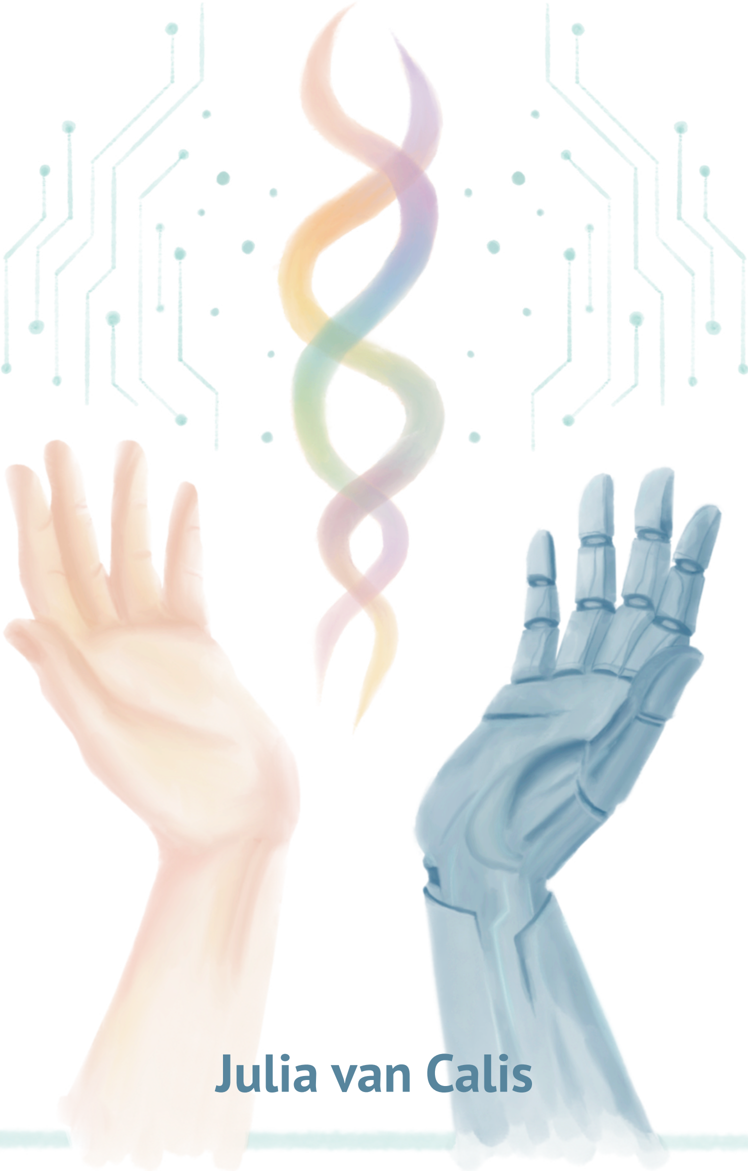
Towards accessible eHealth for people with intellectual disabilities or complex care and support needs

Exploring inclusive eHealth research, design and implementation



Julia van Calis

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CHAPTER

1

GENERAL INTRODUCTION

GENERAL INTRODUCTION

eHealth for people with ID or complex care and support needs

The rapid digitalization of society has profoundly transformed the way people interact with technology in their daily lives [1], including the design of digital tools within the healthcare sector, commonly referred to as eHealth [2]. This broad term encompasses tools like web-based platforms, interactive training modules, wearables and tools equipped with sensors, virtual assistants, and mobile health apps, al increasingly used in the care of people with complex care and support needs, such as those living in care organisations [3].

Given the wide scope of eHealth, various definitions have been introduced over the years, for example, Telehealth, Telemedicine, Digital health Health(care) technology [4, 5]. Oh et al. emphasized eHealth as “not only a technical development, but also a state of mind and a commitment” to global health improvement through ICT [4]. Eysenbach described it as the secure, cost-effective use of ICT in healthcare and health-related fields [6]. In this dissertation, eHealth refers to “the use of technologies to improve health, well-being, and healthcare” [3, 7] , a definition that was chosen for its clarity, broad applicability, and relevance to the diverse needs of people with complex care and support needs. Other definitions appear more technical or conceptual, however, this one emphasizes practical outcomes, such as improved well-being and accessibility, and aligns with the inclusive approach of this research.

eHealth has the potential to improve healthcare accessibility by supporting personalized care, increasing patient independence, and empowering individuals [2, 8]. These benefits are particularly valuable for individuals with complex care and support needs [9], including those with an intellectual disability (ID) [10]. They often experience difficulties in various aspects of everyday life, such as cognitive functioning, executive functioning, language comprehension, and social interaction [11]. As a result, they may struggle to navigate complex digital interfaces, interpret health information, and manage their health online [12, 13]. Most eHealth tools are poorly adapted to the needs and abilities of individuals with ID, leading to low adoption, reduced usability, and unintended barriers to healthcare participation [14]. These challenges are not exclusive to individuals with ID. People with autism spectrum disorder (ASD), low (health) literacy, or other cognitive and communicative difficulties also frequently encounter similar barriers when accessing and using digital healthcare tools [13]. Yet, most eHealth tools are still designed with the general population in mind, often overlooking the people who could benefit the most from such support [2, 15]. This results in challenges with the use of eHealth within the context of people with complex care and support needs as the technologies often do not fit their complex needs and living circumstances [16, 17]. By developing eHealth that is accessible and inclusive, tools that are more usable for a broader range of users can be created.

Healthcare organisations that support people with ID or complex care and support needs, are increasingly exploring the implementation of eHealth, especially as new applications continue to emerge [18]. However, the successful use of eHealth in this population relies heavily on the support provided by caregivers, healthcare professionals, and other intermediaries who assist with the selection, adaptation, and everyday use of these tools. The effectiveness of eHealth in this population is therefore closely linked to the support available from caregivers and healthcare professionals, making eHealth adoption a complex, multi-stakeholder process [17]. The misalignment between technology and user capabilities contributes to a growing digital divide, increasing existing health inequities between people with ID or complex care and support needs and the general population [19]. To ensure equitable access, it is essential to consider the broader social and organizational context in which eHealth is introduced and used [20]. The adoption and integration of eHealth within the care of people with complex care and support needs such as ID, remains significantly lower than in other healthcare domains among elderly and chronic disease care [21]. Although research in this field has grown over the past decade, it often emphasizes effectiveness and usability with less attention paid to how eHealth tools are designed and embedded in practice [8, 11].

Approaches for eHealth design and implementation

Various approaches support the design and implementation of eHealth. The Center for eHealth Research and Disease Management (CeHRes) Roadmap promotes a participatory and iterative approach to eHealth design, ensuring alignment with user needs from the start throughout the full process [7, 22]. Similarly, Design Thinking offers a structured methodology for co-creating digital tools with end users, emphasizing usability, accessibility, and contextual fit [23]. Both of these approaches build upon earlier approaches such as participatory development, human-centred design and persuasive design principles [20, 24].

From an implementation perspective, several frameworks offer structured approaches to understanding complexity and barriers and facilitators when implementing (eHealth) innovations and are widely used in implementation science. More general frameworks include the Consolidated Framework for Implementation Research (CFIR) [25], Wensing and Grol's framework for implementation of change in healthcare [26], the Diffusion of Innovations theory for service organizations [27] and the Non-adoption, Abandonment, Scale-up, Spread, and Sustainability (NASSS) framework [28]. These frameworks emphasize organizational readiness, stakeholder involvement, and policy support as key factors for successful implementation [20, 29].

eHealth-specific frameworks, such as the CeHRes Roadmap and the NASSS framework, are tailored to healthcare technologies [22, 30]. They are empirically grounded in healthcare research, widely adopted, and offer complementary perspectives to guide and reflect on both design and implementation processes in complex healthcare environments [20, 24]. The CeHRes Roadmap emphasizes continuous alignment with stakeholder needs during design, implementation, and evaluation [7], whereas the NASSS framework provides a structured view on the complexity of implementation, covering domains such as technology, value proposition, adopters, and organizational context [28, 31]. It underlines that technology development is a continuous process requiring adaptation to the specific context and emerging needs.

Although these frameworks offer guidance for either design or implementation, few approaches integrate both design and implementation, requiring complementary use to gain a broad perspective into eHealth design and implementation [7]. There is a need for integrated approaches that systematically combine design and implementation perspectives to support the creation of sustainable eHealth tools. Moreover, applying re-design to existing eHealth tools provide the opportunity to ensure a better fit to the needs and capabilities of specific target groups such as people with ID [32]. Research indicates that end-users are often engaged only in the later stages of design which limits their influence on both the design and implementation of eHealth tools [3, 33].

A step towards inclusive eHealth design and implementation approaches

Inclusive research approaches, such as co-design, citizen science, and participatory action research, have gained increasing recognition for their role in reducing digital inequities [34]. Inclusive design originates from user-centred design methodologies [35], and places marginalized groups at the centre of the design process [36-38]. These inclusive approaches aim to reduce digital inequities by actively involving all relevant stakeholders, particularly people with ID, throughout the entire process of design, implementation, and research. This includes positioning individuals with ID or complex care and support needs not merely as study participants, but as co-designers or co-researchers, ensuring that the resulting eHealth tools are better aligned with their real-world needs and preferences [39, 40]. A more inclusive approach to eHealth design and implementation can ultimately contribute to reducing the digital divide, promoting equal access to eHealth tools for people with ID or complex care and support needs [20].

eHealth can prove valuable for people with ID or complex care and support needs, however, it is currently not tailored to meet their needs, and to do so, requires inclusive approaches in both design and implementation [41]. Additionally, the involvement of people with ID or complex care and support needs, their caregivers and other key stakeholders in these processes still remains limited [42]. Engaging a broader group of key stakeholders, including caregivers, healthcare and IT professionals, and policymakers throughout the design and implementation ensures that eHealth tools are well-integrated into existing care structures [43] and are relevant, accessible, and usable in real-world settings [9, 44]. Actively involving end-users and key stakeholders will improve suitability, sustainability, usability and enhance user acceptance and long-term adoption [42, 45]. Despite their potential, such inclusive approaches are still rarely applied or studied with users with ID or complex care and support needs. By investigating the eHealth design and implementation processes and stakeholder involvement, this research aims to generate insights that are both applicable and actionable in practice.

AIMS OF THIS THESIS

This research aims to examine and strengthen inclusive design and implementation processes of eHealth for people with ID or complex care and support needs. More specifically, the sub-aims of this thesis are to:

1. Create an integrated framework for eHealth design and implementation for people with ID or complex care and support needs.
2. Apply the integrated framework to guide or analyze eHealth design and implementation processes for people with ID or complex care and support needs in the healthcare domain.
3. Reflect on inclusive and iterative eHealth design and implementation processes for people with ID or complex care and support needs by gathering first-hand experiences from end users and key stakeholders.

INCLUSIVE RESEARCH AND DESIGN

This thesis followed an inclusive research approach, using the term “inclusive research” as overarching for the involvement of people with ID in research [46]. In 2003 inclusive research was defined as: “research which includes or involves people with intellectual disabilities as more than just objects of research”, by Walmsley and Johnson [47]. In 2018 they proposed an updated definition to better guide the second generation of inclusive research and to reflect its added value, as shown in Box 1.1 [48]. This research involved structural collaboration with co-researcher: Anneke van der Cruijsen. For two-four hours a week, I worked together with Anneke on my PhD-project, combining experiential and research-based knowledge in designing, executing, interpreting the results and dissemination of the studies. In each phase we decided together upon the level of involvement of Anneke, which ranged from consultation, to advising and collaboration.

- Research that aims to contribute to social change, that helps to create a society, in which excluded groups belong, and which aims to improve the quality of their lives.
- Research based on issues important to a group, and which draws on their experience to inform the research process and outcomes.
- Research which aims to recognize, foster, and communicate the contributions people with intellectual disabilities can make.
- Research which provides information which can be used by people with intellectual disabilities to campaign for change on behalf of others.
- Research in which those involved in it are “standing with” those whose issues are being explored or investigated.

Box 1.1 Updated version of definition for inclusive research from Walmsley and Johnson (2018).

Additionally, stakeholders from ID support organizations and people with ID were actively involved in all empirical studies to ensure the integration of experiential, practical, and research-based knowledge. This was realized through meetings with an advisory board. The advisory board consisted of professionals with diverse backgrounds working in care organizations or companies as a project manager, project leader or researcher focusing on eHealth, an expert custom gaming, MedTech expert and eHealth coordinator. This enhanced the connection with practice as they provided feedback on the research design, the formulation of interview and focus group guides, participant recruitment, reflection on results and research dissemination.

Inclusive design was also applied during two studies within this research (Chapter 3 and 5). Inclusive research entails working together throughout all phases of the research process, continuously evaluating what matters most to the target group [46]. Similarly, inclusive design focuses on improving the applicability and usability of technology for the target group, requiring collaboration to ensure the development of relevant and usable eHealth tools [38, 41]. Although inclusive research and inclusive design have different objectives, both require collaboration with co-researchers or co-designers to ensure applicability in practice.

RESEARCH SETTING

This thesis was conducted within the academic collaborative Stronger on your own feet (*Sterker op eigen benen*) [49], which is a collaboration between the research group Intellectual disability and Health of the Radboud university medical center in Nijmegen and six care organizations for people with ID (‘s Heeren Loo, Koraal, Dichterbij, Driestroom, Philadelphia and Siza). The aim of the academic collaborative is to improve the health and healthcare for people with intellectual disabilities by integrating research, education, and patient care.

OUTLINE OF THIS THESIS

Figure 1.1 shows an overview of the studies in this thesis. **Chapter 2** provides a scoping review investigating the inclusive approaches currently applied for the ***design, development, and implementation*** of eHealth for people with ID using an integrated framework based on the CeHRes Roadmap and NASSS Framework. In this chapter, we reviewed how and in what phases people with IDs and other stakeholders were included in these processes. Next, three case studies have been conducted, each representing different settings and contexts. **Chapter 3** investigates the design characteristics and elements crucial for enhancing the accessibility and usability of digital (research) platforms for individuals with mild ID or low literacy skills when involving end-users in the ***design*** process by performing interviews and usability tests. In **Chapter 4,** the smart continence care ***implementation*** process in disability care organizations for people with profound intellectual and multiple disabilities is evaluated. By applying the integrated implementation framework, we gathered first-hand experiences from key stakeholders, including caregivers and project leaders directly involved in applying smart continence care. **Chapter 5** examines the experiences of co-researchers with mild ID or ASD and other key stakeholders in the inclusive ***design*** process of a digital tool for people with complex complex care and support needs. This study was conducted within a consortium of transdisciplinary partners. **Chapter 6** provides a general discussion of the main findings presented in this thesis, reflecting on the inclusive research approach applied during this project. Each chapter contributes to one or more of the sub-aims of this thesis. **Chapter 2** supports the development of the integrated framework (Aim 1). **Chapters 2 and 4** apply this framework in various contexts (Aim 2), while **Chapters 3 and 5** focus on gathering stakeholder experiences to reflect on inclusive processes (Aim 3). **Chapter 6** synthesizes all the insights from the previous chapters.

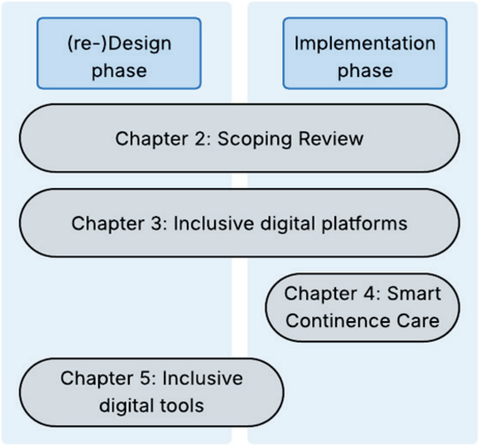

Figure 1.1 Schematic overview of studies.

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CHAPTER

2

TOWARD INCLUSIVE APPROACHES IN THE DESIGN, DEVELOPMENT, AND IMPLEMENTATION OF EHEALTH IN THE INTELLECTUAL DISABILITY SECTOR: SCOPING REVIEW

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ABSTRACT

Background: The use of eHealth is more challenging for people with intellectual disabilities (IDs) than for the general population because the technologies often do not fit the complex needs and living circumstances of people with IDs. A translational gap exists between the developed technology and users' needs and capabilities. User involvement approaches have been developed to overcome this mismatch during the design, development, and implementation processes of the technology. The effectiveness and use of eHealth have received much scholarly attention, but little is known about user involvement approaches.

Objective: In this scoping review, we aimed to identify the inclusive approaches currently used for the design, development, and implementation of eHealth for people with IDs. We reviewed how and in what phases people with IDs and other stakeholders were included in these processes. We used 9 domains identified from the Centre for eHealth Research and Disease management road map and the Nonadoption, Abandonment, and challenges to the Scale-up, Spread, and Sustainability framework to gain insight into these processes.

Methods: We identified both scientific and gray literature through systematic searches in PubMed, Embase, PsycINFO, CINAHL, Cochrane, Web of Science, Google Scholar, and (websites of) relevant intermediate (health care) organizations. We included studies published since 1995 that showed the design, development, or implementation processes of eHealth for people with IDs. Data were analyzed along 9 domains: participatory development, iterative process, value specification, value proposition, technological development and design, organization, external context, implementation, and evaluation.

Results: The search strategy resulted in 10,639 studies, of which 17 (0.16%) met the inclusion criteria. Various approaches were used to guide user involvement (e.g., human or user-centered design and participatory development), most of which applied an iterative process mainly during technological development. The involvement of stakeholders other than end users was described in less detail. The literature focused on the application of eHealth at an individual level and did not consider the organizational context. Inclusive approaches in the design and development phases were well described; however, the implementation phase remained underexposed.

Conclusions: The participatory development, iterative process, and technological development and design domains showed inclusive approaches applied at the start of and during the development, whereas only a few approaches involved end users and iterative processes at the end of the process and during implementation. The literature focused primarily on the individual use of the technology, and the external, organizational, and financial contextual preconditions received less attention. However, members of this target group rely on their (social) environment for care and support. More attention is needed for these underrepresented domains, and key stakeholders should be included further on in the process to reduce the translational gap that exists between the developed technologies and user needs, capabilities, and context.

Keywords: eHealth; digital health; intellectual disability; inclusive research; involvement; participatory development; scoping review; Centre for eHealth Research and Disease management; CeHRes roadmap; Nonadoption, Abandonment, and challenges to the Scale-up, Spread, and Sustainability framework; NASSS; review method; inclusive; inclusivity; accessibility; participatory; iterative; design; develop; intellectually disabled

INTRODUCTION

Background

The number of eHealth applications has increased exponentially over the last years. In general, eHealth can be defined as "the use of technologies to improve health, well-being, and healthcare" [1]. Nonetheless, the implementation of eHealth technology remains challenging and often cannot be sustained over time [2-4]. The use of eHealth is more challenging for people with intellectual disabilities (IDs) compared with the general population, as the technologies often do not fit the complex needs and living circumstances of people with IDs [5, 6]. In the rapidly changing digital environment, people with IDs often need support when using eHealth because they experience difficulties in acquiring digital literacy skills and using digital devices or the internet [7-9]. These difficulties show the translational gap that exists between the developed technology and these users' needs and capabilities, although there are approaches available to overcome this mismatch [10-12], for example, by involving users in the development and implementation processes of the technology. However, more knowledge is needed on these inclusive eHealth trajectories. Therefore, this scoping review examined how inclusive approaches have been used in the design, development, and implementation of eHealth for people with IDs.

IDs can be defined as considerable limitations in both intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical adaptive skills [13]. People with IDs have heterogeneous needs for health and support and are strongly dependent on their social environment for access to, and use of, eHealth [3]. This dependency also causes struggles in communication, personal care, traveling, and living [14]. Reviews by Burke [15] and Vázquez et al [16] showed that eHealth has the potential to increase the level of independence of people with IDs and to support their higher demand for personalized care [15, 16]. However, technological innovations are often too complex for people with IDs to use independently [10, 11]. One explanation is that eHealth is often developed and implemented without the involvement of key stakeholders, such as people with IDs and their caregivers and care provider organizations that use the eHealth applications [1, 17]. Including these stakeholders in the development and implementation of eHealth ensures that eHealth is adjusted to their living environment and needs for health and support, thereby increasing the sustainability of eHealth use over time [1, 18, 19]. This can be achieved by applying inclusive research and design and giving end users and key stakeholders an active role as experiential experts, co-designers, or coresearchers throughout the process [20-22].

Several approaches can be applied to technology design, development, and implementation. For example, design thinking is used to explore the context of complex problems and generate solutions in an iterative process by keeping the users' needs central [23]. Universal design aims to maximize usability by individuals with a wide variety of characteristics by applying 7 principles (e.g., equitable use, flexibility in use, and perceptible information) [24]. Another example is the Consolidated Framework for Implementation Research, which has been developed to guide the systematic assessment of implementation, formative evaluations, and the identification of factors that might influence intervention implementation [25, 26]. Although these approaches are widely used in practice, they do not focus specifically on health care–related technologies [26, 27]. Frameworks that focus on such technologies (e.g., the Health Technology Assessment–inspired Model for Assessment of Telemedicine applications and the eHealth value model) [28, 29] provide evaluation tools to assess the value and effectiveness of health care technologies but only marginally give practical guidance on inclusive design, development, and implementation.

The Centre for eHealth Research and Disease management (CeHRes) roadmap is an example of this and is based on existing evidence-based models, frameworks, and methods such as participatory development and business modelling. This roadmap can be used to guide the development, implementation, and evaluation of eHealth technologies [1, 17]. Another example is the Nonadoption, Abandonment, and challenges to the Scale-up, Spread, and Sustainability (NASSS) framework, which reviews the implementation of health care technology in multiple domains (e.g., technology, value proposition, adopters, and organization) [30]. According to the NASSS framework, the development of technology is a never-ending process in which the technology can be adjusted to fit each specific setting and context [31]. The NASSS framework has been widely applied in eHealth research and extended with the practical NASSS-Complexity Assessment Tool (NASSS-CAT) [32-35]. Both the CeHRes roadmap and the NASSS framework assess eHealth technology in which iterative processes play a central role in the design, development, and implementation while involving end users and other key stakeholders [1, 30].

The term eHealth is broad and has various definitions [36]. For example, Oh et al [36] described it as "characterizing not only a technical development, but also a state of mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology," whereas Eysenbach [37] described it "as the cost-effective and secure use of information and communications technologies in support of health and health-related fields, including health care services, health surveillance, health literature, and health education, knowledge, and research." In this study, we specified the general definition to the context of people with IDs who often live within health care organizations or assisted living facilities [1]. Therefore, we did not focus on technologies with an educational purpose without health, well-being, or health care–related content or medical technologies such as hospital equipment and implanted devices.

Objective

In this scoping review, we aimed to identify the inclusive approaches that were used for the design, development, and implementation of eHealth for people with IDs. In addition, we reviewed how and in what phases people with IDs and other stakeholders were included in the process. We used components identified from the CeHRes road map and NASSS framework to examine the current literature on eHealth design, development, and implementation processes.

METHODS

Study Design

We used the scoping review methodology that is proposed by Levac et al [38] and is based on the framework developed by Arksey and O'Malley [39] to guide the review process. This methodology consists of five stages: (1) identifying the research questions; (2) identifying relevant studies; (3) selecting relevant studies; (4) charting the data; and (5) collating, summarizing, and reporting the results [39].

Identifying Research Questions

The objective was divided into four subquestions: (1) What theories or frameworks are used in the design, development, and implementation of eHealth for people with ID? (2) Who is involved in the process of eHealth design, development, and implementation for people with ID? (3) In what phases and activities of eHealth design, development, and implementation are people with ID and stakeholders involved? and (4) What components from the CeHRes roadmap and the NASSS framework can be identified in the design, development, and implementation of eHealth for people with ID?

Identifying Relevant Studies

A search string was developed with assistance from an information expert, using the Population, Intervention, Comparison, and Outcome approach [40]. The following 7 databases were searched: PubMed, Embase, PsycINFO, CINAHL, Cochrane, Web of Science, and Google Scholar. Multimedia Appendix 1 [1, 13, 41-43] shows the full search strings used for PubMed, consisting of blocks with terms describing "intellectual disability" [AND] "eHealth" [AND] “design” [OR] “development” [OR] “implementation,” which was then adopted for each subsequent database. The terms design, development, and implementation were connected by [OR] to search for a combination of the phases in which the process was described or the studies that described them separately. Gray literature, peer-reviewed reports, and non–peer-reviewed reports, such as Dutch unpublished documentation, were included by contacting 2 intermediate organizations that share the knowledge of producers with knowledge users and 7 care organizations for people with IDs via email for (unpublished) literature. The websites of relevant (health care) organizations were also examined for documentation. Additional articles were identified by manually searching the reference lists of the included articles, including searching for previous or follow-up articles of the included articles.

Selecting Relevant Studies

The PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) [44] guided the selection process (Table 2.1). The search included literature published between January 1995, when the internet is first introduced in health care , and January 2022. Studies were included if at least 1 of the 3 process descriptions (i.e., design, development, or implementation) was present in the article. Both title and abstract and full-text screenings were performed by 1 researcher (JFEC). If the inclusion of a title and abstract was unclear, it was included in the full-text screening and reviewed by another independent reviewer (KEB) in 3 eligibility stages.

Data Charting and Collating, Summarizing, and Reporting the Results

First, the following key information was extracted from each paper: authors, title, year of publication, origin or country, article type, aim or purpose, study population (target end user population), sample size, methodology, and intervention type (purpose of the eHealth) [1]. Next, the theories, frameworks, and approaches used in the design, development, and implementation were extracted. Moreover, the people involved and how and in what phases or activities they were involved were reviewed. The extraction of the design, development, and implementation processes was guided by 9 domains identified from the CeHRes roadmap and NASSS framework, as described in the following paragraph.

Table 2.1 Inclusion and exclusion criteria.

Criteria	Inclusion	Exclusion
Type of studies	• All full-text studies (e.g., articles, dissertations, conference papers, reports, and gray literature from [health care] organizations)	• Abstracts and studies presenting only psychometric data
Period	• From January 1, 1995, to January 31, 2022	• Before January 1, 1995, and after January 31, 2022
Language	• English or Dutch	• All other languages
Population	• People with intellectual or developmental disability	• People with cognitive disabilities caused by traumatic brain injury, stroke, cancer (treatment), or dementia
Intervention	• Technology that is created to improve health or well-being or health care related (e.g., technology to provide support with medication intake or daily [independent] living)	• Educational application of the technology without health, well-being, or health care–related content and medical application of the technology (e.g., hospital equipment, such as heart monitors, and implanted devices, such as pacemakers)
Outcome	• The design process of eHealth interventions for people with intellectual disabilities • The (technological) development process of eHealth interventions • The implementation process of eHealth interventions for people with intellectual disabilities	• Focus on the design (appearance [e.g., colors, visuals, and font style]) of eHealth without describing the process • Focus on the development (e.g., content) of eHealth without describing the process • Focus on the use or effectiveness of eHealth interventions after implementation

The CeHRes roadmap describes clear development activities and combines participatory development, human-centered design, business modelling, and persuasive design in 5 intertwined phases and connecting cycles (formative evaluations): contextual inquiry, value specification, design, operationalization, and summative evaluation [1]. The NASSS framework studies the complexity of 7 domains: the condition (i.e., the nature of the condition, sociocultural factors, and comorbidities); technology; value proposition; adopters; organization; wider system; and embedding and adaptation over time [30]. The NASSS framework emphasizes that the technology needs to fit each specific setting and context and shows important preconditions for implementation. After combining the phases from the CeHRes roadmap and the domains from the NASSS framework, the following nine main domains with their corresponding components were defined for this study:

1. Participatory development: the approach actively involves all stakeholders in the development process to help ensure that the result meets their needs and is usable [1, 17]. This includes cocreation, multidisciplinary project management, and the inclusion of stakeholders' perspectives.
2. Iterative process: continuous evaluations are performed during the design, development, and implementation of the technology. The evaluation is interwoven

with all stages in the development process [1], including continuous evaluation and checking whether the outcomes of the previous phases are accounted for.

3. Value specification: creating the optimum level of return for end users and other stakeholders involved by identifying, analyzing, gathering, and mapping their values, for example, easy-to-read text and accessibility of the technology [1, 17]. This consists of end users, conditions or illnesses, sociocultural factors, stakeholder identification, stakeholder analysis, and value identification.
4. Value proposition: this involves explicating the value that the technology might generate for different groups of people. Values can be financial, such as profit, or nonfinancial, such as control of symptoms [1, 45]. This includes the business model, the supply and demand model, and ownership.
5. Technological development and design: describing the technology (e.g., a tool or piece of software) and how it might affect care [30], this includes technology requirements, prototyping (lo-fi and hi-fi), and usability tests.
6. Organization: considering the changes needed for the (health care) organizations to implement and use the technology and the consequences of the technology after it is introduced [30, 35], this covers the capacity and readiness to innovate, nature of adoption and funding decisions, and changes in organizational routines.
7. External context: external conditions that could complicate the adoption and spread of the technology [27], including the political and policy context, regulatory and legal issues, professional bodies, and interorganizational networking, are considered.
8. Implementation: this includes developing an implementation plan with a set of conditions or activities designed to start using technology in practice [1] and discovering whether the implementation is accounted for from the start and determining activities for the implementation plan.
9. Evaluation: this includes understanding the relative benefits and costs of the technology in the context of the proposed implementation [1, 30], determining the impact on the context and stakeholders, and analyzing the uptake of the technology.

Multimedia Appendix 2 shows a table with the 9 domains and their corresponding descriptions used for data extraction. The data extraction chart table was created iteratively based on feedback from the authors and a sounding board consisting of coresearchers and eHealth project managers from disability health care organizations. A test analysis was performed on 3 studies by using the first version of the data extraction chart table. The test analysis was used to refine the data extraction chart table. The Results section covers these 9 domains, following the research questions specified in the Identifying Research Questions section.

RESULTS

Article Selection

The identification phase resulted in 10,639 records. There were 1784 duplicates, and these together with 3studies from before 1995 were removed, leaving 8852 (83.20%) studies. Title and abstract screening was performed using the inclusion and exclusion criteria (Table 1). In the screening phase, the main reasons for exclusion were that the target group did not fit our criteria and that the technology did not match the definition of eHealth used in this study. The absence of a description of how the eHealth was developed, designed, or implemented (referred to as process description in this study) was the main reason for exclusion in the eligibility phase. Of the 8852 studies, 8778 (99.16%) studies were removed, resulting in 74 (0.84%) studies whose full texts were read by the first author (JFEC) to screen for inclusion. In the event of doubt, the studies were read by another independent reviewer (KEB). After the full-text screening, 15 (20%) of the 74 studies were eligible for inclusion. The same method was applied to the gray literature, in which 2 studies were included, leaving a total of 17 studies included (Figure 2.1).

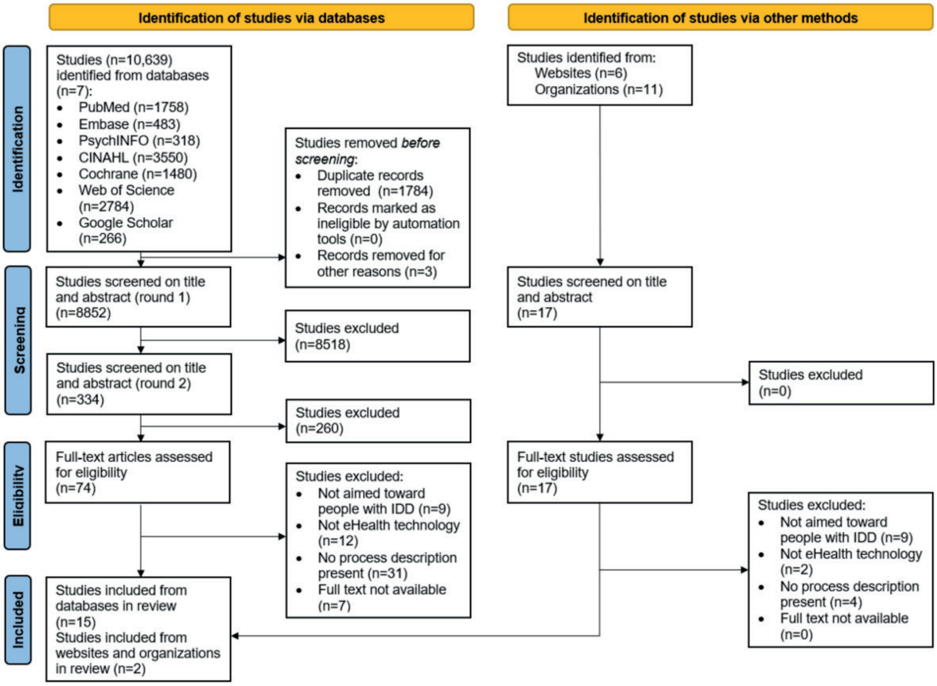

Figure 2.1 PRISMA-ScR (Preferred Reporting Items of Systematic Reviews and Meta-Analyses extension for Scoping Reviews) flowchart. IDD: intellectual and developmental disability.

Study Summary

An overview of information obtained from the included studies is presented in Table 2.2. Table 2.2 shows the distribution of the studies across the continents. Of the 17 studies, most studies (n=10, 59%) were conducted in Europe, 4 (24%) studies were performed in the United States, and the remaining 3 (18%) studies were conducted in Australia. These studies included a variety of topics and purposes of eHealth technologies, such as supporting and training life skills and communication. End users of the eHealth technologies included, for example, adults with intellectual and developmental disabilities and people with IDs and other impairments such as sensory and speech impairments.

Table 2.2 Overview of information from the included studies—source and country; the identified eHealth purposes; the approaches, theories, or frameworks used; the processes presented; and the targeted end users (n=17).

Source, country	**Purpose of eHealth**	**Approach, theory, or framework**	**Design, development, or implementation**	**Targeted end users**
Bayor [46], 2019, the United States	Support life skills development	Competency-based design and participatory action research with collaborative technology workshops	Design and development	Young adults with IDs[a]
Brown et al [47], 2011, the United Kingdom	Skill development for route learning	Phased development and implementation with user-sensitive inclusive design	Design, development, and implementation	People with IDs and additional sensory impairments
Brown et al [48], 2016, Australia	Learning and training life skills	Iterative co-design processes by Brereton et al [49], 2015	Design, development, and implementation	Adults with IDs
Davies et al [50], 2015, the United States	Accessible interface for Facebook	Iterative design and development	Development	Adults with IDs
Dekelver et al [51], 2015, Belgium	Traveling independently	Human-centered design: methods to support human-centered design (Maguire) [52], 2021, 10 heuristics for user interface design (Nielsen) [53], 1994, and designing for users with cognitive disabilities (Friedman and Bryen) [54], 2007	Development	People with IDs
Dekelver et al [55], 2015, Belgium[b]	Accessible mobile apps	Human- or user-centered design with persona and WAI[c] guidelines	Design and development	People with IDD[d]
Duval et al [56], 2018, the United States	Speech articulation therapy	Iterative user-centered design	Design and development	Adults with developmental disabilities co-occurring with speech impairment

Source, country	Purpose of eHealth	Approach, theory, or framework	Design, development, or implementation	Targeted end users
Engler and Schulze [57], 2017, Germany	Managing daily activities independently	User-centered design	Design	People with Down syndrome
Furberg et al [58], 2018, the United States	Decision support	Feature-driven design approach and user-centered design process	Design and development	Individuals with Fragile X syndrome
Igual et al [59], 2014, Spain	Living independently	Requirement's engineering	Development	People with IDs and older people
Kaimara et al [60], 2021, Greece	Daily living skills training	5W2H[e] framework and participatory design	Design and development	Children with SENs[f]
Kerkhof et al [19], 2017, the Netherlands	Structure and support for daily activities	Participatory design and iterative process	Development and implementation	Clients with IDs
Kranenborg et al [61], 2013, the Netherlands	Accessible user interfaces	Situated cognitive engineering	Design and development	People with IDs
Lennox et al [62], 2009, Australia	Accessible web-based learning	W3C[g] guidelines—accessibility guidelines double A	Design and development	Adults with IDs and diabetes
Read et al [63], 2013, the United Kingdom	Support in case of a bereavement	Participatory action research	Design and development	People with IDs
Robb et al [64], 2019, Ireland	Cognitive training game	Participatory design	Design and development	Children with a rare genetic syndrome linked to ID
Wilson et al [65], 2016, Australia	Support with communicating	RAID[h] process	Design and development	Young adults with IDs

[a] ID: intellectual disability.
[b] To separate and identify the two studies from the same author and year of publication.
[c] WAI: Web Accessibility Initiative.
[d] IDD: intellectual and developmental disability.
[e] 5W2H: What, Where, When, Who, Why, How, and How much.
[f] SEN: special educational need.
[g] W3C: World Wide Web Consortium.
[h] RAID: Reflective Agile Iterative Design.

Domains

We identified 10,639 studies with our search strategy. Of these identified studies, only 17 (0.16%) provided a process description of eHealth design, development, or implementation for people with IDs, and these were analyzed based on the 9 domains. Regarding the first domain, 14 (82%) of the 17 studies [19, 46-48, 51, 55-58, 60, 62-65] applied participatory development by involving end users and other stakeholders in different phases. For the second domain, 13 (76%) of the 17 studies [19, 46-48, 51, 56, 58, 60-65] performed an iterative process through continuous evaluations, the use of prototypes, and the retrieval of user requirements. The third domain was reflected in 11 (65%) of the 17 studies [19, 46, 50, 51, 56-58, 61, 62, 64, 65], which performed a value specification or part of it, such as the description of end users' characteristics and the identification of other stakeholders besides end users. Similarly, in 7 (41%) of the 17 studies [47, 48, 55, 59, 60, 62, 63], only small parts were written about the fourth domain, value proposition, such as the values retrieved and the origin of these values. In all (17/17, 100%) studies, information on the fifth domain regarding technological development and design was provided, in which the development of prototypes based on requirements and testing of the prototypes was described. Only 1 (6%) of the 17 studies [19] provided information about the sixth and seventh domains concerning the organization and the external context. In total, 7 (41%) of the 17 studies [19, 46-48, 50, 56, 65] referred to the eighth domain, implementation, with implementation accounted for from the start and future implementation mentioned. The last and ninth domain, evaluation, was mentioned by 9 (53%) of the 17 studies [46, 51, 56, 57, 59-61, 63, 65] describing uptake and seven (41%) of the 17 studies [19, 48, 50, 57, 58, 65] showing impact.

Theories, Frameworks, and Approaches Used (Domains 1 and 2)

Overview

This section presents 2 domains covering theories: frameworks and approaches from the included papers that were intertwined with participatory development (domain 1) and iterative processes (domain 2; Table 2.2 provides an overview). Various inclusive theories and frameworks were used such as the sensitive inclusive design approach [47], human- or user-centered design [51, 55-58], participatory design [19, 60, 64], participatory action research [46, 63], and co-design [46, 48, 65]. The iterative approach was applied using various frameworks such as the Reflective Agile Iterative Design (RAID) [65], phased development [47], and iterative design [19, 48, 50, 56]. Participatory development with iterative approaches was shaped by the level of engagement, type of stakeholders, and reason for involvement.

Participatory Development (Domain 1)

The studies showed different levels of end users' engagement and participation throughout the design and development process. The 14 (82%) of the 17 studies that applied an inclusive theory or approach involved people with IDs as primary stakeholders throughout the full development process to facilitate a full understanding of users' perceptions, needs, and abilities [19, 46-48, 51, 55-58, 60, 62-65]. In total, 2 (12%) of the 17 studies reported end user involvement in early-stage prototype testing to ensure that important usability and accessibility issues (e.g., language use and button size) could be corrected [47, 56]. Moreover, 3 (18%) of the 17 studies did not adopt a theoretical approach to guide inclusive development [59, 61], and in 1 of these studies, the end user provided feedback only through informative interviews [50].

In total, 9 (53%) of the 17 studies reflected a design process that was collaborative with other key stakeholders such as family, care providers, and other professionals [19, 50, 51, 56-58, 61, 62, 64]. These stakeholders facilitated the studies by providing input in interviews about the needs of the target group or were involved as active participants in the development process [19, 58]. Of these, 1 study described secondary users' (e.g., caregivers and parents) and tertiary users' (e.g., teachers) experiences with using the technology in addition to the use by the primary users (e.g., people with IDs) [57]. The stakeholders were also included in the studies to gather important values and needs to shape the eHealth technologies, for example, by interviewing them to retrieve specific technical objectives [50]or operational requirements [61]. In another study, board members of an association representing most people with IDs were contacted as stakeholders to explain the specific needs that were not covered by the existing technological device [59].

Iterative Process (Domain 2)

Of the 17 studies, 13 (76%) studies mentioned an iterative process approach in which the end users or other stakeholders were involved in developing and improving eHealth technologies. In 11 (65%) of the 17 studies, iterations were performed with the stakeholders by gathering their feedback [19, 46-48, 56, 58, 60, 62-65]. This was done by performing continuous evaluations [19, 47, 48, 51, 56, 60, 63, 65]; creating and improving prototypes based on observations and design challenges identified by using the technology [46, 58, 62, 64]; and gathering, refining, and validating user requirements [61]. Furthermore, 4 (24%) of the 17 studies did not mention iterative cycles during development [55, 59] and 2 (12%) of the 17 studies suggested future iterations [50, 57].

Value Specification and Value Proposition (Domains 3 and 4)

Regarding value specification, the included studies used various strategies to describe and identify their end users' needs and values to create an optimum level of return. First, end users' specific characteristics were identified, including their age; gender; literacy level; or syndromes and disorders such as Cerebral Palsy [56], Down Syndrome [56, 57], Autism Spectrum Disorder [56], Fragile X Syndrome [58] and Prader-Willi Syndrome (PWS) [64].

Second, existing definitions were used, for example, those of the American Psychiatric Association [66] and the American Association on Intellectual and Development Disabilities [67] [51, 65]. In total, 4 (24%) of the 17 studies described the end users' characteristics and the values that were related to the cognitive ability to manage, for example, tasks switching [64] and the targeted end users' exposure to, and degree of (independent) use of, technology [46, 50, 61]. A total of 9 (53%) of the 17 studies reported the identification of other stakeholders in addition to the end users (e.g., family, friends, teachers, support workers, health care professionals, communities, and coaches) [19, 50, 51, 56-58, 61, 62, 64, 65]).

The value proposition of the included studies differed depending on the kind of value that the developed technology could generate for potential end users. These studies mainly focused on nonfinancial values (e.g., symptom control); in contrast, financial values (e.g., profit) were not mentioned. Independent access to transport [47, 51, 55], social participation skills [46], and communication were found as examples of values for potential end users [50]. Development of the value proposition was, in most cases, based on findings or recommendations found in previous research [47, 48, 50, 58, 60, 62-64] or end users' demand for greater accessibility or needs ascertained from the researchers' findings [57, 59, 65]. In total, 2 (12%) of the 17 studies reviewed the content and design of existing comparable technologies and based the development on these insights [56, 58].

Technological Development and Design (Domain 5)

To translate the identified values into technology, 4 different steps in the development and design process were described in 10 (59%) of the 17 studies. First, technological requirements based on the values were identified and analyzed so that they could be applied in the technologies to match end users' accessibility and usability [47, 50, 55, 57]. Second, interaction design patterns, which are a formal way of documenting a solution to a common design problem, were specified and translated for implementation in the prototype [61]. Third, the technology was developed in 2 phases. During the first phase, the end users' needs considering the desired design were ascertained and converted into a program of requirements in the second phase [19]. Finally, user requirements were translated into design requirements in 4 (24%) of the 17 studies, for example, by consulting the end users at the start of the project regarding their preferences [46, 51, 59, 64].

Methods that were performed for specifying user requirements were as follows: interviews with stakeholders [56]; advisory group input [62]; surveys assessing needs, requirements, and use of the technology [57]; an environmental scan evaluating apps to determine the features that needed to be included [58]; or a reflective conversation with stakeholders in the problem context [65].

The development and use of prototypes, mock-ups, or test versions based on the identified requirements were mentioned in most studies, 16 (94%) out of 17 studies [19, 46-48, 50, 51, 56-65]. To adjust the development process to specific end user groups (i.e., people with IDs), methods such as RAID allowed for an approach that linked prototyping with an approach that emphasized the use and importance of creating prototypes when working with individuals for whom abstraction of thought could be difficult [65]. Furthermore, a sensitive way of designing was used, offering the target group the opportunity to test the lo-fi and prototype versions, ensuring that the goals of the overall system could be met [47].

Prototypes were used to address and improve the usability of the developed technology, and usability tests were performed with (proposed) end users [19, 48, 51, 56, 58] and other stakeholders such as caregivers, parents, and coaches [51]. Technology workshop sessions were used to identify and consider usability issues [46]; questionnaires were administered to provide feedback on the use of the technology [64]; and expert reviews and usability evaluations with test interface sketches [61] were performed. The reasons mentioned for using these procedures included improving usability [19, 46, 47, 50, 51, 56, 58], improving accessibility [56], and identifying issues related to the technology such as the use of widget symbols and the need for community safety [47]. Only a few studies conducted field tests [57, 58] or tests under real-life conditions [57]. Only 1 study did not mention usability testing with the prototypes [55].

Organization and External Context (Domains 6 and 7)

The included studies did not examine the changes needed within the organization after the introduction of technology. Moreover, the external context with conditions that could complicate adoption and spread was underrepresented, as these studies focused predominantly on the individual use of the technology and addressed organizational and external contexts only marginally. Only 1 study took place within a health care organization in which a shift in the caregivers' approach from supply-driven care to client-centered care aimed at improving the personal strength of clients with disabilities was mentioned as a change needed [19]

Implementation and Evaluation (Domains 8 and 9)

Only 3 (18%) of the 17 studies addressed implementation from the start [19, 47, 65],and 1 study showed 2 implementation phases performed by the designers [47]. Future implementation of technologies received some attention in the recommendations of the studies. In total, 4 (24%) of the 17 studies stated that the design of the technology needed to be improved before it could be ready for future (iterative) testing and implementation in practice [48, 50, 56, 65]. Another study engaged end users to participate in an app to develop more confidence and sustain independent participation and appropriation over time [46]. Further work required to examine strategies to promote access to the technology for people with IDs and to identify options for future iterations of the system was also mentioned [50].

For the evaluation phase, studies described the analysis and reported on whether the uptake of the technology was as intended by the developers [46, 51, 56, 57, 59-61, 63, 65]. Evaluations focused on several aspects: (1) users' understanding of the content of the technology [60], (2) the use of the developed eHealth technology as intended [59, 63], (3) independent use in the long term and its challenges [46, 61], and (4) the integration and support of the technology in end users' daily lives [57, 65]. The impact of the technologies on the individual user was evaluated by measuring general outcomes such as increased independence [19, 48, 57], inclusion [50], confidence [48], and self-expression and socialization [65]. Other types of impact mentioned in the studies were related to topic-specific outcomes, such as better reducing the need to travel [58], and the ability to structure and support daily activities better [19].

DISCUSSION

Principal Findings

This study was the first to review inclusive approaches used in eHealth design, development, and implementation processes for people with IDs and assessed 9 domains based on the CeHRes roadmap and the NASSS framework. Our findings showed that the domains participatory development, iterative process, and technological development and design use inclusive approaches that were applied reflectively and iteratively and based on participatory approaches including human- or user-centered design and participatory development. End users were involved primarily early in the process to ascertain their needs and during usability testing, whereas their and other stakeholders' involvement was mostly lacking in later phases. The domains external context, organizational context, and the financial side of the value proposition were underrepresented in the literature because the focus was predominantly on the individual use of eHealth technologies. However, members of the target group rely on their (social) environment for care and support. Involving these key stakeholders in the ID sector during the design, development, and implementation phases and giving more attention to the underrepresented domains can improve the fit between the technology, end user, and context.

By combining the CeHRes roadmap and the NASSS framework for technologies within health care, we created a broad perspective regarding the design, development, and implementation processes of eHealth for people with IDs [32, 68]. CeHRes roadmap describes clear development activities and elements, and the NASSS framework shows important preconditions for implementation [17, 30]. The 9 identified domains can be used in every iteration to ensure and report stakeholders' involvement in every domain of the process. Our study demonstrates the applicability of integrated frameworks and their potential to investigate and describe eHealth design, development, and implementation in future studies and supports the use of inclusive approaches in each domain. Reporting the process of inclusive design, development, and implementation along the 9 different domains of our integrated framework facilitates the sharing of experiences and knowledge about inclusive eHealth development and implementation.

The studies using inclusive approaches [19, 46-48, 51, 55-58, 60, 62-65] showed that specific problems experienced by people with IDs as end users (e.g., difficult language use and usability issues) can be addressed only through a user-centered approach [17]. Notably, the included studies focused mainly on people with IDs as end users, and they often strongly depend on support persons (e.g., caregivers) for access to and use of eHealth services. Therefore, future research should investigate the roles of support persons in relation to eHealth solutions and include them in the development and implementation processes [3]. This also raises the question of whether a universal design is a plausible goal. Persons with disabilities, particularly IDs, are a very heterogeneous group in which this goal could be difficult to reach [10]. However, when developing eHealth for people with IDs, it does provide access to a large group of people because elements such as accessibility, usability, cognitive capacity, digital skills, and low literacy are taken into account. In addition, our study showed that inclusive approaches go hand in hand with iterative processes, such as iterative design and RAID. These approaches allowed for improvements to the design by performing continuous evaluations. Iterations were identified mainly in the design and development processes of the included studies. However, by performing these iterations during the implementation, usability issues that emerge after implementation in practice can be addressed [17]. Altogether, the development, implementation, and evaluation overlap and are iterative rather than separate linear phases [69]. It is important to consider this overlap to reduce the misuse and abandonment of technologies and to ensure that important barriers to implementation are not overlooked during development [1]. We suggest that future eHealth trajectories consider at the start whom they need to involve and when to improve the use of, and access to, eHealth by people with IDs [1, 18]. By performing iterations together with end users and stakeholders, a good fit between the technology, context, and users can be ensured [1].

This review further indicates that the organization and external context domains are less addressed in the included papers. A possible explanation is that the described technologies focused mainly on the individual use of eHealth applications, with the result that less attention was given to the organization and external context. Themes related to the organizational context (e.g., capacity and readiness to innovate and changes in organizational routines) and themes related to the external context (e.g., political context and legal issues) can influence implementation at the individual and organizational levels. In line with this, financial values, such as the profitability of technologies, were also addressed marginally. However, these are important preconditions for sustainable implementation and can facilitate the adoption and spread of the technology [30, 32]

Strengths and Limitations

This scoping review included a broad, comprehensive, and systematic search performed to identify and select both published and unpublished gray literature and peer-reviewed scientific literature. The search strategy did not include studies on the evaluation process of eHealth technology after the implementation phase, although this can provide useful and important information about implications for development and implementation. We suggest that future studies explore other literature, for example, on the evaluation of the effectiveness and feasibility of eHealth for people with IDs, to collect more evidence on the evaluation process of eHealth for people with IDs.

Second, the wide variety of terminology presented a challenge for the formulation of the search strategy. The term eHealth is regularly used as an umbrella term with diverse definitions [36] and different focuses, with the term, in a broader sense, characterizing not only a technical development but also a state of mind to improve health care by using information and communication technology [37] and indicating cost-effectiveness and secure use of information and communications technologies [70]. In addition, different terms are used for inclusive approaches in design, development, and implementation processes such as participatory development and design and user-centered design, thereby complicating the identification of inclusiveness in these approaches. We attempted to create a complete picture of the literature and avoid bias as much as possible by applying a wide search strategy (Multimedia Appendix 1) developed with the assistance of an information expert. A more specific mention of inclusiveness in the design, development, and implementation process of eHealth helps to make inclusive eHealth research easier to identify.

Conclusions

This scoping review has demonstrated the applicability of the integrated frameworks—the CeHRes roadmap and the NASSS framework—and the potential of the 9 identified domains to investigate and describe eHealth design, development, and implementation processes in future studies. Participatory development, an iterative process, and technological development are the primary domains that surfaced. Most studies showed end user involvement and iterations in the design and development phases, whereas only a few studies involved end users and iterative processes during the implementation phase. The external and organizational context domains, the financial side of the value proposition, and the application of inclusive approaches with stakeholders other than the end user received little attention. However, members of this target group specifically rely on their (social) environment for care and support. By paying more attention to these underrepresented domains and including key stakeholders further on in the process, the translational gap that exists between the developed technologies and user needs, capabilities, and context can be reduced. This study is the first step toward creating a better understanding of inclusive eHealth design, development, and implementation processes for people with IDs.

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Conflicts of Interest

None declared.

Abbreviations

CeHRes: Centre for eHealth Research and Disease management
ID: intellectual disability
NASSS: Nonadoption, Abandonment, and challenges to the Scale-up, Spread, and Sustainability
NASSS-CAT: Nonadoption, Abandonment, and challenges to Scale-up, Spread, and Sustainability-Complexity Assessment Tool
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews
RAID: Reflective Agile Iterative Design

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APPENDIX 1: SEARCH STRATEGY

Definition Intellectual disability: “significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills”.

(Deuel RK. Mental retardation: definition, classification, and systems of supports (10th ed). Pediatric Neurology. 2003 07/01/;29(1):80. doi: 10.1010/S0887-8994(03)00213-3.)

Definition eHealth: “the use of technologies to improve health, well-being, and healthcare”.

(van Gemert-Pijnen J, Kelders S, Kip H, Sanderman R. eHealth Research, Theory and Development. Milton Park, Oxfordshire: Taylor & Francis; 2018.)

Definition design: “a drawing or set of drawings showing how a building or product is to be made and how it will work and look.” (Cambridge Dictionary of American English. Definition of ‘Design’. Accessed on 12/05/2021, retrieved from DESIGN | English meaning - Cambridge Dictionary)

Definition development: “The systematic use of scientific, technical, economic and commercial knowledge to meet specific business objectives or requirements”. (L. Al-Hakim, X. Wu, A. Koronios and Y. Shou. (2016). Handbook of Research on Driving Competitive Advantage through Sustainable, Lean, and Disruptive Innovation. https://www.igi-global.com/book/handbook-research-driving-competitive-advantage/142171)

Definition implementation: “a specified set of activities designed to put into practice an activity or program of known dimensions”. (D.L. Fixsen, S. Naoom, K. Blasé, R. Friedman & F. Wallace. (2005). Implementation Research: A Synthesis of the Literature. http://ctndisseminationlibrary.org/PDF/nirnmonograph.pdf)

1. Database: PubMed

Search Strategy:

#	Query
1	(“Intellectual Disability”[MeSH] OR “Persons with Mental Disabilities”[MeSH] OR “Developmental Disabilities”[MeSH] OR “Learning Disabilities”[MeSH:noexp] OR “Cognitive Dysfunction”[MeSH] OR “intellectual disab*”[Tiab] OR “intellectually disab*”[Tiab] OR “learning disab*”[Tiab] OR “developmental disab*”[Tiab] OR “developmentally disab*”[Tiab] OR “mental disab*”[Tiab] OR “mentally disab*”[Tiab] OR “mental retard*”[Tiab] OR “mentally retard*”[Tiab] OR “mental handicap*”[Tiab] OR “mentally handicap*”[Tiab] OR “mental deficien*”[Tiab] OR “mentally deficien*”[Tiab] OR “mental impair*”[Tiab] OR “mentally impair*”[Tiab]) NOT (“dement*”[Ti] OR “alzheimer*”[Ti] OR “parkinson”[Ti] OR “psychiatr*”[Ti] OR “injur*”[Ti])
2	Telemedicine[MeSH] OR Telenursing[MeSH] OR Internet[MeSH] OR “Educational Technology”[MeSH] OR “Telecommunications”[MeSH] OR Programmed instruction as Topic[MeSH] OR “Computers”[Mesh] OR Cell Phones[MeSH] OR “Online Systems”[MeSH] OR “Computer-Assisted Instruction”[MeSH] OR “Self-help Devices”[MeSH] OR “Information Technology”[Mesh] OR “Electronic Health Records”[Mesh] OR “Patient Portals”[Mesh] OR “Computer Simulation”[Mesh] OR “Wearable Electronic Devices”[Mesh]
3	eHealth[tiab] OR e-health[tiab] OR “Electronic health”[tiab] OR Telehealth[tiab] OR Tele-health[tiab] OR Telemedicine[tiab] OR Tele-medicine[tiab] OR Telepractice[tiab] OR Tele-practice[tiab] OR Mhealth[tiab] OR M-health[tiab] OR Etherap*[tiab] OR E-therap*[tiab] OR “Electronic therap*”[tiab] OR Teletherap*[tiab] OR Tele-therap*[tiab] OR “Mobile health”[tiab] or m-health[tiab] OR mhealth[tiab] OR Ereferral*[tiab] OR E-referral*[tiab] OR “Electronic referral*”[tiab] OR Eprescri*[tiab] OR E-prescri*[tiab] OR Teleconsult*[tiab] OR Tele-consult*[tiab] OR Telepsychiatr* OR Tele-psychiatr* OR Telenursing[tiab] OR Tele-nursing[tiab] OR Telecare[tiab] OR Tele-care[tiab] OR Telemonitor*[tiab] OR Tele-monitor*[tiab] OR Telerehab*[tiab] OR Tele-rehab*[tiab] OR Telecommunication*[tiab] OR Tele-communication*[tiab] OR “Digital health”[tiab] OR “Information technology”[tiab] OR “Medical informatic*”[tiab] OR “Remote consult*”[tiab] OR Computer*[tiab] OR Microcomputer*[tiab] OR “Cell phone*”[tiab] OR Handheld[tiab] OR Mobile[tiab] OR Smartphone*[tiab] OR Iphone*[tiab] OR Tablet*[tiab] OR Ipad*[tiab] OR Internet[tiab] OR “Online system*”[tiab] OR Software[tiab] OR “User-Computer Interface”[tiab] OR “User interface”[tiab] OR Website*[tiab] OR Webpage*[tiab] OR Webinterface[tiab] OR “Web interface”[tiab] OR Ios[tiab] OR Android[tiab] OR “Electronic mail”[tiab] OR Email*[tiab] OR e-mail*[tiab] OR “Short message service*”[tiab] OR SMS[tiab] OR “Text messag*”[tiab] OR Multimedia[tiab] OR “Multimedia message*”[tiab] OR “Mobile application*”[tiab] OR “Mobile APP*”[tiab] OR “Electronic application*”[tiab] OR App[tiab] OR Apps[tiab] OR “Personal digital assistant*”[tiab] OR “Communications media”[tiab] OR Whatsapp[tiab] OR Skype[tiab] OR Social media[tiab] OR Podcast*[tiab] OR “Online education”[tiab] OR “Online training”[tiab] OR “Online instruction*”[tiab] OR “Educational technology”[tiab] OR “Programmed instruction*”[tiab] OR “Self-help device*”[tiab] OR “Assistive device*”[tiab] OR “Assisted device*”[tiab] OR “Serious gam*”[tiab] OR Wearable*[tiab] OR “Computer simulation*”[tiab] OR Virtual[tiab] OR “Virtual reality”[tiab] OR “Augmented reality”[tiab] OR “Computer-assisted therapy”[tiab] OR “Computer-assisted instruction*”[tiab] OR “Computer-assisted diagnos*”[tiab] OR Domotic*[tiab] OR “Electronic health record*”[tiab] OR Web-based intervention*[tiab] OR “Online intervention*”[tiab] OR “Remote monitor*”[tiab] OR “Remote patient monitor*”[tiab] OR Web-based[tiab]
4	(Develop*[tiab] OR Implement*[tiab] OR Design*[tiab]) OR Creat*[tiab] NOT (Design:[tiab])
5	(#1) AND (#2 OR #3) AND (#4) AND (“english”[Language] AND (humans[Filter]) AND (1995:2021[pdat]))

2. Database: Embase

Search Strategy:

#	Query
1	(exp *mental deficiency/ or *intellectual impairment/ or *learning disorder/ or exp *developmental disorder/ or *mentally disabled person/ or exp cognitive defect/ or (intellectual disab* or intellectually disab* or learning disab* or developmental disab* or developmentally disab* or mental disab* or mentally disab* or mental retard* or mentally retard* or mental handicap* or mentally handicap* or mental deficien* or mentally deficien* or mental impair* or mentally impair*).ti,ab,kw.) not (dement* or alzheimer* or parkinson or psychiatr* or injur*).ti.
2	exp telehealth/ or exp internet/ or educational technology/ or telecommunication/ or teleconference/ or exp telemetry/ or exp assistive technology/ or exp assistive technology device/ or computer assisted therapy/ or communication aid/ or exp mobile phone/ or exp mobile application/ or exp microcomputer/ or exp e-mail/ or exp information technology/ or exp multimedia/ or audiovisual aid/ or self help device/ or exp rehabilitation equipment/ or exp “dressing and undressing assistive device”/ or exp text messaging/ or exp text to speech technology device/ or exp electronic health record/ or exp mobile application/ or web browser/ or computer simulation/ or exp augmented reality/ or exp virtual reality/ or exp social media/ or exp smartphone/ or exp tablet computer/ or exp personal digital assistant/ or online system/ or head-mounted display/ or display system/ or wearable computer/ or smart glasses/ or virtual reality head mounted display/ or body area network/ or remote control/ or exp information technology device/
3	eHealth/ or e-health/ or Electronic health/ or Telehealth/ or Tele-health/ or Telemedicine/ or Tele-medicine/ or Telepractice/ or Tele-practice/ or Mhealth/ or M-health/ or Etherap*/ or E-therap*/ or Electronic therap*/ or Teletherap*/ or Tele-therap*/ or Mobile health/ or m-health/ or mhealth/ or Ereferral*/ or E-referral*/ or Electronic referral*/ or Eprescri*/ or E-prescri*/ or Teleconsult*/ or Tele-consult*/ or Telepsychiatr*/ or Tele-psychiatr*/ or Telenursing/ or Tele-nursing/ or Telecare/ or Tele-care/ or Telemonitor*/ or tele-monitor*/ or Telerehab*/ or Tele-rehab*/ or Telecommunication*/ or Tele-communication*/ or Digital health/ or Information technology/ or Remote consult*/ or Computer*/ or Microcomputer*/ or Cell phone*/ or Handheld/ or Mobile/ or Smartphone*/ or Iphone*/ or Tablet*/ or Ipad*/ or Internet/ or Online system*/ or Software/ or User-Computer Interface/ or Website*/ or Webpage*/ or Web interface/ or Ios/ or Android/ or Electronic mail/ or Email*/ or Short message service*/ or SMS/ or Text messag*/ or Multimedia/ or Multimedia message*/ or Mobile application*/ or Mobile APP*/ or Electronic application*/ or App/ or Apps/ or Personal digital assistant*/ or Communications media/ or Whatsapp/ or Skype/ or Social media/ or Podcast*/ or Online education/ or Online training/ or Educational technology/ or Programmed instruction*/ or Self-help device*/ or Assistive device*/ or Assisted device*/ or Serious gam*/ or Wearable*/ or Computer simulation*/ or Virtual/ or Virtual reality/ or Augmented reality/ or Computer-assisted therapy/ or Computer-assisted instruction*/ or Computer-assisted diagnos*/ or Domotic*/ or electronic health record*.ti,ab,kw.
4	Develop*/ or Implement*/ or Design*/ or Creat* NOT Design:.ti,ab,kw
5	Search: (#1) AND (#2 OR #3) AND (#4)
6	limit 5 to (english language and yr=”1995 -Current”)

3. Database: APA PsycInfo

Search Strategy:

#	Searches
1	(exp *intellectual development disorder/ or *delayed development/ or *developmental disabilities/ or *learning disabilities/ or *cognitive impairment/ or (intellectual disab* or intellectually disab* or learning disab* or developmental disab* or developmentally disab* or mental disab* or mentally disab* or mental retard* or mentally retard* or mental handicap* or mentally handicap* or mental deficien* or mentally deficien* or mental impair* or mentally impair*).ti,ab,id.) not (dement* or alzheimer* or parkinson or psychiatr* or injur*).ti
2	exp assistive technology/ or exp human technology interaction/ or exp "information and communication technology"/ or exp communication systems/ or exp telemedicine/ or exp computer assisted therapy/ or exp electronic health services/ or exp online therapy/ or exp teleconferencing/ or exp teleconsultation/ or exp telepsychiatry/ or exp telepsychology/ or exp telerehabilitation/ or exp computer applications/ or exp computer mediated communication/ or exp digital interventions/ or exp health care services/ or exp health knowledge/ or exp internet/ or exp telecommunications media/ or exp videoconferencing/ or exp mobile phones/ or exp mobile devices/ or exp telephone systems/ or exp smartphones/ or exp mobile applications/ or exp mobile application/ or exp wireless technologies/ or exp online therapy/ or exp mobile health/ or exp microcomputers/ or exp multimedia/ or exp communications media/ or exp audiovisual communications media/ or exp text messaging/ or exp electronic communication/ or exp electronic health records/ or exp Computer Software/ or exp Virtual Reality/ or exp augmented reality/ or exp virtual reality exposure therapy/ or exp social media/ or exp tablet computers/ or exp distance education/ or programmed instruction/ or computer assisted instruction/ or exp Computer Assisted Therapy/ or exp Computer Assisted Diagnosis/ or exp Websites/ or wearable devices/ or mobile technology/ or digital technology/ or simulation/ or computer simulation/ or simulation games.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]
3	(Develop*/ or Implement*/ or Design*/ or Creat*.mp.) not Design:.ti,ab,id.
4	S1 AND S2 AND S3
5	Limit 4 to (english language and yr="1995-Current")

4. Database: CINAHL

Search Strategy:

#	Searches
S1	(MH "Mentally Disabled Persons") OR (MH "Developmental Disabilities") OR (MH "Intellectual Disability+") OR (MH "Learning Disorders") OR TI ("intellectual disab*" OR "intellectually disab*" OR "learning disab*" OR "developmental disab*" OR "developmentally disab*" OR "mental disab*" OR "mentally disab*" OR "mental retard*" OR "mentally retard*" OR "mental handicap*" OR "mentally handicap*" OR "mental deficien*" OR "mentally deficien*" or "mental impair*" OR "mentally impair*") OR AB ("intellectual disab*" OR "intellectually disab*" OR "learning disab*" OR "developmental disab*" OR "developmentally disab*" OR "mental disab*" OR "mentally disab*" OR "mental retard*" OR "mentally retard*" OR "mental handicap*" OR "mentally handicap*" OR "mental deficien*" OR "mentally deficien*" or "mental impair*" OR "mentally impair*") NOT TI (dement* or alzheimer* or parkinson or psychiatr* or injur*)

#	Searches
S2	(MH “Telecommunications+”) OR (MH “Telehealth+”) OR (MH “Telerehabilitation”) OR (MH “Internet+”) OR (MH “Social Media+”) OR (MH “World Wide Web+”) OR (MH “Educational Technology”) OR (MH “Assistive Technology”) OR (MH “Programmed Instruction+”) OR (MH “Computer Assisted Instruction”) OR (MH “Computers and Computerization+”) OR (MH “User-Computer Interface+”) OR (MH “Cellular Phone+”) OR (MH “Text Messaging+”) OR (MH “Online Systems”) OR (MH “Assistive Technology Devices+”) OR (MH “Information Technology+”) OR (MH “Electronic Health Records+”) OR (MH “Wearable Sensors+”)
S3	TI (“Computers and Computerization” OR “Educational Technology” OR “Telehealth” OR “eHealth” OR “Teleconferencing” OR “Internet” OR “Telemedicine” OR “Telenursing” OR “Telepsychiatry” OR “Telenutrition” OR “Teledentistry” OR “Telerehabilitation” OR “Telecommunications” OR “Communications Media” OR “Email” OR “Interactive Voice Response Systems” OR “Telephone” OR “Text Messaging” OR “Videoconferencing” OR “Wireless Communications” OR “Electronic Health Records” OR “Patient Portals” OR “Mobile Health Units” OR “Remote Consultation” OR “Software” OR “Mobile Applications” OR “Multimedia” OR “Webcasts” OR “Virtual Reality” OR “Virtual Reality Exposure Therapy” OR “Augmented Reality” OR “Computer Simulation” OR “Text Messaging” OR “Instant Messaging” OR “Smartphone” OR “Computers, Hand-Held” OR “Computers, Portable” OR “Microcomputes” OR “Social Media” OR “Cellular Phone” OR “Digitizers” OR “Voice Recognition Systems” OR “Keyboards” OR “Mouse Computer” OR “Scanners” OR “Computer Input Devices” OR “Online Education” OR “Programmed Instruction” OR “Computer Assisted Instruction” OR “Online Systems” OR “Therapy, Computer Assisted” OR “Diagnosis, Computer Assisted” OR “Assistive Technology Devices” OR “Ambulation Aids” OR “Communication Aids for Disabled” OR “Wearable Sensors” OR “Accelerometers” OR “Smart Glasses” OR “User-Computer Interface” OR “World Wide Web Applications” OR “Website Development” OR “Video Games” OR “Games”) OR AB (“Computers and Computerization” OR “Educational Technology” OR “Telehealth” OR “eHealth” OR “Teleconferencing” OR “Internet” OR “Telemedicine” OR “Telenursing” OR “Telepsychiatry” OR “Telenutrition” OR “Teledentistry” OR “Telerehabilitation” OR “Telecommunications” OR “Communications Media” OR “Email” OR “Interactive Voice Response Systems” OR “Telephone” OR “Text Messaging” OR “Videoconferencing” OR “Wireless Communications” OR “Electronic Health Records” OR “Patient Portals” OR “Mobile Health Units” OR “Remote Consultation” OR “Software” OR “Mobile Applications” OR “Multimedia” OR “Webcasts” OR “Virtual Reality” OR “Virtual Reality Exposure Therapy” OR “Augmented Reality” OR “Computer Simulation” OR “Text Messaging” OR “Instant Messaging” OR “Smartphone” OR “Computers, Hand-Held” OR “Computers, Portable” OR “Microcomputers” OR “Social Media” OR “Cellular Phone” OR “Digitizers” OR “Voice Recognition Systems” OR “Keyboards” OR “Mouse Computer” OR “Scanners” OR “Computer Input Devices” OR “Online Education” OR “Programmed Instruction” OR “Computer Assisted Instruction” OR “Online Systems” OR “Therapy, Computer Assisted” OR “Diagnosis, Computer Assisted” OR “Assistive Technology Devices” OR “Ambulation Aids” OR “Communication Aids for Disabled” OR “Wearable Sensors” OR “Accelerometers” OR “Smart Glasses” OR “User-Computer Interface” OR “World Wide Web Applications” OR “Website Development” OR “Video Games” OR “Games”)
S4	TI ((Develop*) OR (Implement*) OR (Design*) OR (Creat*) NOT (Design:)) OR AB ((Develop*) OR (Implement*) OR (Design*) OR (Creat*) NOT (Design:))
S5	S1 AND (S2 OR S3) AND S4
S6	**Limiters** - Published Date: 19950101-20211231 **Narrow by Language:** - dutch/flemish **Narrow by Language:** - english

5. Database: Cochrane Library

Search Strategy:

#	Searches
1	([mh "Intellectual Disability"] OR [mh "Learning Disabilities"] OR [mh "Developmental Disabilities"] OR [mh "Cognitive Dysfunction"] OR Intellectual NEXT disab* OR Intellectually NEXT disab* OR Learning NEXT disab* OR Developmental NEXT disab* OR Developmentally NEXT disab* OR Mental NEXT disab* OR Mentally NEXT disab* OR Mental NEXT retard* OR Mentally NEXT retard* OR Mental NEXT handicap* OR Mentally NEXT handicap* OR Mental NEXT deficien* OR Mentally NEXT deficien* or mental NEXT impair* OR mentally NEXT impair*):ti,ab,kw NOT (dement* or alzheimer* or parkinson or psychiatr* or injur*):ti
2	(eHealth OR "Electronic health" OR "Electronic healthcare record" OR Telehealth OR Telemedicine OR Tele-medicine OR Telepractice OR Mhealth OR Etherap* OR E-therap* OR "Mobile health" OR Ereferral* OR "Electronic referral" OR "Electronic referrals" OR Eprescri* OR Teleconsult* OR Telenursing OR "Digital health" OR Software OR Telecommunication* OR Tele-communication* OR "Remote consultation" OR "Remote consultations" OR Podcast* OR Virtual OR "Virtual reality" OR "Virtual reality therapy" OR SMS OR App* OR Application* OR "Short message service" OR "Short message services" OR "Text message" OR "Text messages" OR "Text messaging" OR "Multimedia message" OR "Multimedia messages" OR Email* OR "Social media" OR Mobile OR "Cell phone" OR "Cell phones" OR Smartphone* OR Ios OR Android OR Ipad* OR Iphone* OR Tablet* OR Computer* OR Microcomputer* OR "Online education" OR "Online training" OR "Personal digital assistant" OR Internet OR "Communications media" OR "Programmed instruction" OR "Programmed instructions" OR Handheld* OR "Mobile application" OR "Mobile applications" OR "Mobile app" OR "Mobile apps" OR "Electronic application" OR "Electronic applications" OR "Electronic app" OR "Online system" OR "Online systems" OR "Computer-assisted instruction" OR "Self-help device" OR "Self-help devices" OR "Assistive device" OR "Assistive devices" OR "Assisted device" OR "Assisted devices" OR Telecare OR Telemonitoring OR Wearable*):ti,ab,kw
3	((Develop* OR Implement* OR Design* OR Creat*) NOT (Design:)):ti,ab,kw
4	(#1) AND (#2) AND (#3)
5	"#4 - (#1) AND (#2) AND (#3)" with Cochrane Library publication date Between Jan 1995 and Jun 2021

6. Database(s): Web of Science

Search Strategy:

#	Searches
1	TOPIC: ("Intellectual disab*" OR "Intellectually disab*" OR "Learning disab*" OR "Developmental disab*" OR "Developmentally disab*" OR "Mental disab*" OR "Mentally disab*" OR "Mental retard*" OR "Mentally retard*" OR "Mental handicap*" OR "Mentally handicap*" OR "Mental deficien*" OR "Mentally deficien*" or "mental impair*" OR "mentally impair*") NOT TITLE: (dement* or alzheimer* or parkinson or psychiatr* or injur*)

#	Searches
2	(eHealth OR e-health OR "Electronic health" OR Telehealth OR Tele-health OR Telemedicine OR Tele-medicine OR Telepractice OR Tele-practice OR Mhealth OR M-health OR Etherap* OR E-therap* OR "Electronic therap*" OR "Mobile health" OR Ereferral* OR E-referral* OR "Electronic referral*" OR Eprescri* OR E-prescri* OR Teleconsult* OR Tele-consult* OR Telenursing OR Tele-nursing OR "Digital health" OR Digihealth OR Software OR Telecommunication* OR Tele-communication* OR "Remote consultation*" OR Podcast* OR Virtual OR "Virtual reality" OR SMS OR app OR Apps OR "Short message service*" OR "Text messag*" OR "Multimedia message*" OR Facebook OR Email* OR "Social media" OR Mobile OR "Cell phone*" OR Smartphone* OR Ios OR Android OR Ipad* OR Iphone* OR Tablet* OR Computer* OR "Online education" OR "Online training" OR "Personal digital assistant*" OR Internet OR "Communications media" OR "Programmed instruction*" OR Computers OR Handheld OR "Mobile application*" OR "Electronic application*" OR "Cell phones" OR "Online system*" OR "Computer-assisted instruction*" OR "Computer-assisted diagnos*" OR "Self-help device*" OR "Assistive device*" OR "Assisted device*" OR Telecare OR Tele-care OR Telemonitoring OR Tele-monitoring)
3	(Develop* OR Implement* OR Design* OR Creat*)
4	(S1 AND S2 AND S3)
5	S4 AND 1995-2021 AND English

7. Database: Google Scholar

Search Strategy:

#	Searches
1	"Intellectual disability" "eHealth development"
2	"Intellectual disability" "eHealth implementation"
3	"learning disability" "eHealth development"
4	"learning disability" "eHealth implementation"
5	"developmental disability" "eHealth development"
6	"mental disability" "eHealth implementation"
7	"mentally disabled" "eHealth development"
8	"mentally disabled" "eHealth implementation"
9	"mentally handicapped" "eHealth development"
10	"mental impairment" "eHealth implementation"
11	"cognitive impairment" "eHealth development"
12	"cognitive impairment" "eHealth implementation"
13	"intellectual disability" "e-Health development"
14	"intellectual disability" "e-Health implementation"
15	"learning disability" "e-Health implementation"
16	"learning disability" "e-Health development"
17	"developmental disability" "e-Health development"
18	"developmental disability" "e-Health implementation"
19	"mental disability" "e-Health implementation"
20	"mental disability" "e-Health development"
21	"mentally disabled" "e-Health development"
22	"mental impairment" "e-Health development"
23	"cognitive impairment" "e-Health implementation" (2)
24	"cognitive impairment" "e-Health development"

#	Searches
25	“Intellectual disability” “Telehealth development” (3)
26	“Intellectual disability” “Telehealth implementation”
27	“learning disability” “Telehealth development”
28	“learning disability” “Telehealth implementation”
29	“developmental disability” “Telehealth implementation”
30	“mental disability” “Telehealth development”
31	“mental disability” “Telehealth implementation”
32	“mentally disabled” “Telehealth development”
33	“mentally disabled” “Telehealth implementation”
34	“mental impairment” “Telehealth development”
35	“mental impairment” “Telehealth implementation”
36	“cognitive impairment” “Telehealth development”
37	“cognitive impairment” “Telehealth implementation”
38	“Intellectual disability” “Telemedicine development”
39	“Intellectual disability” “Telemedicine implementation”
40	“learning disability” “Telemedicine development”
41	“learning disability” “Telemedicine implementation”
42	“developmental disability” “Telemedicine development”
43	“developmental disability” “Telemedicine implementation”
44	“mental disability” “Telemedicine implementation”
45	“mentally disabled” “Telemedicine development”
46	“mentally disabled” “Telemedicine implementation”
47	“mentally handicapped” “Telemedicine development”
48	“mentally handicapped” “Telemedicine implementation”
49	“mental impairment” “Telemedicine implementation”
50	“cognitive impairment” “Telemedicine development”
51	“cognitive impairment” “Telemedicine implementation”

8. Database: Google Scholar

Search Strategy:

#	Searches
1	“ehealth implementatie” “verstandelijke beperking” filetype:pdf
2	“e-health implementatie” “verstandelijke beperking” filetype:docx
3	“ehealth ontwikkeling” “verstandelijke beperking” filetype:pdf
4	“e-health ontwikkeling” “verstandelijke beperking” filetype:docx
5	“telehealth implementatie “verstandelijke beperking” filetype:pdf
6	“telehealth implementatie “verstandelijke beperking” filetype:docx
7	“telehealth ontwikkeling “verstandelijke beperking” filetype:pdf
8	“telehealth ontwikkeling “verstandelijke beperking” filetype:docx
9	“telemedicine implementatie “verstandelijke beperking” filetype:pdf
10	“telemedicine implementatie “verstandelijke beperking” filetype:docx
11	“telemedicine ontwikkeling “verstandelijke beperking” filetype:pdf
12	“telemedicine ontwikkeling “verstandelijke beperking” filetype:docx

9. Terms for grey literature (Dutch)

Verstandelijke beperking	eHealth	Design, ontwikkeling & implementatie
Verstandelijk beperkt	e-Health	Ontwikkelen
Verstandelijk gehandicapt	Electronic health	Ontwikkeld
Verstandelijke handicap	Telehealth	Implementatie
Verstandelijke ontwikkelingsstoornis	Tele-health	Implementeren
Geestelijke handicap	Telemedicine	Implementeert
Geestelijk gehandicapt	Tele-medicine	Design
Geestelijk beperkt	Telepractice	Creatie
Intellectuele beperking	Tele-practice	Creëert
Intellectueel beperkt	Telecare	Creëren
Intellectueel gehandicapt	Tele-care	
Intellectuele handicap	Telemonitoring	
Intellectuele stoornis	Tele-monitoring	
Mentale handicap	Telenursing	
Mentale retardatie	Tele-nursing	
Mentale beperking	Telecommunicatie	
Cognitieve beperking	Tele-communcatie	
Cognitieve handicap	Teleconsultatie	
Ontwikkelingsstoornis	Tele-consultatie	
	Mhealth	
	M-health	
	Digital health	
	Wearable	
	Domotica	
	Virtual reality	
	Augmented reality	
	Serious game	
	App	

APPENDIX 2: DOMAINS AND COMPONENTS FOR DATA EXTRACTION

Domain	Components	Explanation
Participatory design/ research: Approach to design/ research attempting to actively involve all stakeholders in the design/research process to help ensure the result meets their needs and is usable.	Co-creation	Stakeholder participation is essential. Stakeholders' involvement spans the full development process. Stakeholders can be considered as actors that have different roles in the development of eHealth technologies, from ideation to evaluation. Through their roles in identifying needs, or specifying critical issues for design and implementation, they help to create the technology.
	Multidisciplinary Project Management	Multidisciplinary project management facilitates the cooperation between those who are responsible for producing the technology (e.g. technical designers and health care professionals) and those who participate to ensure that eHealth technologies fit in with the needs and values (e.g. end users and health care insurers/payers).
	Including stakeholders' perspective	Different methods should be used to gather information from the stakeholders and context to continuously include their perspectives in the activities and outcomes of the development, implementation and evaluation of the technology.
Iterative process: Continuous evaluation of the technology needs to be interwoven with all stages in the development process.	Continuous evaluation	The created technology need to be evaluated continuously.
	Checking whether outcomes of previous phases are accounted for	During the whole process of development and implementation it should be checked whether the outcomes of previous phases have been accounted for in the current phase and that the outcomes of all phases are related to each other.
Value specification: Creating the optimum level of return for all stakeholders involved by identifying, analysing, gathering, and mapping their values.	End users	The person who in the end uses or is intended to ultimately use the technology.
	Condition/illness	The condition/illness of the end users should be clearly defined, also think of comorbidity, variable manifestations that can occur and the uncertain course of the illness/ condition. These factors could affect the ability to benefit from the technology.
	Sociocultural factors	The sociocultural situation of the end users could affect the ability to benefit from the technology. By mapping the social or cultural factors of the end users these can be taken into account when developing and implementing the technology.
	Stakeholder identification	Anyone who affects or is affected by the technology should be identified.
	Stakeholder analysis	It should be clear what the tasks and roles of the stakeholders are in order to identify the key stakeholders. Next to the end users, other people might have to work with the technology. It is important to identify these people and what changes it will bring for them (e.g. staff, ICT & carers).
	Value identification	By identifying the values from all involved (key-) stakeholders, it can be clarified what the added value of the technology should be according to them. A value map can be used to prioritize and categorize the identified values.

Domain	Components	Explanation
Value proposition: Think about what kind of value the technology might generate for different groups of people. ('Value' can be financial, such as profit, or non-financial, such as control of symptoms)	Business model	By creating a business model the idea for the technology can be defined and easily communicated, moreover it is a plan for the developer on how to make profit from it.
	Supply- and demand model	Identify the interaction between the seller/supplier of the technology and the buyer/demander. The law of supply and demand defines the relationship between the price of the technology and the willingness of people to either buy or sell it.
	Ownership	The ownership of the technology needs to be accounted for, think of where the support of the technology embedded and who is accountable for the service and contact with the supplier.
Technological development and design: Think about the technology (e.g. a tool or piece of software), and how it might affect care.	Technology requirements	The identified stakeholder values should be translated into specific technological requirement, including material properties, that state what is required from the technology.
	Prototyping (lo-fi & hi-fi)	Both low-fidelity and high-fidelity prototypes of the technology have to be developed, so they can be tested before further development.
	Usability tests	Usability tests of the prototypes have to be conducted with end users, experts and possibly other involved (key-) stakeholders. These usability tests provide input on further development of the technology and what knowledge is needed for use.
Organisation: Think about the (healthcare) organisation and what changes are needed and what changes for them after the technology is introduced.	Capacity and readiness to innovate	The organisation's capacity and readiness to take on technological innovations. Think of the ICT structure and acceptance of staff.
	Nature of adoption- and or funding decision	The organisation has to commission/purchase the technology. Is there a department that deals with this, who has to approve the purchase?
	Change in organisational routines	The work needed to plan, implement and monitor change should be identified to be able to change existing organisational routines.
External context: Conditions that could complicate adoption and spread of the technology.	Political/policy context	What is the political context towards the technology? How does this influence development or implementation?
	Regulatory/legal issues	Are there any legal issues concerning the technology? How can these legal issues be addressed?
	Professional bodies	A professional body is an organisation with individual members practicing a profession or occupation in which the organisation maintains an oversight of the knowledge, skills, conduct and practice of that profession or occupation. What is the attitude of the professional bodies and patient organisations towards the technology?
	Interorganisational networking	Introduction of the technology/innovation could be threatened by external changes that impact on the organisation, those changes should be identified and addressed.

Domain	Components	Explanation
Implementation: A plan with a set of conditions or activities designed to put into action to start to use a technology in practice.	Implementation accounted for from start	The conditions for implementation should be taken into account from the start of the project. Potential implementation issues such as limited resources (e.g. time and money) or personal drawbacks (e.g. motivation and anxieties) should be identified.
	Determine activities for implementation plan	Determine concrete activities to implement the technology in practice. Think of appointing ambassadors and giving presentations. Using the business model, input of the stakeholders and implementation theory (in this the NASSS framework) to create a plan to make sure that the technology is introduced and used in practice in the long term.
Evaluation: Understanding the relative benefits and costs of the technology in context of the proposed implementation.	Determine impact on context and stakeholders	The impact of the technology on the context and stakeholders should be determined, based on the values from the stakeholders and value proposition.
	Analyse uptake of technology	The uptake of the technology should be analysed in terms of adoption or use of the technology by predetermined users and implementation, and use within the intended context.

CHAPTER

3

INCLUSIVE DIGITAL PLATFORMS: DESIGNING FOR AND WITH USERS WITH MILD INTELLECTUAL DISABILITIES OR LOW LITERACY SKILLS

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ABSTRACT

Background: There are diverse general guidelines about improving the accessibility of digital platforms. Literature is scarce on the specific elements that make digital platforms accessible and inclusive for individuals with mild intellectual disability (MID) or low literacy (LL).

Objective: This study investigated key design elements crucial for individuals with MID or LL that enable their access to and participation in digital platforms.

Methods: We applied a user-sensitive inclusive research approach to re-design and implement the digital research platform ‘I co-research’ for individuals with MID or LL. Qualitative data were gathered through semi-structured interviews and usability tests.

Results: Apart from general design characteristics such as clarity, readability, comprehensibility, and intuitive design our results showed specific elements for creating an inclusive digital environment. Crucial design elements for an inclusive digital environment included the use of recognizable and suitable well-designed visuals that align with and reflect the diversity in society, and comprehensible naming of the platform to enhance the findability. The importance of an accessible onboarding process and intuitive navigation features including read-aloud and read-along functionalities also emerged.

Conclusions: In conclusion, employing a user-sensitive inclusive research approach for the re-design of a digital research platform enabled the identification of design characteristics and elements specifically important for people with MID or LL to enhance accessibility and usability. By integrating participatory methodologies and incorporating these key design elements, digital platforms can be tailored to meet the diverse needs of individuals with MID or LL facilitating greater inclusion and participation in digital research.

Keywords: digital platforms; accessible technology; mild intellectual disabilities; low literacy; inclusive design; public health

INTRODUCTION

People with intellectual disabilities (ID) or low literacy (LL) form a large proportion of people in the Netherlands: an estimated 4 to 8% of the Dutch population have a borderline to mild ID (MID), and approximately 19% of the population over 16 years old (i.e., 2.5 million people) have limited reading, writing, or numeracy skills [1-3]. Although people with MID and LL have distinct cognitive and literacy characteristics and the causes of MID and LL vary, both subpopulations face functional difficulties in acquiring and comprehending (digital) information because of low information management thresholds, limited reading ability or comprehension, or reduced visual acuity [4, 5]. Research has demonstrated that either having MID or LL is associated with low health literacy, leading to suboptimal healthcare, poor health outcomes, and health disparities [3, 5-8].

Accurate health data about both subpopulations are lacking because they are often underrepresented in (public) health and scientific research, limiting efforts to address health inequities [5, 9, 10]. They have been excluded from research because study designs and technology are not adapted to their cognitive levels or (digital) literacy skills [11-14]. For example, digital platforms often have complex interfaces and use difficult language, and consequently many people refrain from using it. Therefore, there is need for improved accessibility of research methods and techniques to engage these subpopulations and enable better representation of these populations in research [5, 10, 14]. As both subpopulations face similar problems in using digital environments, this study addressed the needs for individuals with cognitive or literacy-related challenges concurrently. We used participatory and inclusive methods to address the knowledge gaps in previous studies on digital accessibility for these marginalized groups [15-17].

There are diverse guidelines about improving the accessibility of information provision and technology [3, 18-22] as well as inclusive design frameworks that emphasize the importance of adapting digital platforms to meet the needs of diverse user groups. For example, Universal Design [23], Design for All [24], and the World Wide Web Consortiums (W3C) of the Web Content Accessibility Guidelines (WCAG) [25]. These guidelines and frameworks provide principles for simplifying content, improving navigation, and incorporating multimodal feedback [26, 27]. Specific design elements are addressed, referring to interface features such as navigation structures and text presentation to enhance the accessibility and usability of digital platforms for users with diverse cognitive and literacy needs. For example, it is advised to address specific design elements referring to simplify text and use plain language (e.g., by avoiding jargon) [28] or use visual aids alongside the text (e.g., icons, illustrations, symbols, or drawings) [29]. While useful as a foundation, they provide limited guidance on how to specifically design for highly heterogeneous user populations, such as people with MID or LL.

They are too generic and deemed to have 'common sense validity' in their recommendations about paying attention to content, format, information use, and how the use of information is supported [26]. So, despite these recommendations, little is known about how specific design elements in such guidelines effectively ensure accessibility for individuals with MID or LL [26, 27]. To address this gap, our study uses an user-sensitive inclusive design, stemming from user-centered design methodologies [30], placing marginalized groups at the core of the design process and adopting tailored methods to capture their specific needs [31, 32].

User- or human-centered designs and approaches have been widely applied in healthcare (e.g., CeHRes Roadmap & Design Thinking) to develop and implement information provision and technology or to evaluate prior development processes [33-35]. These approaches prioritize end-user experiences through collaborative interdisciplinary teams and follow an iterative process, using rapid prototyping and feedback loops to refine solutions [35]. By collaborating with participants like people with MID or LL as intended end-users, specific elements contributing to accessibility and usability can be identified more rigorously. Meaningful participation by the target audience as participants, co-designers, or co-researchers are essential at all stages of the design and research process [26, 36, 37]. This approach enhances traditional user-centered design by enabling more meaningful participation of diverse end-users in the development process. However, conventional research methods, which often rely on verbal communication (e.g., in single interviews or brainstorming in focus groups) about abstract concepts, may be insufficient for obtaining a full understanding of their needs [38, 39]. Using realistic-like situations – for example, having group discussions using a theatre form or providing feedback on multiple mock-ups and prototypes – enables participants to conceptualize and reason their actions or preferences because they can identify and empathize with reality [39-41]. Therefore, participatory methods with flexible and adaptive approaches have been demonstrated to be well-suited to placing the participants and co-researchers at the center of the design or research process [14, 42-44]. Previous studies indicate that after the design process, the focus often shifts to (cost-)effectiveness, impact, or uptake, while follow-up on the design process during implementation with key stakeholders receives less attention [45]. Given that practical use insights gathered during this implementation phase remain valuable for future development [35], this study employed a user-sensitive inclusive research approach to re-design and implement a digital research platform taking into account the highly characteristic skills and competences of individuals with MID or LL. By applying this inclusive approach as the foundation of our research, we aimed to generate evidence-based findings that enhance digital accessibility and usability for individuals with MID or LL, with the following research question: Which design characteristics and elements for enhancing accessibility and usability are crucial in the development and implementation of digital (research) platforms according to people with MID or LL skills?

METHODS

Study design and setting

The study applied a user-sensitive inclusive research approach to re-design and implement the digital platform 'I co-research' for individuals with MID or LL. Qualitative data were gathered through semi-structured interviews and usability tests. 'I co-research' is an inclusive digital citizen science research platform that researchers can use to co-create and disseminate questionnaires. Including the perspectives and experiences of the participants themselves provides the researchers with an opportunity to broaden their perspective within the research topic.

Fig. 3.1 shows a timeline representing the re-design and implementation process, together with the goal of the steps, the methods used, and the participants in each step. In the first three steps, the platform was re-designed, using the Design Thinking method, to ensure greater accessibility and usability for people with MID or LL, allowing additional iterations to further develop existing platform components. In the second three steps, the platform was implemented for a national study to research the impact of the COVID-19 measures on the mental health of people with MID or LL [46]. The re-design and implementation were reviewed by the institutional review board for ethical approval (2020-6541 and 2020-7033).

Qualitative data were gathered during the re-design process (steps 1 – 3) through semi-structured interviews about exemplar websites, walk-throughs, and usability tests with mock-ups and prototypes. The 'I co-research' followed the stages of Design Thinking re-design process and was conducted by a multidisciplinary team comprised of a researcher, a co-researcher with MID, a social designer, and a software developer. Co-researchers are persons with a mild intellectual disability that serve as researchers alongside those with academic training, to add value to research through the sharing of their lived experiences [47, 48]. The co-researcher's involvement as a project team member consisted of providing input on design and study methods, the informed consent procedure and of attending meetings with the social designer to help translate the findings from the feedback sessions into viable solutions. All interviews and co-design sessions of this phase were conducted online due to COVID-19 restrictions. Video conferencing tools were used, and the platform prototypes were shared through screen-sharing features allowing participants to explore and provide feedback. The research team provided technical assistance when needed to ensure participants could engage fully despite the remote format.

The implementation (steps 4 – 6) was conducted around the use of the 'I co-research' platform in the 'COVID-19 Monitor Study' administered by the municipal health service (GGD) as an accessible equivalent of the national COVID-19 survey. The adapted version of the national survey ensured that individuals with MID or LL could participate on equal terms [46]. With strict pandemic restrictions and the urgent need for rapid data collection within the target group, the 'I co-research' platform proved suitable for this study. However, the participants did not have the option to provide questions themselves, as this questionnaire was not open. After the COVID restrictions were lifted, face-to-face feedback sessions about the usability of the platform were organized between October 2020 and December 2021.

Figure 3.1 Timeline of the 'I co-research' re-design and implementation process.

Participants

Participants were recruited via the network of the Academic Collaborative Stronger on your own feet, which is a collaboration between the Radboud university medical center and seven care provider organizations for people with ID [49]. The care organizations provide help and/or care for people with MID. The inclusion criteria for the re-design phase were individuals aged ≥16 years, residing in the Netherlands, with a MID. Their MID was determined by the organization where they were recruited, and all participants had difficulties in reading and writing. Each participant received an information letter and provided informed consent via a MID-friendly consent form. Both documents were co-developed with a co-researcher with MID, incorporating simplified text, graphic support, large fonts, and increased white space.

Fourteen individuals with MID participated in the re-design phase of the digital citizen science research platform 'I-co-research' (Fig. 3.1, steps 1 – 3). Two participants were included in their role as a co-researcher with a MID. Seven participants were included via the organization they receive care from. The remaining five participants were involved from a consultancy firm specialized in supporting the development of digital healthcare innovation and involving the target group. Table 3.1 shows the demographics of the participants in the re-design phase. Most participants could participate independently (n=9); some needed assistance from family members (n=3) or a remote coach who joined digitally (n=2).

Table 3.1 Demographics of the participants in the re-design phase

Phase		**Empathize and Define**			**Ideate and Prototype**		**Test**		
Round		1	2	3	1	2	1	2	Int.
Gender	Male	N=6	N=5	N=4	N=3	N=3	N=3	N=2	N=4
	Female	N=7	N=7	N=4	N=3	N=3	N=1	N=4	N=4
Age range		30-50	30-50	32-42	30-50	30-50	35-42	30-50	30-50

For the implementation phase, secondary data from the COVID-19 monitor study was used [46, 50]. Participants with MID or LL skills were recruited through various organizations that specifically target or work with these subpopulations, including advocacy groups, care facilities, language education organizations, libraries, social workplaces, and the Dutch center of expertise on health disparities 'Pharos' [46]. Control questions to assess participants' literacy or intellectual abilities were not administered because it was considered potentially too sensitive for participants and might have posed ethical concerns. Specific details regarding the recruitment process of our secondary data can be found elsewhere [46, 50]. The recruitment process resulted in a panel of 26 people with diverse ages and genders consisting of four people with MID or LL skills, fourteen experts by experience (i.e., someone with lived experience of MID or LL, trained to support peers in research and data collection processes [51]) and twelve professionals supporting these groups, who evaluated and tested the broader implementation of the COVID-19 health monitor within the platform [46] (Fig. 3.1, steps 4–6). The primary aim of the COVID-19 health monitor study was to administer an accessible COVID-19 questionnaire, therefore no demographic information about the panel that pre-tested the accessibility of the platform and questionnaire was collected.

Study procedure

Empathize and Define

The two re-design phases – empathize and define – aimed to identify the challenges, preferences, and needs of people with MID in using a digital platform. Data were collected by interviewing the participants individually or in pairs in three successive rounds (Fig. 3.1, step 1). In the first two sessions, six existing websites were discussed to facilitate the interview conversations and gather participant feedback on design elements (see Appendix A for the interview guide). Five websites were selected based on their application of accessibility guidelines relevant to people with MID (e.g., readability and clear navigation), while one was intentionally chosen for its lack of accessibility to stimulate critical discussion (see Appendix B for a detailed description of the websites). During both interview sessions, the researcher showed the websites one at a time while asking questions such as: 'What do you like about this?' and 'What do you dislike?.' The participants were free to determine the direction and flow of the interview topics to ensure that an open perspective was created based on their own views. Having discussed the website from this open perspective, the researcher, taking existing accessibility guidelines into account , asked open questions about elements that the participants had not mentioned. In the third interview round, participants shared their opinion and preference on various types of answering categories such as grading, stars, and smileys (see Appendix A).

To ensure the data collection process was accessible for participants with MID, several adjustments were made. In collaboration with the co-researchers, the questions were carefully formulated in simple language, and additional explanations were provided as needed to avoid misunderstandings. Questions were asked verbally and supported with visual aids, such as screenshots and pictograms of the websites. Complex terminology was avoided, and interviews were conducted at a relaxed pace, allowing sufficient time for breaks. Participants could take part individually or in pairs, creating a safe and comfortable environment where they felt more confident sharing their opinions.

Ideate and Prototype

During the ideate and prototype phases, six meetings took place with the social designer (Fig. 3.1, step 2). The social designer translated the findings and appropriate elements that emerged from the empathize and define phase into low fidelity prototypes. The low-fidelity prototypes were interactive, clickable online versions of the platform, enabling participants to explore and provide feedback on key functionalities and design elements. Feedback was gathered through guided walkthrough sessions with the researcher and social designer where participants interacted with the clickable prototypes while responding to open-ended prompts such as: "How easy is it to find what you are looking for?", "What do you think of this page's layout?", and "What would you change to make this clearer or easier to use?". This feedback was used to revise the low fidelity prototypes until a high-fidelity prototype was created for final testing.

During these sessions, visual and physical aids were utilized, including printed prototypes and schematic representations of design concepts. Participants provided feedback by pointing out or directly interacting with elements, making the process more intuitive. Sessions were interactive and tailored to the pace and abilities of the participants.

Test

Feedback from two usability test rounds conducted with the high-fidelity prototype led to design improvements and additional platform revisions (Fig. 3.1, step 3). During the test sessions, participants were asked to perform specific tasks such as navigating the platform, locating information, and completing various response formats, including multiple-choice questions, smiley scales, and star ratings. This allowed the research team to evaluate the platform's usability, navigation structure, and overall functionality. At the end of the iterative process, an evaluation was conducted. Feedback about usability were gathered using a think-aloud procedure, where participants shared their thoughts aloud while completing tasks, to explore areas where they encountered difficulties. These guided walkthroughs were conducted alongside usability testing. During these sessions, the researcher systematically reviewed all platform sections with participants, ensuring that no features were overlooked. Participants were encouraged to ask questions, share spontaneous feedback, and highlight unclear or challenging sections.

Accessibility was ensured during the test phase by using intuitive visual tools like smileys and star ratings to simplify the evaluation process. Questions and forms were explained in plain language to accommodate participants with reading difficulties. Sufficient time was provided for participants to share their feedback, which was carefully documented for further design iterations.

Implementation

During the implementation phase (Fig. 3.1, steps 4–6), cognitive interviews were conducted with members of the COVID-19 panel with MID or LL. These interviews incorporated usability testing elements, evaluating the platform's language, questionnaire content, navigation, and interactive features. Participants engaged with a clickable high-fidelity prototype, completing tasks such as navigating the platform, locating specific sections, understanding instructions, and interacting with response formats like smiley scales and multiple-choice questions. A think-aloud approach was employed, where participants verbalized their thoughts while performing tasks, providing real-time insights into usability challenges. These sessions also included cognitive interviews to explore clarity, design appeal, and additional feedback [52]. The primary aim of the cognitive interviews was to gather substantive input from people with MID or LL and relevant professionals on aspects such as question routing, clarity, and overall platform usability. Based on this feedback, platform functionalities and questionnaire components were refined iteratively to enhance accessibility and usability before formal implementation rounds began. During the implementation process, the platform's language and questionnaire items were further adjusted before each of the three survey rounds in collaboration with experts-by-experience. Documentation was systematically maintained through interim evaluation summaries, final reports, meeting notes, and (email) conversation records, ensuring continuous improvement based on real-world use and expert input.

Data analysis

The data from the platform re-design process were analyzed using thematic analysis to discern and analyze patterns in the data [53]. The qualitative analysis software ATLAS.ti (version 9.1.6) was used to conduct the analysis in several steps. This allowed the data from the re-design process to be supplemented with data from the implementation. The data from the re-design phase provided rich information that was complemented by the data from the implementation phase as the iterative steps of the re-design and implementation process built on each other, resulting in decreasing feedback throughout. Moreover, the focus was not on when design characteristics and elements emerged in the process, but rather on identifying which, and understanding why they were mentioned.

First, the researchers read the transcripts of the three first-step interview rounds to familiarize themselves with the data and relevant sections of the transcripts. Second, the main author (JvC) and two research assistants (MB & CP) applied open coding to the transcripts from the first interview round. Relevant quotes and codes that focused on insights into design elements were identified in line with the aim of this study. Third, the quotes and codes were regularly discussed within the research team, including the co-researcher (JvC, KB & AvdC). This resulted in a coding structure that was subsequently applied by one researcher (JvC) to the transcripts from the second interview round. Fourth, the research team's main authors (JvC, KB & JN) regularly discussed the coded data to identify overlap and connections between the codes. Fifth, the codes were clustered into broader themes relating to the research question, identifying design elements within each main theme. Sixth, the final coding structure was applied to the round-three interviews, and all remaining data from the second and the third step were analyzed similarly by the main author (JvC). For the analysis of the documents from the implementation phase, a rapid coding approach [54, 55] was adopted based on the coding structure identified from the re-design phase. Data from the implementation phase were analyzed by the first author (JvC) and discussed with the full research team until al transcripts were coded (Table 3.2). Lastly, the codes were clustered into groups, resulting in three overarching main themes, representing design characteristics: 1) clarity and readability, 2) comprehensibility, 3) intuitive design. To ensure the validity and reliability of the data analysis, the coding team held regular consensus meetings. During these sessions, codes and themes were discussed, refined, and finalized through mutual agreement, ensuring consistency throughout the analytical process.

Table 3.2 Consecutive steps, actions and aims of the coding process.

Step	Action	Aim
1	Reading transcripts of first interview round from step 1	Familiarize with data and relevant sections of the transcripts
2	Open coding of transcripts of first interview round from step 1	First conceptual coding structure with relevant quotes focusing on insights into design elements
3	Applying conceptual coding structure to transcripts from second interview round from step 1	Discussing coded data to identify overlap and connections between codes
4	Systematically applying coding structure to all data from re-design phase	Bottom-up coding of data
5	Clustering of codes into broader themes relating to the research question	Identifying design elements within each main theme
6	Applying rapid coding approach based on coding structure to data from implementation phase	Bottom-up coding of data
7	Discussing clusters of codes	Identifying definite design elements and their mutual relations within each main theme, representing design characteristics

RESULTS

Five overarching main design characteristics with design elements as subthemes were identified from the participants' input (Table 3.3). Each main theme that presents design characteristics consisted of two to three subthemes supported by quotes from the data. All design characteristics and associated design elements have been identified as crucial for the participants and together they contribute to increasing the accessibility and usability of digital (research) platforms.

Table 3.3 Final coding structure

Main themes: design characteristics	Sub themes: design elements	Explanation
1. Clarity and readability	1.1 Visuals	Use of images, icons, and illustrations
	1.2 Text	Font type, size, spacing and formatting
	1.3 Color contrast	Contrast between text and background
2. Comprehensibility	2.1 Onboarding process	Steps involved when users first engage with the platform
	2.2 Language use and textual content	Clarity, tone, and simplicity of language
3. Intuitive design	3.1 Navigation	Menu structure, links, and site map clarity
	3.2 Functionalities to enhance accessibility and usability	Assistive features such as read-along and read-aloud features
	3.3 Perceptions on answering categories	Understanding and use of response options

Clarity and readability

Clarity and readability are interconnected design characteristics. The first impression made by a digital platform is important and influences its ability to engage readers. Design elements like visuals, text, and color contrast play key roles in enhancing clarity and readability.

Visuals

Visual aids are important in enhancing the general appearance and clarity of an online research platform. Well-designed and recognizable illustrations and photographs were particularly noted to provide clarity, especially when aligned with textual content. The participants did not unanimously prefer illustrations over photographs for visuals. Illustrations were sometimes preferred over photographs because of their perceived straightforwardness. However, it was also mentioned that illustrations could sometimes be more evocative than photographs because they appealed more to the participants' imagination.

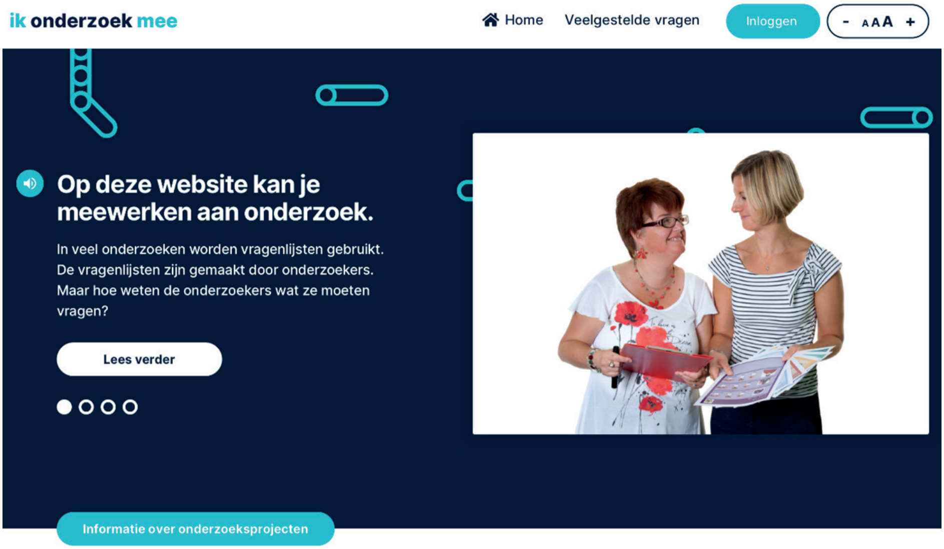
If the visuals fit the text and contain a representation of various people, this creates an inclusive environment and helps users to remain engaged on the platform. Displaying an inclusive environment to align with the diversity that exists in society increases recognizability and the feeling of being included among the participants. A universal homepage with diverse illustrations with children, older people, and people with a (physical) disability (visual Fig. 3.2) is an example of this. Incorporating well-designed icons was also emphasized as ensuring clarity for users. Since icons are often used in other platforms, they are recognizable and can substantiate text on the page when properly designed. Participant five illustrated this: "*I found those icons very nice because they are clear and substantiate the text*" [about website #2].

Text

The design of textual content was regarded as crucial for readability given the varying literacy levels. Starting each sentence on a new line, bold headings, and adequate line spacing enhance readability. There is a need for clear, concise language and clear font sizes to accommodate the users in reading the text. The option to enlarge text size was welcomed, as it allowed users with reduced vision or reading difficulties to adjust readability according to their needs (top right in Fig. 3.2 and Fig. 3.3), as described by participant 8: "*Maybe they can add the option to enlarge or thicken the text for users to choose.*"

Color contrast

Color contrast is a significant design element influencing readability, preferably with calm color schemes such as black, white, and (light) blue. For instance, a webpage containing a white background with black and blue letters (or the other way around) was experienced as easily readable by participant 11: "*Yes, on this background [white] with these color letters [black] I can read everything clearly*" [about website #1]. Attention to color contrast between text and background improved readability particularly for the participants with visual impairments or color perception difficulties.



Op deze website kan je meewerken aan onderzoek.

In veel onderzoeken worden vragenlijsten gebruikt.
De vragenlijsten zijn gemaakt door onderzoekers.
Maar hoe weten de onderzoekers wat ze moeten vragen?

Figure 3.2 Screenshot of the 'I co-research' homepage.

Comprehensibility

Comprehensibility was identified as a critical design characteristic to ensure ease of understanding for users with MID or LL, encompassing the onboarding process, language use, and textual content.

Onboarding process

Onboarding refers to how (new) users are guided in getting to know the platform and how to use it. A user-friendly onboarding process is essential to lower participation barriers for individuals with MID or LL. Participants recommended the use of illustrations, simplified language, step-by-step instructions, and instructional videos to facilitate platform navigation. Diverse instructions take account of different information processing abilities and contribute to positive experiences, as noted by participant 7*:* "*Everything is well explained. Extensive and with steps, which is nice*" [about website #4]. To prevent confusion, the onboarding must be clear about what the platform is used for and how it must be navigated, particularly for individuals who may require additional support or guidance. The length of onboarding instructions needs to be minimized, with content spread over a few screens to reduce excessive clicking.

Language use and textual content

Complex and lengthy words make the textual content harder to understand, as illustrated by participant 4: "*What I did notice is that, if you go through this site* [website #2]*, the language becomes increasingly difficult due to the long and unknown word*s." Long words and dense text increase the likelihood that users will skip content. Shorter texts are easier to pick up and to remember and are also read more often because they are easier and take less time to read, as described by participant 7: "*It is easy to read, just a little long. If it is too long, people will not read it. Short and to the point is better because it is easier and takes less time*."

Using simple language to enhance comprehension also applies to the naming of the platform. The name must be easy to type and error-free, ensuring accessibility for all users. For example, renaming the digital research platform from its original acronym name *'Crowdience'* (Crowd science) to the Dutch name *'IkOnderzoekMee'* ('I co-research') improved accessibility through more comprehensive language use. Consistent use of the same terms and sequence of concepts throughout the platform also enhanced usability. Avoiding many verbs and time-related terms (e.g., "weeks" or "months") is critical, as these concepts can be challenging for people with MID. Participants emphasized concise textual content while cautioning against text that sounds too simplistic. An LL professional clarified this balance: "*There is a very thin line between clear language and too simple language*."

Additionally, platforms need to carefully select linked websites, as their textual content is not always tailored to the MID and LL target groups. This issue was highlighted by participant 4: "*Well, the page about [website #2] is very easy in the beginning and easy to follow, and then there is quite a difficult part and reference is also made to a site where the language is very difficult. So, when people use this easy site, it can be difficult when a site is referred to that gives difficult explanations or uses a lot of verbs and time indications*."

Intuitive design

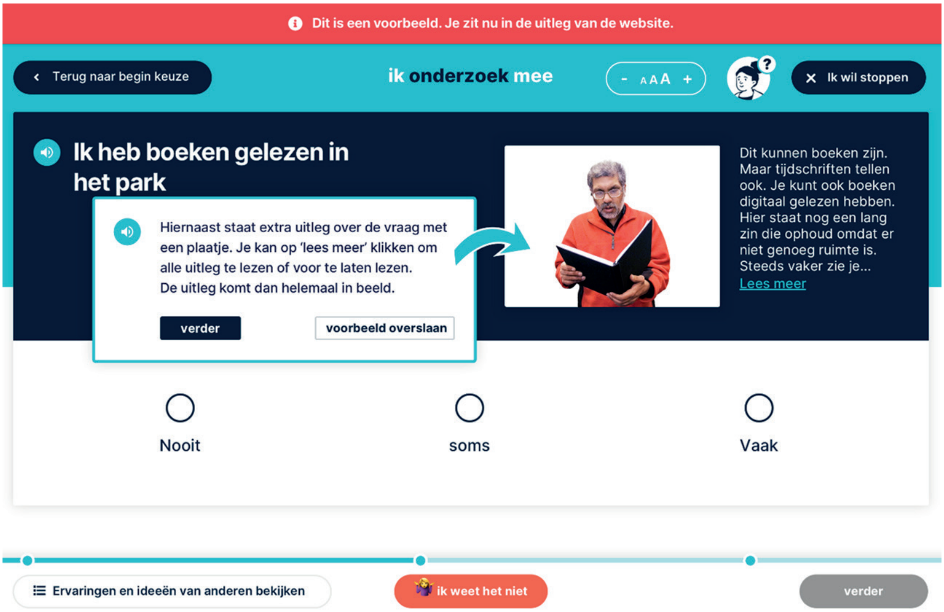
Intuitive design aimed at ensuring that the research platform's ease of access and user-friendliness were tailored to the skills and needs of individuals with MID or LL.

Navigation

Intuitive navigation enhances user experience and usability for individuals with cognitive impairments or limited literacy skills. This is achieved through clear menu structures, minimal scrolling, and a step-by-step information approach, as described by participant 12: "*I think that is easier, just press the button with an arrow and I also do not think everyone can scroll. Not everyone has a mouse, for example*." Additionally, clear button design and an indication of user progress support a positive user experience, especially for individuals who may require additional guidance or support in navigating digital interfaces. Blinking buttons to help users to navigate were perceived as irritating and distracting, as stated by participant one about website #4: "*The flashing 'continue' button is distracting to me*." Clear cursor changes to indicate buttons, such as borders around, or discoloration of, the button itself when the user hovers over it with the mouse, are helpful in assisting users to know where to click. Participant 1 illustrated this: "*In principle, they could also improve that button by making a border around it. If you click on that, you will know: oh, it is a working button*."

Functionalities to enhance accessibility and usability

Read-along and read-aloud features are functionalities that are considered helpful. If it is not necessary to read the whole page aloud, participants favored the option to choose what is read aloud when, as also stated by participant 8: "*I would choose an option for people who want to choose whether they want to hear it, as for myself I think it's nice that I can turn it on and off*." Adding a text-to-speech option increases the target-group reach and creates an opportunity to include those who have difficulties with reading and writing (on a keyboard), as illustrated by participant 13: "*By means of a record button, people who find it difficult to write an answer can also be reached*." Lastly, attention to browser compatibility and settings – such as for phones, tablets, or computers – was emphasized for catering for diverse user needs and abilities.



Dit is een voorbeeld. Je zit nu in de uitleg van de website.

Ik heb boeken gelezen in het park

Hiernaast staat extra uitleg over de vraag met een plaatje. Je kan op 'lees meer' klikken om alle uitleg te lezen of voor te laten lezen. De uitleg komt dan helemaal in beeld.

Dit kunnen boeken zijn. Maar tijdschriften tellen ook. Je kunt ook boeken digitaal gelezen hebben. Hier staat nog een lang zin die ophoud omdat er niet genoeg ruimte is. Steeds vaker zie je...

Figure 3.3 Screenshot of the explanation of the questionnaire in 'I co-research'.

Perceptions on answering categories

On survey platforms, different types of questions can be asked and answered. It was found important to optimize answering categories to ensure accessibility for the intended users. Advocating for clear and recognizable options, the participants preferred dichotomous options such as only 'agree and disagree' or 'yes and no' (participant 8): "*I would try to keep it simple and say agree and disagree. I would just leave the middle option out then*." Other preferences included the use of icons and color-coded scales, along with the inclusion of 'I don't know' and or 'I don't want to say' options. By adding these options, socially desirable answers can be avoided if users cannot, or do not want to, answer. The participants stated that the 'I don't know' button needs to be clearly visible and have an appropriate icon and should not be too close to the other answering options (see middle bottom Fig. 3.2).

DISCUSSION

This study, employing an inclusive user-sensitive research approach, investigated crucial design characteristics and elements for enhancing the accessibility and usability of digital research platforms for individuals with MID or LL. Specifying the target group's needs enabled the identification of design characteristics and elements not covered in existing guidelines but crucial for these users. General design characteristics such as clarity, readability, comprehensibility, accessibility, and usability, were found to be important. Next to those more generic design characteristics, we identified specific and crucial design elements for an inclusive digital environment, such as the recognizability and suitability of visuals, comprehensible naming of the platform and onboarding processes to enhance the findability and comprehensibility of the platform, and intuitive navigation features including read-aloud and read-along functionalities. By integrating user feedback and employing participatory methodologies, this study emphasizes the significance of co-designing digital platforms for inclusivity and equal access to digital resources for individuals with diverse abilities.

The study findings showed that, although the use of appropriate visuals is often recommended in general guidelines [18, 56], their effectiveness is context dependent and should reflect the diversity of an inclusive society. Although existing literature discussed the use of visuals to provide key information additional to the textual content to ensure clarity [18, 57], it mentions little about the preference for diversity in visuals. Only one study emphasized that the inclusion of diverse visuals featuring individuals from various demographics is imperative for universal recognition [58]. Considering this, accommodates the need of users with MID or LL for more diversity and recognizability.

In line with previous studies, we found that using simple, easy-to-read, and short sentences is important for people with MID or LL [56, 57]. Our study adds to the existing literature and guidelines that concise, step-by-step, user-friendly onboarding instructions help avoid demotivation and premature discontinuation of platform activity. People with MID or LL value support in using new digital platforms, and internal onboarding can enhance their sense of independence [59]. The ISO standard Plain Language mentions 'Findable' as one of its four key pillars, showing the relevance of using clear language to improve findability [60]. This includes adapting elements such as platform names, which was proven to be essential in our study to ensure that a platform is findable, thereby increasing its accessibility [28, 36].

Furthermore, this study found various functionalities to enhance accessibility and usability, including read-along and read-aloud features. Intuitive features such as clear menu structures and minimal scrolling were also found to facilitate ease of use. Dam et al. 2023 described this as 'breadcrumbs to guide navigation' and demonstrated to be suitable for users with MID [4]. Next to preferences and skills of the target group in terms of language, we also identified features of support in layout and functionalities. For example, in the case of an online questionnaire, optimizing answering categories for accessibility was emphasized (e.g., through use of mood colors or smiley faces), advocating for clear and recognizable options tailored to user preferences, as also underpinned by Gilbert (2019) [61]. Moreover, adding "I don't know" or "I don't want to tell" options minimized acquiescence or random responding

[62]. The addition of these functionalities facilitates users with MID and LL to participate (independently) in online questionnaires.

This study applied a user-sensitive inclusive design, which is deemed appropriate for design processes when marginalized people are part of the potential user group [39]. User-sensitive inclusive design stems from the user-centered design methodology and is designed to ensure that developers focus on the end-users as central to the design process [30]. However, these user-centered design methods can be challenging when the user population is very heterogeneous. Moreover, these design methods provide little or no guidance about how to design for people with MID or LL [31]. Therefore, we incorporated an inclusive design approach in which the needs of the participants with MID or LL were accounted for in the design process [63]. It facilitated the identification of key design elements important for people with MID or LL for the digital research platform that are unknown or unspecified in the existing guidelines. The participatory design approach may contribute to skill development in technology use and help to gain experience in participating in research for the co-designers and co-researchers [4, 15]. Moreover, the co-designers and co-researchers potentially experience empowerment and a sense of contribution due to their involvement in research and the platform's development [48]. Due to their active contributions, the developers gained valuable insights, ensuring the final design was both practical and reflected the needs of the intended end-users. We suggest that future research and technological design consider using this inclusive approach and discussed key design characteristics and elements with the target group to reduce the gap that exists between technologies and user needs, capabilities, and context [35, 45].

Strengths and limitations

Strengths of this study are its user-sensitive inclusive approach and multidisciplinary collaboration, involving a social designer and various stakeholders including people with MID and LL throughout the re-design and implementation phases. Our qualitative and inclusive approach focused on a modest but diverse participant sample to gain a deeper understanding of their various needs rather than a large sample [64]. The strength of this qualitative approach lies in the depth of insights gained through repeated interactions with participants across multiple iterations. Moreover, this study demonstrated that development and implementation should not be viewed as separate phases, since valuable input for optimizing the design can still be collected during implementation [35, 45]. The feedback gathered during implementation helped refine key design elements, emphasizing the value of the iterative nature of user-centered design.

A few limitations need to be addressed. First, this study used existing data about the implementation process, which complemented the re-design efforts but introduced a methodological challenge. Since the data was originally collected as part of a separate study, participants were not consistently asked to explain their design preferences in detail, limiting deeper insight into their underlying motivations. Future research could address this by employing more structured data collection and documentation strategies throughout both the development and implementation phases to ensure reproducibility and transparency [35, 45]. Second, data collection was conducted remotely due to COVID-19 restrictions. This may have affected the engagement of participants or their ability to participate in certain evaluation tasks. Nevertheless, the research team used visual aids, simplified language, and personalized support to address these challenges. Third, MID and LL participants were combined in this study due to the similar challenges they face in acquiring and comprehending (digital) information. Our primary goal was to ensure a diverse representation of this broad target group since they are both underrepresented in (public) health and scientific research. We acknowledge, however, that differences between these groups may exist and could lead to distinct needs affecting the generalizability of our findings. To gain deeper insights into specific design preferences we recommend future research to explore these groups separately.

Conclusion

For people with MID and LL, it is important that a digital (research) platform is inviting, clear and non-distracting. Employing a user-sensitive inclusive research approach for the re-design of the digital research platform ‘I co-research’, to enhance accessibility and usability, helped identify design characteristics and elements specifically important for people with MID or LL, based on feedback from participants involved in the platform’s development and implementation process. This study extended fundamental design characteristics covered in existing guidelines and literature, such as clarity, readability, comprehensibility, and intuitive design. Crucial design elements for an inclusive digital environment included the use of recognizable, diverse, and appropriate visuals that align with and reflect the diversity in society, and comprehensible and clear naming of the platform to enhance the findability. The importance of an accessible onboarding process and intuitive navigation features including read-aloud and read-along functionalities also emerged. In conclusion, by adopting user-centered design approaches and incorporating key design characteristics and elements identified through empirical research, digital platforms can be tailored to meet the diverse needs of individuals with MID or LL, facilitating greater inclusion and participation in digital research.

CRediT authorship contribution statement

Julia F.E. van Calis: Writing – review & editing, Writing – original draft, Visualization, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization.

Jenneken Naaldenberg: Writing – review & editing, Supervision, Methodology, Investigation, Conceptualization. Anneke W.C. van der Cruijsen: Visualization, Methodology, Investigation, Formal analysis, Conceptualization. Monique C.J. Koks-Leensen: Writing – review & editing, Project administration, Methodology, Investigation, Data curation. Geraline L. Leusink: Writing – review & editing, Supervision, Methodology, Investigation, Conceptualization. Kirsten E. Bevelander: Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Investigation, Data curation, Conceptualization.

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Declaration of Generative AI and AI-assisted technologies in the writing process

During the preparation of this work the author(s) used ChatGPT for editing and grammar checks. After using this tool, the author(s) reviewed and edited the content as needed and take full responsibility for the content of the publication.

Declaration of competing interests

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.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.chbr.2025.100617

Data availability

Data will be made available within the Radboud Data Repository upon request.

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APPENDIX A. INTERVIEW GUIDES

Interview guide 1

- Print out this interview protocol. During the interview, share your screen with the participant; you won't be able to view the protocol on your screen.
- In advance, check with the participant or their supervisor whether they have a working microphone and camera and are familiar with Skype. We will use Skype (personal account or Business) so that we can share our screen and record the interview.
- The participant does not necessarily need a camera. The main focus is on the audio recording of the conversation. If the participant does not have a microphone or if it isn't working, call them via phone. Place the phone on speaker near your laptop's microphone so that the video recording also captures the participant's audio.
- If recording through a computer is not feasible (e.g., because the interview is conducted using different software), record the screen (including audio) using a separate camera or phone. Ensure in advance that everything is set up and that you have sufficient storage.
- Pre-load the websites you will be discussing in your browser.

Opening of the interview

Introduce yourself and ask how the participant is doing. Make some small talk and then explain that you will be discussing the websites they have viewed.

Inform them that you will be recording the session. This information should have already been communicated beforehand (e.g., in the information letter and consent form). Remind the participant about the recording, then start recording. Ask for consent again to participate in the study and to be recorded, ensuring that verbal consent is captured in the recording.

- Did you manage to view the websites? → No? That's fine. Shall we reschedule?
- Yes? Which device did you use to view the websites: an iPad, computer, or phone?

Explain that you will share your screen so that you can look at the same website together. Now, share your screen.

Open **www.steffie.nl**

- What do you like and dislike about this website?
  - Dislike? How could it be improved?
- What else do you think about the website? / What else stands out to you?

Let the participant mention everything on their own. Encourage them by asking, “Is there anything else you liked/disliked or that stood out?” Meanwhile, scroll slowly through the page. Check whether the topics below have been addressed. Only ask about the topics that have not been mentioned by the participant. **Avoid leading questions (e.g., regarding ‘real people’).**

Questions:

- What do you think of the colors?
- What do you think of the icons, pictures, and images?
- What do you think of the font, text size, and the amount of text?
- What do you think of the website layout? Does it feel too busy, clear, or just right?
- How can you tell which elements are clickable buttons?
  - → What do you think of Steffie reading the buttons aloud?
  - → The buttons in the menu bar are underlined in white. Buttons like ‘health’ are highlighted with a red border. Which is clearer? (Show this on the website.)

Go to the page about organ donation. Press play and let Steffie finish speaking.

- What do you think of the colors on this website?
- Did you press the purple button to start the video? After their answer, press the purple button and wait for Steffie to finish speaking.
- What do you think about Steffie reading the text aloud?
- Do you read along with the text, or do you primarily listen to what Steffie says?
- What do you think about Steffie’s movements?
- What do you think about the ‘Next’ button moving?
- What do you think of the placement of the text?
- Do you know what the blue bar below means? If not, explain that it shows the progress of the video.
- Do you find this feature useful, or could it be shown in a different way? How?
- Do you have any further comments about this website?

Okay, let’s move on to the next website. Open **www.meerdanliefde.nl**

- What do you like and dislike about this website?
  - o Dislike? How could it be improved?
- What else do you think about the website?

Let the participant mention everything **on their own**. Encourage them by asking, “Is there anything else you liked/disliked?” Scroll slowly through the page. Check whether the topics below have been addressed. Only ask about the topics that have not been mentioned by the participant. **Avoid leading questions.**

Questions:

- What do you think of the colors?
- What do you think of the icons? Open a theme and scroll down.
- **What do you think of these pictures?** Compare them with those on Steffie's site (go back to the organ donation page). → Avoid leading questions about 'real people.'
- What do you think of the font size and the amount of text?
- What do you think of the website layout? Does it feel too busy, clear, or just right?
- How can you tell which elements are clickable buttons?
- **What do you think about how text can be read aloud on this site?** Click 'Read aloud' on the homepage and show the colors. Compared to Steffie's site, which method do you prefer?
- Do you read along with the text, or do you primarily listen?
- Did you notice that the menu can be expanded? Expand the 'theme' menu. What do you think of this feature?
- Do you have any further comments about this website?

Okay, let's move on to the next website. Open www.lfb.nu

- What do you like and dislike about this website?
    - Dislike? How could it be improved?
- What else do you think about the website?

Let the participant mention everything on their own. Encourage them by asking, "Is there anything else you liked/disliked?" Scroll slowly through the page. Check whether the topics below have been addressed. Only ask about the topics that have not been mentioned by the participant. **Avoid leading questions.**

Questions:

- What do you think of the colors?
- **What do you think of the icons, pictures, and images? → Avoid leading questions about 'real people**.'
- What do you think of the font size and the amount of text?
- What do you think of the website layout? Does it feel too busy, clear, or just right?
- How can you tell which elements are clickable buttons?

Scroll to the middle of the page where ‘Projects’ is displayed with three yellow columns.

  - → Did you notice the two blue arrows that allow you to move the yellow columns left and right? They are also displayed below. Scroll to ‘Experience Experts’ and show it there as well.
  - → At Steffie’s site, there was a similar feature. Go back to the Steffie homepage and show the white arrows that change color when you hover over them.
  - → Did you notice these arrows?
- On the organ donation website, you can stay on one page, whereas this site allows for extensive scrolling.
  - o Is this okay for you?
  - o Do you often scroll down on websites?
- When we look at the menu bar, we see that it disappears on this page. At Steffie’s site, the menu bar is always visible. Show this on Steffie’s site. Is this important and useful for you, or does it not matter?
- Do you have any further comments about this website?

Closing

Explain that this is the end of the interview. Stop screen sharing so they can see you larger on their screen. End the recording.

- Thank them for their participation.
- Ask whether they would be willing to participate in another part of the study. This could involve websites or response scales.
- We will gather all the information and share it with a designer. This designer will create a new website for us to test in future research.

Save the recording in the key files folder!

Interview Guide 2

- Print out this interview protocol. During the interview, share your screen with the participant; you won’t be able to view the protocol on your screen.
- In advance, check with the participant or their supervisor whether they have a working microphone and camera and are familiar with Skype. We will use Skype (personal account or Business) so that we can share our screen and record the interview.
- The participant does not necessarily need a camera. The main focus is on the audio recording of the conversation. If the participant does not have a microphone

or if it isn't working, call them via phone. Place the phone on speaker near your laptop's microphone so that the video recording also captures the participant's audio.

- If recording through a computer is not feasible (e.g., because the interview is conducted using different software), record the screen (including audio) using a separate camera or phone. Ensure in advance that everything is set up and that you have sufficient storage.
- Pre-load the websites you will be discussing in your browser.

Opening of the interview

Ask how the participant is doing and express your gratitude for their participation. Make some small talk and explain that, just like last time, you will be discussing the websites they viewed.

Inform them that you will be recording the session again. This information is not new. Remind the participant about the recording, then start recording. Ask for consent again to participate in the study and to be recorded, ensuring that verbal consent is captured in the recording.

- Did you manage to view the websites? → No? That's fine. Shall we reschedule?
- Yes? Which device did you use to view the websites: an iPad, computer, or phone?

Explain that you will share your screen again so that you can look at the same website together. Now, share your screen.

Open www.allesoverdedood.nl and www.steffie.nl

- What do you like and dislike about this website?
    - Dislike? → How could it be improved?
- What else do you think about the website? / What else stands out to you?

Let the participant mention everything on their own. Encourage them by asking, "Is there anything else you liked/disliked or that stood out?" Scroll slowly through the page. Check whether the topics below have been addressed. Only ask about the topics that have not been mentioned by the participant. **Avoid leading questions.**

Questions:

- What do you think of the colors?
- What do you think of the icons? Is it clear what the first icon (burial/cremation) represents? Check if the participant mentions the 'wish booklet' icon.

- What do you think of the font size and the amount of text?
- What do you think of the website layout? There are several buttons with text listed vertically. Does it feel too busy, clear, or just right?
- How can you tell which elements are clickable buttons?
  - → On this site, the icons with text are outlined. Previously, on **steffie.nl** (go to the website to show this), only a line or border was used. Go to the next website **www.uniekdating.nl** and show how here the entire button changes color. Which method is clearer for you? Or does it not matter, and are they all clear? Go back to www.**allesoverdedood.nl**.
- Do you have any further comments about this website?

Open www.uniekdating.nl

- What do you like and dislike about this website?
  - o Dislike? How could it be improved?
- What else do you think about the website?

Let the participant mention everything **on their own**. Encourage them by asking, "Is there anything else you liked/disliked?" Scroll slowly through the page. Check whether the topics below have been addressed. Only ask about the topics that have not been mentioned by the participant. **Avoid leading questions.**

Questions:

  - o What do you think of the colors? Scroll down the page.
  - o What do you think of the images? Go to the homepage image with the shoes.
  - → There is text that moves over the image. What do you think about that?
  - → Did you notice that you can click the side arrows?
  - → Scroll down a bit further. There is a button (at the bottom right) to return to the top of the page. Did you notice this button? Would you use it?
  - o What do you think of the font size and the amount of text?
  - → What do you think about the use of different text colors? Show **UniekDating**.
  - o What do you think of the website layout? Does it feel too busy, clear, or just right?
  - o How can you tell which elements are clickable buttons? (This has been partially discussed earlier, but now it refers specifically to the red buttons.)
- Do you have any further comments about this website?

Open **www.deanoakley.com**

- What do you like and dislike about this website?
    - Dislike? How could it be improved?
- What else do you think about the website?

Let the participant mention everything on their own. Encourage them by asking, “Is there anything else you liked/disliked?” Check whether the topics below have been addressed. Only ask about the topics that have not been mentioned by the participant**. Avoid leading questions.**

Questions:

- What do you think of the colors?
- What do you think of the images?
- What do you think of the font size and the amount of text?
- What do you think of the website layout? Does it feel too busy, clear, or just right?
- How can you tell which elements are clickable buttons? Show how the buttons shift slightly.

Was this clear to you? Click the buttons and navigate through the page.

- Do you like navigating horizontally on this website, or do you prefer scrolling vertically from top to bottom? Open a website where vertical scrolling is used.
- Do you have any further comments about this website?

Closing

Explain that you have now completed the interview. Stop the recording.

- Thank the participant for their participation.
- Turn off screen sharing.
- Ask whether they would be willing to participate in another part of the study.
- We will gather all the information we receive and share it with a designer. The designer will create a website that we will test in future research. Would they be willing to participate in reviewing the new website to ensure everything has been implemented correctly?

Save the recording in the key files folder!

Interview Guide 3

- Print out this interview protocol. During the interview, share your screen with the participant; you won't be able to view the protocol on your screen.
- In advance, check with the participant or their supervisor whether they have a working microphone and camera and are familiar with Skype. We will use Skype (personal account or Business) so that we can share our screen and record the interview.
- The participant does not necessarily need a camera. The main focus is on the audio recording of the conversation. If the participant does not have a microphone or if it isn't working, call them via phone. Place the phone on speaker near your laptop's microphone so that the video recording also captures the participant's audio.
- If recording through a computer is not feasible (e.g., because the interview is conducted using different software), record the screen (including audio) using a separate camera or phone. Ensure in advance that everything is set up and that you have sufficient storage.
- Pre-load the websites you will be discussing and the Word document where the scales are shown.
- Make sure you know how to draw a red circle, cross, or line in Word, as you will need to mark the answer directly in the document.
- Save your document regularly after marking answers.
- When participants explain their choice, ask, "Can you tell me what you think about the text being read aloud/the website being difficult/etc.?" DO NOT ask, "Can you tell me why you chose the answer 'Not pleasant'?" as this may cause participants to adjust their response to match the scale/smiley/thumbs they just selected.

Opening of the interview

Ask how the participant is doing and express your gratitude for their participation (again). Make some small talk, then explain that you will ask a few questions about the websites they have already seen. Clarify that you will first visit the website to refresh their memory, after which you will ask a question that they can answer using a response scale. These scales include smileys, thumbs, or lines. The participant should first select an answer on the scale, then explain their answer. (See the note above.)

Inform them that you will be recording the session (again). Remind them about the recording, then start recording. Ask for consent again to participate in the study and to be recorded, ensuring that verbal consent is captured in the recording.

- We have sent you an email with different images representing various answers, such as thumbs and smileys. Do you have any questions or comments about this?

During the interview

We will now use the response scales for five questions about the websites you have previously seen.

Go through the questions prepared for each participant. Zoom in on each question so that only the question and the answers are visible. After each answer, ask the follow-up question related to the response scale.

Question for smileys:

- Draw a red cross or circle on the answer in the Word document so the participant can see their response.
- Can you tell me more about what you think of [INSERT topic of the question, e.g., website/reading aloud/etc.]? The second interviewer will note the response.

Question for thumbs:

- Draw a red cross or circle on the answer in the Word document so the participant can see their response.
- Can you tell me more about what you think of [INSERT topic of the question]?
- The second interviewer will note the response.

Question for stars:

- Draw a red cross or circle on the answer in the Word document so the participant can see their response.
- Can you tell me more about what you think of [INSERT topic of the question]?
- How did you decide on .../4/5 stars? The second interviewer will note the response.
- What would it take for [INSERT topic of the question] to receive all stars from you?
    - And what would earn it a 1-star rating? The second interviewer will note the response.

Question for VAS (Visual Analog Scale):

- Draw a red cross or circle on the answer in the Word document so the participant can see their response.

- How did you decide on …/4/5/6/7/… as your answer?
- What would it take for [INSERT topic of the question, e.g., website/reading aloud/etc.] to receive a 10 from you?
    - And what would earn it a 1? The second interviewer will note the response.
- Afterward, there will be four additional questions about the colors used in response scales, for which we would like your opinion.

Lastly, we would like you to share your thoughts on the following:
There are some answers where you need to indicate how often you do something or how strongly you agree with something. For example:

- never, sometimes, often, always
  How could we represent these with images? Show the images at the end of the individual document.
  or
- Strongly disagree, somewhat disagree, somewhat agree, strongly agree.
  How could we represent these with images?

Closing

Explain that you have now completed the interview. Stop the recording.

- Thank the participant for their participation.
- Turn off screen sharing.
- Ask whether they would be willing to participate in another part of the study. We will share all the information we receive with a designer. This designer will create a website that we will test in future research. Would they be willing to participate in reviewing the new website to ensure everything has been implemented correctly?

Save the recording in the key files folder!
Note: If you did not have a second interviewer, immediately process the responses to the questions yourself.

Images answering categories

1. Smileys:

Figure 4 Smileys

2. Thumbs:

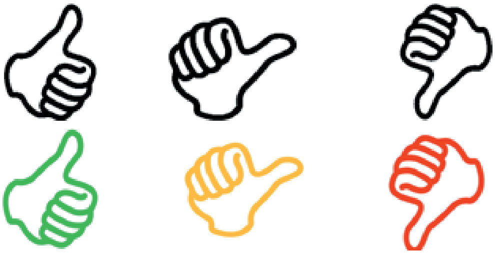

Figure 5 Thumbs

3. Stars:

Figure 6 Stars

4. Scale (line with grades)

Figure 7 Scales

APPENDIX B. DESCRIPTION OF WEBSITES.

Website	Explanation of website
1. www.steffie.nl	Steffie.nl is a website on which do avatar Steffie difficult things are explained in an easy way. The topics on this website vary from making friends, money matters to visiting the general practitioner.
2. www.hoewerktorgaandonatie.nl/nl/	Hoewerktorgaandonatie.nl is a subpage from Steffie.nl that explains the topic of organ donation in an easy way.
3. www.meerdanliefde.nl	At meerdanliefde.nl people with ID can find accessible information about entering social and sexual contacts.
4. www.lfb.nu	The lfb.nu website provides an accessible overview of all information about the LFB, a national interest organization by and for people with ID.
5. www.allesoverdedood.nl	Allesoverdood.nl is another subpage of Steffie.nl where everything about death is explained in an easy way.
6. www.uniekdating.nl	Uniquedating.nl offers people with an MID from the age of eighteen the opportunity to look for a relationship and to date under supervision or to make friendly contact.
7. www.deanoakley.com	deanoakley.com shows the portfolio of a website designer and is not specifically developed for people with ID or low literacy.

CHAPTER

4

THE IMPLEMENTATION OF SMART CONTINENCE CARE FOR PEOPLE WITH DISABILITIES: A QUALITATIVE STUDY OF KEY STAKEHOLDERS' FIRST-HAND EXPERIENCES

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ABSTRACT

Introduction: Innovative technological applications like smart continence care (SCC) offer potential benefits in healthcare delivery, particularly for individuals with profound intellectual and multiple disabilities (PIMD). SCC aims to prompt caregivers to change continence materials, potentially improving clients' quality of life and reducing caregivers' workload. Although the use of SCC in PIMD care is promising, research is needed to improve its use in these complex settings.

Objective: The aim of this study was to reflect on the SCC implementation process in care organizations for people with PIMD.

Methods: Fifteen semi-structured interviews were conducted with key stakeholders, caregivers, and SCC project leaders, across four care organizations. Interviews utilized an integrated framework drawing from the centre for eHealth research roadmap and the nonadoption, abandonment, scale-up, spread, and sustainability framework, both addressing eHealth implementation. Thematic analysis and open coding were employed to identify key themes and sub-themes in the implementation process.

Results: Four main themes emerged as crucial for successful SCC implementation: creating support, communication between stakeholders, problem-solving, and willingness to adopt SCC. The first three themes were perceived as contributors to the success of SCC implementation, whereas the last theme showed factors impacting willingness to adopt SCC. Early involvement of key stakeholders and clear communication about expectations of their roles was perceived as crucial and created clarity. Adequate problem-solving was identified as influential in SCC utilization and willingness to adopt person-centred continence care.

Conclusions: Implementation of SCC requires changes in the work routines of those involved, and key stakeholders' early involvement appears to improve support for these changes. Fostering communication between key stakeholders and adequate problem-solving contributes to positive experiences and the perceived success of sustainable implementation. This study offered a rich understanding of day-to-day practices around implementing SCC in disability care organizations. The findings may also be relevant for the implementation of technologies in other care settings.

Keywords: Continence care; care technologies; implementation; qualitative study; experiences; disability care; person-centred care; eHealth

BACKGROUND

Incontinence is common among people with profound intellectual and multiple disabilities (PIMD) [1–4]. Most people with PIMD cannot notify professional caregivers in residential care (hereafter referred to as caregivers) when their incontinence material needs to be changed because of their limited communication, cognitive, and motor skills [1–4]. This leads to a highly intensive care process [5,6]. Advanced technologies, such as the ones used for continence materials for smart continence care (SCC), can help people with PIMD to notify their caregivers when their continence material has reached a certain saturation level and needs to be changed [7].

The use of technological applications, such as for SCC, in (health)care settings may contribute to the improvement of the quality of care and person-centred care [8,9]. The implementation in daily care is challenging and complex considering the magnitude and the heterogeneity of the disabilities among people with PIMD [10]. Therefore, caregivers need to be aware of the specificity of the disabilities and needs of each individual [5,10]. However, usually, caregivers change incontinence materials at fixed times. Providing continence care at the time when incontinence material is saturated prevents leakages and avoids unnecessary changes of incontinence material, which leads to more sustainable and personalized care [11]. This is predicted to enhance clients' quality of life while reducing the workload for caregivers [7]. Previous studies have demonstrated the applicability and effectiveness of various SCC systems in elder care settings [11–13]. Despite its potential to enhance the care for people with PIMD [7], experiences with SCC implementation in disability care organizations have not yet been structurally investigated.

Numerous theoretical frameworks exist on technology implementation [14]. More general frameworks are, for example, the updated Consolidated Framework for Implementation Research (CFIR) [15], Wensing and Grol's work [16], or diffusion of innovation in service organizations [17], Additionally, there exist eHealth frameworks specifically tailored to implementation processes of healthcare technologies [18], such as the centre for eHealth research (CeHRes) roadmap and the nonadoption, abandonment, scale-up, spread, and sustainability (NASSS) framework. In the current study, we reflected on the SCC implementation process by using an integrated framework combining elements from the CeHRes roadmap and NASSS [19] to ensure a comprehensive understanding of the complexities involved within the context of implementing healthcare technologies.

The CeHRes roadmap and NASSS have an empirical base in healthcare technology research [20–23]. The CeHRes roadmap can be applied to guide and reflect on the development, implementation, and evaluation of eHealth technologies [24,25]. The NASSS framework guides and reviews the implementation of health and care technology in multiple domains (e.g., technology, value proposition, adopters, organization) [26]. According to NASSS, technology development is a never-ending process in which technology can be adjusted to fit each specific setting and context, showing important preconditions for implementation [27]. The two frameworks complement each other and provide a comprehensive and iterative perspective on the complexity of the implementation process in healthcare and can be applied to guide and reflect on this process [25].

The main objective of this study was to reflect on the SCC implementation process in disability care organizations for people with PIMD by applying the integrated implementation framework [19] in gathering first-hand experiences from key stakeholders, i.e., caregivers and project leaders directly involved in applying SCC.

METHODS

Study Design

This study used a qualitative design with semi-structured interviews to gather the experiences of key stakeholders from four disability care organizations involved in SCC implementation. The COREQ checklist was used as a reporting guideline (see Appendix 1). The participants gave their informed consent for their interview and recording. Ethical approval was obtained from the Medical Ethics Committee of Radboudumc (NL72751.091.20).

Study Setting

This study was part of a 3-year cluster randomized trial aimed at researching the (cost-) effectiveness of SCC for people with PIMD [7]. Six disability care organizations participated in the trial, of which four were invited to participate in the present study because of the stage of the implementation at the time. Each of these care organizations implemented SCC for 26–31 persons with PIMD, distributed over four to seven residential homes. All these care organizations set up a project team and appointed a project leader specifically for SCC implementation. An implementation guideline, which will be published in due course, was developed a priori based on implementation theories and evidence [15, 16, 28–30] and refined through co-creation with the participating care organizations. Additional consultation was available during the implementation process. The SCC used in this study consists of diapers and pads that contain urine sensors. A removable clip attached to the incontinence material sends information about the saturation level to a receiver via Bluetooth and subsequently to an app on the caregiver's mobile phone. Caregivers receive colour-coded notifications depending on the set saturation level per user: change desired (orange), risk of leakage (red), or OK (green).

Participants

Purposive sampling was used to include a broad diversity of the experiences of the key stakeholders responsible for coordinating and executing SCC implementation in the four participating care organizations. The researchers involved in the implementation process identified key stakeholders who were closely involved in the implementation process of SCC. Of the 16 invited key stakeholders, 15 participated (14 females, 1 male). The study sample consisted of project leaders (n = 8) involved in the implementation process at these four organizations and caregivers (n = 7). The project leader group consisted of four participants specifically appointed to lead SCC implementation in their organization. Five participants were closely involved because of their daily work, two as team coordinators, one project coordinator, one programme manager, and a person combining the role of team manager and project leader. The caregivers interviewed were appointed or volunteered as SCC ambassadors, meaning that they were responsible for implementing SCC in their team and serving as the key SCC user. They were the spokesperson to the project leader and the SCC supplier. We, therefore, refer to the caregivers with an ambassador role group as 'ambassadors' when they spoke about their role as ambassador. We refer to them as caregivers when they spoke about their own role as professional caregivers, or their team members' caregiver role. Since this interview was part of the trial they were already participating in, all interviewees were informed beforehand that they would receive an invitation for an interview.

Study Procedure

Interviews were conducted between January 2022 and December 2022 by JvC and VvC. The duration of the interviews varied between 30 and 60 min. Twelve interviews were online, using Microsoft Teams; the other interviews were conducted onsite at a location of the interviewees' choice. The interviews were transcribed, and participants were offered a member check, which did not lead to any changes.

The interviews were tailored to match project leaders, caregivers, and their specific organizations based on the implementation logbook, kept by VvC, which contained information about salient events. This resulted in two topic lists developed based on the integration of the CeHRes roadmap and NASSS framework.19 The topic lists incorporated nine domains derived from this integrated framework: (1) participatory development, (2) iterative process, (3) value specification, (4) value proposition, (5) technological development and design, (6) organization, (7) external context, (8) implementation, and (9) evaluation [19]. Tables 4.1 and 4.2 give an overview of how the topics, interview questions, and domains relate to one another. The first interview with a project leader served as a pilot, after which minor adjustments were made.

Table 4.1 Topic guide interviews project leaders

Interview topics	Example questions	Domains [19]
1. Stakeholders	Who are the stakeholders in this project and how did they become involved?	Participatory design/ research
	How have the expectations of the various stakeholders been dealt with?	Value specification
2. Locations	What changes in routines were needed to implement SCC?	Implementation
3. (Technical) Implementation	What did the technical implementation of SCC within the organization and participating locations look like?	Technological development and design
		Organization
	Were any problems encountered?	Implementation
4. Iterative process	Was there room for feedback and evaluation during the implementation	Iterative process
5. Upscaling	What is your view towards upscaling smart continence care within your organization?	Organization
	Who had ownership during the project?	Value proposition
6. Lessons learned	What is the most important lesson that you learned?	All domains represented
7. Evaluation	What is the impact of SCC on the users (clients and healthcare providers) according to the interviewees?	Evaluation

Table 4.2: Topic guide interviews ambassadors

Interview topics	Example questions	Domains [19]
1. Usage of innovation/SCC	What are the experiences of you and your colleagues with using SCC?	Implementation
2. Implementation process	How do you fulfil the role of ambassador?	Implementation
		Iterative process
3. Impact of SCC	What added value did SCC give?	Evaluation
4. Upscaling	Would you like to continue using SCC?	Organization
		Value proposition
5. Evaluation	What are your suggestions for implementing SCC within other teams?	Evaluation

Data Analysis

After transcription, the qualitative data were analysed thematically, supported by the ATLAS.ti 9.1.6 software, in several steps, as described by Braun and Clarke [31,32]. To gain familiarity with the data, transcripts were read, and audio recordings were listened to. The frameworks (CeHRes and NASSS) were used to reflect on the implementation process. We applied open coding to the data and analysed the data inductively, with the aim of formulating new themes based on the data itself rather than assessing the existing frameworks. Two authors

(JvC, VvC) separately open-coded three transcripts. Relevant quotes and codes were identified and similarities and differences in coding were discussed, resulting in a first conceptual codebook. This codebook was subsequently applied to six transcripts independently by the two main authors (JvC, VvC). Discussing and comparing the codes between three authors (JvC, VvC, KB) led to the addition of new codes, rephrasing codes, and merging codes, resulting in a coding structure. This coding structure was applied to the remaining transcripts by two authors (JvC, VvC).

Next, two authors (JvC, VvC) discussed all coded data. In several rounds, codes were clustered into broader overarching categories. A third author (KB) joined in the last rounds of this step, leading to a final review and (re)naming the main themes and sub-themes. For example, the codes 'discuss', 'inform', 'evaluate', and 'advise' were clustered into the sub-theme 'continuous communication' as part of the main theme 'communication between stakeholders'. Three authors (JvC, VvC, KB) grouped the sub-themes, resulting in four main themes described in the results section below.

RESULTS

The analysis resulted in four main themes: (1) create support, (2) communication between stakeholders, (3) problem-solving, and (4) willingness to adopt SCC. Each theme has two or three sub-themes, which are described in this section and illustrated by quotes in the tables. The first three themes can be defined as contributors to the success of the SCC implementation, whereas the last theme shows how these factors impact the willingness to adopt SCC.

Create Support

Support for SCC use was created through engagement during implementation itself and included several roles that key stakeholders played in the process (Table 4.3).

Engagement During Implementation

Early in the implementation process, stakeholders were engaged consciously by the project leaders. This was perceived as having a positive influence on creating support for SCC implementation by the caregivers. For instance, the early involvement of support services such as IT and logistics departments was important, because they provided essential preconditions to contribute to the implementation, and by early involvement they were able to think along and prepare the implementation from their side [Quote 1.1.a]. Early involvement of managers is important to support SCC use in the organization and to ensure joint decision-making for possible further uptake.

Table 4.3: Sub-themes and quotes of the theme create support.

Sub-themes	Quote-reference	Quotes
Engagement during implementation	1.1a	'Then, I look for the account manager [of the IT department] at the different regions within our organization. Then, when I knew this, I involved them. So that they knew what was going to happen. Next, they looked for IT persons who can provide support on-site. So, when there were questions, this was the person to go to. So, in all, that's how we involved them' (Project coordinator, organization 4).
	1.1b	'I appreciate the fact that they informed me before starting to use the smart diaper. That's good, (…) because, often they forget the night team in such a project' (Ambassador and night care coordinator, organization 1).
Roles in the implementation process	1.2a	'The guidance [of the project leader and program manager] was good. They even visited our location. They were happy to give an explanation and we discussed how things can be put to practice for the night care team' (Ambassador and night care coordinator, organization 1).
	1.2b	'I haven't even spoken with my manager. Therefore, all the problems we encountered are still there' (Ambassador and caregiver, organization 4).
	1.2c	'Ambassadors get hours for this project, like 4 h per week. If they need more, they should tell me. I don't check the hours as a program manager, but I do report these hours at the end of each quarter of a year for the administration and internal budgeting' (Program manager, organization 1).
	1.2d	'Yes, however, I must admit that some colleagues changed diapers out of precautions, although we did not receive a notification on the phone. They were actually scared that if they waited, then within one hour there would be a notification, and then it would not be a good moment. So, yes, that is not the way we are supposed to act. But, yeah, it just happens out of precautions, because then you think, "I don't have to change diapers at 15 h of 16 h"' (Ambassador and caregiver 1, organization 3).

Participants stated that the SCC implementation meant a change in work routine, from changing diapers at fixed times to diaper changing when a notification indicated full incontinence material. Caregivers felt supported when they were informed about the project before the implementation started [Quote 1.1.b]. Because of this early involvement, the expected added value of SCC for the client and the workplace was more evident to those involved; this was experienced as motivating and increased willingness to cooperate. Caregivers described the expected added value as the increased well-being of the clients with PIMD, elimination of unnecessary material changes, improved skin condition, and learning about clients' voiding patterns.

Roles in the Implementation Process

Project leaders had a managing role in the implementation process, entailing the management of implementation at participating locations and keeping all stakeholders involved and connected by coordinating the necessary implementation steps and communicating with management and the SCC supplier. In this role, project leaders also had to deal with resistance from the caregivers, for instance, regarding diaper-changing routines. Therefore, proximity of the project leaders and ambassadors to first-hand users on the work floor – the caregivers – was considered important and led to positive experiences [Quote 1.2.a]. In line with this, a lack of contact and proximity resulted in negative experiences [Quote 1.2.b].

Caregivers who were ambassadors in the implementation process acted as key users to their colleagues. In this role, they were the liaison between the project leader, their team, and the supplier. This role was new to them and included tasks to involve and support colleagues in using SCC, changing work routines, and signalling issues as well as communicating with the project leader and the SCC supplier. Allocating dedicated hours and being explicitly assigned the role of ambassador was an important facilitator [Quote 1.2.c], as were their skills in dealing with resistance. Ensuring a collaborative feeling through close contact between the teams, ambassador, and project leaders created a feeling of 'doing it together', thereby contributing to a positive experience.

SCC implementation and use eventually takes place on the work floor. It is the caregivers that need to change their way of working. Although the caregivers stated that they understand the potential added value of SCC and understand that the existing routine is not optimal, it still can be hard for them to let go of the fixed schedules [Quote 1.2.d] and change on request indicated by the SCC has an impact on the rest of the day's programme.

Communication between stakeholders

Communication between different stakeholders entailed two sub-themes: continuous communication and communication channels (Table 4.4). Communication took place with external stakeholders, such as the supplier of the SCC material, but also between internal stakeholders, such as different care teams, the project leader, support services, and management of the care organization.

Table 4.4: Sub-themes and quotes of the theme communication between stakeholders.

Sub-themes	Quote-reference	Quotes
Continuous communication	2.1a	'We had our team meetings, in which we evaluated. And the "[person] from IT or innovation" came by every week to evaluate. And, if I was downstairs, the locations are downstairs, if I was at the residence, I always asked them "how is it going?" "how is it?" These were the informal moments which were highly informative' (Team manager and project leader, organization 4).
	2.1b	'It felt like we were muddling along. Things were discussed during that meeting [2 months ago]. But the [person] from innovation didn't do anything with this. And the manager neither, I haven't even spoken with my manager. Therefore, all the problems we encountered are still there' (Ambassador and caregiver, organization 4).
Communication channels	2.2a	'In my opinion, the communication is handled in very different ways. There are caregivers who are in panic and frustrated [as the SCC was not working properly]. They send not-so-nice WhatsApp messages [to the supplier of SCC] and are not happy if they don't get a response within 20 s. On the other hand, having a message in text can be tricky as well' (Team coordinator 1, organization 3).
	2.2b	'[The product specialist of the supplier] had a few locations he preferred, and therefore spent more time on these locations. Other locations hardly got any attention' [irritated tone of voice] (Project leader, organization 2)

Continuous Communication

Continuous communication gave the participants the experience of support and direction in what was needed for implementing SCC at multiple stages of the implementation process. During the preparation phase, this included informing many people throughout the organization and asking for their advice, for example, about the size of material to use and where to place the Bluetooth receivers. During SCC use, the care teams, together with the supplier, often discussed and evaluated SCC per individual client, so that adjustments could be made to ensure optimalization for the client. These junctures, together with informal points of contact [Quote 2.1.a], ensured continuous communication. This was an important prerequisite to keep the implementation on track and prevent delays arising from unsolved problems and inaction, which could result in a negative experience of 'muddling through' [Quote 2.1.b].

Communication Channels

The continuity of communication as described above was facilitated in different ways and through various channels, such as email, WhatsApp, phone, online meetings, and live meetings. Both online and offline meetings between care teams from different locations were scheduled, thereby ensuring that everyone could be involved in the changes that took place and in the agreements that they made with one another.

Caregivers experienced WhatsApp as a fast, accessible, and direct way of communication between the work floor and the supplier. A risk with this type of communication was that expectations were not always met and that misunderstanding could arise as a result of differences in the interpretation of written text in WhatsApp [Quote 2.2.a]. Frequent face-to-face contact was experienced as pleasant and helpful, especially when client-specific cases needed to be discussed. When there was too little face-to-face contact, this led to frustration [Quote 2.2.b].

Problem-solving

When starting the SCC implementation process, teams encountered problems and challenges relating to working routines, everyday-care situations, and technical or practical problems with the product itself. During the process, different strategies to address challenges and problems were used, as discussed below (Table 4.5).

Table 4.5: Sub-themes and quotes of the theme problem solving

Sub-theme	Quote-reference	Quote
Solving problems on the work floor	3.1a	'You notice that the perspective of the product specialist [of the supplier] was very different from our perspective about the process of changing diapers and wet diapers. You do notice that in every discipline, and whether you're talking about night care, or someone working during the day, or the product specialist, everyone has their values and norms and has an opinion. Sometimes it was difficult to come to an agreement about what kind of choice we make. Especially at night, do we let someone lie down or do we go with the app? Yes, these are things that I sometimes found difficult to agree upon and to deal with' (Ambassador and night care coordinator, organization 1).
	3.1b	'(…) within the night care team, people dealt differently with the agreements [about SCC during the night] we made. I could send them an email with 'that is not what we agreed upon, we have not decided yet', but still they did their own thing. And if that happens repeatedly, well, yeah, that's that I think' (Ambassador and caregiver 1, organization 1).
	3.1c	'One of the persons with PIMD had a severe form of autism. Caregivers noticed that this person found it very difficult to get used to it [the SCC clip and not having continence care at fixed moments during the day]. So, we stopped using SCC, and then he had to adjust again. So, for some persons, this is very burdensome' (Project leader, organization 2).

Sub-theme	Quote-reference	Quote
Solving problems with the product	3.2a	'Well, yes, my experience was pleasant with this. They [supplier] were very willing to help. They always came up with solutions when something was wrong, and they never made things difficult. The corporation was very pleasant, I must say. They kept their promises. We just had a good working relationship with them' (Team coordinator 2, organization 3).
	3.2b	'Contact with the people from IT was not good, very often we got this "easy answer" that "the mobile signal strengths just are not good enough". We experienced the same with [employee of supplier]. [This person] did follow up on our questions, but then, nothing. Most of the problems we experienced with communication were about technical issues' (Project leader, organization 1).
	3.2c	'Some locations struggled to work according to the notification of the app and waited to change the diaper. Sometimes, notifications were incorrect, decreasing the trust' (Project leader, organization 1).
	3.2d	'The technical adjustments that need to be made: fewer incorrect and defective notifications, otherwise we will not implement it. Because then you need somebody to fix these problems, making the business case more difficult. We discussed this with the supplier and wrote this down in the advisory report, which we will discuss internally' (Program manager, organization 1).

Solving Problems on the Work Floor

The situation occurred that one team's caregivers provided continence care in a way that the other team viewed as inappropriate. This arose because of differences in the vision on quality of care and that sleep is more important than changing continence materials. For example, night-care teams contended that the night was for sleep and that their clients should not be woken up for a diaper change, even if this could result in a leakage. Day-care teams, however, felt that waking a person at night was preferred to decrease the possibility of them having a wet bed. It could be difficult to overcome these differences [Quote 3.1.a]; participants felt that it was important to communicate and agree upon how care is delivered; however, this did not always happen [Quote 3.1.b]. In general, the most important thing to do according to the participants is to communicate and explain each other's point of view and together agree upon what is best for the specific client and then keep checking whether the change in continence care provided has the desired effect.

Caregivers encountered several problems in matching the SCC material with their clients' individual characteristics. This included finding a comfortable size and absorption capacity, determining the notification saturation level that suited the person's skin condition, and determining the right time for a diaper change in line with the client's programme of daily activities. When information about an individual voiding pattern was made available through the online portal, this helped caregivers to determine a care strategy per person. Caregivers could even decide to stop using SCC for some persons with PIMD to match their needs [Quote 3.1.c].

Solving Problems With the Product

Problems relating to technical and practical issues with the SCC product, if not possible for the caregivers or the care organization's IT department to solve, were solved by the supplier. One such problem that appeared, for example, was malfunctions with the Bluetooth clips that either did not work or did not send information to caregivers adequately; this needed to be solved by changing the clip or installing additional receivers. Often, this and other problems were adequately and promptly addressed by the supplier, thereby helping the working relationship between the supplier and caregivers and the caregivers' work [Quote 3.2.a]. When there were delays in responses, unhelpful solutions, or differences in perceptions of how a problem had to be addressed, this led to frustrations with the caregivers and ambassadors [Quote 3.2.b,] and affected the trust in the product [Quote 3.2.c]. Project leaders indicated that the way in which technical problems were addressed during implementation influenced the decision on further SCC uptake within the organization [Quote 3.2.d].

Willingness to Adopt SCC

Willingness to adopt SCC was influenced by three key factors: product usability, care teams' attitude and motivation, and the skills and competencies available within the care teams (Table 4.6).

Product Usability

Participants had different experiences regarding the usability of the product. For example, the absorption capacity could be different than their usual product, or characteristics like closing mechanisms were experienced as less favourable [Quote 4.1.a]. This influenced willingness to adopt the product after having experienced it. Technical issues or product malfunctions influencing the quality of care [Quote 4.1.b] had an impact on the trust in the product itself and was an important issue raising doubt about its further adoption.

Table 4.6: Sub-themes and quotes of the theme willingness to adopt SCC

Sub-theme	Quote-reference	Quote
Product usability	4.1a	'I didn't like this product [diaper of the SCC system] as much as the products we used before and using again now. In my experience, these diapers (…) don't stick that well [the closing mechanism of the diaper]. And I feel that, even the heavy diapers, don't have that much absorptive capacity compared to the ones we are used to' (Ambassador and night care coordinator, organization 1).
	4.1b	'Quite often they [people with PIMD] were wet, while the SCC system indicated green [no need for change]' (Ambassador and caregiver 2, organization 3).

Sub-theme	Quote-reference	Quote
Attitude and motivation to adapt new way of working	4.2.a	'Yes, however, I must admit that some colleagues changed diapers out of precautions, although we did not receive a notification on the phone. They were actually scared that if they waited, then within one hour there would be a notification, and then it would not be a good moment. So, yes, that is not the way we are supposed to act. But, yeah, it just happens out of precautions, because then you think, "I don't have to change diapers at 15 h of 16h"' (Ambassador and caregiver 1, organization 3).
	4.2b	'In the beginning, in the first three weeks, it was just "How are you doing this? How are you doing this?" We really had to support each other in attaching the clips and cleaning it. "You have to put on the diaper this way." "Ow! Is that how you do it!". Being proud when you attached the clip. That was during the first few weeks. […]. We proudly informed each other when we attached the clip the right way. That really gave us the feeling of doing it together' (Ambassador and caregiver 3, organization 1).
	4.2c	'Our fixed staff did show interest in the product and the app [of the smart diaper], however not everybody was positive (…) [there were earlier experiences with the smart diaper a few years ago]. Then people said, "There we go again, again the same project". They did not like it then, so they already had their assumptions, they had already formed their opinion before we even started. It was hard to change their minds' (Ambassador and night care coordinator, organization 1).
	4.2d	'We changed the diaper of the client 4 times per day, which was our standard. But since we use the smart diaper we now know that we did this at the wrong time. We removed a clean one [diaper] and an hour later, you were lucky [diaper contained urine]… I think that we have learned to see technology as a tool, rather than something which will take our jobs' (Team coordinator 1, organization 3).
	4.2e	'Well in the beginning, before we started using the smart diaper, almost nobody got a new diaper before the night started. We had our fixed round between 18 h and 19 h, when everybody got into their pajamas and got a new diaper. With this [diaper], we put them to bed. In the first week [of the smart diaper] it was wonderful to see the data [generated by the smart diaper]. We came to the conclusion that some people were wet during the night. I have sent an email, so that more people get a new diaper before the night [between 21 h and 22 h]. We benefit from this, as we really have more dry beds, and our clients a better sleep' (Ambassador and caregiver 1, organization 1).
	4.2f	'There is one client, who pees a lot at the beginning of the night, and then nothing the rest of the night. The nightcare team tried to change his diaper a few times, but this put a lot of burden on the client. He did not like this at all. So yeah, then you really put stress on him. It was very stressful for him. (…) He was also wearing a leg splint. (…) So, we choose to leave him in bed with a full diaper' (Ambassador and caregiver 2, organization 3).
	4.2g	'There are clients for whom we agreed upon [new] working arrangements. During our round [in the night], we check the app to see the status of the smart diaper. This we do for clients we already agreed upon for visiting in the night. With the app, we can see if we must do the visit now, or if we wait a bit. So, per residence and per client, we have different arrangements in how we deal with the app' (Ambassador and night care coordinator, organization 1).

Sub-theme	Quote-reference	Quote
Training and skills	4.3a	'I did get extra courses and explanations. But in principle, the whole team is educated [on the use of smart diaper], so in that sense they already have a lot of information. I [as an ambassador] did not have to do much in that sense' (Ambassador and caregiver 1, organization 3).
	4.3b	'The training was lacking a lot, it was incomplete, time was spent on less relevant subjects, leaving no time for things that matter (…). And there were locations [the product specialist] preferred and spent more time on, while other locations did not get any, or less attention' (Project leader, organization 2).
	4.3c	'Yes, the [online portal], was explained and they [supplier] assumed that we used it. However, the caregivers did not use it. That is a missed opportunity. It has been mentioned, and yes, at least in my experience, a password was sent, but it was never checked if the caregivers could use it and wanted to use it. So, a missed opportunity if you ask me. And if it is them [supplier] to blame, or my care teams, well we just leave it at that' (Team manager and project leader, organization 4).
	4.3d	'It helps if you have a certain level of knowledge, (…) some people just handle it [technology] easily, others less. I am lucky with one of my caregivers, he really was "top chef smart diaper". But he really has the competence to sift through and go above and beyond' (Team coordinator 1, organization 3).
	4.3e	'Ambassadors (…) had a leading role (…). They were selected by the team lead and must be able to motivate. I always select people based on "someone who shows enthusiasm and has enough working hours". It does not have to be the most technical person, but someone who can motivate the team to change. It is even good if the person is not too technical, because then you can check if everything is explained properly' (Program manager, organization 1).

Attitude and Motivation to Adapt to a New Way of Working

Teams struggled to adapt to the new working routines, as, with SCC, diapers should be changed promptly, instead of according to a fixed time schedule [Quote 4.2.a]. Adapting to this new work routine also meant that a team had to learn how to use SCC. An ambassador explained that her team learned together and helped one another [Quote 4.2.b]. However, previous negative experiences with SCC by colleagues resulted in a less favourable attitude towards using SCC, decreasing motivation, and making implementation more challenging [Quote 4.2.c].

Caregivers experienced the SCC as a tool to achieve person-centred continence care [Quote 4.2.d]. Considering the personal information about each participant's voiding volumes and patterns, caregivers were rethinking the thickness of the incontinence products used and the time at which they were putting on a diaper for the night [Quote 4.2.e]. Thinking about how to provide continence care in such a way that it best suits the needs of that specific person was a motivator for caregivers to use SCC. However, this also meant that sometimes the best thing to do was not to adhere to the SCC notifications [Quote 4.2.f].

Another example of when care teams did not adhere to the SCC notifications was when they decided to combine changing of continence material with the transfer of the person with PIMD to bed during the day. They explained that, because of the transfer by patient lift, they preferred to change the diaper during this transfer, avoiding an extra burdensome transfer later on. Thus, caregivers carefully considered when to provide continence care, for which SCC provided them with additional information to guide their decision [Quote 4.2.g].

Training and Skills

Caregivers received training on how to use SCC. This entailed instructions on how to put on the diaper and how to use the mobile app. There was additional training about the web portal. The experiences of the training differed across organizations and even between teams [Quote 4.3.a and b]; the instruction on the web portal provided by a product specialist from the supplier was not always enough for the caregivers to put this knowledge into practice [Quote 4.3.c]. The training, together with skills such as technological capability and interest, the ability to motivate others [Quote 4.3.d and e], and personal motivation contributed to a more positive or negative experience in implementing SCC.

DISCUSSION

The aim of this study was to reflect on the SCC implementation process in disability care organizations for people with PIMD. Based on the analysis of the interviews, we identified four main themes important to the implementation process: create support, communication between stakeholders, problem-solving, and willingness to adopt SCC. The first three themes related to the success of SCC implementation, whereas the last theme related to SCC's practical use impacting the willingness to adopt it. Our findings showed that it is crucial that key stakeholders are involved early in the implementation process and that communication between all the key stakeholders is important to create clarity about expectations of their roles. In addition, adequate problem-solving is important, as it influences SCC use and thus the willingness to provide person-centred continence care.

In line with other implementation theories [16, 33, 34] our findings showed that creating support for the implementation of technology is important. This can be achieved when project leaders responsible for the implementation process ensure early involvement and close proximity of its end-users and by appointing project leaders and caregivers as ambassadors. The ambassador's role can facilitate the implementation process on the work floor. This role is similar to that of change agents as described by Greenhalgh et al [17] it is suggested that change agents are successful if they are selected on the basis of their credibility with the potential users, develop strong personal relations, communicate users' needs to the supplier, and empower users to evaluate the innovation in order to decide about further uptake [17]. Both ambassadors and project leaders do this by creating support at different organizational levels, by engaging with other key stakeholders, and by having an intrinsic motivation to use a new (health)care technology. Implementation requires behavioural change among stakeholders in order to implement technological applications properly. Change agents are therefore needed to create and guarantee this behavioural change. This study added empirical evidence on how stakeholders can actually fulfil this change agent role as ambassadors. These findings suggest to involve stakeholders early in the implementation process and ensure clear communication about their roles and expectations. Additionally, we recommend to appoint project leaders and caregivers to facilitate this process by fostering support at all organizational levels.

According to the NASSS framework and CeHRes roadmap, close proximity and good cooperation are seen as fostering for implementation [24, 26]. Our study showed the close proximity of the project leaders' with the care teams and other departments such as IT and management, which was experienced as helpful. Shared problem-solving allowed the care teams to learn from one another about using SCC. Problem-solving at the product level could be used to further develop the product during implementation [23,25]. For example, the supplier of study has been working on an updated version of the product that addressed the issues also raised by the participants of this study. This illustrates the opportunity to further develop a product during implementation.

Our study also demonstrated that a shared vision and cooperation between the key stakeholders is important for incorporating new working routines, thereby ensuring adequate SCC use. This is in line with the constructs of the CFIR framework that should be taken into account when a (technological) innovation is being implemented [15]. For example, the framework's constructs 'teaming', 'planning', and 'tailoring strategies' show the importance of working together in a team, aligning expectations, and adapting to the context. Careful consideration of these constructs can assist the appropriate and effective implementation of SCC use in care teams' day and night work routines.

Additionally, communication between stakeholders and across departments about the expected value of an innovation and interpersonal relations within an organization contribute to positive experiences and the perceived success of sustainable implementation. For example, the project leaders in our study kept close contact with care teams and departments such as IT and management by keeping them informed and engaged throughout the implementation and by ensuring communication about their roles and what was expected from them. Part of the project leaders' and the caregivers' motivation was found to be determined by the expected value of SCC for the people with PIMD and for them as caregivers. This is in line with research by Damschroder et al [33] and Greenhalgh et al [17] underlining the importance of intra-organizational communication and inter-organizational networks and how effective communication across these domains enhances the success of the implementation and routinization of new structures [17].

Furthermore, our study showed the importance of skills and training and how this influenced the willingness to adopt SCC. The literature contends that the complexity of a technological innovation can hamper its adoption or at least lead to frustration in using the technological innovation adequately [34]. Training is one way to overcome these difficulties – and some persons need less training than others – but it is as important to have a support network, i.e., caregivers helping one another to use SCC [33]. In discussions with relevant stakeholders, the question of the potential added value of implementing the new technology should be raised with them. Doing so can foster the intention to change work routines by creating a common sense of the relative advantage, by planning carefully, and by involving key stakeholders [16].

Our main findings suggest that shared problem-solving among care teams, ongoing training, and the development of a strong support network are essential to overcome challenges related to SCC. Finally, a shared vision between stakeholders of SCC's value will encourage the adoption and sustainability of new work routines. These recommendations can be used to inform and supplement the implementation guide used in this project.

Limitations

This study is one of the first that addressed experiences with implementing SCC in disability care. We used an integrative framework combining the NASSS framework and the CeHRes roadmap to develop a broad topic list for data collection to obtain a broad perspective of the implementation process from the interviewees [19]. Although the frameworks were not used in the analysis of the data, our findings provided insight into a number of the nine domains. For example, the domains participatory design/research, iterative process, value specification, and implementation were reflected in all themes, because the key stakeholders were actively involved and the implementation process was continuously evaluated to ensure that their needs and requirements were met. Having a shared vision gave substance to the domain value proposition, as it ensured that stakeholders knew what the added value was and fulfilled their role in this regard. The domain organization was elaborated on in all four themes; they showed which changes were necessary to implement and how these changes were achieved.

However, various other frameworks, theories, and models can be used to research and reflect on the implementation process for healthcare technologies such as technology acceptance model, unified theory of acceptance and use of technology, and CFIR [14]. Using these theories might have highlighted different factors and components of healthcare technology implementation other than those in the NASSS framework and the CeHRes roadmap. Nevertheless, this study only used the integrated CeHRes roadmap and NASSS framework to collect the data structurally. We coded the data openly to leave room to identify other themes.

Four organizations and 15 interviewees participated in this study. The inclusion of all project leaders of these four organizations, combined with purposive sampling for caregivers, provided a broad range of experiences with the implementation process. Including different perspectives from other stakeholders, such as managers in the care organizations and the SCC suppliers, can capture additional important aspects of the implementation process.

Conclusion

SCC implementation requires various stakeholders to be involved, contributing to the process to ensure use and make the implementation a success. Creating a common goal towards the expected value by ensuring early engagement and offering support are valuable and necessary steps. Moreover, the implementation of advanced care technologies in working routines requires efforts to communicate, coordinate, and motivate on the part of key stakeholders, such as caregivers, IT and logistics departments, and management. This study suggested that fostering communication between these key stakeholders and adequate problem-solving contribute to positive experiences and the success of sustainable implementation. This study offers a rich understanding of day-to-day practices around implementing SCC in disability care organizations – an understanding that may be of use for the implementation of technologies in other care settings too.

Appendix

Supplementary File 1: COREQ checklist, can be accessed online at: https://journals.sagepub.com/doi/10.1177/20552076241290399#supplementary-materials

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APPENDIX 1. COREQ (CONSOLIDATED CRITERIA FOR REPORTING QUALITATIVE RESEARCH) CHECKLIST

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	5
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	NA
Gender	4	Was the researcher male or female?	NA
Experience and training	5	What experience or training did the researcher have?	NA
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	NA
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	NA
Interviewer characteristics	8	What characteristics were reported about the inter viewer/ facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	NA
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g.grounded theory, discourse analysis, ethnography, phenomenology, content analysis	5-6
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	5
Sample size	12	How many participants were in the study?	5
Non-participation	13	How many people refused to participate or dropped out? Reasons?	5
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	4-5
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	NA
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	5

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	No
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	5
Field notes	20	Were field notes made during and/or after the interview or focus group?	5
Duration	21	What was the duration of the inter views or focus group?	5
Data saturation	22	Was data saturation discussed?	No
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: Analysis and Findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	6-7
Description of the coding tree	25	Did authors provide a description of the coding tree?	6-7
Derivation of themes	26	Were themes identified in advance or derived from the data?	6-7
Software	27	What software, if applicable, was used to manage the data?	6
Participant checking	28	Did participants provide feedback on the findings?	No
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/ findings? Was each quotation identified? e.g. participant number	7, Table 3
Data and findings consistent	30	Was there consistency between the data presented and the findings?	7-12
Clarity of major themes	31	Were major themes clearly presented in the findings?	7-12
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	7-12

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357.

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include thischecklist as part of the main manuscript document. It must be uploaded as a separate file.

CHAPTER

5

REFLECTIONS ON THE INCLUSIVE CO-DESIGN PROCESS OF A VIRTUAL ASSISTANT FOR INDIVIDUALS WITH COMPLEX CARE NEEDS: MIXED METHODS STUDY

Published as: **van Calis, J.F.E.**, Bevelander, K.E., van der Cruijsen, A.W.C., Naaldenberg, J., Leusink, G.L. Reflections on the inclusive co-design process of a virtual assistant for individuals with complex care needs: mixed methods study. **Journal of Medical Internet Research Human Factors** 2026;0:e0, doi: 10.2196/81941.

ABSTRACT

Background: The digitalization of society has transformed daily life and health care, offering opportunities for accessibility and independence for individuals with complex care needs. However, users with limited digital skills still experience challenges because the technologies do not to align with their needs. Inclusive research and design approaches can improve technology by actively involving end users and stakeholders.

Objective: This study investigated the experiences of co-researchers with a mild intellectual disability or autism spectrum disorder and other key stakeholders over time regarding the inclusive design process for a digital tool for individuals with complex care needs that was developed in a transdisciplinary consortium.

Methods: The project that was examined applied an inclusive design process to develop a sensitive virtual assistant using the Vision in Product Design method and the design thinking approach. Nine consortium members, including 3 co-researchers, participated in semi structured interviews and a group discussion about the inclusive design process after each of the project's 5 work packages (WPs). This resulted in 31 interviews and 5 group discussions in total. Individual experiences were gathered during interviews, and group discussions facilitated collective reflection. During the interviews, an adapted questionnaire was used for each WP with Likert scales and open-ended questions. The data analysis was conducted using a thematic approach and descriptive statistics for the questionnaire data

Results: Quantitative findings from questionnaires were complemented with qualitative insights from interviews and group discussions, with results presented chronologically per WP. The qualitative analysis resulted in 3 main themes: project approach, collaborative dynamics, and co-design in practice. Project approach showed how the team adapted its inclusive collaboration through expectation management, structured processes, and accessible materials. Collaborative dynamics described how communication and support evolved and how inclusive design principles were applied in practice. Co-design in practice outlined co-researcher involvement and content adaptations across the 5 WPs, highlighting how experiential knowledge directly informed design decisions. These findings show that inclusive collaboration developed over time and contributed meaningfully to both process and content.

Conclusions: This study shows that, to accommodate an inclusive research and design process, tensions between project efficiency and meaningful inclusion need to be addressed, underlining the importance of continuous coordination, collaboration, and flexibility in transdisciplinary settings. Further, applying a stepwise approach in inclusive collaborations supports coordination, continuous evaluation, and flexibility. Inclusive methods, like preparatory activities, clear role division, accessible materials, and iterative feedback, enabled active co-researcher participation. These methods contributed to a shift in ownership, allowing co-researchers to gain greater influence and co-shape both the development process and the content. The findings provide insights into how to enhance equity and relevance in inclusive technology design for individuals with complex care needs, such as individuals with a mild intellectual disability or autism spectrum disorder.

Keywords: mild intellectual disabilities; autism spectrum disorder; inclusive design; citizen science; inclusive research; sensitive virtual assistant

INTRODUCTION

The rapid digitalization of society has transformed the way in which individuals interact with technology in health care and in their daily lives [1, 2]. As digital innovations become more integrated within society, it is essential that they meet the needs of diverse user groups such as those requiring complex care. These individuals often rely on a wide range of health and social support services, making accessibility to digital health tools particularly relevant. However, such tools can be difficult to use and less accessible for individuals with limited digital skills. For example, individuals with a mild intellectual disability (MID) or autism spectrum disorder (ASD) often experience difficulties acquiring digital literacy skills and using digital devices or the internet [3, 4] because of limited cognitive skills and challenges with processing information efficiently [5]. Both groups frequently struggle with understanding complex instructions, problem-solving, and adapting to new technologies [5, 6]. This can place them in a vulnerable position, as it limits their ability to fully participate in today's complex society [7, 8]. Digital tools designed to fit their living situation may reduce challenges, increase their empowerment, and contribute to more effective care, ultimately decreasing health disparities in these populations [9, 10].

Although digital health tools can enhance accessibility and independence, they are often not developed to align with these users' specific needs and skills [2, 11, 12]. Despite the growing inclusion of these target groups in technology research and design projects [11, 13, 14], the participation of end users with MID and ASD remains limited [15-17]. This gap highlights the need for inclusive research and design approaches that incorporate the perspectives of these end users in the development of health technologies [18-20]. In this study, inclusive design is defined as an approach to make the design and development process accessible, equitable, and participatory for individuals with diverse abilities and experiences. Drawing from the Vision in Product Design (ViP) methodology [21] and design thinking [22], inclusive design refers to a flexible, iterative process that values multiple forms of expertise, including experiential knowledge, and adapts its methods, materials, and facilitation strategies to ensure meaningful involvement of all participants.

User-centered approaches [23] place user groups at the center of the design process by using tailored methods to address their specific needs [24, 25]. These approaches follow an iterative process, applying rapid prototyping and prioritizing end-user experiences through collaborating within interdisciplinary teams [26]. Inclusive, flexible, and adaptive approaches have been shown to be well-suited to involving people without prior experience in technological design [11, 14]. Recent work in inclusive participatory design further demonstrates how design processes can be adapted to respect diverse sensory, cognitive, and communicative modes of engagement [27-30]. These studies provide important methodological insights into how participation can evolve into equitable collaboration, ensuring accessibility and involvement across all stages of technological development. In research, inclusive approaches such as inclusive research or citizen science actively involve end users in all phases of technological research and development processes. In these approaches, end users are experts-by-experience and co-researchers [31, 32] who serve as advisors, cooperators, or nonprofessional researchers alongside those with academic or design training to add value through the sharing of their lived experiences [13, 33]. User-centered and inclusive research and design approaches can be applied to develop (health) care technologies that are not only functional but also accessible and usable for all [14, 34]. However, no research has been conducted into how end users with limited digital skills experience collaboration in technological research and development processes or into the adaptations that are necessary to involve them.

In addition to the participation of co-researchers and experts-by-experience, the involvement of other stakeholders in technological research and development is essential [20, 26]. Examples of these stakeholders include (informal) caregivers, support workers, IT developers or other specialists to align with the end user context and support in practice [35]. This gives technologies a greater chance of successful implementation and use [18, 36, 37]. However, previous studies have found that less attention is given to involving key stakeholders and end users throughout all design iterations or to the continuous monitoring of the design process during implementation [20, 26]. Reflecting on the collaboration during technology development and implementation phases can provide practical insights valuable for (future) development [26]. Therefore, this study aimed to examine how inclusive design methods facilitate the development of digital health tools, focusing on the experiences of co-researchers with MID or ASD and other stakeholders over time on the inclusive design process of a digital tool for individuals with complex care needs, developed within a transdisciplinary consortium. Rather than assessing the design outcomes of the digital tool itself, the research focused on the process-level learning, that is, the iterative adaptations, facilitation strategies, and collaborative dynamics that enabled or hindered inclusive participation over time. The research question guiding the analysis was: *What process modifications and content adjustments were made over time to accommodate an inclusive design process with co-researchers with MID or ASD in the development and implementation of a digital tool for individuals with complex care needs?*

METHODS

Study Setting

Within this study the inclusive design process for a digital tool in the form of a sensitive virtual assistant (SVA) for individuals with complex care needs was investigated. A consortium of transdisciplinary partners aimed to develop an SVA that could guide individuals with complex care needs toward appropriate support for questions related to mental and physical care [10]. Artificial intelligence technology was used to enable the SVA to adapt its responses in a sensitive manner.

The consortium consisted of 5 partners: (1) a university department with expertise in technology and chatbots in service settings; (2) an academic collaborative conducting research with and about people with intellectual disabilities; (3) a social design agency; (4) a foundation for social care organization informing, advising, supporting, and employing people with complex care needs such as individuals with ASD and intellectual disability; and (5) an IT company. In this project, 3 individuals with ASD or MID, representing the target group, participated as co-researchers and experts-by-experience throughout the entire research and design process. The co-researchers work for the academic collaborative and the social care organization. Their involvement enabled the consortium to consider the challenges underlying the complexity of different living and care situations. Their roles varied across project phases such as sharing lived experiences, co-designing prototypes, recruiting participants, co-moderating focus groups, and preparing data collection materials. By combining inclusive research and user-centered design, the project aimed to ensure meaningful participation.

The SVA was developed using the ViP method [21], incorporating the design thinking approach [22]. Each design thinking phase was operationalized as a separate work package (WP1-WP5), aligned with the steps of the ViP method (Figure 5.1) [22]. In the Empathize phase (WP1), the focus was on identifying and mapping the needs of the end users through focus groups and a literature review. The Define phase (WP2) analyzed the insights from WP1 to develop a user profile, which included user needs and desired experiences. In the Ideate phase (WP3), a wide range of creative solutions was generated. Among these activities, personas were created, representing fictional user profiles designed to represent typical users' behaviors, motivations, and needs. Additionally, the development of user scenarios and user journeys helped define functional requirements and typical user experiences. In the Prototype phase (WP4), these ideas were turned into early-stage functional designs (ie, low-fidelity prototypes) and tested for usability and performance. This phase also included making the ethical approval application for user testing. Finally, the Test phase (WP5) involved developing 3 functional versions of the SVA, each with a different interaction style. These were tested with real users in actual care settings to evaluate and refine the solution.

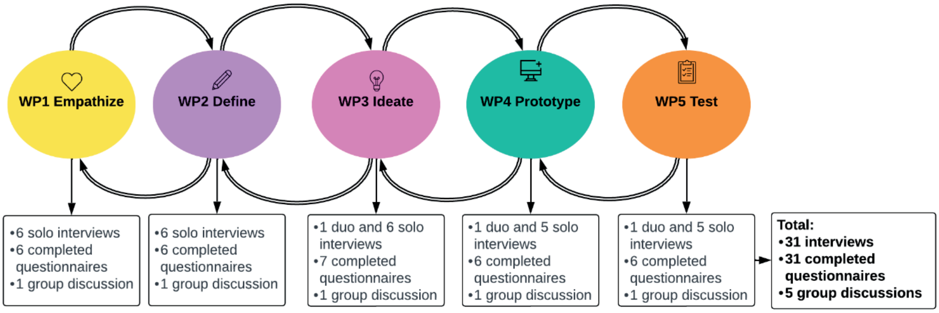

Figure 5.1 Flowchart of the SVA project and data collection for the reflection on the inclusive design approach.

Study Design

This study used a mixed methods approach to reflect iteratively with co-researchers and consortium members on the SVA's inclusive design process over time; see Figure 5.1. The SVA functioned as a context and illustrative case that allowed the research team to analyze inclusive processes in practice rather than to evaluate the final design outcome. Qualitative data were gathered through (1) semi structured interviews with co-researchers and key stakeholders followed by (2) group discussions with co-researchers at the end of the 5 phases or respective WPs. During the group discussions, the co-researchers reflected together on the insights from the interviews. Quantitative data were collected during the semi-structured interviews by filling in a digital questionnaire adapted for each WP. The integration of qualitative and quantitative methods ensured structural reflection over time across the entire process with all participants. Further, this study was conducted in collaboration with a co-researcher with a MID, whose perspective was actively integrated into the research process.

Participants

Representatives from all 5 consortium partners participated in the study, with a total of 9 participants, including the 3 co-researchers. The other 6 participants were consortium partners involved in various roles: researchers, social designers, project leader, and technology developers. Table 5.1 shows the participants' distribution in the interviews and questionnaires. The first 3 group discussions took place with 3 co-researchers and the last 2 discussions took place with 2 co-researchers.

Table 5.1 Participant distribution in the interviews.

Total participants per work package (WP)	Co-researchers, n	Researchers, n	Social designers, n	Project leader, n	Technology developers, n
WP1 (n=6)	3	1	1	1	0
WP2 (n=6)	3	1	1	1	0
WP3 (n=8)	3	1	1	1	2
WP4 (n=7)	2	1	1	1	2
WP5 (n=7)	2	1	2	1	1

Ethical Considerations

Primary data collection was conducted in compliance with the current data protection regulations of the General Data Protection Regulation and the Declaration of Helsinki. Each participant received an information letter and provided informed consent via a comprehensible consent form. Both documents were co-created with the co-researcher with MID to enhance accessibility (eg, by incorporating simple text, graphic support, large font, and increased white space). Data collection was anonymous, and no conclusions can be drawn about individuals in the presentation of results. Since the participants were part of the consortium and were compensated for their input as members, they were not compensated separately for this study. The entire study was submitted for ethical review to the Research Ethics Committee CMO Radboudumc and waived from further ethical assessment (reference number 2023-16400) because it does not constitute medical scientific research according to the Medical Research Involving Human Subjects Act (WMO) [38]. This waiver is consistent with national and institutional policies that specify that research falling outside the scope of the WMO does not require further review. Relevant guidance can be found in the CCMO framework for non-WMO research (CCMO, Niet-WMO-onderzoek) [39], as well as the CMO Radboudumc policy on non-WMO assessment [40]

Procedure and Data Collection

The aim of this study was to identify key adaptations in both the collaborative process and the content of inclusive research practices over time (May 2023–May 2024). After each WP was completed, semi-structured interviews were conducted with the consortium members, including the co-researchers. These semi-structured interviews focused on participants' engagement, lessons learned, and overall experiences and were conducted with 6 to 8 participants per WP. As the interviews were conducted after each phase, experiences were still recent and therefore easier to retrieve. During the interviews, quantitative data were collected using digital questionnaires, adapted for each WP. The interviewer filled in the quantitative responses using *I Co-research (IkOnderzoekMee;* Crowdience), an inclusive digital research platform for accessible dissemination of questionnaires [14, 41]. The questionnaires consisted of quantitative elements using Likert-scale items (see Table 5.2), incorporating simplified text, graphic support, large fonts, and increased white space to facilitate the participants [14]. Examples of how the scales were used in the questionnaires can be found in Appendix A. During the interviews, open-ended questions were asked regarding specific activities of the WP and the clarity of roles and tasks within these activities, experiences within the collaboration in the consortium, goals of the WPs, lessons learned, and individual reflections. The open-ended questions provided a deeper understanding of how adaptations were implemented and experienced. Appendix A provides the interview guide combining the interview questions and a WP1 questionnaire. Following the interviews with questionnaires, a group discussion was held with the 3 co-researchers involved in the project. During these discussions, insights, and areas of interest from the interviews and questionnaires such as participant engagement, challenges, and overall perceptions were discussed. An independent researcher (JFEC) moderated these sessions. In line with the paradigm "nothing about us without us" of the international treaty from the United Nations "Convention on the Rights of Persons with Disabilities [40], the data collection process was designed to ensure that the voices of co-researchers with MID or ASD were central. At the same time, consortium members without disabilities were included to investigate how inclusive collaboration was experienced and facilitated across roles. This comprehensive inclusion allowed us to identify how the participatory process was shaped. Importantly, although all perspectives were collected, the reflections of co-researchers in the group discussions formed the primary reference point for interpreting and discussing results in later stages of the analysis.

Table 5.2 Scales used in the questionnaire.

Type of scale	Color	Points	Distribution (Lowest to highest)
Visual analog scale	Black and white	10	1=Totally not clear, 10=Very clear
			1=Totally not nice, 10=Very nice
Stars	Yellow	5	1=Very negative, 5=Very positive
			1=Little contribution, 5=Great contribution
Smileys	Green, yellow, orange, and red	4	1=Very good, 4=Bad
Thumbs	Green, yellow, and red	3	1=Yes, 2=Partially, 3=No

Data Analysis

Descriptive statistics were applied to analyze the quantitative data from the digital questionnaires. Microsoft Office Excel was used to calculate frequencies, median scores, and range distributions, allowing for a clear overview of participants' response patterns, medians, and range distributions.

All interviews and group discussions were recorded and transcribed for analysis. Table 5.3 presents the consecutive steps of the qualitative data analysis, which was conducted in multiple phases using a thematic approach. After each WP, the transcripts of the semi-structured interviews were rapidly coded [43, 44] to gain an initial impression of participant engagement, challenges, and overall perceptions. The results from this phase were included in the subsequent group discussions with the co-researchers. During these discussions, key themes based on the research questions were identified, forming an initial framework to guide the analysis of the semi structured interview data of the corresponding WP. This framework guided further rapid coding of the interview and discussion data to identify overarching themes and subthemes [43-45]. The analysis process was conducted separately for each WP, ensuring a structured and iterative evaluation of the data.

In addition to the thematic analysis of interview and group discussion data, a structured analysis of co-researcher involvement and activities per design phase was conducted (Table 5.3, step 8). This analysis, based on data extracted from the interviews, focus groups, and a logbook, resulted in a table summarizing the activities conducted within each work WP, the content adaptations made, and the involvement of co-researchers in these activities, supported by participants' experiences.

Table 5.3 Consecutive steps, actions and aims of the coding process.

Step	Action	Aim
1	Reading transcripts of interviews	Become familiar with data and sections of the transcripts
2	Initial rapid coding (JFEC, AWWC) of the semi structured interviews and questionnaire responses after each work package (WP)	Gain first impression of interview data and explore areas of interest such as participant engagement, challenges, and overall perceptions
3	Using first impression on which to reflect in the subsequent group discussions with the 3 involved co-researchers (JFEC, AWWC)	Identify key themes and reflections based on research question and create initial coding framework with thematic categories
4	Applying initial coding framework and using rapid coding approach to guide second analysis	Conduct bottom-up coding, identify overlap and connections between codes, and ensure collective reflection
5	Clustering of codes into broader themes relating to the research question (JFEC, AWWC, KEB)	Identify emerging and overarching themes and subthemes
6	Discussing clusters of codes using insights from group discussions (JFEC, AWWC, KEB, JN)	Refine subthemes and analyze their relationships within each main theme, creating the final coding structure
7	Repeating steps 1-6 for each WP separately	Generate an overview of insights per WP
8	Collectively analyzing WPs	Develop a comprehensive overview of the full process and conduct qualitative data analysis, which resulted in 3 main themes: project approach, collaborative dynamics, and co-design in practice

RESULTS

The thematic analysis resulted in 3 main themes that together describe how inclusive collaboration was shaped and experienced throughout the design process. The thematic coding map of the inclusive design process is visualized in Figure 5.2. The first 2 themes show how the team adapted methods, facilitation, and collaboration over time. The subthemes are first represented by quantitative results from the questionnaires then further illustrated by qualitative results with quotes from the interviews and group discussions. The last theme gives an overview of the core activities, co-researcher involvement, and content adaptations to the inclusive research and design process during each WP, illustrated by participants' quotes about experiences. The results are described chronologically, structured by the 5 WPs. Because the SVA functioned as a use case, the emphasis here is on process adaptations rather than design evaluation of the tool itself. Where relevant, the results indicate whether adaptations were particularly beneficial for the co-researchers with MID or ASD, or more generally valuable for all consortium members.

All quantitative outcomes have been integrated into a single comprehensive table. Table 5.4 presents these results collectively, offering a consolidated overview of the rating ranges and median scores across all WPs.

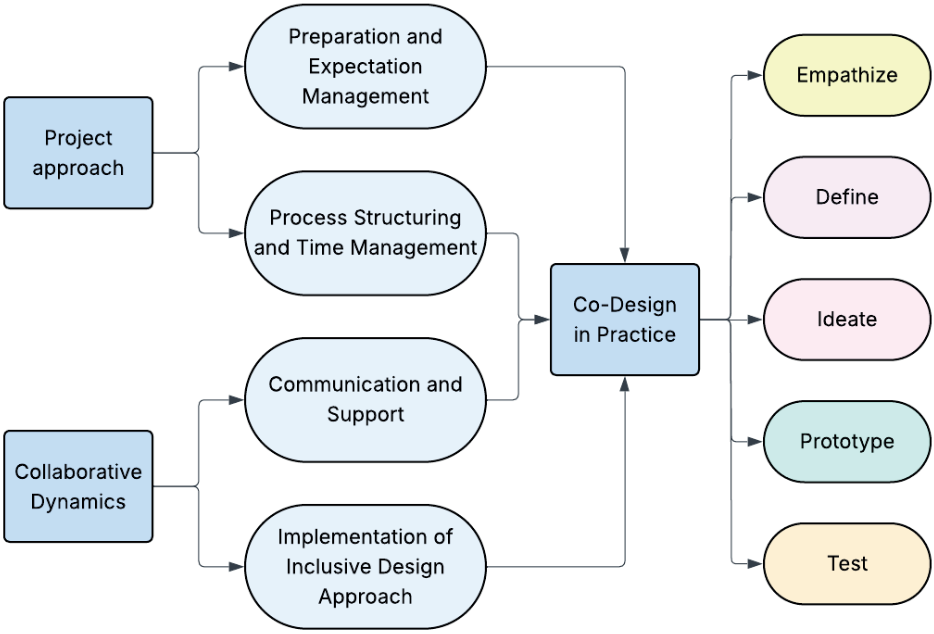

Figure 5.2 Thematic coding map of the inclusive design process.

Table 5.4 Quantitative outcomes of the grading of all work packages (WPs).

Scale	Grading for	Metric	WP1 (n=6)	WP2 (n=6)	WP3 (n=7)	WP4 (n=6)	WP5 (n=6)
1–5 stars (Low to High)	Contribution from the co-researchers to achieving the goals of each WP	Range	2–3	3–4	3–4	2–5	3–5
		Median	3	3	3.5	4	4.5
Visual analogue scale 1–10 (Low to High)	Clarity of the tasks within each WP	Range	5–8	2–10	2–8	3–10	5–9
		Median	7.5	6.5	7	7	7.5
1–5 stars (Low to High)	Overall experience of the collaboration within each WP	Range	3–5	3–5	3–5	3–5	3–5
		Median	4	4	4	4	4.5

Project Approach

Three subthemes describe how the team adapted the project approach to facilitate inclusive collaboration: preparation and expectation management, process structuring and time management, and the accessibility and clarity of materials and meetings.

Preparation and Expectation Management

Table 5.4 shows the grading for the co-researchers' contribution to achieving WP's goals. The median ratings went from low to medium to high across the WPs, with a widening grade range particularly in WP4, suggesting both improvements as well as ongoing difficulties in the contributions in achieving the goals of each WP.

In WP1, considerable time was spent preparing the project and designing the research approach. This led to a strong methodological foundation by combining the ViP approach with clearly defined research questions aimed at developing the SVA in a grounded and well-substantiated way. This preparatory phase was experienced as valuable by the participants: *"A lot of work before the start, especially substantiating the fundamental research. That intensive pre-application phase is paying off now"* [Group discussion WP1, co-researcher 1]. Although these efforts were experienced as beneficial, participants emphasized that role clarity and mutual expectations were not sufficiently addressed in this phase. Co-researchers noted that roles and meeting purposes were not always clear, thereby hindering inclusive participation: *"The division of roles and their descriptions should be clearer in advance, and the purpose behind a meeting should also be better explained"* [Group discussion WP1, co-researcher 3].

In WP2, the co-researchers' role was more clearly defined, and preparatory work was focused on aligning tasks with their expertise and ensuring that they were adequately informed to contribute meaningfully to the research activities. The participants stated that, in WP3, issues identified in WP1 and WP2 were addressed, such as more structure and explicit planning, leading to process improvements. In WP4, expectations were more explicitly defined, as indicated by co-researchers. Preparations for WP5 were also experienced as well-structured. However, uncertainty about project progress remained a recurring point, especially regarding coordination with external partners. Despite the high workload and challenges, WP5 was experienced as successfully completed. Nevertheless, reflections on the full project indicated that expectation management on roles and expectations should have been addressed earlier. Clarifying roles and meeting purposes proved beneficial for all team members, while the clearer explanation of individual tasks and meeting goals was particularly important for the co-researchers to understand their expected contribution.

Process Structuring and Time Management

Process structuring and time management varied across the WPs. In WP1, a co-researcher was present at all focus groups acting as a second chairperson, contributing to continuity. In WP2, the team revisited earlier steps when clarification was needed and repeated certain elements of the methodology; this was experienced as supportive and necessary: *"More attention was paid to repeating and explaining the steps, so planning those extra sessions was really helpful"* [Interview WP2, consortium member 1]. These repetitions and slower pacing were adaptations that specifically supported the co-researchers by providing predictability and reinforcing understanding, while improved scheduling and process visibility benefited the entire consortium.

Co-researchers reported that certain steps in the process had been skipped or insufficiently addressed. They felt they had not been adequately informed, which led to uncertainty about their role in specific sessions. This was especially apparent in WP2, where feedback loops discussing and revisiting important aspects of the care setting were not applied consistently over time, leading to confusion, a feeling of unpreparedness and missing structure among some co-researchers: *"I didn't get enough explanation about what was expected of me, so it felt like some steps were missing and I wasn't well prepared, it felt like the structure was missing a bit"* [Interview WP2, co-researcher 3]. In WP3, the design process was structured using personas and value scenarios. These tools helped visualize user needs and supported decision making. The use of visual tools was initially introduced to make abstract information more accessible for the co-researchers, but later proved equally valuable for all team members to align perspectives and trace decisions. However, not all choices made during the design process were clearly traceable to earlier input, consequently raising questions about the origin of decisions: *"It's still unclear where some decisions and information come from, but I do have confidence in the process and what it will lead to"* [Group discussion WP3, co-researcher

2]. In WP5, the fast pace of data collection limited opportunities for deeper engagement, particularly among co-researchers not involved in day-to-day activities. This moderate level of involvement indicates the tension between project deadlines and inclusive participation.

Accessibility of Meetings and Clarity of Materials

The low to high gradings indicated varying experiences with the clarity of the tasks within each WP (Table 5.4). These variations are reflected in both improvements and persistent challenges in the clarity of materials and meetings.

Throughout the project, accessibility of documents and the clarity of meeting structures were important for structuring inclusive collaboration. In WP1, the importance of aligning language and terminology across disciplines was raised. One co-researcher explained how this led to misunderstandings: "*There was a moment I got stuck on the terminology, some explanations were missing, so I misinterpreted terms like 'advisory group' and 'focus group*'' [Interview WP1, co-researcher 1].

In WP2, the team experienced difficulties with access to shared documentation because of unclear file structures and inconsistent uploading of materials. Despite this, valuable insights were still generated through collaborative analysis sessions. In addition, some participants found the abstract language used by the social designer difficult to follow, particularly during the initial explanation of the design concepts and framework. This suggests that the issue was not limited to participants with MID or ASD. Sessions about the design requirements were considered too complex or intensive, thereby negatively impacting participation. There was a clear need for better guidance and coordination: *"That session was much harder than I expected. I underestimated the approach, reading all the design requirements aloud was too much for 1 co-researcher, especially with all 3 co-researchers in 1 session. Better preparation would have helped"* [Interview WP2, consortium member 3]. Simplifying terminology and using concrete examples primarily supported the co-researchers, whereas improvements in file organization, consistent upload practices, and meeting agendas were generally beneficial for all participants.

During WP3, difficulties in managing large amounts of information were expressed, particularly regarding working with personas. This emphasized the need for better preparation and briefing. Collaboration in smaller groups improved clarity, and strategic selection of who attended meetings helped structure discussions more effectively: *"It was helpful that we could build on earlier experiences and realized that sometimes it's better to meet in smaller groups and have a clear agenda with a focused question for the co-researchers"* [Interview WP3, consortium member 4]. This adaptation was initially designed to meet the communication preferences of the co-researchers but was later appreciated by the entire team for improving efficiency and focus. In WP4, the inconsistent involvement of co-researchers in different sessions revealed the need for a more transparent selection and planning process; this was subsequently addressed by clarifying the tasks and communicating planning and agendas more openly and in advance.

Collaborative Dynamics

This theme describes how the team experienced and shaped collaboration throughout the project. We identified 2 subthemes: (1) communication and support and (2) the implementation of the inclusive design approach.

Communication and Support

Over the course of the project, the importance of structured communication and tailored support became more evident, with improvements throughout all phases. In WP1, the involvement of a researcher with experience in working with the target group contributed significantly to inclusive interaction and understanding. This early investment in a collaborative dynamic created a foundation that contributed to more effective coordination and inclusive dialogue in later phases, although some team members indicated that communication within the broader group was occasionally fragmented in WP2 and WP3. The team became more aware of the need for regular status updates and accessible coordination, particularly for co-researchers. These structured updates were introduced to help co-researchers stay connected and informed. In WP3, this learning resulted in more targeted communication and the introduction of structured feedback sessions. One co-researcher reflected: *"I sometimes miss status updates, and, as a result, I feel less connected to the group and the project"* [Group discussion WP3, co-researcher 3].

From WP4 onwards, lessons from earlier phases were applied. Project roles became more clearly defined, and coordination across team members and with co-researchers improved. For example, responsibilities for preparing test sessions were allocated in advance, and co-researchers were actively involved in reviewing prototypes, leading to smoother collaboration and more targeted feedback. In WP5 external factors, such as delays in receiving feedback from the tests, posed challenges, partly because of scheduling difficulties and the time required for internal approvals. The team members emphasized the value of having expertise with inclusive approaches embedded within the team from the start: *"Looking back, I now see how important it is to have knowledge and experience with the target group. This must be secured in advance"* [Interview WP5, consortium member 2]. Overall, the experiences with communication and support illustrate a learning trajectory in which the team increasingly recognized and applied the conditions required for sustainable inclusive collaboration. The growing emphasis on inclusive communication was therefore both a targeted accessibility measure for the co-researchers and a general facilitator of cohesive teamwork.

Implementation of Inclusive Design Approach

Consistent gradings were present for the overall experience of the collaboration within each WP (Table 5.4), indicating that this was experienced as fairly stable.

In WP1, the team paid attention to aligning tasks with co-researchers' strengths and availability. These early decisions, such as involving co-researchers in defining project goals and choosing methods, helped create a foundation for shared ownership and equitable participation. This was reflected in how co-researchers took the initiative during planning meetings and felt empowered to provide critical feedback on design choices. In WP2, several team members and co-researchers described stronger group dynamics and increased peer support during meetings, suggesting a growing sense of cohesion. The team became more responsive to individual needs and made deliberate choices about when and how to involve co-researchers. This thoughtful approach contributed to a respectful and adaptive working environment: *"There is a conscious decision whether or not to involve specific consortium members or co-researchers in certain activities. Their added value or potential overload is always considered carefully"* [Group discussion WP2, co-researcher 2]. Adjusting task complexity and workload was particularly beneficial for the co-researchers, supporting autonomy and confidence in their role.

In WP3, the inclusive approach was further strengthened. Co-researchers suggested setting up a test group; this marked a shift toward more proactive engagement. Their suggestion was adopted and built upon in WP4 and WP5, where co-researchers played active roles in testing and presenting outcomes to various stakeholders, including care and support organizations, technology developers and intended target users. These contributions were experienced as motivating and valuable: *"For me, it was a real highlight that I got to join and answer questions at an event, it made me feel even more part of the team"* [Interview WP5, co-researcher 1]. Throughout the project, the team also gained insight into how different forms of experiential input could be used effectively. The distinction between experiential expertise (derived from personal lived experience) and experiential knowledge (the ability to reflect on and articulate that experience for others) became more visible, leading to more intentional use of individual contributions. For example, during user-testing phases, some co-researchers contributed best by evaluating content based on their personal experience, whereas others translated those insights into concrete design suggestions. This initiative specifically empowered the co-researchers, reinforcing their agency within the design process, while also fostering a stronger sense of shared ownership of the team.

Co-Design in Practice

A summary of the core activities within the design phases, co-researcher involvement, and content adaptations to the inclusive design process made across the 5 different WPs is provided in Table 5.5. The adaptations were informed by the input from and collaboration with co-researchers. The following section elaborates on the rationale behind these adaptations resulting from this input, and reflects on participants' experiences with the content adaptations made.

Table 5.5 Summary of core activities, co-researcher involvement levels, and content adaptations.

Phase High: The, core activities and level of co-researcher involvement	**Description of co-researcher involvement**	**Content adaptations to inclusive research practices**
Empathize (map the end users' needs): conducted focus groups to gather insights from end users and performed a literature review to identify user challenges and context		
High	Co-researchers were actively engaged throughout all phases of the focus group (preparation, recruitment, data collection, and evaluation).	Themes for the focus groups were refined collaboratively with co-researchers to ensure inclusiveness by representing diverse care perspectives.
Limited	In the literature review, co-researchers were kept informed, contributed to discussing the research question, and reviewed summaries.	The literature review content was contextualized using insights raised by co-researchers during earlier discussions.
Define: (analyze insights from Empathize phase to create a user profile of the intended end users with the needs and desired experiences): identified and clustered contextual factors into core care intentions and developed an interest framework to capture users' underlying motivations		
Low	Co-researchers contributed to reviewing the contextual factors but were not involved in clustering them.	Terminology and categories were adjusted in response to co-researcher feedback to improve clarity and accessibility for all consortium members.
Moderate	Reasonably active contributions in developing the interest framework, supported through peer conversations and guided sessions.	Interest profiles (summaries of key user motivations) and design missions (goals guiding the design process) were co-developed with co-researchers and refined based on their feedback to ensure alignment with users' real needs.

Phase High: The, core activities and level of co-researcher involvement	**Description of co-researcher involvement**	**Content adaptations to inclusive research practices**
Ideate (generate a wide range of creative solutions): created user scenarios based on complex care experiences, mapped user journeys and defined functional needs and designed personas (fictional profiles representing typical users), and formed test groups to explore concepts collaboratively		
High	The co-researchers co-created scenarios.	Scenarios were modified to reflect lived experiences and concrete examples provided by co-researchers.
Moderate	Feedback was provided by the co-researchers during sessions on the mapped journey and functional requirements.	Personas and requirements were refined based on feedback from the co-researchers to ensure alignment with real-world user experiences. Tools were used to visualize the input of the co-researchers.
High	Test groups were formed and initiated by a co-researcher.	Recruitment effort via the consortium network resulted in diverse groups, including individuals with lived experience and professionals.
Prototype (create functional designs and explore them through performance and usability tests): created and tested low-fidelity prototypes (simplified early versions) of the sensitive virtual assistant and prepared and submitted an ethical approval application for user testing		
High	The co-researchers actively interpreted and responded to user feedback.	Prototype elements, such as navigation, instructions, and tone of voice, were adapted by the co-researchers during user feedback sessions.
Moderate	A co-researcher supported the drafting of the ethical application to test the prototypes.	Ethical approval documents, such as the information and informed consent letter, were edited in consultation with a co-researcher.
Test (evaluate functional designs with real users to refine and improve the solution): developed 3 functional sensitive virtual assistant versions with different interaction styles and evaluated these versions in real care environments with end users		
Moderate	Co-researchers contributed insights during evaluation sessions, which informed improvements to the sensitive virtual assistant.	Adjustments to interaction styles (e.g., tone, responsiveness) in the 3 tool versions were explicitly informed by earlier co-researcher feedback regarding communication preferences.
Moderate	Co-researchers played a key role in guiding the evaluation, interpreting user feedback, and expressing a strong sense of ownership in the process.	Adjustments were made to enhance usability, clarity of instructions, and emotional accessibility based on real-world feedback from participants and co-researchers.

In WP1, the focus group themes, and literature review content were collaboratively refined with co-researchers, enabling diverse care perspectives to shape the discussions and ensure inclusive representation and contextual relevance. One consortium member reflected that they unintentionally excluded co-researchers from the later stages of the literature review, as they still saw it as a task that they had to carry out individually: "*I did discuss with the co-researchers what would be a relevant research question, but after that I unconsciously no longer* *really involved them because I still had the idea that this was something I had to do myself*" [Interview WP1, consortium member 1].

WP2 showed that structured feedback rounds were used to discuss and cluster contextual factors. The process and individual roles were initially unclear to some co-researchers, which led to adaptations to improve task explanation and structure for greater accessibility: "*My task was not explained well. This made it unclear what my specific contribution was. We discussed this and it was clearer afterwards*" [Interview WP2, co-researcher 2]. The iterative co-development of an interest framework was supported by facilitation from the researcher; these sessions involved a process of adaptations: "*It was very helpful that the postdoc supported the translation of the interest framework so that it could be properly presented, even though it took some trial and error*" [Interview WP2, consortium member 3]. Terminology, categories, interest frameworks, and design missions were adapted based on co-researcher input to enhance clarity and alignment with user perspectives.

The scenarios and personas were informed by the co-researchers' concrete input, their contributions reflected real-life situations and ensured the inclusion of diverse user experiences. Tools, like an interactive online board where team members could brainstorm and collaborate, enhanced clarity and enabled their lived experiences to be visibly integrated: "*There was a strong sense of contribution, you can see that on the board with all the input we have generated*" [Group discussion WP3, co-researcher 3]. One co-researcher illustrated the challenges, caused by strict ethical requirements, regarding the planning of test groups: "*I found setting up this plan challenging, especially because of the strict requirements of the ethics committee*" [Interview WP3, co-researcher 1].

In WP4, prototype elements and ethical documents were co-developed with co-researchers to support usability, comprehensibility, and accessible communication. Co-researchers' clear understanding of their role, as exemplified during feedback sessions, appeared to support their engagement and involvement in the testing process, as suggested by their proactive participation and comments on ownership: "*When testing, I knew exactly what to do, that worked very well"* [Group discussion WP3, co-researcher 2]. However, ethical procedures caused frustrations among the team, with 1 co-researcher describing his frustrations: "*Meeting all these requirements was time-consuming and sometimes frustrating*" [Interview WP4, co-researcher 1].

In WP5, interaction styles and instructional clarity were refined based on participant and co-researcher feedback to improve responsiveness, accessibility, and emotional engagement. The initial design of the functional tool versions was shaped more by prior input than by direct co-creation in this phase, contributing to stress and frustration when delays in deployment occurred: *"I really had no idea if it would work, that was stressful"* [Interview WP5, co-researcher 1]. Despite this, the testing phase was positively evaluated because of adequate preparation: "*My tasks during the testing were clear because the postdoc had provided good explanations in advance*" [Interview WP5, co-researcher 2].

Together, the adaptations and accompanying reflections demonstrate that co-researcher involvement shaped not only the content, but also the form and accessibility of the research process. They highlight how continuous feedback and flexible collaboration were essential in aligning the design with real-world needs. Overall, accessibility-focused adaptations such as simplified language, smaller-group sessions, and pacing adjustments were particularly supportive of the co-researchers, whereas measures like role clarification, structured planning, and consistent documentation were more generally beneficial for all consortium members.

DISCUSSION

General Findings

This study reflects on an inclusive and iterative design approach involving co-researchers with MID or ASD in the development of a digital health tool, examining how inclusive design methods facilitated the development of the tool and shaped collaboration within the consortium. Through adaptations, such as thorough preparation, role clarity, accessible communication, and iterative feedback, co-researchers made meaningful contributions in the inclusive research and design process. Three overarching themes, project approach, collaborative dynamics, and co-design in practice, provided insights into how inclusive collaboration was accommodated throughout different design phases. The inclusive collaboration was supported by structured engagement, cognitive accessibility strategies, and iterative methods, which collectively facilitated a greater sense of ownership and active involvement over time.

This study showed that the use of a flexible, inclusive framework deepened stakeholder engagement and enabled concrete content adaptations through its stepwise approach, in this case through Design Thinking [22, 46]. However, design thinking is not the only framework suitable for inclusive development. Inclusive design frameworks such as Design for the whole population by Clarkson et al [47], universal design by Goldsmith [48], and user-sensitive inclusive design by Newell et al [25], offer complementary approaches that emphasize accessibility, user diversity, and context-sensitive solutions. In addition, complementary frameworks such as the CeHRes (Center for eHealth Research) Roadmap [26] and the NASSS (Non-adoption, Abandonment, Scale-up, Spread, and Sustainability) Framework [47] are other valuable approaches, emphasizing stakeholder alignment and long-term implementation contexts, respectively. The ViP method used to develop the digital tool draws from these traditions and emphasizes collaborative approaches, shared ownership, and flexibility across project phases [21]. Involving co-researchers in the design process made it possible for them to actively influence both the collaborative workflow and the development of the tool itself. This participatory approach not only shaped the structure of the design meetings and the inclusivity of the design materials, but also enhanced the value and the applicability of the outcomes [32, 48]. This study contributes experiential and theoretical insights into how inclusive design methods can be operationalized within transdisciplinary (health care) technology development.

Within the flexible and iterative approach, the tension between project efficiency and meaningful inclusion emerged as an ongoing challenge, as it required increased time, support, and adaptive capacity from the team. This tension has also been shown in previous studies, particularly in the context of complex design environments where timelines are tight and deliverables fixed [51, 52]. Future research could therefore investigate how inclusive design practices affect collaborative dynamics and decision-making processes in project environments such as planning or iterative technology development. This would help clarify how to balance inclusivity with time constraints and resource limitations and offer practical strategies for managing this tension [31,51]. Understanding the value of shared expectations [53] and how teams navigate this can inform inclusive design processes that aim for meaningful inclusion throughout all phases of research and design [32].

Further, a shift toward co-researcher ownership emerged in the collaboration. In the earlier phases of the project, co-researchers were involved primarily in predefined tasks, whereas, in later phases, they initiated concrete activities such as forming user test groups. This illustrates how lived experience can transition from consulting to initiating in the design process [54]. The active involvement of co-researchers enhanced both the usability and the real-world relevance of the tool. This finding aligns with previous research suggesting that long-term, repeated engagement with end users allows them to influence the design process more deeply and ensures outcomes that better reflect their needs [50, 55]. Cognitive accessibility, through visual aids, simplified materials, repetition, and small group formats, was particularly important in early phases and supported the meaningful contributions from the co-researchers [56, 57]. This relates to prior literature on accessible formats [52] and dedicated support time [56] in inclusive research and technology development. Future research could further explore how to embed these inclusive practices in technology development projects with interdisciplinary teams and the involvement of co-researchers while maintaining methodological integrity and meaningful participant roles [13, 31, 32].

Strengths and Limitations

A key strength of this study is its design, which included structured reflection moments after each of the 5 design phases. This approach enabled the participants to share their experiences immediately after each phase, while also identifying changes and adaptations across the full design trajectory. Another strength lies in the mixed methods approach, which combined qualitative interviews and group discussions with tailored quantitative questionnaires executed within an inclusive digital platform [14]. Using both experiential insights and continuous group reflections allowed the team to adapt the collaboration dynamically. As a result, the co-researchers could engage more meaningfully, which led to deeper, more context-specific findings [54]. Some limitations must be acknowledged. The study was conducted within a single consortium, working on 1 digital (health) tool in a specific context. Additionally, the relatively small sample size may limit the diversity of perspectives captured and the broader applicability of the results [58]. Therefore, future research should examine other and larger settings.

Recommendations

Drawing from the findings of this study, a set of practical recommendations for researchers and designers aiming to conduct inclusive design with individuals with complex care needs, such as individuals with MID or ASD [59, 60] was formulated. These recommendations translate the experiential insights of the inclusive design process into actionable guidance for future research and practice;

- *Engage end users early and continuously.* Involve individuals with MID or ASD from the start of the project and maintain their involvement across all design phases. Early participation fosters ownership, while continuous engagement ensures that adaptations remain relevant as the project evolves.
- *Adapt sessions to fit participants' abilities and needs.* Prepare accessible materials and ensure that meetings are structured, predictable, and easy to follow. Use clear and jargon-free language, concrete examples, and visual supports. Naming, visuals, and text should be recognizable and understandable.
- *Build long-term and trusting relationships.* Sustainable collaboration requires time to establish mutual trust. Create a safe and comfortable setting where participants can meaningfully shape the design process. Especially in early stages, consider including trusted stakeholders (eg, family members or support workers) to facilitate familiarity and confidence.

- *Address power dynamics and clarify roles*. Discuss expectations, roles, and decision-making responsibilities early and explicitly. Move beyond consultation by showing participants how their input has influenced decisions. Continuous reflection and transparent communication strengthen mutual respect and shared accountability.
- *Use methods close to lived experience*. Apply participatory methods that connect to everyday contexts, such as contextual interviews, observations with discussion, cognitive walkthroughs, or think-aloud sessions. Conducting co-creation activities in familiar environments ensures that insights reflect participants' real-life experiences and capacities.
- *Monitor group dynamics*. Be attentive to how participants experience group settings. Some individuals with MID or ASD may find large groups overwhelming. Adjust group size and facilitation to participants' comfort levels and communication styles.

Conclusions

Reflection on an inclusive research and design process revealed that attention must be paid to tensions between project efficiency and meaningful inclusion, underlining the importance of ongoing coordination of the design process, collaboration, and flexibility in transdisciplinary settings. A stepwise approach, such as design thinking, proved helpful in structuring the process, continuous evaluation, and reducing these tensions. Inclusive methods, such as preparatory work, clear roles, accessible materials, and iterative feedback, supported active engagement throughout the project. These methods led to a shift in ownership, allowing co-researchers to gain more influence and actively shape both the development process and the content of the technology. These findings extend understanding of how inclusive design methods facilitate development processes and provide insights into how to enhance equity and relevance in inclusive technology design for individuals with complex care needs, such as individuals with MID or ASD.

Data Availability

Anonymized data are made available within the Radboud Data Repository upon reasonable request (e.g., for research purposes on a similar topic).

Conflicts of Interest

None declared.

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Authors' Contributions

JvC, KB, AvdC, JN and GL designed the study. JvC collected the data. JvC and AvdC conducted the analysis. JvC and KB drafted the manuscript. AvdC, KB, JN and GL provided critical feedback, and all authors provided critical inputs on multiple iterations. All authors have approved the final version.

Supplementary files

Appendix A. Interview guide and questionnaire Work Package 1 co-researchers

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ABBREVIATIONS

MID: mild intellectual disability
ASD: autism spectrum disorder
SVA: sensitive virtual assistant
WP(s): work package(s)
CeHRes: Center for eHealth Research
NASSS: Non-adoption, Abandonment, Scale-up, Spread, and Sustainability

APPENDIXA.INTERVIEWGUIDEANDQUESTIONNAIRE WORK PACKAGE 1 CO-RESEARCHERS

Introduction:

Welcome to this interview, thank you for participating. We will be discussing the project in which we are collaboratively and inclusively developing and implementing a chatbot for vulnerable care recipients. I'm particularly interested in your personal experiences during this past work package.

As stated in the information letter, this interview will be recorded so that I can review it later for research purposes. The recording will be stored securely and will only be accessible to the researchers. The interview will last approximately one hour, during which we will go through and complete a questionnaire together. If you have any questions or wish to stop at any time, please let me know.

Background information

1. What is your role/position in de project?

Evaluation of activities:

Focus groups with care recipients

2. Preparation: Drafting protocol, recruitment & pilot
3. Execution: Conducting focus groups with care recipients
4. Processing: Evaluating focus groups with care recipients

Focus groups with care providers

5. Preparation: Drafting protocol and recruitment
6. Execution: Conducting focus groups with care providers
7. Processing: Evaluating focus groups with care providers

Establishing interest profiles

8. Formulating themes based on data from focus groups
9. Translating themes into interests

Setting up a sounding board group

10. Preparation: Recruiting participants and drafting the agenda
11. Execution: Holding the sounding board group
12. Processing: Evaluating the sounding board group

Literaturstudy

13. Collecting literature
14. Analazing literature
    a. What was your role in the *activity*?
    b. What tasks were involved?
    c. Were the tasks related to the *activity* clear to you? Please give a score.

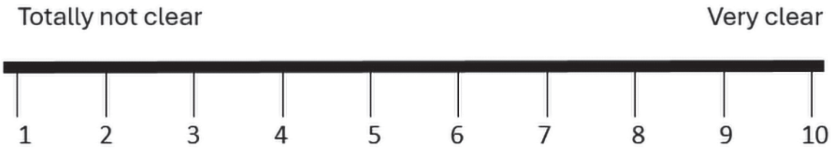

Figure 3 Scale questionnaire

1. Why do you think that?
2. Who did you work with on these tasks?
3. How did you experience the collaboration during this task?

Figure 4 Smileys questionnaire

    a. What went well and what could have been improved?

15. Are there any activities missing?

Figure 5 Thumbs questionnaire

16. If so, which activity is still missing?

Evaluatie project algemeen:

17. What were the goals of this work package?
18. Have these goals been achieved?

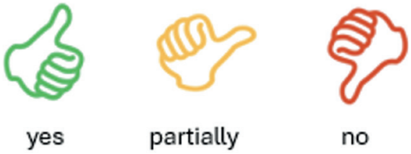

Figure 6 Thumbs questionnaire (1)

19. Why do you think that?
20. How many stars would you give your own contribution to the goals of this work package?

Figure 8 Stars questionnaire

21. Why did you give that number of stars?

Personal evaluations

22. Did you learn anything from collaborating as a citizen scientist on this work package?

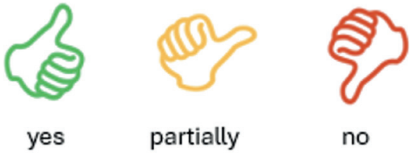

Figure 6 Thumbs questionnaire (1)

23. If so, what did you learn?
24. What went well in the collaboration during this work package?
25. What could have been improved?
26. How will you take this forward into the next phase of the project?
27. How many stars would you give the collaboration between citizen scientists within this work package?

Figure 9 Stars questionnaire

28. Why did you give that number of stars?
29. How do you feel about participating in this project? Please give a score.

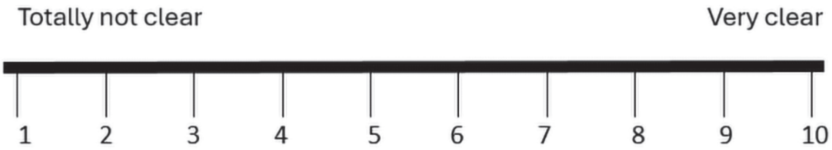

Figure 3 Scale questionnaire

30. Why do you give this score?

Closing

31. How did you experience completing this questionnaire together?
32. Do you have any questions or anything else you'd like to share?

CHAPTER

6

GENERAL DISCUSSION

GENERAL DISCUSSION

Overview of main findings

Through a combination of theoretical development, practical application, and reflection, this thesis explored how inclusion of end users with intellectual disabilities (ID) or complex care and support needs and key stakeholders can be strengthened at every stage of the eHealth design and implementation process.

Existing frameworks mainly focus on either design or implementation and do not sufficiently address the complexity of developing accessible eHealth technologies. As a result, important factors such as user diversity, contextual challenges, and the need for continuous adaptation across the development process are often overlooked. By integrating two existing frameworks, namely, The Center for eHealth Research and Disease Management (CeHRes) Roadmap [1, 2] and the Non-adoption, Abandonment, Scale-up, Spread, and Sustainability (NASSS) framework [3], an integrated framework was developed that facilitated iterative processes while involving end users and other key stakeholders. Both frameworks address eHealth technology in which iterative processes play a central role in the design and implementation while involving end users and other key stakeholders. Applying the integrated framework provided concrete insights into how inclusive eHealth (re-)design and implementation processes are interconnected, demonstrating that inclusion cannot be achieved through design or implementation alone, but only when both are addressed in an integrated, iterative way. In Chapter 2, the framework was used to analyze a platform development process, revealing that early design decisions directly influenced implementation outcomes, especially regarding accessibility and stakeholder engagement. In Chapter 4, the framework structured both data collection and analysis during the evaluation of smart continence care. It helped identify key contextual factors, such as organizational readiness and staff involvement, that affected implementation. This shows that the framework supports a deeper understanding of implementation processes and helps bridge design and implementation in complex care contexts. Throughout all chapters the value of ongoing participation and co-creation based in inclusive approaches was highlighted, demonstrating that including end users is not a one-time step in a linear development and implementation process, but most valuable when approached iteratively. Only when inclusion is embedded throughout the entire process can eHealth solutions become genuinely accessible, usable, and meaningful for those who rely on them most. Thereby this thesis has shown that inclusion is not optional, but essential in the design and implementation of eHealth for people with ID or complex care and support needs.

Based on the findings, we highlight three overarching insights that extend current eHealth practices and together provide both theoretical depth and practical guidance for inclusive and iterative eHealth design and implementation. The first insight is about moving beyond 'eHealth design and implementation' by embracing iterative and inclusive approaches. The second insight shifts the focus beyond 'usability' by embedding accessibility and inclusion within broader eHealth contexts. The third insight extends beyond 'user involvement' by actively including hard-to-reach groups in research, design, and implementation, ensuring that eHealth becomes truly accessible, usable, and beneficial.

Beyond 'eHealth design and implementation': towards iterative and inclusive approaches

Many existing frameworks and models used to guide eHealth design and implementation tend to follow a linear, phase-based structure and lack explicit attention to inclusivity. For example, Universal Design [42] focuses on general accessibility but not on co-creation or adaptation during use. The Consolidated Framework for Implementation Research (CFIR) [43] and Wensing and Grol's work [44] emphasize structured implementation but do not integrate design and implementation as mutually shaping, iterative processes. This thesis demonstrates that combining structured design methodologies, such as CeHRes [3, 4], Design Thinking [5, 6] and Vision in Design [7], with iterative and inclusive approaches can lead to flexible, participatory processes that translate theoretical models into practice and respond to real-world needs [4, 5]. These insights are grounded in the empirical findings presented in Chapters 2, 3, and 5, where the frameworks were applied to research, guide or reflect on eHealth (re-)design or implementation processes.

Rather than viewing eHealth design and implementation as separate, sequential phases, this thesis demonstrates the value of a dynamic, iterative approach that continuously involves end users and key stakeholders. Integrating these processes proves particularly valuable in inclusive eHealth for people with ID, as it enables ongoing alignment between the technology and the complex, evolving needs of users and their care environments (Chapters 2-5) [6]. Implementation should be considered from the outset, and design decisions must remain adaptable during use in practice. Iterative working methods were key to adapting to evolving needs and feedback, allowing for continuous refinement and inclusiveness in both the technology and the implementation strategy by incorporating feedback use in practice (Chapters 2, 3 and 5) [7]. By embedding iterative cycles and inclusive approaches within eHealth design and implementation, developers can respond to emerging barriers and opportunities, thereby reducing the risk of misuse, abandonment, or poor adoption [7]. For example, usability issues often only become visible during actual use in practice and addressing them requires flexibility and ongoing evaluation (Chapters 3 and 4).

People with ID or complex care and support needs form a highly heterogeneous group, and the environments in which eHealth technologies must be implemented vary just as widely [8, 9]. This diversity makes a one-size-fits-all approach unsuitable and underlines the importance of context sensitivity and adaptability throughout both design and implementation. The findings from this thesis (Chapters 2-5) show that successful eHealth development does not depend on applying a fixed set of steps, but on the ability to respond flexibly to specific user needs, challenges, and contexts through continuous feedback [10, 11]. Needs often evolve over time and become clearer through interaction with the technology [2, 12]. This heterogeneity also highlights the critical role of context. For example, the implementation of smart continence care (SCC) (Chapter 4) required changes to existing work routines. Support for these changes was strengthened when key stakeholders were involved early, when communication was ongoing, and when training and practical problem-solving were provided [13]. These elements contributed to positive experiences and perceptions of successful, sustainable implementation.

While iterative and inclusive approaches are universally relevant, their concrete application must always be tailored to the end users' context. Several key implementation principles for the implementation of SCC were revealed (Chapter 4): implementation of SCC changes the work routines of those involved, and key stakeholders' early involvement have proven to improve support for these changes, fostering communication and a shared vision between key stakeholders, training the intended end users, and adequate problem-solving contributes to positive experiences and the perceived success of sustainable implementation. These lessons underscore the value of iterative and inclusive approaches not only in design but also in long-term integration, applicability and sustainability of use of eHealth technologies [13]. The integration of inclusive approaches and existing design methodologies enabled a more responsive and human-centered design process, tailored to the context of people with ID or complex care and support needs (Chapters 3 and 5). The findings from this thesis illustrate that iterative working and inclusivity should not be treated as add-ons, but as core elements embedded within structured design and implementation strategies [14, 15].

Beyond 'usability': embedding accessibility and inclusion in eHealth contexts

The success of eHealth technologies not only depends on whether users can operate them, but also on whether they are embedded in a supportive system of key stakeholders. Without their involvement, eHealth technologies risk being misaligned with daily practice and may fail to achieve meaningful adoption [16]. Chapters 2 to 5 show that the active involvement of end-users and key stakeholders proved essential, not only for ensuring relevance and usability, but also for fostering ownership and trust in the eHealth technologies [17, 18]. Examples of these stakeholders include (informal) caregivers, support workers, and organizational stakeholders such as IT developers or other specialists to align with the end-user context and support in practice [19]. By involving key stakeholders and co-researchers from the targeted end users, they can actively influence both the collaborative process between designers, researchers, and users, and the development of eHealth itself (Chapter 5).

Through applying these collaborative processes, this thesis highlights several design principles that add to existing literature and guidelines and that help to embed accessibility and inclusion in eHealth (Chapter 3 and 5). These principles include: 1) the use of recognizable and suitable well-designed visuals that align with and reflect the diversity in society, 2) comprehensible naming of the platform to enhance the findability, 3) the importance of an accessible onboarding process, and 4) intuitive navigation features including read-aloud and read-along functionalities. Incorporating these design principles into eHealth design and implementation proved valuable for the target group, while also showing potential for broader application [18, 20]. Successful application depends on more than well-formulated principles. For instance, practical barriers during onboarding, which is the phase where users are first introduced to and begin using the eHealth technology, often determine whether tools are adopted at all. Prior research has emphasized that people with ID encounter barriers in basic onboarding steps such as logging in, navigating, and interpreting digital health information, making early support and clear instructions essential for successful use [21]. Without sufficient attention to onboarding, even well-designed eHealth technologies risk abandonment. Rather than asking “how user-friendly is this?” a more inclusive question like “how can we collaboratively shape an inclusive onboarding process that supports meaningful engagement from the start?” [22].

Beyond ‘user involvement’: towards inclusive research and design

While inclusive research and inclusive design differ in their primary objectives, knowledge production versus product development, both approaches share a commitment to collaborative engagement and responsiveness to the needs and preferences of the target group [40, 43]. When developing eHealth for people with ID or complex care and support needs, inclusive design enables access for a wider group by taking into account factors such as accessibility, usability, cognitive capacity, and digital and literacy skills. While the inclusive approach itself is widely transferable, the specific strategies and tools must always be adapted to the context in which they are applied. Its success relies not on rigid methods, but on genuine collaboration, flexibility, and a shared commitment to valuing all forms of knowledge.

In this thesis inclusive research and inclusive design reinforced each other, both shaping processes, tools, and knowledge *with*, rather than *about,* people with ID or complex care and support needs [23]. The level of co-researcher Anneke's involvement varied across studies, ranging from consultation and advising to active co-researching. This flexible and responsive approach ensured that her contributions were aligned with the nature of each study [24]. For example, in the development of interview guides (Chapter 4), her feedback led to the use of simpler language and more relatable examples. In Chapter 5, she emphasized the importance of visual information and helped refine visual elements in the co-design activities. These contributions helped ensure that the tools were better matched to the needs and preferences of the intended users.

Stakeholders from ID support organizations and people with ID or complex care and support needs were actively involved in all studies (Chapters 2-5). Their participation was facilitated through an advisory board composed of professionals with diverse backgrounds, including project managers, researchers in eHealth, MedTech experts, and specialists in custom gaming. These stakeholders provided critical input on research design, the development of interview and focus group guides, recruitment strategies, interpretation of findings, and dissemination activities [25]. Their involvement strengthened the connection between research and practice, ensuring that the studies remained grounded in practical relevance. The inclusive approach had broad and concrete impacts across stakeholder groups:

- *For people with ID*, participating in the research process fostered ownership, skill development (e.g., communication, reflection, digital engagement), and increased visibility as contributors to knowledge creation (Chapters 2-5).
- *For support professionals*, it led to a deeper understanding of how to apply inclusive (research and design) methods in practice, including how to collaborate meaningfully with people with ID or complex care and support needs (Chapters 3 and 5).
- *For researchers*, integrating experiential knowledge enriched the quality of analysis and led to more context-sensitive and usable findings (Chapters 2-5).
- *For the broader public and professionals,* accessible infographics and plain-language summaries facilitated knowledge transfer and increased awareness of inclusive practices (Chapters 2-5).

Personal reflections: working together in inclusive research and design

Working together was a continuous process throughout this project. Anneke contributed to all phases of the research process. To illustrate the practical implementation of inclusive research, I offer several examples from our shared journey, many of which are further elaborated in the easy-to-read thesis [26] that Anneke and I developed alongside this academic version. For example, in the scoping review (Chapter 2), we co-developed a poster to visualize the entire review process. While working on this poster, we realized that it was important for both of us to fully understand the topic. It's essential to communicate with each other and ensure that everyone shares the same understanding.

We therefore translated the theoretical frameworks into easy-to-understand versions (visualized on the infographic in Appendix I) to enable informed dialogue and shared decision-making. Anneke helped reflect on which concepts were understandable and relevant, shaping how we selected and interpreted the models. In the empirical studies, we collaborated on formulating accessible interview and focus group questions, testing them for clarity and tone. For instance, Anneke pointed out that certain terms were too abstract or difficult, encouraging us to rephrase them more conversationally.

Across all studies, we co-created accessible materials such as, summaries and infographics in Dutch (Appendix I), using Anneke's feedback to simplify language, adjust layout, and add visual supports such as icons and a consistent structure. To visualize and support our collaboration, we also developed research posters based on the research clock tool, which we updated weekly to reflect progress, responsibilities, and decisions. The research clock outlines all phases of the research process, from formulating questions to sharing results, and helped us decide together what each step would involve and how we would collaborate during that step. These tools supported transparency and shared ownership. While inclusion was not the explicit focus of each chapter, it was a consistent and embedded part of the research process.

Together we reflected on the entire trajectory and explored both our shared and differing perspectives. We found that inclusion became natural through routine and shared learning. Anneke described how she "gained confidence and saw her input valued". For me, the process taught the "importance of slowing down, ensuring accessibility of the research (materials) by preparing our sessions, and staying open to experiential input from Anneke". Applying inclusive research sometimes was a challenge, but the space to check in, clarify, and adjust made our collaboration stronger. We learned that inclusive research is not only about who is involved, but how we work together, with time, trust, and reflection. The reflective process helped us clarify our roles, values, and expectations as (co-)researchers. Ultimately, this collaboration showed that creating space for inclusion benefits both the participants and the research outcomes, fostering more relevant, impactful and practical research [27].

Collaborating in inclusive research throughout this project has deeply shaped both the research and my own perspective as a researcher. Anneke's experiential knowledge challenged me to reflect on my assumptions and to remain open and adaptive to ensure meaningful participation. For example when creating the questionnaires for Chapter 5, she suggested using pictograms to make response scales in the questionnaire more understandable. This helped me realize that accessibility is not just about language, but also about visual clarity and intuitive design. Working closely with Anneke taught me the value of shared decision-making, relationship-building, and trust, while also emphasizing that inclusive research requires time and space for stakeholders to influence key moments in the process [28]. For example, when planning the timeline for the 'Smart Diaper' study (Chapter 4), we adjusted the pace together to allow extra time for preparation and discussion, ensuring Anneke could meaningfully contribute to decisions about data collection and interpretation. More broadly, this collaboration made me aware of whose voices are heard in research and strengthened my commitment to equity and co-creation in future work. I have learned that meaningful inclusion requires conscious effort, openness to feedback, and a willingness to adjust not only methods but sometimes also the research questions themselves [29].

Methodological considerations

Methodological considerations were taken into account throughout this thesis to ensure its reliability and validity. This thesis followed real life development and implementation processes (Chapters 3-5). While research and evaluation were integrated into these projects, they were not always initially designed for this purpose, which in some cases limited availability and consistency of data. Future research could address this by employing more structured data collection and documentation strategies to improve transparency and support reproducibility. Data triangulation was applied by combining multiple methods and diverse data sources, thereby strengthening both the credibility and consistency of the findings [41]. The methods employed include a scoping review (Chapter 2), interviews and user tests with ID or low literacy (LL) skills (Chapter 3), interviews with project leaders and professional caregivers (Chapter 4), and interviews with questionnaires and focus groups with member from a transdisciplinary consortium and co-researchers with autism spectrum disorder or ID (Chapter 5). Moreover, this thesis adopts multi-method (Chapter 3) and mixed-method (Chapter 5) research designs, which offers distinct advantages in addressing complex, practice-oriented questions [30, 31]. By integrating qualitative and quantitative approaches, the thesis shows a more comprehensive understanding of the topics researched [32].

To broaden the scope and applicability of the findings, three case studies have been conducted, each representing different settings and contexts: 1) a user-sensitive inclusive research approach for developing an inclusive digital platform for people with ID or LL skills (Chapter 3), 2) focus on the implementation process of smart continence care for people with profound intellectual multiple disabilities in four care organizations (Chapter 4), and 3) the application of an inclusive design approach in a consortium with transdisciplinary partners for developing a sensitive virtual assistant for people in a vulnerable position with complex care and support needs (Chapter 5). At the case study level, methodological considerations include sample size and contextual specificity. The case studies were conducted within specific context with one online tool in each context and relatively small sample sizes, which may limit the diversity of the perspectives captured [33]. Therefore, future research could examine other and larger settings. While the findings may not be universally applicable, they offer valuable insights for similar settings and contribute to theory-building.

Special attention has been given to the inclusion of individuals with ID or complex care and support needs, next to working with a co-researcher, such as people with ASD or LL skills (Chapter 3 and 5). Engaging these groups meaningfully in design and research presents both methodological challenges and opportunities [34]. It requires adaptive strategies, accessible tools, and a reflexive stance from the researcher [23]. Their participation, however, enriches the design and research processes by introducing perspectives that are often overlooked in conventional studies [24, 34]. Inclusive working, however, goes beyond involving the target group alone. It also requires the active participation of key stakeholders, such as healthcare professionals, support staff, and technology developers, who influence or are influenced by the implementation of eHealth technologies (Chapters 2-5).

Implications and recommendations for future research and practice

This thesis highlights the value of inclusive, iterative, and transdisciplinary approaches in the design and implementation of eHealth technologies for people with ID. These approaches foster collaboration across experiential, professional, and academic domains. Future research can build on these foundations, not only by involving diverse stakeholders but also by embedding iterative and inclusive processes throughout all phases of eHealth research, design, and implementation.

From a practice perspective, adopting an inclusive approach enhances the usability, acceptance, and sustainability of eHealth technologies [35]. It supports professionals and organizations in aligning technology with the lived experiences and needs of people with ID or complex care and support needs. The integrated framework developed in this thesis not only serves as a guidance tool but can also be used to evaluate practical eHealth design and implementation across diverse contexts. However, further application, refinement, and contextual adaptation are needed to strengthen the practical utility of the integrated framework.

Based on the findings in this thesis, several concrete guidelines for inclusive co-creation in design and development can be given [36]:

1. Adapt sessions to fit participants' abilities and needs. Actively involving people with a mild intellectual disability (MID) requires thorough preparation with accessible materials and meetings. Make sure these methods and materials are well-structured and in easy-to-understand language. Naming, visuals, and text should be suitable, recognizable, understandable, and jargon-free, and should also refrain from underestimating or infantilizing individuals with MID: maintaining autonomy and dignity is key. Make sure to take enough (mini-)breaks to avoid cognitive overload.
2. Collaborate on a long-term basis, beyond single sessions. This builds rapport and fosters trust in the relationship. Create space to meaningfully shape the design process by making sure the settings are comfortable and safe. Especially in the early stages of the collaboration, the presence of trusted stakeholders is important (e.g., a family member or support worker), and getting to know each other.
3. Address power dynamics openly and discuss roles, decisional accountability, and shared decision making. Not just consult but show how input was used. Provide feedback, manage expectations through continuous reflections and planning.
4. Use methods that remain close to lived experience. For example, by using methods such as contextual interviews, observations with discussion, cognitive walkthroughs and think aloud sessions. To best reflect participants' daily realities and connect to their skills, co-creation activities can be situated within everyday contexts where the technology will ultimately be used.
5. Keep an eye on group dynamics, participants might get overwhelmed in larger groups or even in settings with more than one participant. Bringing a support worker of family member can help create a safe environment but could also influence their participation and answers. Therefore, make sure group settings fit participants' needs.
6. Involve the participant's network to better understand their daily context and to support research tasks that go beyond the capabilities of the target group. Not everything you will want to research, or each method you want to use, will be within the capabilities of persons with MID. In those cases, make sure to involve people from the person's own support network to reflect on the issues at hand.

Future research can address the long-term effects of inclusive eHealth trajectories. While this thesis focused primarily on design and early implementation, questions remain about how inclusive processes influence sustained use, empowerment, and outcomes in daily practice after implementation. Understanding these dynamics is essential for realizing the full potential of inclusive eHealth [37].

Conclusion

This thesis demonstrated that inclusive and iterative approaches are not optional, but essential for the successful design, implementation, and long-term sustainability of eHealth technologies for people with ID or complex care and support needs. By developing and applying the integrated framework, the research bridged theory and practice, offering a structured yet flexible approach to guide inclusive and iterative processes across diverse contexts. This thesis shows that inclusive and iterative approaches must remain central to any eHealth design and implementation process because no one size fits all approach exists. Together, these insights offer a strong foundation to center end users and their environments in every step of the eHealth journey.

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CHAPTER

7

SUMMARIES

NEDERLANDSE SAMENVATTING

De snelle digitalisering van de samenleving biedt kansen voor gepersonaliseerde en toegankelijke zorg, maar mensen met een verstandelijke beperking (VB) of complexe zorgvragen ondervinden vaak belemmeringen bij het gebruik van eHealth. Veel digitale zorgtoepassingen sluiten onvoldoende aan bij hun mogelijkheden en context, wat leidt tot een digitale kloof en ongelijke toegang tot zorg. Deze kloof kan verkleind worden door inclusieve benaderingen in het ontwerp en de implementatie van eHealth, waarbij mensen met VB en andere betrokkenen (zoals mantelzorgers, zorgprofessionals en IT-experts) actief worden betrokken. Dit proefschrift introduceert een geïntegreerd raamwerk gebaseerd op bestaande modellen (de The Center for eHealth Research and Disease Management (CeHRes) Roadmap en het Non-adoption, Abandonment, Scale-up, Spread, and Sustainability (NASSS) Framework), en past dit toe in verschillende settingen. Daarbij worden participatieve methoden zoals co-design en inclusief onderzoek ingezet, met als doel eHealth toepassingen beter te laten aansluiten bij de behoeften van mensen met VB of complexe zorgvragen. In alle fases van het onderzoek is structureel samengewerkt met een co-onderzoeker met een licht verstandelijke beperking (LVB). Dit proefschrift beoogt bruikbare inzichten te genereren voor de ontwikkeling van duurzame, toegankelijke en relevante eHealth voor mensen met een VB of complexe zorgvragen.

Hoofdstuk 2 richtte zich op het identificeren van inclusieve benaderingen voor het ontwerpen, ontwikkelen en implementeren van eHealth voor mensen met een VB. Aan de hand van een scoping review van wetenschappelijke en grijze literatuur werden 17 studies geanalyseerd. Uit deze studies zijn gegevens verzameld over onder meer methodologie, doelgroep, en het type eHealth-interventie. De betrokkenheid van eindgebruikers en andere stakeholders werd beoordeeld op basis van 9 domeinen uit de CeHRes Roadmap en het NASSS Framework. Hoewel er diverse inclusieve methoden werden toegepast, zoals user-centered en participatory design, richtte de meeste betrokkenheid zich op de ontwikkelingsfase. Stakeholders buiten de eindgebruikers werden minder gedetailleerd beschreven, en de implementatiefase kreeg beperkte aandacht. De literatuur richtte zich voornamelijk op individueel gebruik van technologie, met weinig aandacht voor organisatorische of sociale context, terwijl mensen met VB vaak afhankelijk zijn van hun omgeving. Meer nadruk op deze onderbelichte domeinen is essentieel om de kloof tussen technologische oplossingen en de daadwerkelijke behoeften van gebruikers te verkleinen.

In **Hoofdstuk 3** onderzochten we essentiële ontwerpelementen die de toegang tot en participatie in digitale platforms mogelijk maken voor mensen met een LVB of laaggeletterheid. Met een gebruikersgevoelige en inclusieve onderzoeksaanpak werd het digitale platform

'Ik co-onderzoek' herontworpen en getest met deelnemers uit de doelgroep. Kwalitatieve gegevens werden verzameld via semigestructureerde interviews en gebruikerstests. Naast algemene ontwerpprincipes zoals duidelijkheid, leesbaarheid en intuïtief gebruik, werden specifieke elementen geïdentificeerd die inclusie bevorderen. Belangrijke aspecten waren het gebruik van herkenbare en cultureel passende visuele elementen, begrijpelijke benaming van functies om vindbaarheid te vergroten, en een toegankelijke onboarding. Ook werden functies als voorlees- en meeleesopties gewaardeerd als onderdeel van een intuïtieve navigatie. Concluderend maakte de inclusieve onderzoeksaanpak het mogelijk om ontwerpkenmerken te identificeren die van specifiek belang zijn voor mensen met LVB of laaggeletterheid. Door deze elementen te integreren in digitale platforms kan inclusie en deelname aan digitaal onderzoek aanzienlijk worden vergroot.

De implementatie van slimme incontinentiezorg (SCC) voor mensen met een ernstig verstandelijke en meervoudige beperking (EVMB) onderzochten we in **Hoofdstuk 4**. Daarbij brachten we de belangrijkste succesfactoren in kaart binnen zorgorganisaties. SCC geeft zorgverleners een seintje wanneer incontinentiemateriaal moet worden verschoond, wat de levenskwaliteit van cliënten kan verbeteren en de werkdruk van zorgverleners kan verlagen. Ondanks deze potentie blijkt effectieve implementatie in complexe zorgomgevingen een uitdaging. Er werden vijftien semigestructureerde interviews afgenomen met sleutelpersonen, zorgverleners en projectleiders van SCC binnen vier zorgorganisaties. De interviews waren gebaseerd op het CeHRes Roadmap en het NASSS Framework voor eHealth-implementatie. Thematische analyse bracht vier hoofdthema's aan het licht: draagvlak creëren, communicatie tussen betrokkenen, probleemoplossend vermogen en bereidheid tot acceptatie van SCC. Draagvlak, communicatie en probleemoplossing werden gezien als bevorderende factoren voor succesvolle implementatie. De bereidheid om SCC te omarmen werd beïnvloed door de waargenomen meerwaarde en praktische haalbaarheid. Vroege betrokkenheid van sleutelpersonen en heldere communicatie over hun rolverwachtingen bleken essentieel om draagvlak te creëren. Effectief problemen oplossen droeg bij aan persoonsgerichte zorg en vergrootte de acceptatie. Concluderend vereist de implementatie van SCC aanpassingen in dagelijkse werkroutines. Vroege betrokkenheid van stakeholders en goede communicatie zijn daarbij cruciaal. Deze studie biedt waardevolle inzichten voor de toepassing van soortgelijke technologieën in andere complexe zorgomgevingen.

Hoofdstuk 5 beschrijft het inclusieve ontwerpproces van een Sensitieve Virtuele Assistent (SVA) voor mensen met complexe zorgbehoeften, ontwikkeld binnen een transdisciplinair consortium. Door co-onderzoekers met een LVB of autismespectrumstoornis (ASS) actief te betrekken, werd gestreefd naar een toegankelijke en betekenisvolle digitale zorgoplossing. Het project volgde een iteratief design thinking proces in vijf fasen, waarbij na elke fase kwalitatieve interviews en groepsgesprekken plaatsvonden. De analyse leverde drie hoofdthema's op: projectaanpak, samenwerkingsdynamiek en co-design in de praktijk. De resultaten tonen aan dat gestructureerde voorbereiding, heldere rolverdeling, toegankelijke materialen en voortdurende feedback cruciaal waren voor inclusieve samenwerking. Co-onderzoekers leverden steeds meer inhoudelijke bijdragen, wat leidde tot een gevoel van eigenaarschap en invloed op zowel proces als inhoud. De studie benadrukt de spanningen tussen projectefficiëntie en inclusie, en het belang van flexibiliteit, coördinatie en voortdurende evaluatie. Deze aanpak biedt waardevolle inzichten voor het ontwerpen van technologie die aansluit bij de leefwereld van mensen met LVB of ASS.

In **hoofdstuk 6** is besproken hoe deze thesis bijdraagt aan het versterken van inclusieve en iteratieve ontwerp- en implementatieprocessen voor eHealth, specifiek gericht op mensen met een VB of complexe zorg- en ondersteuningsbehoeften. Door het integreren van de CeHRes Roadmap en het NASSS Framework is een nieuw geïntegreerd raamwerk ontwikkeld dat zowel gebruiksgericht ontwerpen als systeemniveau-implementatie ondersteunt. Dit raamwerk werd toegepast in meerdere casestudies, wat de praktische bruikbaarheid aantoonde voor co-creatie en duurzame implementatie. De bevindingen onderstrepen het belang van doorlopende samenwerking met eindgebruikers en stakeholders gedurende het hele traject, niet alleen in de ontwerpfase maar juist ook tijdens implementatie in de praktijk. Deze thesis gaat verder dan het concept 'bruikbaarheid' door structurele inbedding van toegankelijkheid, contextsensitiviteit en inclusieve betrokkenheid te laten zien. Werken met een co-onderzoeker met ervaringsdeskundigheid bleek hierin van grote meerwaarde. Concrete ontwerp- en implementatierichtlijnen zijn geformuleerd, en de resultaten tonen aan dat inclusieve en iteratieve benaderingen niet optioneel zijn, maar essentieel voor succesvolle eHealth. Het geïntegreerde raamwerk biedt hierbij een waardevol praktisch hulpmiddel.

ENGLISH SUMMARY

The rapid digitalization of society creates opportunities for accessible and personalized healthcare. However, people with intellectual disabilities (ID) or complex care and support needs often face barriers when using eHealth, due to a lack of fit with their abilities and daily context. This contributes to a growing digital divide. Inclusive approaches to the design and implementation of eHealth, such as co-design and participatory research, can help ensure these tools are accessible and relevant. This dissertation introduces an integrated framework based on he Center for eHealth Research and Disease Management (CeHRes) Roadmap and the Non-adoption, Abandonment, Scale-up, Spread, and Sustainability (NASSS) Framework, applied across various real-world cases. The research involved structural collaboration with a co-researcher with a mild ID. Stakeholders from care organizations were actively engaged throughout all phases. The goal of this work is to strengthen inclusive research and design methods and to generate actionable insights for creating sustainable, user-centered eHealth for people with ID or complex care needs.

In **Chapter 2** we aimed to identify the inclusive approaches currently used for the design, development and implementation of eHealth for people with ID. With a scoping review, we included both scientific and gray literature through systematic searches, with 17 studies included in the final sample and analyzed. Key information was extracted, including methodology, target population, and type of eHealth intervention. User involvement was examined across nine domains derived from the CeHRes roadmap and NASSS framework. While various inclusive approaches, such as user-centered and participatory design, were identified, most focused on the development phase. The role of stakeholders beyond end users was less clearly described, and the implementation phase was largely overlooked. The literature primarily addressed individual-level use of eHealth technologies, with limited attention to the broader organizational or social context, despite the reliance of people with ID on their environment for care and support. Greater focus on these underrepresented areas and inclusion of key stakeholders throughout the process is needed to bridge the gap between developed technologies and real-world user needs and contexts.

In **Chapter 3** we explored essential design features that support access and participation in digital platforms for individuals with mild intellectual disabilities (MID) or low literacy (LL) skills. Using a user-sensitive inclusive research approach, the digital platform ‘I co-research’ was re-designed and tested with participants from the target group. Qualitative data were collected through semi-structured interviews and usability testing. In addition to general design principles such as clarity, readability, and intuitive use, the findings highlighted key elements that enhance inclusivity. These include the use of recognizable and culturally reflective visuals, clearly named platform features to improve findability, and accessible onboarding. Features like read-aloud and read-along options also proved valuable for intuitive navigation. In conclusion, applying an inclusive research approach enabled the identification of specific design features crucial for improving accessibility and usability for individuals with MID or LL. Integrating these elements into digital platforms can foster greater inclusion and participation in digital research.

Within **Chapter 4** we examined the implementation of smart continence care (SCC) for individuals with profound intellectual and multiple disabilities (PIMD), highlighting key factors that influence success in care organizations. SCC notifies caregivers when continence materials need to be changed, potentially improving quality of life for clients and reducing caregiver workload. Despite its promise, effective implementation in complex care environments remains a challenge. Fifteen semi-structured interviews were conducted with stakeholders, caregivers, and SCC project leaders across four organizations. The interview framework was based on the CeHRes roadmap and NASSS framework for eHealth implementation. Thematic analysis revealed four key themes: creating support, stakeholder communication, problem-solving, and willingness to adopt SCC. Creating support, communication, and problem-solving were viewed as enablers of successful implementation, while willingness to adopt SCC was influenced by perceptions of added value and feasibility. Early involvement of stakeholders and clear role expectations were critical in building support. Effective problem-solving contributed to more person-centred care and increased acceptance. In conclusion, SCC implementation requires adjustments to daily care routines. Early stakeholder engagement and strong communication are essential to support these changes. The study provides valuable insights for implementing similar technologies in other complex care contexts.

Chapter 5 describes the inclusive design process of a Sensitive Virtual Assistant (SVA) for people with complex care needs, developed by a transdisciplinary consortium. By actively involving co-researchers with MID or autism spectrum disorder (ASD), the aim was to create a digital health tool that is both accessible and meaningful. The project followed an iterative design thinking process over five phases, with reflections gathered through interviews and group discussions after each phase. Thematic analysis revealed three main themes: project approach, collaborative dynamics, and co-design in practice. Key enablers of inclusive collaboration were thorough preparation, clear roles, accessible materials, and continuous feedback. Over time, co-researchers became more influential in shaping both the process and the content, leading to a sense of ownership. The study highlights the tension between project efficiency and meaningful inclusion, and the need for flexibility, coordination, and ongoing evaluation. These findings offer practical insights into developing inclusive technology for people with MID or ASD.

Chapter 6 reflected on how the thesis contributes to strengthening inclusive and iterative eHealth design and implementation processes for people with ID or complex care and support needs. By integrating the CeHRes Roadmap and the NASSS Framework, a new combined framework was developed that supports both user-centered and system-level perspectives. It was successfully applied in multiple case studies, demonstrating its practical utility for co-creation and sustainable implementation. Findings highlight the importance of ongoing collaboration with end users and key stakeholders across all phases, not just during initial design but also during real-life implementation. This thesis moves beyond 'usability' by showing deeply embedded accessibility, context sensitivity, and inclusive engagement. The involvement of a co-researcher with lived experience proved particularly valuable. Concrete guidelines for inclusive design and implementation were established. Ultimately, this thesis shows that inclusive and iterative approaches are not optional but essential for the success and sustainability of eHealth innovations. The integrated framework offers a useful tool for both research and practice.

CHAPTER

8

DATA MANAGEMENT STATEMENT

DATA MANAGEMENT STATEMENT

Ethics and privacy

This thesis is based on the results of research involving human participants (or existing data from published papers), which were conducted in accordance with relevant national and international legislation and regulations, guidelines, codes of conduct and Radboudumc policy. Statements that the studies in **Chapter 3 and 5** were not subject to the Dutch Medical Research Involving Human Subjects Act (niet-WMO), were obtained from the recognized Medical Ethics Review Committee 'METC Oost-Nederland'; **Chapter 3** re-design process of 'I co-research' (2020- 6541) and implementation of the COVID-19 monitor (2020-7033), and **Chapter 5** evaluation of the design process of the sensitive virtual assistant (2023-16400). The recognized Medical Ethics Review Committee 'METC Oost-Nederland' has given approval to conduct the study in **Chapter 4** about the experiences of the implementation of smart continence care (file number: NL72751.091.20).

The privacy of the participants in these studies was warranted by the use of pseudonymization. The pseudonymization key was stored separately from the research data on a secured network drive that was only accessible to members of the project who needed access to it because of their role within the project. Informed consent was obtained from participants to collect and process their data for this research project. The sensitivity and confidentiality of the raw qualitative data (i.e. interviews, focus groups and usability tests) makes sharing of the data without compromising confidentiality and privacy impossible, therefore consent for sharing of the raw data was not asked from the participants.

Data collection and storage

Data from **Chapter 2** was collected by literature reviews. The data from **Chapter 3** was collected through interviews and usability tests. Data from **Chapter 4** was collected by performing interviews. The data for **Chapter 5** was collected through interviews with questionnaires and group discussions. Data from Chapter 2 to 5 were stored and analysed on the department server and were only accessible by project members working at the Radboudumc. After publication, the data from **Chapter 4** was transferred to the internal storage - of the University of Tilburg Tranzo for archiving. These secure storage options safeguard the availability, integrity and confidentiality of the data.

Data sharing according to the FAIR principles

All studies will be, if not already, published open access. The processed data and documentation (codebook, interview guides and readme file) of **Chapter 3** is published in a Data Sharing Collection (DSC) in the RDR under the CC0-1.0 license. The same is done for **Chapter 5** upon final publication. were made reusable by adding sufficient documentation (codebook, interview guides and a readme file), by using preferred and sustainable data formats and by publishing under the CC-BY-NC-4.0 license. The raw data underlying **Chapter 3 and 5** are not suitable for reuse because of the sensitivity and confidentiality of the data, Table 8.1 shows were the DSC of the chapters are archived and published on the RDR. They will be archived with closed access in DACs of the Radboud Data Repository. The data used for **Chapter 4** are not owned by Radboudumc. The data are archived by University of Tilburg Tranzo. Questions about the data can be addressed to vivette.vancooten@academyhetdorp.nl.

Table 8.1 Findability of the data and research documentation for each chapter of this thesis in the Radboud Data Repository.

Chapter	DSC	DSC License
3	DOI: https://doi.org/10.34973/nw4q-5677	CC0-1.0
4	Not applicable	
5	DOI: https://doi.org/10.34973/sn8t-gr11	CC-BY-NC-4.01

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1. Wilkinson, M.D., et al., The FAIR Guiding Principles for scientific data management and stewardship. Scientific Data, 2016. **3**(1): p. 160018.

CHAPTER

9

DANKWOORD

DANKWOORD

Het is zover: het laatste hoofdstuk dat ik schrijf voor mijn proefschrift. Ik kijk terug op een bijzondere periode vol onderzoek, schrijven en waardevolle samenwerkingen. Daarom wil ik graag de mensen bedanken die mij tijdens dit traject hebben gesteund, geïnspireerd en aangemoedigd!

Allereerst wil ik **Anneke** bedanken, co-onderzoeker, sparringpartner en grote steun tijdens mijn promotie. Wat hebben we een bijzondere samenwerking gehad! Je betrokkenheid, bijdragen en warme persoonlijkheid waren van grote betekenis. Ze hebben het onderzoek niet alleen inhoudelijk versterkt, maar ook veel plezier gebracht. Gelukkig mogen we onze samenwerking nog voortzetten om onze lessen uit te werken en te delen met andere onderzoekers en geïnteresseerden. Ik hoop dat dit ook anderen zal inspireren om inclusief onderzoek toe te passen.

Ook mijn promotieteam - Kris, Jenneken en Geraline - ben ik zeer dankbaar voor hun begeleiding.

Kris: jouw dagelijkse sturing, scherpe vragen en analytische blik hebben mijn kennis en vaardigheden verdiept. Je gaf me vertrouwen om dit traject tot een goed einde te brengen. Wat fijn dat we onze samenwerking hebben kunnen voortzetten in de RAPIDE en Menofood projecten.

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Geraline: bedankt voor je scherpe inhoudelijke adviezen en de fijne gesprekken. Je bracht steeds weer een nieuwe invalshoek, positieve motivatie, en hielp me om overzicht en vertrouwen te houden.

Een woord van dank aan de **leden van de manuscriptcommissie**: Prof. Dr. Maroeska Rovers, Prof. Dr. Petri Embregts en Prof. Dr. Philip van der Wees, en de leden van de **oppositie**: Prof. Dr. Paula Sterkenburg en Dr. Marjolein Herps, dank voor jullie investering in dit proefschrift en bijdrage tijdens de verdediging.

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Lieve **Amina, Masha & Meike**, dank jullie wel dat jullie mijn paranimfen wilden zijn. Jullie zorgzaamheid, mentale support, onze "Help Julia promoveren" overleggen en Chai Latte momentjes waren van grote waarde tijdens dit traject!

Aan mijn vriendinnen en vrienden van **Bobba you**: dank jullie wel voor jullie steun en luisterende oor. Wat bof ik met zulke lieve vrienden, jullie mogen me nu echt Dr. Julia noemen ;). In het bijzonder wil ik graag mijn lieve vriendinnen **Estelle, Rianne, Femke, Jori & Mirte** bedanken voor de fijne gesprekken en afleiding, wat fijn dat ik altijd bij jullie terechtkan. Ook een woord van dank aan **Peut zaterdag** voor de gezellige momenten. **Sophie & Wendy,** dank voor jullie hulp bij het ontwerp van dit boekje, wat is het tof geworden! Lieve **Aafke, Marlous, Evie en Eclaire**, de Master Health Sciences Chicks, hoe bijzonder dat we tijdens onze mastertijd in Enschede zo'n fijne vriendschap op hebben kunnen bouwen en bedankt voor jullie steun!

Ook buiten de academische bubbel vond ik rust en plezier bij de **waterpoloteams** waar ik speelde en coachte (speciale vermelding voor **Linda & Maaike**, jullie zijn toppers!), met mijn **personal trainer Maikel**, bij het padellen, en bij het koken met de **dames van De Wik**. Dank voor het lachen, het zweten, het koken en het delen - het gaf me balans, energie en bovenal even afleiding van het werk.

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CHAPTER

10

ABOUT THE AUTHOR

CURRICULUM VITAE

Julia van Calis is geboren op 15 januari 1997 te Geldrop. Na het behalen van haar HAVO-diploma aan het Peellandcollege in Deurne, startte ze de bacheloropleiding Gezondheidszorgtechnologie aan Avans Hogeschool in Tilburg/Breda. Tijdens deze studie volgde ze met succes de pre-master Health Sciences aan de Universiteit Twente, waardoor ze aansluitend de masteropleiding Health Sciences kon volgen. Binnen deze master specialiseerde ze zich in het onderzoeken, ontwikkelen, implementeren en evalueren van eHealth-toepassingen. In haar masterthesis onderzocht ze het design en de implementatie van een Virtual Reality applicatie voor in de behandeling van de forensische GGZ. Na haar afstuderen in september 2020 startte Julia haar promotietraject aan de afdeling Eerstelijnsgeneeskunde van het Radboudumc, binnen de academische werkplaats Sterker op Eigen Benen. Naast haar wetenschappelijke werkzaamheden nam ze gedurende de eerste jaren van haar promotie ook de praktische en coördinerende ondersteuning van co-onderzoeker Anneke op zich. In oktober 2025 heeft Julia haar proefschrift afgerond. Sinds mei 2025 is ze werkzaam bij het Radboudumc als postdoctoraal onderzoeker en projectleider op de RAPIDE en Menofood projecten. Daarnaast blijft ze actief betrokken bij inclusief onderzoek binnen de academische werkplaats. Julia woont in Deurne.

Julia van Calis was born on January 15, 1997 in Geldrop, The Netherlands. After completing her secondary education at the Peellandcollege in Deurne, she started the Bachelor's program in Healthcare Technology at Avans University of Applied Sciences in Tilburg/Breda. During this program, she successfully completed the pre-Master's in Health Sciences at the University of Twente, which enabled her to directly enroll in the Master's program in Health Sciences. Within this Master's, she specialized in the research, development, implementation, and evaluation of eHealth applications. For her Master's thesis, she studied the design and implementation of a Virtual Reality application for use in forensic mental healthcare. After graduating in September 2020, Julia began her PhD trajectory at the Department of Primary and Community Care at Radboudumc, within the academic collaborative collaborative Sterker op Eigen Benen. In addition to her research work, she also took on practical and coordinating responsibilities in support of co-researcher Anneke during the early years of her PhD. In October 2025, Julia completed her doctoral thesis. She has been working at Radboudumc as a postdoctoral researcher and project leader on the RAPIDE and Menofood projects since May 2025. She also remains actively involved in inclusive research within the academic collaborative. Julia lives in Deurne.

PHD PORTFOLIO OF JULIA VAN CALIS

Department: **Primary and Community Care**
PhD period: **19/10/2020 – 21/10/2025**
PhD Supervisor(s): **Prof. G. L. Leusink**
PhD Co-supervisor(s): **Dr. J. Naaldenberg & Dr. K. E. Bevelander**

Training activities	Hours
Courses	
- Pubmed (2020)	2.80
- Endnote (2020)	2.80
- Introductiecursus Kwalitatief Onderzoek in de Gezondheidszorg (2021)	28.00
- RIHS - Introduction course for PhD candidates (2021)	15.00
- RIHS PhD introduction course (2021)	21.00
- EBROK (2021)	42.00
- Projectmanagement for PhD candidates (2021)	56.00
- RU - Open Science for PhD candidates (2022)	28.00
- Radboudumc - Scientific integrity (2022)	20.00
- RU - Writing Scientific Articles (2022)	96.00
- The Art of Finishing Up (2024)	10.00
- Career development for PhDs (2024)	14.00
- Radboud Data Repository - Archiving & Publishing (2025)	1.50
- Active Bystander training (2025)	3.00
Seminars	
- IASSIDD Technology and Disability Affinity group (2022)	2.00
- Meet the Expert - How to prepare for you PhD defense (2024)	1.50
- Meet the Expert – Career perspectives (2025)	1.00
Conferences	
- Webinar: Innovatie en slimme zorg (2020)	2.80
- Webinar: Online recruitment of study participants (2020)	2.80
- Citizen Science Conference (oral presentation) (2020)	2.80
- Special Olympics 2020 (2020)	2.80
- Volwaardig leven 2020 (2020)	2.80
- Webinar: Zo ontwikkel je succesvol technologieën voor de zorg (2021)	2.80
- Webinar: Een wereld te winnen in persoonlijke digitale zorg (2021)	2.80
- Etmaal van de Communicatiewetenschap 2021 (oral presentation) (2021)	19.70
- Webinar: Implementatie van de Feelix app (2021)	2.80
- Health by Tech Conference (poster presentation) (2021)	14.00
- European Citizen Science Association Conference (poster and oral presentation) (2022)	28.00

- Conversations 2022 Conference (2022)	2.00
- Etmaal van de communicatiewetenschap (oral presentations) (2023)	28.00
- Health by Tech Conference (oral presentation) (2022)	14.00
- CaRe days 2023 (2023)	28.00
- Focus op Onderzoek 2023 (oral presentation) (2023)	14.00
- Citizen Science 4 Health (poster and oral presentation) (2023)	14.00
- Health Valley (2024)	5.00
- Researchdag AAWBV - passende zorg (2024)	5.00
- Heerlijk Duidelijkdag (2024)	4.00
- IASSIDD World Conference Chicago (poster and oral presentation) (2024)	28.00
- Congres: 'Inzicht door data, zorg met impact. Gelijkwaardige zorg voor mensen met een verstandelijke beperking.' (2025)	5.00
- Congres ELG Verbind (2025)	5.00
- CaRe Days 2025 (2025)	28.00
Other	
- PhD Retreat 1.0 (2021)	14.00
- PhD Retreat 2.0 (2022)	28.00
- Research Integrity Round 20 (2024)	1.50
- Qualitative research workshop about analysis/coding (2024)	1.50
- DMP Training (2024)	1.00
- Research Integrity Round 11 December 2024 (2024)	1.50
- Webinar Betekenisvol participeren, wat betekent dit voor wie? (2025)	1.00
- Webinar: Hoe kan jij meer impact maken met een gezondheidsaanpak? (2025)	1.00
Teaching activities	
Lecturing	
- Minor ELG: Practicum communication with people with ID (2023)	4.00
- Minor Psychiatry: Communication training (2023)	4.00
- Summer school Equity in Health: Consultation with inclusive researchers (2023)	4.00
Supervision of internships / other	
- Supervision Master thesis student Health Sciences (University of Twente) (Feb-Aug 2022)	56.00
Total	**696.0**

LIST OF PUBLICATIONS

Peer-reviewed:

van Calis, J. F. E., Bevelander, K. E., Cruijsen, A. W. C., Leusink, G. L. & Naaldenberg, J. (2023). Toward Inclusive Approaches in the Design, Development, and Implementation of eHealth: a Scoping Review into the Intellectual Disability Sector. *Journal of Medical Internet Research. 2025;25. doi:10.2196/45819*.

van Calis J. F. E., van Cooten V. J. C., Smeets O, Naaldenberg, J. Leusink, G. L. & Bevelander, K. E. (2024). The implementation of smart continence care for people with disabilities: A qualitative study of key stakeholders' first-hand experiences. *DIGITAL HEALTH. 2024;10. doi:10.1177/20552076241290399*

van Calis J. F. E., Naaldenberg, J., van der Cruijsen, A. W. C., Koks-Leensen, M. C. J., Leusink, G. L. & Bevelander, K. E. (2025). Inclusive digital platforms: Designing for and with users with mild intellectual disabilities or low literacy skills. *Computers in Human Behavior Reports. 2025;03. doi:10.1016/j.chbr.2025.100617*

Hermsen, S., **van Calis, J. F. E.,** & Bevelander, K. E. (2025) Inclusive design, co-creation and evaluation of digital health for individuals with a mild intellectual disability. Positioning paper workshop Design With Or Design By, 19th EAI International Conference on Pervasive Computing Technologies for Healthcare 2025.

van Heijster, H., **van Calis, J. F. E.**, Liebrecht, C., Bol, N., Antheunis, M., Muller, M., Cruijsen, A. W. C., Tromp, E. & Bevelander, K. E. (2026). The taxonomy of human goals in technology development: supporting needs of long-term care recipients and their caregivers in finding and accessing appropriate care. *10.21203/rs.3.rs-4755152/v1*.

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Published conference abstracts:

<u>IASSIDD 6th Europe Conference (2021)</u>

van Calis, J. F. E., Bevelander, K. E., Naaldenberg, J. & Leusink, G. L. (2021). Integrated framework for developing, implementing and evaluating eHealth for people with ID. *Journal of Applied Research in Intellectual Disabilities, Special Issue: Proceedings of the 6th IASSIDD Europe Congress: Value Diversity. 34(5), 1298. doi:/10.1111/jar.12917*

Bevelander, K. E., Borremans, M., **van Calis, J. F. E**. & Leusink, G. L. (2021). The value of inclusive design in eHealth development for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, Special Issue: Proceedings of the 6th IASSIDD Europe Congress: Value Diversity. 34(5), 1298. doi:10.1111/jar.12917*

CONVERSATIONS (2022)

van Heijster, H., Liebrecht, C., Bol, N., **van Calis, J. F. E.**, van der Cruijsen, A. W. C., Dijkgraaf, M., Feitz, W., Muller, M., Tromp, E., Bevelander, K. E., & Antheunis, M. (2022). Inclusive design of a sensitive virtual assistant to support people in vulnerable positions in their access to care. *In CONVERSATIONS 2022: the 6th International Workshop on Chatbot Research, Applications and Design (pp. 1-6).*

IASSIDD 17th World Conference (2024)

van Calis, J. F. E., van Cooten, V. J. C., Smeets, O., Naaldenberg, J., Leusink, G. L., Bevelander, K. E. & Boon, B. (2024). The implementation of smart continence care for people with disabilities: key stakeholders' first-hand experiences. *Journal of Intellectual Disability Research, 68(7), 791. doi:10.1111/jir.13166*

van Calis, J. F. E. & Bevelander, K. E. (2024). The accessibility of digital health for people with mild intellectual disability. *Journal of Intellectual Disability Research, 68(7), 817. doi:10.1111/jir.13166*

van Calis J. F. E., Naaldenberg, J., van der Cruijsen, A. W. C., Koks-Leensen, M. C. J., Leusink, G. L. & Bevelander, K. E. (2024). The inclusive re-design of a digital research platform for people with mild intellectual disabilities. *Journal of Intellectual Disability Research, 68(7), 817. doi:10.1111/jir.13166*

Bevelander, K. E., van der Cruijsen, A. W. C., Zhu, A., Krijgsman, S., van Geenen, J., Thoonen, J., **van Calis, J. F. E**., Theunissen, M., Berends, J. & Koks-Leens, M. C. J. (2024). Experiences of co-researchers in inclusive research collaborations. *Journal of Intellectual Disability Research, 68(7), 832. doi:10.1111/jir.13166*

Bevelander, K. E., van der Cruijsen, A. W. C., Zhu, A., Krijgsman, S., van Geenen, J., Thoonen, J., **van Calis, J. F. E.**, Theunissen, M., Berends, J. & Koks-Leens, M. C. J. (2024). Experiences of co-researchers in inclusive research collaborations. *Journal of Intellectual Disability Research, 68(7), 841. doi:10.1111/jir.13166*

APPENDIX I. INFOGRAPHICS EN SAMENWERKINGSSTAPPEN PER HOOFDSTUK

Inclusieve ontwikkeling en implementatie van eHealth voor mensen met een verstandelijke beperking

Julia van Calis (1,2) , Kris Bevelander (1,2), Anneke van der Cruijsen (1,2), Geraline Leusink (1,2) & Jenneken Naaldenberg (1,2).
1. Radboudumc, Eerstelijnsgeneeskunde, Nijmegen, Nederland
2. Academische werkplaats Sterker op Eigen Benen (SOEB), Nijmegen, Nederland

1 Waarom dit onderzoek?

Het gebruik van eHealth is uitdagender voor mensen met een verstandelijke beperking (VB) omdat de technologieën vaak niet aansluiten bij de complexe behoeften en leefomstandigheden. Ondanks dat er verschillende aanpakken bestaand om gebruikers te betrekken bij het ontwerpen en implementeren (in de praktijk gebruiken) van eHealth wordt hier nog maar weinig over geschreven.

Doel: We wilden erachter komen met wie, op welke manier en wanneer er wordt samengewerkt tijdens het maken en in gebruik nemen van digitale zorg voor mensen met een VB.

2 Wat hebben we gedaan?

We hebben een plan gemaakt om te zoeken naar alles wat er is geschreven over het onderwerp.
Ook hebben we een plan gemaakt om weten hoe we moeten kijken naar wat er geschreven is.
We hebben 17 artikelen gelezen over hoe andere onderzoekers eHealth voor mensen met VB ontwikkeld en in de praktijk gebracht hebben.
We hebben in deze artikelen naar deze 9 onderdelen gekeken:

Samenwerken aan het maken van de digitale zorg
Telkens tussendoor beoordelen
De wensen van de eindgebruiker in kaart brengen
Bedenken waar de digitale zorg zou kunnen helpen
De digitale zorg ontwerpen
De organisatie waar de gebruiker woont
De omgeving (woonplek, dagelijkse begeleiding, etc.) van de eindgebruiker
De technologie in de praktijk brengen en in gebruik nemen
De kosten en voordelen in kaart brengen

3 Wat hebben we gevonden?

Wat ging al goed?
- Veel samenwerrking tijdens het bedenken en ontwerpen
- Samen testen met eindgebruiker
- Aandacht voor telkens tussendoor beoordelen

Wat kan er beter in de toekomst?
- Meer betrokkenheid van eindgebruikers bij het in de praktijk brengen
- Vaker mensen uit de omgeving van de eindgebruiker betrekken
- Meenemen van de organisatie waar de eindgebruiker woont

4 Wat kunnen we hiermee?

Door met deze punten in de toekomst rekening te houden kan ervoor gezorgd worden dat eHealth voor mensen met een VB beter past bij hun behoeften en leefomgeving.
Hierdoor kan deze doelgroep ook de voordelen van eHealth ervaren.

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Samenwerkingsstappen van hoofdstuk 2

Stap 1: Stappenplannen bekijken

We zijn het onderzoek begonnen met samen naar de twee bestaande stappenplannen te kijken.
Hierdoor kwamen we er al snel achter dat deze niet begrijpelijk waren.
Waardoor de co-onderzoeker en de onderzoeker ze nog niet konden gebruiken voor het onderzoek.
We besloten om de twee stappenplannen samen eerst te vertalen.

Stap 2: Stappenplannen vertalen

We zijn met het stappenplan *de CeHRes Roadmap* begonnen.
Eerst hebben we dit vertaald naar het Nederlands.
En toen zijn we gaan kijken naar hoe we de inhoud begrijpelijker konden maken.
Dit deden we door lange zinnen op te knippen en moeilijke woorden aan te passen.
Zie figuur 1 voor het vertaalde stappenplan.
Daarna hebben we *het NASSS Framework* vertaald, deze was wat lastiger.
Daarom hebben we hiervoor de hulpmiddel in de vorm van een vragenlijst gebruikt die al was ontwikkeld.
Dit hebben we ook eerst naar het Nederlands vertaald en toen de lange zinnen en moeilijke woorden aangepast.
Daarnaast hebben we ook de picto's en kleuren veranderd.
Zie figuur 2 voor deze uitwerking.

Stap 3: Samenvoegen van de vertaalde stappenplannen

Omdat we graag beide stappenplannen wilde gebruiken in het onderzoek, zijn we deze gaan samenvoegen.
We hebben daarvoor de vertaalde stappenplannen naast elkaar gelegd.
En toen hebben we gekeken waar de overlap zat en hoe we de informatie die wij nodig hadden voor het onderzoek het beste konden beschrijven.
Deze informatie hebben wij gebruikt om één stappenplan te maken.
Hier zijn 9 domeinen uitgekomen. Deze domeinen vind je in figuur 3.
Domeinen zijn onderwerpen die iets zeggen over de informatie die in het stappenplan staan.

Stap 4: Plan maken voor het onderzoeken van de stukken tekst

Daarna zijn we gaan bespreken wat we uit de stukken tekst wilde halen.
Dit hebben we een onderzoek document gezet samen met de domeinen uit ons stappenplan.

Stap 5-8: Stukken tekst zoeken

Julia is daarna aan de slag gegaan met het zoeken naar de stukken tekst.
Daarnaast heeft ze in de stukken tekst die ze heeft gevonden gekozen welke stukjes tekst geschikt waren voor ons onderzoek.
Uit de gekozen stukken tekst heeft ze met behulp van het onderzoek document informatie gehaald die bruikbaar is om de onderzoeksvraag te beantwoorden.
Deze informatie heeft ze samengevat en vertaald naar het Nederlands en begrijpelijke taal.

Stap 9: Samen kijken naar de samenvatting van de stukken tekst

Samen hebben wij naar deze samenvattingen in begrijpelijke taal gekeken.
Hier hebben we uitgehaald wat opviel en wat we dachten dat belangrijk was om meenemen in het onderzoek.

Stap 10: Onderzoeken van de opgehaalde informatie

Daarna hebben we samen bedacht waar de informatie past.
Wat we ervan vonden.
En wat we konden gebruiken om de onderzoeksvraag te beantwoorden.

Stap 11: Uitwerken van de resultaten en discussie

Hierna heeft Julia de resultaten uitgewerkt.
En hebben we dit besproken voor de conclusie en discussie van het onderzoek artikel.

Stap 12: Begrijpelijk lezen samenvatting en poster maken van het onderzoek

Als laatste hebben we deze begrijpelijk lezen samenvatting van het onderzoek geschreven.
Deze samenvatting hebben we ook nog vertaald naar een begrijpelijk lezen poster.

Inclusieve digitale platformen voor iedereen

Interviews en gebruikerstesten met mensen met een licht verstandelijke beperking (LVB) of laaggeletterdheid

Julia van Calis[1,2], Jenneken Naaldenberg[1,2], Anneke van der Cruijsen[1,2], Monique Koks-Leensen[1,2], Geraline Leusink[1,2] & Kris Bevelander[1,2]
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2. Academische werkplaats Sterker op Eigen Benen (SOEB), Nijmegen Nederland

1. Waarom dit onderzoek?

- Er bestaan verschillende richtlijnen om de toegankelijkheid van informatie en technologie te verbeteren.
- Er is alleen nog weinig bekend over wat passend is uit deze richtlijnen voor mensen met LVB of laaggeletterdheid bij deelname aan onderzoek.
- Daarom doen mensen met LVB of laaggeletterdheid vaak niet mee.
- Er zijn wel methoden om deze mensen toch mee te laten doen. Daarom onderzoeken wij:

Welke ontwerpelementen voor het vergroten van de toegankelijkheid en bruikbaarheid zijn volgens mensen met LVB of laaggeletterdheid van groot belang bij de ontwikkeling en implementatie van digitale (onderzoeks)platforms?

2. Wat hebben we gedaan?

In dit onderzoek verbeterden we het toegankelijke online onderzoeksplatform 'Ikonderzoekmee' met en voor mensen met een LVB en/of laaggeletterdheid. Het figuur laat de verschillende stappen zien. Tijdens deze stappen werd door middel van **interviews** en **gebruikerstesten** informatie verzameld.

2.1 Wat is 'IkOnderzoekMee:

'IkOnderzoekMee' is een inclusief digitaal burgerwetenschappelijk onderzoeksplatform dat onderzoekers kunnen gebruiken om vragenlijsten te co-creëren en te verspreiden.

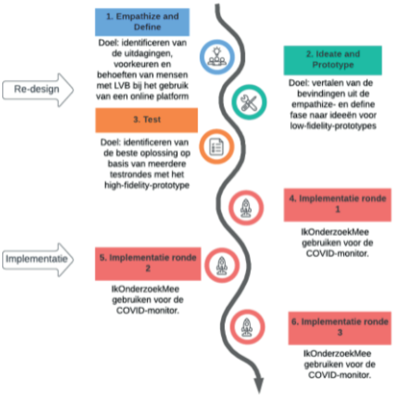
Je kan 'IkOnderzoekMee' bekijken door deze QR code te scannen:

2.2 Wat is re-design?

De stappen van de Design Thinking methode werden gevolgd om het platform door te ontwikkelen, de deelnemers gaven gedurende drie tot zes individuele sessies input.

2.3 Wat is implementatie?

De implementatie vond plaats in 3 rondes bij het gebruik van 'IkOnderzoekMee' voor de COVID-19 gezondheidsmonitor voor mensen met LVB en/of laaggeletterdheid.



Re-design

1. Empathize and Define
Doel: identificeren van de uitdagingen, voorkeuren en behoeften van mensen met LVB bij het gebruik van een online platform

2. Ideate and Prototype
Doel: vertalen van de bevindingen uit de empathize- en define fase naar ideeën voor low-fidelity-prototypes

3. Test
Doel: identificeren van de beste oplossing op basis van meerdere testrondes met het high-fidelity-prototype

Implementatie

4. Implementatie ronde 1
IkOnderzoekMee gebruiken voor de COVID-monitor.

5. Implementatie ronde 2
IkOnderzoekMee gebruiken voor de COVID-monitor.

6. Implementatie ronde 3
IkOnderzoekMee gebruiken voor de COVID-monitor.

3. Wat hebben we gevonden?

Duidelijkheid en leesbaarheid

Het gebruik van herkenbaar en passend beeldmateriaal die aansluit bij en de diversiteit in de samenleving weerspiegelt.

Begrijpelijkheid

Een begrijpelijke naam van het platform om de vindbaarheid te vergroten is belangrijk.

ik onderzoek mee

Passend ontwerp

Een toegankelijk begeleidingsproces bij het in gebruik nemen van het platform. Logische navigatiefuncties, waaronder voorlees- en meelees functionaliteiten.

4. Wat kunnen we hiermee?

- Door de inclusieve aanpak hebben we belangrijke ontwerpelementen voor mensen met LVB of laaggeletterdheid als eindgebruikers kunnen ophalen.
- Deze ontwerpelementen zijn belangrijk om de toegankelijkheid en bruikbaarheid te verbeteren.
- Door de belangrijke ontwerpelementen en de inclusieve aanpak samen te voegen kan worden voldaan aan de behoeften van deze eindgebruikers.
- Hierdoor kunnen zij ook betrokken worden en deelnemen aan onderzoek.

ZonMw SIDNfonds

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Radboudumc STERKER OP EIGEN BENEN

Samenwerkingsstappen van hoofdstuk 3

Stap 1: Uitleg gegeven over het project

Julia is pas later betrokken bij het project.
Anneke was al vanaf het begin betrokken.
Daarom heeft Anneke uitleg gegeven over 'IkOnderzoekMee', het project en de stappen.

Stap 2: Onderzoeksvraag opstellen

Samen hebben we nagedacht oven een onderzoeksvraag voor het project.
Wat ook past bij het onderzoek van Julia.

Stap 3: Informatie die er was bekijken

Daarna zijn we samen naar de informatie die was verzameld gaan kijken.
Dingen die opvielen of waarvan we dachten dat ze belangrijk waren hebben we eruit gehaald.

Stap 4: Plan voor we hoe naar de informatie kijken

We hebben een plan gemaakt van wat we precies uit de informatie wilde gaan halen.
Dit plan sloot aan op de onderzoeksvraag.
We hebben dus voornamelijk gekeken naar de onderdelen.

Stap 5: Kijken naar de informatie

Julia is toen de informatie gaan bekijken aan de hand het plan dat is gemaakt.
Wat hieruit gekomen heeft ze samengevat tot de resultaten.
Anneke is tijdens deze stap wel steeds op de hoogte gehouden.

Stap 6: De resultaten bekijken

De samenvatting van de resultaten hebben we samen bekeken.
Daarna hebben we samen bedacht waar de informatie past.
Wat we ervan vonden.
En wat we konden gebruiken om de onderzoeksvraag te beantwoorden.

Stap 7: Uitwerken van de resultaten en de discussie

Hierna heeft Julia de resultaten uitgewerkt.
En hebben we dit besproken voor de conclusie en discussie van het onderzoek artikel.

Stap 8: Begrijpelijk lezen samenvatting en poster maken van het onderzoek

Als laatste hebben we deze begrijpelijk lezen samenvatting van het onderzoek geschreven.
De samenvatting hebben we ook nog vertaald naar een begrijpelijk lezen poster.

De implementatie van slim incontinentie materiaal voor mensen met een ernstig meervoudige beperking

Interviews over de ervaringen van zorgverleners en projectleiders

Julia van Calis[1,2], Vivette van Cooten[3,4], Odile Smeets[3], Jenneken Naaldenberg[1,2], Geraline Leusink[1,2], Brigitte Boon[3,4,5] & Kirsten Bevelander[1,2]

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1. Waarom dit onderzoek?

- Het slim incontinentiemateriaal (SCC) kan ondersteuning bieden in de zorg voor mensen met een ernstig meervoudige beperking (EMB)
- SCC is een hulpmiddel waarmee door middel van een clipje op een speciale luier gemeten kan worden of iemand heeft geplast
- De zorgverleners krijgen dan een signaal op hun telefoon zodat ze weten wanneer de luier verschoond kan worden
- De implementatie van de SCC is nog lastig en er is meer onderzoek nodig om te kijken hoe het kan worden geïmplementeerd in de zorg voor mensen met EMB

Doel: Reflecteren op het implementatie proces van de SCC in organisaties die zorg leveren aan mensen met een EMB door ervaringen van belangrijke stakeholders te verzamelen en analyseren.

2. Wat hebben we gedaan?

15 interviews met:

8 project leiders + 7 professionele zorgverleners

van 4 zorgorganisaties voor mensen met EMB

De onderwerpen voor de interview vragen zijn gemaakt op basis van 9 onderdelen uit twee bestaande modellen, voorbeelden van deze onderdelen zijn:

- De organisatie waar de eindgebruiker woont
- De omgeving (dagelijkse begeleiding, etc) van de eindgebruiker
- De technologie in de praktijk brengen en in gebruik nemen

3. Wat hebben we gevonden?

We hebben vier hoofdthema's gevonden die gingen over de ervaringen van de zorgverleners en projectleiders bij het implementeren van de SCC:

1. Draagvlak creëeren

Iedereen die van belang is betrekken en vroeg meenemen in het proces van de implementatie

2. Communicatie tussen de betrokkenen

Steeds in contact blijven, passende middelen voor communicatie gebruiken en duidelijk zijn over de taken en rollen

3. Problemen oplossen

Goed de technische en praktische problemen herkennen en oplossen

4. Bereidheid om de SCC te gebruiken

Bereidheid om de SCC toe te passen wordt beïnvloed door de bruikbaarheid van de SCC en de houding en vaardigheden van de gebruikers om een nieuwe manier van werken op te pakken

4. Wat kunnen we hiermee?

- De eerste drie thema's laten zien wat er nodig is voor een geslaagde implementatie van de SCC
- Het laatste thema laat zien hoe de eerste drie thema's het gebruik in de praktijk beïnvloeden

De inzichten uit dit onderzoek kunnen zorgorganisaties ondersteunen bij de implementatie van technologieën in de zorg zoals de SCC

Dit onderzoek is gefinancierd door ZonMw, de Nederlandse Organisatie voor Gezondheidsonderzoek en Ontwikkeling (grant 80-85300-98-19110).

ZonMw

ACADEMY HET DORP

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STERKER OP EIGEN BENEN

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Samenwerkingsstappen van hoofdstuk 4

In dit onderzoek hebben Anneke en Julia wat minder samengewerkt.
Dit komt omdat het al een samenwerking was met Academy Het Dorp en Tilburg universiteit.
Hierdoor hebben we maar op een aantal stappen samengewerkt.
Anneke is wel steeds op de hoogte gehouden door Julia.

Stap 1: Kennismaken met het project

Samen hebben we gekeken naar wat het project inhield en wat we eruit wilde halen voor Julia's onderzoek.
Ook hebben we bedacht of we informatie die we al hadden konden gebruiken.

Stap 2: Doel en methode bedenken

Julia heeft samen met de andere onderzoeker een doel bedacht, en dit met Anneke besproken.
Toen hebben we nagedacht over hoe we het doel kunnen behalen.
We hebben bedacht om interviews af te nemen bij zorgverleners en projectleiders.

Stap 3: Plan voor informatie verzameling

Om de interviews vorm te geven, hebben we de domeinen uit studie 1 gebruikt.
De vragen in de interviews gingen over deze domeinen.
Anneke en Julia hebben samen deze vragen bedacht en besproken.
Zodat ze goed aansloten bij de domeinen en of de vragen begrijpelijk waren.

Stap 4: Plan voor informatie bekijken

We hebben een plan gemaakt van wat we precies uit de informatie wilde gaan halen.
Dit plan sloot aan op het doel.
We hebben dus voornamelijk gekeken naar de ervaringen van de zorgverleners en projectleiders.

Stap 5: Informatie verzameling

Julia en de andere onderzoeker hebben daarna door middel van de interviews de informatie verzameld.

Stap 6: Informatie bekijken

Daarna zijn we samen naar de informatie die was verzameld gaan kijken.
Dingen die opvielen of waarvan we dachten dat ze belangrijk waren hebben we eruit gehaald.
En ook hebben we gekeken naar de verschillende ervaringen tussen de deelnemers.
Julia en de andere onderzoeker zijn toen de informatie gaan bekijken aan de hand van het plan dat is gemaakt.
Wat hieruit is gekomen heeft Julia samengevat tot de resultaten.
Anneke is hiervan wel steeds op de hoogte gehouden.

Stap 7: De resultaten bekijken

De samenvatting van de resultaten hebben we samen bekeken.
Daarna hebben we samen bedacht waar de informatie past.
Wat we ervan vonden.
En wat we konden gebruiken om het opgestelde doel te behalen.

Stap 8: Uitwerken van de resultaten en discussie

Hierna heeft Julia samen met de andere onderzoeker de resultaten uitgewerkt.
En hebben we dit besproken voor de conclusie en discussie van het onderzoek artikel.

Stap 9: Begrijpelijk lezen samenvatting en poster maken van het onderzoek

Als laatste hebben we deze begrijpelijk lezen samenvatting van het onderzoek geschreven.
De samenvatting hebben we ook nog vertaald naar een begrijpelijk lezen poster.

De inclusieve ontwikkeling van een chatbot voor kwetsbare zorgvragers

Interviews en focusgroepen over de ervaringen van co-onderzoekers en het ontwikkelteam

Julia van Calis (1,2) , Kris Bevelander (1,2), Anneke van der Cruijsen (1,2), Jenneken Naaldenberg (1,2) & Geraline Leusink (1,2).
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2. Academische werkplaats Sterker op Eigen Benen (SOEB), Nijmegen, Nederland

Waarom dit onderzoek?

- Steeds vaker wordt er technologie ingezet in de zorg.
- Voor mensen met een licht verstandelijke beperking (LVB) of autisme is technologie vaak moeilijk te gebruiken.
- Digitale hulpmiddelen kunnen deze mensen juist helpen, maar sluiten nu niet goed aan bij hun behoeften.
- Het is belangrijk dat zij zelf meedenken bij het ontwerpen van deze hulpmiddelen.
- Inclusief ontwerpen, waarbij co-onderzoekers meedoen, maakt technologie toegankelijker.
- Tot nu toe zijn co-onderzoekers nog te weinig betrokken bij de ontwikkeling van digitale zorg en hulpmiddelen.

Het doel van dit onderzoek is om te ontdekken hoe je mensen met LVB of autisme het beste kunt betrekken bij het maken van een digitale hulp, en welke aanpassingen daarvoor nodig zijn.

Wat hebben we gedaan?

Het project

In dit onderzoek is gekeken hoe mensen met een LVB of autisme goed kunnen meedoen bij het ontwerpen van een digitale hulp.
De digitale hulp is een gevoelige digitale assistent die mensen met complexe zorgvragen helpt bij het vinden van passende hulp voor problemen op sociaal, mentaal of lichamelijk gebied.
De digitale assistent maakt gebruik van slimme technologie (kunstmatige intelligentie) en moest gevoelig en aanpasbaar zijn aan iemands situatie.

Aanpak

Het project bestond uit vijf fasen, van het verzamelen van wensen tot het samen ontwerpen en testen van de digitale hulp.
Na elke fase werden interviews en groepsgesprekken gehouden om te bespreken wat goed ging en wat anders moest.
De interviews en groepsgesprekken gingen over hoe de projectleden de samenwerking, hun rol en de activiteiten hadden ervaren.

De onderzoekers verzamelden zowel tekst (kwalitatieve data) als cijfers (kwantitatieve data), bijvoorbeeld met smileys, sterren en duimpjes in digitale vragenlijsten.
De vragenlijsten waren speciaal aangepast met eenvoudige taal, plaatjes en veel witruimte, zodat iedereen ze goed kon begrijpen.
De verzamelde informatie werd per fase bekeken om patronen en belangrijke thema’s te ontdekken.

Wat hebben we gevonden?

We hebben drie hoofdthema’s gevonden die samen beschrijven hoe de inclusieve samenwerking was gevormd en ervaren tijdens het ontwikkelproces.
- Het eerste hoofdthema was **project aanpak,** hieronder viel dat het belangrijk is om goed voor te bereiden en de rollen en verantwoordelijkheden samen af te spreken. Daarnaast hebben we gevonden dat er een duidelijke structuur van het project moet zijn, en dat er rekening moet worden gehouden met de tijd die er nodig is.
- Het tweede hoofdthema beschreef de **samenwerkingsdynamiek**, dit wil zeggen hoe het projectteam de samenwerking gedurende het project heeft ervaren en vormgegeven. Hierbij waren goede communicatie en ondersteuning van groot belang.
- Het derde en laatste hoofdthema was **samen ontwerpen in de praktijk**. Dit thema liet laat alle fases en activiteiten binnen het ontwikkelproces zien.

Wat kunnen we hiermee?

Deze studie laat zien hoe co-onderzoekers met een LVB of autisme goed kunnen meewerken aan het maken van een digitale hulp. Het onderzoeksteam zorgde ervoor dat de co-onderzoekers zich op hun gemak voelden en goed mee konden doen. Ze gebruikten duidelijke taal, visuele hulpmiddelen, herhaling en werkten in kleine groepen. Hierdoor konden de co-onderzoekers echt iets bijdragen.

STERKER OP EIGEN BENEN

Radboudumc

In samenwerking met:

MEE Gelderse Poort

Tilburg University

Reframing Studio

mobile water

Gefinancierd door:

ZonMw

NL Health~Holland

Contact:
Julia van Calis, PhD Candidate
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Samenwerkingsstappen hoofdstuk 5

Stap 1: Kennismaken project en het projectteam

Aangezien dit project een samenwerking was met nieuwe partners, hebben we een kennismaking gehad.
Samen hebben we gekeken naar wat het project inhield, wat we eruit wilde halen en wat iedereen kon bijdragen het project.

Stap 2: Doel en methode bedenken

Samen met de andere onderzoekers en de co-onderzoekers is een doel bedacht.
Toen hebben we nagedacht over hoe we het doel kunnen behalen.
We hebben besloten om interviews met vragenlijsten af te nemen bij alle projectleden na alle werkpakketten.
Daarnaast bedachten om focusgroepen te doen met alleen de co-onderzoekers na alle interviews met vragenlijsten.

Stap 3: Plan voor informatie verzameling

Om de interviews af te nemen, hebben we een toegankelijke vragenlijst gemaakt in IkOnderzoekMee.
De vragen gingen over hoe de projectleden de samenwerking, hun rol en de activiteiten hadden ervaren.
Anneke heeft Julia tips gegeven over hoe de vragenlijst zo toegankelijk en begrijpelijk mogelijk gemaakt kon worden.
Zodat het aansloot bij het project en het doel van het onderzoek.

Stap 4: Plan voor informatie bekijken

Julia heeft een plan gemaakt van wat we precies uit de informatie wilde halen.
Dit plan sloot aan op het doel.
Omdat Anneke deelnemer was, is ze niet betrokken in de opzet van het plan voor het kijken naar de informatie.

Stap 5: Informatie verzamelen

Julia heeft door middel van de interviews met vragenlijsten en de focusgroepen de informatie opgehaald bij de deelnemers.
Dit deed ze door opnames en aantekeningen te maken.

Stap 6: Informatie bekijken

De informatie werd tijdens het project in de focusgroepen al gedeeltelijk met de co-onderzoekers bekeken.
Daarnaast hebben we de informatie als geheel achteraf bekeken.
Dingen die opvielen of waarvan we dachten dat ze belangrijk waren hebben we eruit gehaald.
Julia is toen de informatie gaan bekijken aan de hand van het plan dat is gemaakt.

Stap 7: De resultaten bekijken en uitwerken

Wat hieruit is gekomen heeft Julia samengevat tot de resultaten.
De resultaten hebben Anneke en Julia tussendoor samen besproken.
Zo konden hebben we steeds rekening gehouden met het opgestelde doel en wanneer nodig was om het samen te bespreken.

Stap 8: Schrijven van discussie

Hierna hebben de resultaten besproken om discussie punten eruit te halen.
Dit heeft Julia uitgeschreven tot een discussie en conclusie voor het onderzoek artikel.

Stap 9: Begrijpelijk lezen samenvatting en poster maken van het onderzoek

Als laatste hebben we deze begrijpelijk lezen samenvatting van het onderzoek geschreven.
De samenvatting hebben we ook nog vertaald naar een begrijpelijk lezen poster.

Radboudumc
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IN DEI NOMINE FELICITER

Radboud University