Expectations of people in vulnerable situations on Check@Home digital home-based screening for type II diabetes and heart and kidney conditions - a qualitative focus group study

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Abstract

Background: Artificial intelligence (AI) tools are increasingly introduced into the healthcare system. Not only healthcare professionals but also patients and citizens are increasingly asked to use digital health technologies to perform preventative care tasks for e.g. health monitoring and prevention purposes. Previous research showed that digital health technologies do not always fit the needs and wishes of end-users.

Objective: Therefore, in this paper we investigated how prospective users, in our case people in vulnerable situations, e.g. having migration backgrounds, poverty, low literacy or intersections of those examples, envision to (not) use a currently developed home-based AI screening technology for the for the early detection of conditions of the heart, kidney and type II diabetes called Check@Home.

Methods: Data were collected through five in-depth focus groups. Participants were recruited trough being at spaces where people in vulnerable situations spend time e.g. local community centres. To validate the results from the focus groups, our findings were discussed in two reflection sessions with professionals (representatives from patient organisations and social workers).

Results: We found three common themes. First, our results show that participants believed they could reduce the burden on the health care system trough participating in healthy behaviour, such as preventative digital testing. Second, we found that people in vulnerable situations feared the digitalisation of the healthcare system. They expect to have less access to healthcare, for example because the skills needed to use digital health applications cannot always be used, e.g. because of a lack of head space due to financial worries. Not having access to healthcare that would otherwise be available to them just because it was digitalised, added to their already existing idea that the healthcare system was not taking care of them. Third, we found that people living in vulnerable situations have to make continuous trade-offs about what has priority at that moment in their lives because of challenging everyday life situations. For some participants this meant not participating in the screening technology in the way it was intended or not at all.

Conclusions: Our results show that while respondents accept the digital screening technology, they cannot always use the technology because of their everyday life situations in which they lack the opportunities or capabilities to do so. Our paper adds to our understanding of when, how and why people in vulnerable situations expect to (not) use digital AI screening technologies. Articulating needs and wishes of prospectives users in the early stages of a technology development is useful, as it can provide building blocks for e.g. technology developers and policymakers to create more accessible and inclusive healthcare systems in the future.

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Key words: digital health technology, people in vulnerable situations, patient participation, responsible innovation

Introduction

In recent years, we have witnessed the introduction of digital technologies in healthcare, such as video consultations with doctors, care robots for the elderly or artificial intelligence (AI) based health monitoring apps [1-3]. Healthcare professionals (HCPs), policymakers and technology developers expect digital health technologies to solve current problems in the healthcare system e.g. rising costs, increasing need for palliative over curative care and increasing shortages of HCPs [4]. Currently, these digital technologies are not only used by HCPs in e.g. hospitals, but also create situations in which citizens can use digital health technology at home for health monitoring and prevention purposes. For example, to test if they are at risk for disease or to track behaviour in order to nudge citizens to change lifestyles [5].

We study home-based digital health technology in the context of Check@Home. The Check@Home's consortium aims to develop digital home-based screening for the early detection of chronic conditions related to the heart, kidneys and type II diabetes in the Netherlands (more details are provided in the methods section). Since people are asked to perform digital preventative tasks at home, multiple questions arise: How does someone's daily life at home look like? Do people have the time, resources or social network to perform digital prevention tasks, interpret results and deal with related emotions [6, 7]? Previous research has shown that technologies do not always fit the needs, capabilities and resources of users [6, 8, 9]. When developing new care technologies, developers have many assumptions about the prospective users [10]. Developers for example often assume that people can and want to actively engage in care activities such as measuring and monitoring their health [3]. In the case of the Check@Home digital screening, it is expected that people are able to perform digital screening tests at home. This requires particle resources, such as a smartphone and internet, and knowledge on (un)healthy behaviour, illness as well as being able to interpret results and seeking follow-up care. Yet, previous research already showed that people have all kinds of creative ways of using care technologies that do not always match the intended use that was expected by the developers [8]. For example, in a study of patients' use of ambulatory ECG recording devices, Oudshoorn [6] showed how patients use the device in selective ways that fit their everyday lives, e.g. only recording heart rates on fixed days instead of when they felt an irregularity in their heart rate, as instructed. In another example, Wendrich et al. [9] studied first experiences of patients on digital self-monitoring devices for multiple sclerosis and showed for instance that quantitative data resulting from apps and activity trackers evoked emotional responses. While developers expected patients to monitor themselves multiple times a days, patients indicated to desire to have more flexibility in using these tools, depending on their disease status.

As Oudshoorn [8] already argued, when digital health technologies do not fit users' needs, it might hinder people to get access to healthcare systems. Therefore, digital health technologies have been criticized for the potential of worsening challenges for people who live in vulnerable life situations [11]. People living in vulnerable life situations, e.g. having migration backgrounds, poverty, low literacy or intersections of those examples, often experience higher disease burden and have less social or digital experiences, resources and relationships to navigate a digital healthcare system compared to people who are highly educated, living in well-off neighbourhoods and are from non-minority backgrounds [12-14].

In this paper, we study what people in vulnerable life situations expect from preventative digital home-based screening. While Check@Home is meant for Dutch citizens between 50-75, we deliberately decided to focus on people in vulnerable situations for two reasons. First, health researchers, HCPs and technology developers expect the most health gains to be made because of high onset, progression and morbidity rates of chronic diseases in these groups [15]. Second, at the time of writing, the Check@Home digital screening technology is still in the development phase and not yet in use. This provides the possibility to research expectations of people in vulnerable situations early in the development process about a possible future technology. Early engagement of prospective users in technology development enables us to gain insight into what is at stake, for whom and what actions are required to move towards more desired futures or away from undesired futures [16-18]. Yet, current public and patient engagement endeavours to discuss the development and implementation of new technologies often lack to include the perspectives of diverse actors stemming from different backgrounds and with different types of knowledges [18, 20, 21]. Therefore, little is known about the needs, expectations and experiences of people in vulnerable situations in the development of digital health technologies. In this paper, we aim to fill this gap by investigating the expectations of people in vulnerable situations through a qualitative focus group study.

Methods

Research context

Check@Home is a nationwide project in the Netherlands in which academic hospitals collaborate with, among others, healthcare companies and health funds. The project has the ambition to develop a screening program for conditions of the heart, kidney and type II diabetes to prevent progression of disease and related economic burden on society. The screening will consist of four phases and for all these phases we elicited the perspectives of participants. Phase 1) The invitation phase: Dutch citizens between the ages of 50-75 are invited to participate via a letter mailed to their home addresses with information and instructions regarding the digital home-based screening. Phase 2) Digital home-based testing: once a citizen decides to participate, they have to download an app on their smartphone in which an AI technology is built to perform testing. Phase 3) Diagnostic phase: when risk for disease is found based on the home-based testing, participants are asked to join follow-up tests done by HCPs, e.g. nurses, in screen- and treat facilities newly set-up for the screening. Phase 4) Care pathway: if someone gets diagnosed based on the testing in the screening, they enter the care pathway which could consist of nudges towards lifestyle changes or treatment, depending on what is considered necessary by their general practitioners or the HCPs at the screen- and treat facilities.

Participant selection

After approval by the Research Ethics Committee of the Faculty of X of University X ([*blinded manuscript: REC number*]), participant selection was performed in two different ways. First, via door-to-door flyers in both low income and non low-income neighbourhoods in a suburban region of the Netherlands. Second, we built upon the work of Horstman & Knibbe [13] and joined activities at social spaces where different people could participate. Author (blinded manuscript X) joined existing activities at a local library for people with low literacy, a social gym for people on welfare and local community centres. She also volunteered at a local initiative to introduce e-health applications to people who live in low-income neighbourhoods. Through these activities of ‘being there’ she had the opportunity to build a network, introduce people to the research topics and invite them to participate in the focus groups. In the end, 24 people (16 women and 8 men) participated in 5 focus groups (table 1).

Table 1. Overview of focus groups

Focus group	**Number of participants**	**Average age at time of the focus groups**	**Sampled via**
1	6	59	Local library
2	3	60	Local library
3	4	73	Local community centre
4	8	69	Social gym for people on welfare
5	3	72	Social gym for people on welfare

Data collection

We performed 5 focus groups at locations already familiar to the participants, e.g. community centres. We chose for group discussions, because the group interactions allow people to respond to others which creates a saver environment to discuss new and sensitive topics, e.g. emerging digital health technology or disease experiences, compared to one-on-one interviews for people in vulnerable situations [22]. The focus groups had an average duration of 114 minutes excluding a 30-minute break per focus group. Since the digital home-based screening is not a reality yet and participants do not have experiences with it, we built upon previous research that shows that participants need imagination to think about emerging technologies e.g. [23]. Therefore, we developed and used a photo story (appendix 1); a narrative and picture-based scenario in which the story of a person participating in the digital screening is told and shown [24]. During the focus groups, we discussed how participants care for their health in daily life, we explored participants' expectations on the four phases of the screening as mentioned above and we discussed expectations by developers of Check@Home. What kind of needs, wishes or worries can arise in a potential future with Check@Home's digital screening? When saturation occurred in the data and new themes no longer emerged, we stopped organising focus groups.

In order to get a deeper understanding of the experiences, expectations and perspectives in the context of the focus group participants everyday lives, we also organised two reflection sessions of 1 hour with professionals in which we discussed and validated our results. For the reflection sessions we invited representatives from patient organisations and social workers active in the residential areas of the focus group participants. We invited them to learn from their professional perspective and experience regarding testing for disease and living in vulnerable situations. In the reflection sessions we formulated questions based on our results from the focus groups. For example, 'Why do you think citizens in your work district would use the home-based digital tests?' and 'Do you expect citizens in your district to experience feelings of anxiety caused by digital home-based testing. And if so, why?'. These questions were discussed from their own experiences. After each discussion, we presented the results related to that question on which the professionals could respond. After the first three focus groups, we organised a reflection session with representatives from patient organisations. Based upon the discussion during the first reflection session, we decided to discuss people's need to make informed choices and challenges during waiting for results (table 2) in more detail during the last two focus groups. After all five focus groups, a reflection session with social workers took place (figure 1).

[redacted]

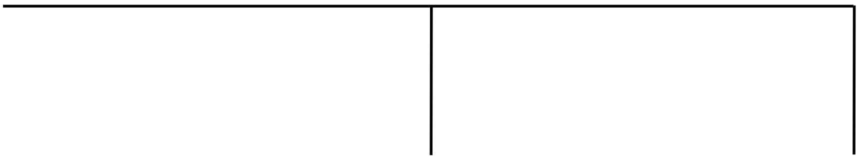

Figure 1. Schematic overview of the data collection process in which we combined focus groups and reflection sessions.

Data analysis

All focus groups were recorded and transcribed verbatim. Content analysis was used to analyse the data [22]. We coded the first two focus groups to develop a codebook. The codebook was created with the help of deductive and inductive coding (table 2). After consultation with author Y on the codebook, all transcripts were coded by author X using ATLAS.ti23 software. The findings were discussed in regular meetings throughout the data analysis. While the participant selection, data collection and data analysis are presented here as separate for explanatory purposes, we moved iteratively between the analytical components.

Table 2. Overview of inductive and deductive (sub)themes.

Main themes	Subtheme	
Facilitators for screening participation	Access to healthcare Creative ways of using technology Experienced responsibility for one’s own health	Deductive
	Resigning oneself to the digitalisation of healthcare People’s need to make informed choices e.g. clear point of contact Caring for the self	Inductive
Barriers to screening participation	Lack of access to (digital) healthcare Feelings of fear regarding outcomes of the tests Ethical concerns e.g. right not to know	Deductive
	Challenges during time of waiting for results/diagnosis Not feeling cared for Distrust regarding the healthcare system	Inductive

Results

Daily live activities influence the way people, including patients and their relatives, assess new technologies that enter their lives [25]. Our methodological approach of ‘being there’, enabled us to gain insight into the realities of vulnerable everyday life situations on which we will elaborate below. These can be grouped into three overarching themes: 1) Feeling responsible for one’s health, 2) Not feeling cared for, and 3) Trade-offs to deal with vulnerable life situations. Below we will describe the three themes and accompanying activities in more detail and show how vulnerable life worlds influence people’s assessment of new digital home-based screening technologies. Illustrative quotes have been translated from Dutch.

Feeling responsible for one’s health

Living in extreme conditions such as living on welfare benefits, not always having a place to sleep or having family and friends living with addiction, shape the way people care for themselves. For instance, some respondents choose to drink less alcohol because they saw devastating effects of alcohol addiction of close relatives. Caring for the self was considered an important responsibility to avoid living in physical pain, being dependent on others or no longer being able to do what they considered important such as being around people. When the digital screening technology would enter their vulnerable life situations in the future, almost all participants expected to embrace it as a tool for self-care. We found that participants felt responsible for their own health, because they wanted to avoid becoming dependent on others as a result of disease development or progression. Participants saw digital home-based testing (phase 2) as an opportunity to be reassured about their own health status. They were looking for the reassurance that they were either not ill or, in case they were ill, there would be treatment to avoid further disease progression. The phrases ‘what gets measured, gets managed’ and ‘better safe than sorry’ were used in the focus groups to argue why preventative testing is a suitable way according to them to obtain this reassurance. We found that participants placed reassurance about diagnoses in the context of previous illness related experiences of themselves or others. In the following quote, AE illustrates this in the context of their own experience:

> AE (FG5, age 74): ‘If [digital self-testing] would be possible, it would be interesting. I had to wait before they found out I had cancer. That took them 10 years. That was a shame. If there had been tests available back then, it would have been caught earlier.’

While participants expected digital screening to be a tool for self-care by avoiding severe disease or treatment trajectories, participants also discussed what it could mean for their future self to perform the tests in the context of their daily lives. For example, participants discussed their expectations on phase 3, finding the letter with test results on their doormat. They mentioned feelings of anxiety based on the thickness of the letter because ‘otherwise you would get one page saying everything is fine. It [a thick envelope] does scare you’ (L, FG2, age 58). Mostly the feelings of anxiety would be caused by uncertainty about a future with or without illness while waiting in the time between testing and return of results:

> AB (FG4, age 68): ‘Anxious?’
>
> V (FG4, age 69): ‘Yes, as in what will [the test result] be? My goodness, my goodness, I have to do the test again. When is [the result] coming anyway? The day after tomorrow? [Sights] What would the result be?’

Besides feeling responsible for one’s own health, we found that participants also felt responsible for the resilience of the healthcare system considering current shortages in staff and resources. They considered the shift of HCPs performing care tasks to citizens as normal or even needed because they were of the opinion that this would be a solution for the shortages in healthcare. What came up in this context is that the participants felt the need to respond actively upon the assumed individual responsibilities of maintaining good health through digital preventative screening. Participants viewed phase 2 of the digital screening as a way to take on this responsibility instead of ‘whine about it to the doctor' (P, FG3, age 65). We found that participants felt responsible to unburden the healthcare system through their individual behaviour regarding their health. This is illustrated in the following discussion:

> AF (FG5, age 73): 'I think it is important to unburden healthcare. I feel like, perhaps because of all the messages in the papers and on television, that our healthcare is already overburdened now. I feel that it is important, if you can prevent unnecessary doctor visits or prevent illness. And that is why I think this [digital home-based testing] is important.'
>
> Moderator: 'because you do not want to burden healthcare?'
>
> AF (FG5, age 73): 'I indeed have that feeling (…) I think "gosh, they [HCPs] have a huge pile of elderly coming their way".'
>
> AE (FG5, age 74): 'We are living longer, aren't we? [laughs] but yes, we will have to unburden them [HCPs].'

We also found that participants considered the implementation of digital care innovations something that they cannot control and as part of the future because 'in the future some things will have to be digitised anyway' (L, FG2, age 58). Even when they were unsure and scared about what a future with digital care would entail exactly:

> W (FG4, age 68): 'Artificial intelligence indeed, so the care [tasks] of doctors are taken away and then they implement artificial intelligence so the doctors can focus more on other things and have more time for other things. (…)'
>
> V (FG4, age 69): 'But it is a scary idea.'
>
> W (FG4, age 68): 'Yes, it [artificial intelligence in healthcare] is kind of scary, so I wonder if can be done in a safe way and if they can really clearly say "well this person has these complains, what can we do with that and how can we solve that?" And can they achieve that with artificial intelligence? Look… a doctor will surely be able to find a solution but can such a device, which people call artificial intelligence, also solve it?.'

Not feeling cared for

People also felt the need to take care of themselves, because they experienced the healthcare system, and the state in general, does not care for them. For many, living in vulnerable situations meant being somewhat reliant on the state e.g. being on social welfare benefits or spending time at a local community centre. This reliance on the state also means that they are in contact with helpdesks a lot to get access to support services, such as food banks, sorted. The access to those services is often surrounded by rules, regulations and bureaucratic procedures which resulted in people often hearing 'no' as an answer to their requests for help. In the reflection sessions with social workers, we found that the elderly people, approximately around 70 and older, feel that there is not enough care available for them. Especially considering the kind of citizenship that they feel that was expected from them in the Netherlands throughout their lives. Namely, if one participates actively in society, e.g. contributing via paid work through skill and taxes, one was promised to be taken care of when they were older. Yet, now that they are older, there is not enough resources to provide the care that was promised. People experience a lot of frustration regarding the policies that aim to increase digital applications in healthcare. One social worker said about this:

> ‘It is mainly that they want to be in the digital world, on a digital level, as little as possible. Their frustration comes from their idea of “well, when I was living in a welfare state and a participatory society, they would take care of me later”. But we just can’t. We have too little manpower to do that. The frustration comes from the many budget cuts over the last few years and the reduction of many support places out there. Those are no longer there, but people were counting on that.’

Participating in phase 1 to 4 of the digital screening, asks (digital) health literacy, management and emotional skills from people. People need to have digital literacy skills to operate the digital tests. Health literacy skills to process and utilize the health-related information [26]. Management skills and a sense of responsibility to complete the digital tests in a timely and accurate manner. As well as emotional skills to deal with test results and related feelings of anxiety and uncertainty. We found that it is not as straightforward as often assumed by technology developers that everyone has these skills or is in a life situation where these skills can flourish. Lack of access needed to use the digital screening was discussed in every focus group and included topics like not owning a smartphone to not having money to pay for health-related costs, such as health insurance or treatment costs. For example, V (FG4, age 69) said:

> ‘Hold up, people who do not have any money, not a penny to their name, cannot even get health insurance, they are not insured. (…) I don’t agree with it either, but in happens. I am among those people; it is really painful to witness.’

Some of the participants of the focus groups self-identified as being low literate in the Dutch language. Most of the people who identified as low literate had a Dutch background and some a migration background. During the joint reading of the information material on the digital home-based testing (phase 1), we found that reading and assessing the information was not as straightforward. We also found that adjusting the information for people with low literacy is not clear-cut, because using words that enhance understanding, in order to make informed decisions on digital care, differed per background. For example, we found that choosing words that enhance the understanding for people relatively new in the Netherlands, reduced understanding of people with Dutch backgrounds. Yet, the photo story (appendix 1) used to support the focus groups, was highly appreciated by the participants, especially by those who self-identified as low literate, to further their understanding of the screening technology. In all focus groups we discussed difficulties with the digital aspect of the screening technology. Participants were reluctant towards the idea that health gets more and more digitalised. Some said explicitly that while they were positive towards screening, they fear that they would be excluded involuntarily from participating because of their limited (digital) literacy skills. For some it was frustrating that the digitalisation of healthcare might exclude them from receiving quality care that is available yet inaccessible. For example, G (FG1, age 56) said:

> ‘And I also think it's a very big, big mistake, it used to be that you could just go to the hospital, to do a bowel test or whatever and now none of that is possible. And now it all has to be done through the app, why? There are also people just like us [with limited literacy in the Dutch language] who can't do that.’

During the focus groups, we discussed what the lack of access to the digital screening would mean for them in their everyday lives. We found that participants felt not being cared for in a future healthcare system that would by digital. The digital home-based tests are introduced into people’s lives without their knowing; the invitation to participate in the digital screening just falls on their doormat (phase 1). Hence, in the information letter it is stated that there is a possibility that they are ill without symptoms. Many participants said they ‘get scared even before you have done the test’ (G, FG1, age 56). After being confronted with the information on their possible ill-health, they feared missing out on good health care, because they would be unable to perform the tests, that would otherwise be available to them. G (FG1, age 56) said about this regarding their limited digital and literacy skills:

> G (FG1, age 56): ‘I mean that [another digital test] has never been done. Because that app just didn't work [for me]’
>
> Moderator: 'would that [not able to perform the digital tests] give concerns maybe?’
>
> G (FG1, age 56): 'At that point ... if something is wrong with you, yes. (…) I do think I miss out on a lot of uhm stuff [tests]. Then things start playing in the back of your mind'.

For others the lack of access to the digital screening was another example of a feeling they already had; being written off by society. Screening programmes often have an age limit and when someone grows older, they are no longer allowed to participate. For some this was experienced as a message from society that they no longer mattered because of their old age. Participants discussed this feeling in the context of earlier experiences, as illustrated in the following discussion:

> M (FG4, age 76): So [HCPs] do nothing [to help me]. That hurts, those blows. Considering what I went through with my wife in those years [referring to their time as an informal care giver]. Then I think “damn, I am just thrown in a corner”.’
>
> P (FG4, age 65): I have experienced that for a long time as well, and I am younger (…) I have had all kinds of conditions throughout my life, so I learned how to deal with it. There is a limit when you have to say, “I cannot do it by myself anymore”. But then you get no help, never ever, they are super difficult about it, so businesslike, self-efficacy, self-efficacy … It makes me think “if I had the self-efficacy, I would not ask”. So that is when you run into a huge wall. That evokes a lot of anger in me.’
>
> M (FG4, age 76): ‘Internally it starts to fester. Like damn, [you have to take] another kick.’

Trade-offs to deal with vulnerable life situations

With the risk of generalising, because every life is different, people in vulnerable situations have to deal with worries that other people do not. These worries are often related to a lack of resources. For example, some respondents mentioned that they have to deal with financial instable situations and live in neighbourhoods where they are confronted with violence, both inside and outside of their house. We found that these worries resulted in coping mechanisms such as drinking alcohol or using soft drugs as ways to stay mentally healthy. The continuous challenges that living in vulnerable situations give, requires people to continuously make trade-offs in what is important in the moment for their daily life; what seems important right now can be unimportant tomorrow when another challenge arises. While people felt responsible for their health, participating in preventive care tasks such as the digital home-based tests did not always have priority because it did not always fit the needs that arise in challenging daily lives. Yet, most still wanted to use the digital home-based tests. Participants started suggesting solutions to overcome their expected barriers to use. The solutions were mostly related to their need for preventative care without a digital component and ‘all the difficulties of an app’ (M, FG3, age 76). Participants discussed other forms of preventive care that could avoid their use digital home-based self-tests (phase 2), such as working out and eating healthy. Participants also started looking for ways to modify the digital home-based tests in ways that fit their personal needs and possibilities in the context of their vulnerable life situations. For example, many participants suggested setting up test facilities for phase 2 at already existing infrastructures such as blood draw locations or the hospital. These physical locations were spaces that felt familiar and safe for many participants because they already visited these facilities often to be checked for diseases such as type II diabetes. For example, G (FG1, age 56) said:

> ‘I would say “just let me go to the hospital”. Get the tests done there and have it over with, than I would participate [in preventative testing]. (…)’

We also found that for some participants taking care of themselves and their own needs meant avoiding participation in digital screening all together. In almost all focus groups, participants discussed avoidance because they did not want to know everything about their health status. Many participants wished for a healthy and long life but simultaneously asked ‘are we still allowed to die?’ (e.g. AA, FG4, age 65). One of the reasons preventative testing for heart conditions, kidney conditions and type II diabetes is being developed is because people can be asymptomatic but still ill. Yet, some participants reasoned that testing was unnecessary because they did not feel bodily signs that indicated otherwise. Another reason to avoid participation in digital screening was related to feelings of anxiety that possible positive test results could evoke. For example, J (FG2, age 62) said:

> ‘It is a trade-off, and like you [participant K] already said, do you want to hear bad news? That is very confronting.’

Many participants expressed distrust towards the digital self-testing. They wondered which organisations were behind the screening technology and ‘who is making a sweet profit from this?’ (O, FG3, age 75). To protect themselves from unforeseen healthcare costs in the future or possible exploitation e.g. by pharmaceutical companies earning money based on their health data, participants felt reluctant about the digital screening. This is illustrated in the following discussion:

> J (FG2, age 62): ‘I would be afraid that insurance companies are going to exploit this’
>
> K (FG2, age 59): ‘That they will start looking for something?’
>
> J (FG2, age 62): ‘Yes, if you have to fill in, for example, those things [asked in the digital home-based testing technology] “Do you smoke?” “Do you drink?” those questions.’
>
> L (FG2, age 58): ‘Yes, yes, I can see what you mean. That would become a nasty argument because then they [insurance companies] care going to exclude that in their health insurance, leaving you to pay the bill… yourself.’

Discussion

With this paper, we aimed to provide insight into which expectations, responses and emotions digital home-based screening evokes in people in vulnerable situations. Although everyday life is more complex and layered than what we were able to show, we did find three main results throughout the focus groups: 1) feeling a responsibility to remain healthy; 2) not feeling cared for; and 3) having to make trade-offs.

First, people feel a sense of responsibility to remain healthy for both their future self and the maintenance of the healthcare system. The introduction of digital applications in healthcare shifts the responsibility of performing care tasks from the healthcare professional to the citizen [2]. We found that people have taken up new responsibilities and were striving to be ‘good biocitizens’ [27] by being active in their health through the expected use of digital applications such as the digital screening technology. They did not only feel responsible for their own future health, but also for the stability of the healthcare system. By participating in healthy behaviour, such as preventive testing, participants believed to reduce the burden on the healthcare system.

Second, people felt the need to take care of themselves because previous experiences with the healthcare system showed them that they are not being cared for by that system. People in vulnerable situations feared the digitalisation of the healthcare system. They expect to have less access for example because the skills needed to use digital health applications cannot always flourish in their vulnerable life situations, e.g. no head space to learn new digital skills when worried about financial problems. Not having access to healthcare that would otherwise be available to them just because it was digitalised, added to their already existing idea that the healthcare system and society at large were not taking care of them as individuals.

Third, we found that people living in vulnerable situations had to make continuous trade-offs about what had priority at that moment in their lives. This confirms previous findings. As Horstman & Knibbe [13] for example found, when someone is living with chronic stress caused by unsafe surroundings one’s future health can be viewed as less of a priority to take care of because the current life situation already requests full attention. In our research, participants started looking for ways to take care of their own needs in the context of what was possible in their vulnerable life situations. For some this meant getting tested at already existing care infrastructures. Another study on participation in a diabetes screening program, reported a positive influence of testing at existing facilities as well because people considered it easy and accessible [28]. For other participants in our research, making trade-offs included not participating in the screening technology in the way it was intended or not at all, because they preferred other ways of caring for themselves. Thus, it can be a deliberate action to not use digital preventative testing by caring for the current self instead of the future self given their current and often challenging everyday life situations.

The overarching finding of this study is that technology acceptance does not equate technology use. As Dijkstra & Horstman [29] already argued, when people in vulnerable situations do not use new technologies or do not participate in healthcare programs, it is often assumed by e.g. scientists and policy makers, as too unwilling or unknowing to participate in healthy behaviour or preventative care practices. However, our research showed that people can accept new technologies and are willing to use the technologies, but lack the opportunities or capabilities to do so. For example, as we have shown in our results it can be challenging to navigate instructions and execute digital home-based self tests when someone is living with limited literacy. It can also be too difficult to deal with test results when everyday life is already challenging due to e.g. financial worries. These findings resonate with the work of Wyatt [29-31] and Weiner & Will [32] who already showed that people can be involuntarily excluded from using technologies, e.g. because of the design of those technologies. Thus, people do want to benefit from screening but expect that they are not always able to do so due to various circumstances. Therefore, when the aim is to reach as many people as possible with digital screening programs, we argue to utilize existing and existing infrastructures that provide support when needed, such as national digital support services or support initiatives at local community level e.g. at the community centre.

Strengths and limitations

Via in-depth focus group discussions and reflection sessions with representatives of patient organisations and social workers, we aimed to gain insight into when, how and why people in vulnerable situations would (not) use digital AI screening technologies. While we aimed to create a safe environment by grouping people based on the characteristics they were oversampled for, we acknowledge that some individuals can be naturally more dominant or demure [22]. Therefore, during the focus groups, it could have been difficult for some to speak up when they did not agree with the discussions. This could have resulted in the group perspective overruling the individual perspective without the researchers knowing. Moreover, while we included a diverse group of people from different cultural, social and educational backgrounds, this study is limited by the participant selection process. As detailed in the methods section of this paper, we selected participants by joining existing activities in low-income neighbourhoods. We did so to take into account the intersectional, situational and structural aspects of vulnerability and to avoid classifying and labelling people as vulnerable based upon characteristics such as socioeconomic status or migration background [33, 34]. However, also when joining existing activities, one has to be aware that not every person in a vulnerable situation has the opportunity to gather at social spaces such as local community centres. Therefore, while our approach allowed us to uncover a rich variety of perspectives, there might be other experiences and visions that we did not cover.

Further research

Our suggestion for future research is to also adopt other methods to include perspectives that we did not cover during our research. Pols [35] already argued, that methods which are less deliberative and focal as e.g. focus groups, can be especially useful when one wants to include people who are less likely to speak up. For example, people living in vulnerable situations as they might feel less comfortable with deliberative processes since they are not used to being listened to by people with decision-making power. Pols [35] argues for researchers taking part in activities with people, e.g. volunteering work or going on a walk together, to learn what is important to them in their everyday lives related to healthcare.

This paper aimed to articulate needs and wishes of prospectives users in the early stages of a technology development. This is useful as it can provide building blocks for e.g. technology developers and policymakers to create more accessible and inclusive healthcare systems in the future. This study however only focused on one stakeholder group while there are many in the context of digital health technology development and implementation, e.g. various HCP groups, insurance companies and health ministries. As e.g. Rip & te Kulve [17] and Krabbenborg [36] already pointed out, how new technologies are developed and implemented results from decisions, considerations and negotiations made between many stakeholders, such as technology developers, insurance companies and HCPs. Our suggestion for further public engagement studies is therefore to inquire iteratively into needs, wishes and visions of various stakeholders during all stages of technology development. Intermediaries, such as social scientists, can point out similarities and discrepancies between stakeholder needs and use their (empirical) insights to create interactive spaces such as scenario workshops, where multiple stakeholders can assemble to discuss and reflect upon topics that raise conflict or divergence. By creating these spaces ‘to stop and think’, cf. Arendt [37], Schot & Rip [38], Krabbenborg [36], during the whole technology development and implementation process, which is also the ambition of the Check@Home project, opportunities are created for stakeholders to learn about each other’s perspectives and to better align the development and implementation of digital health technologies with various user needs.

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Supplementary Files

Multimedia Appendixes

Photo story.
URL: http://asset.jmir.pub/assets/c7d848501eb985ebc18fb4c556f47978.pdf