# CREATING ADDED VALUE BY INVOLVING VULNERABLE PEOPLE IN THE DESIGN OF EHEALTH TECHNOLOGIES

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# Abstract

## Background

Research has shown that involving vulnerable people is useful in designing eHealth technologies. Despite barriers and exclusion from research, vulnerable people need to be involved in the design of eHealth technologies to ensure that the technology aligns with the wants and needs from the vulnerable population.

## Objective

This paper has the objective to identify what the added value is of involving vulnerable people in the design of eHealth technologies, to determine positive aspects of involving vulnerable populations in the design process of eHealth technologies.

## Methods

To fulfil the objective, a scoping review was executed to find literature clarifying the current knowledge on the added value of including vulnerable people in the design of eHealth technologies. From the found literature themes were identified to relay the positive aspects of involving vulnerable people in the design process. Furthermore, expert interviews were conducted to relay the themes found in the literature and to explore whether the experts acknowledge the themes found in literature and if there are subjects that were not found in literature but were identified by the experts.

## Results

This research identified the following themes from the literature found through the scoping review: insights in experiences, preferences, priorities, and capabilities, cultural appropriateness, better accessibility, safety, having trust or a bond between researchers and vulnerable participants, and hearing the voices of the vulnerable participants. The experts that were interviewed acknowledged these themes and showed how added value is created through involving vulnerable people in the design of eHealth technologies. The only theme that was recognized but not experienced by the experts was cultural appropriateness. The experts did however note on the importance of having a culturally diverse vulnerable population to ensure the best alignment of the technology with the vulnerable population. Furthermore, the experts mentioned that assumptions that researchers have before working with the vulnerable group tend to be wrong and the importance of expressing that the vulnerable people are experts on their situation throughout the research, both of which were not distinctly found in literature.

## Conclusions

In conclusion, by combining a scoping review with expert interviews, themes surrounding the added value of including vulnerable people in the design of eHealth technologies were identified and explored. Adding to the literature found in the scoping review, the expert interviews gave additional information on the positive aspects of involving vulnerable people in the design of eHealth technologies.

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# Introduction

With the rapid growth of mobile phone and computer usage, healthcare and health information can be accessed easily from anywhere. For example, through the 'Health' application on iPhone to track daily movement and basic cardiac health, or the Dutch website thuisarts.nl for information on symptoms of common diseases and whether to go to the doctor.(1) Technologies that are accessible through mobile phones and computers are known as eHealth technologies. According to the WHO, eHealth is defined as "the cost-effective and secure use of information and communications technologies in support of health and health-related fields, including health-care services, health surveillance, health literature, and health education, knowledge and research"(2). This includes, but is not limited to, websites with information about diseases, mobile phone applications to track your medication or smartwatches to track your fitness level.

Due to shortages in healthcare, eHealth is used more often to bridge the gap in healthcare.(3) Vulnerable people are among the highest users of health care and eHealth can help manage disease better in vulnerable people, however, it is not widely used among vulnerable populations.(4–6) In this research vulnerable people are "people in vulnerable situations that, due to this vulnerability, have a higher chance to adverse (mental) health outcomes. Vulnerable situations include poverty, low (health) literacy, language barriers, and discrimination related to age, disability status, ethnicity/ race, gender."(7) Cashen et al. have defined barriers as to why eHealth is not as widely used in these populations.(4) One of these barriers is literacy, for people with low literacy healthcare can be difficult to navigate. For example, explanations from the doctor why a new medication is prescribed is hard to understand for low literate people, but these are important things when talking about one's health. Cheng et al. have also found this to be a problem when implementing eHealth for vulnerable populations.(8) In their research Cheng et al. found that by not involving the vulnerable population in the design process, literacy problems, as well as other factors, impact the engagement and adherence to eHealth technologies. This same problem was identified by Schouten et al, input from the vulnerable population is needed to create an accurate technology for the population.(7) However, these barriers also lead to 'super users', individuals from the vulnerable population who have partaken in research before, being chosen above individuals new to research. Super users can lose track of the vulnerable population they are a part of since they are immersed in the research for longer periods of time. This can impair the research as these individuals can lose sight of principles as opposed to people who have not partaken in research before.(9) For example, super users can lose sight of the oppression for their population because in the research they are participating in this is experienced less, or the super users can oversee barriers towards partaking in research because they have done it more often.

As a consequence of these barriers creating an eHealth technology with vulnerable people remains difficult. Additionally, vulnerable people are often excluded or belied when creating an eHealth intervention, even when creating an intervention aimed at this group of people.(9) Bonevski et al. have identified why vulnerable populations are often excluded, for example due to mistrust from the vulnerable population towards research and healthcare professionals, fear of authority, but also literacy of the vulnerable population.(10) However, because of continuously changing healthcare and the surrounding innovations, including the vulnerable people in the design of eHealth technologies is important to ensure that the technology aligns with the vulnerable target group.(11) To prevent a miscommunication between the technological and human aspects of the eHealth intervention, collaboration between experts on the technological and psychosocial subjects and end-users is necessary.(12) This is said to improve, for instance, engagement (13,14), adherence (11), and uptake.(13,15).(11) 14 To create an intervention that fits end-users, several approaches have been developed to incorporate the feelings, daily life, surroundings, and morals of everyone involved with the technology. There are a lot of terms to describe these approaches, such as co-design, human-centred design, and participatory design, but for this research the term co-design will be used. The term co-design is mostly utilised to describe the activity of combining creativity during the design process from professional designers and people not trained for design with experiences from the field.(12) Therefore, in co-design the ideation is that primary end-users are closely involved in the creation of the intervention and are seen as equals to the other parties of the design team.(11) The reason for using co-design in this research is that it felt like the best description of the undertaking of involving vulnerable people throughout the design and development process and iteratively creating an eHealth technology that fits their wants and needs.

Co-design is particularly difficult when including vulnerable people. When vulnerable people are included, they might be reluctant to participate or do not perceive themselves as suitable for cooperation in the co-design process.(16) O'Brien et al. explain that vulnerable groups feel barriers towards using health services and how to set up the co-design of a mental health service for people with culturally and linguistically divers (CALD) backgrounds.(17) They identified that CALD people experience a lack of understanding of their cultural and linguistic difficulties, even when being included in the design process. Additionally, safety is important when working with historically marginalized communities. This means that attention should be paid to sensitivity to authority figures in the design group and creative measures for a safe and inclusive space may be needed. Marginalisation and tokenism should be considered when deciding on the inclusion of people for the design group.(9) Building relationships with the group to be researched is important as it will alleviate some of the pressure of taking part in research and ensures the roles and responsibilities for everyone to avoid tokenism.(18) The same thing applies to building trust, sharing perspectives and creating a customary vision for the design of the eHealth technology.(19) Therefore, because it takes time and effort to involve vulnerable people, it is important to see what working with the vulnerable group can add to the design and development of eHealth technology.

Although there is quite some research done on co-design with vulnerable adults, it is unclear what co-design generates in terms of, for example, empowerment or if there are specific circumstances in which co-design should be done. Many articles describe the process of co-designing with vulnerable groups, but not many report the actual added value of co-designing an eHealth technology for vulnerable people. (20–22) For this reason, this scoping review will research what literature there is surrounding the positive aspects of co-design for and with vulnerable people and what this can provide for the researcher, the design team, and the vulnerable participants. Additionally, this found information will be relayed with experts in co-design research for eHealth technology with vulnerable people, to see whether the information found in literature is also recognized in practice.

## Objective

The aim of this paper is to identify what the added value can be of involving vulnerable people in the design of eHealth technologies. The complementing research goals are to identify how co-design has been applied in the design of eHealth technologies for vulnerable people, and to determine positive aspects of involving vulnerable populations in the design process. The research question we will be answering in this research is therefore:
*"What is the current knowledge on creating an added value on psychosocial aspects of eHealth technology design by involving vulnerable people in the design process and what this provides for both researcher and vulnerable participants?"*

## Scoping review method

For this research, we used a scoping review to gather information around the current literature available for the positive aspects of co-design of eHealth technologies with vulnerable people.(23–25) A scoping review was chosen because to the researcher's knowledge there is minimal information of the positive aspects of involving vulnerable people in the co-design process of eHealth technologies. Therefore, we wanted to explore the current literature surrounding this topic to answer the research question.

For the review of the literature, Covidence was used.(26) The guideline that was used is the PRISMA guideline for reporting the literature search.(27) Covidence makes a PRISMA flow chart that is updated throughout the review of literature, when the review is done it can be downloaded and imported into the research.

### Literature search

The literature search was conducted on 28 March 2023 using SCOPUS and PubMed search engines. SCOPUS and PubMed were the chosen search engines since they contain a great deal of health-related literature, and the University of Twente library is connected with these search engines which aids in searching for literature. Additionally, a hand search of the Design for Health Journal and the Codesign Journal was done, a snowball search was not executed because the articles were too recently published to already have follow-up research published.

To start the scoping review a search matrix and search string were set up. For the search matrix the initial words were eHealth, co-design, value, and vulnerable populations. Then synonyms or alike terms were researched to find literature fitting to the research aim. For the vulnerable populations it was decided to use words describing the populations according to the definition mentioned earlier instead of using the word 'vulnerable' itself since that claimed to be a broad term in this context. The full search matrix can be found in Appendix 1 – search matrix.

With the use of the search matrix, the following search string was set up:

*Table 1. Literature search-string*

| |
|---|
| (ehealth OR telehealth OR telemedicine OR "digital health" OR mhealth)<br>AND (codesign OR cocreation OR participatory* OR human-cent*)<br>AND (value OR gain OR benefit OR advantage)<br>AND (divers* OR income OR socioeconomic OR ethnic* OR rural OR poor OR poverty OR "remote communit*") |

### Eligibility criteria

A two-stage screening process was used to evaluate the relevance of articles identified with the search string. Studies were included when they included the following: 1) involved a vulnerable population, 2) explained the co-design process used, 3) explained why co-design is beneficial, 4) the technology was tested or piloted, and 5) explained what was valuable about involving the vulnerable people. Only articles written in English or Dutch will be included. No limits were set on the period in which the research was done.

Articles were excluded when 1) they only described the co-design process, 2) they did not test or pilot the technology, 3) they did not co-design the eHealth technology, 4) they did not redesign a current technology using a co-design process, and or 5) were secondary research articles. The pilot or testing of the technology is important to gain information about how well the co-design of the eHealth technology with vulnerable people worked in terms of usability and alignment with the target population.(28) The pilot or testing can inform whether the positive aspects of co-design are useful for the technology, the process, the research team, and the vulnerable participants.

### Title and abstract screening

The first stage of screening was done on the title and abstract of the articles found. The title and abstract were screened by one reviewer and articles that did not have a readily available abstract in Covidence (26) were added to the full text screening in the data extraction stage.

### Full text review

Next the articles that were found to be eligible were full text reviewed. Here it was ensured that all eligibility criteria were described in the full text. The full texts that were deemed not eligible were removed and the remaining articles were added to the data extraction part of Covidence. The reasons for excluding articles from the review were different study design, for example a systematic review, wrong outcome, such as not having a workable prototype to test, wrong setting, for example not a co-design setting, or wrong intervention, like not designing an eHealth technology.

Additionally, articles that were not openly available were also excluded at this stage. Contact was tried to be made with authors of these articles, as well as trying to receive them through ResearchGate, however, this did not acquire the articles. After this effort the articles were permanently excluded.

### Data extraction

Covidence was used for the included articles to extract data and characteristics from the studies. The established data were then analysed and compared to determine the value of co-designing an eHealth technology with vulnerable populations. To fulfil data extraction, a template was made to guide the process. The template used can be found in Appendix 2 – data extraction template.

### Data items

The data that were extracted were 1) general information (title, author, publishing date, rationale for co-design, and country in which the study is conducted), 2) study design and study team, 3) design method and design phase, 4) methods to involve the vulnerable group and activities to do during these sessions, 5) type of eHealth technology, 6) whether it is an iterative process, 7) pilot or test of the technology, 8) reimbursement of the participants, 9) population description with inclusion and exclusion criteria if available, and 10) reported added value of including the vulnerable group. To clarify why certain data items were extracted, they are explained below.

There are different phases of where in the co-design process the research can be based(29); the pre-design phase, the early design phase, the post first prototype phase and the full co-design process. For the included articles, the phase in which the researchers decided to use co-design was noted.

Involving the vulnerable group can happen in many ways.(30) For example, focus groups and workshops are used to involve the vulnerable group. Therefore, the methods of involving the vulnerable group were noted. Additionally, there are activities to let the vulnerable group participate during a focus group or workshop. The activities used during participation were noted to see if there are specific methods that stand out for creating an added value to the eHealth technology.

Whether the technology is designed with an iterative process was noted. Using an iterative process is important in creating an eHealth technology because in the process of designing new things or problems come up that need to be addressed.(11) Additionally, whether the technology is tested or has a pilot trial was noted. For some technologies, testing or piloting the technology before implementation is needed to see the usability and functionality of the technology.

Next the use of a participation incentive was noted. It was interesting to see whether researchers give participants a reward for partaking in the design. With vulnerable groups there are more barriers to participate in research(31), so giving an incentive can maybe motivate people to partake in the research process and to create equality with the vulnerable group and the researchers.(32)

The population description was noted with the purpose to extract the specific population and their vulnerability. If there are certain inclusion and or exclusion criteria these were also noted. How the researchers recruit the participants was also noted, to see whether there is a preferred method of recruitment.(33)

### Risk of bias

No risk of bias analysis was done, since this is a scoping review the risk of bias is not a priority in the research.(34,35) We are interested to see what current literature on creating added value by involving vulnerable people there is, regardless of methodological quality and risk of bias.

### Data synthesis

The data was analysed by using a narrative summary.(36) In a narrative summary, the found literature is summarized using easily readable language. Easily readable language means that it is readable for people of various educational backgrounds and understanding of scientific findings. Scientific and medical jargon are avoided where possible and otherwise the terms are explained and substantiated with examples. This method was chosen because it gives a concise summary of the found literature and gives an overview of the most important parts of the literature. Consequently, the data is grouped and incorporated into the review. In the narrative values were included when explicitly mentioned by the authors of the original articles. In addition, the researcher analysed the papers to identify any values that were discussed implicitly, for example through quotes of the original vulnerable research participants.

## Expert interviews

To discern whether the found information from the literature search aligns with the practice of involving vulnerable people in the design of eHealth technology, interviews with experts in the field of designing eHealth technology with vulnerable people were done. Interview participants were searched through the University of Twente and through a connection at a company that facilitates knowledge and guidance for other companies that design eHealth technologies with and for vulnerable people. It was a convenience sampling strategy through the network of the researchers. Additionally, interview participants were also searched through the LinkedIn network of one of the researchers.

The inclusion criterion was that the participant has experience with co-designing an eHealth technology with vulnerable people. Participants mainly consisted of PhD students and researchers of the University of Twente. Ethical approval of the interviews was attained through the Faculty of Behavioural, Management and Social Sciences of the University of Twente and was registered under the reference number 231088. All participants gave both verbal and written informed consent. The interviews were structured, the questions will be based on the themes found in the included literature from the scoping review. A full interview guide can be found in Appendix 3 – interview guide

The interviews were done either online via Microsoft Teams (Version: 1.6.00.22155 for MacOS) or in person. Transcription of the interviews was done by hand with the help of Microsoft Teams automatic transcription. Transcripts were coded via ATLAS.ti (version: 23.2.1 for MacOS). ATLAS.ti is a qualitative data analysis software that organizes transcripts and helps coding for overview of found data. The codes of the transcripts were based on the subjects around which the questions are based, to ensure alignment with the subjects of the literature found through the literature search. The codes used to identify subjects can be found in Appendix 4 – codes for data extraction from the interviews

# Results

## Citation management

170 articles were uploaded into Covidence.(26) SCOPUS resulted in 74 articles and PubMed in 96 articles. In total, 53 duplicates were removed, resulting in 117 unique articles. The hand search of journals resulted in 8 articles, of which three made it to the full text screening but none were included. In total 125 unique studies were screened for abstract and title, after which 61 studies were deemed irrelevant. 64 studies were thought to be relevant for this research.

64 studies were read in full for a full text screening. 54 studies of these were excluded for the following reasons:

- 39 studies had a different study design, meaning that they, for example, did not follow the process of co-design, did not focus on the inclusion of the vulnerable group, or did not test or pilot the technology,
- 9 studies had the different outcome, where, for example, studies followed the full co-design process but did not end with the value of including the vulnerable group,
- 2 studies were not openly available,
- 3 studies had the wrong intervention, meaning they did not design an eHealth technology,
- 1 study had the wrong setting, where there was a co-design process with the vulnerable population, but it was about the architectural technology instead of an eHealth technology.

Ten studies were extracted for data. The data extraction template can be viewed in Appendix 2 – data extraction template. The following subjects will describe the data that was extracted from the included studies.

The flow chart of the literature review is as follows:

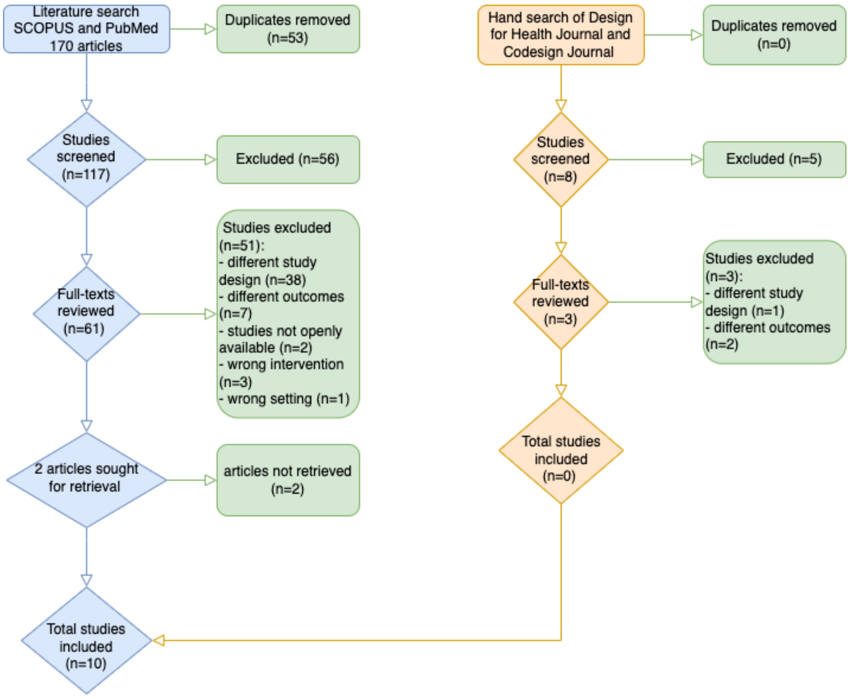

*Figure 1. PRISMA flowchart*

## General study information

Of the ten included studies, five were done in North America (Canada (37,38) and United States (39–41)), two were executed in Australia (42,43) and the last three were in other countries, namely Germany (44), Uganda (45), and Argentina (46).

The study design of the included studies is as following, six studies are mixed methods studies (39–43,45), four are qualitative studies (38,44,46) and one is a second analysis of a randomised controlled trial (37). All studies had a multidisciplinary study team, including researchers combined with IT-developers, community workers and or medical professionals but none of them included patients or end-users in the study team. All details from the studies can be found in the tables below. Table 2 provides the article information, study design, type of design approach, design phase and the population description.

*Table 2. Article information*

| **Author** | **Year** | **Country** | **Title** | **Study design** | **Type of design method** | **Co-design phase** | **Population description** |
|---|---|---|---|---|---|---|---|
| Maar et al. (37) | 2019 | Canada | Wise practice for cultural safety in electronic health research and clinical trials with Indigenous people: Secondary analysis of randomized | Secondary analysis of randomized controlled trial (RCT) | Community based participatory research | Full co-design process | Indigenous peoples who participated in the RCT of Short Message Service (SMS) messages for DREAM-GLOBAL |

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| | | | controlled trial | | | | |
| Steele Gray et al. (38) | 2016 | Canada | Improving patient experience and primary care quality for patients with complex chronic disease using the electronic patient-reported outcomes tool: Adopting qualitative methods into a user-centred design approach. | Qualitative research | User-centred approach | Pre-design | People experiencing multiple chronic diseases |
| Yin et al. (39) | 2021 | United States | Adapting Chinese Qigong mind-body exercise for healthy aging in older community-dwelling low-income Latino adults: Pilot feasibility study | Mixed method study | Community based participatory research | First prototype | Community dwelling older Latino adults from Texas |
| Vigil-Hayes et al. (40) | 2021 | United States | Integrating Cultural relevance into a behavioural mHealth intervention for Native American youth | Mixed method study | Community based participatory research | Full co-design process | Native American (tribal) youth form urban areas in the United States |
| Brewer et al. (41) | 2019 | United States | Promoting cardiovascular health and wellness among African Americans: Community participatory approach to design an innovative mobile-health intervention | Mixed method study | Community based participatory research | Full co-design process | African American Church going adults in Minnesota |

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| Champion et al. (42) | 2020 | Australia | A Web-Based Intervention to Prevent Multiple Chronic Disease Risk Factors Among Adolescents: Co-Design and User Testing of the Health4Life School-Based Program. | Mixed method study | Co-design | Early design | Secondary school students between 12 and 15 years old |
| Ospina-Pinillos et al. (43) | 2019 | Australia | Using Participatory Design Methodologies to Co-Design and Culturally Adapt the Spanish Version of the Mental Health eClinic: Qualitative Study. | Mixed method study | Participatory research | Full co-design process | Community-based young people aged 16 to 30 years native Spanish speakers living in Australia and native Spanish-speaking young people attending headspace Camperdown and headspace Campbelltown. Native Spanish speaking health professionals and supportive others. |
| Noack et al. (44) | 2021 | Germany | Designing an App to Overcome Language Barriers in the Delivery of Emergency Medical Services: Participatory Development Process. | Qualitative research | Participatory research | Full co-design process | Paramedics communicating with foreign patients in rural Germany |
| Kabukye et al. (45) | 2021 | Uganda | Implementation of an Interactive Voice Response System for Cancer Awareness in Uganda: Mixed Methods Study. | Mixed method study | Participatory research | Full co-design process | Women over 30 years old undergoing HPV self-testing who attend the public health system |

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|---|---|---|---|---|---|---|---|
| Sanchez Antelo et al. (46) | 2020 | Argentina | Developing SMS Content to Promote Papanicolaou Triage Among Women Who Performed HPV Self-collection Test: Qualitative Study. | Qualitative research | Co-design | Pre-design | Adults from Uganda and surrounding countries speaking English or Luganda, wanting to seek cancer information |

## Rationale for co-design

Table 3 provides information on the rationale for co-design, how participants were involved, activities during participation, type of eHealth technology, method of recruitment and participation incentive.

*Table 3. Additional article information*

| **Author** | **Rationale for co-design** | **Methods of involving vulnerable population** | **Activities during participation** | **Type of eHealth technology** | **Method of recruitment** | **Participation incentive** |
|---|---|---|---|---|---|---|
| Maar et al. (37) | • to gain an in depth understanding of Indigenous determinants of health in the participating population.<br>• building a trust-based relationship<br>• creating ethical space for dialogue | Focus groups, interviews | Guided discussions | SMS for blood pressure control | Via DREAM-GLOBAL RCT participants | No reimbursement reported |
| Steele Gray et al. (38) | • understanding the care experiences and needs of patients with Complex Chronic Disease and Disabilities (CCDD) by paying attention to | Focus groups, interviews | Going through a sequence of tasks | Electronic patient reported outcome tool | Not reported | No reimbursement reported |

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|  | the context in which their physical and mental health and social needs are intertwined<br>- capture the complexity and breadth of patients with CCDD |  |  |  |  |  |
| Yin et al. (39) | - develop a culturally tailored exercise program<br>- accommodate personal and cultural preferences and needs | Workshops | Think aloud | Web-based Qigong program | Voluntary through Church | $30 US for completing baseline assessment, $40 US after completing the post-test |
| Vigil-Hayes et al. (40) | - align the technology with psychological best-practices for cultivating healthy mindfulness skills in youth.<br>- be culturally relevant for Native Youth | Focus groups, interviews | Paper prototyping, active debate, guided discussions | Mental well-being smartphone application | Via community members and snowballing | No reimbursement reported |
| Brewer et al. (41) | - incorporate views of end users to maximize user acceptability and satisfaction.<br>- build rapport, trust, and credibility | Focus groups | Think aloud, active debate, semi-functional app prototype walkthrough | Mobile phone application for cardiac health information | e-mail, flyers | $50 US |

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| | with AA community.<br>• naturally stimulate idea exchange and real-life contextual understanding and cultural influences. | | | | | |
| Champion et al. (42) | • to engage young people in the co-creation and refinement of the Health4Life program.<br>• gain richer understanding of user needs<br>• to foster the engagement and satisfaction needed for web-based interventions to success among young people | Focus groups, survey | Guided discussion, script writing | Web-based health modules for teaching secondary school students about health | Via school | $30 AUS for students, $50 AUS for teachers |
| Ospina-Pinillos et al. (43) | • obtain information for the content, functionality, and the look and feel of the prototype | Workshops | Mock-ups, end-user sketching | Web-based mental health tool | Clinic patients, social media, universities, educational, vocational, and training institutes | No reimbursement reported |
| Noack et al. (44) | • meet specific needs of paramedics<br>• accommodate settings of emergency | Workshops | Mock-ups, guided discussions, role plays, click dummies | Smartphone application for triaging in foreign languages | Directly from paramedics' department | No reimbursement reported |

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| | medical devices | | | | | |
| Kabukye et al. (45) | - ensure a thorough understanding of user needs and contextual issues that might affect implementation and adoption.<br>- increase empowerment and buy-in | Focus groups, workshops, interviews | Active debate | Interactive Voice Response (IVR) messages with information on cancer | Phone, clinic patients, in person | No reimbursement reported |
| Sanchez Antelo et al. (46) | - learn wants and needs of the population regarding receiving HPV-self testing results | Focus groups | Guided discussions | SMS | Clinic patients | No reimbursement reported |

### Design approach

Two of the articles used co-design as a design approach (42,46), four used community based participatory research (37,39–41), three used participatory research (43–45), and one used a user-centred approach (38). Six articles described the full co-design process (37,40,41,43–45), two were pre-design (38,46), one was post-first prototype (39), and one was early design(42). Nine out of ten studies designed the eHealth technology with an iterative process(38–46).

Involving the vulnerable group in the design process happened in different ways in the included articles. Seven of the articles held focus groups (37,38,40–42,45,46), four used workshops (39,43–45), four used interviews (37,38,40,45), and one held a survey (42). Focus groups and interviews were used together three times(37,38,40), and one study used focus groups, interviews, and workshops to ensure the wants and needs of their vulnerable population were included(45).

During the design processes the methods used to talk with the vulnerable population and include their opinions and values were as follows; guided discussions, mock ups, think aloud, active debate, and paper prototyping. Some other methods that were used were walk through with a sequence of tasks of the eHealth technology, script writing, role playing, click dummies, semi-functional app prototype, collage and card sorting, interaction with the prototype and rating cultural appropriateness strategies. For example, Noack et al. (2021) made a mock up, which was a digital image template to show the design of the technology, and later on they made click dummies, which was an early prototype of the technology where the paramedics could click through the different buttons designed in the mock up.(44)

### eHealth technology

Methods described above were used to design eHealth technologies together with the vulnerable populations. The eHealth technologies that were designed in the included articles were smartphone applications(40,41,44), web-based programs(39,42,43), a patient reported outcome tool(38) and SMS or interactive voice response messages from the health care provider(37,45,46). Most of the studies tested on usability or whether all discussed features were incorporated into the technology. For example, the Noack et al. (2021) tested the translation smartphone application for paramedics in two rescue station simulations to see if it worked according to the expectation of both the paramedics and the researchers. (44)

### Value of including the vulnerable population

At first a narrative summary of the value of including vulnerable people in the design of eHealth technologies was created per included study. From this narrative summary the following themes were identified: insight in experiences, insight in perspectives, insight in priorities, insight in capabilities, cultural appropriateness, better accessibility, safety, creating trust or a bond with the vulnerable participants, and hearing the voices of the vulnerable population. Table 4 gives an overview of the themes with corresponding identified values and quotes from participants in the included articles. Below, an overview of the found added values of including vulnerable populations in the development of eHealth technologies is briefly described.

#### *Insight in experiences*

Insight in experiences is identified to gain knowledge of past and current experiences or hardships from the target population, and how the target population want to experience the eHealth technology. For example, Brewer et al. made sure to understand the experiences of daily life from African American Church going adults as to align the technology with those experiences. This included adapting African American recipes to make them less fatty and less salty to help with cardiac disease, because current applications are surrounding western foods and therefore not aligned with the African American Church going adults.

#### *Insight in preferences*

Insight into preferences is identified to gain information on how the vulnerable population looks at different situations surrounding eHealth technology and their look at eHealth technology. For example, Brewer et al. describe that by collaborating with African American church going adults the outlook of the eHealth technology was aligning with the African American culture.

#### *Insight in priorities*

Insight into priorities surrounds gaining information about the priorities from the vulnerable target population for the eHealth technology and what they find important to be incorporated into the technology. For instance, the vulnerable target population expressed a need for trustworthy sources on the application in both the study from Yin et al. and Ospina-Pinillos et al.

### Insight in capabilities

Insight into capabilities is found to surround awareness of and information about the current capabilities of the target population, such as current knowledge or physical capabilities. To illustrate, Champion et al. learned about the current knowledge of the students about health and based on that knowledge designed health modules for the students to educate them on what the students can do to maintain their health.

### Cultural appropriateness

Cultural appropriateness surrounds creating an eHealth technology that aligns with the culture of the vulnerable population and incorporate cultural elements in the technology. For example, Vigil-Hayes et al. discussed culture with the vulnerable population and ensured to incorporate elements from this culture into the technology.

### Better accessibility

Better accessibility is identified to inform about the access necessary for the eHealth technology and the restraints of location or cellular network. To illustrate, Noack et al. recognized that paramedics need to be able to use the eHealth technology a without cellular network connection due to being in rural areas where cellular network is not always available.

### Safety

Safety is identified to inform about safe ways to work with and use the eHealth technology. For instance, Ospina-Pinillos et al. found that their vulnerable participants needed an emergency button incorporated in the eHealth technology, to ensure that when experiencing urgent mental health problems, the vulnerable population could immediately contact help.

### Trust and or bond with participants

Trust or bond between researchers and participants surrounds creating a bond with participants and ensure all parties trust each other. Sanchez Antelo et al. identified that their vulnerable participants were pleased that they could trust the researchers and that researchers creating a relationship with the participants helped gaining insights from the vulnerable participants.

### Voices being heard

Hearing the voices of the vulnerable population is identified to take the thoughts and opinions from the target population in mind when designing the eHealth technology. For example, Yin et al. discovered that the vulnerable participants noted to be happy that their voices were heard and that the participants could point out their adjustments to the technology.

*Table 4. Identified themes of creating value*

| **Theme** | **Value** | **Quotes of participants from included papers** |
|---|---|---|
| Insight in experiences | • Create a technology that takes current health experiences of the population into account.(38)<br>• Learn more about populations health.(44) | African American adults on how much information should be given in the technology after experiencing too much information in a different application - *"Sometimes a lot of stuff will come up, and then. . .you* |

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| | • Understand the population experiences in daily life.(38,40,41)<br>• Diversity in participants leads to knowledge that would not be apparent without including the population.(44) | *click on it and you have to click on something else, and then you still don't have what you need."* (41) |
| Insight in preferences | • Ensure webpage is according to the wants and needs of the students.(43)<br>• Students want characters that they can identify with.(42)<br>• Being aware of racism and oppression while working with Indigenous peoples.(37)<br>• Understand the population perspectives.(41)<br>• Address apprehension toward eHealth technologies.(44)<br>• Ensure alignment with way of interpretation of the population.(46) | *"[Participants] want us to rephrase all messages that "compel". So, for example: "keep taking your meds as instructed…." This phrasing elicited a really emotional response and active resistance in our participants. "Don't tell me what to do like I am a kid – offer us choices and reminders instead". So, these will need to be changed to "It is a good idea to take medications as indicated by your health care provider" or 'Have you taken your meds today?' etc."* (37) |
| Insight in priorities | • Participants want trustworthy sources on the webpage.(39,43)<br>• Understand what the population finds most important in the technology.(41)<br>• Create technology according to priorities of the population.(39,40,44) | *"[The app] could [be] more about the culture…because it just kind of sounds like it just wants you to meditate. It doesn't seem like it's made for a specific people, it just wants you to calm down."*(40) |
| Insight in capabilities | • Knowing the population beforehand to create a technology adapted to the students.(42)<br>• Get to know the current average knowledge of the population.(39,41,45)<br>• Gain knowledge of the capabilities in the daily life of the population.(38,40)<br>• Create a script that was understandable for population with as much information as possible.(42,45,46) | *"I think it's being simple enough so that everybody can understand it. 'Cause some things, some people may understand, and some may not. So, if it's simple enough for all age groups, backgrounds. . ."*(41) |
| Cultural appropriateness | • Have sources on the website related to Spanish-speaking culture and mental health.(43)<br>• Make sure elements from culture are incorporated.(40)<br>• Create technology with culture of the population in mind.(39,46)<br>• Determine the cultural tone of the messages with population.(45,46) | *"...the difference between the city and the village...here what makes the difference is the closeness, we all know one another, it's more familiar. The relationship with the professionals isn't as distant as with the professionals in the city."*(46) |
| Better accessibility | • Ensure the webpage is available from all devices.(43)<br>• Ensure the technology is usable without cellular reception.(40,41) | On access of information/help in the correct language - *"...we will know exactly where to go and not to waste time going from one place* |

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|---|---|---|
| | - Know the accessibility of information in the technology.(45,46) | *to another, searching for someone that understands me…"*(43) |
| Safety | - Have an emergency button clear and directly visible on the home page.(43) | *No direct quotes from participants available.* |
| Trust/bond with participants | - Create a bond with the community.(37,46)<br>- Valuable connections with the community.(39)<br>- Improve feeling of belonging.(44) | *"In First Nation communities, that's huge, relationship building. The level of comfort is there [with the research team]. People come into the room and sit and talk when the DREAM-GLOBAL team is here, so that means they feel comfortable. And then, when they have that level of comfort, they're open to what you have to say."*(37) |
| Voices being heard | - Participants happy that their voices are being heard and incorporated into the technology.(39,41,44) | *"The app comes together, and it's like, wow! Your input all matters, and it actually will help in the end and improve not just our health, but others."* (41) |

## Expert interviews

Following the interview guide, five expert interviews were executed. The results of the interviews can be found in Table 4. All five participants had a research background and had experience with eHealth technology, either in designing it (n = 3) or implementing and evaluating it (n = 2). The technologies designed or implemented were mobile phone applications (n = 2) and Virtual Reality (VR) technology (n = 3). Three participants noted to have started the co-design with vulnerable people from the pre-design, starting with a contextual inquiry(47), and two participants noted to have started after already having a prototype available(48).

### Design approaches

The methods of involving the vulnerable group in the design process was mostly done by focus groups (n = 4) and interviews (n = 3), context mapping was mentioned once. Similarly, to what was found in the included articles, focus groups and interviews were combined by two participants. Both participants explained doing the focus groups first and creating a design from those focus groups. Most focus groups were guided by having a presentation, sensitizing booklets, or experiencing the already existing prototype. Interview participants noted that it is important to have a way of guiding the focus groups as to not overwhelm the vulnerable population and not spend too much time on information that is not necessary for the current research or technology. Interviews were done by the researchers to collect information on how the vulnerable group experienced the technology after adapting it with the points made during the focus groups. The interviews were mostly done while the vulnerable group was using the technology or after using the technology to see what their thoughts on the technology were after adaptation and also for the researchers to see how the vulnerable group was using the technology. From these interviews the researchers could adapt the technology further where needed and identify struggles with the technology that need to be addressed.

### Added value of including vulnerable people

The interviewees were asked what they thought the added value of including the vulnerable group was, before going into the themes that were identified from literature. All the interview participants said that they got insights into the vulnerable group and learned about the experiences and priorities from the vulnerable group through the co-design process. Most interviewees also mentioned that without involving the vulnerable group they would not have made the same technology as they have now, because they learned from their participants what drives them to use the technology and what they would like to gain from using the technology. Following the themes identified in the literature, Table 5 gives an overview of the themes together with examples from the expert interviews and quotes from these interviews.

#### *Insight in experiences*

The first theme, insight in experiences, was recognized by the interview participants as important. For example, participant 5 noted that without the lived experiences from the vulnerable group the technology they were designing would probably not be as effective. Participant 5 worked with forensic psychiatric patients with aggression regulation problems. By getting to know the lived experiences from the vulnerable group participant 5 was able to adapt the technology so that the vulnerable group recognized themselves and their lived experiences in it and create a surrounding that compared with the surroundings the vulnerable group were used to. For example, the living room participant 5 had designed was adapted to how the living room of the vulnerable group would look like, the initial living room was apparently too clean and tidy for the vulnerable group to identify with it.

#### *Insight in preferences*

Insight in preferences was also recognized by the interview participants, some of the participants noticed that the vulnerable group they worked with did not see the eHealth technology as the main tool and therefore also did not see an added value in having an eHealth technology next to their current care trajectory. The idea of the technology is that with the application the vulnerable people would not need consultations at the hospital anymore. For instance, participant four explained that during the interviews they did with the vulnerable group, the vulnerable group told participant 4 that the current care trajectory they were in was enough and having an eHealth technology beside that would be too much. The vulnerable group in this case did not understand that the eHealth technology would not be used beside in-person health care but instead of in-person health care. Participant 4 had to adapt their way of integrating the technology in the health care trajectory of the vulnerable group to ensure that the vulnerable group understood the use of the eHealth technology better.

#### *Insight in priorities*

Another theme that was recognized by the interview participants was insight in priorities. Both participant 1 and 2 learned during their focus groups with the vulnerable people, that the vulnerable group wanted informal caregivers and family members to also be able to have access to the eHealth technology as well. At first both technologies from participant 1 and participant 2 were only focused on the vulnerable group and did not involve the informal caregivers and family members. However, after learning the vulnerable group wanted and needed them included, both interview participant 1 and 2 decided to change the technology so that the informal caregivers and family members could use the eHealth technology as well.

### *Insight in capabilities*

Insight in capabilities was a theme that had some opposing statements between interview participants. For example, participant 1 and 4 noticed that, since most people already know how to navigate a mobile phone, being handed a mobile phone application was not a problem and most vulnerable people could navigate it. On the other hand, participant 2 noticed that their vulnerable group had difficulty with being handed a mobile phone application without an explanation as to how to use it and where to find certain functionalities.

### *Cultural appropriateness*

Cultural appropriateness was a theme that was recognized to be important but was not widely experienced in the research of the interview participants. Only participant 5 noted on the importance of having a culturally diverse vulnerable group. Participant 5 explained in their interview that because they had a culturally diverse vulnerable group, they made an eHealth technology that aligned more with their vulnerable group than when the mainly white research team would have made it. This led participant 5 and their research team to find out that including women with a hijab was a trigger for most of their vulnerable population, so they could not include women with a hijab in the surroundings of their VR technology.

### *Better accessibility*

Another theme that was acknowledged in the expert interviews was better accessibility. This theme in the expert interviews however did not only surround having the eHealth technology available on multiple devices but also ensuring that the technology is easily accessible in the health care setting. For example, participant 3 is adapting a current VR eHealth technology that will be used in a clinic where patients reside for treatment. Participant 3 explained that the technology should be in a place where both health care provider and patient can access it. They also noted that the technology is only available on a certain headset that is quite expensive and that not all health care organizations have the budget to buy this certain technology even though it might help the care trajectory of the vulnerable group of the clinic.

### *Safety*

Safety was also a theme that was acknowledged in the expert interviews, even more so than in the literature. For instance, two interview participants, namely participant 3 and participant 5, noted on the importance of having a safe environment for the vulnerable group to use the eHealth technology. Both participants work with a VR technology in a clinic where patients stay during their treatment, and the participants explained that the surroundings where the VR is used should be safe. This means that there should be a health care provider present with the patient to guide the patients while using the technology. Participant 5 also noted that it should be safe for the health care provider since the technology can evoke aggression or anger, so the health care provider should have a safe surrounding in case the patient they are working with becomes aggressive.

### *Trust and or bond with participants*

Creating a bond or a trustworthy relationship with the vulnerable group during research was noticed to be very important by the expert interview participants. The most mentioned subject in this theme was that the researchers created a comfortable environment for their vulnerable group. This led to the vulnerable group having a safe space to express their emotions and opinions on the technology. Additionally, the interview participants expressed that they made sure the vulnerable group felt engaged with the research and made the vulnerable group feel equal to the rest of the research team.

### *Voices being heard*

In line with creating a bond was the theme of hearing the voices of the vulnerable group during the research. The interview participants mentioned that hearing the voices of the vulnerable group was closely related to creating a bond with them. Most mentioned regarding this theme was that the interview participant clearly stated that they made sure that the vulnerable group knew that being part of the vulnerable group meant that they were the experts on the vulnerable situation. The participants mentioned that this was important to keep doing during the research period.

*Table 5. Identified themes and examples from expert interviews.*

| **Theme** | **Examples** | **Quotes** |
|---|---|---|
| Insight in experiences | • Researchers taking the mental state of the vulnerable people into account after a cardiac situation. P1<br>• Patients experienced the breathing belt not fitting around their thorax-circumference. P3<br>• Participants were used to having a lot of functions in apps in daily life, so they expected more from the technology than currently available. P4<br>• The patients helped to make scenarios more realistic by talking about their lived experiences. P5<br>• Researchers learn what triggers certain behaviour. P5 | Forensic psychiatric patients about what triggers their aggressive behaviour:" So *they said that drug dealers are like a huge trigger, and it's of course also related to crime. So, they actually told us how to identify drug dealers, how to kind of make them in VR"* – P5 |
| Insight in preferences | • The researchers learned if there was a need for eHealth technologic support. P1<br>• The patients wanting to work on their health with eHealth technology. P1<br>• The patients not seeing the eHealth technology as the main tool but an additional tool next to in person health care. P2<br>• Participants need to have a slight interest in mindfulness. P3<br>• Patients did not see the value of the app because of already existing care trajectory. P2, P4 | • *"They don't seem to view e-health as the main tool. So, they kind of see it as a helping hand, like for the healthcare provider, so that the personal contact actually was still more important to them than, yeah, working with technology itself. They constantly said like: "yeah, but what is a little app going to do for me, I should be seen by the healthcare provider, like this app is not going to, you know, change or Improve my care quality." So that, yeah, that that was very surprising to me that they still* |

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| | | *it had maybe a little bit of a negative view on like what an app could do for them"* – P2 |
| Insight in priorities | • The technology should not cost too much time. P1<br>• Patients needed to include informal caregivers in the technology. P1, P2<br>• Patients needed help with guiding through the app. P2<br>• Patients needed an app next to VR to be able to use the system outside of clinic hours. P3<br>• Researchers getting to know what is liked and not liked by the target group. P5 | • *"One of the priorities we found is that it shouldn't intervene too much with the daily life. These patients have just had something shocking happen, for example a heart attack or surgery. So, their mind is quite fuzzy, and they don't have the priority to start working hard on their current situation. By taking that into consideration, we went for something that was very easy and they could engage with for like four or five minutes"* – P1 |
| Insight in capabilities | • Most people can navigate a mobile phone, so the app was no problem. P1, P4<br>• Patients had difficulty just being handed an app without guidance. P2<br>• Patients not having the best VR capabilities didn't stop them from using the technology. P3<br>• Patients having the technical skills to navigate VR. P5 | • *"I think they are very open to use technology and because they are also used to make use of their phones in, in daily life. And so, I think they see it as an easy tool to also use in their treatment, for example."* - P4 |
| Cultural appropriateness | • Researchers adhering to different cultures in the app. P1<br>• Researchers having a very white population was a problem. P2<br>• The technology was designed on eastern meditation. P3<br>• Having a culturally diverse population helped creating a technology that aligned with the vulnerable group. P5 | • A researcher about not having a culturally diverse vulnerable population, even though they wanted to create the technology with a culturally diverse group: *"I mean a downside in a way was that the population that I researched fit the population of the hospital, basically. So, it is very white, there is not really a culturally diverse group in the hospital itself. I did look for the recruitment, I specifically looked to make it more diverse, but I couldn't find people with a diverse background"* – P2 |
| Better accessibility | • Having the application available on multiple devices and/or phone operating systems (Android/IOS). P1, P2<br>• Expensive device which not all health care organizations have money for. P3 | • *" So, we also have our application available on the web."* - P1<br>• *"DEEP is can only be played at an Oculus headset device… Those headsets are quite expensive and not all healthcare. Organizations do* |

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| | - The technology is easily accessible in the work environment. P5<br>- It should not take the researchers too much time to set up the technology. P5 | *have the means to. Pay that much money for intervention."* – P3 |
| Safety | - Having a disclaimer on the app to ensure patients contact a health care provider and not the app. P1, P4<br>- Having an asynchronous help page to contact health care provider. P2<br>- Having a health care provider present when using the VR technology. P3<br>- Researchers being aware that asking questions can induce craving. P4<br>- Have a safe space to use the technology with health care provider. P4<br>- Making sure the surroundings are safe for the health care providing while working with the VR. P5<br>- Making sure the technology is not too intense for certain patients to not induce psychosis. P5 | - *"What we did is we have a help page, but if there is suddenly something wrong with the patient maybe they try to contact us because they link us to healthcare. So that is a safety issue because I cannot help them at that point. So, we made a disclaimer saying that if you have serious medical issues or you need attention, please contact your cardiologist, or call 911."* - P1<br>- *"We are working with forensic psychiatric patients and a lot of them have aggression regulation problems. So, there were some concerns from therapists, like what happens if somebody gets too angry? They were kind of worried about that."* – P5 |
| Trust/bond with participants | - Researchers making sure the patients feel engaged. P1<br>- Researchers having a safe space for the participants to express their feelings and emotions. P1, P2, P3, P5<br>- Researchers using action research with the community. P1<br>- Having food and beverages available during the sessions. P2<br>- Giving the participants a thank you or gift card or parking voucher. P2, P5<br>- Making the participants feel equal to the rest of the project team. P1, P5 | - *"So, I do find that an interesting thing, we haven't uhm really strategized creating a sort of researcher participant bond. … At one point though, I did find having a little bit of a good relationship with the patient that I did research with, because they just they had fun with the session and connected that with me and became also more open because I was not part of their treatment program."* – P3<br>- *"These are just one-off focus groups and interviews, but I still made sure that it was very accessible, but also bring like coffee, tea, cake, cookies or just like treats so in the break we could sit down and talk and enjoy a moment together."* – P2 |
| Voices being heard | - Having a backlist of questions to listen to the participants | - *"So, we had these sessions, we got the information from the* |

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|---|---|---|
| | but also pay attention to your time. P1, P3<br>• Ensuring participants know that they are seen as experts about their situation throughout the research period. P1, P3, P4, P5<br>• Showing how you incorporate the feedback. P2 | *participants, and we incorporated it. The next time we saw them, so then we actually showed them; last time you said this, and this is how we've incorporated in the design and then reflecting on those decisions with them.”* – P2<br>• *“What we always did in the introduction was really explicitly say you're the expert. We need your expertise and they totally appreciated that because they're a kind of stigmatized group and they're not often asked for their inputs*. And so many patients really liked being in the expert seat.” – P5 |

Two participants mentioned not using an iterative process, because they were using already existing technologies instead of creating a new technology from scratch and they did not adapt this technology together with the original technology developers. Both participants co-designed the surrounding in which the technology will be used and to see what might be necessary to adapt the technology for this surrounding. For example, the VR application from participant 3 where forensic psychiatric patients use deep breathing to navigate a biofeedback game. This VR game is an already existing technology but participant 3 is co-designing to see how this game can help the forensic psychiatric patients while they are residing in the clinic. The other participants did mention using an iterative process and found it important as, even in the implementation phase, there are things that come up that need to be changed so that the technology can and will be used as intended. Participant 3 did notice that oftentimes technology implementation happens top-down, but they said that to ensure that the patients and caregivers use the technology as intended and if it aligns with the patients as the technology was designed, it needs to be implemented with the stakeholders. What every interviewee mentioned when asked about the reason of choosing a co-design process, was that it is the most important thing to keep your target group involved in the design process. As a researcher you can have great ideas but to execute them and create a technology that the vulnerable group will actually use and fit their needs, you need to involve them. And not just for designing the technology but also implementation, to again make sure that it is used as intended and having the intended outcome of using the technology. Participant 1 said the following: “It is the most important thing; I think without involving the end-user you cannot do a successful design project. You have a lot of assumptions about what you think can work for you, but for a group that thinks differently, or that has different needs than you, you cannot think for them”.

In the interviews the importance of reimbursing the vulnerable people who participated in the study was mentioned by three interviewees. These three interview participants explained that they at least had some food and drinks available while doing the workshops, focus groups or interviews. Participant 2 mentioned also giving a reimbursement for parking costs and handing out gift cards to the vulnerable people who participated in the research. Participant 1 and 2 mentioned that participants felt appreciated by these small acts and that they felt valued for their contribution. Participant 5 had an even better example from one of the patients that was included in the project team. This patient had a hard time finding a job after being in prison and getting forensic psychiatric treatment. Their confidence was low but through working in the project team they felt they had expertise again and had a voice that was wanted to be heard. Reimbursing the patient from the research of participant 5 therefore led to them feeling equal to the other project team members and appreciated for the work they were doing for the project team. On the other hand, only four of the eleven the included articles have reported giving a reimbursement to the research participants. For example, Yin et al. reimbursed their participants $30 for completing the baseline assessment and again $40 for completing the post program test. All seven other studies did not report giving reimbursements to the vulnerable people participating in the research, and the studies that did report on giving reimbursements did not note on why it is important to give reimbursement to the vulnerable people participating in the design of eHealth technology.

The interview participants were asked how an added value can be created while designing an eHealth technology with vulnerable people. Participant 1 and 2 mentioned that only involving the target group already creates an added value to the technology and the design process. Both participants said that with involving the vulnerable group you learn about their experiences and perspectives that researchers cannot know beforehand since they are not experiencing the same situation as the vulnerable group is. According to them this creates value for the researchers themselves as well as for the technology they are designing for the vulnerable group.

### Additional findings

Some additional subjects were found in the expert interviews, compared to the included literature. In three expert interviews it was noted that assumptions that researchers have before working with the vulnerable group tend to be wrong. Participant 1, for example, mentioned how some people from their vulnerable group did not speak Dutch, but they still wanted to use the phone application even though the application was in Dutch. The vulnerable people said that they have family or friends or neighbours that can help them understand the content of the app. Expert interview Participant 2 mentioned that they had thought that all the functions of their application would be too much or too difficult for the patients to use, however, the patients said that even though it was a lot they got used to it quite quickly. Participant 4 said that their research participants acknowledged that they use their phone a lot in their daily life, which makes that they find it an easy-to-use tool in their treatment. On the other hand, participant 4 also mentioned that the vulnerable group wanted more functions in the application, but participant 4 also saw that more functions made it unclear and harder to navigate. Their challenge was to find a compromise in this for their application. All of these examples show how assumptions about the capabilities of participants can be wrong, and that this can only be found when co-designing the technology with your vulnerable group. One interviewee talked about how creating value of the technology is not only in the design process but also in ‘increasing enthusiasm, increasing engagement, increasing involvement and ownership’ [Participant 3]. They additionally mentioned that these mindset changes can help especially vulnerable people learn that they have a voice in their health care and treatment plan.

Another subject that was mentioned various times in the expert interviews and shortly in the literature was the importance of ensuring that the vulnerable people that are included know that their opinion is valued and necessary for the development or research team to design this technology, and to express that the research participants are experts on their own situations. Both literature and interviews mention the importance of seeing the research participants as equals as well. Participant 5 from the expert interviews explained about treating the vulnerable group as equals in their interview. In the project participant 5 is working on, the included two patients from a forensic psychiatric clinic in the project team from the start, and the researchers noted that they learned the most from including these patients in the project team and seeing them as experts in this research. Since it is difficult to imagine what certain situations feel like, especially if the researchers are not familiar with aggression regulation problems, the input from the patients changed the way the project team looked at the technology they were designing. Participants 1 and 3 mentioned comparable experiences, they identified that it is imperative to the design, and implementation, to express that the vulnerable group is the expert in this research since without them the technology could not work as intended. Both participant 1 and 3 said that having the vulnerable group as equals in the research is most important when designing with vulnerable people and wanting to learn about their experiences and perspectives and wants and needs from the technology.

In contrast to the included articles, where cultural appropriateness was largely acknowledged to be an important subject to design an eHealth technology with vulnerable people, the interviewees did not experience this to be a theme that came up during the design of the eHealth technology. The included articles had participants from different cultural backgrounds and ethnicities, whereas the interviewees had mostly participants from similar cultural backgrounds. Despite a lack of a culturally diverse population for most of the interview participants, cultural appropriateness was recognized to be important even though it was not directly experienced in the design of eHealth technology with vulnerable people. Only participant 1 noted on different cultures in the context of the importance of diet in cardiac rehabilitation, they said that it was difficult to comply to all different cultures in one application. Participant 2 noted on how the lack of a culturally diverse group was difficult, since they wanted their technology to align with a broad public. However, the hospital population of participant 2 that were included in the research were primarily white, which made it difficult to incorporate different cultures.

In two expert interviews onboarding was mentioned to be necessary for the uptake of the technology. Both interviewees said that their vulnerable group needed the extra help to know how to navigate the technology and to use it as was intended by the researchers. The vulnerable groups of both interviewees noticed that it was difficult to be handed a technology and find out for themselves how it worked and where to find everything. This was not something that was found in the literature but was noticeably mentioned in the interviews. One of the interviewees said that this is a part of why they find it important to keep involving the vulnerable group also in the implementation and evaluation phase, and to keep thinking about how to improve the technology after the design process.

Apart from the onboarding of the technology with the vulnerable group and the cultural appropriateness of the technology, all remaining values found from the literature review were recognized by the interviewees. The definitions of the themes did not need to be changed after the interviews to still align with the research, the interviewees noted on the same things as the literature did and described similar experiences as can be seen in the table above. Table 6 gives an overview of the themes and their recognition in literature and the expert interviews.

## Discussion

In this research, the aim was to identify what the added value is of including vulnerable people in the design of eHealth technology. By doing a literature search and executing five interviews with experts in the design of eHealth technologies with vulnerable people, the question: *"What is the current knowledge on creating an added value on psychosocial aspects of eHealth technology design by involving vulnerable people in the design process and how can this added value be created?"*. From the literature, the added value of including vulnerable people surrounds the insights in experiences, preferences, priorities, and capabilities that can be acquired from the participants, creating a safe space in the eHealth technology, ensuring cultural appropriateness and the voices of the participants are heard, and creating a bond with the participants during the design and development process. These added values lead to clarity around what the vulnerable population wants and needs from the eHealth technology and assist the design and development to create a technology that aligns with the vulnerable population. The interviews with experts attest to these values and express the importance of treating the participants as experts as well and reinforce that feeling throughout the research period.

Besides the literature found in this scoping review and the information gathered from the interviews, a few other subjects were discovered. As is seen in this research, different people define value in different ways. Some define the value as for the researchers to create a better technology, others define value for the participants of the research to be more involved and understand the technology better. The article from Jacob et al. explores the value of patient engagement in the development of eHealth solutions.(49) The reason this study was not included in the scoping review is because Jacob et al. do not specifically design an eHealth technology but describe the overall value of patient engagement in the development research. In their research, Jacob et al. asked experts in the eHealth research field to explain their view on patient engagement and how this adds value. This can be compared to what has been done in this paper, identifying the value of involving patients in research and identifying the value of involving vulnerable people in co-design. For example, the possibility to identify unmet needs and to foster trust between researcher and participants were values attributed to both co-design and patient engagement. Jacob et al. also found that patient engagement, according to their definition, in part means including the voices of the patients.(49) In the research of Jacob et al. eHealth research experts note on the importance of including the voices of the patients in eHealth technology research.(49) Similarly, in this paper participants from the included articles noted on how they thought it was valuable for participants to be able to voice their opinion. On the other hand, Jacob et al. mentioned how vulnerable people are often included too late into the design process, after a prototype has already been made, and that this impedes the design of the eHealth technology and the engagement of the vulnerable people with the technology. (49) However, in this paper two expert interview participants co-designed an eHealth technology with a vulnerable population by using an already existing technology and they did not mention any difficulties with the vulnerable population included in the co-design. This can be due to the way the interview questions were asked, they were not focussed on subjects that impede the design, and because only eHealth research experts were interviewed and not vulnerable research participants.

Another article that talks about the engagement is the article from Unertl et al.(50) In this article they explain the benefits of using Community Based Participatory Research (CBPR). The article by Unertl et al. was not included in the scoping review, since it is an overview of using CBPR in eHealth technology engagement and not a specific technology. CBPR is a collective process between researchers, community organizations and other stakeholders(51), which can be used for co-creating and co-designing eHealth solutions among other things. The most important benefits of using CBPR are better fit between interventions and target beneficiaries, improved internal validity, and more rapid translation of research into action.(50) Faster translation of research into action was not mentioned in the included literature or the expert interviews of this paper. An explanation for this could be that in this paper the researcher only looked at primary research studies and not secondary research. For the expert interviews it could be because the research is not finished yet and the time span of the process is not compared to earlier research. However, even though it is not recognized in this paper, it could be an outcome that co-design with vulnerable people can lead to a faster translation of research into action. A better fit between interventions and target beneficiaries is something that is found in this research, looking at the insights into experiences, preferences, priorities, and capabilities, because these themes explain important aspects of the vulnerable people's lives and how they can interact with the technology. By exploring these themes in eHealth technology design with vulnerable people, the technology is created to align with every aspect of the vulnerable people's daily life and what they want and need from the technology, ensuring a better fit between technology and target population. According to Unertl et al. this also contributes to improved internal validity, researchers learn things about the vulnerable group that they could not have thought about, since the researchers are not experiencing the same problems. All expert interviewees mention similar findings, that not being in the same situation as the vulnerable group, it is difficult to decide for them because they are not familiar with the feelings and situations the vulnerable group is going through. Unertl et al. also mention that the content of the technology aligns better with the vulnerable population when including them in the process of designing and developing the technology as well as help with the implementation of the technology.(50) One of the things noticed in this research was that sometimes the insights from participants changed certain parts of the technology or the technology all together. Participants 1 and 5 mention this clearly in their interviews, that without the insights from the vulnerable group they would not have had the same technology and not have a technology that aligns with the wants and needs from the vulnerable group. Unertl et al. also found this in their research, that involving the community resulted in more relevant research by incorporating interests from the community instead of interests or ideas from the researchers. In their research this also sometimes led to a total change of focus for the technology or an expansion of certain areas.

From the literature found in this paper, only three of the ten the included articles have a reimbursement for the research participants. However, none of the included articles that mention reimbursement have noted anything on the importance of this reimbursement for their participants. Black et al. have researched the value of reimbursing participants for their time and work with the research team.(52) The article by Black et al. is not specifically written for eHealth solutions but is focused on the importance of reimbursing participants in CBPR work. Black et al. explain that not only monetary values are important but also giving community experts, as they call their participants, opportunities to improve their CBPR skills, and gaining new employment.(52) None of this is seen in the included literature in this paper but from the expert interviews in this paper, it is gathered that providing food and drinks during design sessions and giving parking vouchers helps in gaining trust and creating a bond with the vulnerable group participants

Only participant 5 from the expert interviews mentioned the value for their process in involving two patients in their project team. None of the included articles have people from the vulnerable group in their research team. Black A. et al. have dedicated research to see what makes involving patients in research teams meaningful, though not specifically for eHealth technology but more in general.(53) Black A. et al. define certain aspects to involving patients and family members in research teams, one of which is financial support. As is explained earlier, Black A. et al. also show that covering engagement related costs such as food or parking is important as well as paying participants for their contribution. Aside from financial support, Black A. et al describe the importance of having patients and family members in research teams. For example, they explain that the patients in the research team benefits other patients and the health care system, as it is more personalized for this specific group of patients.(53)

Lastly, Jackson et al. have written an article about the benefits of using co-design when designing an mHealth intervention for African American and Hispanic adults.(54) The added values that were found in this paper were also addressed by Jackson et al., however this article was not included in the scoping review because they did not pilot the technology designed in their research. In their article Jackson et al. have given four primary reasons for positive participation experiences, namely “1) the opportunity for their views to be heard, 2) collectively working together in the design process, 3) having their apprehension about mHealth reduced, and 4) an opportunity to increase their knowledge of how they could manage their health through mHealth”.(54) All these reasons were also acknowledged in the literature and the interviews from this scoping review. Additionally, Jackson et al. have also given four lessons and recommendations for racial and ethnic groups who experience health inequality. The main takeaways are that community partnerships are important in involving vulnerable groups in mHealth research and that having interactive design sessions are important to discover the needs of the vulnerable group in regard to the eHealth technology.

## Strengths and limitations

Strengths of this research are the extent to which the positive aspects of co-design with vulnerable people are explored. By identifying themes that specify the positive aspects, these themes can help with future research to clarify what to pay attention to while co-designing with vulnerable people. Furthermore, the expert interviews attest to the positive aspects and values found in this research. The information from the expert interviews clarified how the themes are perceived and the themes relate to the experience in the co-design of eHealth technology with vulnerable people.

There are a few limitations to this research that need to be mentioned. Firstly, the research was conducted by only one person. This can lead to bias and important subjects or articles being missed. In this scoping review mostly articles with positive views on co-design with vulnerable groups have been found, which can be due to selection bias. Since the research was surrounding the added value of including vulnerable people in the design of eHealth technologies, there was a bias toward positive articles. This positive bias may also have led to creating interview questions that were only focused on the positive aspects of co-design with vulnerable people, so no specific things that can impede the design of eHealth technologies with vulnerable people were mentioned.

Another limitation is the inclusion of experts for the expert interviews that work in Dutch research or Dutch institutions. This can be seen from the lack of experience with cultural appropriateness in the interviews. According to literature it is important to take cultural diversity into account (55), however when working with primarily Dutch speaking vulnerable groups the majority of the research will not include much cultural diversity.

Lastly, it is important to mention that this is not a set up for a specific co-design process. The values identified in this paper show the importance of including the vulnerable people in the design process to create an added value for both the vulnerable people as the researchers. A study that does investigate specific co-design methodologies is Grosjean et al. (56), they have written an article on patient engagement in a co-design process and mention the values that can be achieved through these methodologies. Adding to the study from Grosjean et al., this scoping review specifies added values from involving vulnerable people in the design of eHealth technologies. Combining the knowledge from Grosjean et al. and this scoping review, a specific co-design process for creating an added value by involving vulnerable people can be set up and tested. An idea to execute this is to combine this scoping review with the knowledge from Grosjean et al. and substantiate this with additional literature to create a co-design set-up for creating added value. This co-design set-up can then be piloted with a vulnerable group to see if indeed the added values found in this scoping review and the study from Grosjean et al. are represented through this set-up.

### Recommendations for future research

A recommendation for future research is to conduct more extensive research on the added value of including vulnerable people in the design of eHealth technology with more than one researcher to decrease the chance of bias and add more knowledge to the information found in this research. Another recommendation is to research difficulties with vulnerable people and aspects that impede the co-design of eHealth technologies with vulnerable people.

Additionally, a recommendation is to have expert interview participants with a more culturally diverse vulnerable group and including vulnerable people in the interviews as well to explore whether the vulnerable people also recognize these values. By including more experts with culturally diverse vulnerable groups the added value of involving vulnerable people with regards to cultural appropriateness can be extended.

A final recommendation is to research specific methodologies to include in the design of eHealth technologies with vulnerable people to create an eHealth technology that best aligns with the vulnerable population and see how these methodologies affect the adherence and engagement of the eHealth technology.

## Conclusion

In conclusion, this research investigates the current literature available on the added value of including vulnerable people in the design of eHealth technologies. The values identified from the literature show that it is important to include vulnerable people in the design of eHealth technologies. The expert interviews recognized the values from working with vulnerable people in the design process, and they gave additional information on the added value of involving vulnerable people. To create an eHealth technology that aligns with the experiences, preferences, priorities, and capabilities of the vulnerable group, involving the vulnerable group is an important step. Furthermore, taking accessibility and safety of the technology into account ensures that the vulnerable group can use the technology as intended. Listening to the voices of the vulnerable group and creating a bond with them were identified as important for both the researchers and the vulnerable group, to ensure a smooth research and design process.

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# Appendix

## Appendix 1 – search matrix

| **eHealth** | **Co-design** | **Vulnerable** | **Value** |
|---|---|---|---|
| telehealth | Cocreation | Diversity | Gain |
| Telemedicine | Participatory | Low income | Benefit |
| Digital health | Human-centred | Low socioeconomic status | Advantage |
| mHealth | | Ethnicity | |
| | | Rural | |
| | | Poverty | |

# Appendix 2 – data extraction template

## General information

**Study ID:**

**Title:**

Title of paper / abstract / report that data are extracted from.

**Lead author:**

**Country in which the study conducted:**

1. United States
2. UK
3. Canada
4. Australia
5. Other:

## Characteristics of included studies

### Methods

**Aim of study:**

**Study design:**

1. Randomised controlled trial
2. Non-randomised experimental study
3. Cohort study
4. Cross sectional study
5. Case control study
6. Systematic review
7. Qualitative research
8. Mixed method study
9. Other:

**Study team:**

1. Multidisciplinary
2. Researchers only
3. Researchers and ICT specialists

**Type of design method:**

1. Co-design
2. Community based participatory research
3. Participatory research
4. Other

**Phase of co-design:**

1. Pre-design
2. Early design
3. Post first prototype
4. Full co-design process

**Methods of involving participant group:**

1. Focus groups
2. Design sessions
3. Workshops
4. Interviews
5. Other:

**Methods used during participation:**

1. Mock-ups
2. Think aloud

3. Paper prototyping
4. Active debate
5. Guided discussions
6. Other:

**Type of eHealth technology:**

**Iterative process:**

1. Yes
2. No

**Pilot study of eHealth technology:**

1. Yes
2. No

**Method of evaluation of pilot study:**

**Participation incentive:**

## Participants

**Population description:**

**Inclusion criteria:**

**Exclusion criteria:**

**Method of recruitment of participants:**

1. Phone
2. Mail
3. e-Mail
4. Flyers
5. Clinic patients
6. Voluntary
7. Other:

**Total number of participants:**

## Results

**Value of including vulnerable group:**

**Using quotes from participants:**

**Reading between the lines for value:**

## Appendix 3 – interview guide

| Topic | Question |
|---|---|
| Introduction interview | • Introduce myself<br>• Explain interview context/goal*<br>• Time estimation (30-45 minutes) |
| Privacy and consent | • Address confidentiality<br>• Request recording approval<br>• Informed consent |
| Introduction study context | • Repeat purpose of the study |
| Introduction Participant | • Can you give a short introduction of yourself?<br>○ Age?<br>○ Gender?<br>○ Experience in eHealth research?<br>• Can you tell me about your background in eHealth technology research? |
| Co-design | • Do you have experience in co-designing eHealth technology with vulnerable people?<br>• If yes, what was the vulnerable group?<br>• And what was the eHealth technology?<br>• In what phase of your technology design did you use co-design?<br>• What type of methods did you use to include people in the design process? (Focus groups/workshops, interviews, design sessions)<br>• How did you guide these sessions? (Guided discussions, think aloud, paper prototyping, mockups, active debate)<br>• Was the design process an iterative process?<br>• Did you pilot your technology at any point in development?<br>• If yes, how?<br>• If not, are you planning to? |
| Identified themes | • Why did you adopt a co-design approach in you work with [vulnerable group]?<br>• If yes, what was the added value to you?<br>• Did you consider any other design methodologies?<br>• In literature we found certain themes; cultural appropriateness, safety, trust, better insight in perspectives, priorities, better accessibility and voices being heard. |
| Better insight in perspectives | • Better insight in the perspectives of the vulnerable group is a broad theme in the found literature. For example, it is found in the context of specific requirements for the eHealth technology.<br>• What did you notice in the perspective of your participants towards the eHealth technology?<br>• Were there specific things that you did not think about that the participants put your attention toward? |
| Priorities | • Another broad theme in the literature was priorities of the vulnerable group. This was mostly surrounded in what the group found to be most important for the technology. |

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| | - How did you consider priorities from the vulnerable group in your eHealth technology design?<br>- What kind of priorities did you find while designing the eHealth technology?<br>- What did you notice in the priorities of your participants towards the eHealth technology?<br>- Were there specific priorities that you did not think about that the participants put your attention toward? |
| Cultural appropriateness | - Regarding cultural appropriateness, what did you notice about the culture of the vulnerable group you were working with?<br>- And how did you incorporate this into your<br>  - Co-design process<br>  - eHealth technology<br>- Do you think there is an added value related to the culture of the vulnerable group in creating an eHealth technology for this specific group?<br>- And what do you think this added value is?<br>  - How do you notice this?<br>  - Can you give an example?<br>  - What do others see of this added value? |
| Better accessibility | - The theme of accessibility came to the surface. For example, in one study the accessibility of the webpage should be accessible both from a laptop or tablet as well as a mobile phone to ensure that it could be accessed anywhere.<br>- Were there any instances in which you noticed accessibility to be a theme in your:<br>  - Co-design process?<br>  - eHealth technology?<br>- If yes, what was the instances?<br>- How did you address this in your design of the eHealth technology? |
| Safety | - The theme safety in the found literature was identified around for example an emergency button in a web-based mental health clinic.<br>- Were there any safety problems in your eHealth technology?<br>- If yes, how did you address them? |
| Trust/bond with researchers | - In some papers, the vulnerable group acknowledged that being able to trust the researchers and create a bond with them was important in their involvement with the research.<br>- Did you pay attention to creating a bond with your participants?<br>- And if so, how did you create this bond?<br>- How did you make sure that your participants trust you? |
| Voices being heard | - In quite a few of the studies found, participants acknowledged how they were excited about their voices being heard while designing the technology. For example, African American participants in a study for creating a smartphone application for |

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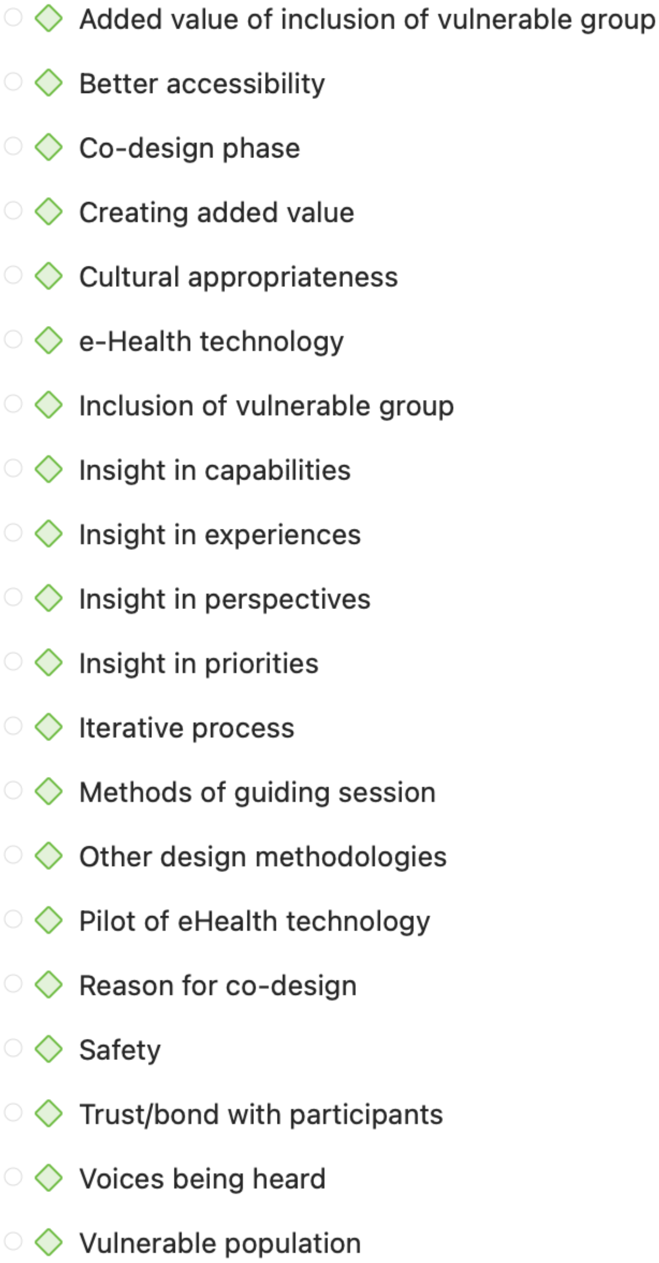
| | cardiovascular health information said that they were glad that their voices were heard regarding what they wanted to incorporate in the technology.<br>• Did you notice this in your own design process with your participants?<br>• How did you make sure that the voices of your participants were being heard? |
| Added value | • How do you think you can create added value in designing eHealth technology for vulnerable people?<br>• What are things you would recommend doing in a design process that will help create this added value?<br>• Do you think there are specific things to consider creating added value in a design process for eHealth technology?<br>• If so, what are these things?<br>• And how would you incorporate them in existing design methods for eHealth technology? |

*Interview context and goal: I am working on a thesis for the master Health Sciences at the university of Twente. My thesis is about creating an added value by involving vulnerable people in the design of eHealth technologies. Vulnerable people here are "people in vulnerable situations that, due to this vulnerability, have a higher chance to adverse (mental) health outcomes. Vulnerable situations include poverty, low (health) literacy, language barriers, and discrimination related to age, disability status, ethnicity/ race, gender." There is a limited amount of literature available surrounding this subject, so the incentive is to gather the knowledge from the current literature and relay this with experts on eHealth technology design.

The goal for this interview is to see whether the information that I found in the literature is also something that is currently used and acknowledged in eHealth technology design.

## Appendix 4 – codes for data extraction from the interviews



- Added value of inclusion of vulnerable group
- Better accessibility
- Co-design phase
- Creating added value
- Cultural appropriateness
- e-Health technology
- Inclusion of vulnerable group
- Insight in capabilities
- Insight in experiences
- Insight in perspectives
- Insight in priorities
- Iterative process
- Methods of guiding session
- Other design methodologies
- Pilot of eHealth technology
- Reason for co-design
- Safety
- Trust/bond with participants
- Voices being heard
- Vulnerable population