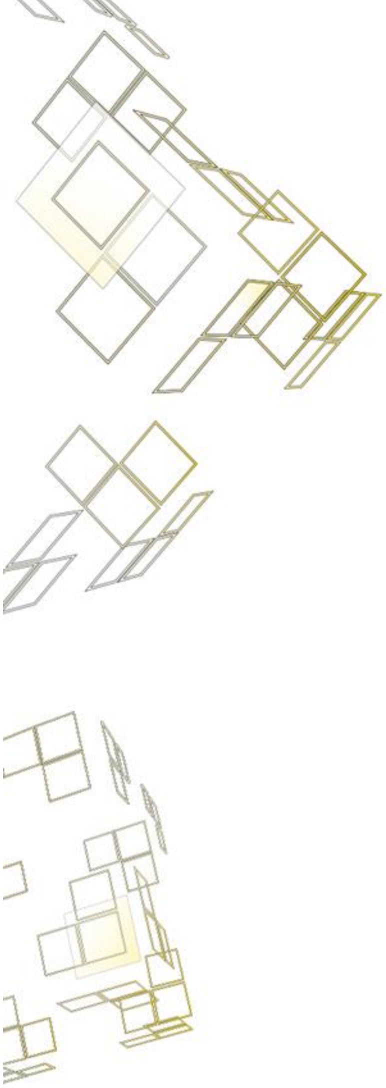

MASTER THESIS

PARTICIPATORY DEVELOPMENT OF EHEALTH TECHNOLOGIES FOR PEOPLE WITH INTELLECTUAL DISABILITIES

RECOMMENDATIONS AND LESSONS LEARNED

N.E. Klein
S2627760

Faculty of Science and Technology
Master Health Science
Track: Personalized monitoring and coaching

Supervisors University of Twente
Dr. A. Van Dongen (first)
Dr. H. Kip (initial first supervisor)
Dr. L.L. Kramer (second)

External supervisors Radboud UMC
J.F.E. van Calis, MSc
Dr. K.E. Bevelander

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STERKER
OP EIGEN BENEN

Radboudumc

UNIVERSITY OF TWENTE.

Preface

For my Master Health Science at the University of Twente, I wrote a master thesis which researched the participatory development of eHealth technologies for people with intellectual disabilities. This research was conducted at the academic workplace 'Sterker op eigen benen', Radboud UMC.

I would like to thank my supervisors at the Radboud UMC Julia van Calis and Kris Bevelander, for the guidance and feedback provided during my thesis period. With a special thanks to Anneke van der Cruijsen with whom I had the opportunity to work together to make this research more inclusive. Further, I would like to thank my supervisors at the University of Twente, Anne van Dongen, Hanneke Kip and Lean Kramer for the good and critical feedback provided. Besides I want to express my gratitude to the (healthcare) professionals for partaking in this research. Lastly, I would like to thank my friends and family who took the time and effort to help me improve my thesis.

Naomi Klein

Enschede, November 2022

Abstract

Background: The use of digital technologies, such as smartphones and computers, has increased noticeably for people with intellectual disabilities (ID). Digital technologies focusing on health opens doors for better participation in society and independence in the everyday lives of people with ID. However, these eHealth technologies do not always meet the needs of people with ID, as this group often gets excluded from the development of new eHealth interventions. This could therefore impair the benefits eHealth technologies can provide for this specific and complex group of people. Participatory development (PD), in which people with ID are involved throughout the entire development process could help meet the needs of this target group, as PD will allow the development of an eHealth technology more suited for people with ID. However, only a scarce number of studies focus on stakeholder involvement in the eHealth development process, amplifying the need for PD for people with ID.

Aim: The aim of this study, therefore, focuses on the key factors for a successful PD of eHealth technologies for people with ID. More concretely the study aims to identify frameworks, models and approaches used for PD, which stakeholder groups could contribute to PD and how stakeholders are currently involved in the development process, as well as aiming to describe the best practices and lessons learned from PD for people with ID.

Method: A qualitative multi-method research approach was used in this study. Consisting of a scoping review and semi-structured interviews. The scoping review was performed to get insight into the PD processes described in the literature, the interviews focused on gaining knowledge about the practical experiences of professionals who had involved people with ID in the development process of eHealth. Both methods were carried out separately and consisted of a data extraction process and an iterative coding process, data was later synthesized and combined into overarching categories.

Results: A total of 22 studies focusing on PD for people with ID were included in the scoping review, complemented by five interviews with professionals with experience in ID and PD. Frameworks, models and approaches were used in almost all (n=20) studies, the variation in frameworks used was wide, as almost all studies used their own specific framework. Compared to the interviews the use of frameworks was scarce, as not one interviewee mentioned the direct use of a framework. The identified stakeholders could be divided into seven stakeholder groups, healthcare professionals were the largest group mentioned in the identified studies and relatives the biggest group mentioned in the interviews. The current involvement of stakeholders and people with ID in the PD could be divided into different subsections, which highlighted: communication, roles of people with ID and other stakeholders, moment of PD, effects on people with ID when participating in PD, benefits for research and eHealth, pitfalls and problems and PD session formats, structures and methods. The best practices and lessons learned derived from the identified studies and interviews mainly highlighted the focus on equality, emerging yourself in the target group, visualizing PD sessions and including all stakeholders in PD.

Conclusion: Following the results, the recommendation and lessons learned from this research focus on communication, set-up of PD sessions and the involvement of relatives and support staff. Frameworks models and approaches can be taken as guidelines for PD combined with critical thinking. PD should be flexible and add value to all involved stakeholders. Nevertheless, further research is needed to validate these recommendations to help optimize PD with people with ID.

Makkelijk lezen Samenvatting

Waar gaat dit onderzoek over?

De zorg voor een iemand met een verstandelijke beperking kan voor iedereen anders zijn.
De zorg in Nederland wordt duurder.
Er is een tekort aan zorgpersoneel.
Het is nodig de zorg beter te maken voor mensen met een verstandelijke beperking.
eHealth kan hierbij helpen.

eHealth zijn digitale technologieën die helpen bij de gezondheid, bijvoorbeeld een gezondheidsapp op je mobiel of computer.
eHealth kan je helpen bij meer zelfstandig zijn.
eHealth kan ook de begeleider helpen.
eHealth kan op maat gemaakt worden, ook voor jou.

Wat is het probleem?

Maar eHealth sluit niet altijd goed aan bij mensen met een verstandelijke beperking.
Daarom is het belangrijk dat mensen met een verstandelijke beperking meedenken bij eHealth ontwikkelingen.
Dit kan door samen te ontwikkelen.

Bij samen ontwikkelen wordt iemand met een verstandelijke beperking in het hele ontwikkelproject betrokken.
Er is alleen nog niet veel over bekend.
Er wordt niet vaak iemand met een verstandelijke beperking bij het eHealth project betrokken.
Waardoor de eHealth niet goed past.
Daarom hebben wij dit onderzoek gedaan.

Wat wilden wij graag weten?

We kijken naar hoeveel en hoe vaak mensen met een verstandelijke beperking worden gevraagd in het samen ontwikkelen.
Er worden gesprekken gehouden en gekeken wat er al is.
Hier komen tips uit over het samen ontwikkelen.
Dit wordt gedaan om te onderzoeken wat het belangrijkst is in het samen ontwikkelen.
Dit zorgt dat samen ontwikkelen goed past.

Wat hebben wij gedaan?

Er worden gesprekken gehouden met 5 personen met kennis over eHealth en samen ontwikkelen.
Er wordt gevraagd hoe zijn mensen met een verstandelijke beperking mee laten denken en doen.
Er wordt op internet gezocht naar wat er al geschreven is.
Uit de gevonden teksten worden stukjes gehaald.
Deze stukjes gaan over hoe mensen met een verstandelijke beperking meegenomen worden.
De gesprekken en stukjes worden eerst apart bekeken.
En daarna samen bekeken.

Wat zijn wij te weten gekomen?

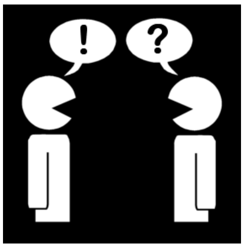
Er worden stappenplannen gebruikt voor eHealth

Er worden veel verschillende soort stappenplannen gebruikt voor eHealth ontwikkeling.
Veel stappenplannen richten zich op het betrekken van mensen die de eHealth gaan gebruiken.
Veel stappenplannen richten zich ook op het betrekken van andere mensen zoals, familie en begeleiders.
De mensen in de gesprekken maakten nog niet veel gebruik van stappenplannen.

Veel mensen kunnen helpen bij samen ontwikkelen van eHealth

Er zijn veel groepen mensen met kennis over eHealth.
De grootste groep van mensen met kennis die mee kunnen doen zijn begeleiders en familie.
Daarnaast worden soms ook onderzoekers, eHealth makers, scholen en de zorgorganisatie gevraagd om mee te denken.

Goede communicatie is belangrijk



Contact hebben met elkaar is ook erg belangrijk.
Het is belangrijk dat eHealth makkelijk is en niet te moeilijk.
Het is ook belangrijk dat er uitgelegd wordt hoe alles werkt.
Voor andere mensen met kennis is communicatie ook belangrijk.

eHealth wordt vaak uitgeprobeerd door mensen met een verstandelijke beperking

Mensen met een verstandelijke beperking worden het meest gevraagd om hun mening te geven en eHealth te proberen.
Andere mensen met kennis geven ook vaak hun mening of helpen de onderzoekers met het verplaatsen in een ander.
Er werd over de samenwerking ook gezegd dat iedereen even belangrijk is.

Samen ontwikkelen kan op veel verschillende momenten

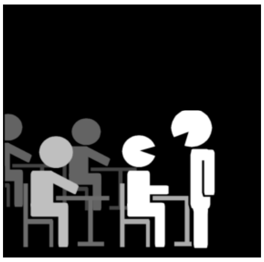
Mensen met een verstandelijke beperking worden het meest tussendoor gevraagd mee te denken en eHealth uit te proberen.
Ze worden ook veel aan het eind gevraagd om de eHealth uit te proberen als deze al klaar is.
Ze worden minder gevraagd aan het begin van de eHealth ontwikkeling.

Soms is samen ontwikkelen moeilijk

Als mensen met een verstandelijke beperking mee mogen denken met de eHealth ontwikkeling, past de eHealth beter bij mensen met een verstandelijke beperking.
Wel zijn er verschillende dingen die fout kunnen gaan als mensen met een verstandelijke beperking meedenken.
Zo kan er voor iemand met een verstandelijke beperking besloten worden.
En kan een persoon met een verstandelijke beperking niet voor iedereen spreken.
Ook is het soms moeilijk om mensen met een verstandelijke beperking te vinden die graag mee willen denken.

Duidelijke uitleg is belangrijk

Wanneer je meedenkt met een nieuwe eHealth technologie is het belangrijk dat je duidelijke uitleg krijgt.
Dat je zelf mag beslissen of je meedoet.
En dat je weet hoe de eHealth werkt.



Plaatjes zijn handig

Ook blijkt het goed te werken als je mag kiezen tussen verschillende eHealth ideeën.
En is het gebruik van plaatjes erg handig.

Wat is de conclusie?

Meedenken in de eHealth ontwikkeling heeft veel voordelen!
Het is vooral belangrijk dat het contact met elkaar makkelijk en begrijpelijk is.
Dat mensen die je goed kent en je veel helpen ook meedenken.
Dat je weet wat je moet doen en dat er veel plaatjes gebruikt worden.
Ook is het belangrijk dat het leuk en leerzaam is!

Table of content

1. Introduction

Intellectual disabilities (ID) can be defined as 'a neurodevelopmental disorder with onset in childhood and characterized by limitations in both intellectual and adaptive functioning' (1, 2). People with ID can have intellectual deficits in reasoning, problem-solving, planning and learning from experience, just as adaptive behavior deficits in conceptual, social and practical domains (1-3). The severity of an ID can be classified as 'mild', 'moderate', 'severe' and 'profound' (1). Globally, the prevalence of ID varies between 1% and 3% of the population (4, 5). In the Netherlands, 440.000 people live with an ID of which approximately 84% (370.000 people) have a mild ID (6). These people with mild ID can learn practical life skills, which allows them to function normally in life with minimal support. People with severe ID are often provided care by family or in supervised settings, where they are assisted in engaging and learning simple daily activities. People with profound ID cannot live independently and require 24/7 care and help with daily activities (1). In the Netherlands, the group of people with severe and profound ID consist of around 70.000 people (6). People with ID are a heterogeneous group, with causes varying, from genetic disorders (Down Syndrome, Fragile X Syndrome) to prenatal disorders and postnatal complications to causes being fairly unknown (1, 5-7). Furthermore, many other disorders, such as visual and hearing impairment, epilepsy and gastroesophageal reflux disease, co-occur next to ID (1, 5). Care for people with ID is therefore complex and requires specific skills and knowledge to promote inclusivity and equity within healthcare for this group (8, 9). Stating that for each person with ID, health can differ in severity and complexity and thus, requires care that is adapted to their individual needs (10). In addition, due to an aging population, increased demands for support and (healthcare) services are seen for people with ID (11). In the Netherlands, this demand has led to increased healthcare costs for this group (6). However, problems in meeting this demand occur due to challenges in hiring, training and retaining (healthcare) staff, showing the need to optimize healthcare for ID, challenged by the specific person-centered care needed to provide inclusivity and equity for people with ID (8, 11, 12). To help optimize this specific healthcare demand, technology can provide a solution (11). More specifically, the use of eHealth can provide opportunities and supports the heterogeneous characteristics of each individual with ID to adapt to their individual needs in care (13).

eHealth can be described as 'the use of digital technologies and interventions to support health, well-being and healthcare' (14, 15). eHealth technologies such as mobile apps, virtual reality and wearables can be used across a wide range of activities in healthcare, varying from prevention, diagnosis, and treatment to the monitoring of diseases (16, 17). Nevertheless, it can also be used in the personal management of health and lifestyles (18). For people with ID, eHealth technologies can be the key to increased independence and are important in creating more opportunities and support for this group (2, 11). eHealth can help people with mild ID in making their own choices in various life domains, enhancing independent functioning and allowing significant contribution to participation in society (13). For people with severe ID, eHealth can create opportunities for more efficient support of relatives and healthcare professionals and help to discern and interpret the preferences of people with severe ID, as it can be hard to determine these due to the formulation and communications problems (19, 20). eHealth technologies can support and help teach people with ID to manage their specific healthcare and lifestyle needs in an accessible and understandable way (21). Given that eHealth technologies have already demonstrated their effectiveness in general and elderly care, as well as in chronic disease management, such as by facilitating independent living (13, 16, 18, 22, 23). Besides, eHealth can be tailored and personalized to individual users and therefore has the potential to target heterogeneous populations, such as people with ID, enabling a lot of opportunities in ID care (13, 16, 18).

However, a review by Vázquez et. al. (2018) has shown problems in the accessibility and usability of eHealth technologies within care for people with ID (18). The use and application of eHealth technologies for people with ID have been largely neglected or don't meet the needs guaranteeing successful use, research by Sheehan and Hassiotis (2017) states this neglect (18, 24). People with ID are often excluded from the development and implementation of new eHealth interventions. Even though these technologies focus on health problems that often occur among people with ID (24). Resulting in the fact that people with ID encounter several barriers before they can successfully use the technology (18, 24). Besides, only a scarce number of studies focused on the use of eHealth technologies by people with ID are performed (18). Showing the growing need for suitable eHealth technologies that support the unique and individual needs of people with ID (18, 25). A clear example of an eHealth technology not fitted for people with ID is the mobile weight management app mentioned in the research by Smyth et. al. (2017) (26). This weight management app is used by people with ID but the design was not developed with this group in mind, which resulted in an app that was not functional in supporting weight reduction for people with ID and therefore could not be successfully used by this group (18, 26). Thus, the app could not be used by everyone and was hard to use for people with ID, hence, resulting in accessibility and usability problems.

These problems in the accessibility and usability of eHealth technologies can result in a failed implementation (27, 28). Failure of eHealth implementations can arise from poor design in the development process of the technology (18, 29). Considering that the implementation and development processes are both complex processes themselves (18, 30). Developing eHealth for people with ID is even more complex, due to the different natures of the disabilities and their severity and complexity (10, 29). To understand the process and the factors involved in development and implementation, different models and frameworks exist to enhance the effectiveness of eHealth interventions (27, 30). These frameworks provide a systematic way for the development, management and evaluation of eHealth interventions (27, 30). Despite the existence of these frameworks, some eHealth implementation still tempts to fail (27, 28). Considering eHealth interventions for people with ID, this could be due to the poor understanding of the eHealth designers about the special needs and the heterogenous characteristics of people with ID (18, 29). Therefore, eHealth technologies should be developed with the individual needs of a person with ID considered, to help increase the acceptance and adoption of the technology (13, 28).

Thus, earlier mentioned problems in the acceptance, usability and implementation of eHealth technologies can occur due to a poor development process not focusing on the special needs of people with ID (18, 29). Involving people with ID and other stakeholders within this development process are therefore deemed essential (15). Participation in the development of an eHealth technology can engage stakeholders in this technology and therefore, strengthen the interventions effectiveness and usability (31). Applying participatory development (PD) allows for an eHealth development process ‘with’ instead of ‘for’ stakeholders, allowing them to be actively involved throughout the entire process (15). Within PD the roles of different stakeholders can vary from giving information to actual co-creation (15). Co-creation can be seen as an active contribution by the target group to the development of eHealth technologies, enhancing their sense of purpose and commitment, allowing eHealth to suit the needs of people with ID (13, 31). However, even though the importance of PD is known, people with ID often get little say in the processes surrounding eHealth often leaving little room to explore how eHealth could match their personal needs and preferences (13). This limited level of involvement of people with ID, next to the limited involvement of other stakeholders, such as relatives and nursing staff, results in usability problems because the technology simply does not correspond with the individual needs (11, 13, 15, 18, 21, 30, 32). Different systematic reviews have emphasized the importance of the involvement of all stakeholders, as early as possible in the development process of eHealth technology focused on people with ID (13, 28). The systematic review by Oudshoorn et. al. (2020) also emphasizes that the personal needs and preferences of people with ID aren’t taken into account to find the most appropriate eHealth technology (13). Only amplifying the importance of PD in the development of eHealth technologies for people with ID.

The scarcity of studies done researching the use of eHealth technologies by people with ID can be complemented by the limited involvement of stakeholders in the eHealth development process, even though the importance of stakeholder involvement is highlighted in numerous studies (2, 11, 13, 15, 18, 21, 28-30, 32). Therefore, this research aims to gain insight into the PD in eHealth processes for people with ID. This insight can be obtained by conducting a qualitative multimethod research approach consisting of semi-structured interviews and a scoping review, allowing to gather knowledge about PD for people with ID and experiences about which and how stakeholders can be involved. This input can then be translated to concrete and practical recommendations for stakeholder participation in eHealth processes for people with ID. These recommendations can help guide future researchers, eHealth developers and other stakeholders to integrate PD in the (re-)development of existing or new eHealth technologies focused on people with ID. This research, therefore, aims to answer the following research question: “What are key factors for a successful PD of eHealth technologies for people with ID?”

The following sub-research questions are created to help answer the research question:

1. Which development frameworks, models and approaches are used for PD of eHealth technologies for people with ID?
2. Which groups of stakeholders can be identified in the PD of eHealth technologies for people with ID?
3. How are stakeholders and people with ID currently involved in the development processes of eHealth technologies?
4. What are the best practices and lessons learned from both literature and people with practical experience on how to involve stakeholders and people with ID in the eHealth development process?

2. Method

2.1 Research design

In this study, a qualitative multi-method research approach was used. A combination of two qualitative methods, a scoping review and semi-structured interviews can contribute to a better understanding of the research problem. Providing a complete understanding of the problem allows for an extensive view of PD, following more substantiated recommendations (33). These recommendations for PD arise from experiences and lessons learned from practice, connected and synthesized with literature. Thus, the scoping review and semi-structured interviews are conducted parallel to each other. The four sub-research questions (sub-RQ) are connected to the scoping review and semi-structured interviews. The scoping review was performed to get insight into the PD processes described in the literature. Semi-structured interviews were held with stakeholders who had prior knowledge about eHealth technologies, ID and had involved people with ID in the development process of these technologies. The interviewed stakeholders varied from healthcare professionals and project managers to researchers. After conducting each method separately, the results were synthesized and analyzed on the similarities and differences whilst answering the main research question (main RQ). These synthesized results and answers to the main RQ and sub-RQ are translated into concrete recommendations.

A scoping review seemed suitable for this research, as it can present a more general view on a verily "new" topic (34, 35). Allowing a greater range of studies to be included and providing a descriptive overview of the reviewed scientifical articles (36).

Semi-structured interviews aligned with the research problem allowing the use of a predetermined set of questions, whilst conducting a more flexible approach with deepening questions to get to the essence of the topic. Therefore, flexibility was allowed within the semi-structured interviews, offering the participants the chance to elaborate on the issues they feel are important (37, 38).

2.2 Scoping review

This section contains the method for the scoping review. The PRISMA extension for scoping reviews (PRIMSA-ScR) was kept in mind throughout this section and the review (39).

2.2.1 Data search

A comprehensive search strategy was conducted focusing on the three main points within this study: eHealth, people with ID and PD. Because of the scarcity of studies done, six databases were selected for the scoping review: PubMed, CINAHL, Embase, Web of Science, PsycINFO and ACM Digital Library. These databases range from medical-specific to multidisciplinary. For each database, an individual search string was created based on the main search string used for PubMed. The PubMed search string consisted of three components, the first covers "Intellectual disabilities", the second "eHealth technologies" and the last "Participatory development". Additionally, for these three components, two filters were used. Restricting the search strategy to only English or Dutch articles and stating that articles from 1995 until the present should be included. 1995 underscores the year the first examples of eHealth use among healthcare professionals were recorded (40). The final PubMed search string and the full search strategy for all databases can be found in *Appendix A*. The search strings were refined throughout discussions with the second reviewer and two information specialists from the University of Twente and Radboud UMC to optimize the search strategy for this scoping review.

2.2.2 Eligibility-, inclusion and exclusion criteria

Because of the scarcity of studies performed on this topic a broad range of studies, focusing on all of the three main points; eHealth, PD and ID, could be included in this scoping review. The only eligibility criterion is that the article is peer-reviewed. Additionally, no quality assessment of the articles was performed. Different inclusion and exclusion criteria were set for the title and abstract screening and the full-text screening, allowing a narrower focus during the progression of the review. These criteria were made by one reviewer (NK) and discussed on relevance with the second reviewer (JC).

The inclusion criteria for the **Title and abstract** screening were:

- People with ID or disorders who can be classified as an ID
- Mentioned an eHealth technology
- Mentioned some form of participatory development or inclusion in the development

Here all three inclusion criteria should be met, otherwise the article should be excluded.

The inclusion criteria for the **Full-text** screening were:

- The main target group on which eHealth is focused are people with ID. Thus, the main focus should be on people with ID.
- The technology can be classified as eHealth and therefore, is a digital technology supporting health, wellbeing, or healthcare (14, 15).
- The main focus should be on the development phase of eHealth technologies. Studies that equally mentioned the development phase next to other phases were also included.
- A description of how stakeholders can be included in the development of eHealth and thus, the inclusion of stakeholders or PD is described. A clear description of PD is given not just merely mentioned.

Within the **full-text** screening the articles should be excluded when:

- The full text of the article is not available.
- The article is focusing on educational applications of the technology without focusing on health and (mental) wellbeing.
- The article is focusing on a medical device, such as an ultrasound, MRI, X-ray, or infusion pump.

2.2.3 Screening

The results from the final search for all six databases were uploaded in Covidence, in which duplicates were removed. After the removal of duplicates, the title and abstract were screened by two reviewers (NK and JC). The reviewers both screened all the articles individually and afterwards discussed their screening results and resolved conflicts with one another. After the title and abstract screening, both reviewers did a full-text screening. Here one reviewer (NK) first screened the full texts and wrote down her conclusion about the in- or exclusion of the article. The second reviewer (JC) then read the conclusion and in case necessary, the full text. Both reviewers solved the conflicts of the full-text screening together. From the included articles the references/related work was assessed to identify additional articles via snowball sampling for this scoping review. This was only done when an included article referred to a different article focused on PD. The articles found through snowball sampling were included in the title and abstract screening and screened as mentioned above. A simplification of the screening process can be found in *Appendix B*.

2.2.4 Data extraction and analysis

After the full-text screening, the data from the included articles were extracted. Data extraction was guided by the following information:

- **General information:** Article name, author, country, data and the article type.
- **Goal and design:** The goal of the study and study design.
- **eHealth technology:** eHealth technology used in the study, type of technology and the goal of the technology.

- **Target group:** The target group the eHealth is focused on, the specific target group in the study, the sample size and the target group setting.
- **Method:** The method used.
- **Framework:** The described frameworks, approaches and models and the decision for this framework.
- **Identified stakeholders:** Stakeholders who participated in the development process and a description of how stakeholders were involved.
- **Best practices:** Lessons learned and best practices about PD for people with ID.

The data extraction is done by one reviewer (NK) and discussed with the second reviewer (JC) at two moments: after the first five articles are extracted and when the extraction was completed. From the completed extraction the following categories were summarized and exported to Microsoft Word: frameworks, identified stakeholders and best practices. After the reviewer (NK) got familiarized with the data extraction results, the data were coded applying an iterative process (41). The codes were grouped in overarching themes divided into: current stakeholder involvement, best practices and lessons learned, identified stakeholders and frameworks. Supplemented with subcategories in which similar codes were grouped. Once this process was completed the results were synthesized with the interview results as further described in *2.4 multi-method analysis*.

2.3 Interviews

In this section, the method for the semi-structured interviews is described.

2.3.1 Participants

Selecting which stakeholder group should be interviewed was done with input from both literature and experts opinions. The expert opinion was gathered via a so-called “soundboard group”, a group consisting of multiple professionals in ID care, researchers and a co-researcher, all with knowledge of ID and eHealth.

The interviews aimed to include approximately five participants with expertise in eHealth, ID and PD. This could include different kinds of professionals, from healthcare professionals to project managers and researchers. The three main inclusion criteria for participating in the interviews were as followed:

- The professional should work in ID care or their work activities focus on people with ID.
- The professional works with eHealth technology or is an expert in the eHealth technology field.
- The professional has experience with involving people with ID in the development process of eHealth.

In addition, to the three main criteria, the participant had to speak Dutch or English. To find professionals for the interviews a general advertisement in Dutch was placed on LinkedIn (*Appendix C*). Supplemented with internet searches into ID care homes and researchers working with eHealth, when a professional seemed qualified for an interview, the professional was contacted. Furthermore, snowball sampling was applied by the already participating interviewees.

2.3.2 Interview preparations

The participants who were interviewed received an information letter (*Appendix D*) and a informed consent *(Appendix E)*. When the participant agreed to be interviewed and signed the informed consent, the interview could be conducted face-to-face or online (Microsoft Teams). In both situations, the interview was recorded. The choice for one of these two methods was based on the availability and convenience of the participant and the interviewer. The interviews were conducted by one researcher (NK) and lasted approximately between 45 and 60 minutes.

2.3.3 Interview guide

The focus of the interview questions was divided into topics. Main questions were asked within each topic, accompanied by more deepening questions, allowing a flexible and open mind applied within the interviews. The interviews focused on the following topics:

- **Introduction:** A brief introduction about the participant and their role in the eHealth development process.
- **Motivation for PD:** Questions focusing on how they experience and understand PD.
- **PD for people with ID:** Focusing on when and how people with ID participate in the development processes of eHealth and what the participant thinks are the advantages and disadvantages of PD.
- **PD with other stakeholders:** Questions about which other stakeholders are relevant in PD and how these stakeholders can be involved.
- **Frameworks:** Deepening question about if the participant has used frameworks or models for PD.
- **Learned lessons:** Summing up the most important aspects of the involvement of people with ID in the development process.

The full interview guide can be found in *Appendix F*.

2.3.3 Interview Analysis

After the interviews were conducted the interviews were transcribed verbatim by the interviewer only leaving out some non-significant words such as “uh”. After transcribing, the interview was coded. The first step of this coding process is getting familiar with the context of the interview. The first version of the coding process was done with open codes. Here fragments based on each research question were selected and labelled. Open coding was done more explorative with descriptive codes. To structure these open codes, axial coding was conducted in which connections between the open codes were made as these can be placed into various categories with codes that have the same sort of context. After structuring the codes, selective coding was conducted. The identified categories from the axial codes were connected forming new main categories. This allowed the codes to be reduced to a few important and main topics connected to the main and sub-RQ. The coding process was an iterative process which required the researcher to repeat and go back in the coding process numerous times to achieve optimal results (41).

The coding of the interviews was done by one researcher (NK). But the axial and selective code sets were discussed and redefined with a second researcher (JC). This was done after approximately three interviews were coded. Allowing a guide for the researcher (NK) to focus on while coding the remaining interviews. But still allowing an open mind in finding new coding categories.

2.4 Multi-method analysis

Both codes of the interviews and the scoping review were categorized into groups which represent a sub-RQ. To synthesize the analyzed data, the codes fitting for each sub-RQ were analyzed and described in a combined document. The codes could complement and amplify each other. The used frameworks and models found in both interview and scoping review were described, just like the stakeholder groups. Lessons learned and best practices were grouped in an overarching category which both enclosed the codes of the scoping review as of the interviews. The codes were also supplemented with information about where the code was mentioned, only in the interview or in the scoping review or both.

The synthesized findings of both methods will answer the main RQ. From here clear recommendations and lessons learned about the involvement of stakeholders in the development process were described, just as a clear timeline sketched on where to involve these stakeholders.

3. Results

Within the study, a scoping review and interviews were conducted. First, an introduction in the scoping review and interview characteristics are given followed by synthesized results matching the (sub) research questions.

3.1 Scoping review

3.1.1 Selection process

Six databases were searched for relevant literature. In total 907 articles were imported for screening, from which 253 duplicates were removed. In total four articles were added from snowball sampling. 654 articles were screened on title and abstract of which 512 studies did not match the inclusion criteria. In total 142 studies were screened on the full text of which 120 were excluded, the main reason for exclusion was a wrong target group (n=47). Other exclusion reasons can be found in *Figure 1.* In total 22 studies from 2015 to 2021 were included.

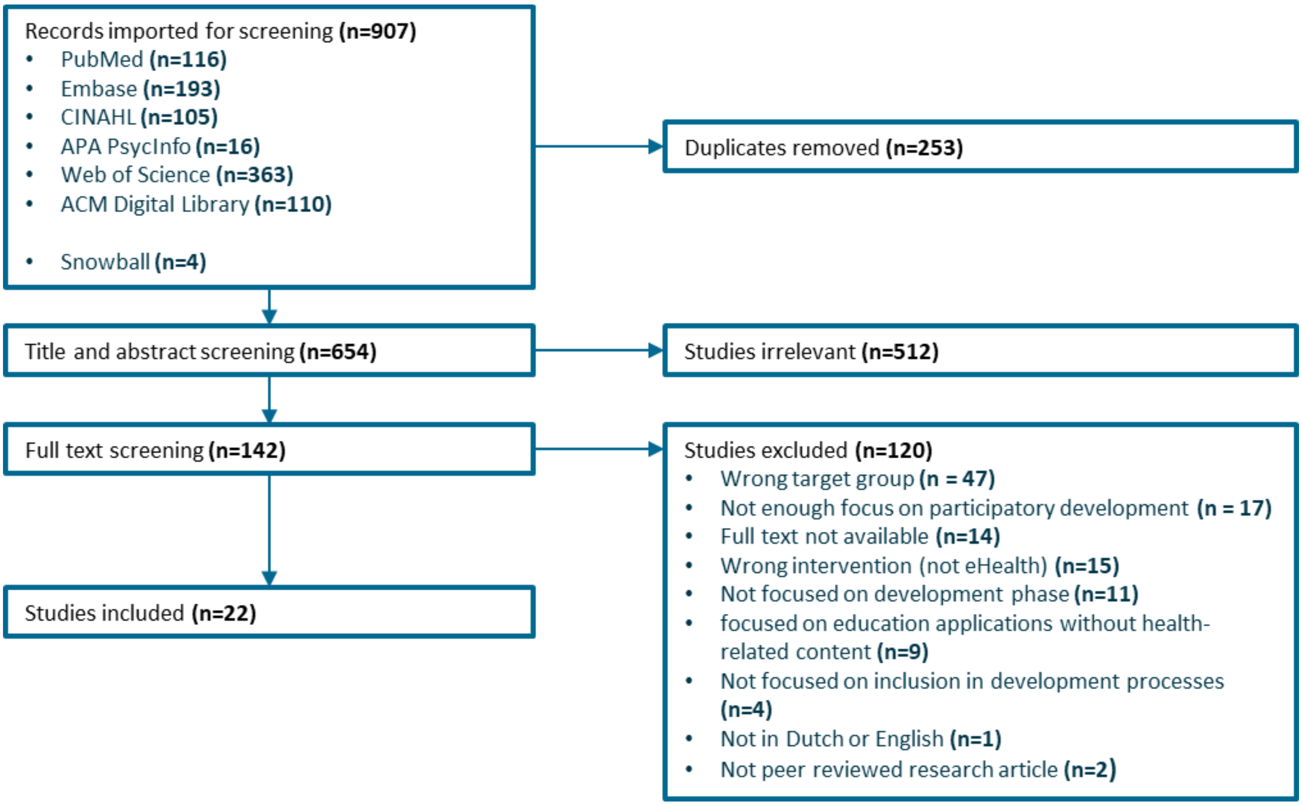


Figure 1: PRISMA flow diagram study selection process: literature studies scoping review

3.1.2 Included literature studies

A summary of the included articles and their general characteristics can be found in *Appendix G*. Most studies focused on people with ID, in which the ID is not always defined or includes a broad spectrum of ID (n=15). Most studies therefore aligned with Sitbon et. al. (2019), who stated*; " … we focused on the needs of the participants rather than their specific disabilities"* (42). Thus, studies mostly looked at specific skills a person with ID posed to be able to contribute to the development. Of the studies focusing on people with ID, five focused on young adults with ID (42-46) and three studies stated the severity of the ID (47-49). Three studies focused on children (50-52), four studies focused on people with Down Syndrome (DS) (51, 53-55) and two studies focused on different specific disorders (Prader Willi Syndrome (52) and Fragile X syndrome (56)). One study focused on ID and specific communication deficits (57) and three studies focused on ID and other mental disabilities (e.g., brain injuries and learning disabilities) (48, 58, 59).

Mobile applications were found most reported as the targeted eHealth intervention (n=17), a mobile application can be defined as a software application designed to run on mobile devices (60). Other technologies mentioned were virtual reality (n=2) (42, 44), serious games (n=1) (47), an interactive wall (n=1) (48) and computer game based technology (n=1) (50). An often-mentioned goal of these eHealth technologies was the development of a variety of skills supporting independent living. Some studies focused solely on very specific tasks such as medication management (58), navigating public transportation (45, 61) or making healthier food choices (55).

3.2 Interviews

A total of five interviews were held from the end of May 2022 until halfway through July 2022, interviews were held both at the location of the healthcare institute (n=2) and online (n=3). The interviewees characteristics can be found in *Table 1*. All interviews were conducted in the Netherlands and in Dutch. Two of the interviewees had experience in involving people with ID throughout the entire development process, the other three only had experience with PD in a specific part of the development process. The majority of the participants fulfilled a role similar to coordination innovation projects (n=3), from the other two respondents one had a role as a healthcare professional in ID healthcare and one was a PhD candidate.

Table 1: *Characteristics of the participants in the interviews*

Function	Function description	Role in eHealth development
Coordinator innovation	Implement new healthcare technologies for people with ID.	Clarify problems and questions within the organization and find suitable eHealth solutions.
GZ psychologist and program leader eHealth	Leading projects e.g., the B-Appy app.	Leading a development project for a new eHealth technology and looking at new eHealth developments that may be suitable for problems.
PhD candidate	Researching the application of technology for people with severe and multiple ID.	Researching and involving experience experts.
Healthcare professional Living Lab	Working with technological innovations and which products can be applied within a practice.	Testing and collaborating with people with ID in the usage of eHealth technologies. In between person.
Program manager health innovation	Coordinator health technologies for people with mild ID and misunderstood or risky behavior, e.g., living labs and innovation groups.	Providing feedback on existing technologies and supporting the development of an e-module treatment program.

3.3 Development frameworks, models and approaches

From the identified studies obtained in the scoping review, almost all (n=20) described their used framework, model or approach. In total 22 different frameworks could be identified, these frameworks and their description can be found in *Table 2*. Within this table, the focus is solely on the frameworks identified in the scoping review as the mentioning of the frameworks in the interviews were scarce. Even though there was a wide variety of frameworks identified in the scoping review, some studies used the same framework or approach. The specific use of the participatory design approach (n=3) (55, 57,

62) and the user-centered approach (n=5) (48, 53, 54, 59, 63) was emphasized in different studies. The reflective agile iterative design (RAID) framework (n=2) (43, 46) , agile approach (n=2) (52, 56) and universal design (n=3) (45, 59) were also used in multiple studies. Of the total 20 studies containing a framework, model or approach only 13 studies gave a clear description of the decision made to use the framework. Some of these studies gave an extensive description of the importance and benefits of their used framework. The study by Augusto et. al. (2017) used for example, a User-centered intelligent environment development process (U-C IEDP), which is described as a model more tailored for end users, based on the fluid dialogue used with stakeholders (53). Another example is the RAID-model used in the study of Wilson et. al. (2016), which emphasizes the use of prototypes and states that these are important to use when working with individuals for which abstraction of thoughts is difficult (46). Different frameworks and models align in centering the user, such as the human-centered design approach (61), Inclusive Design for Individuals with Down Syndrome (ID4IDS) methodology (51), RAID framework (43, 46), statement of inclusive health research (47) and user-centered design (48, 53, 54, 59, 63). Universal design which focuses on design for all and not so much focusses on one specific user was mostly used for the development of criteria or specific components for an eHealth technology, for example, audiovisual app components (45). Next, other frameworks and models also aligned in including different stakeholders, with examples as the Delphi technique (58), the medical research council's framework for complex interventions (49), the resource-oriented approach (62), the team science approach (56) and a transdisciplinary approach (58).

Compared to the broad mention of frameworks in literature, within the interviews, not one interviewee directly mentioned using a framework. After giving a more extensive explanation about what can be seen as frameworks and models and asking more deepening questions. Three interviewees mentioned a model that could kind of pass as used frameworks in their eyes. One interviewee mentioned using a Delphi study which was also mentioned in the identified study by Salgado et. al. (2018) (58). Another interviewee mentioned knowing different methods for the development of innovations, but not being a fan of working with these, addressing not wanting to use predefined ‘Lego’ blocks for innovation. This interviewee mentioned using ‘the dialogue’ which referred to open communication with each other. Another interviewee who developed an e-module treatment program used the ‘customer journey’ for this. The customer journey was part of the treatment process which looked at how eHealth could play a role in that process.

Table 2: Frameworks, models and approaches with the description of a framework: identified in the scoping review

Frameworks, approaches and models used	Description of frameworks, approaches and models	Sources
Accessibility guidelines	Supporting the development of design criteria by giving information about the accessibility guidelines for public transportation for people with ID.	(45)
Action engagement	Iterations of the action engagement cycles improve the quality of professional development. By undertaking different steps towards building mutual trust.	(50)
Action research methodology	Action research emphasizes evidence-based research and values the everyday experiences of the users that can be applied to generate actionable knowledge.	(50)
Feature-driven process	Feature-driven development is an iterative and incremental software development process.	(56)
Agile approach	An agile approach is a technique in the development of software in which requirements and solutions evolve	(52, 56)

	through collaboration between self-organizing, cross-functional teams.	
Competency-based approach	Focuses on revealing and designing with users' competencies. It is grounded in leveraging users' competencies.	(43)
Delphi technique*	An approach to answering a research question by gathering the opinions of experts on areas of interest. Allowing reflection and reconsideration of opinions based on anonymized opinions of others (64).	(58) **Mentioned in one interview*
design science research (DSR)	A qualitative research approach in which the object of the study is the design process (65).	(57)
Human-centered design	Centering users in the development process.	(61)
ID4IDS methodology	In the ID4IDS methodology, a design thinking approach is used. It is a methodology to include people with DS, using the creativity of individuals with DS to enrich the final design.	(51)
Iterative ethnographic design process	Here each iteration consisted of discussing requirements and questions and then presenting them to people with ID for verbal and behavioral feedback.	(42)
Iterative testing and refinement approach	Enchases the innovations beyond what was early developed, delivering value and more efficient and responsive products.	(56)
Medical research council's framework for complex interventions	Helps researchers collaborate with other stakeholders to identify the key questions about complex interventions. Also supports conducting research with a diversity of perspectives (66).	(49)
Participatory design approaches	The approach in which innovations are developed 'with' instead of 'for' the users. Active involvement throughout the development process (15).	(55, 57, 62)
RAID framework	An approach which engages people with ID as full partners in collaborative design.	(43, 46)
Resource-oriented approach	An approach which involves the caregivers and support workers to assist with the implementation of the intervention.	(62)
Statement of inclusive health research	The research includes or involves people with ID as more than a research object (67).	(47)
Team science approach	Bringing together different disciplines that can address problems more effectively (68).	(56)
Theory-guided approach	Application of a theory in research including quality improvement and knowledge development (69).	(63)
Transdisciplinary approach	A research approach that integrates knowledge across academic disciplines and with non-academic stakeholders to address challenges (70).	(59)
Universal designs	Designing products that are usable for the 'general population' (71).	(45, 59)
User centered approaches	An approach which places the user in the center of the design (72).	(48, 53, 54, 59, 63)

3.4 Identified stakeholder groups

Both qualitative research methods allowed for the identification of stakeholder groups who could be involved in eHealth development for people with ID. The identified stakeholder groups found in *Table 3* are categorized into seven main groups. In this table people with ID are not included, noting that in both literature and interviews people with ID were always part of the development and therefore always identified as stakeholders. An important remark here is the mention of the involvement of people with severe ID which was lacking in the literature. Studies mostly looked at what was needed to contribute to the research and development, resulting mostly in the person with ID being able to use the technology or provide feedback (42, 43). The participants in the identified studies were mostly people with mild ID, which aligned with the interviewees who also mentioned mostly involving people with mild ID. Two interviewees mentioned that involving people with a severe ID is difficult. One of these interviewees mentioned that involving people with a development age under two years is almost impossible, but later suggested involving relatives when wanting to involve people with severe ID and stated that, when possible, people with severe ID should be involved. The other participant highlighted that involving a person with a severe ID was certainly possible.

Table 3: Identified stakeholders groups from literature and interviews

Main and subcodes	Definition of codes	Literature[1]	Interviews[2]
Healthcare professionals		12/22	3/5
Support workers	Regarding healthcare professionals such as nurses, social workers, caregivers and support workers for activities. Support workers are working in direct care for the person with ID and are closely involved in their lives.	10/22	3/5
eHealth-specific healthcare professionals	Healthcare professionals as; behavior scientists, psychologists, remedial educationalists, occupational therapists, speech therapists, positive health advocates, lifestyle coaches, physicians and experts familiar with ID. The involvement of these professionals is dependent on the technology and can be direct or indirect.	5/22	2/5
Relatives		9/11	4/5
Parents*	Parents of the person with ID.	6/22	2/5
Relatives	Regarding family members or friends who are actively involved in the lives of people with ID.	2/22	4/5
Research stakeholders		9/22	1/5
Researchers	Researchers who are researching the development of a (new) eHealth technology.	8/22	-
Co-researchers	People with ID who work as co-researchers. In which they contribute to making scientific research more inclusive.	2/22	1/5
Technical stakeholders		7/22	2/5
eHealth designers**	Stakeholder who is responsible for creating the eHealth technology.	6/22	1/5
IT	Stakeholders who maintain the technical aspects of the eHealth technology.	1/22	1/5
Schools/universities		7/22	1/5
Students	Students at universities and the universities themselves help with the eHealth project.	2/22	1/5

Specialized teachers	Special schools for people/children with ID and involvement of (special education) teachers and other educators and support organizations tutors.	6/22	1/5
Organization stakeholders		4/22	4/5
Board of directors	Governing body of the company or organization.	-	1/5
Companies	Companies with interest in eHealth technology or producers of the technology.	1/22	1/5
Management	For the application of the eHealth technology within the organization as well as the financial picture.	1/22	2/5
Project leaders	Project leaders and consultants leading the project.	2/22	-
User organizations	Organizations are related to users so in this case people with ID.	1/22	-
Extern eHealth advisor	eHealth advisor that is not connected to the healthcare organization.	-	1/5
Other		1/22	3/5
Ethical points	Involve people with experience in ethical viewpoints towards eHealth.	-	1/5
Privacy	Involve stakeholders who can guarantee the privacy of the eHealth technology users.	-	1/5
Infrastructure	Stakeholders as bus drivers and local authorities.	1/22	-

[1] *Number of articles the code is present/total number of included articles*

[2] *Number of interviews the code was mentioned/total number of conducted interviews*

**Three studies mentioned the involvement of parents including children with ID*

***eHealth designer was in some articles also the researcher conducting the study*

Support workers were the most mentioned stakeholder group as seen by literature. interviewees mentioned the involvement of relatives as the biggest involved group. Within the interviews, one interviewee mentioned that the biggest focus should be on involving people with ID. Followed by two interviews stating that the main stakeholder focus should be on the support staff of people with ID. Three interviews mentioned the importance of involving people who are close to the person with ID in the development. One of these interviewees said:

> *"Support staff (3x) and the relatives who are closest to the client are the most important."*

These support workers and relatives have direct involvement in the development process. Just as the persons with ID. The studies by Augusto et. al. (2017) and Engler & Schulze (2017) divided these into the primary users; the persons with ID and the secondary users; support workers and relatives (53, 54). The involvement of research stakeholders, technical stakeholders, schools/universities and organizational stakeholders could be direct or indirect depending on the specific research conducted. An example of this could be the direct involvement of engineering students in the research by Kang et. al. (2020). In which the students were working together closely with children with ID (50). The indirect involvement of universities was mentioned by one interviewee, which stated that universities could help advise about technology.

3.5 Current involvement of stakeholders and people with ID

The current involvement of stakeholders and people with ID is described in the following subsection. Topics covered include communication, the activities and roles of people with ID and other stakeholders in the PD process, as well as PD applications and methods. This extends to the problems in the current situation of conducting PD.

3.5.1 Communication and approaches towards people with ID and other stakeholders

From both literature and interviews, communications methods and approaches toward people with ID could be derived. These can be found in *Table 4*. Four interviewees emphasized that a clear explanation towards the person with ID was needed. One participant said the following about communication:

> *"… and need to keep communicating with them [people with ID] so they know what is expected of them."*

The main focus in the literature was on the understandability and use of easy language (n=9). Followed by making the person with ID feel at ease, both in their environment and with the use of the technology (n=6).

Table 4: Communication and approaches from both interviews and literature ***toward people with ID***

Main codes	Description of code	Interviews	Literature
Do not overwhelm people with ID	Do not overwhelm people with ID by over asking, approaching them last minute and constantly dropping tasks on them.	3/5	-
Explain what is being asked	Explaining what happens with data, what is asked of individuals and what they have to do. Also, for removing the stigma on ID.	4/5	-
Feeling at ease	Make a person with ID feel at ease by creating a safe or known environment. Make them feel comfortable with the technology they have to use and make them feel at ease with peers and other stakeholders.	1/5	6/22
Getting to know a person with an ID	Get to know the person with ID and build trust and a friendship. Get insight into ideas and interests and ID in general.	2/5	4/22
Familiarity	Let a person with an ID be assisted by a familiar person, for easier contact.	1/5	3/22
Time to adapt	Give a person with ID enough time to be prepared and comfortable in their surroundings. Also, consider that more time is needed to adapt to the technology.	1/5	2/22
Understandability/easy language	Communication towards people with ID and the used technology should be adapted to their communication levels. Thus, be easy to understand and simple, while also making sure that the person with ID understands what is being asked of them.	3/5	9/22

The following table *(Table 5)* underscores the approach and communication tactics toward other stakeholders who can be involved in the development. These codes were scarcely mentioned in both literature and interviews. With a maximum occurrence in two of the interviews and one study. Two codes, keep communicating and keep stakeholders up-to-date were both mentioned in the literature and the interviews. Regarding keeping stakeholders up-to-date, Augusto et. al. (2017) emphasized that a process should be put in place to secure dialogue with stakeholders and developers so that each party can be respected in their expertise (53).

*Table 5: Communication and approaches from both interviews and literature toward **other stakeholders***

Main codes	Description of code	Interviews	Literature
Be open and transparent	Be open and transparent about the development process towards stakeholders.	2/5	-
Connecting person	Have a connecting person as a stakeholder who knows the target group and the technical side of healthcare. Allowing to bring different stakeholders in contact with each other more effectively.	2/5	-
Involvement guide	Have a guide for whom to involve in the development of the technologies. Allowing to see who can help within this process.	2/5	-
Keep communicating	Keep communicating fluently with stakeholders throughout the entire development process.	2/5	1/22
Keep up to date	Keep stakeholders up to date to avoid surprises.	1/5	1/22
Maintain strong connection	Maintain a strong connection with stakeholders to gain a better understanding of interaction ways.	-	1/22
Trust	Trust is needed among stakeholders	-	1/22

3.5.2 Involvement in the development

The actual involvement of the people with ID in the development process of eHealth technologies can vary between the developed technology. A person with ID can adopt different roles and conduct different activities to contribute to the development. *Table 6* shows these roles and activities. Both in literature and the interviews the most named activities in which people with ID contributed to the development were providing feedback and their opinion (n=4 and n=10) and testing the prototype (n=4 and n=10).

Table 6: Person with ID's roles and activities in the involvement in the development process of eHealth technologies

Main codes	Description of code	Interviews	Literature
Demonstrating the use of already existing technology and daily life skills	People with ID showed how they do everyday tasks or how they use already existing technologies and apps.	-	4/22
Observed in the learning of using technology prototype	People with ID are observed in how they learn to use the eHealth technology created in the development process.	-	3/22
Observed in using eHealth	People with ID get observed using eHealth technology.	1/5	9/22
Providing impressions, opinions, advice and feedback	People with ID give feedback, their opinions and advice about eHealth. Done in different ways.	4/5	10/22

Receive information about technology	Having an active listener role, in which the eHealth idea is explained to a person with ID.	-	2/22
Testing prototype	The person with ID tests the eHealth prototype/concept version.	4/5	10/22
Testing understandability and use of eHealth	People with ID test if they understand the eHealth prototype. Or are being tested if they understand the content of the eHealth technology.	-	5/22

Next to people with ID, other stakeholders were also involved in the development process. Their role is divided into four main activities. These roles can be found in *Table 7*. The first role in which stakeholders contributed themselves to the eHealth development was separated into different activities. The main activities other stakeholders undertook were found to be giving feedback and advice (n=7). Contributing of the stakeholder themselves to the eHealth technology was the most undertaken activity of the four roles, according to literature (n=10). Another significant role could be seen in helping the researchers with observing and interpreting people with ID (n=1 and n=7). About interpreting the needs of a person with an ID, one interviewee mentioned that other stakeholders can be too quick with filling up the actual needs of a person with an ID with their interpretation of needs. Another interviewee aligned with this by saying the following about not being able to involve people with ID:

> *"I should mainly, I think, involve the relatives. But yeah, then you still do not have the person themselves. And is it still an interpretation of a relative."*

In the study by Torrado et. al. (2020), the needs of people with ID were interpreted by caregivers, family and experts (59). Another way in which the stakeholders helped with observing or interpreting people with ID, was for example with confirming answers a person with ID gave (57), or by giving feedback on the observations towards people with ID (42).

Table 7: *Involvement of other stakeholders separated into four different roles. supplemented with sub-activities if needed.*

Main and subcodes	Description of Code	Interviews	Literature
Contribution themselves to eHealth technology		-	10/22
• Giving feedback and advice about the technology	Giving feedback, their opinions and advice about the eHealth technology for people with ID.	-	7/22
• Contributing to design sessions	Contribute to design sessions, e.g., as co-creators	-	3/22
• Discussing ideas	Discussion of ideas for eHealth	-	1/22
• Reporting problems	Reporting problems in the eHealth technology people with ID are using.	-	1/22
• Testing of the eHealth technology	Testing of the eHealth technology.	-	2/22
Encouraging people with ID to use technology	Motivating and encouraging people with ID to use the eHealth technology and to help in the development.	1/5	3/22
Helping researchers with observing and interpreting people with ID	Helping the eHealth technology staff or the researchers with observing the person with ID or with interpreting their reactions and needs.	1/5	7/22

Supporting and helping people with ID in testing technology*	Support people with ID in testing the eHealth technology the person with ID is using.	1/5	4/22

One literature study in this code category concerned a child being supported in using technology

Next to separate activities people with ID can conduct, some activities were also suitable for conducting together with other stakeholders, these are described in *Table 8*. These codes were divided into two main categories. The first describes activities done to participate in the development as providing feedback and testing eHealth. The second category mentions the setting of the involvement. One code mentioned here is equality. In the research by Derks et. al. (2021) researchers and co-researchers with ID were seen as equal partners, who worked side by side and were equally important at presentations at congresses and meetings (47). One interviewee also really highlighted equality and conducting an equal conversation with people with ID in which they could openly give their opinion. While another interviewee sketched a situation of a client with ID who was able to visit a tech company and helped in presenting the technology that could help him. The participant said the following about this situation:

> *"But just the fact that he [the person with an ID] was able to visit [the tech company] and that people took him seriously, that he was seen as a normal person. That was for him important."*

Table 8: *Development process involvement of* ***both*** *stakeholders and people with ID* ***together*** *in the involvement*

Main and subcodes	Description of code	Interviews	Literature
Actual involvement method			
Asking for feedback	Both are being asked for feedback on the eHealth technology.	-	2/22
Both testing and using eHealth technology	Testing or using an eHealth technology together.	-	3/22
Observed in daily activities	Being observed in conducting daily activities by support staff and people with ID.	-	1/22
Talking about technology	Persons with ID and support staff talk together with researchers/developers about elements of the technology.	1/5	1/22
Setting of involvement			
Equality	Here people with ID (co-researchers) work side by side and together as equal partners.	2/5	1/22
Mixed groups	People with ID work together with other stakeholders in advisory groups, just as being paired with support persons or relatives in the development process.	1/5	3/22

About the involvement of people with ID and other stakeholders, separately or together, a lot of information was extracted and is discussed within this subchapter. Some literature studies and interviews made a clear statement about if people with ID should be separately involved or together. These can be found in *Table 9*. Elbæk et. al. (2018) stated that it was valuable to connect to staff and ID separately to achieve pure insight (48). But also mentioned that the interplay between people with ID and staff provided valuable insights (48).

Table 9: *conducting development and design activities separate between support staff and people with ID, or interplay of design activities together.*

Main and subcodes	Description of codes	Interviews	Literature
How to involve people with ID and their support staff/carers in development activities?			

Together	Involve people with ID and support staff only together in development.	-	-
Separate	Involve them separately to achieve purer insights.	1/5	1/22
Both	Involve them both separate and together.	2/5	1/22

3.5.3 Moment of involvement in the development process of people with ID

In the following subsection, only people with ID are considered. The moment or iteration at which a person with ID is involved in the development process is described. The involvement of other stakeholders is done in the entire process. Here only the stakeholders who are involved vary between iterations, therefore the focus here is solely on people with ID.

In *Table 10* the moment at which people with ID participate in the development process is described. Given that some literature studies which were included only focused on one stage of the development process. For example, some studies, such as the one of Salgado et. al. (2018), did not describe the last development iterations because the technology still had to be further developed (58). Some articles also did not mention the state of involvement of people with ID in the development process.

Table 10: *Table with information about in what moment people with ID participated in the development process of eHealth technologies from both interviews and literature.*

Main codes	Description of code	Interviews	Literature
Beginning	People with ID participate at the beginning of an eHealth development, they are asked about ideas and problems they see and are involved before the eHealth will be designed. (Input for ideas for eHealth)	2/5*	7/22
During	Involvement of people with ID when the new eHealth idea is being actively developed and tested. (Input for ideas in the eHealth)	4/5	22/22
End	People with ID are involved when the eHealth technology is almost completely developed and can be tested in a pilot if it fits the target group.	5/5	16/22
Entire process	People with ID participate in the entire development process from beginning to end. Also, in the idea-generating process.	2/5	7/22

**Only two out of five interviewees mentioned involving people with ID from the beginning, but the importance of this was mentioned 4/5.*

When looking at each iteration cycle in the process, only two out of five interviewees mentioned that the eHealth idea input came from people with ID themselves. But four out of five interviewees highlighted that they found involving people with ID from the beginning important. In one interview the eHealth idea input for people with severe ID was mentioned to come from the healthcare professional. In another interview, the idea came from governmental organizations. Next, all interviewees mentioned involving people with ID at the end of the eHealth development, but only four during the development process. These four interviewees had a common opinion about involving people with ID from the start of the eHealth development to not miss important points. One of these interviewees said the following about involving people with ID:

> *"I believe that behind a desk, you can start inventing all sort of things. But you never know what another person's point of view is. If you do not hear, if you do not see it and if you do not participate in*

> *it. So, you have to include people from the beginning. That involvement, because even when I think, I put myself in the shoes of: I miss a lot of things."*

The other remaining interviewee stated that people with ID should be involved when the product is almost finished. The interviewee experienced involving them earlier could lead to missing the goal of the technology created. Because people with ID want to add all kinds of different things that do not fit with the aim of the technology. Involving them at the end seemed the most fitting according to the interviewees experience. When asked by the interviewer if the end of the development process is the best part to involve people with ID, the interviewee responded with the following:

> *"Yes, and it can be, I think, also be too much, too overambitious for them [people with ID]."*

Also specified by two interviewees was the importance of developing an eHealth step by step. Asking for feedback in each step was deemed to be necessary. Just as, constantly returning to a previous stage in the development when something did not work. Different studies (n=6) also mentioned the importance of going back in development iterations before moving to the next stage (42, 46, 50, 58, 61, 62). By applying new information learned from a previous iteration in a new one (42), or by going back and forth in iterations until the task performance of users was improved (50).

3.5.4 People with ID in the development

Being involved in the development has its effects on a person with an ID. From the conducted interviews effects on people with ID, pitfalls when including them and different problems came alight. Therefore, the main focus in this subsection is on these effects as mentioned in the interviews.

In *Table 11* the current effects on people with ID are described, three interviewees mentioned benefits for people with ID when they are allowed to think along in the development of eHealth. One of these interviewees together with two others also mentioned problems occurring in people with ID when they participate in the development. One interviewee specifically mentioned what could be the reasons people with ID do not want to participate in the development.

Table 11: *Current effects* ***on*** *people with ID When they participate in the development (only from interviews)*

Main and subcodes	Description of code	Interviews
Benefits for people with ID		3/5
Being included and taken seriously	People with ID can feel that they are being taken seriously and included.	1/5
Giving a feeling of importance	People with ID get a feeling of importance because they can make decisions in the development process of an app for themselves.	2/5
Participate in society	Get a feeling of participating in society.	1/5
Problems occurring among people with ID during the development		3/5
Pressure	People with ID can experience pressure from being involved in the development process of eHealth technologies.	1/5
To responsible	People with ID feel too responsible when they get involved in the development.	1/5
Hard to tell what they want or think.	People with ID find it hard to say what they want and what they think about eHealth. Having problems with making it abstract.	2/5
Language problems	Language can be hard to understand for people with ID.	1/5
Tense	People with ID can get tense when going to another environment.	1/5

Overambitious	It is too overambitious for people with ID to be involved in the entire development process.	1/5
Reasons people with ID do not want to participate in the development		1/5
Not wanting to give an opinion	Not every person wants to participate in development.	1/5
Not participate in equal healthcare	Not all people with ID want to participate in equal healthcare in which the person with ID also has a lot of input.	1/5
Not wanting to be seen as a person with an ID	People with ID do not want to be seen as people with ID.	1/5
Not wanting to represent the target group	People with ID do not want to represent the target group in testing eHealth.	1/5

The reasons why a person with ID does not want to participate are mentioned in only one interview. The following quoted part of the interview could be linked with these reasons:

"People do not want to be seen as someone with a mild intellectual disability. For example, you will ask someone; "Hey, do you want to test this for me?" and then they say; "Well, I won't do anything with it, so why should I test it? What should I do with it and why are you asking me?" (…) "Well, I will not want to be the representative of that target group, because I am just a human." (…) Yes, people do not see themselves as part of the society, but more of a: I am just somebody who is just needed to think along for a bit."

Further explaining that there could be a stigma on having an ID. Later suggesting that this stigma can be removed by giving a clear description of what is needed from them. To help them open up to participate in development.

Another mentioned perspective regarding people with ID by another interviewee stated that people with ID want to think along and give their opinion. One interviewee also mentioned that a person with an ID wants to help others. Further, four interviewees mentioned that involving this target group resulted in more valuable information and new insights. In *Table 12* other benefits of involving people with ID are described as well. One interviewee described a benefit of the involvement of people with ID in eHealth developments as followed:

"That it is probably just really fun and very informative"

Table 12: Research and eHealth benefits from involving people with ID and stakeholders

Main and subcodes	Description of code	Interviews	Literature
Benefits from involving people with ID in the development		5/5	1/22
Better (fitted) eHealth technology	The eHealth technology will be better and fits better with the needs of people with ID.	3/5	-
A better understanding of people with ID	A better understanding of a person with ID when involving them.	2/5	-
Fun and informative	Involving people with ID is fun and informative and it makes people with ID more enthusiastic!	2/5	-
More value information and new insights	When involving people with ID new insights and a new angle of view are provided. Having another vision than expected. And therefore,	4/5	1/22

	new ideas and valuable information can be gathered.		
Positive experience	People with ID have a positive experience in helping in the development.	1/5	-
Target more population	When involving people with ID in general eHealth development, more populations (the target group) can be targeted.	1/5	-
Benefits from both involving people with ID and other stakeholders in the development.		-	1/22
Honest reporting	Caregivers can help ensure honest reporting by people with ID.	-	1/22
Make eHealth more usable	Caregivers can help personalize the eHealth to make it more usable for participants.	-	1/22
Insight into opportunities and limitations	Getting insight into opportunities and limitations the technology is focused on.	-	1/22

Also mentioned in the interviews, were certain pitfalls and reasons to not include people with ID. These can be found in *Table 13*. A reoccurring topic in one of the interviews was the representation of the target group. In this interview was voiced that when involving one user with ID, for example, that this user then represented the entire target group of people with ID. Saying that this is not the case because the diversity within the target group is huge. So having a large group of people with ID who can be involved and provide feedback is deemed to be desirable. Also mentioning that it can be extremely hard to get a good representation with different people from the target group. Another interviewee also complemented this mentioning that it is already hard to find people with ID who want to be involved. Not even yet taken into account the vulnerability of this target group who can have other (health) priorities than contributing to an eHealth development, as said by one of the interviewees.

Table 13: *involving people with ID; pitfalls, problems, and reasons not to include people with ID (only from interviews)*

Main and subcodes	Description of code	Interviews
Pitfalls when involving people with ID		3/5
Cannot ask: “What do you want?”	It is too broad to just ask a person with an ID “What do you want?”	1/5
Deciding for people with ID	Complement to fast what people with ID want and therefore deciding for people with ID.	2/5
Not knowing a person with an ID	Hard to involve people with an ID you do not know in a development process.	1/5
Pushing ideas in certain directions	Pushing an eHealth idea in a certain direction for people with ID.	1/5
Representation of target group	One person with an ID cannot represent an entire target group. Just as only involving proactive people with ID	1/5
Problems for the eHealth technology		1/5
Missing goal	When involving people with ID in the (entire) development process they can miss the goal of the eHealth product.	1/5
Wanting more	People with ID can want more than where the eHealth technology is made for.	1/5
Reasons to not include people with ID		4/5
Hard finding good representation	Hard to find a good representation of people with ID, partly due to the huge diversity within the ID population.	1/5

Hard to find people to involve	It can be hard to find people to involve in the development process.	1/5
Hard to involve people with severe ID	It can be hard to involve people with severe ID.	2/5
Extreme opinion	People with ID's opinion about eHealth is in the extreme	1/5
Vulnerable group	People with ID are a vulnerable group who can have other priorities than participating in eHealth development.	1/5

3.5.5 Application of PD

Another matter coming forward in both literature and the interviews was the settings of PD sessions. Some articles and participants mentioned how they involved people with ID, for example, in one-on-one sessions or group sessions. A preference for real-life conversation was given by two interviewees but knowing that this was not always possible in the past due to the Covid-19 pandemic. Next to this, also other points regarding a session derived mainly from literature. Such as what was done at the beginning of a PD session and what was done during a PD session. Just as the mindset during these sessions was mentioned in two studies (46, 58). These PD session formats and structures can be found in *Table 14*.

Table 14: *PD session formats and structures*

Main and sub codes	Description of code	Interviews	Literature
Beginning of session		3/5	2/22
Explaining what is being asked of the person	Before each workshop participants were briefed on the study structure and explained what is being asked of them, what the purpose is and what they have to do.	3/5	2/22
Instruction about eHealth technology	Instructions about how to use eHealth technology and what the purpose of this technology is (sometimes by video).	1/5	1/22
During session		-	1/22
Breaks	Comfort breaks between each task for a person with ID.	-	1/22
Open mind		-	2/22
Free in participating	Participants were able to participate in all rounds or less in wanting to.	-	1/22
Free in using the app	Users were given freedom in how to use and interpret the app.	-	1/22
Setting		4/5	3/22
Accessible open talk	Having an accessible and open talk with people with ID.	2/5	-
Group sessions	Having group sessions, also with other stakeholders. For example, in soundboard groups or advisory groups.	1/5	1/22
One-on-one sessions	Smaller one-on-one session with a person with ID.	1/5	1/22
Real-life conversation	Better communication when speaking with someone face to face, these types of conversations with people with ID are preferred instead of online ones.	2/5	-
Workplace for people with ID	Workplaces where people with ID work together with others.	3/5	2/22

Set up a group	Sitting around the table ensuring collaboration, interaction and supporting each other.	-	1/22

Consequently, in the PD session format and structures, it was emphasized by one interviewer to critically look at the context in which people with ID could think along, hence, implement a PD session. The interviewee said the following about involving people with ID:

"Well, of course, you cannot give complete control at all times on every level, so where do you draw the line? So that you do honestly ask, where you choose, thinking along is asked? That it is also suitable, so to say."

Stating that the right context to think along or participate in the development is needed. The study by Robb et. al. (2019) also named this fact (52). By stating that there should be reflected on the usefulness of people with ID to contribute to PD before allowing people with ID to engage within PD. Next focus on the parts of PD that people with ID can reasonably be expected to contribute to.

Next to the different settings conducted for PD, mainly in literature different methods were emphasized. The different methods can be found in *Table 15*. The most named methods were the use of images and letting people with ID choose between different versions of an eHealth technology.

Table 15: *PD session methods*

Main codes	Description of code	Interviews	Literature
Choosing	Let people with ID choose between or vote for the prototype version/option they like best.	1/5	5/22
Icebreaker and warmup sessions	Have icebreakers or warmup sessions to let people feel at ease and get comfortable with the development tasks.	-	2/22
Using images	Provide visual help and cues, pictures and image boards. Provide this in an immediate form and translate verbal comments into visual images (e.g., with sketches). Visualize the ideas.	1/5	4/22
Paper mock-ups	Create paper prototypes or mock-ups to test interaction flow. This also allows people with ID to place and move the paper objects to various positions in the mock-up. Some paper objects can be specified (as a back button) or can be left blank for a person's interpretation.	-	2/22
Sticky notes	Use sticky notes to capture concepts in real-time and to show that what is said by people with ID is not set in stone.	-	3/22
Storyboarding	Create storyboards (e.g., by a graphic designer). Allowing verbal comments to be translated to drawing can be a way to get comfortable with the development workshops.	-	2/22
Thinking aloud	People with ID were prompted to "think aloud"	-	1/22

3.6 Best practices and lessons learned

3.6.1 Most emphasized practices and lessons from the interviews

From both interviews and literature, best practices and lessons learned came forward. Firstly, focusing on the interviews. According to one of the interviewees, the most important thing in PD of eHealth is 'expectation management'. Explaining that it is important for a user to discover if technology will fit their needs. And mentioning that it can work, but that it still depends on the user and the context if it will fit their needs. The same applies for support staff who came with a problem for which they wanted a suited eHealth technology. This interviewee said the following about a problem that could be brought in:

> *"If you come to me with a question, I always say, I will try as hard as I can to solve the problem. But I don't promise you that I have an answer for you next week, also not in two weeks. In some cases, it can take up to two years before I can come to you with an answer or an impossible solution. But know, that I always keep it in mind."*

Stating that it is important that people know that an answer does not always come right away and that it can take time. Also mentioning that a disadvantage of involving people with ID can be that they want to hope or wish for more than what is available. Making clear what can be expected of technology or the 'expectation management' is, therefore, even more important. A second statement this participant makes is that an entire team must support eHealth development. Stating that from his experience, 'expectation management' towards other stakeholders is also important.

One of the other interviewees named equal conversations between stakeholders and people with ID one of the most important things for an eHealth development, as mentioned earlier in *subsection 3.5.1* and *Table 8*. Saying it is important to tell people with an ID that you came up with something and what they think about that; does it fit? Are we on the right way or not? Just again highlighting the importance of an equal conversation between a developer and a person with ID. Regarding other stakeholders, this participant also said that keep communicating and updating the stakeholders is most considerable. Emphasizing the fact that open, transparent communication seemed to work best in their eyes. Also, about things that went wrong in the development. So being transparent about those also really helps others to know they can rely on you.

Immersing yourself in the target group is one of the tips one other interviewee gave about what he learned from his experience. Stating that it is important to adjust your overall communication to the level of the person with an ID and know whom you going to work with. For example, do not use expensive words in a presentation in which a developer tries to sell an eHealth product. Underscoring the fact that people with ID are less likely to ask a question when they do not understand something. Resulting in that they do not understand what is going on, even though they may have great ideas. The participant stated the following:

> *"But due to an expensive word, to put it another way, the person [with ID] does not understand and then wonders; "But what should I do now" (..) when you are in a classroom, and you do not understand something. Not every person will raise their finger. (..) And for them, the threshold is the same, maybe even higher, than it would be for someone without a disability. You must considered the person in front of you."*

Also mentioning that you can think you know someone on paper, but that still does not mean you know that person in real life. Next to knowing the target group, this participant also mentioned that it is important to establish an environment in which a person with an ID feels at ease.

The experience of another interviewee is that the connection of a person with ID towards eHealth technology can be very individual. An eHealth technology can have the potential to work well for one person with ID but cannot work for someone else. Stating that it is therefore important that the person with ID can test the eHealth and gets guided in the use of the technology. Saying that you do not always know if an eHealth will fit a person with ID and how they will use it and that is, therefore, also important to keep an eye on this. This could align with the view on eHealth of another interviewee, who says that eHealth solutions for big or multiple groups do not work.

3.6.2 Literature best practices and lessons learned

A few of the identified literature studies from the scoping review were noticeably clear in describing the exact development process and how people with ID were included. One of these studies was the research conducted by Lazar et. al. (2018), in which a participatory design approach was executed for a mobile application for people with DS (55). In this development process, three cycles of design workshops were held, in which storyboarding was central. The design sessions started with a warm-up period in which a storyboard drawer, drew avatars of people with DS who were present in the sessions, expressing their interests and hobbies. The following about this storyboarding approach could be quoted from the study by Lazar et. al. (2018):

> *"This extended and highly visual warm-up period was believed to be essential to help the self-advocates learn about one another using a visual medium with which they are comfortable, as well as to help them get comfortable with the story-boarding process throughout which their verbal comments would be translated into visual representations (55)."*

Further, storyboarding was used to visualize the ideas and experiences of a person with DS and other people with DS could add to this experience. After the storyboarding experience, a paper prototype was created. This allowed for an effective and quick interaction flow of the 'to-be-developed' mobile application. The paper prototype complemented with sticky notes had the additional benefit that it was clear to the people with DS that nothing in the design was set in stone and that they could easily contribute to the design. After creating the initial paper prototype a larger one was drawn, which showed different scenarios of the mobile application. People with ID and caregivers could then add sticky notes to the prototype adding comment and new ideas. This study further highlighted the importance of using primarily visual cues in the development process. Because of this visual strength in people with DS, providing immediate visual feedback in the form of sketches was useful. Other main PD approaches in this study, included involving people with DS themselves but also their parents or caregivers. But also taking extra time to get the person with DS comfortable by using storyboarding. This approach specifically was new and turned out to be highly successful in getting a person comfortable. Lazar et. al. (2018) therefore believed that these approaches will ensure the eventual success of the project (55). Other lessons derived from this study were that the needs of people with ID are individual and using a framework does not make the technology more useable for this group. Also, including caregivers or parents was needed because not all participants with DS were able to explain their motivation and the choices they made. Parents and caregivers, on the other hand, could (55).

Another study by Robb et. al. (2019) is at odds with the earlier named approaches (52). Stating that the support of parents and simplified information with visual elements stand for a successful development when involving people with ID. Including a wider range of disabilities in the design and development process also turned out to be a valuable lesson learned to help add to this successful development (52). Involving a heterogenous group of people with ID, was also a lesson derived from the study by Derks et. al. (2021) (47). This study also recommended the involvement of co-researchers, as these co-researchers could represent the target group resulting in a better-fitted intervention (47).

When focusing on the involvement of other stakeholders, the study by Torrado et. al. (2020) clearly described best practices and lessons learned from their study (59). Torrado et. al. (2020) made use of a transdisciplinary team from the beginning of the development process. This team allowed a space in which all involved parties could try different ways of involving the end users, e.g., people with ID. The study stated that this early involvement of the transdisciplinary team was needed, because of reducing the need for iteration over the design process and allowing flexibility in the interaction of stakeholders in terms of mutual trust and availability. Stating that fluent communication between stakeholders is needed. The study by Furberg et. al. (2018) also mentioned that the success of their project was due to the team's recognition of the importance of stakeholder engagement (56). Other lessons derived from the study by Torrado et. al. (2020), are that it can be advisable to replace classic techniques of user-centered models such as think aloud, or a cognitive walkthrough for other techniques based on caregivers or parents' proxy or adapting the design activities to the needs of users through multi-media (59).

Deepening into the involvement of stakeholders and people with ID. Vereenooghe & Westermann (2019) mentioned involving all end-users in the design of an eHealth technology and not being satisfied with input from only one group, e.g., people with ID or support workers (62). The study conducted by Kang et. al. (2021) also learned that understanding the feelings and thoughts of a person with ID increases their participation in the development process and mitigated inappropriate assumptions or interpretations other people may have about this group and its role in the development (50).

Within the study of Elbæk et. al. (2018) lessons learned such as, involving people with ID is time-consuming and requires patients, empathy and critical reflection were identified (48). In this study, the researcher's experience with ID seemed to be valuable just as the fact that knowledge about ID made communication easier for the researchers and helped emphasizes staff communication (48).

3.7 Data syntheses

A clear summary of the earlier mentioned results can be found in the form of an infographic in *Appendix H*. In which these results are formalized in recommendations suitable for a broad target group to understand.

4. Discussion

This study aimed to identify the key factors that could lead to a successful PD of eHealth technologies for people with ID. These key factors and recommendations for successful PD can be found in *Appendix H*. This list with recommendations for PD can be used by different stakeholders such as researchers, eHealth developers, healthcare professionals or anyone interested in PD for people with ID, to help with a more fitted and successful development of their technology. In the following section the main RQ: "What are key factors for a successful PD of eHealth technologies for people with ID?" and the matching sub-RQ, focusing on 1) development frameworks, models and approaches, 2) identified stakeholders, 3) current involvement of stakeholders and 4) best practices and lessons learned, are answered. Interesting findings in the study are discussed, followed by strengths, limitations and recommendations for further research.

4.1 Main findings

In short, key factors for successful PD appeared to require the involvement of people closest to the person with ID, clear and easy communication, familiar and visualized PD sessions and involvement of a person with ID throughout the entire development process. This contributes to valuable information and insights and helps eHealth developers in better understanding a person with ID, which could support the development process and therefore add to the successful development of eHealth. Because these main findings focus mostly on the main RQ, the next sections are more focused on the sub-RQ, which supports the distribution of the data as presented in the results.

4.1.1 The use of a development framework to support PD

The use of frameworks in the development process of eHealth technologies can be complex and should, therefore, be taken as a guideline. When looking at the identified frameworks, models and approaches within this research, there was not one type of framework that was used consistently. A lot of studies used different kinds of frameworks, with minimal overlap between studies using the same framework. Within the scoping review, some studies also focused on publishing their findings on using a framework or described the use of a newly developed one, such as in the study by Macias et. al. (2018), which developed the ID4IDS framework for people with Down Syndrome (DS) (51). Within the interviews, on the other hand, the use of frameworks was barely mentioned. This could be because specific frameworks were unknown by some interviewees, did not fit the heterogenous characterizes of people with ID or had been chosen not to use due to already acquired experience with PD. This could be elaborated by the research of Lazar et. al. (2018), mentioning that frameworks do not always align with the needs of people with ID due to the heterogenous characteristics of this group (55). Frameworks that not align with the needs of people with ID could explain the scarce use of frameworks in practice. Besides, this statement could be strengthened by the research of Rycroft-Malone and Bucknall (2010) (73). According to which the use of frameworks and models in practice is complex and depends on involving individuals, teams and organizations and their achievements (73). Nevertheless, a study by van Gemert-Pijnen et. al. (2011) mentioned that it is not always clear what the frameworks are used for, for example, being a debating tool for research or functioning as a practical guideline for developers (32). When using a framework, model or approach end users and other stakeholders involvement should be emphasized. Especially because communication between different stakeholders seems to be hard to realize in practice (32). A flexible, creative framework, fitting the individual aspects of people with ID should be taken as a guideline and helps debate areas that would otherwise stay unanswered in eHealth developments (32). Taking this, and the experiences of healthcare professionals in mind, in the PD process.

4.1.2 Involvement of relatives and support staff, is important but comes with pitfalls

Caution should be taken with interpreting the needs of people with ID by support staff and close relatives. From both the interviews and the scoping review, the involvement of relatives and support staff, in other words, people who are close to people with ID, seemed to be the primary stakeholder group. By knowing the person with ID, it will be easier to support them in using or testing eHealth technologies, just as adequately responding to their needs to help support researchers. However, knowing a person with ID well can still lead to misinterpretation of their needs, as mentioned by two interviewees. The study by Wilson et. al. (2016) also mentioned that due to the difficulty for people with ID in communicating their needs, others often try to communicate on their behalf (46). Even though people with ID need to be given the opportunity to speak up and express their own needs (46). Therefore, Wilson et. al. (2016) recommended that a critical look is necessary to determine when interpreting the needs of people with ID seemed fitted (46). For example, when wanting to involve people with severe or profound ID in the eHealth development, within this specific target group sometimes the only option is to rely on the interpretations of caregivers and relatives as the ability to communicate can be limited for people with ID (1). Furthermore, when relying on the interpretation of support staff and relatives, wishes of people with ID should be taken into account, just as trying to keep an open dialogue with people with ID (74). Concluding, that involvement of both people with ID and people close to them gives valuable and pure insights, just as the interplay between both (48).

But not only the interplay between these two groups is important, but also the involvement of other stakeholders, especially technical stakeholders, is deemed necessary. The results showed that other stakeholders involvement was limited, especially the involvement of IT specialist or technical-focused eHealth developers. Even though this specific group has a significant role in the eHealth development process. This limited stakeholders involvement aligns with different literature suggesting that communication and involvement of other stakeholders are hard and barely done (11, 13, 15, 18, 21, 30, 32). But especially the involvement of technical stakeholders can lead to an eHealth technology which poorly fits the needs of people with ID (18, 29). This statement could be confirmed by the research by Smyth et. al. (2017), in which a weight management app did not fit the needs of people with ID and thus, was not suitable for this target group (26). Withal, the involvement of all stakeholders in an inclusive PD process is important to obtain more value and new insight and information from people with ID.

4.1.3 At which moment do people with ID have to be involved

Involvement of people with ID throughout the entire development process seems most optimal and contributes to a successful eHealth technology. However within the scoping review and interviews only a small amount of studies and interviewees actually involved people with ID throughout the entire development process. Even though the importance of the involvement of people with ID throughout the entire development process is known and recognized, a lack of involvement throughout the entire process is still seen. The active involvement of stakeholders in the entire development process can be seen as the fundamental factor of PD (15). Throughout the development different stakeholders can adapt a variety of roles, from giving information to testing eHealth, dependent on which seems most suitable at a specific moment in the process (15). However, an interesting statement in the study by Robb et. al. (2019) was made regarding the involvement of people with ID, mentioning that there should be reflected on the usefulness of involvement of people with ID in PD (52). As critical thinking can be needed here to determine if the involvement of people with ID is needed at a specific moment in the development process. A second statement regarding the moment of involvement was mentioned in the results and contradicts the involvement throughout the entire development process and only focusses on involving people with ID at the end of the development. But this moment of involvement contradicts PD and results in limited levels of involvement of people with ID, which could result in usability problems because the eHealth technology simply does not meet the individual needs of people with ID (11, 13, 15, 18, 21, 30, 32). The reasons why a person should only be involved at the end could derive from the thought that sometimes it is easier to tell someone that something is not possible, for example, involve people with ID throughout the entire eHealth development process, even though this is not entirely true (75). But as this research did not specifically focus on this part, a real answer to this contradiction cannot be given but seemed advisable to focus on in further research and interviews.

4.1.4 How to involve people with ID

When involving people with ID in the development of an eHealth technology a problem-based approach is needed to withdraw the most valuable input from a person with an ID. Within the results different methods for PD sessions were highlighted and when looking at these PD approaches a pitfall mentioned by one interviewee came alight, this regarded the question 'What do you want?'. This question can, most times, not be asked at a person with ID, as this can be too broad. But when looking more problem-orientated and asking a specific question regarding problems or situations people with ID experience during their daily life, a more fitted and valuable input from the person with ID can be withdrawn (76). This perspective aligns with Design Thinking (DT), in which deep empathy for end-users desires, needs and challenges is needed to fully understand a problem (76). DT can effectively be combined with PD, as shown in the research by Paracha et. al. (2019) (77). In this research, a range of PD methods are used to refine design ideas and support DT in children. The serious game developed in this research focused on bullying in elementary schools. Results from this study showed that these children made valuable design contributions and DT and PD stimulated reflection and empathy in these children (77). But, considering that this study did not include children with an ID makes it hard to generalize these results to people with ID. Another study using DT and PD included students with autism spectrum disorder, Here DT was used to engage these students in PD (78). This study by Fabri et. al. (2016) concluded that DT proved to be suitable for involving students with autism in creating solutions that aligned with their own needs (78). The combination of DT and PD seemed to be effective in different target groups, generalization of these effects to people with ID seemed necessary, as the use of DT as a framework for PD is not identified in this research. Nevertheless, DT on its own seemed to be suitable for people with ID (79). Research by Milroy et. al. (2021) conducted DT events with college students with intellectual and/or developmental disabilities (IDD) (79). These Design Thinking methods were used to develop an innovation with high relevance and feasibility for people with IDD (79). Within DT the person with ID is central and the focus is on understanding the person with ID, aligning with the key points of PD. Further research is still needed to determine the effects of the combination of PD and DT for people with ID and how these two methods complement each other.

4.2 Strengths and limitations

4.2.1 The strengths

One of the most important aspects of this thesis and the one thing this entire thesis entails is the involvement of people with ID by applying inclusive research. This means this research was conducted in collaboration with a co-researcher with an ID. Together we worked on setting up the interview guide, the information letter for the interviews, the recruitment infographic, discussing the results and making an inclusive recommendations infographic and creating an easy-to-read summary of this research, to only name a few. This collaboration significantly contributed to the strengths and relevance of this research.

A second strength lies within the preparations and execution of the scoping review. As the search strategy included the search of six databases focusing on multiple disciplines. The search strings were refined with two independent information specialists. Moreover, the screening process of the entire scoping review was done independently by two reviewers, in which disagreements on inclusion or exclusion were discussed. The only part done by one reviewer was the data extraction, but this was still discussed with the second reviewer.

Another strength lies in the multimethod approach of this research as within this research a lot of individual studies and opinions of experts were gathered and brought together. All these studies individually reported the effects and success of PD in their project, some studies did this more excessively than others, the combination of these, strengthens and reflects on PD for a target group of which simply not a lot of eHealth-specific research is focused on.

4.2.2 The limitations

The interviews were only conducted and coded by one researcher, which can be seen as a limitation of this study. Within the data analysis process, the codes of the interview were discussed with, but not coded by another researcher. The coding of one interview by the other researcher could have increased the validity of the coding process. Allowing a comparison between the coding strategies (80). The interview guide, however, was thoroughly discussed with another researcher and the co-researcher. consecutively, coding by more than one interviewer could have positively influenced the reliability of the coding process. As this could have allowed for the measurement of the intercoder reliability which improves the transparency of a coding process (81).

Secondly, only a small group of participants was interviewed. Interviewing more participants could add new valuable information, but was e.g., due to time constraints not possible, considering that the recruitment process for five interviews already took roughly two months. Additionally to these interviews, a self-selection bias could be present (82). As from the general LinkedIn post only one participant was derived. Two others were recommended after contacting other professionals who were possibly fitted to interview e.g., the snowball sampling process. The other two participants were directly approached, and all of the participants decided if they want to participate in the interview.

4.3 Further research

The involvement of people with ID should be highlighted in future research. Talking to people with ID about how they experience or want to experience PD and how they want to be involved is considered important. This is while keeping in mind that finding a good representation of the target group can be difficult. Therefore, an approach is needed which allows for involvement of a variety of people with different kinds of ID. First of all variety in the severity of the ID seemed necessary, involvement of people with mild ID would be the most accessible, involvement of people with severe ID requires a bit more care, but together with support staff or relatives also seems feasible. Secondly, to reduce the threshold for people with ID to participate in the development process a proactive person with ID can be chosen to represent the target group. This representative can both go to meetings with the eHealth developers as to informal meetings with other people with ID. It is therefore, important to advocate for informal meetings among people with ID at which the representative and support staff is present, this way the threshold to be involved in the development is lowered and participating can feel less overwhelming. The representative and the support staff can then take the information gathered at these informal meetings to the eHealth development team. This way a wider range of people with ID can be involved in the development process. Beside the involvement of a wide variety of ID, people with ID should also be interviewed. Main recommendation for future research therefore, focusses on conducting interviews with people who have an ID. Knowledge needs to be gathered about how people with ID themselves want to be involved in the development and at which moment they think their involvement seemed most feasible. As well as focusing on the motivation for participating in the development and what they think is needed to be involved successfully. This all could contribute to further shape and sharpen the recommendation for the involvement of people with ID in PD of eHealth interventions.

Secondly, research validating the lessons learned and best practices for PD with people with ID is deemed to be essential. As in some interviews merely thoughts or work processes for PD are mentioned, which seemed to be important steps towards a successful PD of eHealth technologies, but still, need validation to achieve this successful PD. Validating is also needed due to the fact that some lessons learned and best practices within the recommendations (*appendix H*) are based on only a few studies. Just as some studies corresponded with interviews but some also did not. Also taking into account that this research focused on the development process. Therefore, the focus of the data analysis of the identified studies was on the PD process, implementation and success of the eHealth technology in daily practice were not covered. But taking into consideration that the development process influences the success of the implementation of the eHealth technologies (27-29). Validating and assessing the effect of eHealth technologies created with people with ID, should be considered in further research. This may lead to new insights about the effects of PD on the accessibility and usability of eHealth technologies used by people with ID in daily life. Further research should therefore, focus on the development of a eHealth technology using the recommendations made in the research. By focusing on these recommendations and describing the full process of PD, the eHealth technology developed and the PD process can be evaluated. This allows for validation of the recommendations by looking at how successful the PD process was according to the stakeholders and if the developed eHealth technology fits the needs of people with ID. Nevertheless, before the validation of the best practices and lessons learned is done, caution should be taken with interpreting the effectiveness of these recommendations. Validation is needed to determine if the recommendations are, truly, evidence based (83). When developing an eHealth technology with these recommendations in mind, Participatory research (PR) could be taken into account. PR aligns with the thoughts of PD, and is focused on the involvement of a specific population and immediate feedback. As partly done by including a co-researcher in this study. PR outcomes are resulting in more relevant, tailored and actionable, supporting the evidence-based practice of the research design undertaken (83).

Thirdly, future research focusing on supplementing the already made recommendations, should include a solid interview structure. Recommendations for sharpening the interview structure include more deepening questions and using the expertise of the interviewees. When interviewing other participants with experience in ID care and eHealth more deepening questions can be asked about what kind of person with ID they have in mind when talking about their PD involvement, is it more focused on severe ID, or a very actively involved person with ID. The expertise of interviewees with PD can also be used to help formulate further interview questions, as interviewees can give recommendations about further questions that seemed to be essential to ask about PD. Further, the formulation of questions that is asked towards a person with ID is also important, interviewees should therefore try to clearly state how questions about what people with ID want are formulated. Helping to uncover if these approaches towards people with ID align with methods such as, for example, Design Thinking (DT) which seemed to be a feasible approach regarding people with ID (79). Highlighting that the interview structure could be optimized for further research to support the evidence collected from the PD processes.

4.4 Conclusion

Within this multi-method qualitative research, recommendations and lessons learned for the involvement of people with ID in the development process of eHealth were described. With main focusses on communication, set-up of PD sessions and involvement of relatives and support staff, in which frameworks, models and approaches can be taken as guidelines for PD combined with critical thinking surrounding the PD process. The PD process should be flexible and add value to all involved stakeholders to ensure a successful PD. When entering a PD process eHealth developers, researchers and other stakeholders should consider that the involvement of people with ID takes extra time and requires patience and empathy. However, this does not compete with the new values and insights derived from the involvement of people with ID, merely mentioning a more successful and better-fitted eHealth technology. It is therefore essential that further research should focus on validating best practices for PD with people with ID.

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Appendix A: Completed Search Strategy

Search strategy focusing on **intellectual disabilities**, **eHealth** and **participatory development**. Searched in 6 databases from 1995 till 2022 (April). Work published in English or Dutch.

Search conducted on **25-04-2022** for all databases.

PubMed

	Search string	Hits
#1	("Intellectual Disability"[Mesh] OR "Persons with Mental Disabilities"[Mesh] OR "Developmental Disabilities"[Mesh] OR developmental disabilit*[tiab] OR developmental disorder*[tiab] OR developmentally challenged[tiab] OR developmentally disabled[tiab] OR down syndrome[tiab] OR downs syndrome[tiab] OR down's syndrome[tiab] OR fragile X syndrome[tiab] OR Huntington*[tiab] OR intellectual development disorder*[tiab] OR Intellectual disabilit*[tiab] OR intellectual disorder*[tiab] OR Intellectually challenged[tiab] OR Intellectually disabled[tiab] OR learning disabilit*[tiab] OR learning disorder*[tiab] OR low IQ[tiab] OR Mental Deficiency[tiab] OR mental disabilit*[tiab] OR Mental Retardation[tiab] OR mentally challenged[tiab] OR mentally disabled [tiab] OR Mentally Handicapped[tiab] OR special need*[tiab])	192.901
#2	("Telemedicine"[Mesh] OR "Remote Sensing Technology"[Mesh:NoExp] OR "Mobile Applications"[Mesh] OR AI [tiab] OR app[tiab] OR apps[tiab] OR artificial intelligence[tiab] OR augmented reality[tiab] OR biometric sensor*[tiab] OR communication technolog* [tiab] OR digital health[tiab] OR eHealth[tiab] OR e-Health[tiab] OR electronic health[tiab] OR Mhealth[tiab] OR M-health[tiab] OR mobile app*[tiab] OR mobile application*[tiab] OR mobile health[tiab] OR mobile phone*[tiab] OR mobile technolog*[tiab] OR remote support service*[tiab] OR robot*[tiab] OR serious gam*[tiab] OR smartphone*[tiab] OR tablet*[tiab] OR telehealth[tiab] OR telemedicine[tiab] OR telenursing[tiab] OR Virtual reality[tiab] OR VR[tiab] OR Wearable*[tiab] OR Web-based module*[tiab] OR digital inclusion[tiab] OR e-inclusion[tiab])	353.658
#3	("Stakeholder Participation"[Mesh] OR “User-centered design”[Mesh] OR co-creation[tiab] OR co-design[tiab] OR end user input[tiab] OR end user involvement[tiab] OR Inclusive design[tiab] OR participatory approach[tiab] OR participatory design[tiab] OR Participatory development[tiab] OR participatory health[tiab] OR participatory technique*[tiab] OR shared decision making[tiab] OR stakeholder involvement[tiab] OR Stakeholder Engagement[tiab] OR Stakeholder Role*[tiab] OR stakeholder-driven approach[tiab] OR user centered design[tiab] OR stakeholder*[tiab] OR inclusive[tiab] OR participatory[tiab] OR human centered design*[tiab] OR user-centered[tiab] OR human-centered[tiab] OR User-centered design*[tiab] OR engagement[tiab] OR inclusion[tiab] OR person centred[tiab] NOT inclusion criteria[tiab])	354.026
	#1 AND #2 AND #3	119
	From 1995-2022, Dutch and English	116

Embase

	Search string	Hits
#1	(intellectual impairment/ or exp mentally disabled person/ or exp learning disorder/ or exp mental deficiency/ Or (developmental disabilit* OR developmental disorder* OR developmentally challenged OR developmentally disabled OR down syndrome OR downs syndrome OR down's syndrome OR fragile X syndrome OR Huntington* OR intellectual development disorder* OR Intellectual disabilit* OR intellectual disorder* OR Intellectually challenged OR Intellectually disabled OR learning disabilit* OR learning disorder* OR low IQ OR Mental Deficiency OR mental disabilit* OR Mental Retardation OR mentally challenged OR mentally disabled OR Mentally Handicapped OR special need*).ti,ab,kf.) not (dement* or alzheimer*).ti.	269.795
#2	(exp telehealth/ or exp telemedicine robot/ or exp telecommunication/ or exp telemedicine/ or exp teleconsultation/ or exp mobile application/ OR (AI OR app OR apps OR artificial intelligence OR augmented reality OR biometric sensor* OR communication technolog* OR digital health OR eHealth OR e-Health OR electronic health OR Mhealth OR M-health OR mobile app* OR mobile application* OR mobile health OR mobile phone* OR mobile technolog* OR remote support service* OR robot* OR serious gam* OR smartphone* OR tablet* OR telehealth OR telemedicine OR telenursing OR Virtual reality OR VR OR Wearable* OR Web-based module* OR digital inclusion OR e-inclusion).ti,ab,kf.)	512.251
#3	(Exp stakeholder engagement/ or exp user-centered design OR (co-creation OR co-design OR end user input OR end user involvement OR Inclusive design OR participatory approach OR participatory design OR Participatory development OR participatory health OR participatory technique* OR shared decision making OR stakeholder involvement OR Stakeholder Engagement OR Stakeholder Role* OR stakeholder-driven approach OR user centered design OR stakeholder* OR inclusive OR participatory OR human centered design* OR user-centered OR human-centered OR User-centered design* OR engagement OR inclusion OR person centred NOT inclusion criteria).ti,ab,kf.)	468.147
	1 and 2 and 3	194
	From 1995	193

CINAHL

	Search string	Hits
#1	(MH "Intellectual Disability+") OR (MH "Developmental Disabilities") OR (MH "Mentally Disabled Persons") OR TI(“developmental disabilit*” OR “developmental disorder*” OR “developmentally challenged” OR “developmentally disabled” OR “down syndrome” OR “downs syndrome” OR “down's syndrome” OR “fragile X syndrome” OR “Huntington*” OR “intellectual development disorder*” OR “Intellectual disabilit*” OR “intellectual disorder*” OR “Intellectually challenged” OR “Intellectually disabled” OR “learning disabilit*” OR “learning disorder*” OR “low IQ” OR “Mental Deficiency” OR “mental disabilit*” OR “Mental Retardation” OR “mentally challenged” OR “mentally disabled” OR “Mentally Handicapped” OR “special need*”) OR AB (“developmental disabilit*” OR “developmental disorder*” OR “developmentally challenged” OR “developmentally disabled” OR “down syndrome” OR “downs syndrome” OR “down's syndrome” OR “fragile X syndrome” OR “Huntington*” OR “intellectual development disorder*” OR “Intellectual disabilit*” OR “intellectual disorder*” OR “Intellectually challenged” OR “Intellectually disabled” OR “learning disabilit*” OR “learning disorder*” OR “low IQ” OR “Mental Deficiency” OR “mental disabilit*” OR “Mental Retardation” OR “mentally challenged” OR “mentally disabled” OR “Mentally Handicapped” OR “special need*”)	62.874
#2	(MH "Telehealth+") OR (MH "Telemedicine+") OR (MH "Digital Technology+") OR (MH "Mobile Applications") OR TI (“AI” OR “app” OR “apps” OR “artificial intelligence” OR “augmented reality” OR “biometric sensor*” OR “communication technolog*” OR “digital health” OR “eHealth” OR “e-Health” OR “electronic health” OR “Mhealth” OR “M-health” OR “mobile app*” OR “mobile application*” OR “mobile health” OR “mobile phone*” OR “mobile technolog*” OR “remote support service*” OR “robot*” OR “serious gam*” OR “smartphone*” OR “tablet*” OR “telehealth” OR “telemedicine” OR “telenursing” OR “Virtual reality” OR “VR” OR “Wearable*” OR “Web-based module*” OR “digital inclusion” OR “e-inclusion”) OR AB (“AI” OR “app” OR “apps” OR “artificial intelligence” OR “augmented reality” OR “biometric sensor*” OR “communication technolog*” OR “digital health” OR “eHealth” OR “e-Health” OR “electronic health” OR “Mhealth” OR “M-health” OR “mobile app*” OR “mobile application*” OR “mobile health” OR “mobile phone*” OR “mobile technolog*” OR “remote support service*” OR “robot*” OR “serious gam*” OR “smartphone*” OR “tablet*” OR “telehealth” OR “telemedicine” OR “telenursing” OR “Virtual reality” OR “VR” OR “Wearable*” OR “Web-based module*” OR “digital inclusion” OR “e-inclusion”)	128.958
#3	(MH "Stakeholder Participation") OR (MH "Participation: Health Care Decisions (Iowa NOC)") OR TI (“co-creation” OR “co-design” OR “end user input” OR “end user involvement” OR “Inclusive design” OR “participatory approach” OR “participatory design” OR “Participatory development” OR “participatory health” OR “participatory technique*” OR “shared decision making” OR “stakeholder involvement” OR “Stakeholder Engagement” OR “Stakeholder Role*” OR “stakeholder-driven approach” OR “user centered design” OR “stakeholder*” OR	190.673

	"inclusive" OR "participatory" OR "human centered design*" OR "user-centered" OR "human-centered" OR "User-centered design*" OR "engagement" OR "inclusion" OR "person centred") OR AB ("co-creation" OR "co-design" OR "end user input" OR "end user involvement" OR "Inclusive design" OR "participatory approach" OR "participatory design" OR "Participatory development" OR "participatory health" OR "participatory technique*" OR "shared decision making" OR "stakeholder involvement" OR "Stakeholder Engagement" OR "Stakeholder Role*" OR "stakeholder-driven approach" OR "user centered design" OR "stakeholder*" OR "inclusive" OR "participatory" OR "human centered design*" OR "user-centered" OR "human-centered" OR "User-centered design*" OR "engagement" OR "inclusion" OR "person centred") NOT TI (inclusion criteria)	
	#1 AND #2 AND #3	105
	From 1995, English	105

APA Psycinfo

	Search string	Hits
#1	(exp Intellectual Development Disorder/ or exp Intellectual Development/ Or (developmental disabilit* OR developmental disorder* OR developmentally challenged OR developmentally disabled OR down syndrome OR downs syndrome OR down's syndrome OR fragile X syndrome OR Huntington* OR intellectual development disorder* OR Intellectual disabilit* OR intellectual disorder* OR Intellectually challenged OR Intellectually disabled OR learning disabilit* OR learning disorder* OR low IQ OR Mental Deficiency OR mental disabilit* OR Mental Retardation OR mentally challenged OR mentally disabled OR Mentally Handicapped OR special need*).ti,ab,id.) not (dement* or alzheimer*).ti.	112.229
#2	(exp Telemedicine/ or exp Electronic Health Services/ or exp Mobile Applications/ OR (AI OR app OR apps OR artificial intelligence OR augmented reality OR biometric sensor* OR communication technolog* OR digital health OR eHealth OR e-Health OR electronic health OR Mhealth OR M-health OR mobile app* OR mobile application* OR mobile health OR mobile phone* OR mobile technolog* OR remote support service* OR robot* OR serious gam* OR smartphone* OR tablet* OR telehealth OR telemedicine OR telenursing OR Virtual reality OR VR OR Wearable* OR Web-based module* OR digital inclusion OR e-inclusion).ti,ab,id.)	75.796
#3	co-creation OR co-design OR end user input OR end user involvement OR Inclusive design OR participatory approach OR participatory design OR Participatory development OR participatory health OR participatory technique* OR shared decision making OR stakeholder involvement OR Stakeholder Engagement OR Stakeholder Role* OR stakeholder-driven approach OR user centered design OR human centered design* OR user-centered OR human-centered OR User-centered design*.ti,ab,id.	8.892
	#1 AND #2 AND #3	16
	From 1995	16

Web of Science

	Search string	Hits
#1	TS=("developmental disabilit*" OR "developmental disorder*" OR "developmentally challenged" OR "developmentally disabled" OR "down* syndrome" OR "fragile X syndrome" OR "Huntington*" OR "intellectual development disorder*" OR "Intellectual disabilit*" OR "intellectual disorder*" OR "Intellectually challenged" OR "Intellectually disabled" OR "learning disabilit*" OR "learning disorder*" OR "low IQ" OR "mental deficiency" OR "mental disabilit*" OR "mental retardation" OR "mentally challenged" OR "mentally disabled" OR "mentally handicapped")	180.735
#2	TS=("AI" OR "app" OR "apps" OR "artificial intelligence" OR "augmented reality" OR "biometric sensor*" OR "communication technolog*" OR "digital health" OR "eHealth" OR "e-Health" OR "electronic health" OR "mhealth" OR "m-health" OR "mobile app*" OR "mobile application*" OR "mobile health" OR "mobile phone*" OR "mobile technolog*" OR "remote support service*" OR "robot*" OR "serious gam*" OR "smartphone*" OR "tablet*" OR "telehealth" OR "telemedicine" OR "telenursing" OR "virtual reality" OR "VR" OR "wearable*" OR "web-based module*" OR "digital inclusion" OR "e-inclusion")	987.447
#3	TS=("co-creation" OR "co-design" OR "end user input" OR "end user involvement" OR "inclusive design" OR "participatory approach" OR "participatory design" OR "participatory development" OR "participatory health" OR "participatory technique*" OR "shared decision making" OR "stakeholder involvement" OR "stakeholder engagement" OR "stakeholder role*" OR "stakeholder-driven approach" OR "stakeholder participation" OR "user centered design" OR "stakeholder*" OR "inclusive" OR "participatory" OR "human centered design*" OR "user-centered" OR "human-centered" OR "User-centered design*" OR "engagement" OR "inclusion" OR "person centred")	1.030.974
	TS=("co-creation" OR "co-design" OR "end user input" OR "end user involvement" OR "inclusive design" OR "participatory approach" OR "participatory design" OR "participatory development" OR "participatory health" OR "participatory technique*" OR "shared decision making" OR "stakeholder involvement" OR "stakeholder engagement" OR "stakeholder role*" OR "stakeholder-driven approach" OR "stakeholder participation" OR "user centered design" OR "stakeholder*" OR "inclusive" OR "participatory" OR "human centered design*" OR "user-centered" OR "human-centered" OR "User-centered design*" OR "engagement" OR "inclusion" OR "person centred") AND TS=("AI" OR "app" OR "apps" OR "artificial intelligence" OR "augmented reality" OR "biometric sensor*" OR "communication technolog*" OR "digital health" OR "eHealth" OR "e-Health" OR "electronic health" OR "mhealth" OR "m-health" OR "mobile app*" OR "mobile application*" OR "mobile health" OR "mobile phone*" OR "mobile technolog*" OR "remote support service*" OR "robot*" OR "serious gam*" OR "smartphone*" OR "tablet*" OR "telehealth" OR "telemedicine" OR "telenursing" OR "virtual reality" OR "VR" OR "wearable*" OR "web-based module*" OR "digital inclusion" OR "e-inclusion") AND TS=("developmental disabilit*" OR "developmental disorder*" OR "developmentally challenged" OR "developmentally disabled" OR "down* syndrome" OR "fragile X syndrome" OR "Huntington*" OR "intellectual development disorder*" OR "Intellectual disabilit*" OR "intellectual disorder*" OR "Intellectually challenged" OR "Intellectually disabled" OR "learning	381

	disabilit*" OR "learning disorder*" OR "low IQ" OR "mental deficiency" OR "mental disabilit*" OR "mental retardation" OR "mentally challenged" OR "mentally disabled" OR "mentally handicapped")	
	Refined by: publication year: 2022 or 2021 or 2020 or 2019 or 2018 or 2017 or 2016 or 2015 or 2014 or 2013 or 2012 or 2011 or 2010 or 2009 or 2008 or 2007 or 2006 or 2005 or 2002 AND English	363

ACM Digital Library

	Search string	Hits
#1	“Intellectual Disabilit*” OR “Persons with Mental Disabilities” OR “developmental disabilit*” OR “developmental disorder*” OR “developmentally challenged” OR “developmentally disabled” OR “down syndrome” OR “downs syndrome” OR “down's syndrome” OR “fragile X syndrome” OR “Huntington*” OR “intellectual development disorder*” OR “Intellectual disabilit*” OR “intellectual disorder*” OR “Intellectually challenged” OR “Intellectually disabled” OR “learning disabilit*” OR “learning disorder*” OR “low IQ” OR “Mental Deficiency” OR “mental disabilit*” OR “Mental Retar*” OR “mentally challenged” OR “mentally disabled” OR “Mentally Handicapped” OR “special needs” OR “intellectual impairment” OR “mentally disabled perso*” OR “mental deficiency” OR “mental handicap” OR “mental deficien*”	1.150 Restricting to abstract (searched in ACM guide to computing literature)
#2	“Stakeholder Participation” OR “User-centered design” OR “co-creation” OR “co-design” OR “end user input” OR “end user involvement” OR “Inclusive design” OR “participatory approach” OR “participatory design” OR “Participatory development” OR “participatory health” OR “participatory technique*” OR “shared decision making” OR “stakeholder involvement” OR “Stakeholder Engagement” OR “Stakeholder Role*” OR “stakeholder-driven approach” OR “human centered design*” OR “user-centered” OR “human-centered” OR “User-centered design*” OR “stakeholde*” OR “inclusive” OR “participat*” OR “engagement”	23.744 Restricting to abstract (searched in ACM guide to computing literature)
	#1 AND #2	110
	From 1995 to 2022	110

Appendix B: Flow-chart screening process

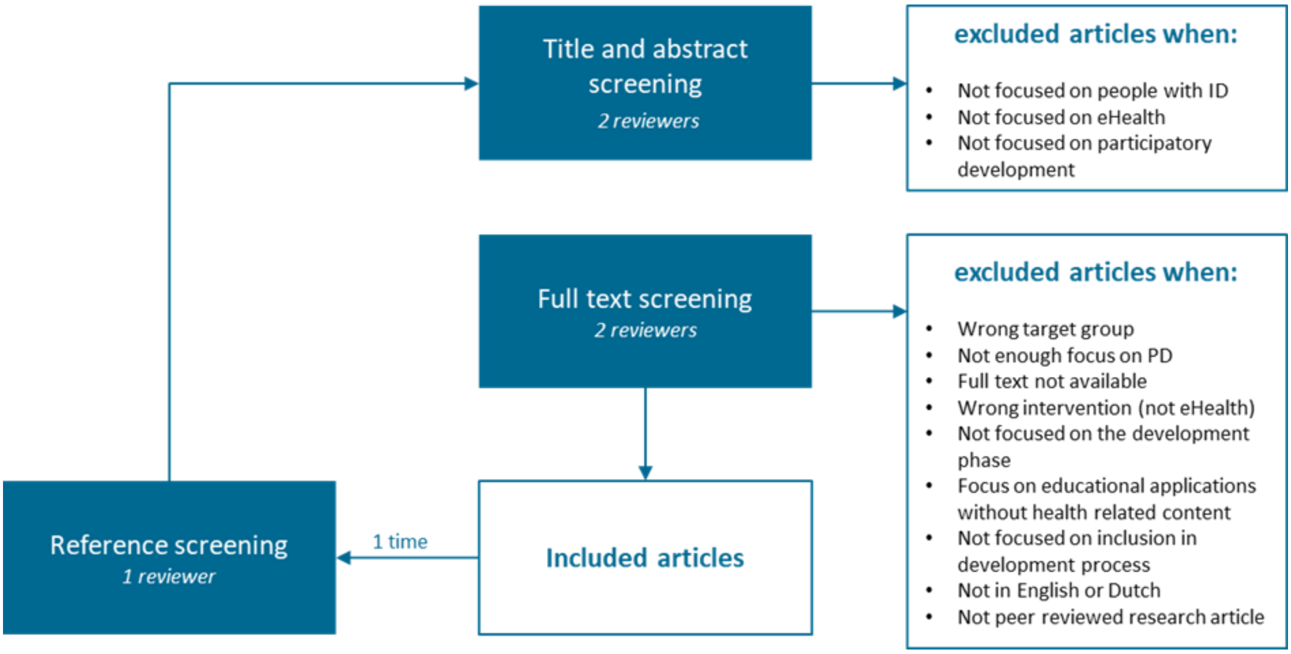


Figure B1: Flowchart showing article screening process and in- and exclusion criteria

Appendix C: recruitment infographic interviews

The recruitment of participant is done in Dutch.

Recruitment text:

Deelnemers interview gezocht: samen ontwikkelen van eHealth voor mensen met een verstandelijke beperking

Bent u werkzaam binnen de verstandelijke gehandicaptenzorg en bent u binnen uw werkzaamheden veel bezig met eHealth, of doet u onderzoek naar beiden? Heeft u hiernaast ervaring in het betrekken van mensen met verstandelijke beperkingen in het ontwikkelproces van eHealth? Dan ben ik opzoek naar u!

Voor mijn afstudeerscriptie aan de University of Twente en het Radboudumc doe ik onderzoek naar het samen ontwikkelen van eHealth voor mensen met een verstandelijke beperking. Op dit moment blijkt dat eHealth niet altijd goed aansluit bij de behoefte van mensen met een verstandelijke beperking. Om te zorgen dat eHealth goed aansluit is het samen ontwikkelen van eHealth met de doelgroep en andere stakeholders erg belangrijk. Hier is alleen nog vrij weinig onderzoek naar gedaan. Het doel van dit onderzoek is dan ook om concrete aanbevelingen te krijgen over hoe eHealth het best samen ontwikkeld kan worden met mensen met een verstandelijke beperking. Maar hiervoor heb ik u nodig!

Heeft u dus ervaring in het betrekken van mensen met een verstandelijke beperking of hun directe netwerk zoals familie, vrienden en zorgverleners bij het ontwikkelen van eHealth (apps, serious games, virtual reality, wearables, etc.). Of heeft u werkzaamheden verricht die hierop lijken. Bent u daarnaast geïnteresseerd in deelname aan dit onderzoek dat bestaat uit een interview (ca. 45 minuten).

Neem dan gerust contact op bij vragen of interesse! U kunt mij een berichtje of mailtje sturen (Naomi.Klein@radboudumc.nl)

Alvast bedankt!

Onderzoek samen ontwikkelen van eHealth voor mensen met een verstandelijke beperking

Doe mee en help eHealth toegankelijker te maken voor mensen met een verstandelijke beperking!

Bent u:
- Werkzaam binnen de **verstandelijke gehandicaptenzorg** of werkt veel met deze doelgroep?
- Zijn uw werkzaamheden (deels) gericht op **eHealth** (eHealth expert, onderzoeker, projectleider, etc.)?
- En heeft u wel eens samen met mensen met een verstandelijke beperking gewerkt aan de **ontwikkeling** van eHealth technologieën?

Dan ben ik opzoek naar u!

Interview van ca. 45 minuten (online of op locatie)

Neem contact op bij vragen en interesse:
Naomi.Klein@radboudumc.nl

Radboudumc

Figure C1: *Recruitment infographic interviews*

Appendix D: Information letter research eHealth

Informatie voor deelname aan wetenschappelijk onderzoek

Samen ontwikkeling van eHealth voor mensen met een verstandelijke beperking

Beste heer/mevrouw,

Wij vragen u om mee te doen aan een wetenschappelijk onderzoek naar eHealth ontwikkeling voor mensen met een verstandelijke beperking (VB). Meedoen is vrijwillig, maar vereist wel uw schriftelijke toestemming. U ontvangt deze uitnodiging voor deelname omdat u werkzaam bent binnen de VB-zorg en ervaring heeft met de ontwikkeling of van eHealth. Voordat u beslist of u wilt meedoen aan dit onderzoek, krijgt u uitleg over wat het onderzoek inhoudt. Lees deze informatie rustig door en vraag de onderzoeker om uitleg als u vragen heeft. De contactgegevens van de onderzoeker worden aan het eind van deze informatiebrief genoemd. U kunt over het onderzoek praten met anderen.

1. Achtergrond en doel van het onderzoek

Het gebruik van eHealth door mensen met een verstandelijke beperking (VB) neemt toe maar is in vergelijking met de algemene bevolking nog laag. eHealth blijkt niet altijd goed aan te sluiten bij de behoefte van mensen met VB. eHealth is zo ontwikkeld dat het niet goed past bij deze doelgroep. Hiernaast is er nog vrij weinig onderzoek gedaan naar hoe eHealth het best toegepast kan worden voor mensen met een VB. Dit onderzoek richt zich dan ook op het samen ontwikkelen van eHealth voor mensen met VB. Door ervaringen en protocollen met eHealth uit de praktijk en theoretische raamwerken te combineren kunnen aanbevelingen gemaakt worden die het eHealth gebruik voor mensen met een VB kan ondersteunen. Op deze manier kan eHealth toegankelijker worden gemaakt voor mensen met een VB.

2. Wat houdt meedoen in voor u?

De onderzoeker houdt met u een interview van 45-60 minuten. De onderzoeker maakt met u een afspraak op een tijdstip dat u uitkomt. U mag hierbij de voorkeur aangeven of u online (videobellen) of op locatie het interview wil afnemen. De onderzoeker zal het interview alleen met u afnemen. De interviews opgenomen met een audiorecorder, zodat we het gesprek kunnen terugluisteren en uitschrijven. Hierdoor kan de onderzoeker zonder afleiding luisteren tijdens het interview en kan alle informatie worden meegenomen in het onderzoek. Wij vragen u voorafgaand aan het interview toestemming voor de audio opname. Ook willen wij u vragen om alleen aan het interview deel te nemen en u zo goed mogelijk te ontdoen van mogelijke afleidingen tijdens het interview, zodat het interview in alle rust kan worden afgenomen. U zal na afloop van en bij volledige deelname aan het interview worden gevraagd of u de behoefte heeft om mee te lezen bij de uitwerking van uw interview (member check).

3. Wat zijn de afspraken als u meedoet?

Meedoen aan het onderzoek is vrijwillig. Er zijn geen goede of foute antwoorden en we willen graag dat u eerlijk uw mening geeft in het interview. U kunt op elk gewenst moment stoppen tijdens het onderzoek. U hoeft niet te zeggen waarom u stopt. Als u stopt, beslist u of de onderzoekers de informatie die al verzameld is mogen gebruiken of dat zij alles moeten wissen. Er zijn geen nadelen aan dit onderzoek. Het voordeel van dit onderzoek is dat u ons kan helpen bij het creëren van inclusieve eHealth ontwikkeling, waardoor de voordelen van eHealth toegankelijker worden voor mensen met een VB. Het onderzoek is goedgekeurd door een ethische commissie.

4. Wat gebeurt er met de uitkomsten?
Uw gegevens en antwoorden op de vragen worden gecodeerd en anoniem verwerkt. Het verzamelen, gebruiken en bewaren van deze gegevens is nodig om onze onderzoeksvragen te beantwoorden en de resultaten te kunnen publiceren. De uitkomsten worden gepubliceerd in wetenschappelijke publicaties vanuit het Radboudumc en gedeeld met de subsidieverstrekker (ZonMw). In de rapporten en (wetenschappelijke) publicaties worden de gegevens anoniem gepubliceerd, zodat de gegevens niet tot u te herleiden zijn. De onderzoeksgegevens worden na het onderzoek nog 10 jaar bewaard bij het Radboudumc om in de loop van dit onderzoek nog nieuwe inzichten op te kunnen doen die te maken hebben met dit onderzoek.

Voor de persoonsgegevens die we over u opslaan geldt de Algemene verordening gegevensbescherming (AVG). Dat betekent dat u de onderzoeker mag vragen om uw gegevens in te zien, te rectificeren of te ontvangen. Bij vragen of klachten over de verwerking van uw persoonsgegevens kunt u ook contact opnemen met de Functionaris voor de Gegevens-bescherming van het Radboudumc via gegevensbescherming@radboudumc.nl.

5. Ondertekening toestemmingsformulier
Wanneer u voldoende bedenktijd heeft gehad, wordt u gevraagd te beslissen over deelname aan dit onderzoek. Indien u toestemming geeft, zullen wij u vragen deze op de bijbehorende toestemmingsverklaring schriftelijk te bevestigen. Door uw schriftelijke toestemming geeft u aan dat u de informatie heeft begrepen en instemt met deelname aan het onderzoek. Zowel uzelf als de onderzoeker ontvangen een getekende versie van deze toestemmingsverklaring.

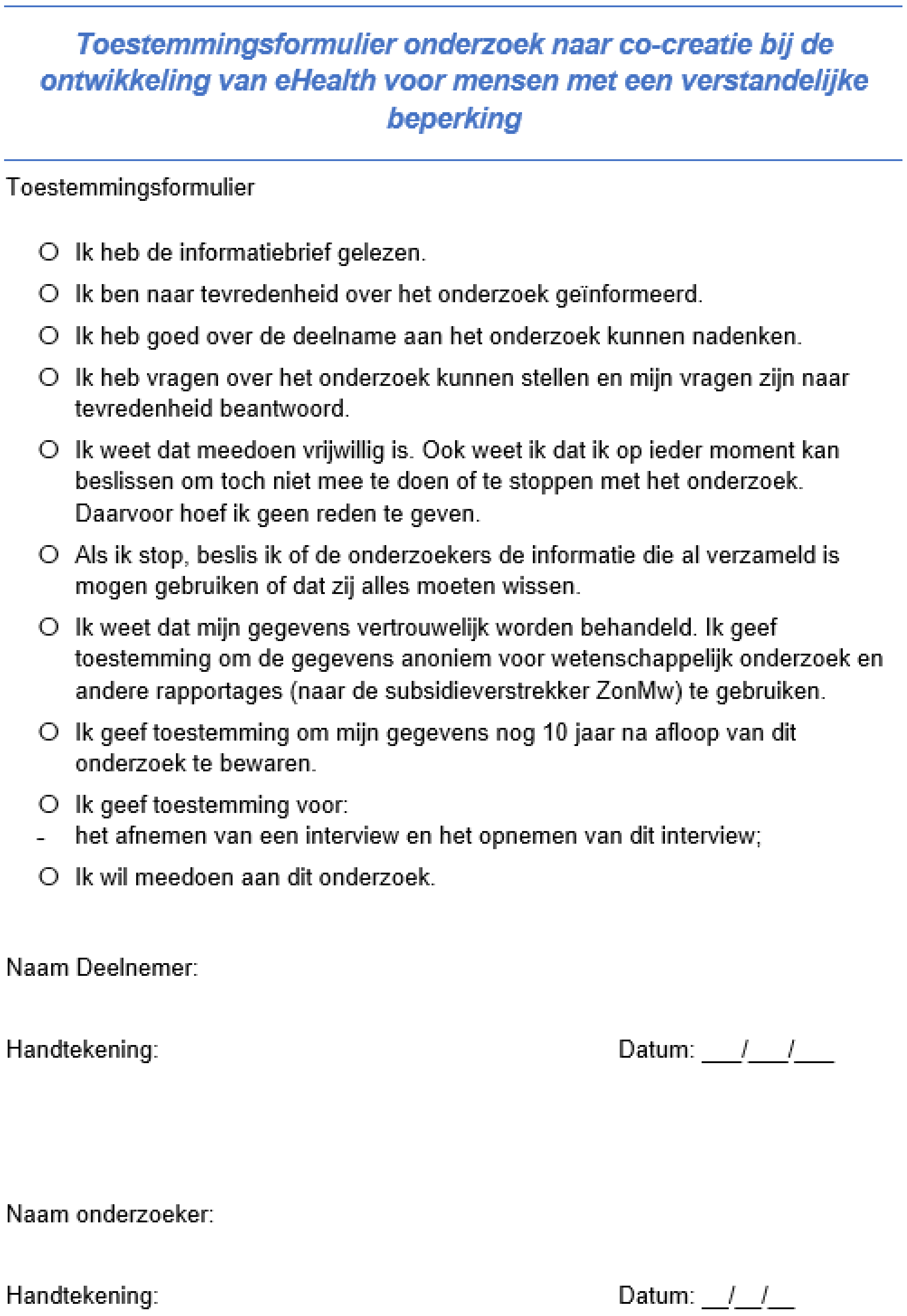
6. Heeft u vragen?
Bij vragen kunt u contact opnemen met de onderzoekers:

Naomi Klein
Tel: 06-20821994
Email: Naomi.Klein@radboudumc.nl

Julia van Calis
Tel: 06-36553275
Email: Julia.vanCalis@radboudumc.nl

Vermeld in uw email het onderwerp ‘Inclusieve eHealth ontwikkeling VB'.

Appendix E: Informed consent



Toestemmingsformulier onderzoek naar co-creatie bij de ontwikkeling van eHealth voor mensen met een verstandelijke beperking

Toestemmingsformulier

- ○ Ik heb de informatiebrief gelezen.
- ○ Ik ben naar tevredenheid over het onderzoek geïnformeerd.
- ○ Ik heb goed over de deelname aan het onderzoek kunnen nadenken.
- ○ Ik heb vragen over het onderzoek kunnen stellen en mijn vragen zijn naar tevredenheid beantwoord.
- ○ Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen om toch niet mee te doen of te stoppen met het onderzoek. Daarvoor hoef ik geen reden te geven.
- ○ Als ik stop, beslis ik of de onderzoekers de informatie die al verzameld is mogen gebruiken of dat zij alles moeten wissen.
- ○ Ik weet dat mijn gegevens vertrouwelijk worden behandeld. Ik geef toestemming om de gegevens anoniem voor wetenschappelijk onderzoek en andere rapportages (naar de subsidieverstrekker ZonMw) te gebruiken.
- ○ Ik geef toestemming om mijn gegevens nog 10 jaar na afloop van dit onderzoek te bewaren.
- ○ Ik geef toestemming voor:
- het afnemen van een interview en het opnemen van dit interview;
- ○ Ik wil meedoen aan dit onderzoek.

Naam Deelnemer:

Handtekening: Datum: ___/___/___

Naam onderzoeker:

Handtekening: Datum: __/__/__

Appendix F: Interview guide: eHealth experts

Introductie onderzoeker

Hallo, ik zou mij graag eerst aan u voor willen stellen voordat ik het interview begin. Mijn naam is Naomi Klein, ik ben master student Health Science aan de universiteit van Twente, op dit moment ben ik bezig met master scriptie in een vorm van een stage bij het Radboud UMC. Hier ben ik stagiaire op de academische werkplaats sterker op eigen benen, een academische werkplaats gericht op mensen met een verstandelijke beperkingen. Tijdens mij master heb ik mij gespecialiseerd in gepersonaliseerde monitoring en coaching, waaronder eHealth valt. eHealth kan gezien worden als het gebruik van digitale technologieën voor het ondersteunen van gezondheid. Dit interview gaat dan ook over eHealth voor mensen met een verstandelijke beperking.

U heeft van tevoren aangegeven toestemming te geven om uw gegevens te verwerken en dat ik dit interview mag opnemen. Had u hier verder nog vragen over?

Introductie en doel onderzoek

Het onderzoek waar ik mee bezig ben richt zich op mensen met een verstandelijke beperking en het gebruik van eHealth. Uit mijn vooronderzoek is gebleken dat eHealth voor mensen met een verstandelijke beperking meestal niet goed aansluit bij hun behoefte, eHealth is zo ontwikkeld dat het niet goed past bij de doelgroep. Daarnaast is er ook vrij weinig onderzoek gedaan naar hoe eHealth het best toegepast kan worden bij mensen met een verstandelijke beperking. Mijn onderzoek richt zich dan ook op het samen ontwikkelen, ook wel co-creatie genoemd, van eHealth voor mensen met een verstandelijke beperking. Mijn doel is om uiteindelijke concrete aanbevelingen te krijgen hoe eHealth het best samen ontwikkeld kan worden met mensen met een verstandelijke beperking. Dit interview dat ik met u afneem is onderdeel van dit onderzoek.

Start interview

Introductie

1. Ik zou graag eerst wat meer over u willen weten, wat voor een functie heeft u en bij welk bedrijf/organisatie?

2. Wat voor een rol heeft u in ontwikkeltrajecten van eHealth?

Motivatie co-creatie

U heeft eerder mensen met VB en bijhorende stakeholders betrokken in het ontwikkelen van eHealth, Ik zou hier graag wat meer over willen weten.

3. Wat verstaat u onder het betrekken van mensen met VB en stakeholders bij de ontwikkeling van eHealth technologieën?
    a. Wat vindt u hiervan?
    b. Bij wat voor een soort projecten heeft u deze groepen betrokken?

Co-creatie mensen met VB

Ik zou nu graag wat vragen stellen over het betrekken van mensen met VB in het eHealth proces.

4. Wanneer heeft u mensen met VB betrokken bij de ontwikkeling van eHealth technologieën als u naar het ontwikkeltraject kijkt?
   Mogelijke doorvragen:

   a. Op welk momenten of in welke fase van het project heeft u mensen met VB betrokken? U zou dit kunnen zien als een tijdlijn.
   b. Waarom heeft u ervoor gekozen om mensen met VB deze momenten te betrekken?

5. Kunt u vertellen hoe u mensen met VB betrekt in de praktijk bij een ontwikkeling van eHealth?
   Mogelijke doorvragen:
   a. Kunt u voorbeelden geven over hoe dit is gedaan?
   b. Waarom zijn mensen met VB op deze manier betrokken?

6. Welke voor- en nadelen ziet u in het betrekken van mensen met VB?
   Mogelijke doorvragen nadelen:
   a. Tegen welke barrières wordt eraan gelopen omtrent het betrekken van mensen met VB?
   b. Hoe zouden de barrières waartegen aan gelopen wordt opgelost kunnen worden?
   Mogelijke doorvragen voordelen:
   c. Wat werkt volgens u het best om te zorgen dat mensen met VB zo goed mogelijk betrokken kunnen worden?

Co-creatie stakeholders

Ik zou nu graag wat vragen willen stellen over het betrekken van andere personen dan mensen met VB in de ontwikkeling van eHealth.

7. Naast mensen met VB zelf, welke andere stakeholders vindt u nou het belangrijkst te betrekken bij de ontwikkeling van eHealth.
   Per stakeholdergroep doorvragen:
   a. Waarom zijn deze stakeholders zo belangrijk om te betrekken?

8. Hoe heeft u deze stakeholders betrokken bij de ontwikkeling van een eHealth technologie?
   Mogelijke doorvragen:
   a. Wanneer zijn deze stakeholders betrokken in de eerdergenoemde projecten?

Framework

9. Heeft u in uw projecten ook gebruik gemaakt van modellen of frameworks ter ondersteuning voor het betrekken van stakeholders en mensen met VB?
   Doorvraag; zo ja:
   a. Welk model of framework? (human centered design, PDS model, BCTs)
   b. Wat waren u ervaringen met dit framework?
   Doorvraag; zo nee:
   c. Waarom heeft u geen gebruik gemaakt van een framework?

Geleerde lessen

10. Wat zijn de belangrijkste punten die u heeft geleerd van het betrekken van mensen met VB en stakeholders bij het ontwikkelen van eHealth technologieën?
   Mogelijke doorvragen:
   a. Welke manieren zijn er om duidelijkheid te creëren voor mensen met VB als zij mee mogen denken met eHealth technologieën?
   b. Wat moet er veranderen of juist niet, om het betroken worden in eHealth ontwikkelingen beter te maken voor mensen met VB?
   c. Welke tips zou u meegeven aan andere die mensen met VB en andere stakeholders zouden willen betrekken in de ontwikkeling van eHealth?

Afsluiting

11. Heeft u aan de hand van al deze vragen nog opmerkingen? Zou u nog wat kwijt willen?

Het interview is nu afgerond. Ik bedankt u erg voor het deelnemen aan dit interview.

Appendix G: characteristics included scoping review studies

Table G1: Main characteristics of the included studies from the scoping review

Author (year) and country	Target group	eHealth technology
Augusto et al. (2017), United Kingdom (53)	People with Down Syndrome	Mobile application **Goal:** Supporting people with Down syndrome and their carers to manage their daily life activities as independently as possible.
Bayor et al. (2021), Australia (43)	Young adults with ID	Social media app **Goal:** Enhancing social skills and learning practical everyday skills.
Brown et al. (2016), Australia (44)	Young adults with ID	Virtual reality **Goal:** Learning and training a range of life skills to enhance independence, confidence and self-esteem.
Carniel et al. (2019), Brazil (57)	People with ID with communication deficits	Tablet communication tool **Goal:** Supporting communication.
Dekelever et al. (2015), Belgium (61)	People with ID	App for mobile devices. **Goal:** Traveling more independently.
Derks et al. (2021), The Netherlands (47)	Adults with mild to borderline ID	Serious game **Goal:** Enhancing social functioning through improvements in metalizing abilities and stress regulation.
Elbæk et al. (2018), Denmark (48)	People with mild to moderate ID, acquired brain injuries and learning difficulties	Interactive e-wall **Goal:** Creating learning, health living and inclusive experience through interactions via touch sensors.
Engler & Schulze (2017), Germany (54)	People with Down Syndrome	Mobile application **Goal:** Supporting people with Down syndrome and their carers to manage their daily life activities as independently as possible.
Farhin et al. (2018), Australia (45)	Young adults with ID	Mobile application **Goal:** Help navigate and use public transportation.
Furberg et al. (2018), United States (56)	People with Fragile X syndrome	Tablet based decisions support tool **Goal:** Help to participate in trials to make complex decisions.
Gibson et al. (2020), United Kingdom (49)	Adults with mild ID	Augmentative and alternative communication (ACC) technologies **Goal:** Promoting communication between patients with mild ID and general practitioners.

Kang et al. (2020), Taiwan (50)	Children with ID	Computer game-based technology *(Games based on kinect's gesture recognition technology)* **Goal:** Supporting daily life skills (hand hygiene) and maintaining and independent life in school and at home.
Kerkhof et al. (2017), The Netherlands **(84)**	People with ID	Digital application **Goal:** Structing and supporting daily activities.
Lazar et al. (2018), United States (55)	People with Down Syndrome	Mobile application **Goal:** Help make healthier food choices when eating out and track personal nutrition goals.
Macias et al. (2018), Mexico (51)	Children with Down Syndrome	Communication technology. **Goal:** Making communication with people around children with Down Syndrome easier
Robb et al. (2019), Ireland (52)	Children with Prader-Willi Syndrome	Web-based application **Goal:** Training task switching.
Salgado et al. (2018), United States (58)	People with diverse developmental disabilities	Mobile application **Goal:** Promoting independence in the medication management process.
Sitbon et al. (2019) Australia (42)	Young adults with ID	Virtual reality **Goal:** Support life skills training.
Torrado et al. (2020), Spain (59)	People with ID, brain injury and an autism spectrum disorder.	Assistive technologies for cognition (ATCs) for smartphones. **Goal:** Different apps for prompting daily life tasks and finding directions.
Vereenooghe & Westermann (2019), Germany **(62)**	Adults with ID	Digital psychoeducational intervention **Goal:** Promoting mental well-begin by providing tips.
Vereenooghe & Westermann (2019), Germany **(63)**	People with ID	Digital psychoeducational intervention **Goal:** Improving mental well-being.
Wilson et al. (2016), Australia (46)	Young adults with ID	Mobile application **Goal:** Supporting communication, and interests and helping with goal planning.

Appendix H: infographic recommendations

Samen ontwikkelen van eHealth technologieën met mensen met een verstandelijke beperking (VB)

Hoe doe je dat?

Waarom is dit belangrijk?

Het is belangrijk dat een eHealth technologie bedoelt voor mensen met VB zo goed mogelijk aansluit bij hun behoeftes. Om hiervoor te zorgen is het belangrijk dat mensen met een VB mee kunnen denken in het ontwikkelproces.

Maak gebruik van makkelijke taal

Zorg dat mensen met VB zich op hun gemak voelen

Zorg voor een gelijkwaardige samenwerking

Kom niet met te veel en te moeilijke informatie

Breng verschillende stakeholders in contact door een connectie persoon

stakeholders betrekken

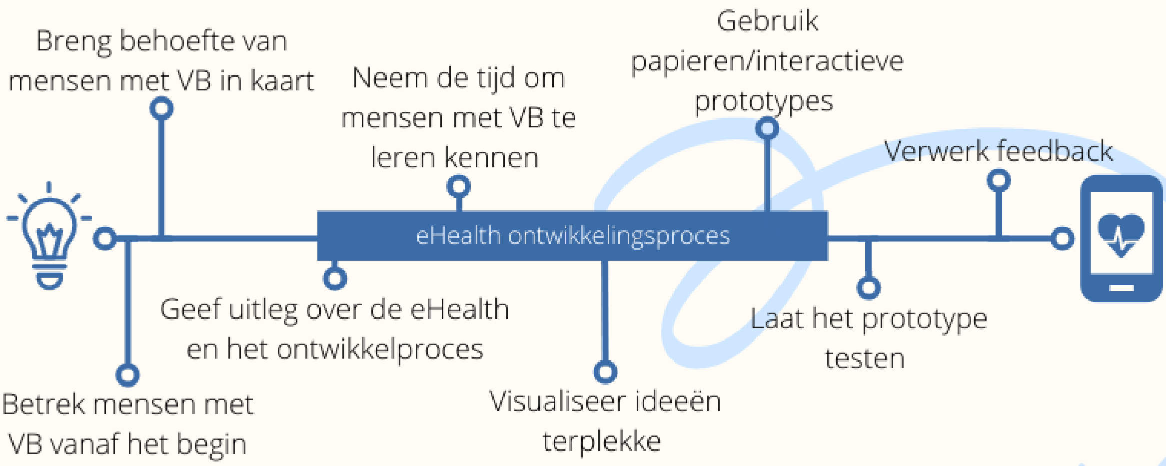
- Betrek naast mensen met VB ook familie en andere stakeholders die baat hebben bij de eHealth technologie
- Hou stakeholders up-to-date
- Wees open en transparant over het ontwikkelproces

Rollen van mensen met VB

- Geven van mening en advies over eHealth
- actief informatie over eHealth ontvangen
- Testen van eHealth prototype
- geobserveerd in gebruik van eHealth

Rollen andere stakeholders

- Zelf de eHealth testen en feedback geven
- motiveren van mensen met VB om technologie te gebruiken
- Onderzoekers helpen observeren en interpreteren van mensen met VB
- Mensen met VB helpen in het testen van eHealth



eHealth ontwikkelingsproces

Betrek mensen met VB vanaf het begin

Breng behoefte van mensen met VB in kaart

Geef uitleg over de eHealth en het ontwikkelproces

Neem de tijd om mensen met VB te leren kennen

Visualiseer ideeën terplekke

Gebruik papieren/interactieve prototypes

Laat het prototype testen

Verwerk feedback

Voordelen betrekken van mensen met VB

- Beter passende eHealth technologie
- Geeft waardevolle informatie en nieuwe inzichten
- Is leuk en informatief
- Helpt bij het beter begrijpen van mensen met een VB

- Blijf je continue afvragen of het idee nog aansluit bij de behoefte
- Vraag je af op welke momenten in het ontwikkelproces het meerwaarde heeft mensen met VB te betrekken
- beslis niet te snel voor mensen met een VB

Master Thesis: Participatory development of eHealth technologies for people with intellectual disabilities
Master Health Science, N.E. Klein

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