker et al., 2019; Merder, 2015; Greenhalgh Shaw, 2017; Ingemann et al., 2020; Jones & Grech, 20 Lemon et al., 2019; Jones & Grech, 20 Lemon et al., 2020; Liddy et al., 2020; Liddy et al., 2020; Liddy et al., 2010; Molina-Recio et al., 2020; Moi et al., 2017; Palacholla et al., 2020; Stokke, 2016; Rach Walker et al., 2019) Perceptual outcomes (n=32, 71%)					Recio et al., 2020; Morrison et al., 2014; Morton et al., 2017;
Negative emotions 16 (36) Concerns A sense of frustration					O'Keefe et al., 2021; Palacholla et al., 2019; Rincon et al.,
Negative emotions 16 (36) Concerns Concerns					2017; Sakaguchi-Tang et al., 2017; Simen A Steindal et al.,
Negative emotions 16 (36) • Concerns Wildenbos et al., 2019; Werder, 2015; Wesselman et al., 2018 Negative emotions 16 (36) • Concerns (Barken et al., 2019; Brunton et al., 2015; Greenhalgh Shaw, 2017; Ingemann et al., 2015; Greenhalgh Shaw, 2017; Ingemann et al., 2015; Greenhalgh Shaw, 2017; Ingemann et al., 2020; Jones & Greeh, 20 • A sense of uncertainties Lemon et al., 2020; Liddy et € • Dissatisfaction 2016; Lim et al., 2019; Molina-Recio et al., 2020; Moi et al., 2019; Molina-Recio et al., 2020; Moi et al., 2019; Sakaguchi-Tang et al., 2017; Simen A Steindal et al., 2020; Stokke, 2016; Raw • Worries Walker et al., 2019)					2020; Stokke, 2016; Swanepoel & Hall III, 2010; Rachael C
Negative emotions 16 (36) • Concerns (Barken et al., 2019; Brunton et al., 2015; Greenhalgh Shaw, 2017; Ingemann et al., 2020; Jones & Grech, 20 • Fears A sense of uncertainties Lemon et al., 2020; Leonardsen et al., 2020; Liddy et ε 2016; Lim et al., 2019; Molina-Recio et al., 2020; Stokke, 2016; Raguchi-Tang et al., 2017; Simen A Steindal et al., 2020; Stokke, 2016; Raguchi-Tang et al., 2019) Perceptual outcomes (n=32, 71%)					Walker et al., 2019; Werder, 2015; Wesselman et al., 2019;
Negative emotions 16 (36) Concerns (Barken et al., 2019; Brunton et al., 2015; Greenhalgh • Fears Shaw, 2017; Ingemann et al., 2020; Jones & Grech, 20 • A sense of uncertainties Lemon et al., 2020; Leonardsen et al., 2020; Liddy et a. • Dissatisfaction A sense of frustration et al., 2017; Palacholla et al., 2020; Molina-Recio et al., 2020; Stokke, 2016; Ray • Worries Worries Walker et al., 2019)					
 Fears Pears A sense of uncertainties Dissatisfaction A sense of frustration A sense of frustration A sense of insecurity A sense of insecurity Worries Perceptual outcomes (n=32, 71%) 	Negative emotions		•	Concerns	(Barken et al., 2019; Brunton et al., 2015; Greenhalgh &
 A sense of uncertainties Dissatisfaction A sense of frustration A sense of insecurity Worries Perceptual outcomes (n=32, 71%) A sense of uncertainties A sense of insecurity Walker et al., 2019; Molina-Recio et al., 2020; Molina-Recio et			•	Fears	Shaw, 2017; Ingemann et al., 2020; Jones & Grech, 2016;
 Dissatisfaction A sense of frustration A sense of insecurity Worries Perceptual outcomes (n=32, 71%) Dissatisfaction A sense of frustration A sense of insecurity Worries Walker et al., 2019; Molina-Recio et al., 2020; Stokke, 2016; Racker 2016; Racker 2016; Racker 2016; Racker 2016; Racker 2016; Racker 2016 			•	A sense of uncertainties	Lemon et al., 2020; Leonardsen et al., 2020; Liddy et al.,
 A sense of frustration A sense of frustration A sense of insecurity Worries Worries Perceptual outcomes (n=32, 71%) 			•	Dissatisfaction	2016; Lim et al., 2019; Molina-Recio et al., 2020; Morton
 A sense of insecurity 2017; Simen A Steindal et al., 2020; Stokke, 2016; Rac Worries Walker et al., 2019) Perceptual outcomes (n=32, 71%) 			•	A sense of frustration	et al., 2017; Palacholla et al., 2019; Sakaguchi-Tang et al.,
• Worries Walker et al., 2019) Perceptual outcomes (n=32, 71%)			•	A sense of insecurity	2017; Simen A Steindal et al., 2020; Stokke, 2016; Rachael C
Perceptual outcomes (n=32, 71%)			•	Worries	Walker et al., 2019)
######################################	Perceptual outcome	ss (n=32, 71%)			

Table 3-5. Themes, subthemes, and evaluation indicators of patient outcomes of the digital patient experience (continued).

Themes and	Studies	Evaluation indicators	References
subthemes	(n=45), n (%)		
Empowerment	23 (51)	 Perceived values Quality of life Confidence Self-efficacy Comfort 	(Barello et al., 2016; Barken et al., 2019; Brunton et al., 2015; Cox et al., 2017; Feather et al., 2016; Firth & Torous, 2015; Greenhalgh & Shaw, 2017; Ingemann et al., 2020; Jalil et al., 2015; Jones & Grech, 2016; Kuijpers et al., 2013; Lemon et al., 2020; Leonardsen et al., 2020; Liddy et al., 2016; Molina-Recio et al., 2020; Morrison et al., 2014; Morton et al., 2017; Rincon et al., 2017; Slater et al., 2017; Simen A Steindal et al., 2020; Stokke, 2016; Wesselman et al., 2019)
Acceptability	19 (42)	Degree to which technology, treatment, and care services are accepted: willingness to use, intention to use, intention to continue using, and likelihood to recommend	(Ames et al., 2019; Barello et al., 2016; Brigden et al., 2020; Choi et al., 2020; Feather et al., 2016; Firth & Torous, 2015; Jalil et al., 2015; Jones & Grech, 2016; Lattie et al., 2019; Lemon et al., 2020; Leonardsen et al., 2020; Liddy et al., 2016; Lim et al., 2019; Molina-Recio et al., 2020; Morton et al., 2017; Slater et al., 2017; Stokke, 2016; Swanepoel & Hall III, 2010; Wesselman et al., 2019)
Connectedness	16 (36)	Relationships between patient and provider: closeness, detachment, trust, or doubts	(Barello et al., 2016; Barken et al., 2019; Cox et al., 2017; Feather et al., 2016; Greenhalgh & Shaw, 2017; Ingemann et al., 2020; Jalil et al., 2015; Jones & Grech, 2016; Lemon et al., 2020; Molina-Recio et al., 2020; Morton et al., 2017; Palacholla et al., 2019; Simen A Steindal et al., 2020; Swanepoel & Hall III, 2010; Rachael C Walker et al., 2019; Yanxia Wei et al., 2020)

Table 3-5. Themes, subthemes, and evaluation indicators of patient outcomes of the digital patient experience (continued).

subthemes (n=Attitudes 14	(n=45), n (%)			
	t (31)		Initial beliefs, preferences, and expectations	(Ames et al., 2019; Barello et al., 2016; Cox et al., 2017; Feather et al., 2016; Firth & Torous, 2015; Greenhalgh &
		•	Impression of the excellence of	Shaw, 2017; Jalil et al., 2015; Jones & Grech, 2016; Molina-
			the DHIsa	Recio et al., 2020; Morton et al., 2017; Palacholla et al.,
		•	Interpretation of the DHIs	2019; Sakaguchi-Tang et al., 2017; Swanepoel & Hall III,
		•	Motivation to change behavior	2010; Wesselman et al., 2019)
Burden 12	2 (27)	•	Perceived burden and restriction	(Barken et al., 2019; Brunton et al., 2015; Cox et al., 2017;
		•	Discomfort	Ingemann et al., 2020; Jones & Grech, 2016; Molina-
		•	Unconfident	Recio et al., 2020; Morton et al., 2017; Rincon et al., 2017;
				Sakaguchi-Tang et al., 2017; Stokke, 2016; Swanepoel &
				Hall III, 2010; Rachael C Walker et al., 2019)
Capability outcomes (n	=19, 42%)			
Autonomy and 19 (42)) (42)	•	Participants' level of informed	(Barello et al., 2016; Barken et al., 2019; Cox et al., 2017;
knowledge-			state of mind after using the	Feather et al., 2016; Greenhalgh & Shaw, 2017; Jalil et
gaining			DHIs: clinical awareness	al., 2015; Jones & Grech, 2016; Kuijpers et al., 2013;
		•	Patients' level of health	Leonardsen et al., 2020; Morrison et al., 2014; Morton et
			knowledge: health literacy,	al., 2017; Palacholla et al., 2019; Rising et al., 2018; Slater
			skills, and understanding	et al., 2017; Simen A Steindal et al., 2020; Stokke, 2016;
		•	Patients' ability to make clinical	Swanepoel & Hall III, 2010; Rachael C Walker et al., 2019;
			decisions: problem-solving and	Wesselman et al., 2019)
			shared decision-making	

Table 3-5. Themes, subthemes, and evaluation indicators of patient outcomes of the digital patient experience (continued).

Themes and	Studies	Evaluation indicators	References
subthemes	(n=45), n (%)		
Adherence	19 (42)	 Initial, sustained use of certain features Download and deletion rates Completion rates Dropout rates Speed of task completion 	(Barello et al., 2016; Firth & Torous, 2015; Greenhalgh & Shaw, 2017; Jalil et al., 2015; Jones & Grech, 2016; Kuijpers et al., 2013; Lattie et al., 2019; Lemon et al., 2020; Leonardsen et al., 2020; Liddy et al., 2016; Molina-Recio et al., 2020; Morrison et al., 2014; Morton et al., 2017; O'Keefe et al., 2021; Rincon et al., 2017; Rising et al., 2018; Sakaguchi-Tang et al., 2017; Stokke, 2016; Wesselman et al., 2019)
Self-management behaviors	17 (38)	Number of individuals exercising regularly or using dietary behaviors compared with the total number of participants Engagement of treatment, self- care, and help-seeking behavior	(Barello et al., 2016; Barken et al., 2019; Brigden et al., 2020; Brunton et al., 2015; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Feather et al., 2016; Firth & Torous, 2015; Greenhalgh & Shaw, 2017; Jalil et al., 2015; Kuijpers et al., 2013; Lemon et al., 2020; Leonardsen et al., 2020; Molina-Recio et al., 2020; Morrison et al., 2014; Morton et al., 2017; Rincon et al., 2017; Wesselman et al., 2019)
Patient-provider communication	11 (24)	 Number and frequency of patient-provider contacts Engagement of patient-provider communication Quality of patient-provider communication (eg, percentage of patients reporting that HCPsb communicated well) 	(Barello et al., 2016; Barken et al., 2019; Brigden et al., 2020; Cox et al., 2017; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Greenhalgh & Shaw, 2017; Jalil et al., 2015; O'Keefe et al., 2021; Palacholla et al., 2019; Rising et al., 2018; Simen A Steindal et al., 2020)

Table 3-5. Themes, subthemes, and evaluation indicators of patient outcomes of the digital patient experience (continued).

Themes and subthemes	Studies (n=45), n (%)	Eva	Evaluation indicators	References
Clinical outcomes (n=23, 51%)	(n=23, 51%)			
Health conditions	23 (51)	•	Level of pain and symptoms	(Barello et al., 2016; Brigden et al., 2020; Chaudhry et al.,
			control	2021; Choi et al., 2020; M. F. De La Cruz Monroy & A.
		•	Status of physical health	Mosahebi, 2019; Firth & Torous, 2015; Greenhalgh & Shaw,
		•	Level of health or treatment-	2017; Jalil et al., 2015; Jones & Grech, 2016; Lattie et al.,
			related anxiety, depression, and	2019; Lemon et al., 2020; Leonardsen et al., 2020; Liddy et
			stress	al., 2016; Molina-Recio et al., 2020; Morrison et al., 2014;
		•	Mortality rates	Morton et al., 2017; O'Keefe et al., 2021; Palacholla et
		•	Morbidity rates	al., 2019; Rincon et al., 2017; Rising et al., 2018; Simen A
		•	Adverse effects	Steindal et al., 2020; Stokke, 2016; Wesselman et al., 2019)

^aDHI: digital health intervention.

^bHCP: health care provider.

Table 3-6. Themes, subthemes, and evaluation indicators of health care system impact of the digital patient experience.

Themes and	Studies (n=45).		Evaluation indicators	References
subthemes	n (%)			
Economic outcomes (n=16, 36%)	1=16, 36%)			
Cost-effectiveness	14 (31)	•	Out-of-pocket expenses for patients:	(Chaudhry et al., 2021; Cox et al., 2017; M.
			care costs and travel costs	F. De La Cruz Monroy & A. Mosahebi, 2019;
		•	Time efficiency of using the DHIsa:	Greenhalgh & Shaw, 2017; Ingemann et al.,
			waiting time, travel time, and	2020; Jones & Grech, 2016; Liddy et al., 2016;
			consultation time	Morrison et al., 2014; O'Keefe et al., 2021;
		•	Reduction in overuse of services: printed	Reduction in overuse of services: printed Palacholla et al., 2019; Rising et al., 2018;
			materials	Slater et al., 2017; Swanepoel & Hall III, 2010;
				Rachael C Walker et al., 2019)
Health care service	8 (18)	•	Duration of consultations	(Barken et al., 2019; M. F. De La Cruz Monroy
nse		•	Number of hospitals, primary care, and	& A. Mosahebi, 2019; Greenhalgh & Shaw,
			emergency department visits	2017; Jones & Grech, 2016; Leonardsen et al.,
		•	Hospital admissions	2020; Liddy et al., 2016; Morrison et al., 2014;
		•	Hospitalization	Palacholla et al., 2019)
		•	Proportion of referrals	

^aDHI: digital health intervention.

Intervention Outputs

Intervention outputs are partially determined by the intervention inputs and processes (ie, influencing factors and design considerations, such as personalized design) (Tingting Wang, Guido Giunti, et al., 2022b). We identified 3 themes and 8 subthemes within this category (Table 3-2). The first theme, functionality, refers to the assessment of whether the DHIs work as intended. The subthemes included (1) the consistency of intended value (eg, the ability of the DHIs to collect the amount of accurate clinical metrics in real time (Firth & Torous, 2015; Greenhalgh & Shaw, 2017; Leonardsen et al., 2020; Slater et al., 2017)), (2) the quality of content and information (eg. tailored content (M. F. De La Cruz Monroy & A. Mosahebi, 2019; Jones & Grech, 2016; Lim et al., 2019; Morrison et al., 2014; Palacholla et al., 2019; Rincon et al., 2017; Slater et al., 2017; Søgaard Neilsen & Wilson, 2019)), (3) the appropriateness of intervention features (eg., the degree of system setup (Baumel et al., 2017; Jalil et al., 2015)), and (4) the use of intervention theories (eg, the presence of an underlying theoretical basis (Barken et al., 2019; Baumel et al., 2017; Brigden et al., 2020; Greenhalgh & Shaw, 2017; Lim et al., 2019; Morrison et al., 2014; Morton et al., 2017; Søgaard Neilsen & Wilson, 2019; Yanxia Wei et al., 2020)). The second theme, usability, refers to whether the DH system is used as intended (World Health Organization, 2016b). Both technology quality attributes (eg., ease of use (Barken et al., 2019; Baumel et al., 2017; Brigden et al., 2020; Greenhalgh & Shaw, 2017; Lim et al., 2019; Morrison et al., 2014; Morton et al., 2017; Søgaard Neilsen & Wilson, 2019; Yanxia Wei et al., 2020)) and interaction design (eg, intuitive interface design (Molina-Recio et al., 2020; Yanxia Wei et al., 2020; Werder, 2015)) can be used for usability evaluations. The third theme, care quality, refers to effective, safe, people-centered, timely, accessible, equitable, integrated, and efficient care services (World health organization, 2022b). For example, the assessment of convenient care accessibility (eg, care that fits into daily routines (Brigden et al., 2020; Cox et al., 2017; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Feather et al., 2016; Greenhalgh & Shaw, 2017; Jones & Grech, 2016; Leonardsen et al., 2020; Lim et al., 2019) and the credibility of DHIs' owners (Baumel et al., 2017; Feather et al., 2016)).

Patient Outcomes

Studies used a variety of quantitative and qualitative factors and variables to measure and describe patient outcomes (Table 3-3), referring to 5 themes (emotional outcomes, perceptual outcomes, capability outcomes, behavioral outcomes, and clinical outcomes) and 12 subthemes. Emotional outcomes relate to patients' positive or negative feelings that result from the use or anticipated use of DHIs. For example, a high level of patient satisfaction (Barello et al., 2016; Chaudhry et al., 2021; Feather et al., 2016; Firth & Torous, 2015; Ingemann et al., 2020; Jalil et al., 2015; Jones & Grech, 2016; Kuijpers et al., 2013; Lattie et al., 2019; Lemon et al., 2020; Leonardsen et al., 2020; Liddy et al., 2016; Molina-Recio et al., 2020; Morrison et al., 2014; O'Keefe et al., 2021; Palacholla et al., 2019; Rincon et al., 2017; Sakaguchi-Tang et al., 2017; Stokke, 2016; Swanepoel & Hall III, 2010; Werder, 2015; Wesselman et al., 2019; Wildenbos et al., 2018) is a typical positive feeling. Increased

concerns about data privacy and security (Jones & Grech, 2016; Lim et al., 2019; Molina-Recio et al., 2020; Palacholla et al., 2019; Sakaguchi-Tang et al., 2017; Simen A Steindal et al., 2020; Stokke, 2016; Rachael C Walker et al., 2019) is a frequently mentioned negative feeling. Perceptual outcomes are the informed states of mind or nonemotional feelings the patients achieve before, during, or after using the DHIs (Jalil et al., 2015), including patients' initial attitudes toward the DHIs (eg. internal motivation (Barello et al., 2016; Cox et al., 2017; Feather et al., 2016; Greenhalgh & Shaw, 2017; Jalil et al., 2015; Morton et al., 2017; Palacholla et al., 2019)); patient-to-provider relationships, for example, those that are enhanced by perceived improved accessibility to HCPs (Barello et al., 2016; Barken et al., 2019; Feather et al., 2016; Greenhalgh & Shaw, 2017; Jalil et al., 2015; Jones & Grech, 2016; Molina-Recio et al., 2020; Morton et al., 2017; Simen A Steindal et al., 2020) versus those that are interfered with by perceived loss of face-to-face contacts (Cox et al., 2017; Ingemann et al., 2020; Jones & Grech, 2016; Lemon et al., 2020; Palacholla et al., 2019; Simen A Steindal et al., 2020; Rachael C Walker et al., 2019); perceived empowerment (eg. increased confidence in managing their health conditions (Barello et al., 2016; Cox et al., 2017; Jalil et al., 2015; Morrison et al., 2014; Morton et al., 2017; Slater et al., 2017)) and burden (eg., increased perception of restriction (Barken et al., 2019; Brunton et al., 2015; Cox et al., 2017; Jones & Grech, 2016; Morton et al., 2017; Sakaguchi-Tang et al., 2017; Stokke, 2016; Rachael C Walker et al., 2019)); and overall acceptance of the DHIs (eg, willingness to use (Lemon et al., 2020; Leonardsen et al., 2020; Molina-Recio et al., 2020; Swanepoel & Hall III, 2010)). Capability outcomes refer to the improvement in patients' self-management autonomy, health knowledge, and clinical awareness. DHIs may be effective at improving their independency, self-management autonomy, problem-solving, and decision-making skills (Barello et al., 2016; Barken et al., 2019; Cox et al., 2017; Feather et al., 2016; Greenhalgh & Shaw, 2017; Jalil et al., 2015; Jones & Grech, 2016; Kuijpers et al., 2013; Leonardsen et al., 2020; Morton et al., 2017; Palacholla et al., 2019; Rising et al., 2018; Simen A Steindal et al., 2020; Stokke, 2016; Wesselman et al., 2019); gaining health literacy, knowledge, or understanding of their health conditions or care plans (Barello et al., 2016; Barken et al., 2019; Feather et al., 2016; Greenhalgh & Shaw, 2017; Morrison et al., 2014; Rising et al., 2018; Slater et al., 2017; Swanepoel & Hall III, 2010; Rachael C Walker et al., 2019); and raising their clinical awareness to be more certain of when it was necessary to seek medical attention (Barken et al., 2019; Jalil et al., 2015; Morton et al., 2017; Simen A Steindal et al., 2020; Swanepoel & Hall III, 2010). Behavioral outcomes include activities that the patients adopt owing to DHIs (Jalil et al., 2015), including adherence to the intervention (eg., dropout rates (Firth & Torous, 2015; Jalil et al., 2015; Jones & Grech, 2016; Kuijpers et al., 2013; Lattie et al., 2019; Lemon et al., 2020; Wesselman et al., 2019)), self-management behaviors (eg, physical and diet activities (Firth & Torous, 2015; Greenhalgh & Shaw, 2017; Kuijpers et al., 2013; Molina-Recio et al., 2020; Morton et al., 2017; Rincon et al., 2017; Wesselman et al., 2019)), and patient-to-provider communication (eg, increased interactions between patients and HCPs (Barello et al., 2016; Barken et al., 2019; Brigden et al., 2020; Cox et al., 2017; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Greenhalgh & Shaw, 2017; Jalil et al., 2015; O'Keefe et al., 2021; Palacholla et al., 2019; Rising et al., 2018; Simen A Steindal et al., 2020)). Clinical outcomes are related to individual health conditions and the main intentions of the DHIs. For example, a reduction in anxiety, depression, and stress (Barello et al., 2016; Brigden et al., 2020; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Jalil et al., 2015; Jones & Grech, 2016; Lattie et al., 2019; Lemon et al., 2020; Leonardsen et al., 2020; Morton et al., 2017; O'Keefe et al., 2021; Palacholla et al., 2019; Rincon et al., 2017; Simen A Steindal et al., 2020; Stokke, 2016; Wesselman et al., 2019) and increased symptom control (Barello et al., 2016; Chaudhry et al., 2021; Greenhalgh & Shaw, 2017; Jalil et al., 2015; Molina-Recio et al., 2020; Morrison et al., 2014; Morton et al., 2017; Rincon et al., 2017; Simen A Steindal et al., 2020) can help to measure the individual health conditions.

Health Care System Impact

Health care system impact contains 1 theme and 2 subthemes. Economic outcomes refer to the cost-effectiveness and health care services use. In terms of cost-effectiveness, for example, studies report less out-of-pocket expenses for patients because of reduced care and travel costs (M. F. De La Cruz Monroy & A. Mosahebi, 2019; Greenhalgh & Shaw, 2017; Liddy et al., 2016; Morrison et al., 2014; O'Keefe et al., 2021; Palacholla et al., 2019; Rising et al., 2018; Slater et al., 2017; Rachael C Walker et al., 2019) and greater time efficiency owing to shorter waiting, travel, and consultation time (Chaudhry et al., 2021; Cox et al., 2017; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Ingemann et al., 2020; Jones & Grech, 2016; Liddy et al., 2016; Swanepoel & Hall III, 2010). Furthermore, indicators related to health care service use, such as the reduced number of hospital (Jones & Grech, 2016; Leonardsen et al., 2020; Liddy et al., 2016; Morrison et al., 2014; Palacholla et al., 2019) and emergency department visits (Liddy et al., 2016; Morrison et al., 2014), can be used to assess savings regarding health care services.

3.3.5. Evaluation Approaches

Overview of the Approaches

In addition to evaluation timing considerations and indicators, strategies and specifically designed tools for collecting and analyzing data are required to set up the evaluation plan. Various evaluation approaches were identified based on our initial codes; these are depicted in 3 aspects (Tables 3-7, 3-8, 3-9): study designs, data collection methods and instruments, and data analysis approaches. Furthermore, we collected data related to evaluation theories that were used to guide the study designs, data collection, and analysis.

Table 3-7. Study designs for evaluating the digital patient experience.

Study designs	Studies, n (%)	References
Mode of inquiry (n=36, 80%)	(%08	
Qualitative research	35 (78)	(Ames et al., 2019; Barello et al., 2016; Barken et al., 2019; Bashi et al., 2020; Brigden et al.,
 Phenomenology 		2020; Brunton et al., 2015; Chaudhry et al., 2021; Cox et al., 2017; M. F. De La Cruz Monroy
 Ethnography 		& A. Mosahebi, 2019; Eze et al., 2020; Feather et al., 2016; Firth & Torous, 2015; Greenhalgh
		& Shaw, 2017; Ingemann et al., 2020; Jalil et al., 2015; Jones & Grech, 2016; Lattie et al.,
		2019; Lemon et al., 2020; Leonardsen et al., 2020; Liddy et al., 2016; Lim et al., 2019; Molina-
		Recio et al., 2020; Morrison et al., 2014; Morton et al., 2017; Palacholla et al., 2019; Rising et
		al., 2018; Sakaguchi-Tang et al., 2017; Slater et al., 2017; Søgaard Neilsen & Wilson, 2019;
		Simen A Steindal et al., 2020; Stokke, 2016; Swanepoel & Hall III, 2010; Rachael C Walker et
		al., 2019; Yanxia Wei et al., 2020; Wesselman et al., 2019)
Quantitative research	21 (47)	(Bashi et al., 2020; Brunton et al., 2015; Chaudhry et al., 2021; Eze et al., 2020; Feather et al.,
		2016; Firth & Torous, 2015; Greenhalgh & Shaw, 2017; Ingemann et al., 2020; Jones & Grech,
		2016; Lemon et al., 2020; Leonardsen et al., 2020; Liddy et al., 2016; Lim et al., 2019; Molina-
		Recio et al., 2020; Morrison et al., 2014; Palacholla et al., 2019; Sakaguchi-Tang et al., 2017;
		Søgaard Neilsen & Wilson, 2019; Simen A Steindal et al., 2020; Stokke, 2016; Yanxia Wei et
		al., 2020)
Mixed methods	17 (38)	(Ames et al., 2019; Brunton et al., 2015; Feather et al., 2016; Greenhalgh & Shaw, 2017;
research (and multiple		Ingemann et al., 2020; Jones & Grech, 2016; Lemon et al., 2020; Leonardsen et al., 2020;
methods research)		Liddy et al., 2016; Lim et al., 2019; Morton et al., 2017; O'Keefe et al., 2021; Sakaguchi-Tang
		et al., 2017; Slater et al., 2017; Simen A Steindal et al., 2020; Stokke, 2016; Yanxia Wei et al.,
		2020)
Nature of the investigation (n=33, 73%)	ion (n=33, 73%)	
	•	

Table 3-7. Study designs for evaluating the digital patient experience (continued).

Study designs	Studies, n (%)	References
Experimental research	25 (56)	(Ames et al., 2019; Barello et al., 2016; Bashi et al., 2020; Brigden et al., 2020; Brunton et
 Randomized 		al., 2015; Chaudhry et al., 2021; Choi et al., 2020; M. F. De La Cruz Monroy & A. Mosahebi,
controlled trials		2019; Eze et al., 2020; Feather et al., 2016; Greenhalgh & Shaw, 2017; Jones & Grech, 2016;
 Nonrandomized 		Kuijpers et al., 2013; Lattie et al., 2019; Leonardsen et al., 2020; Liddy et al., 2016; Morrison
trials		et al., 2014; Morton et al., 2017; O'Keefe et al., 2021; Palacholla et al., 2019; Rincon et al.,
		2017; Rising et al., 2018; Søgaard Neilsen & Wilson, 2019; Simen A Steindal et al., 2020;
		Stokke, 2016; Swanepoel & Hall III, 2010)
Observational research	9 (20)	(Ames et al., 2019; Brunton et al., 2015; Choi et al., 2020; Greenhalgh & Shaw, 2017; Jones &
		Grech, 2016; Kuijpers et al., 2013; Liddy et al., 2016; Lim et al., 2019; Swanepoel & Hall III,
		2010)
Descriptive research	7 (16)	(Firth & Torous, 2015; Liddy et al., 2016; Sakaguchi-Tang et al., 2017; Slater et al., 2017;
 Case reports 		Simen A Steindal et al., 2020; Swanepoel & Hall III, 2010; Yanxia Wei et al., 2020)
 Case series 		
 Cross-sectional 		
Analytical research	6 (13)	(Choi et al., 2020; Greenhalgh & Shaw, 2017; Liddy et al., 2016; Sakaguchi-Tang et al., 2017;
 Case control 		Simen A Steindal et al., 2020; Werder, 2015)
 Cohort 		

Case control	Simen A Steindal et al., 2020; Werder, 2015)
Number of contacts (n=21	1,47%)
Cross-sectional	(Firth & Torous, 2015; Liddy et al., 2016; Sakaguchi-Tang et al., 2017; Slater et al., 2017;
	Swanepoel & Hall III, 2010; Yanxia Wei et al., 2020)

Table 3-7. Study designs for evaluating the digital patient experience (continued).

Study designs	Studies, n (%) References	References
Longitudinal	6 (13)	(Cheung et al., 2019; Leonardsen et al., 2020; Sakaguchi-Tang et al., 2017; Simen A Steindal et al., 2020; Stokke, 2016; Rachael C Walker et al., 2019)
Before and after	4 (9)	(Brigden et al., 2020; Choi et al., 2020; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Feather et al., 2016; Fouquet & Miranda, 2020; Lattie et al., 2019; Leonardsen et al., 2020; Morrison et al., 2014; O'Keefe et al., 2021; Palacholla et al., 2019; Simen A Steindal et al., 2020; Swanepoel & Hall III, 2010; Wesselman et al., 2019)
Reference period (n=10, 2	22%)	
Prospective	8 (18)	(Choi et al., 2020; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Leonardsen et al., 2020; Liddy et al., 2016; Rincon et al., 2017; Simen A Steindal et al., 2020; Swanepoel & Hall III, 2010; Werder, 2015)
Retrospective	4 (9)	(Choi et al., 2020; Liddy et al., 2016; Slater et al., 2017; Stokke, 2016)
Research through design	ı (n=4, 9%)	
User research	3 (7)	(Choi et al., 2020; Fouquet & Miranda, 2020; Sakaguchi-Tang et al., 2017)
Participatory design or contextual design	1 (2)	(Jalil et al., 2015)
Design sessions	1 (2)	(Sakaguchi-Tang et al., 2017)

Table 3-8. Data collection methods of evaluating the digital patient experience.

Data collection	Studies, n (%)	References
methods		
Questionnaires	33 (73)	(Ames et al., 2019; Barello et al., 2016; Barken et al., 2019; Bashi et al., 2020; Brigden et al., 2020; Brunton et al., 2015; Cheung et al., 2019; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Feather et al., 2016; Fouquet & Miranda, 2020; Ingernann et al., 2020; Jalil et al., 2015; Jones & Grech, 2016; Kuijpers et al., 2013; Lattie et al., 2019; Lemon et al., 2020; Leonardsen et al., 2020; Liddy et al., 2016; Lim et al., 2019; Molina-Recio et al., 2020; Morrison et al., 2014; Palacholla et al., 2019; Rincon et al., 2017; Rising et al., 2018; Sakaguchi-Tang et al., 2017; Slater et al., 2017; Søgaard Neilsen & Wilson, 2019; Simen A Steindal et al., 2020; Stokke, 2016; Swanepoel & Hall III, 2010; Yanxia Wei et al., 2020; Wesselman et al., 2019)
Surveys	32 (71)	(Ames et al., 2019; Bashi et al., 2020; Brigden et al., 2020; Cheung et al., 2019; Cox et al., 2017; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Feather et al., 2016; Firth & Torous, 2015; Fouquet & Miranda, 2020; Ingemann et al., 2020; Jalil et al., 2015; Jones & Grech, 2016; Lattie et al., 2019; Lemon et al., 2020; Leonardsen et al., 2020; Liddy et al., 2016; Lim et al., 2019; Memon et al., 2014; Molina-Recio et al., 2020; Morrison et al., 2014; O'Keefe et al., 2021; Palacholla et al., 2019; Rincon et al., 2017; Rising et al., 2018; Sakaguchi-Tang et al., 2017; Sogaard Neilsen & Wilson, 2019; Simen A Steindal et al., 2020; Stokke, 2016; Swanepoel & Hall III, 2010; Yanxia Wei et al., 2020; Werder, 2015; Wesselman et al., 2019)
Interviews	31 (69)	(Ames et al., 2019; Barello et al., 2016; Barken et al., 2019; Brigden et al., 2020; Brunton et al., 2015; Choi et al., 2020; Cox et al., 2017; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Feather et al., 2016; Fouquet & Miranda, 2020; Ingemann et al., 2020; Jalil et al., 2015; Jones & Grech, 2016; Kuijpers et al., 2013; Lattie et al., 2019; Lemon et al., 2020; Leonardsen et al., 2020; Liddy et al., 2016; Lim et al., 2019; Memon et al., 2014; Molina-Recio et al., 2020; Morton et al., 2017; Sakaguchi-Tang et al., 2017; Slater et al., 2017; Søgaard Neilsen & Wilson, 2019; Simen A Steindal et al., 2020; Stokke, 2016; Swanepoel & Hall III, 2010; Rachael C Walker et al., 2019; Yanxia Wei et al., 2020; Wesselman et al., 2019)

Table 3-8. Data collection methods of evaluating the digital patient experience (continued).

Data collection	Studies, n (%)	References
methods		
Focus groups	19 (42)	(Ames et al., 2019; Bashi et al., 2020; Brigden et al., 2020; Brunton et al., 2015; Choi et al., 2020; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Fouquet & Miranda, 2020; Ingemann et al., 2020; Jones & Grech, 2016; Lim et al., 2019; Molina-Recio et al., 2020; Morton et al., 2017; O'Keefe et al., 2021; Sakaguchi-Tang et al., 2017; Slater et al., 2017; Sogaard Neilsen & Wilson, 2019; Stokke, 2016; Rachael C Walker et al., 2019; Yanxia Wei et al., 2020)
Observations	17 (38)	(Ames et al., 2019; Brunton et al., 2015; Choi et al., 2020; Fouquet & Miranda, 2020; Greenhalgh & Shaw, 2017; Ingemann et al., 2020; Jalil et al., 2015; Jones & Grech, 2016; Kuijpers et al., 2013; Liddy et al., 2016; Lim et al., 2019; Molina-Recio et al., 2020; Morton et al., 2017; Sakaguchi-Tang et al., 2017; Simen A Steindal et al., 2020; Swanepoel & Hall III, 2010; Rachael C Walker et al., 2019)
Log data	13 (29)	(M. F. De La Cruz Monroy & A. Mosahebi, 2019; Firth & Torous, 2015; Jalil et al., 2015; Kuijpers et al., 2013; Lemon et al., 2020; Memon et al., 2014; Morrison et al., 2014; Sakaguchi-Tang et al., 2017; Søgaard Neilsen & Wilson, 2019; Simen A Steindal et al., 2020; Stokke, 2016; Swanepoel & Hall III, 2010; Rachael C Walker et al., 2019)
Open-ended questions	10 (22)	(Ames et al., 2019; Barello et al., 2016; Brigden et al., 2020; Cox et al., 2017; Feather et al., 2016; Leonardsen et al., 2020; Lim et al., 2019; Molina-Recio et al., 2020; Slater et al., 2017; Wesselman et al., 2019)
Likert scales	10 (22)	(Bashi et al., 2020; Cheung et al., 2019; Feather et al., 2016; Kuijpers et al., 2013; Lattie et al., 2019; Liddy et al., 2016; Molina-Recio et al., 2020; Rincon et al., 2017; Simen A Steindal et al., 2020; Wesselman et al., 2019)
Usability testing	8 (18)	(Choi et al., 2020; M. F. De La Cruz Monroy & A. Mosahebi, 2019; Feather et al., 2016; Lattie et al., 2019; Molina-Recio et al., 2020; Palacholla et al., 2019; Søgaard Neilsen & Wilson, 2019; Wildenbos et al., 2018)

Table 3-8. Data collection methods of evaluating the digital patient experience (continued).

Data collection	Studies, n (%)	References
methods		
Diaries	6 (13)	(Ames et al., 2019; Feather et al., 2016; Morrison et al., 2014; Sakaguchi-Tang et al., 2017; Rachael C Walker et al., 2019; Yanxia Wei et al., 2020)
Contextual inquiry	5 (11)	(Ames et al., 2019; Feather et al., 2016; Fouquet & Miranda, 2020; Jalil et al., 2015; Slater et al., 2017)
Needs assessment	5 (11)	(Cox et al., 2017; Feather et al., 2016; Fouquet & Miranda, 2020; Lattie et al., 2019; Søgaard Neilsen & Wilson, 2019)
Performance tests	5 (11)	(Choi et al., 2020; Kuijpers et al., 2013; Lemon et al., 2020; Swanepoel & Hall III, 2010; Wesselman et al., 2019)
Field notes	4 (9)	(Brunton et al., 2015; Jalil et al., 2015; Slater et al., 2017; Rachael C Walker et al., 2019)
Workshops	4 (9)	(Lattie et al., 2019; Molina-Recio et al., 2020; Søgaard Neilsen & Wilson, 2019; Yanxia Wei et al., 2020)
Forms	3 (7)	(Feather et al., 2016; Lattie et al., 2019; Swanepoel & Hall III, 2010)
Think-aloud method	3 (7)	(Feather et al., 2016; Jalil et al., 2015; Yanxia Wei et al., 2020)
Benchmark testing	2 (4)	(Fouquet & Miranda, 2020; Lemon et al., 2020)
Human impact	1 (2)	(Stokke, 2016)
assessment		
methodologies		
Personas	1 (2)	(Fouquet & Miranda, 2020)

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Data analysis approaches	Studies,	References
	(%) u	
Statistical analysis	15 (33)	(Barello et al., 2016; Brigden et al., 2020; Chaudhry et al., 2021; Choi et al., 2020; Eze et al., 2020; Firth & Torous, 2015; Jones & Grech, 2016; Kuijpers et al., 2013; Lattie et al., 2019; Lemon et al., 2020; Liddy et al., 2016; Morrison et al., 2014; Simen A Steindal et al., 2020; Swanepoel & Hall III, 2010; Wesselman et al., 2019)
Thematic analysis	11 (24)	(Ames et al., 2019; Barken et al., 2019; Brunton et al., 2015; Cox et al., 2017; Greenhalgh & Shaw, 2017; Jalil et al., 2015; Jones & Grech, 2016; Lemon et al., 2020; Slater et al., 2017; Stokke, 2016; Rachael C Walker et al., 2019)
Content analysis	9 (20)	(Ames et al., 2019; Barken et al., 2019; Cox et al., 2017; Feather et al., 2016; Jones & Grech, 2016; Lim et al., 2019; O'Keefe et al., 2021; Slater et al., 2017; Rachael C Walker et al., 2019)
Grounded theory	7 (16)	(Ames et al., 2019; Barken et al., 2019; Brunton et al., 2015; Feather et al., 2016; Lemon et al., 2020; Slater et al., 2017; Rachael C Walker et al., 2019)
Framework analysis	5 (11)	(Ames et al., 2019; Barken et al., 2019; Brunton et al., 2015; Slater et al., 2017; Rachael C Walker et al., 2019)
Heuristic analysis	4 (9)	(Ames et al., 2019; Fouquet & Miranda, 2020; Lemon et al., 2020; Molina-Recio et al., 2020)
Cost analysis	4 (9)	(Eze et al., 2020; Greenhalgh & Shaw, 2017; Liddy et al., 2016; O'Keefe et al., 2021)
Task analysis	3 (7)	(Fouquet & Miranda, 2020; Lemon et al., 2020; Søgaard Neilsen & Wilson, 2019)
Text analysis	2 (4)	(Barken et al., 2019; Ingemann et al., 2020)
Document analysis	2 (4)	(Ames et al., 2019; Simen A Steindal et al., 2020)
Failure analysis	2 (4)	(Fouquet & Miranda, 2020; Søgaard Neilsen & Wilson, 2019)
Inductive analysis	2 (4)	(Slater et al., 2017; Rachael C Walker et al., 2019)
Deductive analysis	1 (2)	(Slater et al., 2017)
Formal analysis	1 (2)	(Memon et al., 2014)
Decision analytic approach	1 (2)	(Liddy et al., 2016)

Evaluation Theories

Our findings showed that in some cases, theories are used to guide the evaluation process. An included review (Bashi et al., 2020) mapped various DHI evaluation frameworks and models into conceptual, results, and logical frameworks as well as theory of change. Among the included reviews, the National Quality Forum (O'Keefe et al., 2021; Rising et al., 2018), UX model (Cheung et al., 2019), American Psychiatric Association App Evaluation Model (Lemon et al., 2020), Markov model (Greenhalgh & Shaw, 2017), and Consolidated Framework for Implementation Research (Slater et al., 2017) were mentioned as evaluation frameworks or models for setting up, conducting, or analyzing the evaluation activities. In addition, theories from other fields such as frameworks or models related to health care (eg. diabetes theory (Jalil et al., 2015; Slater et al., 2017), triple aims framework (Liddy et al., 2016), and chronic disease management model (Bashi et al., 2020)), behaviors (eg., social cognitive theory (Brigden et al., 2020; Cheung et al., 2019; Lattie et al., 2019), behavior change theory (Bashi et al., 2020; Brigden et al., 2020; Morrison et al., 2014)), design (eg., human factors principles (Fouquet & Miranda, 2020), and inclusive design (Wildenbos et al., 2018)), and technology (eg, the Unified Theory of Acceptance and Use of Technology (Palacholla et al., 2019; Wildenbos et al., 2018), and Health Information Technology Usability Evaluation Model (Molina-Recio et al., 2020)) can be adopted to assess specific outputs, outcomes, or impact. For example, the behavior change theory can be used to guide the evaluation of patient behavioral outcomes (Brigden et al., 2020).

Study Designs

The terminologies used to describe the study designs were mixed in terms of different classification bases. Following the work on research methodology by Kumar (Arora, 2011), we identified 4 standards for classifying study designs in DH: the perspectives of mode of inquiry, nature of the investigation, reference period, and number of contacts with the study population. From the perspectives of "mode of inquiry," we found 3 types of study. The first used a qualitative study design, such as phenomenology or ethnography studies. The second were quantitative studies. The third type used mixed methods research and multiple methods research (ie, >1 qualitative or quantitative method, such as using both focus groups and interviews to collect data). In addition, based on the nature of the investigation, the collected primary studies among the included reviews were reported as observational studies versus experimental studies (RCTs and nonrandomized trials) and descriptive studies (case reports, case series, and cross-sectional) versus analytical studies (case-control or cohort studies). On the basis of the number of contacts with the study population, cross-sectional, before-andafter, and longitudinal studies were mentioned. Furthermore, in terms of the reference period (the time frame in which a study explores a phenomenon, situation, event, or problem), some studies included prospective designs, whereas others reported retrospective study designs. In addition, we note that others reported study designs from a design perspective, such as user studies, participatory design or contextual design, and design sessions.

Data Collection Methods and Instruments

Various data collection methods were used among the included reviews: questionnaires, surveys, interviews, focus groups, observations, log data, open-ended questions, Likert scales, usability testing, diaries, contextual inquiry, needs assessment, performance tests, field notes, workshops, forms, think-aloud method, benchmark testing, human impact assessment methodologies, and personas. Notably, these data collection techniques appeared as a mixed combination in some studies. In addition, we found various standard evaluation tools and performance tests used to collect the digital PEx-related data in 18 of the included papers (Barello et al., 2016; Brigden et al., 2020; Chaudhry et al., 2021; Feather et al., 2016; Fouquet & Miranda, 2020; Jones & Grech, 2016; Kuijpers et al., 2013; Lattie et al., 2019; Lemon et al., 2020; Liddy et al., 2016; Molina-Recio et al., 2020; Rincon et al., 2017; Rising et al., 2018; Sakaguchi-Tang et al., 2017; Simen A Steindal et al., 2020; Werder, 2015; Wesselman et al., 2019; Wildenbos et al., 2018), including the System Usability Scale (Feather et al., 2016; Lattie et al., 2019; Lemon et al., 2020), Patient Activation Measure (Barello et al., 2016; Kuijpers et al., 2013), Patient Health Questionnaire-9 (Barello et al., 2016; Rincon et al., 2017), and Beck Depression Inventory (Barello et al., 2016; Rincon et al., 2017). However, none of these tools are designed for evaluating the digital PEx; most are designed or modified to evaluate UX, PEx in general, or the usability of specific DHIs.

Data Analysis Approaches

Our findings showed that different types of data were used to evaluate digital PEx, such as self-reported data (Firth & Torous, 2015) and observable or monitored data (Lemon et al., 2020). To analyze the evaluative information, various data analysis methods were reported among the included reviews, including statistical analysis, thematic analysis, content analysis, grounded theory, framework analysis, heuristic analysis, cost analysis, task analysis, text analysis, document analysis, failure analysis, inductive analysis, deductive analysis, formal analysis, and decision analytic approach.

3.4. Discussion

3.4.1. Principal Findings

The goals of this umbrella review were to systematically review the evaluation timing considerations, indicators, and approaches of digital PEx. Furthermore, we identified 5 typical evaluation objectives and related audiences. The timing of a digital PEx evaluation should be a critical consideration when conducting an evaluation study; however, we found limited information about when to measure digital PEx. Moreover, the identified evaluation indicators are often heterogeneous and appear to be related to the different aspects of digital PEx. In terms of evaluation approaches, various theories were reported in the included papers. Furthermore, we noted that not only did the evaluation methods differ between the reviews but also the classification bases or perspectives used to describe these methods. Following our findings on when to measure, what to measure, and how to measure digital PEx, we generated a step-by-step evaluation guide and proposed 6 research directions for

future studies.

3.4.2. When to Measure

DHIs change throughout the product life cycle, so to provide better-quality results and evidence-based health practice, evaluations need to be incorporated into the intervention maturity stages (Ames et al., 2019; Bashi et al., 2020; Sakaguchi-Tang et al., 2017; Slater et al., 2017). Our findings showed that many studies were not performed in a real-world setting for a long period, and most studies were either feasibility or pilot studies; these results are directly in line with previous findings (Brunton et al., 2015; Lattie et al., 2019; Memon et al., 2014; Rincon et al., 2017; Slater et al., 2017; Rachael C Walker et al., 2019; Wesselman et al., 2019). Pilot or feasibility studies can help improve new intervention development but only provide limited evidence for increasing sustained clinical use and large-scale practice (Ames et al., 2019; Bashi et al., 2020). Two studies (Cox et al., 2017; Sakaguchi-Tang et al., 2017) reported a lack of information on the long-term experience. Others have shown that some solutions may be less sustainable outside the trial context (Cox et al., 2017; Sakaguchi-Tang et al., 2017). In addition, it is possible that participants were more adherent during the study period and decreased their use of the apps over time (Firth & Torous, 2015). Therefore, some authors call for further research on digital PEx when incorporating the DHIs into existing health care services and processes (Jones & Grech, 2016); there is a need to move DHIs from promise into policy and practice (Slater et al., 2017).

One study (Swanepoel & Hall III, 2010) reported significantly different evaluation results before and after the treatment. It is likely that patients' initial emotional state or understanding of DHIs may affect their final PEx evaluation outcomes. Therefore, a baseline test on individual differences would be a valuable step to limit evaluation bias, as noted in a previous study (Kuijpers et al., 2013). We found that the data gathered could occur at a specific moment or at different time points along the care pathway to reflect a rapid or delayed digital PEx. Thus, posttreatment evaluations should account for the recall bias caused by the time delay between treatment and recollection of experience, as has been noted in previous studies (Feather et al., 2016; Jones & Grech, 2016). In line with other studies (Palacholla et al., 2019; World Health Organization, 2016b), we believe that real-world testing and direct feedback from actual users will help improve the usability of DHIs and directly benefit new users.

3.4.3. What to Measure

In comparison with intervention outputs and health care system impact, we discovered more evaluation indicators related to patient outcomes. we assume that this is owing to the consideration of the strength of the evidence and duration of the study. Patient outcomes enable the identification of patients' actual experiences and reactions in uncontrolled settings, providing evidence for clinical use and further improvements. However, intervention outputs seem more suitable for exploring experts' (eg, designers, health care professionals, and policymakers) or patients' anticipated understandings of DHIs in the early stages of design

and for addressing any potential system barriers. The health care system impact can be useful in predicting the sustainability of the DHIs on a large scale through a long-term study.

We used a set of themes and subthemes to describe each category. For instance, patient outcomes include emotional, perceptual, capability, behavioral, and clinical outcomes, as noted in 2 studies (Barello et al., 2016; Choi et al., 2020): one study categorized the variables of patient engagement as behavioral, cognitive, and emotional outcomes, whereas the other study used biomarkers, perceptions, and behaviors to describe patient clinical outcomes with regard to DHIs. Furthermore, we noted that the evaluation outcome of one indicator is often unable to anticipate the outcome of another indicator. For instance, some patients reported high acceptance of a certain DHI, but they rarely used it (Stokke, 2016). Aligned with the arguments among the differences between patient satisfaction, PEx, PREMs, and PROMs (Coulter et al., 2009; Kingsley & Patel, 2017; LaVela & Gallan, 2014; Rockville, 2016), our findings indicate that digital PEx evaluations are not equivalent to the measurement of patient satisfaction, PEx, PREMs, or PROMs, but that these measures can be used to assess some of the digital PEx. We showed that the priorities of the evaluation indicators can differ between projects. In terms of what to measure first, as stated in a previous study (Labrique et al., 2018), the goal of evaluations should be to focus on those processes that should be optimized by the digital catalyst. Furthermore, the evaluation indicators need to be continually updated as the DH landscape is rapidly evolving and the technology infrastructure is constantly shifting (Baumel et al., 2017).

3.4.4. How to Measure

As demonstrated in an included review (Bashi et al., 2020), an evidence-based theoretical evaluation framework is helpful in informing the evaluation process. Across the included reviews, we found that not only specifically designed evaluation theories were used to guide the evaluation activities but also theories from other fields were adopted to assess the evaluative data. we identified various traditional approaches Across the included reviews. In addition, our results showed that more than half of the included reviews reported RCTs in their studies. RCTs were recommended in 2 reviews (Chung et al., 2009; Song & Chung, 2010) to evaluate DHIs for stronger evidence. However, a recent systematic review (Pawloski et al., 2019) noted that only a handful of clinical decision support systems have been tested in this way. Others argued that there is a tension between the amount of time needed for evidence generation with traditional approaches and the speed of digital product development and iterative upgrading (Desveaux et al., 2017; Guo et al., 2020), which requires more innovative methods for fast evidence generation (Guo et al., 2020).

We identified a wide range of evaluation methods and instruments, although most were modified based on the evaluations for traditional face-to-face treatment or usability testing in human-computer interactions. This is also in line with the findings from previous studies (Feather et al., 2016; Lemon et al., 2020; Rising et al., 2018; Swanepoel & Hall III, 2010).

Semistructured interviews and questionnaires were the most common evaluation methods for collecting evaluative data among the included reviews, which is in line with previous studies (Feather et al., 2016; Jones & Grech, 2016). Semistructured interviews are the key methods used to understand the details of UX (Brigden et al., 2020; Ingemann et al., 2020; Lemon et al., 2020; Leonardsen et al., 2020; Wesselman et al., 2019), whereas questionnaires are often modified from existing assessments to assess large-scale interventions (Feather et al., 2016; Lemon et al., 2020). It is likely that more in-depth, observational data collection methods are necessary to better capture experience data (Feather et al., 2016; Ingemann et al., 2020). The use of a descriptive approach might be appropriate for a smaller sample size, collecting qualitative data through surveys, focus groups, and interviews (Jones & Grech, 2016). Standard functional questionnaires may be preferred when DHIs are compared with other interventions (Feather et al., 2016). However, we found that detailed interview outlines or questionnaires were generally not published, as mentioned in another study (Feather et al., 2016). Comprehensive information on user evaluation methods and results is often lacking (Wesselman et al., 2019). The determination of evaluation approaches depends on the specific context. In alignment with 2 studies [4, 40], we state that the choice of evaluation approaches heavily depends on evaluation objectives, timing, indicators, and evaluation requirements and resources. An included review (Bashi et al., 2020) recommended using multiple research methods, such as combining qualitative, quantitative, co-design principles, and process measures, for evaluation designs.

Thanks to the use of digital technologies (Barello et al., 2016; Baumel et al., 2017), patients' illness experience and what they feel when participating in a health care intervention can be monitored. However, we found that these may blur the boundaries between interventions, monitoring, and evaluations. For example, the diary function can be used as an intervention feature (eg, a self-management diary to track symptoms and identify exacerbations (Morton et al., 2017)), as a monitoring tool (eg, diary entries (Rachael C Walker et al., 2019) or adherence (Morrison et al., 2014)), or as an evaluation method (eg, to capture user feedback (Feather et al., 2016)). Furthermore, a study indicated that with the advancement of technology, the ability of DHIs to collect "passive data" for assessing digital PEx may gain more attention and eventually eclipse the utility of DH-aided self-report (Firth & Torous, 2015). Finally, we believe that involving multiple stakeholders is not only essential in the design process but is also a requirement for the evaluation process. Both end users and experts can contribute to the evaluation activities (Feather et al., 2016). This aligns with a recent study that suggests that digital solution evaluation requires collective efforts from multiple parties, such as health authorities, HCPs, and manufacturers (Guo et al., 2020).

3.4.5. Design Implications

Our analysis showed that the evaluation of a DHI follows the same evaluative process as that of traditional interventions, which supports a previous study (Feather et al., 2016). To make the evaluation findings more comparable, more rigorous studies and standardized

evaluations are suggested, including unified terminology (Feather et al., 2016; Yanxia Wei et al., 2020; Wesselman et al., 2019), predefined measurable indicators (M. F. De La Cruz Monroy & A. Mosahebi, 2019; Rising et al., 2018), standardized methods (Ingemann et al., 2020; Lemon et al., 2020), validated instruments (Chaudhry et al., 2021; Kuijpers et al., 2013), uniform time intervals (Kuijpers et al., 2013), and adequate patient selection (M. F. De La Cruz Monroy & A. Mosahebi, 2019). Intervention characteristics (eg, aims, expected outcomes, elements, length, frequency, and duration), study designs (eg, sample size, period, regulations, investigator, evaluators, recruitment, ethics, topic guides, or questions asked by the researchers), objectively measured patient health outcomes, and adverse events should be carefully considered when conducting and reporting an evaluation study (Choi et al., 2020; Feather et al., 2016; Jalil et al., 2015; Kuijpers et al., 2013).

Inspired by the challenges for the evaluation of DHIs (Guo et al., 2020); shaped by the Performance of Routine Information System Management framework (Agil et al., 2009), the monitoring and evaluation DHIs guide (World Health Organization, 2016b), PEx measures (Coulter et al., 2009), and our previous publications on influencing factors and design considerations of digital PEx (Tingting Wang, Guido Giunti, et al., 2022a, 2022b); and based on the findings of this study, we have developed a step-by-step evaluation guide for DH innovators, such as designers, developers, and evaluators (Figure 3-2): The first step is to clarify the evaluation objectives and determine the target audiences for the evaluation. We proposed 5 typical evaluation purposes and their related audiences. The selection of evaluation objectives can help determine the stages for evaluating the DHI. For example, we consider effectiveness and implementation studies more appropriate for achieving evidence-based clinical use and increasing adoption and uptake compared with efficacy studies. The second step is to determine the intervention contexts and foci in terms of the intervention maturity stages, including efficacy, effectiveness, and implementation. The determination of the evaluation stage is not only because of the evaluation objective but also because of the current condition of the DHI. The determination of the evaluation objectives and identification of the evaluation stage affect the consideration of influencing factors and evaluation indicators at the next step. For example, the evaluation of patient outcomes in an uncontrolled setting can provide evidence for clinical use and further improvement. The third step includes a set of influencing factors (ie, inputs and processes) and evaluation indicators (ie, outputs, outcomes, and impacts) that can be used for further formulating evaluation constructs. The former is more appropriate for formative evaluations, which often occur during the design and development process, whereas the latter is suitable for summative evaluations, which often occur during and after the implementation process. In the fourth step, we present 2 types of evaluations. On the basis of the frequency of evaluations, we can capture momentary experiences before, during, and following an intervention or monitor continuous feedback throughout the intervention. With regard to the time interval between the intervention and evaluation, assessments can reflect immediate experiences directly after the intervention or recalled experiences over an extended period. In the fifth step, we present

various evaluation approaches that can be used to plan and carry out specific evaluation activities, such as study designs, data collection methods and instruments, and data analysis approaches. The consideration of study designs often affects the strength of the evidence and determines the data collection and analysis methods. Behavioral data may provide stronger evidence than opinion data. Qualitative methods, such as interviews, are more appropriate for collecting in-depth experience data for a smaller sample size in the early intervention development stages, and quantitative methods, such as questionnaires, are more suitable for investigating experience data at a large scale or comparing it with other interventions during or after the implementation stages. In the sixth step, we proposed 6 questions for the evaluation investigators to guide them in reporting the evaluation results and 5 questions to inspire them to generate theoretical or practical implications for responding to the related stakeholder groups. The answers to these 11 questions should reflect the evaluation processes and serve the evaluation objectives.

The guide can be used when setting up a digital PEx evaluation plan or guiding evaluation practice. Notably, the interrelationships between these 6 steps are not fixed; the entire evaluation plan is an iterative process; and the decisions made at the previous steps may influence the following steps, and vice versa. In addition, other considerations beyond this guide can also impact the evaluation process, such as human, time, and financial resources. Our guide presents an ideal way to conduct the evaluation of digital PEx; however, in the real world, the order of these steps may be changed or some steps may even be skipped depending on the specific project context. For instance, in certain assessment procedures, selecting an evaluation construct, such as usability, may come first, rather than taking evaluation objectives or target audiences into account. We developed this guide based on our literature analysis. It provides an overview of the most common evaluation timing considerations, indicators, and approaches used to collect digital PEx-related data. However, it may be incomplete and require updating in the future. For example, owing to the methodological limitations, we did not provide concrete recommendations on which evaluation approaches are superior for what types of DHIs. We believe that without providing a specific context and concrete project requirements, it is difficult to draw a conclusion.

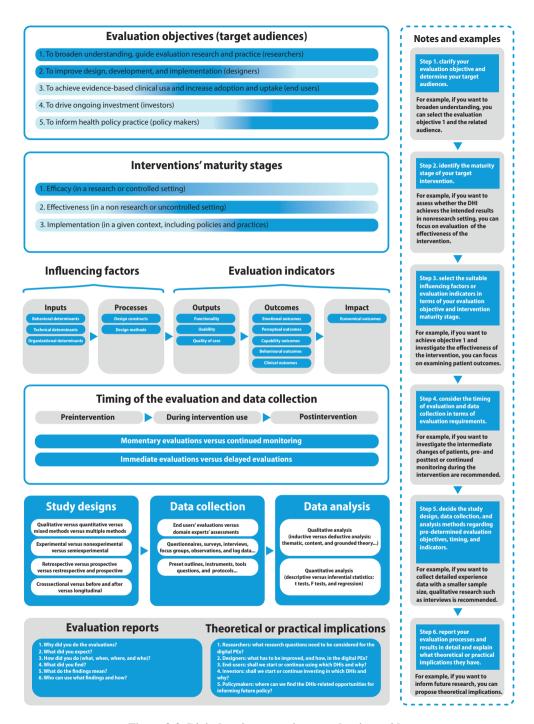


Figure 3-2. Digital patient experience evaluation guide.

3.4.6. Limitations

This study had several limitations. First, we noted possible resource restrictions and the newness of the field, which may have led to missing articles. To overcome this, we searched 3 databases and used the snowballing method. In addition, we performed an updated literature search to check whether there were any meaningful new insights that would significantly change our conclusions. To our knowledge, although there were some newly published reviews in this area, we confirmed that our results were quite stable, and the newly identified studies were unlikely to significantly impact our results. Second, we could not perform a quality assessment because of the diversity in reviews and methodological limitations. As previous studies on investigating umbrella reviews have indicated, there are currently no official standards for determining the certainty of evidence when performing umbrella reviews (Choi & Kang, 2023; Sadoyu et al., 2022). In addition, among the included reviews, only 53% (24/45) of the studies assessed the risk of bias and used diverse quality assessment instruments. After a thorough attempt, we found that none of these instruments were suitable for assessing the various reviews included. These encompass systematic reviews, scoping reviews, comprehensive overviews, and general literature reviews, which incorporate various primary and secondary studies extending beyond RCTs and nonrandomized studies of interventions. This diversity makes it challenging to use a standardized method for assessing the quality of evidence across the extensive range of included reviews. However, we tried to reduce the risk of bias by only including reviews that were published in peer-reviewed journals. Third, reviewing secondary research may have led to the omission of crucial information and reporting bias. To minimize potential bias, we used the most common terms used across the included papers as themes and subthemes. Owing to the cross-disciplinary nature of the topic, there is a lack of consistency or clarity in the terminology used to describe the evaluation indicators and approaches. For instance, in one study (Sakaguchi-Tang et al., 2017), a user study was pitched at the same level as interviews or observations, whereas in another study (Slater et al., 2017), interviews and questionnaires are methods that form part of "user study" research. In addition, information related to the evaluation approaches was reported at different levels among the included studies. For example, one study provided information related to data collection methods, such as focus groups, design sessions, and questionnaires (Sakaguchi-Tang et al., 2017), whereas another study reported information related to study designs, including qualitative, quantitative, and mixed methods designs (S. A. Steindal et al., 2020). These inconsistencies complicated the comparison between different studies. To counter this, we analyzed the different classification bases behind these study designs. Finally, we could not draw firm conclusions regarding which evaluation approaches are better suited for which types of DHIs. Owing to the nature of this study being a review of reviews, details such as the characteristics of DHIs are not always adequately covered in each included review. In addition, the included reviews contained a large number of primary studies, which makes referring back to each primary study challenging. The lack of details about the characteristics of these primary studies limits the classification of DHIs in this study. Moreover, the included reviews represent a wide range of studies, making comparison

across the included reviews challenging. In addition, we decided that this was out of the scope of this study. When planning this study, we deemed it more appropriate to initially offer an overview of diversities rather than begin with a best practice recommendation. Consequently, we aimed to map possible evaluation considerations and approaches for evaluating digital PEx, instead of discussing which approach is better. However, we encourage future research to address this issue.

3.4.7. Future Research

Considering our research limitations, to further facilitate evaluations of digital PEx, we propose 6 future research directions. First, further research into how one indicator mediates another indicator's impact on digital PEx is required. For example, is there a correlation between clinical outcomes and perceptual outcomes? To explore this, we performed an experimental study to investigate whether patients' initial pain perception and technology acceptance (using virtual reality distraction) affected their experienced pain during wound care treatment. Our findings will be published in a future article. Second, the variables that influence the selection or prioritization of evaluation indicators and approaches should be further investigated. For example, it would be valuable to investigate whether some evaluation indicators and approaches are better suited for evaluating certain types of DHIs according to the strength of the evidence and the length of the evidence generation time. Third, agreement is needed on standardized measures to evaluate digital PEx, particularly innovative approaches for faster and high-quality evidence generation. In a follow-up interview study, we aim to summarize the often-used agile evaluation approaches based on designers' experiences. Furthermore, in cases where an interview or questionnaire is used to collect evaluative information, we recommend reporting the detailed interview outlines or questionnaires together with the evaluation results. Fourth, research is needed on how the intervention maturity stages and timing of the evaluation of the evaluation affect the evaluation results. Fifth, future studies should not only investigate whether DHIs achieve the intended results in a research setting but also assess the long-term digital PEx regarding the uptake, institutionalization, and sustainability of evidence-based DHIs in a given context and a real-world setting, including policies and practices. Finally, research is required on how to analyze and respond to the evaluative data. We recommend that future evaluation research and practice provide theoretical and practical guidance on how to use the evaluative information.

3.5. Conclusions

To effectively improve the digital PEx, knowing how to evaluate the digital PEx is as important as knowing what factors influence the digital PEx and how to design the digital PEx. Evaluating digital PEx requires clarifying the evaluation objectives, identifying stakeholder groups, considering reasonable evaluation timings, choosing relevant evaluation indicators, and selecting appropriate evaluation approaches. Following our previous publication on the influencing factors and design considerations of digital PEx (Tingting

Wang, Guido Giunti, et al., 2022b), we first identified 5 typical evaluation objectives and related stakeholder groups. We then described potential evaluation timing considerations in terms of 4 intervention maturity stages and 3 evaluation timings. We collected knowledge on evaluation indicators of digital PEx and grouped them into 3 categories: intervention outputs, patient outcomes, and health care system impact. These were then classified into 9 themes (intervention functionality, usability, care quality, patient emotional outcomes, perceptual outcomes, capability outcomes, behavioral outcomes, clinical outcomes, and system financial outcomes) and 22 subthemes. Furthermore, we noted a set of common study designs, data collection methods and instruments, as well as data analysis methods, which can be used or adapted to evaluate digital PEx. On the basis of our findings, we developed an evaluation guide to help DHI researchers, designers, and developers further evaluate digital PEx. Finally, we recommend 6 directions for further research on digital PEx evaluation. Multimedia Appendix 5 (see in our publication online, the PRISMA checklist) provides more detail on the structure of this review.

Lessons for doing a PhD 03 Design Your Doctoral Path.

"Learning by doing" is a great way to start a new study—provided you know what to do and where to learn. However, it's not uncommon to feel unsure of the next steps or where to acquire the knowledge you need. In such cases, I strongly recommend taking doctoral education courses to systematically learn new concepts or gain clarity about your direction.

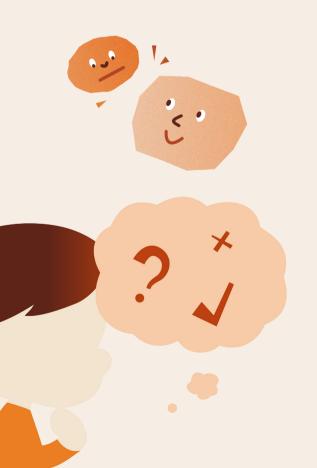
In my second year, for example, I took a course on "Experimental Research" by Dr. Femke van Horen at Vrije Universiteit Amsterdam. Initially, I didn't expect much beyond gaining a better understanding of quantitative research. To my surprise, the course not only opened my mind but also introduced me to the world of experimental studies. Thanks to this course, I co-conducted two prospective observational studies evaluating digital patient experiences in collaboration with Erasmus MC. While the course didn't make me an expert overnight, it gave me the confidence to tackle a new research method I had never tried before.

In addition, as a PhD candidate at TU Delft, I have greatly benefited from the university's well-structured Doctoral Education Programme. This program is carefully designed around three core pillars: research skills, discipline-related skills, and transferable skills. By focusing on these areas, the program not only equips junior researchers with the expertise needed for their specific projects but also fosters the broader skills essential for success in both academic and professional environments. For instance, research skills courses focus on methodologies, ethics, and academic writing, while discipline-related courses deepen subject-specific knowledge. Transferable skills courses, such as public speaking, project management, and networking, prepare candidates for challenges beyond academia. The variety of courses allows me to tailor my learning to my individual research needs and career aspirations. One important piece of advice I received from my supervisors and senior PhDs was not to rush through all the doctoral education courses in the first year. Instead, align the courses with your research progress and needs. For example, when I was preparing for an interview study. I enrolled in a course on "how to design questionnaires and conduct interviews." This allowed me to immediately apply what I learned in my research. At the same time, I could consult the course lecturers when I encountered challenges, which was immensely helpful.

Pursuing a PhD in design is both a structured and highly individual journey. On the one hand, we all work within a set timeline to complete our research, develop our skills, and make both scientific and social contributions. On the other hand, each person's approach to their PhD is unique. Some start with an in-depth literature review, while others begin with an experimental study. The PhD journey requires balancing structured learning with handson research. Your learning path should adapt to your research needs and progress. Taking the right course at the right time can significantly enhance your confidence and capabilities. Consult your supervisors or experienced peers to select courses that align with your research goals. Remember that the PhD is not just about completing a dissertation—it's also about

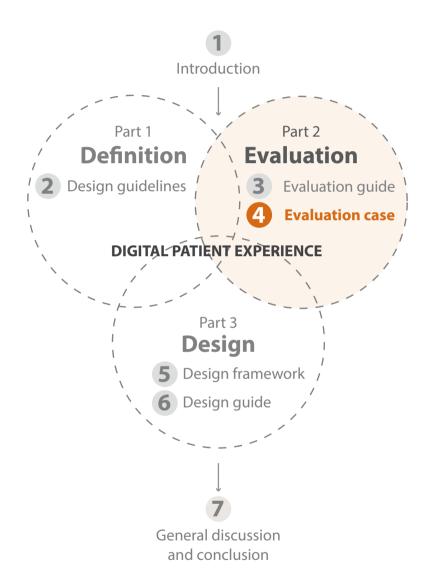
growing as a researcher, learner, and contributor to your field and society.





Chapter 4

Evaluation Case: VR Distraction in Wound Care for Pain Management



The content of this chapter is to be submitted to:

Wang, T.*, Jesse He*, Oest, M., Dekker E., Goetzee, C., Roodenburg, Y., Goossens R, Melles M., Corten E. Evaluating the Digital Patient Experience of Virtual Reality Distraction in Wound Care: a Prospective Observational Study. The manuscript is to be submitted to a peer-reviewed medical journal.

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Abstract

Background:

Virtual Reality (VR) distraction can reduce anxiety and pain in patients during medical procedures. This study aimed to investigate which patients are more willing to use VR distraction in wound care, determine if VR distraction could reduce anxiety and pain in wound care, and evaluate the digital patient experience of using VR distraction in wound care.

Methods:

A prospective observational study was performed with patients receiving in-hospital wound care at a tertiary referral hospital using VR as distraction. Questionnaires before and after wound care were used to measure patient-reported experiences and outcomes. The primary outcome was intention to use VR distraction. Secondary outcomes were pain and anxiety levels.

Results:

96 patients were included in the study. 66% of the patients chose to use VR distraction in their wound care. Patients' intention to use VR distraction in wound care was positively associated with technology acceptance (F(1, 94)=32.49, β =0.507, SE=0.117, p<.001) and higher pain scores in preoperative wound care (F(1, 77)=7.08, β =0.290, SE=0.040, p=.009). The use of VR distraction had no significant influence on reducing pain (F(1,76)=.08, p=.779, partial η 2=.001), nor on reducing anxiety (F(1,76)=.43, p=.515, partial η 2=.006). The average score of digital patient experience after using VR distraction was 3.8 (SD 0.8), which was an improvement from the anticipated digital patient experience score of 3.6 (SD 0.6). Both scored above the midpoint (score =3).

Conclusion and discussion:

We found that patients who had high levels of technology acceptance, pain during previous wound care, or previously used VR distraction in wound care were more willing to use VR distraction in wound care. No evidence was found on the effectiveness of VR distraction in reducing pain or anxiety during wound care. On average, digital patient experience and patient satisfaction with using VR distraction in wound care were positive.

Keywords:

patient experience; digital health; human factors; virtual reality distraction; patient-centered care

4.1. Introduction

4.1.1. Background

Wound care can be a painful and stressful experience for patients. Inadequately managed pain during medical procedures may lead to longer treatment periods, increased need for pain medication, extended hospitalization, and need for anesthesia in the operating room (Bechert & Abraham, 2009), which may further impact patient health outcomes (Wells et al., 2008), satisfaction (Hanna et al., 2012) and quality of life (Lamé et al., 2005). How patients experience wound care is the result of a combination of factors, such as the cause of the wound, pain expectation and perception, and reaction to a pain stimulus (Merskey & Bogduk, 1994; Sussman & Bates-Jensen, 2007). Pain perception is affected by negative thoughts about pain. These can be anticipation to pain, anxiety, fear, attention, understanding, control, expectations, and aversion (Briggs, 2004; McGrath, 1994; Vlaeyen & Linton, 2000).

Virtual Reality (VR) distraction is considered a promising psychological therapy for the reduction of pain, anxiety, and stress experienced during medical procedures (Eijlers et al., 2019; Hendricks et al., 2020; Iannicelli et al., 2019; Patterson et al., 2006; Pourmand et al., 2018; Scapin et al., 2018). VR distraction does not only show the possibility to reduce the time of painful procedures and duration of hospitalization, it also favors epithelization of the injury, increases fun and enjoyment (Scapin et al., 2018), and improves the overall patient experience (Hendricks et al., 2020). Delshad et al. indicated that VR therapy for pain among hospitalized patients was cost-saving when hospitalization was reduced by $\geq 14.6\%$ (Delshad et al., 2018). Mazaheri et al. found that VR shows promise in reducing acute pain and improves patient experiences in wound care(Mazaheri et al., 2023). Aside from possible side effects (e.g., presence of nausea, perceived less steadiness) (Hendricks et al., 2020), existing studies show promising results for the use of VR in both acute and chronic pain management (Pourmand et al., 2018). In addition, some studies found that expectations of performance and effort, social influence, facilitating conditions, attitude, and anxiety of patients towards the technology determine their technology acceptance (Venkatesh et al., 2003; Yousef et al., 2021), which may play an important role in their intention to use VR during wound care and impact patient experiences. Besides, Mithal et al. reported that patients who preferred to look away from the needle during vaccination had higher fear scores than those who preferred to look at the needle (Mithal et al., 2018); therefore, we assume that the patient's needlelooking preference and behavior during vaccination may be associated with their intention to use and experiences of VR distraction in wound care. However, we found little research on investigating whether these factors will and how influence patients' intention to use and experiences of VR distraction in wound care.

Applying VR technology in wound care is affecting the overall patient journey, which ultimately leads to a digital patient experience that may different from patient experience or user experience in general. In our previous study, we defined the digital patient experience as

"the sum of all interactions affected by a patient's behavioral determinants, framed by digital technologies, and shaped by organizational culture, that influence patient perceptions across the continuum of care channeling digital health" (Wang T, 2022). A positive digital patient experience can improve health and care outcomes, but more evidence needs to be generated to avoid over- or under-estimated results of and balance the benefits and costs of using VR distraction in wound care (T. Wang et al., 2022; Wang, Giunti, et al., 2024). Although many studies have investigated the effect of VR distraction on the reduction of pain in different medical procedures (Eijlers et al., 2019; Gupta et al., 2018; Iannicelli et al., 2019; Malloy & Milling, 2010), to our knowledge, the digital patient experience and factors that influence patient-reported experiences and outcomes of using VR distraction in wound care have not yet been evaluated. To bridge this gap, we aim to investigate which patients are more willing to use VR distraction in wound care, determine if VR distraction can reduce anxiety and pain in wound care, and evaluate the digital patient experience of using VR distraction in wound care.

4.2. Methods

4.2.1. Patient recruitment

Participants were recruited from the Wound Expertise Center at Erasmus Medical Center (EMC) in Rotterdam, the Netherlands from September 2022 until December 2023. The Wound Expertise Center covers all wound care for acute and chronic wounds for both inpatient and outpatient clinics. Inclusion criteria were patients receiving wound care, age of 18 years or older, physically able to wear a VR headset, and Dutch speaking. Patients were excluded if they could not view the VR content due to visual disability or if they were cognitively impaired.

4.2.2. Ethics approval and informed consent

The study was approved by the Medical Ethics Review Committee at the EMC and was performed in accordance with the principles of the Declaration of Helsinki and the Medical Research Involving Human Subjects Act. All participants received verbal and written information regarding study purposes and procedures and provided written informed consent prior to participation.

4.2.3. Study procedure

In this prospective observational study, participants were self-selected into either the group using VR distraction, or the no VR distraction group based on their personal preference. Eligible patients were contacted by members of the research team through phone call (outpatient clinic) or a physical visit (inpatient clinic). They received a verbal explanation and a one-minute introduction video about VR distraction in wound care. After consent to participate in the study, a pre-questionnaire was taken prior to the start of wound care to measure the patients' behavioral determinants (T. Wang et al., 2022) and intention to use VR distraction in wound care. Following this pre-questionnaire, patients could choose whether to

use VR distraction during wound care or undergo standard wound care without VR. Wound care treatment was independent of the patient's choice regarding the use of VR distraction. Depending on whether VR distraction was used, different post-questionnaires were taken directly after wound care to measure pain, anxiety, digital patient experience (only for patients who chose VR distraction), and future intention to use VR distraction.

A dedicated researcher was available to aid with the questionnaires and the operation of the VR headset during wound care to ensure smooth use of the VR distraction and to prevent any obstruction to the treatment. Researchers had full control over the VR headset and its content through a tablet. Patients were given the opportunity to ask any questions at any stage and pause or stop the VR distraction whenever they wanted.

4.2.4. Data collection

Pre- and post-questionnaires were completed on a tablet at the outpatient clinic and stored in Qualtrics. The available VR content was viewed on a Pico G2 4K Enterprise and comprised of a wide range of calm nature movie scenes developed by SyncVR (SyncVR Medical), such as elephants in a grass field and underwater dolphins in the ocean. Participants were free to choose one or more scenes to see during wound care.

4.2.5. Outcome measures

The primary outcomes were patient-reported intention to use VR distraction in wound care. The secondary outcomes were anxiety and pain levels, and (anticipated) digital patient experiences of using VR distraction in wound care, patients' needle-looking preference, pain catastrophizing, technology acceptance, VR distraction usage rate (i.e., the proportion of participants who chose VR distraction group), wound care treatment time length, medication use, VR immersion experience, and overall VR distraction satisfaction. A detailed overview of outcome measures and corresponding questionnaire items can be found in Appendix 4-1 (at the end of this thesis).

4.2.6. Statistical analysis

Statistical analysis was performed with SPSS (Statistical Package for Social Sciences, version 28.0.1.0). Since we developed our questionnaires ourselves, reliability was assessed for multiple-item scales (i.e., pain catastrophizing, technology acceptance, pain, digital patient experience, VR immersive experience, satisfaction) by using Cronbach's coefficient alpha ($\alpha > 0.6$). Cumulative scores were calculated only when reliability was achieved. Continuous variables (i.e., age, pain catastrophizing, technology acceptance, intention to use, pain, anxiety, (anticipated) digital patient experience, VR immersive experience, satisfaction, time length) were summarized as mean (standard deviation). Multiple linear regression analyses and one-way ANCOVA were used to evaluate the main effects and interactions (if any) of 1) sub-study 1: patients' needle-looking preference and/or technology acceptance on patients' intention to use VR distraction in wound care, and 2) sub-study 2: VR distraction

during wound care and/or pain catastrophizing on patients' pain and anxiety. Categorical variables (e.g., needle-looking preference and the use of VR distraction) were presented as proportions. We employed a Bonferroni adjustment as a multiple-comparison correction and considered a p-value below 0.025 statistically significant. This study was powered on the primary outcomes.

4.3. Results

4.3.1. Participants

104 patients were recruited of whom 8 patients (7.7%) dropped out and were not included in our analyses (Figure 4-1). Six of them completed the pre-questionnaire but did not receive or need wound care during current admission due to early discharge. Two patients from the outpatient clinic were recruited but did not participate due to technical failure of the VR headset. Therefore, 96 patients completed the whole study and were included in the analyses. 64 patients (66.7%) chose to use VR distraction in their wound care, and 32 of patients did not want to use VR distraction.

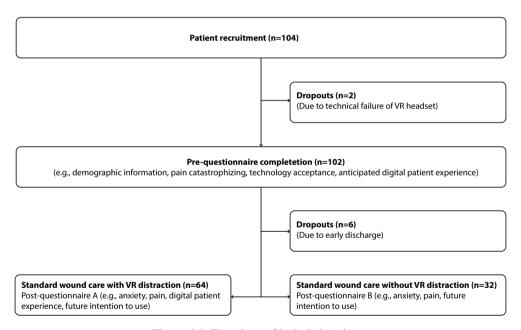


Figure 4-1. Flowchart of included patients.

4.3.2. Baseline characteristics

Participants' baseline characteristics were balanced across conditions (Table 1). They were aged 20–87 and 58.7 years old on average. 59.4% of the participating patients (n=57) reported to prefer to look at the needle when receiving injections. 28.1% of patients (n=27) had prior experience with VR technology. The majority, 82.3% of patients (n=79) had wound care treatment before.

Table 4-1. Baseline characteristics	5.
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	Condition 1		Condition 2	
	Look at (n=57)	Look away (n=39)	VR (n=64)	Non-VR (n=32)
Age (years)	61.0 (SD 14.0)	55.4 (SD 16.7)	58.8 (SD 15.8)	58.6 (SD 14.7)
Women	24 (42.1%)	20 (51.3%)	27 (42.2%)	17 (53.1%)
Have used V	R before			
Yes	16 (28.1%)	11 (28.2%)	18 (28.1%)	9 (28.1%)
No	41 (71.9%)	28 (71.8%)	46 (71.9%)	23 (71.9%)
Have receive	d wound care before			
Yes	48 (84.2%)	31 (79.5%)	56 (87.5%)	23 (71.9%)
No	9 (15.8%)	8 (20.5%)	8 (12.5%)	9 (28.1%)

4.3.3. Intention to use

As Figure 1 presents, 66.7% participating patients chose to use VR distraction in their wound care. Linear regression analysis revealed that a higher level of technology acceptance was associated with a higher intention to use VR distraction (F(1, 94)=32.49, β =0.507, SE=0.117, p<.001). A higher baseline pain was also associated with a higher intention to use VR distraction (F(1, 77)=7.08, β =0.290, SE=0.040, p=.009). In addition, after adjusting for patients' intention to use VR distraction in wound care before treatment, the one-way ANCOVA showed patients who used VR distraction had a higher intention to use VR distraction in the future than those who had not chosen for VR distraction (F(1, 93)=7.86, p=.006, partial η 2=.078).

4.3.4. Pain and anxiety

79 patients reported their baseline pain and anxiety according to their previous wound care experience. The mean scores of patient-reported pain and anxiety levels after standard wound care with and without using VR distraction were for pain 2.5 (SD 2.3) and 2.6 (SD 2.1), and for anxiety 1.3 (SD 1.8) and 1.5 (SD 1.4), respectively. The linear regression analysis revealed that pain catastrophizing was a significant predictor of pain (F(1,94)=6.37, β =0.252, SE=0.201, p=.013). However, after adjusting for patients' baseline pain or anxiety, the one-way ANCOVA revealed that the actual use of VR distraction had no significant influence on reducing pain (F(1,76)=.08, p=.779, partial η 2=.001), nor on reducing anxiety (F(1,76)=.43, p=.515, partial η 2=.006).

4.3.5. Digital patient experience

In the 64 patients who opted for VR distraction in wound care, the mean digital patient experience score at baseline was 3.6 (SD 0.6) and post intervention 3.8 (SD 0.8). The observed patients' VR engagement levels were high, with nearly all participants (93.7%) rating it above average (score≥3), and a mean score of 4.3 (SD 0.9) at 5-point Likert Scale. Patient-reported immersion experiences of using VR distraction were relatively high with a mean score of 6.7

(SD 1.8). The linear regression analysis revealed that both a higher observed VR engagement and patient-reported VR immersion experience were significantly associated with a higher digital patient experience of using VR distraction in wound care (F(1, 62)=15.17, β =0.443, SE=0.098, p<.001) and (F(1, 62)=73.94, β =0.737, SE=0.038, p<.001). Satisfaction ratings for VR distraction in wound care were high, with a mean score of 3.8 (SD 0.8) which was above the midpoint (score=3).

4.3.6. Time length and medication use

Patients who chose VR distraction in wound care spent approximately 7 minutes more than those who chose standard wound care without VR distraction, the former spent 29.1 (SD 11.5) minutes on average, and the latter spent 22.2 (SD 9.2) minutes on average. In addition, 69% of patients in the VR group and 53% of patients in the non-VR group used pain medication.

4.4. Discussion and conclusion

4.4.1. General discussion

Virtual Reality (VR) is an upcoming and promising tool for distraction in various medical settings. This prospective study aimed to investigate which patients are more willing to use VR distraction in wound care, determine if VR distraction could reduce anxiety and pain in wound care, and evaluate the digital patient experience of using VR distraction in wound care. To our knowledge this is the largest prospective study addressing patients' intention to use VR in wound care and their digital patient experience. Similar to a previous study on predicting patients' intention to use a personal health record (Yousef et al., 2021), our findings demonstrate that patients who have higher technology acceptance, higher levels of pain during previous wound care, or have used VR distraction in previous wound care were more willing to use VR distraction in wound care. Although many studies suggest VR distraction can be a promising tool for pain management (Mazaheri et al., 2023; Pourmand et al., 2018), our results did not find an effect on pain or anxiety reduction by using VR distraction in wound care compared to wound care without VR distraction, aligning with a previous randomized controlled trial (Jeffs et al., 2024). In addition, we found the actual digital patient experiences of using VR distraction in wound care at post-intervention were higher than the anticipated digital patient experiences at baseline. This indicates that the use of VR distraction in wound care went beyond patients' initial expectations, aligning with a previous systematic review that claimed that VR distraction shows promise in enhancing patients' experiences of wound care (Mazaheri et al., 2023). Furthermore, higher VR engagement and a better immersion experience significantly led to a higher digital patient experience. Therefore, to improve digital patient experiences, we suggest VR designers and developers to create more immersive VR scenarios (Wang, Zhu, et al., 2024). In terms of time length, our results show that the use of VR distraction led to a longer treatment duration. We assume this was due to extra time spent communicating and setting up the VR environment. Due to the varied health conditions we cannot simply conclude whether this relates to the use of VR distraction in wound care. Therefore, we would suggest future researchers conduct a more strict study design, such as recruiting patients who have the same health condition, to investigate the effect of VR distraction on medication use during wound care. Furthermore, research on generating an evaluation standard for when to measure, what to measure, and how to measure VR distraction in wound care is suggested as well (Wang, Giunti, et al., 2024).

During the study, we found that most patients were eager to try VR distraction in wound care. Reluctant patients tend to be older. They expressed doubts, mainly due to their unfamiliarity with or distrust of technology in general. Therefore, we assumed that age-tailored content would result in a higher use of VR. In addition, we noticed that some patients were too tired or unwell to participate in the study and that the most severely ill patients did not want to use VR glasses because it would cost too much energy. During the use of the VR headset, technical issues could be an obstacle, such as difficulties with connecting the VR headset to the tablet on which researchers could control the VR headset. This highlighted the importance of ongoing technical support and maintenance for technical applications in daily clinical practice. Not all VR content is suitable for use in a clinical setting. While some VR content was created for a 360 degrees view, patients were mostly lying down and could not look over their shoulders or to their sides. This caused patients to see uneventful scenes in front of them, resulting in boredom. Patients often also desired longer content and expressed the wish for an extended duration of VR scenes or movies to remain immersed and engaged, particularly during lengthy wound care procedures. In their interpersonal and verbal interactions with patients, we found that patients who chose to wear VR also expressed more positive views of technology. There were many patients who said that VR had no effect on their pain or anxiety because they did not experience wound care as painful or frightening in the first place, thus making it seem like VR was ineffective. The same patients believed that VR, however, would be useful for painful or anxious patients or in cases where wound treatment takes a long time. Patients who did not want to wear a VR headset during wound care mostly explained that they preferred to watch the wound treatment. These patients indicated that in doing so, they could make sure the wound care at home was also done correctly by themselves, partners, or other caregivers. Another reason that was frequently given was that they did not experience pain or fear during their wound care, and therefore deemed VR unnecessary. The last reason was that communication with their physician or nurse was considered better without the VRglasses, and that they preferred eye contact and conversations with their physician or nurse rather than "being somewhere else".

4.4.2. Limitations

Our study has limitations that need to be addressed. Predefined questions may not cover all important factors determining the use of VR. Reasons other than technology acceptance and needle-looking preference could play a role in not wanting to use VR, such as the importance of interpersonal contact during wound care, having to pass on wound care instructions for self-care at home, or not experiencing pain or anxiety in the first place.

Causal relationships may be harder to derive from cross-sectional questionnaires. These can also be prone to certain biases. Recent positive or negative experiences with technology, or pain and anxiety during wound care may lead to recency bias. This means that recent events are remembered more clearly or are assumed to resemble future events, these perceptions are vulnerable in one-time surveys and may not always reflect the patient's general beliefs. The idea that pain and anxiety have remained the same over repeated wound treatment may lead to the belief that these will not change, regardless of the use of VR. Questions about pain and anxiety during the last wound care are also susceptible to recall bias.

Some patients may have said they wanted to look at their wound treatment only to appear braver to our researchers, rather than admit they would like to be distracted with VR (Hawthorne effect). To avoid the potential bias, researchers encouraged patients to report their needle-looking preference based on their behaviors when receiving vaccination.

The type, extent, and localization of wounds can hugely impact the pain and anxiety experienced by patients, as well as determine whether patients would like to look at their wound. Identifying different patient populations based on types of wounds was not possible due to the unique nature of every wound. However, through the recruitment of all eligible patients over a long period of time, we have gathered a heterogeneous sample of patients that is representative of the general wound care population.

4.4.3. Conclusion

In conclusion, this study indicates that patients who have high levels of technology acceptance, experienced high levels of pain during previous wound care, or have used VR distraction in previous wound care are more willing to use VR distraction in wound care. No evidence was found on the effectiveness of VR distraction in significantly reducing pain or anxiety during wound care. Digital patient experience of using the VR distraction were reported as positive in post-questionnaires after the wound care and higher than baseline digital patient experiences before using the VR distraction, which reveals that patients' initial expectations of using VR distribution were met. This study can serve as an example of evaluating digital patient experience of using VR technologies in clinical settings.

4.4.4. Data availability

Aggregate data analyzed in this study may be made available upon reasonable request by contacting the corresponding author via the email address provided.

Lessons for doing a PhD 04 Multitask Smartly.

Time and resource limitations are challenges that many PhD candidates face, and I am no exception. My research involves working with vulnerable patient groups, which requires me to navigate additional layers of strict ethical considerations. One memorable experience was when my research on evaluating the digital patient experience of virtual reality distraction in wound care was delayed for one and a half years due to waiting for ethical approval. It was a challenging period, as I felt like my progress was at a standstill. However, this experience taught me an invaluable lesson about smart multitasking.

Multitasking does not mean juggling multiple tasks simultaneously in a chaotic manner but rather strategically aligning and arranging tasks over a period of time. I always had two or three research projects in different phases to work on, ensuring that no time was wasted. In the case of waiting for ethical approval, I started drafting my next research proposal and gathering preliminary literature. In another case, while writing the draft of my umbrella review, I was simultaneously collecting data for an interview study and preparing the protocol for my prospective observational study.

One of the greatest benefits of multitasking smartly is that it keeps your mind fresh and flexible. When stuck on a task for too long, it's easy to feel burned out or lost. Switching to a different task for a while can provide a mental reset, allowing you to return to the original task with renewed clarity and insight. It's like staring at a word for too long—it begins to lose meaning. But when you shift your attention elsewhere and return later, the word feels familiar again, and you see it in a new light.

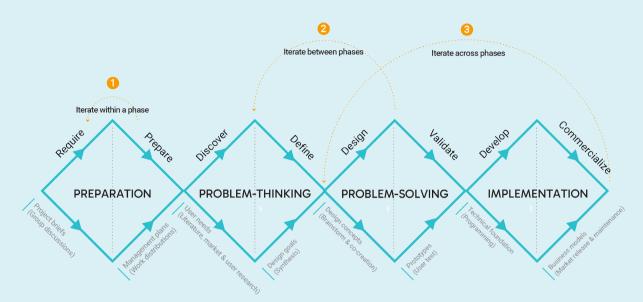
Without clear prioritization, multitasking can easily lead to scattered focus and decreased efficiency. Prioritization is essential to identify the highest-priority tasks and ensure they are completed first. Additionally, some people prefer to schedule tasks of varying difficulty based on their energy levels throughout the day, matching the complexity of the task to their peak productivity periods. In addition, tracking your task completion is helpful as well when multitasking. I developed a habit of starting each workday by creating a detailed to-do list. At the end of the day, I would track my progress and assess the completion of tasks. This simple practice not only helped me stay organized and productive but also ensured that no critical tasks were overlooked.

If managing time effectively still feels overwhelming, I would strongly recommend exploring courses on "time management." These courses provide systematic approaches to allocate time wisely and balance multiple tasks efficiently. Learning such strategies can help transform time management from a source of stress into a tool for achieving success.

By aligning tasks thoughtfully, prioritizing effectively, and embracing moments of mental

flexibility, multitasking can become a powerful tool to maximize productivity and manage the unpredictable journey of a PhD.



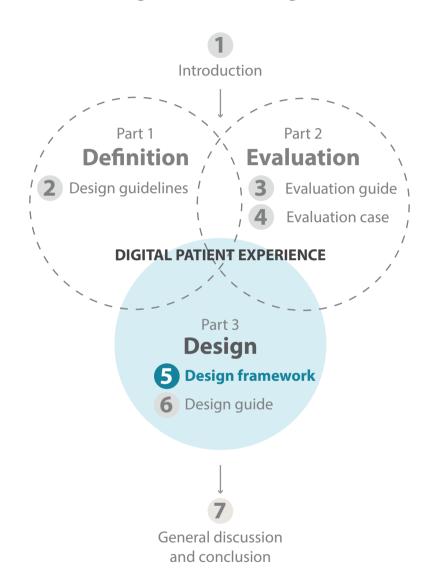




PART CDESIGNING DIGITAL
PATIENT EXPERIENCES

Chapter 5

Digital Health Design Framework: Design Phases, Challenges, and Strategies



The content of this chapter was published in:

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Abstract

Background:

Digital health (DH) brings considerable benefits, but it comes with potential risks. Human Factors (HF) play a critical role in providing high-quality and acceptable DH solutions. Consultation with designers is crucial for reflecting on and improving current DH design practices.

Objectives:

We investigated the general DH design processes, challenges, and corresponding strategies that can improve the digital patient experience (PEx).

Methods:

A semi-structured interview study with 24 design professionals. All audio recordings were transcribed, deidentified, grammatically corrected, and imported into ATLAS.ti for data analysis. Three coders participated in data coding following the thematic analysis approach.

Results:

We identified eight DH design stages and grouped them into four phases: preparation, problem-thinking, problem-solving, and implementation. The analysis presented twelve design challenges associated with contextual, practical, managerial, and commercial aspects that can hinder the design process. We identified eight common strategies used by respondents to tackle these challenges.

Conclusions:

We propose a Digital Health Design (DHD) framework to improve the digital PEx. It provides an overview of design deliverables, activities, stakeholders, challenges, and corresponding strategies for each design stage.

Keywords

Digital health interventions; Patient experience; Human-centered design

5.1. Introduction

According to the World Health Organization, "a health system consists of all organizations, people, and actions whose primary intent is to promote, restore or maintain health. This includes efforts to influence determinants of health as well as more direct health-improving activities" (World Health Organization, 2007). As they state in their Health System Challenges framework (World Health Organization, 2018) there are still many health needs and problems that need to be addressed. Digital health (DH) solutions, such as DH platforms (World Health Organization, 2020), patient portals (Irizarry et al., 2015), mobile health (mHealth) applications (Free et al., 2013), electronic health (eHealth) records (EHR), and appointment scheduling apps (Ammenwerth et al., 2012), have a great potential to tackle many of our current health system challenges, such as access to healthcare information and enhanced self-management (Gopal et al., 2019; World Health Organization, 2018). However, the benefits of DH have not yet been fully demonstrated due to, for example, poor interaction design and patient experience (PEx) (Tingting Wang, Guido Giunti, et al., 2022a, 2022b; Wang, Giunti, et al., 2024). Human Centered Design (HCD) has the potential to meet these underlying healthcare user needs (Erwin & Krishnan, 2016a, 2016b; Martin et al., 2005; Persson, 2017; Tingting Wang, Guido Giunti, et al., 2022b). HCD is defined in ISO 9241-210 as, "an approach to systems design and development that aims to make interactive systems more usable by focusing on the use of the system and applying Human Factors/Ergonomics (HFE) and usability knowledge and techniques" (Aasdahl et al., 2020). However, applying HCD requires a holistic process and poses many challenges (Carayon et al., 2020; Melles et al., 2021). Dedicated approaches to designing digital patient experiences are needed (Tingting Wang, Guido Giunti, et al., 2022a, 2022b), taking into account the many stakeholders working at multiple interfaces in healthcare (Carayon et al., 2020). In this study, we provide a framework to improve the HCD process in both digital healthcare practice and the digital PEx.

5.1.1. Design processes and frameworks in digital health

Dubberly stated (Dubberly, 2004), "Our processes determine the quality of our products". Although many well-known HFE and HCD frameworks and methods, from contextual mapping for understanding human needs to co-creation for generating design solutions, are common to healthcare (Melles et al., 2021), they need to be adapted to DH. Studies show that while design processes across different domains seem similar at an abstract level (Clarkson & Eckert, 2010), their emphasis on specific activities often varies significantly between domains (Eckert et al., 2004; Tingting Wang, Shuxian Qian, et al., 2022). This is also true for DH, as we demonstrated in a previous publication (Tingting Wang, Shuxian Qian, et al., 2022). For example, the Double Diamond framework (Design Council, 2023) is often used by many designers to manage their DH design processes, but their design values and requirements are different (Tingting Wang, Shuxian Qian, et al., 2022). Obviously, to understand how to better design for healthcare, we can obtain insights from design challenges and opportunities

in other mature domains. Bate and Robert (Bate & Robert, 2006) introduced evidence-based design (EBD) in 2006 and stated that "good design" of healthcare services—and the resulting "good experience"—is essentially no different from good design in any sector, including performance (functionality), engineering (safety), and the aesthetics of experience (usability). In addition, Jones argues that given the complexity of the healthcare industry, traditional User-Centered Design (UCD) approaches are inadequate to address the specific problems in the healthcare domain (P. Jones, 2013). Groeneveld et al. agree and add that, considering the vulnerable target users and complex design contexts, healthcare designers are facing more challenges than some designers who work in non-healthcare design domains (Groeneveld et al., 2018). Regarding the functionality, safety, and usability of digital health systems, more rigorous EBD and HCD considerations are needed (Tsekleves & Cooper, 2017).

A design process can be considered a rational process with defined phases that guide designers towards achieving specific goals at each phase. Current examples that focus on general design processes across different domains are the four phases (discover, define, develop, and deliver) in the British Design Council's evolved Double Diamond innovation framework (Design Council, 2023), the three main phases (inspiration, ideation, and implementation) in IDEO's Field Guide to Human-Centered Design (IDEO.org, 2015), and the five modes (empathize, define, ideate, prototype, and test) in Stanford Design School's Design Thinking Process Guide (Stanford). In addition, some others also provide design process directions specifically for healthcare (Healthcare Design Group Cambridge Engineering Design Centre, 2020) or the DH field (Mummah et al., 2016), such as the six elements (understand the context, define the problem, develop the solution, collect the evidence, make the case, and manage the plan) in the Improving Improvement Toolkit (Healthcare Design Group Cambridge Engineering Design Centre, 2020) to understand the healthcare system's complexity and promote improvement in healthcare, as well as the ten phases (empathize, specify, ground, ideate, prototype, gather, build, pilot, evaluate, and share) in the Integrate, Design, Assess, and Share (IDEAS) framework to integrate behavioral theory, design thinking, user-centered design, rigorous evaluation, and dissemination approaches to guide the development and evaluation of more effective digital interventions (Mummah et al., 2016). However, to our knowledge, there are no design frameworks for improving patient experience in digital health. The lack of transparency in current DH design practices is a result of the heterogeneous nature of the healthcare industry, combined with companies' reluctance to disclose their development processes (Martin et al., 2012). There are many poorly designed DH care systems (Persson & Rydenfält, 2021), highlighting the need for a more sector-specific design process framework that guides DH design practices.

5.1.2. Design challenges and strategies in digital health

Designing for DH is challenging and requires thorough preparation. Healthcare itself is significantly conflicted, complex, and adaptive (Perry et al., 2021), and is highly regulated

and constrained by many factors, such as data security and privacy, which limit the efficient use of health information (Gopal et al., 2019). DH is often utilized by multiple user groups such as patients and healthcare providers in various healthcare settings, from preventing, diagnosing to treating diseases (Martin et al., 2012; Perry et al., 2021). This dynamic environment demands a collaborative approach that caters to multiple stakeholders (Erwin & Krishnan, 2016a) and encourages interdisciplinary team engagements (Dinh et al., 2020). However, the goals and values among involved parties may not necessarily be aligned, and the roles and responsibilities of the stakeholders are often unclear upfront (Kleinsmann et al., 2015; Shadlyn et al., 2022). Conflicting goals across stakeholders, such as profitability, convenience, and patient-centeredness, lead to divergent approaches and stagnate performance improvement (Porter, 2010).

Designers often play a critical role in recognizing, prioritizing, and acting on stakeholders' needs, while also facilitating interdisciplinary collaborations between disciplines (Dong et al., 2015; Kessler et al., 2021; Kleinsmann et al., 2015). Despite extensive research on the needs of patients and healthcare providers, less is known about the design processes, challenges, and strategies that designers encounter in practice (Tingting Wang, Guido Giunti, et al., 2022b). To improve existing healthcare design practices, it is therefore paramount to involve design practitioners (Martin et al., 2005). Therefore, in the current study, we focused on investigating designers' perceptions, understandings, and experiences in terms of DH design and digital PEx improvements.

5.1.3. Research Objectives

The overarching goal of this study was to obtain insights into current Human-Centered Design (HCD) practices in the digital health (DH) area in order to propose a generic DH design process. In this two-stage process, we first identified common HCD processes in DH, including design phases, stages, activities, stakeholders, and deliverables throughout the design process. We then identified design challenges and corresponding strategies in DH from design professionals. We conclude this paper with a proposed framework for a human-centered DH design process, including design challenges and strategies.

5.2. Methodology

We used purposive sampling (Etikan et al., 2016) to conduct semi-structured interviews with DH designers until the saturation threshold was reached (Fusch & Ness, 2015). The study was approved by the Human Research Ethics Committee of Delft University of Technology in September 2021.

5.2.1. Participants Recruitment

Using a snowballing recruiting method (Streeton et al., 2004), participants were recruited and interviewed between November and December 2021. The inclusion criteria were:

Over 1 year of working experience

- Involved in at least one DH design-related project that applied HCD or user experience (UX) design approaches.
- English or Chinese speakers related to the researchers' language skills.
- In advance to the interview, participants were asked to think back on a significant DH
 design project they had been involved in and to share relevant project information (if
 applicable) with the interviewer (TW).

5.2.2. Procedure

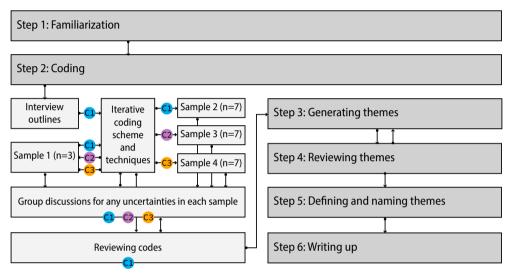
An outline interview with semi-structured questions was developed to discuss experiences and views of designers on how they addressed digital PEx in their design process (Appendix 1, see in our publication online). The interview included several main questions, for example, 'Could you tell me more about the DH design project that you shared (e.g., design context, work distribution, design challenges)' and 'could you walk me through your design workflow on this project'? Each interview lasted between 1-2 hours and was conducted in English or Chinese using online meeting software.

5.2.3. Analysis

All audio-recordings were transcribed, deidentified, and grammatically corrected where necessary to prepare for analysis. For conversations in Chinese, translations to English were made for quotes, codes, and themes. The deidentified transcriptions were imported into ATLAS.ti (Scientific Software Development GmbH; Version 22.1.0; 3475) for analysis. Data extraction focused on the following areas: 1) participants' demographics including gender, major, year of graduation, job title, work domains, work years, numbers of DH projects, company type, company size, and work location; 2) characteristics of self-reported DH design projects, such as design contexts, target users; 3) design processes, such as design phases, stages, activities, deliverables, and stakeholders involved; 4) design challenges and corresponding strategies. This study is part of a wider research initiative, and additional research conducted within the program will be presented in a forthcoming article. Besides, the detailed characteristics of the participating designers and of their self-reported DH design projects, as well as their perspectives on the differences and similarities between UX, patient experience (PEx), and digital PEx, between designing for healthcare and non-healthcare projects, were reported in a previous article (Tingting Wang, Shuxian Qian, et al., 2022).

Following Braun and Clarke's six-phase thematic analysis method (Braun & Clarke, 2006), three coders participated in the entire iterative coding process to analyze the extracted data (Figure 5-1). After data-familiarization, an initial coding scheme was developed by TW. Three sample transcriptions were used to code and modify the coding scheme, followed by a group discussion to resolve any discrepancies. Once consensus was achieved, the remaining 21 transcriptions were randomly assigned to three sets, each comprising seven transcripts. Each coder then independently coded one of these sets. Regular group meetings were scheduled to discuss any ambiguous or newly generated codes. The final, revised

coding scheme can be found in Appendix 2 (see in our publication online). The entire coding process followed five coding techniques: 1) generating codes as close to the original texts as possible; 2) simplifying and clarifying the codes while keeping their original meanings in the texts; 3) using a structured way to formulate the codes (e.g., verb phrases, noun phrases); 4) combining similar codes to minimize the total number of codes; 5) using English codes to code Chinese texts; and 6) marking ambiguous and newly generated codes for later group discussions.



Notes:

- 1. C1: coder TW; C2: coder QS; C3: coder HZ;
- 2. Sample 1 includes 3 randomly selected transcriptions, the remaining 21 transcriptions were randomly divided into samples 2, 3, and 4, each containing 7 transcriptions.

Figure 5-1. Iterative coding process based on Braun and Clarke's six-phase thematic analysis method (Braun & Clarke, 2006)

5.3. Results

We conducted interviews with 24 international human centered or UX designers involved in creating DH solutions. Our research revealed four phases and eight stages in the DH design process. For each stage, we identified design activities, deliverables, and the involvement of different stakeholders. Furthermore, we identified twelve design challenges and their associated strategies that can impact the design process.

5.3.1. Participants

Table 5-1 presents the participant demographics. Most were women, had a master's degrees, underwent design education in the Netherlands, and graduated between 2005 and 2020. Their work experience varied from 1 to >16 years, averaging 5.5 years. Most of the reported DH design projects were conducted for large companies. See Appendix 3 (in our publication online) for additional details about the participants' demographics.

Table 5-1. Description of study participants (N=24)

Characteristics	n
Gender	
Woman	18
Man	6
Education degrees	
 Master's degree 	20
 Bachelor's degree 	2
 Doctoral degree 	2
Education location	
The Netherlands	16
China	3
 The United States 	3
France	1
Finland	1
Years of working experience	
>5 years	10
■ 1-2 years	8
• 3-5 years	6
Current company size	
 Working in large business (over 200 employee 	es) 10
 Working in small business (less than 50 emplo 	byees) 8
 Working in medium business (50-200 employed) 	ees) 4
 Working in academia. 	2
Current work location	
 The Netherlands 	9
China	7
 The United States 	2
 The United Kingdoms 	2
 Canada 	1
Sweden	1
Norway	1
Spain	1
Project context	
 A large company (over 200 employees) 	10
 A small company (less than 50 employees) 	6
 A medium company (50-200 employees) 	4
 An academic context 	4

Table 5-1. Description of study participants (N=24) (continued)

Charac	teristics	n
Project	location	
•	The Netherlands	10
•	China	6
•	The United States	3
•	The United Kingdoms	2
•	Finland	1
•	Spain	1
•	India	1

5.3.2. Projects

Our findings show that designers are involved in diverse design contexts across the healthcare domain. Interviews with participants revealed a mix of digital health projects, showcasing the variety of healthcare services and healthcare issues. These projects (see Appendix 4 in our publication online) can be broadly categorized as follows:

- Interaction Design (17/71%): creating user-friendly interfaces for websites and mobile apps, like migraine management and patient communication.
- Strategic Design (9/37.5%): developing new healthcare models and pathways, such as integrating future health visions into practical design frameworks.
- Product Design (3/12.5%): developing medical products, such as a device for respiratory disease screening.

Notably, some projects were categorized into more than one cluster because their application scopes were quite broad. Besides, healthcare issues addressed were primarily chronic conditions (15/62%), ranging from diabetes, migraine, sleep disorders, and hypertension to kidney cancer, breast cancer, strokes, mental health therapies, and neurological disorders. Acute medical conditions made up 4/17% of the focus, including surgeries, COVID-19, and respiratory diseases, while 5/21% dealt with broader health issues, including reproductive health and general wellness. More details of the project characteristics and design contexts can be found in a previous publication (Tingting Wang, Shuxian Qian, et al., 2022).

5.3.3. Digital health design process

We identified eight stages in the DH design process which we grouped into four phases: (1) preparation, including clarifying requirements and limitations, and creating a project plan, (2) problem-thinking, including conducting desk or field research, and framing design problems (3) problem-solving, including generating and evaluating design concepts, and (4) implementation, including developing design solutions, and making market release and maintenance. Table 5-2 presents the phases and stages, and lists design activities, deliverables, and stakeholders for each stage, along with illustrative quotes.

Table 5-2. Design phases, stages, activities, deliverables, and involved stakeholders in the digital health design process.

1. Preparation 1.1 Clarifying ordinations Group ordinations Project ordinates Clients ordinates (n=7; P1/2/ (Re)design project project 10/ 11/ 14/ 18/ • (Re)design project project 19), Resign professing 19), Project design 10/ 14/ 16/ 23/ Project design 24) Weekly Posigner 24) Weekly Posigner 24) Weekly Posigner 24) Project project Project project 10/ 14/ 16/ 23/ Retermination Posigner 24) Project Project Project	Phases	Stages	Activities	Deliverables	Sta	Stakeholders	Ī	Illustrative quotes
discussions (Re)design tasks Division of Research work work Methods determination Weekly alignment	1. Preparation	1.1 Clarifying	• Group	• Project	•	Clients (e.g.,	•	I started with a project brief
 (Re)design tasks Division of Research work plan Methods Weekly Weekly 		requirements	discussions	brief		purchasers,		[P1].
tasks Division of Research work plan Methods determination Weekly alignment		and limitations		• (Re)design		project	•	First, meet your clients; they
Division of Research work plan Methods determination Weekly alignment		(n=7; P1/2)		tasks		managers).		will say what they would like to
Division of Research work plan Methods determination Weekly alignment		10/11/14/18/			•	Designers:		achieve [P11].
Division of Research work plan Methods determination Weekly alignment		19),				design	•	We had a kick-off meeting for
Division of Research work plan Methods determination Weekly alignment						professionals,		this project [P14].
Division of Research work plan Methods determination Weekly alignment						domain		
Division of Research work plan Methods determination Weekly alignment						experts (e.g.,		
Division of Research work plan Methods determination Weekly alignment						supervisors).		
 Division of Research • work plan Methods determination Weekly • alignment 					•	Others: hospitals.		
work plan • Methods determination • Weekly alignment		1.2 Developing	 Division of 	 Research 	•	Clients	•	You have to make sure your
Methods determination Weekly alignment		a project plan	work	plan		(e.g., project		quality management throughout
determination Weekly alignment		(n=7; P1/3)	 Methods 			managers,		the development process is well
• Weekly alignment		10/ 14/ 16/ 23/	determination			leaders)		built up and well documented
		24)	 Weekly 		•	Designers:		[P2].
profession domain (e.g., qu.			alignment			design	•	The initial part was fieldwork, so
domain (e.g., qu.						professionals,		we created a research plan [P3].
(e.g., qui						domain experts	•	We initiated group discussions
ording						(e.g., quality		with developers to formulate the
- Codocia						groups).		design scope [P19].

Table 5-2. Design phases, stages, activities, deliverables, and involved stakeholders in the digital health design process (continued).

Phases	Stages	Ac	Activities	Del	Deliverables	Sta	Stakeholders		Illustrative quotes
2. Problem-thinking 2.1 Conducting	2.1 Conducting	•	Interviews		Pain points	.	Users: patients,	١.	We spoke to clinicians to carry
	desk or field	•	Observations		Current		patients' family		things out in reality [P9].
	research (n=24;	•	Desk research		patient		members, and	•	I did literature research to understand
	P1-24)		(e.g., market		journey		health care		the definition of patient experience
			research)]	•	Personas		providers.		[P17].
		•	Co-creation	•	Theoretical	•	Designers: design	•	We brought these things together in
		•	Literature research		framework		professionals,		big workshops with 40 to 50 people
		•	Other user	•	Existing		domain experts		[P20].
			research (e.g.,		solutions		(e.g., doctors,	•	We worked on creating a patient
			context mapping)				nurses, marketers,		journey based on what the doctor
		•	Experiments				other colleagues).		said. And then we visualized the
		•	Patient profiling			•	Others: hospitals,		results to the patient representatives
		•	Design intuition				care homes, and		[P16].
		•	Coding				communities.		
	2.2 Framing	•	Synthesis		Design	•	Designers: design	•	Based on the patient and the expert
	design problems	•	Co-creation (e.g.,		insights		professionals,		interviews, where we learned a lot
	[n=24; P1-24]		workshop)	•	Design goals		domain experts		about the treatment and medical
		•	Self-inquiry		Design needs		(e.g., doctors,		background, we defined design
		•	Group discussions	•	Research		clinical partners,		visions [P2].
		•	Prioritize		papers		product managers,	•	Our role as designers is to interpret
			problems and	•	Futuristic		programmers)		what people say and go beneath the
			insights.		patient	•	Users: patients,		surface of the thing [P5].
		•	Filtering user		journeys		healthcare	•	We created these design principles
			needs	•	Service maps		providers		for the future that came out of these
									discussions in the workshops \square
									[P20].

Table 5-2. Design phases, stages, activities, deliverables, and involved stakeholders in the digital health design process (continued).

	Stages	YC.	Activities	Del	Deliverables	Stak	Stakeholders	Ē	Illustrative quotes
3. Problem-solving	3.1 Generating		Brainstorm	•	Design		Designers: design	•	We did the wireframes. We have
•	design concepts		Group discussions		concepts		professionals		a graphic designer and product
	[n=22; P1-7/9/		Wireframes		(e.g.,		(e.g., supervisors,		designer who designed the app [P5].
	11-24]		creation		interface		graphic, product,	•	We brainstormed and developed
			Workshop		sketches)		interaction and		design concepts [P15].
			Industrial design		Design		UX designers),		
			Visualization		directions		domain experts		
					Use flow		(e.g., marketers,		
							developers)		
							Users: patients,		
							healthcare		
							providers		
	3.2 Evaluating		User test		Prototypes		Users: patient	•	We did a first proposal for the app
•	design concepts		Validation		Storyboard		representatives,		prototype; we went back to users and
	(n=18; 1-6/ 8-9/		Group discussions		Design		patient families,		tested it in two iteration cycles of
	11/ 13-15/ 17-22/		Interviews		strategies		citizens, and		improving small things [2].
	24)		Questionnaires		Purchase		healthcare	•	I always do some concept or
			Experiments		advice		providers.		usability testing on different
			Cost evaluations		Innovation		Designers: design		solutions with caregivers and
			Usability tests		roadmap		professionals,		patients [P8].
			(e.g., rapid		Feedback		domain experts	•	We had to prioritize them (design
			prototyping and		from patient		(e.g., doctors,		concepts) based on the value for
			testing)		family		managers, IT		patients and the value for hospitals
			Market research		members		people, and		[P20].
			(e.g., competitive		Advice on		marketers).		
			analysis)		existing				
			Prioritize concepts		solutions				

Table 5-2. Design phases, stages, activities, deliverables, and involved stakeholders in the digital health design process (continued).

Phases	Stages	Ac	Activities	De	Deliverables	Sta	Stakeholders		Illustrative quotes
4. Implementation	4.1 Developing	•	Programming	•	Technical		Designers: design	•	A bit of back and forth between UX
	design solutions	•	Hardware		foundation		professionals (e.g.,		researcher and the programmer to
	(n=9; P2/ 4-6/		development	•	Graphics		UX researchers		finalize the app [P2].
	14/ 18-19/ 21-22)	•	Visual design	•	Content		and designers),	•	We have engineers who were going
		•	Structural design	•	Design		domain experts		to code the APP [P5].
		•	Proofing assembly		solutions		(e.g., programmers,	•	We were trying to start doing the
		•	Technical				developers,		technical foundation of the eye track
			assessment				engineers, and		with them (developers) [P21].
		•	Interview				health care		
							providers).		
	4.2 Making	•	Market release	•	Business		Designers: design	•	The app is accessible on play store,
	market release	•	Usage data		model		professionals,		but only for people who are invited;
	and maintenance		monitoring	•	Limited		domain experts		they can download it from play store
	(n=7; P2/ 5-6)	•	Onboarding		accessible on		(e.g., marketers, IT		[P2].
	18-19/ 21-22)		patients		play store		people, specialists).	•	We released the app, and then
		•	Lean startup	•	Research		Users: invited		onboarded the patients [P5].
			methodology		reports		users.	•	After releasing the APP, we monitor
		•	Expert						system usage data [P18].
			consultations					•	This project was gone and failed,
									probably because the business model
									was not suitable [P19].

Phase 1. Preparation

Stage 1.1 Clarifying project requirements. Receiving the design task from internal or external clients often marks the beginning of a DH design project: "First, meet your clients; they will say what they would like to achieve [P11]." The inception of a DH design project can range from a vague design intuition (e.g., "a thought from daily life [P13]") to a broad design vision (e.g., "improve the PEx [P1]"), or it can be a specific design brief (e.g., "design a digital patient sheet [P18]"). It often follows a typical design process (e.g., "double diamond [P2]"). Design requirements (e.g., "design context [P24]"), resources (e.g., "investment [P13]"), and briefs (e.g., "project purposes [P18]") are typically clarified early on, considering public sector regulations and stakeholder interests and resources.

Stage 1.2 Creating a project plan. A plan gives stakeholders a comprehensive understanding of project complexity and provides a dialogue that breaks down divisions: "project management is your best friend [P3]" and it "needs to be looking at everything [P3]". Initially, this stage was infrequently mentioned by the participants in their workflows. However, on reflection on past projects, many acknowledged the need for "good project management [P22]", "a person who has the vision [P16]", "more structured and continuous inputs [P17]" from varied stakeholders, "making a holistic plan [P6]", and "knowing about how the process was going to be [P1]" from the beginning, if they were to run the project again. "A time plan is an important factor for managing the design process better [P10]". During this stage, typical tasks include building the team, managing time, allocating assignments, determining methodology, and setting milestones.

Phase 2. Problem-thinking

Stage 2.1. Conducting desk or field research. This stage entails desk or field research to identify design problems and opportunities. "Interviews [P2]", "observations [P22]", "desk research [P10]", "literature research [P17]", and "co-creation [P20]" were commonly mentioned as methods to understand the context. Opinions varied regarding when and to what extent end-users should be involved; see more details in Section 3.3. Designers did not always follow rigid, step-by-step design processes such as conducting interviews or making patient journey maps. Sometimes, they chose to proceed based on their "design intuition [P18]". Representative "personas [P2]" and visualized "patient journeys [P16]" are common outputs.

Stage 2.2. Framing design problems. Insights from earlier stages aid in discovering user needs, framing design problems, and creating overarching design goals. These then guide the generation of solutions at later stages. Common techniques used to "interpret what people say and go beneath the surface of the thing [P5]" include "self-inquiry [P1]", "group discussion [P12]", and "co-creation [P20]". This leads to generating prioritized "problems [P9]" and unified "design goals [P18]".

Phase 3. Problem-solving

Stage 3.1 Generating design concepts. In this stage, designers aim to provide a range of solutions to a clearly defined problem by seeking inspiration from different sources and codesigning with different people. This concept generation is typically iterative: "you begin by creating concepts, then check, test, and develop them thousands of times [P11]." Both "brainstorm [P15]" and "co-creation [P20]" are used to generate design ideas, and "wireframe [P2]" is used to refine these concepts.

Stage 3.2 Evaluating design concepts. Providing "evidence-based [P22]" and "validated [P23]" concepts are expected by clients, clinicians, and/or patients. Designers either perform "self-evaluation [P18]" based on pre-defined criteria or invite end-users and domain experts to do "usability tests [P8]". More "tangible metrics [P5]" for user testing was suggested, and "continuous [P6]" user testing was noted for iterative design processes. "The value for patients and the value for hospitals [P20]" is used to prioritize design concepts. "Prototyping [P20]" served as a method to materialize concepts and is commonly used for evaluation.

Phase 4. Implementation

Stage 4.1 Developing design solutions. This stage highlights the importance of "visual design [P2]" and "technical foundation [P21]". To finalize the product, "a back-and-forth between the UX researcher and the programmer [P2]" was mentioned. Both "hardware and software development [P6]" can take place in this stage. This can be followed by another round of evaluation related to "technical issues [P18]". Considerations for "system integration [P8]" are also crucial at this stage.

Stage 4.2 Making market release and maintenance. The last stage of the design process often involves market release (e.g., "released the app and onboarded the patients [P5]") and its subsequent maintenance (e.g., "monitoring system usage data [P8]"). Some designers participated in creating and validating the "business model [P21]", while others expressed dissatisfaction due to their projects failing because of an "unsuitable business model [P19]" or "poor supply chain [P6]". Many projects had limited market release (e.g., "only people who are invited can download it [P2]") and some did not even proceed to market release. In cases where there was no need for a redesign or product iteration, technologists and marketers took responsibility for "collecting user feedback [P6]" and maintenance. A common concern among designers was losing track of maintenance (e.g., not involved in the actual realization [P11]" or "do not know what happened with that [P5]"). Some believed that "we would have to be involved again, but I know when [P2]".

Participants Parti		PROBLEM-THINKING	HINKING	PROBLEM-SOLVING	-SOLVING	IMPLEMENTATION
	PREPARE	DISCOVER	DEFINE	DESIGN	VALIDATE	DEVELOP COMMERCIALIZE
						Deliverables
						Prototypes (care model)
						1 APP (iteration)
		_				Advice on the existing solutions
						Concepts (interface)
						Concept
P10 P10 P20 P24						Interfaces
P10 P20 P6 P6 P6						APP (iteration)
P20 P24 P6		_		_		I APP (iteration)
P24				_		I Innovation roadmap
e 8						Concepts)
8						APP & wearble devices (iteration)
		-				l APP (iteration)
medium companies P22		-		_		Games & devices (iteration)
P23						Concepts (care model)
P2		_				APP (limited market release)
P5		-				APP (limited market release)
Professional projects in P11		-				Concepts (interface)
small companies P13		-				Concepts (platform)
P14						Prototypes (devices & APP)
P21		_				Prototypes (APP)
-		-				l Prototypes (APP)
Professional projects		-				Concepts (interfaces)
in academic contexts P10		-				Prototypes
7d						Design insights

Notes 1.0 or participants have international study and work experiences. For example, participant 13 studied in the Netherlands, works for a large company located in Norway, and initiates a digital health design project in the India not in a sademla, it is made with a rest of the participant accurately work in India and Example and the same Figure 5-2. Participants' design processes. (i.e., involved design phases and stages mapping in terms of project types.)

Figure 5-2 shows that almost all projects entail both problem-thinking and problem-solving phases. Only a small portion of projects in companies encompassed all four phases; the first or the last phase were mainly ignored. For projects in an academic context, the design processes mostly spanned the initial three phases. Most projects culminated in design concepts or prototypes, with only a handful of iterative projects launching their final designs, such as applications or wearable devices. A small number of designers were involved in the market release and maintenance stages.

Among our participants, there was a clear division of opinion about the differences and similarities between designing for patients and designing for healthy people. Some (n=13/54%) argued there is a big difference, while others (n=11/46%) believed that designing for patients and designing for healthy people are the same. The similarities and differences concern three aspects: design principles, user attributes, and design contexts (Tingting Wang, Shuxian Qian, et al., 2022). Additionally, participants provided a range of responses about how they perceive user experience (UX), patient experience (PEx), and digital PEx. Their answers were mapped onto five dimensions: people, contexts, purposes, means, and usage scenarios, which were elaborated in a previous publication (Tingting Wang, Shuxian Qian, et al., 2022). According to their understandings, the concepts of UX, PEx, and digital PEx can be distinguished between:

- designing for "specific" or "general" people: in contrast to PEx, which exclusively focuses on patients, UX aims for all users, such as patients and healthcare providers, that are involved in the entire service plan. Both of them refer to human-centered design; PEx focuses on patient-centered design, while UX relates to user-centered design.
- designing for "continuous" or "momentary" contexts: (digital) PEx is considerably
 more continuous and permeates patients' everyday lives than UX, which is more
 concerned with momentary touchpoints. Due to the sensitivity and vulnerability of
 patients, the impact of human-computer interactions on (digital) PEx is greater than
 that on general UX.
- designing for "emotional" or "functional" purposes: (digital) PEx is far more
 emotionally loaded and is more influenced by patient-specific situations than UX.
 The former focuses more on patients' well-being; it is substantially more complex,
 intangible, and challenging to measure than the latter, which focuses more on overall
 system performance and can be evaluated easier.
- designing through "digital" or "hybrid" means: digital PEx is the digital version of
 the PEx. It highlights more human-technology relationships than general PEx in the
 traditional healthcare context. Notably, the design of digital health and non-digital
 health is not a binary opposition. To some extent, participants reported that digital PEx
 should be incorporated into the offline experience as well.
- designing for "concrete" or "vague" usage scenarios: the usage scenario of digital PEx is clearer than UX, as PEx often emphasizes a specific healthcare situation.

5.3.4. Participation of stakeholders throughout the digital health design process

Types of stakeholders

Table 5-2 shows a varied stakeholder group, including clients, designers (i.e., design professionals and domain experts), and users, being involved throughout the different phases and stages of the DH design process. Clients such as purchasers and managers typically hold high-level positions in hospitals, businesses, or the public sector. They often act as decision-makers in the design, purchase, implementation, and commercialization phases. UX designers, engineers, programmers, as well as medical, policy, and marketing experts often acted as design professionals or domain experts and were responsible for delivering designs. Two key user groups were identified: healthcare providers using DH systems to deliver care services, and healthcare receivers receiving these care services. These users can be either direct or indirect, depending on their degree of interaction with DH. They were often involved in the problem-thinking and problem-solving phases, especially during the fieldwork and user testing stages. Healthcare providers played varying roles in the design process. Some participated actively as clients or domain experts and were part of the design team, while others played passive or temporary roles as end-users or stakeholders. Patients often collaborated with designers as end-users. Moreover, while some stakeholder groups, such as insurance companies, did not actively participate in the design process, their potential influence on future collaborations was acknowledged and considered.

Necessity of patient involvement

There was some disagreement between participants about the necessity of involving patients in the design process. Most participants insisted that patient involvement was crucial for creating user-friendly solutions. They argued that insights drawn from the viewpoints of other stakeholders could lead to biased outcomes. For example, "knowing patients by talking with doctors cannot represent patients' perspectives; doctors transform all patients into one person; we should keep a certain distance from it [P16]". However, as it is often difficult and time-intensive to approach patients, some argued that it was more efficient to learn about patients from other accessible stakeholders who know the patients well, such as nurses, doctors, marketers, and patients' family members: "nurses can actually say a lot about the patients because they've been observing them every day [P13]." Nonetheless, some designers suggested that patient involvement may not be as significant for a business-to-business project, given that the final decision-makers were not the patients themselves. These designers believed that they "already possessed sufficient knowledge about patients through internal collaborators [P19]".

Sequence of user research

There were differing opinions among the participating designers about the order in which to involve healthcare professionals and patients in user research. Their arguments addressed time efficiency, resource availability, and design context. Some believed that speaking to doctors

first and then involving patients could improve their work efficiency: "in the past, we saw lots of confusion and conflicts between the insights of patients and care teams which delayed us from taking decisions and starting to create. Then we decided that we would prioritize care teams [P9]". However, others expressed concern that this approach could lead to bias and preconceived notions before involving patients: "If we (were to) go to the doctor and based on the doctor's answers, create an interview for the patients, then it would have made the decision more focused (on the doctor) [P16]." Additionally, some designers felt that the order of user research "shouldn't matter, as a researcher, you need to be independent, and you need to be without projection and prejudice [P11]". Some suggested that the determination of the user research order should be based on the end-users, design goals, and resource availability: "it depends on your end-users; you should understand your end-users' perspectives at first [P12]".

5.3.5. Design challenges and strategies in digital health

Based on the experiences shared by our participants we identified 12 challenges in DH design, which we classified into four categories: contextual, practical, managerial, and commercial challenges. In addition, we identified 38 strategies the participants mentioned when tackling DH design challenges. Table 5-3 presents our findings.

Table 5-3. Design challenges and strategies in DH.

	Categories Themes	Ex	Example quotes	Str	Strategies
Contextual	Adapting to	•	If you design something for gardening, you can go and do gardening. So, it's	•	Being familiar with the background
challenges	complexity		easy to put yourself in the context. If it's a disease, maybe a bit more empathy		information, such as conducting a
	[n=8; P2/ 4/ 5/ 7/		is required [P2].		literature review and market research
	9/17/18/21]	•	I think it (the biggest challenge) is the level of knowledge that designers have		[P18/23]
			about the technical back-end solutions of things [P17].		
			There are many subdivided medical treatment scenarios [P18]		
	Dealing with	•	(We) have to go through the regulatory barriers, that's going to be quite a	•	Involving legal team [P3]
	documentation		challenging part of the design process [P13].		
	[n=13; P1 / 3/	•	There is a very strong ethical component because we're talking about these new		
	4/ 5/ 7/ 10/ 12/		technologies and how they'll influence the healthcare [P20].		
	13/ 17/ 18/ 19/				
	20/ 21]				
	Attuning to	•	They (the clients) are experiencing massive delays in the clinical trials due to	•	Project, time, team, and risk
	restrictions		COVID-19 and their inabilities [P2].		management [P1/2/3/6/16/24]
	[n=16; P1/2/3/	•	The main challenge is to consider the overall product time cycle and to meet the		Coordinating resources, such as
	4/ 5/ 6/ 8/ 9/ 10/		time constraints [P6].		integrating healthcare systems and
	13/ 14/ 15/ 18/	•	Because we have money and time constraints, we talk to the patients		utilizing advanced technologies
	19/ 21/ 23]		much[P21].		[P4/18/19]

Table 5-3. Design challenges and strategies in DH (continued).

Categories	Themes	Ex	Example quotes	Str	Strategies
Practical	Reaching	•	The big puzzle is for nothing to slip away in between, or there's not so much		Empowering designers [P3]
challenges	agreements [n=10; P3/ 5/ 6/	•	overlap that people (team members) feel like they're in each other's way [P22]. I would say that from a design team standpoint, the biggest conflict was really	•	Setting milestones and common goals [P6/18]
	8/10/12/17/18/		more about methodology. What's the best way to answer these questions? What	•	Group discussions for uncertainties
	20/ 23]		are we really assuming? There were points where some people might have felt more strongly about certain ideas, or that this is what we needed to do [P23].		[P24]
	Involving end-	•	Not all their mental space is there to help you at the moment they're ill or when		Utilizing advanced technology [P19]
	users [n=19; P1/		they're dealing with a lot of stuff [P1].		Explaining everything [P3]
	3/5/6/7/8/12/	•	Managing all the stakeholders who really have anything to do early on is	•	Knowing patients from other available
	13/ 14/ 16/ 17/		difficult [P3].		people [P22]
	18/ 19/ 20/ 21/	•	The user doesn't always tell the truth [P7].	•	Empathy [P2]
	22/ 23/ 24]	•	Reaching out to the right people back in the design process who are available is	•	Understanding everything from desk
			a bit tricky [P13].		research or literature review to inform
		•	We always have the information that crosses gender, different age groups,		conversations with stakeholders [P5]
			and different races, like it's truly diverse, making it difficult to define a digital	•	Prioritizing design value [P9]
			patient experience or solution that considers everyone [P23]		
	Making design	•	The challenge is to keep it (the design solution) personal, to make sure that	•	Designing equitable experience [P3]
	decisions [n=15;		everybody (each patient) feels heard [P1].	•	Systematic view, considering design
	P1/3/5/6/8/9/	•	Making sure we're designing these so that the user experience is equitable [P3].		vision, clients' inputs, and design
	10/ 11/ 12/ 13/	•	What's best for the patient is quite often not what's best for the caregivers or		principles [P2/20]
	15/ 18/ 19/ 21/		finances [P8].		Setting a timeline [P10]
	23]	•	It's hard to fit the technology into users' daily lives [P10].	•	Involving decision-makers in the
		•	What the client thinks is needed and what the actual user needs is often		process [P17]
			different [P11].	•	Group discussions on conflicts [P20]
				•	Empathy [P13]

Table 5-3. Design challenges and strategies in DH (continued).

Categories Themes	Themes	Ex	Example quotes	Stra	Strategies
Managerial	Managing	•	We really have a very good relationship with the company (i.e., client)	•	Being in no direct contact with the client
Citation	P2/ 3/ 5/ 7/ 9/	•	Everybody (i.e., stakeholders) wants their own thing, and I have to give a	•	Involving people who can play active
	15/24]		balanced advice, which always means that somebody will be angry or at least		actors in managing relations with others
			unhappy with you [P8].		[P3]
		•	We did it this way because we felt a lot of pressure from professional	•	Placing domain experts in the right place
			researchers [P24].		[P23]
	Building	•	There's always a gap between what people say they want and what actually	•	Empathy [P2/13]
	understanding		happens in practice [P5].	•	Group discussions on conflicts [P10/20]
	[n=7; P1/2/5]	•	It's a little bit tricky, and you need to be in the patient's position and understand	•	Making things tangible and visualizable
	10/ 17/ 20/ 24]		what it feels like for them [P13]		[P1/10/23]
		•	There was a big misunderstanding; the reason being that the same word meant	•	Writing full sentences when explaining
			different things to different people [P16].		things [P24]
		•	(It was difficult to) facilitate a discussion by expressing what the needs are of		
			different users and why, and together coming to a consensus [P17].		
	Communicating	•	From my perspective, what design could do is just make slight interventions,		Making things tangible and visualizable
	design value		slight changes, slight improvements; that's already very difficult [P7]		[P10/24]
	[n=14; P2/ 3/ 5/	•	I had to work with them quite a lot for them to understand what design research		
	6/ 7/ 8/ 9/ 10/		is and how you execute it [P17].		
	12/ 14/ 17/ 18/	•	The hardest (is) to convince others about taking a human-centered approach		
	23/ 24]		[P23].		

Table 5-3. Design challenges and strategies in DH (continued).

Categories	Themes	Ex	Example quotes	Str	Strategies
Commercial	Providing	•	It's hard to define whether they feel better because of the app itself or because it	•	Telling real user stories, reporting
challenges	evidence [n=7;		created a better connection with their HCP [P5].		quantitative data, showing design
	P5/8/11/17/20/	•	In the lab, everything went well. But in the actual validation study, it was		expertise, and proving solutions [P18]
	22/23]		horrible; it did not work [P11].	•	Conducting systematic reviews [P5/22]
		•	Everything needs to be evidence-based; publish research papers before trying	•	Making things testable [P20]
			something. I think that's a big thing to overcome because we need to speed up	•	Standardizing evaluations and providing
			innovation [P20].		tangible metrics [P5]
				•	Conducting concept or usability tests
					[P8]
	Implementing	•	There was a low usage rate for the software due to poor hardware development, •	•	Involving programming experts [P2]
	solutions [n=12;		so we're looking for new suppliers [P6].	•	Convincing people who are most against
	P2/4/5/6/8/11/	•	Which is quite frustrating in a sense because you went from zero to this		the solution to use it first [P5]
	14/ 15/ 16/ 17/		developed project and everything depends on the client, so you can't really do	•	Involving decision-makers in the
	18/ 20]		anything about it [P5].		process [P17]
		•	The exchange of data between different solutions is really a big problem (The	•	Conducting user training when
			suppliers) allow other APPs to integrate with them [P8].		introducing new technology [P6]
		•	It's hard to implement the solution [P15].		
		•	They (patients) are so stuck in their ways because they've always done it that		
			way[P17].		
	Establishing	•	Because	•	Working with multiple budget holders
	business models	•	It's difficult financially because you're under contract for reimbursement. It's		[P3]
	[n=8; p5/8/10/		not so much about the value of the services. it's what your budget holders are	•	Involving hospitals first then insurance
	13/ 15/ 18/ 19/		willing to reimburse [P3].		companies [P13]
	21]	•	It (the market release) depends on the client; you can't really do anything about		
			it [P5].		
		•	The biggest unknown for us is how the money is going to come to the company		
			[P13].		

Contextual challenges

Contextual challenges refer to healthcare system challenges a designer should consider prior to fieldwork. Includes adapting to complexity, dealing with documentation, and attuning to restrictions.

Challenge 1. Adapting to complexity. The healthcare sector presents intricate scenarios impacted by multiple factors including social settings and individual health conditions. Creating DH solutions necessitates extensive knowledge and diligent efforts. As participants stated, "healthcare itself is pretty complicated [P7]", often involves "many stakeholders [P21]", refers to "many subdivided medical treatment scenarios [P18]", and requires more empathy to understand "certain disease [P2]". "The ownership of the platform, the severity of patients' conditions, and the frequency of usage [P18]" can vary significantly. This complexity requires designers to have a certain "level of knowledge [P17]" about the technology involved.

Challenge 2. Dealing with documentation. When designing for healthcare, "the ethical issue should be taken into more considerations [P7]". Many participants felt overwhelmed due to the "regulatory barriers [P13]" and "ethical component [P20]". Obtaining "approval [P3]" was time-consuming and required many efforts. Additionally, "data security [P10]" and "storing information [P5]" were big concerns.

Challenge 3. Attuning to restrictions (and coordinating design resources). Considering "the overall product time cycle to meet the time constraints [P6]" was a big challenge. Most solutions are built on top of small things instead of "from a bigger perspective [P8]", which often leads to a negative UX. Factors like "COVID-19 [P2]", and "longer feedback chain [P19]" delay the design process and "money and time constraints [P21]" force designers to "limit [P9]" user research. Additionally, many participants struggled to avoid overinvestment of time and energy and felt it was hard to "dig yourself out [P3]" and "decide on when to move forward [P10]".

Strategies to contextual challenges. To address these contextual challenges, designers recommended: 1) initiating the project with design research such as literature reviews and market analysis to "build context and knowledge [P23]" and therefore adapt to complexity; 2) preparing earlier for the required documents by "working closely with the legal team and ethics board [P3]" to deal with documentation; 3) improving project management and resource coordination to attune to restrictions and "lead the team [16]" through time planning, risk management, and utilization of advanced technologies.

Practical challenges

Practical challenges refer to the expected actions a designer should take when working in the field. Includes reaching agreements, involving end-users, and making design decisions.

Challenge 4. Reaching agreements (with and between collaborators). Collaborating across varied parties often leads to "conflicts and different points of view [P9]". This is especially the case between groups like the "product manager and interaction designer [P18]" and "IT people and design advisers [P8]", due to different expectations and perspectives. Some designers complained that HCPs believed more in "scientific methods [P23]" and felt that designers were "intruding [P5]" into the medical field. For designers, introducing a "human-centered approach [P23]" to non-design domain experts was also difficult. Some designers felt "fully patient-centered [P9]" was unrealistic and "user-centered design [P6]" was more like a superficial slogan. Additionally, "what everyone would have done [P16]" is not always clear. Creating a smooth process among different job roles to make sure "nothing slips away in between and not too much overlap [P22]" was a big puzzle. It was sometimes unclear what the roles and responsibilities were in the design process, the people who took on the role might change.

Challenge 5. Involving end-users (and uncovering real needs). Involving sufficient end-users is challenging due to "time [P10]" and resource constraints, privacy issues, and sensitivity of subjects. It required "extra application (for human resources) [P19]" and sometimes designers were even "unable to [P12]" or "not allowed to [P1]" contact patients. Furthermore, engaging end-users "in the right phases [P3]" was difficult and "people are becoming more protective of their time [P3]". If they get involved too early, they "really have anything to work on [P3]". However, they cannot be "well exposed and brought into [P1]" the entire context if they join too late. Approaching vulnerable and self-protective end-users effectively was tricky due to "sensitive topics [P7]" and "personal concerns [P12]". For example, "COVID-19 infection could be a sensitive topic [P10]" for some people at a certain time. When co-creating with patients, designers "have to be very careful [P6]" to make them "feel that their data is secured and protected [P10]", and "sharp on when to ask who [P1]" in terms of their health conditions. Patients do not always have the 'mental space' to help designers "when they're ill or when they're dealing with a lot of stuff [P1]". Additionally, "it's hard to recognize their (patients') preferences and needs [P10]" given "the user doesn't always tell the truth [P7]" and some of them even "know their real needs [P7]".

Challenge 6. Making design decisions. Balancing diverse stakeholder needs with real-world applicability presents a significant challenge in designing "user-friendly [P14]" DH. As one designer stated, "what's best for the patient is quite often not what's best for the caregivers or finances [P8]." This balancing act often creates a "struggle [P23]" in decision-making, such as when "immediate [P12]" patient needs in teleconsultation conflict with doctors' capabilities. Providing "equitable [P3]" UX was recommended □ but not easy. "We, as hospitals, always choose what's best for caregivers and planners over what's best for patients [P8]", said one designer. Clients, representing the involved companies, driven by "money (i.e., profits) [P5]", have "a bigger influence [P19]" on decisions, which can diverge from "actual user needs [P11]". Good decision-making often needs "balance between the

technology, users, and business [P13]", however, "utilizing technology to meet users' actual needs and seamlessly integrate it into their daily lives [P10]" was difficult.

Strategies to practical challenges. Participants employed various strategies to tackle the practical challenges encountered. 1) Designers should be "empowered [P3]" to choose the appropriate design methods and "make infographics from the research [P8]" to communicate visually and inclusively to reach agreements with diverse collaborators. 2) Designers also suggested using "desk research or literature reviews to inform our conversations with the nurses and with the patients [P5]". Caregivers and family members can help involve vulnerable patients (e.g., dementia, children). Moreover, empathy is often required "to be in the patient's position and understand how it feels for them [P13]". 3) To make a better design decision, designers should "make an educated guess [P13]" based on the defined design vision, client inputs, and design principles. To do so, "you always need to design with a systemic view [P20]", which means surfacing different perspectives, facilitating discussions on conflicts, and designing equitable experiences for involved stakeholder groups.

Managerial challenges

Managerial challenges refer to the collaborative atmosphere a designer should create throughout the whole design process. Includes managing relations, building understanding, and communicating design value.

Challenge 7. Managing relations. As one designer highlighted, "everybody wants their own thing, and I have to give a balanced advice, which always means that somebody will be angry or at least unhappy with you [P8]". Some participants voiced frustrations with clients who "did not like our suggestions [P5]" or "did not have a very good relationship [P2]" with them anymore. Designers noted doctors' skepticism, feeling they "necessarily believe in us [P5]" and "tend to trust their own experience over technology [P20]". There were also issues with IT personnel who routinely "thought that I was doing the wrong thing [P8]."

Challenge 8. Building understanding. Designers struggled to reach a consensus "by expressing what the needs of different users are and why [P17]". They noticed a dissonance between "what people say they want and what actually happens in practice [P5]". Additionally, "doctors and patients always speak the same language [P1]", and "different culture and language leads to different understanding on the same project [P15]". "The same word meant different things to different people [P16]", such as 'prototype'. Besides, it was difficult to "generalize and scale [P5]" individual findings to a broader population due to methodological limitations or personal differences.

Challenge 9. Communicating value. Designers seek to "communicate the importance of use-centered design [P6]" and "show your real value to your clients [P12]". However, practical constraints made it impossible to serve "100% of the population [P9]" or "cannot bring more

surgeons to the hospitals [P9]". As one designer put it, the role of design was largely to introduce "slight interventions, slight changes, and slight improvements [P7]". Therefore, clarifying "what design research is and how you execute it [P17]" and "finding a way to tell that story [P3]" became essential.

Strategies to managerial challenges. 1) To manage relations with multiple stakeholders, "positioning them (stakeholders) as the experts seems to have been what really shifted things [P23]". Furthermore, the role of coordinators and bridging various stakeholders proved useful: "they (coordinators) know how to make things happen because they're very well connected and organized [P3]". Some found that "not being in direct contact with the client [P5]" allowed for more freedom. 2) To build understanding, some designers suggested "making things tangible [P1]" and "visualizing in some ways [P23]" to communicate between people who might not speak the same language. 3) Communicating design value means designers have to know how to "tell your story and write your story [P24]" effectively.

Commercial challenges

Commercial challenges refer to the business value a designer should add at the end of the design process. This includes providing evidence, implementing solutions, and establishing business models.

Challenge 10. Providing evidence. It is challenging to generate evidence and convince users to accept design solutions. For example, doctors "won't adopt new technology unless it has proven that it will improve their decisions or patient outcomes [P20]" while patients are often "stuck in the ways that they've always done it [P17]". "Making things testable in the early phase [P20]" and conducting "usability tests [P8]" with both healthcare providers and patients were suggested, though some noted: "in the lab, everything went well. But in the actual validation study, it was horrible [P11]."

Challenge 11. Implementing solutions. Designers sometime lose their 'voice' when working on commercial projects when it comes to implementation: "it depends on the client; you can't really do anything about it [P5]." As some designers stated, "it's hard to implement the solution [P15]" and "it's not easy to convince your clients [P18]". Additionally, they noted operational challenges associated with "the exchange of data between different solutions [P8]". Limited system integration sometimes increased designers' workloads, as one designer mentioned "we had to upload patient profiles manually [P4]."

Challenge 12. Establishing business models. "Implementing cutting-edge technology and establishing a comprehensive business model [P10]" was difficult. Designers were often left wondering, "you might want to create a great PEx, but who will pay for it [P5]?" They must consider factors such as "who impacts the final sales [P22]" and "what the budget holders are willing to reimburse [P3]", as they "sign off on whatever it is that we're creating [P2]". Sometimes the end user may no longer be the primary focus when "thinking about

the business model again [P21]". However, establishing a viable business model is not easy; a participant stated, "the biggest unknown for us is how the money is going to come to the company [P13]." Designers also "need to understand about insurance providers [P5]", and it depends on the location they are working on.

Strategies to commercial challenges. Commercialization requires stakeholder buy-in to the design and willingness to pay. 1) To provide evidence, designers believed that standardizing evaluations, providing tangible metrics, making things testable earlier, and conducting "

systematic literature review [P22]", will "show other people that this solution is much more friendly to use [P8]". Another strategy was "to identify who will be the largest opponents [P11]", because once they are convinced, the others will follow. Moreover, "providing user training [P6]" could enhance the acceptance of digital solutions. 2) To implement solutions and 3) establish business models, designers suggested "working with multiple budget holders [P2]" in the early design phase and "(involving the decision-makers) throughout the process [P17]".

5.4. Discussion

5.4.1. General findings

We explored the DH design process to reveal design challenges and identify potential strategies. Our results show that designers are engaged in various collaborative activities with multiple stakeholders and disciplines throughout the entire design process.

5.4.2. Design implications for digital health design

Based on our findings, in Figure 5-3 we present our novel Digital Health Design (DHD) framework comprising the four design phases and eight stages. We associated required stakeholders and possible design challenges with each phase and summarized eight adaptable strategies to address these challenges. Additionally, each phase depicts typical deliverables and design activities.

In an ideal situation, DH designers undertake a preparation phase by defining project requirements and constraints, as well as formulating project management plans together with clients, managers, and domain experts. Then, they move to the problem-thinking phase, identifying design problems, uncovering user needs through observing or talking with patients and healthcare providers, and defining design insights and goals. Next, they proceed to the problem-solving phase, where they start brainstorming or co-creation to develop design concepts and conduct user testing on small-scale prototypes. Finally, designers collaborate with programmers and marketers in the implementation phase to develop and launch the designs on the market. Occasionally, designers may also maintain or iterate the product post-release.

This process is non-linear, in line with many design process models like the double

diamond innovation framework, human-centered design, and the design thinking process that emphasizes the iterative process (Design Council, 2023; IDEO.org, 2015; Stanford). As illustrated in Figure 5-3, designers can cycle through the entire process several times or iterate within, between, and across phases. Additionally, designers can begin or end at any stage depending on the specific context, and they have the flexibility to skip certain stages or alter the sequence of some stages based on their work preferences or project-specific circumstances.

Our study contributes to previous research in this field in many ways. First, the identified digital health process represents an extended double diamond process (see Figure 3). Compared to the evolved Double Diamond framework (Design Council, 2023; Melles et al., 2021), which begins with understanding the problem and ends with testing out different solutions, our DHD framework begins with a preparation phase for clarifying project management, followed by problem-thinking and problem-solving phases, then concludes with an implementation phase for realizing commercial viability. Second, we recognized broader design challenges that refer to both design research and practice in varied digital health design projects. These provide the design community with a broader overview of which challenges they may face compared to our previous study (Groeneveld et al., 2018). Third, we identified many practical strategies to resolve challenges, which can help designers better equip themselves earlier in the process. Fourth, next to providing a general design process direction that could be also applied to other design domains, we have highlighted the specific activities, deliverables, and stakeholders involved in the DH design process at different design stages. While experience is intangible and volatile, an interactive DH solution is tangible and a mass-produced piece of technology (Cafazzo & St-Cyr, 2012). The way we design the digital PEx in healthcare determines how people will experience it. We believe that with the new DHD framework, designers are empowered to manage their DH design process more efficiently. Fifth, we uncovered designers' understandings of UX, PEx, and digital PEx, which partially align with the comparison of the academic definitions of these concepts. For instance, UX is regarded as "a person's perceptions and responses that result from the use and/or anticipated use of a product, system or service" (Bolton et al., 2018; Jokela et al., 2003), PEx is defined as "the sum of all interactions, shaped by an organization's culture, that influence patient perceptions, across the continuum of care" by the Beryl Institute (Website), and digital PEx is defined as "the sum of all interactions, affected by a patient's behavioral determinants, framed by digital technologies, and shaped by organizational culture, that influence patient perceptions across the continuum of care channeling digital health" in our previous publication (Tingting Wang, Guido Giunti, et al., 2022b). These definitions revealed that UX focuses more on general people's perceptions, which could be patients or healthcare providers, as long as they are the target users of the product, system, or service, while (digital) PEx targets patients in the context of healthcare. In addition, one of the biggest differences between PEx and digital PEx is the emphasis on digital technologies, which mediate all interactions between patients and other subjects in the healthcare system. We believe our findings on the similarities and

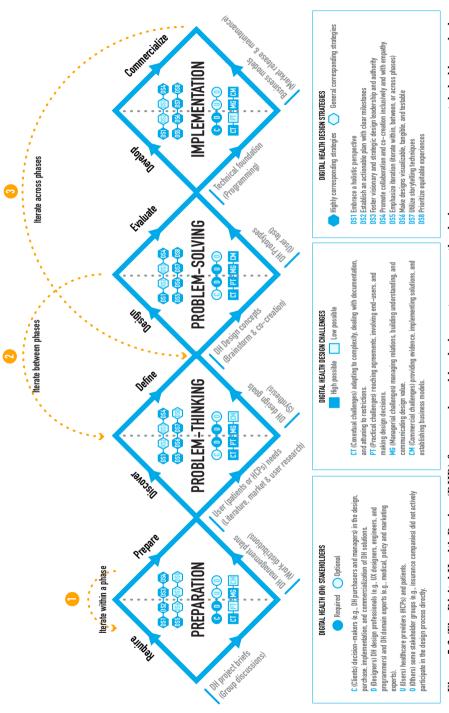


Figure 5-3. The Digital Health Design (DHD) framework enables designers to manage the design process, engage stakeholders, deal with design challenges, and seek out design strategies for improving the digital PEx (based on the evolved Double Diamond framework (Design Council, 2023; Melles et al., 2021))

differences of these concepts will help to build a common understanding of them across interdisciplinary collaborators, bring their attention to the varied elaborations on these concepts, and therefore reduce misunderstandings.

5.4.3. Overthinking or overlooking the preparation and implementation stages?

Most designers felt the processes of their DH design were in many ways similar to the typical design process in other domains; only some specific design activities such as applying for ethical approval were identified as different across domains. This aligns with findings of a previous study (Eckert et al., 2004) which highlighted subtle differences in the design processes across domains. Almost all participants shared the problem-thinking and problem-solving phases in their design processes, while less than half discussed the preparation and implementation phases. We hypothesize that some designers undertook but overlooked preparatory tasks, seeing them as basic project components as this may have been primarily conducted by project managers as described in a previous study (Kleinsmann et al., 2015). Other studies indicate that the design process normally begins with the sales and marketing teams who recognize design needs (Clarkson & Eckert, 2010), and stress the need for coherent, assessable plans early on for process efficiency (Dixon-Woods et al., 2012; Eckert & Clarkson, 2003) and multi-dimension project management, such as process management, personnel management, and risk management (Clarkson & Eckert, 2010).

Although we did not count the duration of each phase, design stages like fieldwork often consume more time than others, like problem framing. We assume that the perceived significance of each design stage might relate to time allocated by designers. Duration, however, does not equate to significance. A phase requiring a longer time and engaging more stakeholders may encounter more design obstacles and require greater design efforts. We found most projects end with generating design concepts or prototypes. The transition from conceptualization to implementation stage was often obstructed by a variety of challenges and resource constraints. In contrast to designers working in small or medium-sized businesses, fewer working in larger businesses reported the implementation stage. We hypothesize that this may be attributed to the highly distributed nature of work in larger companies, where designers are accountable for a particular aspect of the design process rather than the entire process. We believe that designers' characteristics and project contexts significantly affect the design process.

5.4.4. When and who to involve in the design process?

Our findings regarding stakeholder groups align with human factors/ergonomics research (Dul et al., 2012) identifying decision-makers, system experts, actors, and influencers as the key groups. We show that truly patient-centric design is unlikely in the real world, given the involvement of multiple parties and their varying viewpoints. As human factors and ergonomics (Dul et al., 2012) indicated, system experts and decision-makers are more

influential in the design process than actors. We found that clinical outcomes and business achievements were commonly valued more than user experiences. However, the cornerstone of effective DH design lies in a thorough and accurate understanding of both "user reality" and "clinical reality" (Cornet et al., 2019), meeting the needs of both care providers and receivers (Martin et al., 2005). Designing for human experiences requires prioritizing patient and user experience goals equally with process and clinical goals (Bate & Robert, 2006).

Patients and healthcare providers were the most common groups involved in the design process, acting as either domain experts or end-users. When acting as end-users, they were involved during fieldwork and user testing, aligning with a prior study (Martin et al., 2005) that user needs are usually identified during the design and evaluation phases. However, when involved as domain experts, it was less clear when to involve them and what they could contribute. Though some studies (de Wit et al., 2019; Martin et al., 2005) support patient involvement throughout the design process, our findings indicate that designers' opinions vary. Some advocate directly involving patients to improve their experiences, while others find that patient insights can be feasibly and efficiently gained from alternate sources. We believe that when aiming to improve the digital patient experience, patients should, where possible, be involved directly to uncover their real needs. However, in situations where resources are limited, gathering patient insights from alternate sources is practical. To minimize bias and ensure data saturation, we recommend relying on multiple sources, such as literature reviews and market research. There is no one-size-fits-all answer to stakeholder involvement, but we advocate designers actively engaging them in all stages of the project. Managers should lead the preparation phase, initiate relationships and create a holistic plan. Managers or designers should engage and enable clients to make informed decisions. Furthermore, domain experts should be involved, at least during the problem-thinking, problem-solving, and implementation phases to ensure relevant questions are asked and answered. Establishing a more defined distribution of responsibilities and meticulous planning will lead to smoother project progression.

5.4.5. Design challenges in digital health: similarities versus differences?

Our results revealed twelve distinct design challenges, some unique to DH design. These findings align with the previous study (Groeneveld et al., 2018) detailing challenges for design researchers in healthcare, indicating the shared hurdles among healthcare design context. Notably, the challenges we identified in this study only pertain to the obstacles that impede the design process, not the broader healthcare issues that designers seek to address through their design solutions. We show that some challenges, such as adapting to complexity and dealing with documentation, are more specific or demanding to DH design projects, while others, such as attuning to restrictions, are common or universal in general design projects. Restrictions, such as time, cost and resources constraints are prevalent in many design processes; these are not exclusive to digital health (Eckert et al., 2004). However, we believe that dealing with documentation can be more difficult, since the design of digital health often

requires more ethical considerations for involving stakeholders and implementing solutions. These include issues such as limited access to patients due to ethical issues (Paulovich, 2015) and privacy and security concerns emerging from digitalization of healthcare (Cummins & Schuller, 2020). Furthermore, we discovered that practical and commercial challenges were often associated with specific design phases, while contextual and managerial challenges were often present throughout the entire design process. As an illustration, providing evidence was typically a requirement towards the validation phase, whereas managing relationships was an ongoing necessity in the design process. It is worth noting that challenges can be interrelated, with one possibly exacerbating another, or conversely, addressing one can alleviate another. For instance, poor project management could lead to late design accidents, unrealistic expectations, or a lag in technical innovation (Clarkson & Eckert, 2010). Project ownership and role responsibilities can also impact the challenges faced by designers. Self-initiated project designers often grapple more with commercial challenges, whereas designers in large corporations assigned to specific project aspects may experience lesser commercial pressures due to the structured work distribution in such environments.

Developing digital health products often requires interdisciplinary work (Pagliari, 2007) and involves multiple stakeholders (Lupton, 2017), often leading to challenges like reaching agreements, building understanding, communicating value, making decisions, and providing evidence. In healthcare design, interdisciplinarity can be intractable because the involved parties have diverse interests, values, and epistemologies across multiple fields (Bauer, 1990; Hose et al., 2023), as well as distinct ways of working, thinking, and communicating about design (Clarkson & Eckert, 2010). An illustrative example is the tension between the slow process of evidence-based clinical trials and the expected rapid pace of innovation in the real business world. With fast technical development and fierce international competition (Clarkson & Eckert, 2010), the need to design better digital health products becomes paramount. However, the rapid pace of innovation may raise safety concerns due to the lack of quality and evidence-based research (Cummins & Schuller, 2020; Patrick et al., 2016). It can also create difficulties for non-designers to feel assured of the design process and quantify the design quality (Commission, 2014). Stakeholders in healthcare have myriad, often conflicting goals, such as profitability, convenience, and patients-centricity (Porter, 2010). Consequently, the perspectives of end users often differ from or are opposite to those of other stakeholders (Martin et al., 2005), implying that the support of one stakeholder group may risk alienating another (Dixon-Woods et al., 2012).

5.4.6. Design strategies in digital health: challenges versus opportunities?

To solve these challenges, our participants shared differing design strategies, grouped into eight themes. We found that some were mentioned for solving multiple challenges, while others were directed at solving a specific challenge. Challenges and opportunities are essentially two faces of the same coin in DH design. Challenges represent the hurdles that hinder seamless design, while strategies can lead to a successful design outcome. For example,

time restrictions are sometimes both a challenge and an opportunity, causing designers' stress while, at the same time, serving as a motivator to increase work productivity. Therefore, it is beneficial to embrace clear constraints like cost limitations as these often fuel creative thinking (Commission, 2014). Additionally, we discovered that some strategies are difficult to execute and therefore, challenging to implement. For instance, although effectively involving, communicating, and aligning with stakeholders are suggested, achieving these goals can prove challenging, as varied stakeholder goals can lead to divergent approaches and slow performance improvement (Porter, 2010). While aligning the interests of multiple parties can take time and energy, it is more likely to ensure the sustainability of the solutions (Dixon-Woods et al., 2012).

We found that some strategies, such as visualization, are a core design competence, whereas others originate from the broader knowledge of other disciplines, such as project management. Certain strategies pertain to flexible mindsets, while others correspond to technical skills. For example, some participants believed that design thinking, including systematic view and empathy, was valuable for addressing many challenges like involving stakeholders and building understanding. Skills that make things tangible, testable, and visualizable were useful for building understanding and communicating design value. Moreover, empathy equips designers to understand the necessary limitations and context (Commission, 2014), and storytelling can help reveal patients' daily lives (Bate & Robert, 2006). Visionary and strategic leadership with strong links to external stakeholders can effectively handle managerial challenges (McInnes et al., 2015). Nevertheless, this is typically determined by the organization's top tiers (Commission, 2014). Designers need to be empowered to showcase their expertise.

5.4.7. Limitations

The first limitation is that due to the qualitative nature, some challenges or design stages that participants experienced but did not mention during interviews may have been missed. Therefore, the quantitative information may not fully reflect the actual situations. However, the use of semi-structured and open-ended questions enabled participants to freely discuss their work and associated challenges (Martin et al., 2012). The second arises from the complexity of healthcare challenges; this study may not have effectively revealed design strategies to solve them. Some proposed strategies were based on individual experiences and may lack sufficient evidence, but recognizing these issues is the first step towards addressing them in future research (Dixon-Woods et al., 2012).

5.4.8. Future research

A number of aspects should be explored more deeply. First, designers' attributes, such as their educational qualifications and job responsibilities, as well as contextual factors surrounding projects, such as project ownership and location, may affect their design processes, the types and levels of challenges they encounter, as well as the specific strategies and skills

they would use. Future research could investigate the interrelationships between designers' characteristics and their design processes, challenges encountered, and preferred strategies. Second, the duration of each stage can impact how designers perceive its significance, so, investigating the time spent on each phase would add value. Third, our study revealed debates over when and whom to involve during the design process. Understanding the implications of involving, or excluding, specific stakeholder groups could be valuable, especially in resource-limited situations. Fourth, we believe that a predetermined allocation of work and a comprehensive plan would facilitate project management, so additional research is required to identify steps, methods, and criteria for creating a more effective industry design plan. Fifth, we discovered that clients played an important role in deciding what to design and how to implement it. However, it is unclear how to involve them more effectively in the design process to reduce their prejudiced expectations and establish shared goals with other stakeholders. Last, some strategies identified during our study were not tailored to address specific challenges. Therefore, we suggest that future research focus on exploring targeted strategies and presenting evidence to address each challenge identified in this study.

5.5. Conclusions

In this paper, we mapped the process related to design, redesign, and continuous improvement processes in digital health in eight stages and grouped them in four phases: preparation, problem-thinking, problem-solving, and implementation. We also identified twelve challenges and classified them in four categories: contextual, practical, managerial, and commercial challenges. Furthermore, we outlined eight corresponding strategies, recommended by the participants, to address each challenge type. Finally, we created a framework including design deliverables, activities, involved stakeholders, design challenges, and related design strategies for each design stage. The DHD framework not only aids designers in understanding the design practices in the healthcare industry but also guides them when managing their DH design processes and improving the digital PEx.

5.5.1. Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

5.5.2. Acknowledgements

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5.5.3. Authors' Contributions

TW conceived, designed, and led the overall study; conducted data collection; led and coconducted the coding process as well as data analysis and interpretation, and drafted the manuscript. GG, MM, and RG contributed to the study design. SQ and HZ performed the coding process and data analysis. All authors have reviewed and suggested modifications regarding the presentation of results, as well as read and approved the final manuscript.

Lessons for doing a PhD 05 Step Back from Stuck Moments

Research is an adventure full of peaks and valleys. While there are moments of clarity and progress, it's equally common to feel lost or stuck. Whether drowning in an endless sea of literature or entangled in a web of complex data, it's easy to start questioning your research questions, methods, and even yourself. These moments of doubt are an inherent part of the PhD journey. When this happens, my advice is simple yet powerful: step back and take a breath.

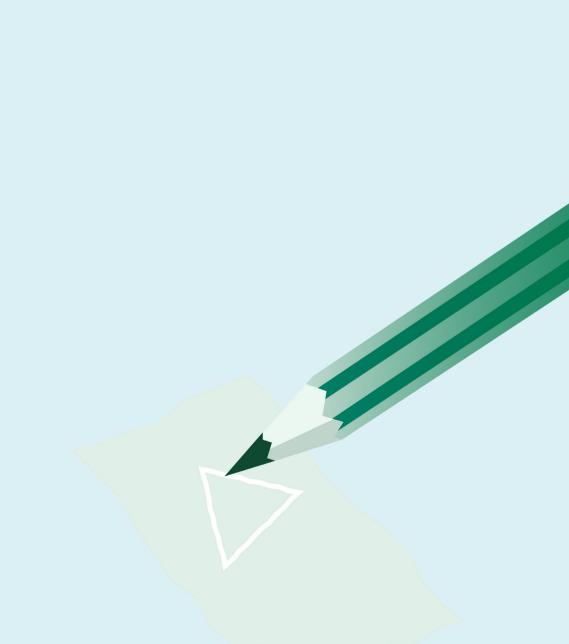
Shifting your focus can help recharge a fatigued brain and reignite your sense of direction. Often, stepping away from a project, even briefly, can provide clarity and open up new perspectives. This was vividly illustrated to me during an unexpected experience on a bus ride from Delft to Rotterdam. The bus driver, an elderly gentleman who seemed to be in his seventies, encountered a challenge just 100 meters into the journey. The bus stopped on an arched bridge due to a red light, but when the light turned green, it struggled to move forward up the slope. After several failed attempts spanning nearly 10 minutes, it seemed like the bus—and the driver—were stuck. Just as we passengers started to worry, the driver shifted the bus into reverse, rolled it back a few meters to a flat section of the road, and then accelerated. The bus crossed the bridge smoothly, and the passengers erupted into cheers. This experience left a deep impression on me. It was a perfect metaphor for how sometimes, when faced with an insurmountable slope in research—or life—the solution isn't to keep pushing forward but to take a step back, reassess, and reapproach the problem.

During my PhD journey, I've often encountered similar "slopes." There were moments when I felt like my research had hit a wall—when nothing I tried seemed to work. In those moments, my mentors often gave me wise advice: "Tingting, take a step back and think again." Every time I followed their advice, I found myself discovering new solutions, rethinking my strategies, or even changing my perspective entirely.

Stepping back isn't just helpful when stuck in research—it's also invaluable for teamwork and collaboration. PhD research often requires working across disciplines and with diverse teams, which can be both rewarding and challenging. Disagreements or misunderstandings can arise due to differing priorities, technical languages, or working styles. When tensions arise, I've learned that stepping back to revisit the original goals and visions of the project can be a game-changer. For example, during one collaborative design research project, our team reached a standstill because of conflicting opinions. Progress stalled, and frustration built up. Instead of forcing a resolution, we paused to reflect on the shared vision we had at the start of the project. Revisiting our common goals helped us realign our efforts and ultimately move forward with renewed focus. In design research, individual contributions are important, but the true power lies in collective efforts and maximizing the synergy of teamwork.

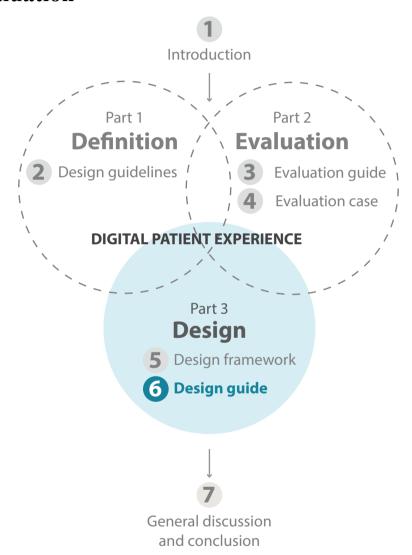
When you're overwhelmed or stuck, don't be afraid to step back, reflect, and recalibrate. Whether it's navigating a complex research problem, or resolving team tensions, the lesson I want to share is this: "Step Back." It's a simple but powerful strategy that I've observed in life and found invaluable in work. By taking a moment to step back, you'll often find the clarity and strength you need to move forward.





Chapter 6

Digital Patient Experience Design Guide: Usability, Usefulness, and Content Quality Evaluation



The content of this chapter is under review in:

Wang, T., Armagan A., Goossens, R., Xiao, D., & Melles M. Digital Patient Experience Design Guide: Method Evaluation Study. Manuscript is under review in a peer-reviewed journal.

Abstract

Introduction:

Designing effective and comfortable digital patient experiences is complex, therefore we created a web-based design guide to support designers through this process.

Objectives:

We evaluated the usability, usefulness, and content quality of the design guide, collected insights for further improvements, and tested design implications.

Methods:

We conducted a method evaluation study during a design workshop with design students. Participants completed pre- and post-questionnaires, a usability test, and six focus group sessions.

Results:

The cumulative System Usability Score was 71, showing the design guide was usable. Comparing pre- and post-design self-efficacy scores showed insignificantly increased design self-efficacy in terms of performing digital patient experience design. The design guide's content quality was rated as good. Analysis of the focus group sessions resulted in twelve themes, divided into four clusters: positive aspects, suggested improvements, future use, and 'other' remarks

Discussion and Conclusions:

Our digital patient experience design guide was evaluated as usable, with suggestions given for further improvement. Our study revealed conflicting tensions in the guide's design, requiring a balance between less and more, specific and general, as well as fixed and flexible. These tensions reveal the diversity and conflicts in students' needs for applicable, effective design guides.

Keywords

Digital health solutions; User experience; Design guidelines; Design knowledge transfer; User test; Human-Centered Design

6.1. Introduction

In the last decade, a rapidly expanding digital transformation in healthcare has facilitated major improvements in patient experience (PEx) (Tingting Wang, Guido Giunti, et al., 2022b). Design researchers and practitioners play a unique role in this challenging transition and increasingly contribute to shaping the user friendliness of future healthcare systems (Groeneveld et al., 2018; Tsekleves & Cooper, 2017). Design in public health faces currently challenges about scale, scope, and speed, including "how to explore human experience on a larger scale, how to manage a larger scope of inquiry, and how to respond to changes in speed (Erwin et al., 2022)". In an earlier paper, Wang, Giunti et al (2022b) describe effective and comfortable digital PEx as "the sum of all interactions affected by a patient's behavioral determinants, framed by digital technologies, and shaped by organizational culture, that influence patient perceptions across the continuum of care channeling digital health". Designing effective, applicable PEx is complex, and research is needed to guide design education and practice. In previous studies (Tingting Wang, Guido Giunti, et al., 2022a, 2022b; Wang, Giunti, et al., 2024; Tingting Wang, Shuxian Qian, et al., 2022; Wang, Zhu, et al., 2024), we investigated the definition, evaluation, and design of digital PEx. To support design students and practitioners to more effectively improve digital PEx, we developed a web-based digital PEx design guide that transferred our research findings into actionable design knowledge and guidelines.

In design education and practice, design guides, methods, and tools are commonly used as appropriate forms to convey research knowledge to a wider audience (Cash et al., 2023; Fu et al., 2016; Reimlinger et al., 2019). Designers use guides to develop new capabilities and mindsets or become aware of and strengthen existing capabilities (Daalhuizen, 2014). To our knowledge, there is a lack of design guides that particularly focus on supporting the design of digital PEx. Existing design guides such as the Delft Design Guide (van Boeijen et al., 2020), focus on design in general rather than on healthcare design. Transferring the knowledge obtained from healthcare design research to support digital PEx design is, therefore, a new frontier.

Websites form a convenient and accessible method of information provision and design education (Cook, 2007; Daniluk & Koert, 2015). Many much-used design guides offer digital versions, such as the evolved Double Diamond innovation framework (Design Council, 2023), the Field Guide to Human-Centered Design (IDEO, 2023), and the Improving Improvement Toolkit (Healthcare Design Group Cambridge Engineering Design Centre, 2020). We therefore chose "website" as the delivery form for introducing our research findings to a wider design community. The main content of our design guide was developed from previous studies (Tingting Wang, Guido Giunti, et al., 2022a, 2022b; Wang, Giunti, et al., 2024; Tingting Wang, Shuxian Qian, et al., 2022; Wang, Zhu, et al., 2024), where we conducted reviews and designer-interviews to identify the influencing factors, design

considerations, evaluations of the digital PEx, as well as a novel digital health (DH) design framework. We also gathered input from three master graduation projects (Li, 2022; Long, 2022; Qian, 2022) on designing "Consultation Room 2030" and two ongoing projects that evaluate the digital PEx in clinical settings: one uses a home-based counseling digital intake tool to reduce outpatient visits in fecal immunochemical test-based colorectal cancer screening programs; another applies virtual reality (VR) distraction in wound care treatment for better pain management.

Bringing actionable knowledge from research to education and practice is challenging, as there are many different channels in which knowledge is transferred, and forms in which knowledge is made explicit and actionable to effectively communicate research results (Zielhuis et al., 2022). The misalignment of dissemination methods between academic researchers and practitioners often result in a research-to-practice gap (Cook et al., 2013; Telenko et al., 2016). Researchers tend to use academic language and formats that prioritize theoretical knowledge, only reaching out to practice when they have concrete results to communicate, thereby limiting the impact of design research on education and practice (Pearce & Huang, 2012; Stappers & Giaccardi, 2017; Zielhuis et al., 2022). The essence of academic research is to produce knowledge, often delivered through research articles (Löwgren, 2013). However, these academic publications are commonly not written for design practitioners, who may have little academic background and limited time to read articles (Telenko et al., 2016).

Thus, there is a need to make research more accessible by generating 'middle-level' knowledge and concrete solutions in the language of design practice. This in turn will impact practice through the transfer of processes, methods, tools, and technology that lead to innovations for societal needs. To achieve this, conducting workshops and seminars with both design students and practitioners should be encouraged (Reimlinger et al., 2019; Telenko et al., 2016; Zielhuis et al., 2022). In addition, engaging students is a powerful mechanism for knowledge transfer; educating future design practitioners and industry leaders is one of the most important ways of bringing research to practice (Telenko et al., 2016). We believe knowing what design students expect and experience can formulate the starting point for generating, evaluating, and improving a design guide in general.

Therefore, in this paper, we conducted a method evaluation study to 1) evaluate the usability, usefulness and content quality of the digital patient experience design guide in a design education context, 2) collect insights for further improving the digital patient experience design guide, and 3) provide design implications for generating and evaluating design guides in general.

6.2. Methodology

6.2.1. Participants

Following purposive sampling (Etikan et al., 2016), design students who enrolled in a 10-

day workshop on Patient Journey Mapping and Digital Patient Experience (PEx) Design at Jiangnan University's School of Design (China) were invited to participate in this study. Students were informed about the research purpose and contents in advance. Participation was voluntary. This study was approved by the Human Research Ethics Committee of Delft University of Technology in September 2023.

6.2.2. Prototype

We tested a functional prototype of our web-based digital PEx design guide (See Figure 6-2). Its development was inspired by the research-through-design process as described by Stappers and Giaccardi (Stappers & Giaccardi, 2017). Based on the synthesis of our previous research findings, we conducted iterative prototyping and a series of user tests to generate and evaluate the design guide. As Figure 6-1 presents, in the generation part, we synthesized our previous research findings into the design guide contents, summarized website design elements from the existing web-based design guides, created a wireframe and a Minimum Viable Product (MVP), developed a functional prototype and improved it iteratively based on evaluation insights, and finally developed a website under the tudelft.nl domain. Particularly, we evaluated and iteratively improved the design guide through conducting walkthroughs, expert reviews, user test workshops, heuristic evaluation tests, and presenting the design guide to related stakeholders. These research and design activities have been reported and published in a related master's thesis (Yun, 2023) and a conference paper (Wang, Wang, et al., 2024).

6.2.3. Materials and procedures

The final prototype used in this study is a functional website (see Figure 6-2), containing six main pages that serve different purposes:

- the "D&H Guide" homepage helps users acquire background knowledge and set expectations, and provides access to templates and articles
- the "Design Process" page provides an overview of the DH design process with four detailed design phases, related stakeholders, challenges, and strategies
- the "Understand Patient" page presents influencing factors and design considerations
 of the digital PEx and provides nine design guidelines to help designers improve the
 digital PEx
- the "Evaluate Experience" page guides designers when evaluating the digital PEx by providing detailed evaluation objectives, timing considerations, indicators, and approaches
- the "Case Studies" page presents three design cases and two evaluation cases to inspire and support designers when designing and evaluating a digital PEx
- the "Resources" page explains terminologies and provides links to other design and evaluation guides in this field.

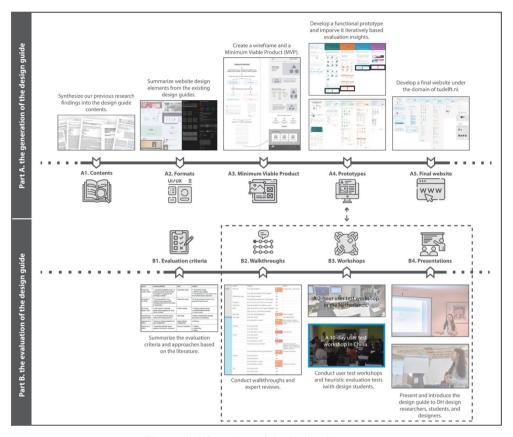


Figure 6-1. Overview of the Design Process.

Procedure

Our evaluation study formed part of a 10-day workshop on Patient Journey Mapping and Digital Patient Experience Design. Figure 6-3 provides an overview of how the data collection points were integrated into the workshop, where participants took part in many other activities, including lectures, self-study through MOOCs (Richard Goossens, 2023), group work, and coaching sessions. In the first week, students learned about patient journey mapping and focused on the problem-thinking phase of the design process. On day 5, the digital PEx design guide was introduced, and students were asked to consider digital PEx and work on problem-solving. To facilitate learning by doing and increase students' engagement in the workshop, we provided four design assignments and asked them to form a team with three or four members. There were four data collection points:

baseline measure: on day 1, we asked students to complete a pre-questionnaire that
contained informed consent, demographics, and a self-efficacy measure. The selfefficacy measure was adapted from Delft University of Technology's rubric for master
graduation projects at the faculty of Industrial Design Engineering (Delft University
of Technology, 2018);

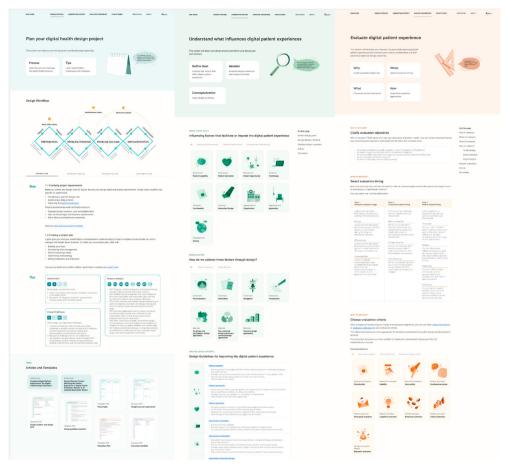


Figure 6-2. The Digital Patient Experience Design Guide Prototype.

- usability test: on day 5, we introduced the web-based design guide in detail. To increase engagement, students were asked to answer five questions by seeking information on the main webpages and then complete a usability questionnaire based on the Usability System Scale (SUS) (Brooke, 1996);
- focus group interview: on day 7, we invited students to join a focus group interview session (4-6 students in each group) and share their thoughts, experiences, and suggestions for using the design guide;
- outcome measure: after the workshop, students were asked to complete a postquestionnaire to report their self-efficacy after using the design guide and evaluate the design guide's content quality. The questions were adapted from the IDE master graduation project rubric (Delft University of Technology, 2018), with method content theory from Jaap Daalhuizen and Philip Cash (Daalhuizen & Cash, 2021) separately.
- The questionnaires and focus group interview outline can be found in Appendices 6-1, 6-2, 6-3, and 6-4.

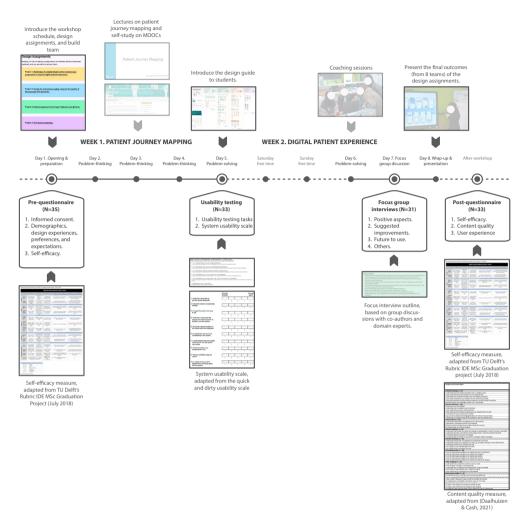


Figure 6-3. The User Test Study Design and Data Collection Points.

To facilitate engagement and teamwork among the participating design students, we created a Figma workplace as a resource library to share workshop arrangements, notifications, daily tasks, design assignments, and related articles (see Figure 6-4).

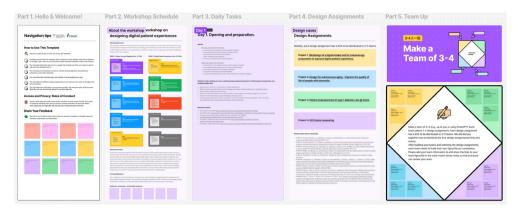


Figure 6-4. Figma Workplace for the Workshop.

6.2.4. Data analysis

We used SPSS (Statistical Package for Social Sciences, version 28.0.1.0 (142), Chicago, IL, USA) to analyze the data collected through the questionnaires. Descriptive analysis was used to analyze the participants' demographic information. Usability and content quality scores were summarized separately as means and standard deviations. Self-efficacy scores before and after using the design guide were compared through paired-samples t-tests. All focus group conversations were audio-recorded, transcribed and deidentified. Transcriptions were imported into ATLAS.ti (Scientific Software Development GmbH; Version 22.1.0; 3475) for thematic analysis (Braun & Clarke, 2006). For conversations in Chinese, translations to English were made for quotes, codes, and themes. Based on the focus group interview outline, data extraction focused on 1) positive aspects, 2) suggested improvements, 3) future use, and 4) other remarks.

6.3. Results

6.3.1. Demographic information

Table 6-1 presents the participant characteristics. Of the 35 design students from six different majors, most (n=24; 68.6%) were registered as master students, the majority (n=28; 80%) were female. A quarter of the students (n=9; 25.7%) had been involved in DH design projects, whereas almost three quarters (n=26; 74.3%) had experience in using general design toolkits such as the Delft Design Guide (van Boeijen et al., 2020). Only one fifth of the participating students (n=7; 20%) had used healthcare-specific design tools such as Patient Journey Mapping (Trebble et al., 2010). Digital design guide formats (n=30; 85.7%) were preferred over a tangible (i.e., non-digital) format (n=5; 14.3%), with websites (n=28; 80%) being the most preferred forms.

Table 6-1. Description of Study Participants.

Characteristics	N=35 (100%)
Age	
Range	20-25
Mean	23 (SD 1.5)
Gender	
Female	28 (80%)
Male	7 (20)%
Education	
Master students	24 (68.6%)
Bachelor students	11 (31.4%)
Majors	
Interaction and experience design	12 (34.3%)
Industrial design	9 (25.7%)
Industrial design and product strategy	6 (17.1%)
Visual communication design	4 (11.4%)
Product design	2 (5.7%)
Service and experience design	2 (5.7%)
Design routines	
Rely on design rationality	21 (60%)
Rely on design intuition	14 (40%)
DH design experiences	
Has been involved in DH design projects	9 (25.7%)
General design toolkits usage experiences	
Has experiences (e.g., the Delft Design Guide)	26 (74.3%)
Healthcare-specific design tools usage experiences	
Has experiences (e.g., the Patient Journey Map)	7 (20%)
Design guide format preferences	
Digital version	30 (85.7%)
Tangible version	5 (14.3%)

Facilitators and barriers listed by participants as influencing their use of design guides were categorized in eight clusters. Facilitators (4 clusters) included 1) applicable to the context of need (n=21 60%) such as assisting in addressing design challenges, completing tasks, and offering broad relevance to design endeavors; 2) effective (n=19; 54.3%) such as enhancing design capabilities, understanding, knowledge, and performance, or improving the rationality, rigor, and evidence of the design process or outcomes; 3) valuable (n=4; 11.4%) such as providing credible, integrated, systematic, and updated contents; or 4) usable (n=3; 8.6%) such as easy to understand and navigate. Conversely, barriers to using a design guide were 1) lacking usability (n = 21; 60%) such as being overly complex, difficult to understand,

learn, use, or time-consuming; 2) lacking in applicability (n = 10; 28.6) such as not aligning with the context of need or design tasks; 3) lacking accessibility (n = 8; 22.9%), such as not having open access resources or difficulties in finding them; or 4) having limited impact (n = 5; 14.3%).

6.3.2. Usability

In total, 33 students (2 dropped out due to sick leave) participated in the usability test, where they spent a range of 4–120 minutes (average 20 minutes) completing five given tasks to familiarize themselves with the design guide. One-third misunderstood some pieces of information on the webpages "understand patients" and "evaluate experiences". Overall, the System Usability Score was 71 on average (see Appendix 6-3) supporting a 'good' usability of the website (Bangor et al., 2009).

6.3.3. Self-efficacy

We conducted paired-samples t-tests with 33 participants to compare the differences in self-efficacy in designing digital PEx before and after using the design guide. Our results (Table 6-2) show that there was no significant difference between the pre and post-design self-efficacy (t(32)=-1.6, p=.123). We note a small increase in self-efficacy from 7.2 (1.3) to 7.6 (1.1) before and after using the guide.

Table 6-2. Self-efficacy Scores (11-point scale)

Categories	Items	Before:	After: M(SD)
		M(SD)	
Knowledge	Collect and analyze knowledge	7.2 (1.3)	7.6 (1.1)
	Generate and evaluate knowledge	7.3 (1.4)	7.5 (1.4)
Methods	The use of methods and tools	7.3 (1.2)	7.7 (1.3)
	Dealing with project complexity	7.1 (1.5)	7.5 (1.5)
Project results	Feasibility	7.2 (1.4)	7.5 (1.2)
	Desirability	7.2 (1.4)	7.6 (1.2)
	Viability	6.6 (1.8)	7.4 (1.5)
Communication	Academic level	6.9 (1.7)	7.5 (1.2)
	Connecting to stakeholders	7.4 (1.5)	7.6 (1.3)
Project	Planning	7.4 (1.7)	7.6 (1.3)
management and	Autonomy & initiative	7.6 (1.5)	7.4 (1.7)
planning	Response to feedback	7.6 (1.6)	7.7 (1.3)
	Time spent	7.5 (1.5)	7.8 (1.3)
Cumulative score	Self-efficacy	7.2 (1.3)	7.6 (1.1)

6.3.4 Content quality

In total, 33 students evaluated the content quality of the design guide as being at least

reasonable. Knowledge quality was evaluated as the highest variable, followed by method mindset, method goal, method rationale, method procedure, role ambiguity, method framing, and goal-means conflict (Table 6-3).

Table 6-3. Method content theory evaluation (N=33; 7-point scale).

Variables	M (SD)
Knowledge Quality: measures the quality of shared knowledge content,	5.7 (0.8)
through six content attributes: relevance, ease of understanding, accuracy,	
completeness, reliability, and timeliness. (α =0.9)	
Method Mindset: the set of described values, principles, underlying beliefs,	5.6 (0.6)
and logic that inform the design guide and its use. (α =0.8)	
Method Goal: the described goals and the prioritization of those goals the	5.4 (0.8)
design guide aims to help achieve through its use. (α =0.8)	
Method Rationale: the performance-goal relationship and motivations	5.4 (0.8)
underlying the goals of the design guide. (α =0.7)	
Method Procedure: the structural activities described in the design. guide and	5.3 (1.0)
their relative chronological and logical ordering. (α =0.9)	
Role Ambiguity: measures both the predictability of outcomes in response to	5.3 (0.9)
one's behavior as well as the presence and clarity of requirements that guide	
behavior and help determine its appropriateness. (α=0.8)	
Method Framing: the context of use described in the design guide and its	4.5 (0.7)
implications and prerequisites for method us.e (α =0.8)	
*Goal-means conflict: measures the conflict that arises from lack of clarity,	3.6 (1.4)
ambiguity and misalignment in relation to goal and procedure. (α =0.9)	

Note: The "*" means question with a negative tone; α >0.6 (i.e., Cronbach's coefficient alpha) means the reliability of multiple-item scales was achieved.

6.3.5. Focus group interview

Analysis of the focus groups with 31 students (another two students dropped out because of personal reasons) revealed twelve themes for evaluating the design guide. These were divided into four clusters: positive aspects (n=26; 78.8%), suggested improvements (n=26; 78.8%), future use (n=11; 33.3%), and 'other' remarks (n=10; 30.3%).

In summary, most students complimented the design guide for giving them a holistic view and complete understanding of the digital PEx, mentioning a sufficient and structured website (n=21; 67.7%) and template contents (n=8; 25.8%), as well as an attractive visual design (n=5; 16.1%). However, many indicated that improvements to the design guide were needed to provide relevant, detailed, and resourceful website contents (n=18; 58.1%), intuitive and interactive interfaces, and simple and ready-to-use (n=11; 35.5) template contents (n=5; 16.1%). Some students felt the design guide was more suitable for long-term design projects

(n=9; 29.0%) and they would continue to use the design guide (n=8; 25.8%) when performing healthcare-related long-term design projects or when the guide keeps updating, and they were willing to recommend it to others (n=3; 9.7%) as well. In addition, students noted limitations of the study design, such as the timing of accessing the design guide (n=8; 25.8%), their own preferences (n=4; 12.9%), and (12) language concerns (n=2; 6.5%).

Cluster 1. Positive aspects

During the focus group interviews, 26 students mentioned positive experiences using the design guide. Most found the website contents easy to understand, complete, and useful, providing a clear, detailed, and structured design process with systematic, integrated, and sufficient information, and giving them a sense of reassurance. For example, they mentioned that the design guide "provides clear design process direction, helps us know what we should focus on [J1]", "is easy to understand with clear functions, complete and integrated information [Z3]", and "provides sufficient, complete, and systematic information to understand the design processes and patients, facilitates a holistic, systematic view, and inspires new design directions [T13]".

Positive feedback on the contents was related to the design processes, understanding patients, evaluating experiences, and case studies, which help them "become familiar with the design context [W26]", "understand patients better [Q23]", "increase evaluation knowledge [H16]", "obtain new inspirations and fresh ideas [P18]", "align their design concepts with reality [Z25]", and "review the design process afterwards [Y27]". Some students felt the template contents were helpful because they provided "clear structure for design actions [Y7]", "useful steps to make a design plan [Q23]" and "a new perspective to understand the design [Z30]". One suggested that "the templates can be used for the final walkthrough to check if the design goals and requirements are met [L4]". A few mentioned the website visual design and said they were satisfied with the "clear, neat, and clean interfaces, nice color themes, and icons [S2]", which provided "clear information structure and navigation [T13]" and were "easy to understand by following the step-by-step instructions [Z14]".

Cluster 2. Suggested improvements

Improvements and/or extensions were suggested by 26 students, mostly related to the website contents. For example, some felt that "the information related to clients and business (in the design process) is irrelevant [P6]"; others suggested "improving the information provision related to clients and business aspects since students are not familiar with them [Q23]". Some felt "the design guidelines are too general, resulting in similar design outcomes that lack novelty [C17]", while others recommended "increasing the specificity of the design guidelines [W26]". Some expected to have "more detailed [L11]" and "regularly updated [Y7]" design cases; they expected to know "how to converge and select the brainstormed ideas [C19]". Moreover, they wanted to have more "hyperlinks [Y12]", "references [T13]", and "visualizations [Y27]" to increase their understanding of some theories and concepts.

In addition, students found it "hard to understand the evaluation-related information [L5]" and wanted to have "guidance on how to select appropriate evaluation indicators [H16]" and access to "validated evaluation instruments [Y12]" and "detailed evaluation cases [Y27]". Some students mentioned potential improvements in website interaction design. For example, some suggested adding "a table of contents [J1]", "add a timeline [Z3]", and "a search bar or filters [K15]" to increase navigation clarity and provide guidance and instructions on "when to use what in which contexts [S2]" and "how to fill out the templates [C17]" to improve the usability of the design guide. Comments related to the template contents included "adding more evaluation information, like measurement instruments and Likert Scales [Y7]", "removing overlapped information between the website and templates [Y29]", and "providing some filled templates as examples [Z14]". These comments revealed three contradictory needs on the guide's design among the workshop students, requiring a balance between specific and general, less and more, as well as fixed and flexible.

Cluster 3. Future use

Thoughts on Future use of the design guide were shared by 11 students. Some discussed the usage contexts of the design guide; they felt "the target users are design students, design beginners, and design professionals [S2]" and "the design guide is more suited to long-term design projects [M9]", as well as "would like to have the design guide at the beginning of the design project [Z3]". In addition, some mentioned they would continue to use the design guide for their future works, such as "master graduation projects [Z3]". Some said they would use it in the future but "won't follow the design guide step-by-step [L11]" and believed "the design guide should be kept updated [Y7]" for sustainable use. In addition, a few stated they would like to recommend the design guide to others, especially the parts related to "design cases [Y7]", and "healthcare or non-healthcare designers [L4]".

Cluster 4. Other remarks

Some students noted limitations to using the design guide in the study; for example, some mentioned the timing at which they started using the design guide in the middle of the workshop finding "it was a bit late [Z3]" and "had limited time to become familiar with the website and templates [Z25]". A few expressed their preferences such as "preferring to use websites instead of templates [Z3]", "preferring a combination of websites and templates [L4]", and "design routines that completely align with the design guide [P6]" or evaluation approaches, such as "usability tests [Y12]". Issues with language were mentioned by some Chinese speakers; the design guide is written in English and they had to use Google Translate to understand the website contents. One found "it is acceptable [Z3]" while the other felt "the translation seems not precise [L5]".

6.4. Discussion

We generated a web-based design guide for guiding DH design with a specific focus on improving the digital PEx. To transfer our research findings on designing digital PEx into

actionable design knowledge, the design guide includes multiple components such as fundamental concepts, guidelines, frameworks, and cases. In this study, we evaluated the guide in a 10-day design workshop with 35 design students. They generally evaluated the guide as usable; they were satisfied with the content quality. However, they noted further improvements needed on the contents and interaction design and further clarity on the usage contexts. The study also resulted in design implications for developing and evaluating design guides in general.

6.4.1. How to balance contradictory needs (the generation of the design guide)?

The focus group interviews revealed three tensions between the design guide's user needs: less and more, general and specific, fixed and flexible. On the one hand, students expected the design guide should provide access to a variety of knowledge for them to consult as a resource library for flexible exploration and use. It should be comprehensive in information and content, provide a systematic overview, give complete conceptual explanations, provide detailed design cases. and integrated design resources. On the other hand, they wanted the design guide to be simple and easy to use, offering concise and clear information with low learning and usage costs, enabling them to effortlessly complete efficient designs. For example, in the cluster of suggested improvements, some students mentioned the information related to clients and businesses was irrelevant and suggested removing it, while others felt they needed more detailed information on this topic due to not being familiar with it. We believe these tensions reflect two considerations for generating design guides. First, to create the right balance, the design guide should contain 'intermediate-level' knowledge such as design methods, tools, guidelines, patterns, concepts, experimental qualities, criticism, and annotated portfolios (Löwgren, 2013). These are more abstract than specific cases, but less than the scope of generalized theories (Höök & Löwgren, 2012) is suggested. Second, there is no one-size-fits-all solution. In alignment with existing literature (Daalhuizen, 2014), a designer's knowledge, capabilities, and preference, as well as the specific design context influence their use of design methods. In addition, to use a design guide effectively, users are expected to have sufficient knowledge and make efforts to apply this (Roozenburg & Eekels, 1995). Understanding design students or designers' mindsets and clarifying the usage contexts of the design guide is important, as is using the guide as a flexible resource instead of strictly following it as a route from start to finish (Daalhuizen, 2014). In addition, we noticed that most comments, whether positive or negative, were related to the contents and presentation of the guide, which highlights the importance of these two aspects. Reflecting on our iterative design guide generation process, we realized that most of our efforts were on modifying its presentation and contents.

To summarize our learning from generating the design guide, we share six key lessons on generating a usable and useful guide. First, learn by doing and start generating the guide; make something simple first, and iteratively improve it. Second, to increase user engagement,

start by asking questions to your future users (i.e. design practitioners) and trigger them to think about the design problems they are facing. Third, use a structure familiar to the user to frame the design guide, which can reduce their cognitive load at the beginning and help them navigate more easily. Fourth, avoid using jargon and academic vocabulary; if necessary, add hyperlinks to explain it. Fifth, use consistent terminologies when introducing the design guide to participants. Lastly, provide examples to help users understand the guide.

6.4.2. How to evaluate the impact (the evaluation of the design guide)?

Generating an "OK" design guide may not be difficult, but evaluating its impact on design education and practice is more complex (Zielhuis et al., 2022). The benefits of using design guides, methods, or tools that allow design students and designers to learn from others across space and time (Daalhuizen, 2014) and increase their chances of achieving successful design solutions (Fu et al., 2016) have been investigated by many researchers, but this does not guarantee successful results (Roozenburg & Eekels, 1995; Wang, Wang, et al., 2024). Many factors influence the impact of a design guide, such as differences between designers, design contexts, and design objects (Dorst, 2008; Gray, 2022), resulting in difficulties in determining what impact can be measured and how to measure it. In our case, we were unable to find a standard, unified, and validated instrument that could measure the design guide's impact. To seek evidence for the guide's impact as well as gain insights on improving it, we chose usability, usefulness (i.e., self-efficacy changes), and content quality as our evaluation criteria. Reflecting on the evaluation part, we found that usefulness is the most difficult to measure. First, compared to usability and content quality, we found few studies evaluating the usefulness of a design guide. To our knowledge, there is no standard instrument available for evaluating usefulness of a design guide for supporting DH design. Second, the evaluation of usefulness often requires more time and repeated measures. When designers get a new design guide, it takes time and requires awareness to familiarize themselves with the guide and to strategically integrate it into the design process (Reimlinger et al., 2019). Those designers who lack related background information may initially feel confused or overwhelmed. In this study, to evaluate our guide's usefulness, we adapted the rubric for evaluating master graduation projects in the Faculty of Industrial Design Engineering at Delft University of Technology (Delft University of Technology, 2018).

In line with the evaluation results presented above, we summarize our key considerations to support future research when evaluating design guides. First, evaluate by using; to increase user engagement, we suggest assigning clear design tasks in using and evaluating a new design guide, method, or tool. For example, in our evaluation workshop, we motivated design students to use the design guide by giving them design tasks and assignments. Second, conduct baseline and outcome measures; to measure the guide's usefulness, we suggest comparing guide users' design knowledge, mindset, capabilities, and preferences before and after using it. For instance, we compared design students' self-efficacy scores before and after using our design guide. Last, collect both qualitative and quantitative evaluative data. For example, we

collected both types of data to not only seek evidence on the impacts of the design guide but also gather insights to further improve it. As noted earlier, it may not be difficult to develop an "OK" design guide, but to iteratively improve the guide and better support designers with different mindsets and in varied usage scenarios, it is vital to understand the users' experiences, preferences, and expectations.

6.4.3. Limitations, strengths, and future research

First, the inclusion of design students limits our study regarding industry perspectives, as designers at novice and advanced levels often face different issues when using a method (Dorst, 2008), and design guidelines impact their performance differently (Reimlinger et al., 2019). However, during the generation and evaluation of the design guide, input was gained from design practitioners and experts by presenting or discussing our research findings at conferences, group meetings, or in informal talks. We believe the overview of the design process (see Figure 1) on generating and evaluating the digital PEx design guide can serve as an example to support future researchers in generating and evaluating their own design guides. We recognize that to further improve the design guide, testing it with design professionals are necessary. A follow-up, separate, and complementary evaluation with design practitioners is a next step.

Second, our design guide contains varied components; we did not evaluate the different components separately. Therefore, some students may have reported their experience based on the whole design guide, while others may have based their impression on a few components of the design guide. To avoid this bias, we introduced questions from different perspectives and required participants to look through the whole guide. For future research, we suggest separately evaluating each component of a multi-component design guide.

The sample size is small, limiting any generalization of our research findings. In addition, the participating students were aware that the researchers (i.e., the authors) were involved in the generation of the web-based design guide, and thus they may have given biased feedback. To reduce bias, we encouraged students to give both positive and negative feedback. In addition, for the focus group interviews, due to the time limitation each participant was not asked all the same questions; therefore, the numbers for some focus group interview themes may not reflect the true balance. However, including both qualitative and quantitative data can help reduce potential research bias. We recommend collecting both qualitative and quantitative data to more comprehensively evaluate future design guides.

6.5. Conclusions

We show that our digital patient experience design guide was evaluated as usable with good content quality, but that it needs further improvement in providing relevant, detailed, and resourceful contents, intuitive and interactive interfaces, as well as simple and ready-to-use templates. We believe these improvement insights are relevant for developing and evaluating

design guides in general. In addition, participants reported conflicting tensions in the guide's design, requiring a balance between less and more, specific and general, as well as fixed and flexible. These tensions reveal the diversity and conflicts in students' needs for useful and effective design guides. On the one hand, users want design guides to hold relevant, detailed information and content, provide a systematic overview, include complete conceptual explanations, detailed design cases, and integrated design resources, enabling them to use the design guide as a resource library for flexible exploration. On the other, they want a design guide to be simple and easy to use, offer concise and clear information with low learning and usage costs, enabling them to effortlessly complete efficient designs. We believe this study serves as an example, inspiring future design researchers to develop and evaluate their own design guides.

6.6. Acknowledgement

We would like to thank all the participating design students in this study for sharing their experiences with using the design guide, master student Yun Wang for developing the design guide website, professor Judith Rietjens and associate professor Jaap Daalhuizen at Delft University of Technology, and professor John Clarkson at the University of Cambridge for providing their valuable suggestions on the study. This work was supported by the [China Scholarship Council] under Grant [201906790084], China Foreign Experts Affairs under Grant [G2023144005], and Delft Health Initiative.

Lessons for doing a PhD 06

Expand Your Social Impact.

As design researchers, our work goes beyond addressing academic challenges and making scientific contributions. We have a unique opportunity—and responsibility—to expand the societal impact of our research. While design research may seem "softer" compared to disciplines like computer science or medicine, it holds incredible potential to translate cutting-edge technologies into meaningful, real-world applications.

During my PhD journey, there were indeed moments of doubt and stagnation that required me to step back and reassess my research. However, there were also countless highlights that made me appreciate the charm and value of design research. As I mentioned in the preface, over the past four years, I have acted as a design researcher, a design communicator, and a designer. I cherish the moments of sharing my research with others and deeply value the societal impact it has made.

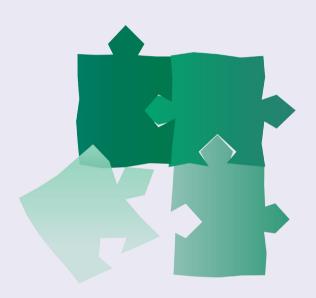
When I first started my PhD, I often questioned the value of my work. Reading studies in fields like medicine or computer science—where researchers develop advanced treatments or cutting-edge technologies—made me feel inadequate. I worried about being marginalized in interdisciplinary teams. Compared to their tangible contributions, I wondered what impact I, as a design researcher, could make. These doubts faded when I began collaborating with doctors and technicians. I realized that design researchers bring a unique and indispensable perspective to interdisciplinary teams. We excel at digesting complex knowledge from other fields and translating it into actionable insights or tangible outcomes. My design background allowed me to communicate scientific concepts in visual, accessible ways that were understandable to both professionals and the public. For example, while working on a project involving virtual reality distraction treatment for wound care, I created a short video introducing the treatment. This simple act had a remarkable impact—our patient recruitment rate increased from 3/10 to nearly 7/10. To any design researchers experiencing similar doubts, my message is clear: do not underestimate the value of our work. We have the power to make technologies and treatments more usable—and therefore more impactful—by placing human needs and experiences at the center of innovation. In late 2024, I had the privilege of participating in the "Chunhui Cup," an event organized by China's Ministry of Education, where I visited high-tech industrial parks and universities across the country. I was inspired to see that many organizations and universities now emphasize interdisciplinary collaboration and problem-driven teaching approaches to cultivate well-rounded talent for societal challenges. This trend gave me hope and reinforced my belief in the growing recognition of design research's value.

After gaining confidence in the value of design research, it's equally important to actively broaden its societal impact. I want to encourage fellow researchers to think beyond academic publications and explore how your work can directly influence the real world by engaging

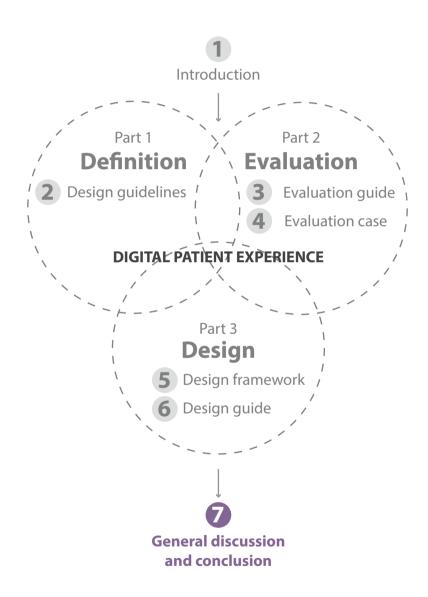
with design practice and education. In my own journey, I created a design guide website to better connect with the broader design community, translating my research findings into practical resources that are accessible to design practitioners and students alike. Additionally, I had the privilege of mentoring undergraduate and graduate students, sharing my research insights and guiding them through their own graduation projects. These experiences not only helped me disseminate my work but also allowed me to gain fresh perspectives and new ideas through meaningful interactions with the next generation of designers.

Expanding your social impact doesn't just amplify the reach of your research; it creates a ripple effect of inspiration and collaboration, driving meaningful change in both design education and practice.





Chapter 7 General Discussion and Conclusion



This chapter includes a synthesis of findings from all five studies with respect to how they contribute to answering the research questions presented in the introduction.

7.1. Key Findings and Research Questions

The experiences of patients often affect how digital technologies can benefit their health outcomes. Therefore, the digital patient experience (PEx) can be a reliable resource for designing, evaluating, and implementing digital health (DH) to reach its full potential (Smits, 2022). However, designing for digital PEx is challenging and requires thorough preparation. The overall purpose of this research was to provide a design guide that facilitates defining, evaluating, and designing digital patient experiences from a human-centered design perspective, thus improving the quality of care in digital health. To achieve this purpose, we came up with five research questions, this thesis has attempted to answer these research questions theoretically (via new knowledge), as well as practically (via a web-based design guide) to facilitate an impact on design best practice in DH and therefore digital PEx.

7.1.1. RQ1. What is the state-of-the-art of the patient experience in digital health in the literature?

Chapter 2 provides a definition of understanding and design guidelines on improving digital patient experience based on the identified influencing factors and design considerations of the digital PEx, which contributes to answering the research question 1. In this Chapter, the concept digital PEx was defined as "the sum of all interactions affected by a patient's behavioral determinants, framed by digital technologies, and shaped by organizational culture, that influence patient perceptions across the continuum of care channelling digital health." 9 design guidelines were proposed to improve the digital PEx by addressing the positive, negative, or double-edged influencing factors, which were captured from 3 aspects (i.e., behavioral, technical, and organizational determinants) and refer to 9 categories (i.e., patient capability, patient opportunity, patient motivation, intervention technology, intervention functionality, intervention interaction design, organizational environment, physical environment, and social environment). 4 design constructs (personalization, information, navigation, and visualization) and 3 design methods (i.e., human-centered design or user-centered design, co-design or participatory design, and inclusive design) were identified as design considerations for digital PEx improvement.

7.1.2. RQ2. How to bridge the gap from the state-of-the-art towards improved digital patient experience?

Chapter 3 proposes an evaluation guide for further improving digital PEx evaluation that respond to the research question 2. In this chapter, we identified five typical evaluation objectives, which include broadening the general understanding of the digital PEx evaluation, improving the design, development, and implementation of the digital helath intervention (DHI) for enhanced digital PEx, achieving evidence-based clinical use and increasing adoption and uptake of DH, driving ongoing investment, and informing health policy practice.

Besides, we identified and classified a set of key evaluation timing considerations into 3 categories (i.e., intervention maturity stages, timing of the evaluation, and timing of data collection). In addition, information on evaluation indicators of digital PEx was identified and summarized into 3 categories (i.e., intervention outputs, patient outcomes, and health care system impact), 9 themes, and 22 subthemes. A set of evaluation theories, common study designs, data collection methods and instruments, and data analysis approaches was captured, which can be used or adapted to evaluate digital PEx.

7.1.3. RQ3. What are the expectations and perceptions of patients about digital patient experience?

Chapter 4 demonstrates an evaluation case evaluating digital PEx in the context of virtual reality (VR) distraction in wound care. It responds to the research question 3. In this study, 3 questionnaires were generated to evaluate the digital PEx of VR distraction in wound care. Using VR distraction in wound care as an evaluation context, we showed how to evaluate digital PEx in a clinical setting. We found patient behavioral determinants, such as technology acceptance and previous wound care experience, had an influence on their intention to use DH solutions (i.e., VR distraction). Although no evidence was found on the effectiveness of VR distraction in significantly improving health outcomes, digital patient experiences and patient satisfaction with using VR distraction in wound care were reported as positive.

7.1.4. RQ4. What are the perspectives and experiences of designers on the human-centered design of the digital patient experience?

Chapter 5 presents a digital health design framework, which provides an overview of design deliverables, activities, stakeholders, challenges, and corresponding strategies to improve the digital PEx. This chapter answers the research question 4. Preparation, problem-thinking, problem-solving, and implementation were identified as the common four design phases, which refer to eight design stages, for designing digital health solutions in practice. In addition, we identified twelve design challenges associated with contextual, practical, managerial, and commercial aspects that can hinder the design process. Eight common strategies that were recommended by DH designers to tackle these challenges were identified as well.

7.1.5. RQ5. What design guidelines can be formulated to the human-centered design of improved digital patient experience?

Chapter 6 evaluates a web-based digital PEx design guide transferring the above research findings into actionable knowledge for supporting design students and practitioners to further improve digital PEx. It serves as an example to inspire future research on developing and evaluating design guides as well. This chapter respond to the final research question. The usability, usefulness, and content quality of the design guide were evaluated in the context of design education as a starting point for iteratively improving the design guide. The design guide was evaluated as usable with good content quality, but that it needs further improvement in providing relevant, detailed, and resourceful contents, intuitive and interactive interfaces,

as well as simple and ready-to-use templates, thus achieving a balance between less and more, specific and general, as well as fixed and flexible. Which reveals the diversity and conflicts in students' needs for useful and effective design guides. On the one hand, users want design guides to hold relevant, detailed information and content, provide a systematic overview, include complete conceptual explanations, detailed design cases, and integrated design resources, enabling them to use the design guide as a resource library for flexible exploration. On the other hand, they want a design guide to be simple and easy to use, offer concise and clear information with low learning and usage costs, enabling them to effortlessly complete efficient designs.

To synthesize all our research findings, we generated a web-based design guide to provide actionable design knowledge to DH designers and developers. It has been made available for free and can be accessed online at: https://www.tudelft.nl/io/delft-design-guide-digitalhealth (See Figure 7-1). The design guide was generated in a master graduation project (Yun, 2023), where varied design activities, from creating a Minimum Viable Product (MVP) to iteratively generating a functional prototype, were conducted. During the iterative improvement process, many formal and informal design activities were performed. For example, we conducted prototype walkthroughs to ensure the completeness of the prototype and avoid basic usability issues and content inconsistencies. We consulted DH researchers and experts by presenting the design guide at international conferences, research meetings at TU Delft and the University of Cambridge, and a Masterclass at TU Delft for suggestions on improving the design guide. We performed 2 user test workshops with 54 design students in total to investigate the impacts of the design guide and seek improvement insights. We conducted one-by-one user tests with 6 design students to seek evidence on the improvement of the design guide. We introduced the design guide to 11 master students in a 10-week master elective course (i.e., Health Psychology) and invited them to apply it to completing the given design assignments and provide usage feedback. In addition, to enrich the usage scenarios of the design guide, two master graduation projects are continuing to work on the application and extension of the design guide, one is titled "Design for next-generation technology-enabled elderly care models for single female Chinese Netherlanders elderly", another is titled "A Toolkit for Digital Health Designers: Facilitating Shared Design Goals Among Multiple Stakeholders through Participatory Design".

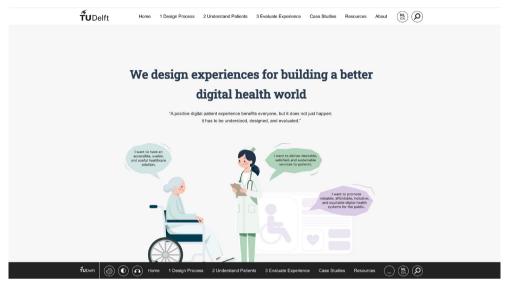


Figure 7-1. Design guide website.

Design Guide Contents

The results of five research studies and three graduation projects together provided direction and grounding for the material development of the design guide. The design guide contains four main webpages: Design Process, Understand Patients, Evaluate Experience, and Case Studies, as well as a homepage and two extra webpages.

- 'Design Process' webpage: results of Study IV (i.e., Chapter 5), the interview study on the DH design process (i.e., design phases, stages, activities, deliverables, stakeholders, challenges, and strategies) formulated the 'Design Process' webpage. This webpage aims to support the users of the design guide, such as DH designers, design students, and researchers, in making plans for managing their DH design processes and familiarizing themselves with the common design stakeholders, challenges, and strategies that occur during the design process.
- 'Understand Patients' webpage: Study I (i.e., Chapter 2), the umbrella review part 1 on the influencing factors, design considerations, and design guidelines shaped the 'Understand Patients' webpage, which provides insights to understand what influences digital PEx and how to manipulate these influences through design towards enhanced digital PEx.
- 'Evaluate Experience' webpage: Study II (i.e., Chapter 3), the umbrella review part 2 provides information for the 'Evaluate Experience' webpage on guiding the evaluation of the digital PEx by questioning and answering why, when, what, and how to measure the digital PEx.
- 'Case Studies' webpage: in addition, Study III (i.e., Chapter 4), the prospective observational study on evaluating the digital PEx of using VR distraction in wound care, together with three master graduation projects (Li, 2022; Long, 2022; Qian, 2022)

on designing 'Consultation Room 2030' and another prospective observational study on evaluating the digital PEx of using a digital intake tool for Fecal Immunochemical Test-based colorectal cancer screening programs, formulated the 'Case Studies' webpage.

- 'D&H Guide' homepage: the homepage provides structured guidance on what and how the readers can learn from using the design guide.
- 'Resource' webpage: this webpage provides additional information and links to the related concepts, references, and toolkits, such as the Improving Improvement Toolkit (Healthcare Design Group Cambridge Engineering Design Centre, 2020), Inclusive Design Toolkit (Engineering Design Centre University of Cambridge, 2024), and NASSS-CAT tools (IRIHS group, 2024), to keep readers on track in improving the digital PEx.
- 'About' webpage: it introduces the team members who have been working on the development and evaluation of the design guide.

Finally, Study V (i.e., Chapter 6), the method evaluation study evaluates the design guide and provides insights to further improve it.

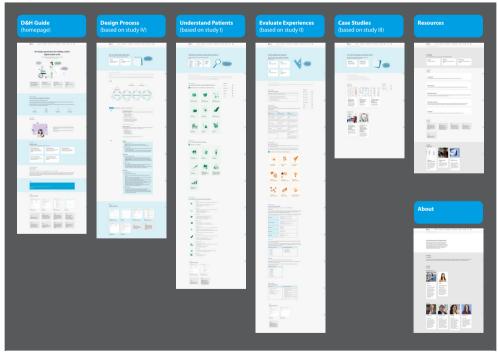


Figure 7-2. Design guide contents.

Design Guide Formats

Webpages, templates, and articles were used as three main forms to convey knowledge and information in the design guide. The form of webpages provides a convenient way of learning

online and allows DH designers and design students to easily access updated information globally. It also serves as a connector where people can access other resources and formats, such as templates and articles. Considering designers and design students often operate in a team that collaborates across disciplines with multiple stakeholders; to provide steps for them to take particular design actions and communicate design directions, we also offer varied templates that can be used digitally but can also be printed in a tangible version. In addition, for DH researchers, designers, and design students who are interested in the research aspects and want to seek evidence or learn more lessons, a set of peer-reviewed published research articles provides them with more rigorous details about the research findings. They are openaccess and can be found easily on the website as well.

Design Guide Usage Scenarios

The design guide provides design knowledge for improving digital PEx, including how to manage the design process, understand patients, evaluate experiences, learn from case studies, and link to related resources. The design guide serves to embody an understanding of design work for evaluating and designing digital PEx, especially when DH designers and design students have limited accessibility to stakeholders, such as patients, or have less experience in terms of DH design. We believe the design guide can be used to support:

- design research, where it can be used by DH researchers to seek evidence on improving digital PEx, learn lessons from conducting research in this field, and gain insights on transferring research knowledge;
- design practice, where it can be adopted by DH designers, developers, and evaluators
 to build a common understanding of the design context, make actionable plans for
 the design process management, and apply guidelines and templates to evaluate and
 improve the digital PEx;
- design education, where it can be utilized by design educators for developing workshops, assignments, and courses towards digital PEx improvements or by design students for understanding patients, managing design processes, as well as evaluating and improving digital PEx.

By serving as a comprehensive and flexible resource, the design guide contributes to improving the digital PEx. It bridges the gap between theory and practice, supporting education, practice, and research in this field. The guide's structured content, practical templates, and evidence-based insights increase the likelihood of designers, design students, and researchers creating digital health solutions that ensure improved digital patient experience.

7.2. Implications

This thesis includes two umbrella review studies (Chapters 2 and 3), a prospective observational study (Chapter 4), a semi-structured interview study (Chapter 5), and a method evaluation study (Chapter 6), which has theoretical, practical, educational, and contributions towards the definition, evaluation, and design of the digital patient experience (PEx).

First, this thesis has theoretical contributions. For example, Chapters 2 and 3 are umbrella reviews, which synthesis of existing review articles to provide thorough overview of the state of knowledge in the PEx in digital health (DH) and identify research gaps and opportunities towards the understanding, evaluation, and design of the digital PEx. Specifically, Chapter 2 proposes and defines the concept of digital PEx to facilitate interdisciplinary communication among researchers and partitioners from design, healthcare, and technology communities that have a focus on the development of DH. In addition, Chapter 5 generates a DH design framework that explains the general human-centered design (HCD) processes, challenges, and strategies in DH design practice, which has contributions to DH design theories as well.

Second, this thesis has practical contributions. For example, Chapters 2, 3 and 5 provide design guidelines, evaluation guide, and DH design framework separately, which can be used by DH designers and developers to design and evaluate the digital PEx in design practice. Chapter 4 provides an evaluation case study that illustrates the evaluation of digital PEx in real-world clinical settings, providing practical insights and lessons learned. In addition, Chapter 6 generates and evaluates a web-based design guide that synthesizes research findings from the previous four chapters, which demonstrates the usability, usefulness, and content quality of the design guide.

Last, this thesis has educational contributions. The generation, extension, and application of the design guide refers to three master graduation projects that under my supervision, one has completed, another two are in progress. For instance, the generation of the design guide is done in the completed master thesis (Yun, 2023). In addition, the evaluation of the webbased design guide also involves varied design education activities. Except for the 10-day design education workshop in Chapter 6, the design guide was introduced to design students in a 2-hour design workshop in a master elective course (Wang, Wang, et al., 2024), in a 10-week master elective course, and to design experts and researchers in a Masterclass at Delft University of Technology. In total, more than 65 design students have used the design guide and shared their feedback on improving it.

In summary, this thesis contributes to the improvement of quality of care in DH by enriching theoretical knowledge, enhancing practical applications, improving educational practices, addressing patient needs, and fostering interdisciplinary collaboration through defining, evaluating, and designing the digital PEx.

7.3. Limitations

There are also several limitations of this thesis. First, this thesis has theoretical limitations on the applicability of theoretical guidelines, frameworks, and guides. This thesis does not have a specific focus on a particular type of patients or digital health interventions, the theoretical knowledge developed in this thesis is quite general; therefore, when applying it to a specific design context, designers need to adapt it according to the specific design context.

For example, the 9 design guidelines in Chapter 2 are synthesised from diverse review studies that refer to varied intervention types and patient groups. To make these guidelines generalizable, many details on the specific design contexts and usage scenarios were not included in the final synthesis. Therefore, designers need to use these design guidelines as flexible resources and adapt them for specific contexts. In addition, Chapters 2, 3, and 5 aimed to provide an overview of related contents, such as influencing factors, evaluation indicators, and design phases, which may be far more than what a designer needs to consider in one design project with limited project time and budget. Therefore, designers need to prioritize on what to focus by themselves, which may lead to challenges on the application of these theoretical knowledge.

Second, this thesis has methodological limitations on the sample size and study design. For example, Chapters 2 and 3 are studies reviewing reviews; the information in the review papers is often based on previously published articles, which may limit our insights into advanced new technologies, especially given the rapid evolution in this area. The rapidly changing landscape of DH technologies and patient expectations may limit the long-term relevance of the findings and recommendations. In addition, there is a limitation to the study design of Chapter 6. Due to the lack of a validated instrument to evaluate design students' pre- and post-design self-efficacy, we used the adapted Rubric IDE Master Graduation Project (Delft University of Technology, 2018) at Delft University of Technology.

Third, this thesis has contextual limitations in considering how cultural differences influence the design of the digital PEx. Differences in healthcare systems, policies, and regulations across regions or countries can limit the applicability of the findings and recommendations to other contexts. However, due to the scope of this thesis, we did not highlight all these differences. Designers are expected to be aware of these specific requirements based on their own knowledge and the specific design context. Especially due to the rapid development of digital technologies, DH is more accessible to international patient groups that have varied cultural backgrounds. But without considering their specific culture, their experiences will be limited.

Fourth, this thesis has practical limitations for investigating other DH stakeholders' experiences. The implementation of DH not only requires the adoption of patients but also the uptake of healthcare providers and continuous maintenance, investment, and supervision from the government. This thesis focuses on the design of DH towards improved digital PEx, but with limited perspectives from other stakeholders, such as how DH could affect the workloads and experiences of care providers, which in turn determines the design of DH as well. Comparing the similarities and differences between conceptualizations, theories, and practices of 'experience' in different design contexts, such as experience design for healthcare versus non-healthcare domains, experience design for healthcare receivers versus healthcare providers, and experience design for digital health versus non-digital health solutions, will

help designers identify and capture the nuances of different perspectives. Without building clear boundaries, it is hard to know what designers need to specifically consider when designing for digital PEx and what they can learn from a broader experience design, such as user experience and patient experience.

Last, this thesis has another practical limitations on implementing and disseminating the web-based design guide to a broader design community in industry. Conducting the evaluation of the design guide only with design students limits inputs from the design practitioners, who may have different requirements for using the design guide. We recognized that further improvements to the design guide, according to feedback from design practitioners, are necessary for implementing and disseminating the design guide in industry. In addition, since becoming familiar with the design guide requires a certain amount of time, given the limited duration of the user test workshop, students may feel an additional burden or may not thoroughly look through the design guide contents, resulting in a biased evaluation.

Although this doctoral thesis aims to contribute to the definition, evaluation, and design of digital PEx and increase the quality of care in DH, there are still some limitations that influence the practical and theoretical contributions. Recognizing these constraints can help guide future research and practice, ensuring ongoing refinement and adaptation of theories, methods, and solutions to better improve the quality of care in DH.

7.4. Future Research

First, future research should investigate individual and cultural differences on DH design and implementation. DH enhances global accessibility of medical services but faces challenges due to varying cultural backgrounds and individual situations, which can impact digital PEx. For instance, healthcare systems designed for one culture may not suit another. Therefore, future research should focus on the impact of individual and cultural differences on DH design and leverage big data to offer personalized digital PEx while balancing localization and international compatibility.

Second, future research should clarify the boundaries of designing for digital PEx. Identify the core elements of healthcare design (e.g., thinking, approaches, and toolkits) and create new perspectives by comparing with and learning from other non-healthcare domains. Investigate the differences between designing for healthcare receivers and designing for healthcare providers and discuss how to balance the healthcare design facing multiple end-users (e.g., varied patient profiles, doctors, and nurses). Explore the advantages and disadvantages of delivering healthcare through digital and non-digital channels and create a hybrid patient journey that enlarges the benefits and reduces risks.

Third, the maintenance and implementation of the web-based design guide should be addressed. To advance the implementation and enlarge the impacts of the design guide and

deepen our understanding of human-centered design that facilitates the required changes in health and care systems, with a particular focus on the clarification, extension, implementation, and dissemination of the design guide. Clarify the current scope, specificity, and boundaries of the design guide by comparing it with other existing design tools. Identify touchpoints for applying the design guide to the health and care improvement processes. Apply the design guide in health and care improvement training and practice continuously, conduct several training courses (e.g., online or offline workshops) with varied stakeholders (e.g., students, designers, healthcare providers, patients), and generate structured training materials (e.g., podcasts, templates, and videos). Introduce and disseminate the design guide and related training courses to practitioners, researchers, educators, and students who are working on health and care improvement across different institutions, organizations, and companies in varied countries.

7.5. Conclusion

We conclude this thesis by reflecting on the research aim, which is to provide a design guide that facilitates defining, evaluating, and designing digital patient experiences from a human-centered design perspective, thus improving the quality of care in digital health. To achieve this aim, first, we systematically reviewed 45 review articles and proposed the term "digital patient experience" as a common concept to communicate patient experience in digital health. We further defined it as "the sum of all interactions affected by a patient's behavioral determinants, framed by digital technologies, and shaped by organizational culture, that influence patient perceptions across the continuum of care channelling digital health" to support the understanding of digital patient experience. We then summarized 9 design guidelines to support digital health designers and developers to improve digital patient experience. Second, based on an umbrella review study, we generated an evaluation guide that contains typical evaluation objectives, stakeholder groups, evaluation timing considerations, indicators, and approaches to support the evaluation of digital patient experience. We also conducted a prospective observational study with 96 patients as a case study of evaluating digital patient experience of using virtual reality for pain management in wound care treatment. Third, we interviewed 24 human-centered digital health design practitioners and synthesized their design processes into a digital health design framework that contains 4 common design phases, 8 design stages, 12 design challenges, and 8 design strategies to support humancentered design for improved digital patient experience. Then we synthesized all research findings into a web-based design guide and tested it with more than 50 design students to support design students, digital health designers, and developers directly in improving the digital patient experience from a human-centered design perspective. Our answer for improving digital patient experience, thus improving the quality of care in digital health, is a 3-step approach: 1) define digital patient experience to build a common understanding of its state-of-the-art and improvement considerations; 2) evaluate digital patient experience to identify the gap from the state-of-the-art towards improved one; and 3) design digital patient experience from a human-centered design perspective to improve it.

Lessons for doing a PhD 07

Embrace the moat of low status.

This is a lesson I learned from Cate Hall during an interview. Although I wasn't familiar with her before and still know very little about her now, her insight on "Learn to Love the Moat of Low Status" (Hall, 2024) resonated deeply with me. She described this "moat" as a period we all go through when making changes or learning new skills—a time when we struggle, feel inadequate, and fail to grasp things that seem obvious to others.

Reflecting on my PhD journey, I realize I've encountered this moat many times. One experience, in particular, stands out: during the first year of my PhD, I was invited to give a presentation to master's students at a department event. It was my first time speaking to a large audience in my second language, and I was terrified. Despite my nerves, I saw it as a chance to improve my public speaking skills, so I decided to go for it. I prepared extensively, but when the day came, my performance was disappointing. My voice trembled, I avoided eye contact with the audience, and I completely skipped any interaction at the end of my talk. Worse still, another presenter in the same session delivered their presentation with ease and confidence, making me feel even more ashamed of my own shortcomings. I regretted accepting the opportunity and shared my embarrassment with my supervisors. Instead of criticizing me, they reassured me that this was part of the learning process and shared their own early struggles with me.

A year later, my supervisor encouraged me to present again at the same event. To my surprise, I performed much better the second time. I was more confident, knew how to engage the audience, and felt at ease on stage. The improvement didn't come by chance—I had spent the past year practicing, refining my skills, and learning from my first attempt. Looking back, I realized that initial failure was a necessary step in my growth.

I share this story because I want to encourage you to embrace the moat of low status, to try things you're not good at yet, even if they feel obvious or easy for others. Growth often comes from stepping into discomfort and facing challenges head-on.

Even as I write this reflection, I find myself in another moat of low status as I work to finalize my thesis. It's an exhausting process that has tested my resilience—causing sleepless nights and even physical symptoms like allergies—but I remind myself that this is all part of learning, growing, and transforming.

If you are reading my thesis and currently facing a challenging moment in your life—perhaps struggling with setbacks in research or obstacles in your personal life—I want you to know that you're not alone. The discomfort you feel now is part of a transformation. Trust in yourself, stay persistent, and keep moving forward. Endure the low moments, face the challenges, and you'll emerge stronger, wiser, and ready to embrace the next chapter. Like

a butterfly breaking free of its chrysalis, you'll discover a better version of yourself on the other side.



Epilogue

I would like to conclude my doctoral thesis by saying that digital health designers and developers should value the digital patient experience and improve the quality of care in digital health by understanding, evaluating, and improving the digital patient experience from a human-centered design perspective. As I stated earlier in the introduction, we are all people, and we are all patients at some points in our life course. I experienced fear, anxiety, frustration, loneliness, sadness, and guilt as a patient six years ago. I could not change what I have experienced; but I believe my reflections on these experiences through my whole doctoral thesis contribute to building a better digital health world in the future, not only for me myself to have better experience of healthcare systems in the future digital world, but also for hundreds and thousands of patients like me who need to be better understood as a person, who want to voice for themselves, and who expect to experience a better digital health world. A designer may not be able to treat and cure patients like a healthcare provider, but if we can create a positive experience for them, that is very valuable as well.

In this thesis, I shared my research findings on defining, evaluating, and designing digital patient experiences as a design researcher and my lessons I learned as a PhD student. Reflecting on my 4-year PhD journey, there were both highlights and lowlights: it was a highlight when I received commitment from my supervisory team; it was a lowlight when I was misunderstood by collaborators and stakeholders; it was a highlight when I shared my research stories with others; it was a lowlight when I couldn't explain my works precisely with others; it was a highlight when I wrote a ten thousand rebuttal letter to argue with my reviewers; it was a lowlight when I stuck on my statistic analysis and ethical application process; it was a highlight when I published my first journal; it was a lowlight when I lost myself in endless data; it was a highlight when my master students graduated... If I have more time for my PhD journey, I believe I can do much more research and learn more lessons. However, time flies quick; now I am excited to move forward and embrace new research and life experiences. I'll continue to work on design for healthcare and dedicate myself to connecting design research, education, and practice.

Last word, if you ask me what is the most regrettable thing about my PhD journey, I would say I hope that I could read more doctoral theses and talk to more PhDs to have an overview of what a PhD in design is about. Therefore, if you are still in your PhD journey, welcome to read my thesis and talk to me.

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Appendices

Appendix 4-1. Study parameters.

Construct	Instrument	(Transformed) score
Pre-questionnaire	e 1. Behavioral determinants and intention to use	
For patients		
VR Distraction Understanding Level (Lewis & Mayes, 2014)	Single question: how would you rate your understanding of using VR in wound care?	1-5 (1 = "poor" to 5 = "excellent")
Demographic Information	What is your year of birth? What is your gender? What is your highest level of education?	N/A
Self-Reported Health Status (Yousef et al., 2021)	Single question: In general, how would you rate your health status?	1-5 (1 = "poor" to 5 = "excellent")
Previous VR Usage (R. Jones, 2013)	Single question: Have you used VR glasses (for any purpose)?	Yes, no
VR Confidence Level (R. Jones, 2013)	Single question: In general, how confident are you in using VR glasses?	1-5 (1 = "not confident at all" to 5 = "extremely confident")
Previous Would Care Experience (R. Jones, 2013)	Single question: Have you experienced wound care before?	Yes, no
Baseline Anxiety (Davey et al., 2007)	Single question: How anxious did you feel during the last wound care?	0-10 (0 = "not anxious at all" to 10 = "extremely anxious")
Baseline Pain (Atzori et al., 2018; Hoffman et al., 2004; Patterson et al., 2022)	Time spent on thinking pain: How much time did you spend thinking about your pain when you were having the last wound care? Pain intensity: How would you rate your worst pain intensity when you were having the last wound care? Pain unpleasant: How unpleasant was your pain during the last wound care?	0-10 (0 = "None of the time/ not pain at all/ not unpleasant at all" to 10 = "all of the time/ Excruciatingly pain/ Excruciatingly unpleasant")

Appendix 4-1. Study parameters (continued).

Construct	Instrument	(Transformed) score
Needle-Looking Preference (Mithal et al., 2018)	Single question: What is your needle-looking preference when getting injections?	Prefer to look away, or prefer to look at
Pain Sensitivity (Wandner et al., 2012)	Single question: What is your sensitivity to pain in general?	1-5 (1 = "not sensitive at all" to 5 = "extremely sensitive")
Pain Endurance (Wandner et al., 2012)	Single question: What is your endurance to pain in general?	1-5 (1 = "not endurance at all" to 5 = "extremely endurance")
Willingness to Report Pain (Wandner et al., 2012)	Single question: What is your willingness to report pain in general?	1-5 (1 = "not willing at all" to 5 = "extremely willing")
Pain Catastrophizing (Bot et al., 2014)	Rumination: I keep thinking about how badly I want the pain to stop. Magnification: It's terrible and I think it's never going to get any better. Magnification: I become afraid that the pain may get worse. Helplessness: I anxiously want the pain to go	1-5 (1 = "strongly disagree" to 5 = "strongly agree")
Technology Acceptance (Yousef et al., 2021)	away. Performance expectancy: By using VR glasses in wound care, I feel more involved in my care. Effort expectancy: I find information in VR glasses understandable. Social influence: My healthcare professionals encouraged me to use VR glasses. Facilitating condition: I find technical help is available when I do not know how to use VR glasses in wound care. Attitude: I think the use of VR glasses in wound care is a valuable service.	1-5 (1 = "strongly disagree" to 5 = "strongly agree")

Appendix 4-1. Study parameters (continued).

Construct	Instrument	(Transformed) score
Technology	Single question: It scares me to think that the use	1-5 (1 = "strongly
Anxiety	of VR glasses in wound care will block my sight.	disagree" to 5 =
(Venkatesh et al.,		"strongly agree")
2003)		
Anticipated	How would you perceive the use of VR glasses in	1-5 (1 =
Digital Patient	wound care?	"unpleasant/ boring/
Experiences	Unpleasant vs. Pleasant	discomfortable/
(Emani et al.,	Boring vs. Interesting	unconfident/
2016; Kayser	Discomfortable vs. Comfortable	worried/ out of
et al., 2018;	Unconfident vs. Confident	control/ burdensome/
Tingting Wang,	Worries vs. Reassuring	useless" to 5 =
Guido Giunti, et	Out of control vs. In control	"pleasant/ interesting/ comfortable/
al., 2022b)		confident/ reassuring/
	Burdensome vs. Convenient	in control/ convenient
	Useless vs. Useful	useful")
Intention to Use	Single question: I will probably use VR glasses in	1-5 (1 = "strongly
(Yousef et al.,	my wound care in the future.	disagree" to 5 =
2021)	9	"strongly agree")
For researchers		
Wound	Cause of the wound	N/A
Characteristics	Location of the wound	
	Surface of the wound	
	Layer of the wound	
	First date of the wound care	
	Last treatment of the wound care	
The Use of VR	Last treatment of the wound care	Vac no
Distraction	-	Yes, no
	res 2. Anxiety, pain outcomes, VR experiences, and	I future to use (VR
group)	res 2. Anxiety, pain outcomes, vic experiences, and	i luture to use (VIX
For patients		
Anxiety (Davey	Single question: How anxious did you feel during	0-10 (0 = "not")
et al., 2007)	the use of VR glasses in wound care?	anxious at all" to 10 =
, ,	~	

Appendix 4-1. Study parameters (continued).

Construct	Instrument	(Transformed) score
Pain (Atzori et al., 2018; Hoffman et al., 2004; Patterson et al., 2022)	Time spent on thinking pain: How much time did you spend thinking about your pain when you were using the VR glasses? Pain intensity: How would you rate your worst pain intensity during the use of VR glasses? Pain unpleasant: How unpleasant was your pain during the use of VR glasses?	0-10 (0 = "None of the time/ not pain at all/ not unpleasant at all" to 10 = "all of the time/ Excruciatingly pain/ Excruciatingly unpleasant")
VR Immersion Experience (Atzori et al., 2018; Hoffman et al., 2004; Patterson et al., 2022)	Fun: How much fun did you have during the use of Virtual Reality glasses? Nausea: To what extent (if at all) did you feel nausea during the use of VR glasses? Presence: While experiencing VR glasses, to what extent did you feel like you went inside the 3D environment, as if it was a place you visited? Real: How real did the objects in the VR glasses seem to you?	0-10 (0 = "Not fun at all/ not nausea at all/ not went inside at all/ completely fake" to 10 = "extremely fun/ vomit/ went completely inside/ Indistinguishable from a real object")
Digital Patient Experiences (Emani et al., 2016; Kayser et al., 2018; Tingting Wang, Guido Giunti, et al., 2022b)	How was your overall experience in the use of VR in wound care? Unpleasant vs. Pleasant Boring vs. Interesting Discomfortable vs. Comfortable Unconfident vs. Confident Worries vs. Reassuring Out of control vs. In control Burdensome vs. Convenient Useless vs. Useful	1-5 (1 = "unpleasant/ boring/ discomfortable/ unconfident/ worried/ out of control/ burdensome/ useless" to 5 = "pleasant/ interesting/ comfortable/ confident/ reassuring/ in control/ convenient/ useful")
Overall Satisfaction (Parmanto et al., 2016)	Comfort: I feel comfortable communicating with the clinician in using VR glasses. Acceptance: The use of VR glasses is an acceptable way to receive wound care. Satisfaction: Overall, I am satisfied with using VR glasses in wound care.	1-5 (1 = "strongly disagree" to 5 = "strongly agree")

Appendix 4-1. Study parameters (continued).

Construct	Instrument	(Transformed) score
Future Intention	Single question: I would use VR glasses in wound	1-5 (1 = "strongly
to Use (Parmanto	care again.	disagree" to 5 =
et al., 2016)		"strongly agree")
For researchers		
Wound Care	Time duration	N/A
Characteristics	Medication use	
Patient Behaviors	VR content	1-5 (1 = "poor" to 5 =
	VR engagement	"excellent")
Post-questionnaires 3. Anxiety, pain outcomes, and future to use (non-VR group)		
For patients		
Anxiety (Davey	How anxious did you feel during the use of	0-10 (= "not anxious
et al., 2007)	Virtual Reality glasses in wound care?	at all" to 10 =
		"extremely anxious")
Pain (Atzori	Time spent on thinking pain: How much time did	0-10 (0 = ``None of)
et al., 2018;	you spend thinking about your pain when you	the time/ not pain at
Hoffman et al.,	were using the VR glasses?	all/ not unpleasant at
2004; Patterson	Pain intensity: How would you rate your worst	all" to $10 =$ "all of the
et al., 2022)	pain intensity during the use of VR glasses?	time/ Excruciatingly
	Pain unpleasant: How unpleasant was your pain	pain/ Excruciatingly
	during the use of VR glasses?	unpleasant")
Future Intention	Single question: I will probably use VR glasses in	1-5 (1 = "strongly
to Use (Parmanto	my wound care in the future.	disagree" to 5 =
et al., 2016)		"strongly agree")
For researchers		
Wound Care	Time duration	N/A
Characteristics	Medication use	

N/A: not applicable

Appendix 6-1. Self-efficacy measure.

Self-efficacy scale (11-point scale)

The following statements are about your capabilities to...

Please rate your confidence level on a scale from 0-10 (cannot do at all, moderately can do, highly certain can do)

Appendix 6-1. Self-efficacy measure (continued).

Self-efficacy scale (11-point scale)

- ...effectively collect, analyze, generate and evaluate knowledge required for a design project related to improving digital patient experience.
- Collect and analyze knowledge: I can effectively collect and analyze the knowledge required for a digital health design project to improve digital patient experiences.
- Generate and evaluate knowledge: I can effectively generate and evaluate the knowledge required for for a digital health design project to improve digital patient experiences.
- ... justify your choices with respect to used methods and/or approaches used in a design project improving digital patient experience.
- The use of methods and tools: I can apply appropriate and meaningful methods and tools
 for a digital health design project to improve digital patient experiences while justifying
 my choices.
- Dealing with project complexity: I can identify and address the complexity of a digital health design project for improving digital patient experiences and justify my choices.
- ... deliver a relevant project result in terms of improving digital patient experience.
- Feasibility: I can deliver a feasible digital health design solution to improve digital patient experiences and demonstrate it can be done.
- Desirability: I can deliver a desirable digital health design solution to improve digital patient experiences and demonstrate that it addresses the patients' values and needs.
- Viability: I can deliver a viable digital health design solution to improve digital patient experiences and satisfy the conditions it needs to survive in the long term.
- ... effectively and thoroughly communicate to and discuss with stakeholders involved in a design project to improve digital patient experiences.
- Academic level: I can convey relevant and structured digital health design content with appropriate references and use of language to improve digital patient experiences.
- Connecting to stakeholders): I can effectively communicate with the stakeholders involved in, such as patients, doctors, and nurses, allowing them to connect.
- ... manage a digital health design or research project independently within the given time in terms of improving digital patient experience.
- Planning: I can plan and structure design activities for a digital health design project to improve digital patient experiences and execute them accordingly.
- Autonomy & initiative: I can show sufficient initiative and execute a digital health design project autonomously to improve digital patient experiences.
- Response to feedback: I can display sufficient responses to feedback and take adequate
 actions for a digital health design project to improve digital patient experiences.
- Time spent: I can complete a digital health design project or task to improve digital patient experiences within the given time.

Appendix 6-2. Content quality measure.

Content quality scale (7-point scale)

The following statements are about...

Please choose the answers from 1-7 (strongly disagree, neither disagree nor agree, strongly agree) that best fit your perceptions.

- ... the framing of the design guide, which is the context of use described in the guide and its implications and prerequisites for guide use.
- I understand when the design guide should be used in a design process.
- I know in what situations the design guide can and cannot be used.
- I understand who should be involved to use this design guide successfully.
- I know what competences are needed to use this design guide successfully.
- I know what materials and other input are needed to use this design guide successfully.
- The design guide offers the knowledge I need to use it successfully.
- ... the mindset of the design guide, which is the set of described values, principles, underlying beliefs, and logic that inform a method and its use.
- I know how to use this design guide.
- I understand what is needed to use this design guide.
- I know exactly what the focus of this design guide is.
- I know what values the design guide is based upon (e.g. user-centered).
- I understand the basic premise of the design guide (e.g., The patient's experiences matter).
- I understand the underlying logic of the design guide (i.e. why the design guide works).
- ... the goal of the design guide, which is the described goals, and the prioritization of those goals a design guide aims to help achieve through its use.
- I understand exactly what I am supposed to do in this design guide.
- I have specific, clear goals to aim for in this design guide.
- If I have more than one goal to accomplish, I know their priority.
- The design guide helps me to attain the goals.
- ... the rationale of the design guide, which is the performance-goal relationship and motivations underlying the goals of the design guide.
- I understand how to determine when the design guide has worked well (i.e. when it has been successful).
- I understand what the end conditions of the design guide are (i.e., when the use of the design guide is finished).
- The design guide explains the reasons for the goal.
- The design guide helps me reflect on how well it is working in relation to the goal.
- ... the procedure of the design guide, which is the structural activities described in the design guide and their relative chronological and logical ordering.
- I understand exactly what I am supposed to practically do in this step.
- I understand exactly how to approach this step (e.g. involve particular stakeholders).

Appendix 6-2. Content quality measure (continued).

Content quality scale (7-point scale)

- I understand exactly how to complete this step.
- I am confident in my understanding of this step.
- I am confident that I can perform the step.
- ... the knowledge quality of the design guide, which is the quality of shared knowledge content, including relevance, ease of understanding, accuracy, completeness, reliability, and timeliness.
- I think the information provided by the design guide was easy to understand.
- I think the information provided by the design guide was complete.
- I think the information provided by the design guide was reliable.
- I think the information provided by the design guide was accurate.
- I think the information provided by the design guide was relevant to the goal.

Appendix 6-3. Usability Testing Tasks and the System Usability Scale (N=33; 5-point scale).

Tasks

- Task 1. Please look through the webpage "D&H Guide" on the design guide and describe the definition of the digital patient experience.
- Task 2. Please look through the webpage "Design Process" on the design guide and describe which stakeholders should be involved at the problem-thinking stage.
- Task 3. Please look through the webpage "Understand Patient" on the design guide and describe design guidelines for addressing the "patient motivation" determinant.
- Task 4. Please look through the webpage "Evaluate Experience" on the design guide and provide three indicators for evaluating negative emotions.
- Task 5. Please look through the webpage "Case Studies" on the design guide, read one case, it can be design or evaluation case, and share your thoughts in several sentences about this case.

Please fill out the time you spent completing the above five tasks.

Items	M (SD)
I think that I would like to use the web-based design guide frequently.	4.2 (0.8)
I find the various functions in the web-based design guide are well-integrated.	4.2 (0.6)
I would imagine that most people would learn to use the web-based design guide very quickly.	3.9 (0.9)
I think the web-based design guide is easy to use.	3.8 (1.0)
I feel very confident using the website.	3.7 (1.0)
*I need to learn a lot of things before I could get going with the web-based design guide.	2.8 (1.0)
*I find the website is unnecessarily complex.	2.3 (0.8)

Appendix 6-3. Usability Testing Tasks and the System Usability Scale (N=33; 5-point scale) (continued).

*I think that I would need the support of a technical person to be able to use the	2.3 (0.9)
web-based design guide.	
*I think there is too much inconsistency on the website.	2.0 (0.7)
*I find the web-based design guide very cumbersome to use.	2.0 (0.9)

Note: The "*" means question with a negative tone.

Appendix 6-4. Focus Group Interview Outline.

Focus group interview questions

- Have you used the design guide during the design process? If yes, when did you start using it? If at the beginning, why did you decide to use it? If it was very late, why did not you use it at the beginning? If not, why use it?
- What are the most positive aspects of the design guide or workshop? If you can keep only one part of this guide, which part would you like to keep?
- What are the most negative aspects of the design guide or workshop? If you have to delete one part of this guide, which part will you delete?
- Do you feel any confusion when using the design guide? Which part led to your confusion? What do you want us to do to make the design guide easier to understand and use?
- Do you find the design guide useful for your workshop assignments? And why?
- Will you use the design guide in the future or introduce it to your peers? And why?
- In what contexts do you think the design guide is more useful? And who will find it more helpful?
- Could you please give us some suggestions or recommendations to further improve the design guide or this workshop?

Propositions

- 1. Neither the patient experience nor the user experience represents the digital patient experience completely (this thesis).
- 2. Digital patient experience is influenced by multifaceted factors that are more complex than facilitators and barriers, which create an additive effect (this thesis).
- 3. At an abstract level, design processes in the digital healthcare industry are similar to those in other domains; however, the emphasis on specific phases or activities is different (this thesis).
- 4. A desired design guide is expected to keep a balance between less and more, specific and general, as well as fixed and flexible (this thesis).
- 5. Designers appreciate tools in the same way master chefs appreciate recipe books: they do not have to follow the recipes step-by-step but can always get inspiration from them
- 6. Conducting a systematic review will make you regret it during your PhD, but not conducting a systematic review will lead to regret after finishing your PhD.
- 7. Lessons learned from a PhD go beyond the research topic.
- 8. A design researcher who wishes to do work well must first sharpen the design tools.
- 9. Do not be afraid of rejection; ask for things that feel unreasonable to make sure your intuitions about what's reasonable are accurate (Hall, 2024).
- 10. A PhD journey of a thousand days begins with a single step.

These propositions are regarded as opposable and defendable and have been approved as such by the promotors, Prof.dr.ir. R.H.M. Goossens and Dr.ir. M. Melles.

List of Publications

Journal papers:

- Wang, T., Zhu, H., Qian, S., Giunti, G., Goossens, R., & Melles, M. (2024). Designing Digital Patient Experiences: The Digital Health Design Framework. Applied Ergonomics, 119, 104289. https://doi.org/10.1016/j.apergo.2024.104289
- Wang, T., Giunti, G., Goossens, R., & Melles, M. (2024). Timing, Indicators, and Approaches to Digital Patient Experience Evaluation: Umbrella Systematic Review. Journal of Medical Internet Research, 26, e46308. doi: 10.2196/46308
- **3. Wang, T.**, Giunti, G., Melles, M., & Goossens, R. (2022). Digital Patient Experience: Umbrella Systematic Review. Journal of medical Internet Research, 24(8), e37952. doi: 10.2196/37952
- 4. Wang, T., Xiao, D., Dong, Y., & Goossens, R. H. (2021). Development of a Design Strategy for Playful Products of Older Adults. The Design Journal, 24(4), 525-545. https://doi.org/10.1080/14606925.2021. 1912903
- 5. Dong, Y., & Wang, T. (2022). Enlightenment of 3TU Interdisciplinary Industrial Design Education in the Netherlands for Chinese "New Engineering" Education. Zhuangshi (12),100-104. DOI:10.3969/j. issn.0412-3662.2021.12.017. 董玉妹&王婷婷.(2021). "新工科"建设背景下荷兰3TU跨学科工业设计人才培养的经验与启示. 装饰 (12),100-104. DOI: 10.3969/j.issn.0412-3662.2021.12.017.
- 6. Wang, T., Xiao D., Dong, Y., & Goossens, R., Framework of Persona Based on the Structural Characteristics of Older Adults' Social Networks. Packaging Engineering, 2021,42(4): 83-89. doi:10.19554/j.cnki.1001-3563.2021.04.010. 王婷婷,肖东娟,董玉妹,Richard Goossens.基于荷兰老年人社会关系结构特征的用户角色构建[J].包装工程,2021,42(4):83-89, 102. doi:10.19554/j.cnki.1001-3563.2021.04.010.
- (To be submitted) Wang, T.*, Jesse He*, Oest, M., Dekker E., Goetzee, C., Roodenburg, Y., Goossens R, Melles M., Corten E. Evaluating the Digital Patient Experience of Virtual Reality Distraction in Wound Care: A Prospective Observational Study. Manuscript is to be submitted to a peer-reviewed medical journal.
- 8. (Under review) **Wang, T.**, Armagan A., Goossens, R., Xiao, D., & Melles M. Digital Patient Experience Design Guide: Method Evaluation study. Manuscript is under review in a peer-reviewed design journal.
- 9. (Under review) Marijnissen, F.E., Rijnders, E.E.C., Tielemans, M.M., van Noord, D., Wolters, L.M.M., Jansen, J.M., Schot, I., Bekkering, F.C., Reijm, A.N., van Baalen, S.M., **Wang, T.**, Melles, M., Goossens, R., Ismail, S.Y., Lansdorp Vogelaar, I., de Jonge, P.J.F., M.C.W. Spaander, P.J.F. Reducing outpatient visits in FIT-based colorectal cancer screening a shift to home-based counselling using a Digital Intake Tool. Manuscript is under review in a peer-reviewed medical journal.

Conference papers and presentations

1. Wang T, Wang Y, Clarkson PJ, Rietjens J, Melles M. Evaluating a Web-Based Guide for Designing Digital Patient Experiences: Preliminary Results of a User Test with Design Students. Proceedings of

- the Design Society. 2024;4:1687-1696. doi:10.1017/pds.2024.171
- (Accepted) Wei, R., & Wang, T. (2024). Designing Digital Patient Experience: a Patent Review of Digital Mental Health Interventions. IEA: The 22nd Triennial Congress of the International Ergonomics Association.
- 3. (Accepted) **Wang, T.**, Xiao, D., Goossems, R., & Melles, M. (2024). Digital Patient Experience Design Guide: Preliminary Results Based on a User Test Workshop. IEA: The 22nd Triennial Congress of the International Ergonomics Association.
- 4. Wang, T., Xiao, D., Miao, X., Zhang, Y., Lan, X., Yan, C. (2023). A Sustainable Product-Service System (PSS) Design for Retail Food Loss and Waste: Research Through Design. In: Fukushige, S., Kobayashi, H., Yamasue, E., Hara, K. (eds) EcoDesign for Sustainable Products, Services and Social Systems I. Springer, Singapore. https://doi.org/10.1007/978-981-99-3818-6 30
- Wang, T.(2023) Digital Patient Experience: Understanding, Improvement, and Evaluation from a Human-Centered Design Perspective, in De Sainz Molestina, D., Galluzzo, L., Rizzo, F., Spallazzo, D. (eds.), IASDR 2023: Life-Changing Design, 9-13 October, Milan, Italy. https://doi.org/10.21606/iasdr.2023.623
- 6. Wang, T., Qian, S., Zhu, H., Goossens, R., Giunti, G., Melles, M. (2024). Building Understanding of Experience Design in Digital Health: Preliminary Results Based on Semi-Structured Interviews. In: Melles, M., Albayrak, A., Goossens, R.H. (eds) Convergence: Breaking Down Barriers Between Disciplines. HEPS 2022. Springer Series in Design and Innovation, vol 30. Springer, Cham. https://doi.org/10.1007/978-3-031-32198-6-28
- Wang, T., Giunti, G., Melles, M., & Goossens, R. (2022). Design-Relevant Factors Affecting the Patient Experience in Digital Health: Preliminary Results of an Umbrella Systematic Review. MEDINFO 2021: One World, One Health–Global Partnership for Digital Innovation, 862-866. DOI: 10.3233/SHTI220202
- Rieff, E., Houtman, T., Vijfvinkel, T., Wang, T., M., & Sweeney, J. (2022). The Generation Care Story and Organizing Framework (1.0). Science Education and Innovation Festival - Sustain the future of healthcare, Rotterdam, The Netherlands. Zenodo. https://doi.org/10.5281/zenodo.8013123
- **9. Wang, T.**, Xiao, D., Goossens, R. H., & Dong, Y. (2019) Research on Design Strategy of Playful Products for Elderly Based on Case Analysis. Heritage & Vision, 94. https://pure.tudelft.nl/ws/portalfiles/portal/67548586/2019 DEW proceedings.pdf#page=99

Books and websites

- 2. Digital Patient Experience Design Guide: https://www.tudelft.nl/io/delft-design-guide-digital-health.

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Curriculum Viate

Tingting Wang was born on April 11, 1995 (the Lunar calendar) in Anhui Province, China.

From October 2020 to February 2025, Tingting did her PhD at the Human-Centered Design Department in the Faculty of Industrial Design Engineering (IDE) at Delft University of Technology (TU Delft), with a specific focus on designing the digital patient experience (i.e., patient experience in digital health) by converging the worlds of healthcare and technology from a human-centered design perspective. Her PhD project belongs to the Consultation Room 2030 flagship program, a convergence research consortium between TU Delft, Erasmus Medical Center, and Erasmus University of Rotterdam. She was supervised by Professor Dr. Richard Goossens and Associate Professor Dr. Marijke Melles.

During the first two years of her PhD, she received supervision from adjunct professor Dr. Guido Giunti, who works at the University of Oulu and Trinity College Dublin. Tingting's PhD was funded by the China Scholarship Council under the collaboration program between TU Delft and Jiangnan University. In 2023, funded by the Delft Health Initiative, she spent three months at the University of Cambridge as a visiting PhD candidate, supervised by Professor Dr. John Clarkson. Tingting has co-initiated and co-conducted both qualitative and quantitative studies, such as umbrella systematic reviews, semi-structured interviews, prospective observational studies, and user test workshops, among China, the Netherlands, and the United Kingdom, with interdisciplinary collaborators from institutions such as the University of Cambridge, Erasmus University Rotterdam, the University of Oxford, etc. In addition, she co-supervised and coached eight master graduation projects, and two master students graduated with Cum Laude. She has been involved in coaching both bachelor and master courses, such as "Health Psychology: Tools and Methods" master elective courses and "Experience, Motivation, and Behavior" bachelor elective courses at TU Delft, and "Service Design and Social Innovation" master elective courses at Jiangnan University.

Before her PhD journey, she obtained her Master of Arts degree in Design Science at Jiangnan University in the Interaction and Experience Design program under the supervision of Associate Professor Dr. Xiao Dongjuan, spending six months at the IDE faculty at TU Delft. She received the 2021 Jiangsu Province Excellent Academic Master Graduation Thesis award for her master's graduation thesis, which focused on strategic design for healthy aging. In 2017, she received her Bachelor of Engineering's degree in the major of Industrial Design at Anhui University as an excellent undergraduate student in first place. After her PhD study, she works as a postdoctoral researcher using a systems approach to health and care improvement research jointly between the TU Delft Faculty of Industrial Design Engineering and the University of Cambridge Engineering Design Centre, with a specific focus on the clarification, extension, implementation, and dissemination of the Improving Improvement Toolkit.



