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Challenging assumptions: narrative analysis of interviews for digital health development

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Abstract

Background We are in a time of transition. Where once health technology was sequestered behind the guarded curtains of research and healthcare, it is now for the masses. Successful digital health research relies on the public to direct what is relevant, representative and useful. However, too often representative and diverse perspectives are absent from digital health development, including artificial intelligence (AI) for health. As a result, assumptions about what individuals (lay persons) want and need from digital health solutions go unchecked. As part of a larger project to develop a risk prediction and prevention app, this interview study will contribute insights about its reach and potential usability amongst lay persons and potential personalization of the app.

Methods In Norway and Spain, interviews with lay persons explored perceptions, expectations and beliefs about health and health technology. Thematic analysis and Lubov's structural model provided a scaffolding for narrative analysis, used to identify nuanced relationships between participants' views of health and health technology.

Results Twenty-one individuals participated in interviews ($n=8$ in Norway, $n=13$ in Spain, ages 18–60 years old, $n=6$ women). Themes included: *personal history*, *societal context*, *social network*, *health status and management*, *health beliefs*, *technology experience*, and *beliefs about AI and technology for health*. Three main narratives described participants' relationships with health technology, "Not for me, but good for you", digitally dependent health users, and "Not on my radar". Two stories are presented for each narrative to exemplify the complexity of relationships between an individual, their health and health technology.

Conclusion By assessing lay persons' relationships with their health and health technology, prior to the development of an app for the prevention of chronic illness, we were able to explore the real world potential of these technologies without a presumption of use and relevance. In doing so, we identified reasons that contributed to participants' choice to use or not to use digital health for prevention. As part of a larger parent project, these results contributed to the personalization and usability assessment of an AI-driven app meant to predict the risk for and provide recommendations for prevention of chronic diseases.

Keywords Human-driven design, Digital health, Artificial intelligence, Lay people, Health inequalities, Digital inequalities

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Introduction

Digital health is constantly evolving, and researchers are not omniscient. Our understanding of the public's needs in health is recycled, upcycled, reused and reimagined. Advancements in digital health also reveal the dangers and inequalities of digital health. Persons who are "non-adherent" or lack awareness, knowledge, skills or personal capacity to engage in their health or technology are labeled "hard to reach" or "seldom heard" by the healthcare field. This tendency to label someone as "hard to reach" is born of assumptions made by health professionals, developers and researchers about what individuals "should" want or believe about their health. However, the human-centered approach to technology development can correct assumptions and address digital and health inequalities. With the advent of artificial intelligence (AI), technology can be trained to, account for, and address more factors than the human brain, with the aim of encouraging greater autonomy in health [1].

The potential of inclusive AI in health

AI has the potential to collect, vet and synthesize information into accessible and useful formats. According to Anderson and Sutherland, "AI can unlock value from the 97% of the health data assets that are unused for decision making" [2]. Proposed benefits include personalized treatment plans and illness-specific recommendations, minimizing the practical and financial burdens of health self-management, and risk prediction through the collation of health registries, medical sensors, patient provided data and public data-bases [2–4]. Tailored and in-depth health recommendations are often out of scope given healthcare providers' limited time and resources. With the help of algorithms that can identify patterns in a person's behaviors and sentiments, outcomes, e.g. recommendations, risk predictions or audio visual support, can be tailored to the individual [3]. This, as well as the mobility of AI to be "always available" could lead to greater patient engagement and access to health resources and support [5].

Challenges to overcome

Unfortunately, the use of AI for health has been criticized for its biased inclusion of data. Furthermore, low retention rates have been reported - in 2023, use of health and fitness apps was only 3.7% after 30 days [6, 7]. Several challenges exist including undifferentiated credible and non-credible technology, misleading information, limited cognitive capacity, and factors that take priority over one's health etc. In other words, the intentions behind digital health development do not meet the reality of the situation.

Algorithms often follow the same patterns of inequalities as the healthcare system; decision-making schemes in healthcare practice and AI are based upon the same non-representative datasets. As a result, AI algorithms are less generalizable and inaccurate in their predictions, which has reinforced and exacerbated societal and health inequalities [8]. There is also much misinformation, misconceptions and misunderstandings of what AI for health is, how it is developed and how it is used. Much of this is due to society's lower ability to vet the information they see online and hear through their social networks. The spread of inaccurate or misunderstood terminology, metaphors, movie depictions and the anthropomorphizing of AI influences the knowledge of and trust in AI for health [9, 10].

Achieving the potential

Because AI in health sits at the intersection of medical, social and technological fields, and is capable of processing vast amounts of diverse data, it is possible to address these shortcomings and achieve "responsible AI" [2, 11]. Scholars suggest applying the lens of intersectionality and situated knowledge, participatory design practices and Equity, Diversity, and Inclusion (EDI) approaches throughout the development of digital- and AI-enabled health solutions. Such evidence-based and human-centered development will enable the ethical, sustainable and relevant application of AI for health.

Shortcomings of participatory design practices

Human-centered design (HCD) involves inviting representative groups of potential end-users for participatory and iterative feedback of evolving versions of a technology through methods involving direct input from end-users. However, "participant driven" and "participatory design" are buzz words that are often used inaccurately [12–14]. Barriers to the effective implementation of HCD methodologies include narrow recruitment, bias, and pre-defined problems (i.e. generated by research teams, not individuals) [15].

Reassessing our approaches to including and understanding end-users

While health and research development hinge upon listening to and meeting individuals' needs, we are unfortunately still in a time of health inequalities and the digital divide, i.e. the continuously widening gap between those who can effectively use and benefit from technology and those who do not or cannot. Clinical health studies are utilizing more digital platforms for recruitment and retention, arguing greater convenience, cost effectiveness, targeted enrollment and higher numbers [16–18]. However, a strong push toward digital participation means fewer resources toward, and reliance on, analog or other options that are more accessible for some groups [19]. The result – exclusion of voices that can explain why

digital health is less successful in certain groups. Other common reasons for exclusion include lack of interest, knowledge, skills or time to engage. Even those who may be interested in, "valuable" to or benefit from digital health research are not included. The term "seldom heard" acknowledges that individuals, health providers, authorities and researchers play a role in a group being underserved, un-reached and/or under-represented in healthcare and research [20].

The digital divide is widened simply by design of studies that use digital formats for recruitment and study purposes [18, 21]. Older generations, those without the resources for digital access (including personal ownership or knowledge about resources where digital solutions are offered), and those who are simply uninterested are excluded based on reach when digital materials are the primary means of recruitment. This evidence highlights the complexity of nuanced bias in the development of AI-based solutions for preventive and predictive health. These complexities have a direct result on the efficacy of digital health.

Purpose

This paper presents interviews of potential users during the development stages of a an app that provides risk prediction and preventative suggestions for cardiovascular disease, diabetes type 2, chronic obstructive pulmonary disease and skin cancer for all citizens, in the WARIFA (Watching the Risk Factors: Artificial Intelligence (AI) and the prevention of chronic conditions) project [22]. This project was a collaboration between partners in Norway, Spain, Romania, Italy, Finland and Ireland and funded as part of the European Union's Horizon 2020 research and innovation program. Work package 7 focused on studies of usability, personalization and validation of the WARIFA app and primarily took place in Spain and Norway, where the partners with the necessary expertise were located. The principles of participatory research were key to these activities which explored lay persons' perceptions, understanding and attitudes toward their health and health technology as well as reasons for, or for not, using digital health. These insights would then contribute to the personalization of the WARIFA app, and a greater understanding of its reach and potential usability amongst lay persons. We also intended for this study to inform digital health stakeholders - especially fellow researchers and technology developers – about priorities of potential users, and more effective methods of reaching, engaging and promoting digital health equality.

Methods

Health technology development rarely represents the voices of those who are considered seldom heard in health and/or health technology; it more often involves those who are already engaged in their health and/or technology. We chose to challenge our perceptions of the situation by addressing the step before health technology use - a person's context, life and relationship with their health. Here we report the narrative analysis of semi-structured interviews following the Consolidated criteria for reporting qualitative research (COREQ) 32-item checklist [see Supplementary file 1] [23].

Framework: human-centered design and ISO standards

This interview study describes pre-design work with lay persons, as part of a User-Centered Design (UCD), or Human-Centered Design (HCD), approach for the development of an AI-based risk prediction and prevention app for chronic diseases. The International Organization for Standardization (ISO) ideals for HCD of digital interventions include iterative, inclusive, and representative human-centered involvement of stakeholders throughout the design and development processes, with guidance from interdisciplinary research teams [15, 24]. As with the ISO 9241 – 210:2019 standard, our use of HCD is preferred over UCD to highlight the inclusiveness of stakeholders who may not necessarily be end-users, e.g. seldom-heard groups [24]. The interviews described in this paper focused on exploring the voices, needs, lived experiences, values and perceptions of those who are typically under-represented in digital health research. Note that, in line with the ISO 9241 – 210:2019 standard, this work precludes the necessities of including medical best practice and self-management recommendations in the development process. These are, instead, covered in a complementary work package of the WARIFA project [25].

Theoretical basis: fit between individual, task (preventative health), and technology

This section describes the theoretical foundation of our approach for semi-structured interviews with lay persons and potentially seldom-heard groups. The use of theories to contextualize and make relevant individuals' stories will aid in the generation of trustworthy nuances, which can serve to fill knowledge gaps [26]. The Health Information Technology Acceptance Model (HITAM) is an extension of the Technology Acceptance Model by Kim et al. HITAM posits that the root of one's perception of health technology is based on their relationship to their health and the healthcare system – with usefulness based on health support needs related to health goals, and ease of use related to tech exposure and education [27]. This provided the foundation for exploring another

theory - The Fit between Individual, Skill, and Task (FIST) model, which is situated at the intersection of the person-task and task-technology models.

The tenets of FIST focus on the extent to which technology functionalities match task requirements and individual- or skills-task fit (i.e. a person's existing relationship to a certain task) which would impact intention to use and future use (termed "agency"). Skills are specified as educational attainment, relevant training and technology experience, which is then superimposed to proposed future technologies [28].

In the context of the WARIFA project, FIST can mean a person's relationship to their health and current use of technology for health in relation to the potential for future use of a new health technology. Through the lens of these theories, we aim to employe human-driven design concepts to provide a deeper and potentially more accurate conceptual link between the person and technology for preventative health. This understanding could then be employed in the development of the WARIFA app and theoretically yield a more feasible solution with more realistic and accurate expectations.

Setting

Recruitment and interviews occurred in Tronsø, Norway and Gran Canaria, Spain where the partners with the necessary expertise were located. Norway is a wealthy country, characterized by high educational attainment and fair salaries, which lead to a reduction in income inequality across occupations compared to other countries. While it offers near "universal" healthcare coverage, it is also plagued with the same trend of human resource shortages and requires the use of digital tools to access most healthcare services [29]. Use of the internet was found to be 98% in 2019, with specific internet use for health information to be 52%, by those 65–74 years old. Residents most commonly use e-mail, text and a digital inbox to receive communications from the healthcare system, which requires a certain level of health and digital competence [30].

The Spanish healthcare system is characterized by universal and free access and limited co-payments for medications and certain medical devices, e.g. classes and hearing aids, based on support by the Spanish national health system (SNS) [31]. However, these benefits are only for those who have secured residency. Despite achieving long-life expectancy, there are still significant differences in health and healthcare access between regions based on income. Spain also experiences shortages of human and financial resources and differences in care quality between regions [30, 31]. Digitization of the healthcare system was thought to be the answer to the lack of coordination and continuity between regional healthcare practice, yet it is also still described as being in its "early stages" and fragmented. Amongst residents, use of the internet was found to be 93%, with specific internet use for health information to be 41%, by those 65–74 years old [30].

Recruitment

In Tromsø, Norway, convenience sampling used flyers in Norwegian and English language and included a phone number and email address through which participants could contact the research team for enrollment. Flyers were posted at local businesses including: a bar/movie theatre, library, a network of churches, a center that offered donates/second-hand items for refugees, an international grocery store, and a pharmacy (the only health-related location). We intentionally chose locations that were not specifically health-related. Interviews were offered in Norwegian or English based on participant preference. Compensation was given in the form of a gift card of NOK 200 for each participant. Snowballing recruitment was also used, by asking participants to ask those in their social network to participate. Researchers in Gran Canaria performed purposive sampling by personally visiting a local social aid office to advertise the interview study with the help of staff. Potential participants visited the social services to inquire about financial assistance.

Semi-structured interview guide

The overall motivation for the interviews was in response to inconclusive evidence of what drives someone to or not to use health technology. The semi-structured interview guide for was developed by MB and KD with the intention of not just human-centered design but also human-driven design through participant driven conversation guided by key concepts of research interest. We aimed to challenge our fundamental understanding of a theory or concept by reexamining the complex lived experiences of individuals [32–34]. Our interview guide followed this tenet by first establishing a social or personal connection between participants and interviewers and gradually becoming more focused on digital health [34, 35]. We aimed to generate knowledge about factors that would affect potential use of digital health solutions by understanding our participants' personal context, values and health beliefs, prior to exploring their perceptions of health technology [24, 33] [see Supplementary file 2]. This is also in line with the ISO 9241 – 210:2019 standard.

Interviews

Interviews in Norway were held in meeting rooms at the Norwegian Centre for E-health Research with one or two female researchers from the research team (MB, KD). KD took field notes. Participants could choose whether to

have the interviews in English or Norwegian. Interviews lasted between 45 and 60 min.

Interviews in Spain were held at the Institute of Biomedical and Health Research (IUIBS) with MLAM. Interviews were held in the participants' native language, Spanish, and lasted between 30 and 60 min and field notes were taken.

All interviews were audio recorded, anonymized and transcribed verbatim. Spanish interviews were translated into English by a research team member in Gran Canaria. Because MB was the primary analyst of all interviews, careful review and clarification of any misinterpretations of the Spanish interviews were discussed and corrected between MB and MLAM. Because interviews in Norway were done in participants' non-native language (all chose English), and Spanish interviews were translated prior to analysis, we chose for all functional and non-functional language elements to be included in the transcripts and responses below for authenticity.

Analysis

The phenomenon studied are the experiences and perceptions of those whom we expected represented lay persons and "seldom heard" groups regarding their health and technology in an age of healthcare service digitization and growth in the digital divide. Excel and Microsoft Word were used to perform analysis.

Analysis model and process: Narratives-under-analysis [36] of interviews using thematic and Labov's structural narrative models

MB and KD first performed a thematic (inductive) analysis by coding the main topics within each participant's response to a question posed by the researchers; MB and KD thoroughly reviewed the transcripts and MB proposed preliminary coding for all interviews. In most cases, participants' responses took the form of narrative blocks which are complete sub-stories within the overall story shared by each participant [37, 38]. MB performed deductive coding based upon Labov's Narrative Model, by identifying six structural elements of each narrative block: *abstract*, *orientation*, *complication*, *evaluation*, *resolution* and *coda* [39]. Like narrative linkage, we identified how the themes and content of each structural element was combined to form a plot, i.e. an intended combination of structural elements to form a story meant to express their reasons and arguments behind their perceptions of health technology. This process included the following steps:

1. Identify narrative blocks that contain enough data for interpretation: participant responses that contain most, if not all, of the six structural elements.
2. Identifying patterns between emergent themes and structural elements.
3. Note quotations that demonstrate these patterns.
4. Compare identified patterns, both within and between participants' transcripts.
5. Interpret meaning of how participants used structural elements to express topics and plots of their stories. These interpretations were iteratively discussed and developed between MB and KD, who have the most experience in qualitative analysis. Three examples of this process are provided in Supplementary file 3 [37, 38].

Narrative development and selection

Narratives were generated based upon patterns of themes and structural elements that emerged between and within participant interviews. Because stories were so unique, some of the narratives were quite distinct. Therefore, we chose to determine narratives deductively based on the main intentions of the study, i.e. identifying the main "plots" about participants' relationships between their health and health technology. The selected narratives describe in detail to highlight the who, what, how and why, and connections therein, of this phenomenon and identify nuances to such connections. Specifically, stories were chosen based on.

1. Richness of data: provided the most complete picture of a person's experiences and relationships demonstrated through points of connection between themes and structural elements.
2. Representativeness and uniqueness: allowed us to demonstrate the depth and range of narratives simultaneously.
3. Theoretical relevance: determined by comparing relationships between themes and structural elements to relevant and existing theoretical models with the aim of providing greater insight and nuance of the theory as it applies to the context of lay persons and seldom heard groups' relationships with their health and health technology.

Special attention was paid to stories within narratives that challenged the typically limited definition of "seldom heard" in health technology. Because most of our participants were immigrants, we noted the influence of culture, location and intersectional influences that were stated to have affected perceptions of health, technology and the healthcare system. We, therefore, referenced the concepts of situated knowledge [40] and intersectionality theory [41, 42].

Results

A total of 21 individuals participated in the interviews. Eight participants from Northern Norway were interviewed between June and August 2023 ($n = 6$ women, age range 18–60 years). Most participants ($n = 6$) were born outside of Norway. Two participants were students who would soon enter undergraduate programs ($n = 2$), and one held several part-time positions in the healthcare and tourist industries. Others were employed as a pharmacist ($n = 1$), a teacher ($n = 1$), and in career development with previous experience in health promotion ($n = 1$) and performance arts ($n = 2$). In Gran Canaria, 13 participants were interviewed in November 2023 ($n = 11$ women, age range 30–62 years). Participants were employed as cleaners, construction workers or waiters ($n = 7$), or were unemployed ($n = 6$). No information was collected about refusal or disinterest in participation due to participant-initiated contact with researchers via asynchronous in Norway, and in-person yet passive presence of the researcher at the social aid center in Gran Canaria.

Interview narratives

Participants' relationships with health and technology

We aimed to simultaneously ensure transparency and participant privacy. Therefore, we provide a summary of comparable characteristics of our participants, their relationships with their health and with health technology [see Supplementary file 4]. Each participant is given a designation of P# where P stands for participant, and either F for female or M for male.

Emergent themes as structural elements to identify plots

The interviews demonstrated the heterogeneity within each narrative while, appropriately, dichotomous, i.e. seemingly opposite yet simultaneously held, meanings within participants' stories. These results focus on the themes of meaning related to one's relationship with their health and health technology, contextualized by parallel comments related to their values and previous experiences. Themes included: personal history, societal context, friends and family (social network), health status and management, health history, health beliefs, technology experience, and beliefs about AI and technology. Health and technology were explored separately during the interviews to gain a broader perception, and then together to understand and identify areas of conceptual interaction. Therefore, the results are presented in such a way that respects that the two parallel plot lines eventually co-exist.

The organization of themes into structural elements emphasized their role in plot or narrative development. *Societal context*, *social networks*, and *health history* predominantly acted as *orientation* and *complication* to situate or explain reasons for and relationships between their *health beliefs* and *technology beliefs*. *Personal history* was used as a means of *orientation* as well as *evaluation*, in which they specifically situated themselves within, and reflected on, past events. *Technology beliefs* most often took the form of resolution and coda as the result of the influence of their personal histories in context of societal context. The ways in which themes and structural elements were linked in each story revealed common narratives.

Three main narratives

While the separate but related perceptions of and relationship with health were considered precursory, they will be presented as cases that demonstrate the diversity of factors that can co-exist with health technology. Common themes that emerged were in line with interview questions and provided context for the narratives including personal priorities, values, occupational status, health support resources, medical history, influences of family and/or friends, experience with health technology and perceptions of AI.

We identified three main narratives based on participants' relationships with health technology. The first is described as technology is "not for me, but good for you" ($n = 2$), in which the themes *societal context*, *personal history* and *technology beliefs* provided the core of participants' stories. The second narrative, "digitally engaged targeted health user" ($n = 2$) describes participants whose *technology beliefs* were based upon the necessity and healthcare needs (health status and management). The third narrative, "not on my radar" ($n = 2$), describes the use of technology, *technology beliefs* and *health status and management* were not conceptually linked.

"not for me, but good for you" Several participants expressed that while they were knowledgeable about health-related technology and saw its value in general, they preferred not to use it themselves. This narrative was based on the intersection between the themes of *societal context*, *personal history and values* and *technology beliefs.* The narrative demonstrates how the participants' understanding of societal values and trends, combined with their personal values, affected their perspectives of technology. Specifically, a cautious optimism for others' use of health technology coexisted with a skepticism for personal use based on their comprehensive knowledge of the potential uses and consequences of technology in general and health technology.

Participant 1 was a woman in her 30's (P1-F), who had immigrated from an Asian country to northern Norway around 2014. Her story existed at the crossroads of a *personal history* that placed a high value on learning and a balanced life, and *technology beliefs* whereby her willingness to use technology, only for specific purposes, was

balanced with a desire to strongly limit its impact on her life. Her beliefs about technology were also impacted by her comprehensive understanding of technology's benefits and dangers for society.

She was proactive and prevention-focused when it came to her health, and skeptical yet optimistic about health technology. The tone of the interview was structured and explanatory, with her taking the lead in the conversation to explain the connections between her past, interest in nature, and analytical and curious perception of the world with how she experiences her health and perceives health technology. She began by defining herself as an immigrant which was a red thread throughout the interview, as many explanations of her current views were based upon the values of her home country in Asia and upbringing compared to her life in Norway.

She perceived health as

> *"a basic, like on a person on a personal level, it's really important to me, it's the sum… it's a basic resource that you need the foundation for everything that you want to do in life. For life. It's the basis for life." [P1-F] However, as an immigrant "there are lots of like differences…that are not obvious. Yeah. And takes a while to understand the system."*

Her mental health was a large part of her perception of health, which was dependent on engaging, exploring and learning in her current environment.

> *"…like being outdoors being in nature, then I feel great. Having a variety of activities like going on excursions to different places"[P1-F].*

She explained that if she actively cares for her mental health, she is unique in her ability to achieve a greater work capacity than most.

> *"If I do the things that I like, then my mental health is generally good…it creates a greater working capacity… I can do a lot at work, and maybe a bit more than other people are used to." [P1-F].*

Her pragmatic and analytical approach to life enabled her to be adaptive. She had an internal locus of control related to her physical and mental health and an ability to step back to identify and measure her options in a given situation.

> *"The seasons here are quite extreme. When you get light, you get a lot of light when you get no lights… So it's about adapting to what kind of attitude you have to the environment and the climate that you're in" [P1-F].*

As a self-described "future oriented" person she sees the changes in not only the natural environment, in which she spends so much time, but also how technology will shape our experiences as humans.

> *"I'm going to lose the winter that I love so much here that I just have to adapt to it and find other ways of coping with it. So I've experienced this grief…but now I'm going to this adaptation phase…how do I cope with the future that's coming? And this is also one of the things I'm interested in the project [the parent project, WARIFA]…I pay a lot of attention to what's like data what's coming in and like trying to imagine what the future is like and how what what my place in the future will be like, how do I cope?" [P1-F].*

Her analytical and curious nature gave way to a dichotomous – equally cautious yet interested – perception to health technology; she valued integrating what she learned into her daily life, which she stated was also linked to her mental health and perception of health technology.

> *"I am open to a certain level of data collection. Yes. But I'm careful about what extent and yeah, what kind of data….I use chatGPT….I don't think most people use it yet. No" [P1-F].*

Her diverse work history and higher education provided her with a deeper understanding and apprehension than the "average joe" of artificial intelligence.

> *"I prefer not to use Google, but I use internet search… you have to be really careful when you search in the internet for any kind of information, not just health related, because there's so much junk out there. And then what is the credibility of the source?…That's something you learn in higher education, like to look to evaluate the credibility of your sources." [P1-F].*

She noted that most have not had the same exposure or opportunity to learn that they should question and be cautious about the implications of personal data security.

> *"I don't blame people for being naive, because there's so much… overwhelming…there's some people who say that we've lost the privacy battle already…The genie is out of the box or… Pandora's box…I do think that people should care much more about privacy than they do. They don't realize what the potential consequences are, and how the data can be misused" [P1-F].*

In fact, she does not consider herself to be representative of the general population.

> *"I think I am not the average person, when it comes to privacy concerns and use of technology or maybe even knowledge of use of technology, because I've had a lot more exposure and experience…So I don't think I'm representative, actually, and the average person I think, will be a lot more receptive to use of technology in healthcare, and also have less concerns about privacy than I do" [P1-F].*

While she retains some cultural values, such as pragmatism, efficiency and tidiness, her more liberal political beliefs made her feel *"not completely at home there" [P1-F]*. She found that connection in Northern Norway with its unique proximity to nature and a small city atmosphere. As a proactive pragmatist, she values health promotion and prevention over treatment, which she exemplified by describing her frustration with the opposite approach taken in Norway. She emphasized a greater trust in the healthcare system and health technology in her home country compared to Norway.

When asked about the future of healthcare and technology,

> *"we definitely need to use a lot more technology, because there's such a shortage of manpower… [Home country] has a similar problem…So I see as inevitable that we will be using more technology… And when I say health care…I'm thinking mostly treatment, not prevention. So I see robots doing a lot of the heavy lifting literally… And that's great, because…it's not good for humans to be doing that a long term basis anyway…also make an artificial intelligence too. It's quite useful. I was really intrigued by how people could be using apps to treat mental illnesses. And I was like, Oh, does that work?" [P1-F].*

The dichotomy of open vs. cautious in response to health technology seemed to be split based on time – awareness that we currently need to be cautious about data security while acknowledging that there is a high potential for good and bad in the future when it comes to AI.

> *"So I think you have to be careful and critical about how you use the technology in general…although I'm open to the use of technology, I actually am very pro, no tech, or low tech. Go for the lowest level of technology that you need and no technology if necessary. I have a great respect, for example, for handicraft and traditional knowledge. Why use technology if something a lot less complicated… A lot simpler works." [P1-F].*
>
> *"Artificial Intelligence… it's a matter of time that its going to be more intelligent than human beings… And so it's interesting, like…what do we need humans for actually? They are not really efficient as energy sources? Should we just get rid of [humans]?… So I am like mhm… the future is a little worrying, but I'm hoping it's beyond my lifetime. But it'll be a great help to people… it's going to accelerate the productivity and it's going to take over a lot of tasks, repetitive tasks… And I've also been really surprised at how creative the like chatGPT is… I think that artificial intelligence will also…offer companionship to the elderly, and also to people with mental illnesses and so forth." [P1-F].*

While she may not want certain technological changes to happen, she does see the inevitability,

> *"it's logical that over time, we'll just be replacing body parts to in… Not that I want to, but I believe humans will do that" [P1-F], which may be another demonstration of her adaptability.*

Participant 2 was a female in her 30's (P2-F) who immigrated from Southern Europe to in northern Norway in 2016. Her story existed at the crossroads of the themes *societal context* and *beliefs about technology* for health. Specifically, she translated a balanced a predominant concern for the pros and cons of society's use of technology into a cautious optimism toward health technology. Her caution toward technology was secondarily connected to her *personal history*, i.e. established values, related to human interaction and relationships.

She presented as engaged in her health with more focus on living her day-to-day life comfortably than achieving a standard "health goal". She was knowledgeable yet skeptical of technology with a strong preference toward human contact and intelligence over AI. An overall thread throughout her interview was balance – in her life and in her responses.

The tone of her interview was matter of fact and decisive, with weighted value toward data and evidence when it came to answering questions. When asked a question, she also considered alternatives to her opinions. This demonstrated not only a balance in perception but also the depth of her knowledge about a topic. She also seemed uncomfortable to present an opinion if she did not feel she was familiar enough to form an opinion. This was evident when she presented both sides related to the rumor that doctors in Norway are dismissive toward patients,

"but yeah, then I don't have sufficient data to say if this is true or not…if it is actually a common problem… I have some friends that had some concerns… about their childbirth. And this lady says that she was actually very listened to… put at ease. So…" (P2-F).

Her parents were health professionals and she described her own experience with the healthcare system in her home country was based upon receiving treatment for a psychological condition. Like her, her parents valued precise routines. She was shocked when she came to Norway and experienced the opposite. Her own "health" was presented in terms of maintenance rather than prevention, as she considered it a state of not just surviving but being able to enjoy daily life. Her experiences with the healthcare system in Norway have been for so-called "serene" things such as regular contraception and testing. Yet she also presented her opinion that health, in general, was linked with intelligence

"So prevention can, in many cases be on the person's intelligence. So how to avoid major accidents and how to avoid, I don't know, dietary habits that…have been proven…to bring to heart disease, or something like this." [P2-F]. However, personally, she considered herself healthy and she was, "not so concerned that it's an everyday concern. But sure, I wouldn't like to have an acute illness. Fortunately…I don't have major chronic health conditions that will make me feel pain for a long period." (P2-F).

However, she acknowledged that her ability to maintain a balanced diet was challenged by moving to a new apartment, as it disrupted her routine.

The concept of "disruption" was also linked to technology, including health technology.

"Some of the health problems are already caused by too much attention to what happens online. Mostly psychological… it can be something that affect the physical too… there's this constant pinging…So of course, if you're responsive…It's really distracting. So that's why I have some critical thoughts about AI… telling a person what to do." [P2-F].

She was very balanced in her perspectives, describing with transparency that she was *"not probably the best person to ask because I didn't try so much [technology]"* [P2-F]. She argued that while technology can be helpful for those with chronic conditions who need constant monitoring, the only reason it would be useful for

"an overall healthy person, [is if] either they're using this to do some service to research, where [otherwise] I don't think it will be intrinsically necessary…" [P2-F].

She posits that technology can be an aid, but not replacement for healthcare providers because; *"it's about understanding what patients or users say" [P2-F].* Instead, she argues that everything has its place,

"it's almost more clever to put chatbots in a place that sells only four or five types of doughnuts, then, in a place that has to do with family's…economical well being financial, physical-site, psychological, something like this, because these things are really nuanced." [P2-F].

While she admits that technology "opens doors" and provides opportunities that would otherwise not exist without technology, her primary argument that it cannot replace human judgement;

"if a code gets, I don't know cancelled or screwed up or put in disorder… Little letter put on the wrong place can give you totally a different result…. I'm imagining a person with a chronic heart condition that needs constant monitoring. Oh, what is this? Oh, my gosh, that person passed away? And then maybe you find out that actually they are okay. And it was just the code that went downhill." [P2-F].

She also believed that research and AI technologies were relevant for the large scale, while practicing resulting recommendations needed to be more specific and human-centered.

"AI…like a bot that can emulate a human controlling any apps, like in the whole world, with how various the human race is… I don't know if it can work properly. [P2-F].

Not only did she provide examples of how technology negatively affects our health;

"If a person really likes to use it, if it is helpful, and if it's not, so time consuming that it will actually not be so healthy for their social life." [P2-F], she also speculated that it would impact our overall ability to learn.

"I just hope it will not prevent humans to get the basics. And I just hope that there will always be some human interactions… Humans actually have a refined mind…and we, we always will get trained, right? If we get too dependent on technology, maybe

we even lose a little bit of this. Because our brains are not training. So it's good to remind ourselves that we are intelligent." [P2-F].

Despite her concerns with large-scale application of AI and technology for health,

"Sometimes I look for things online.... for things that are manageable, even if sometimes are really annoying…it's okay. If I had bad symptoms that really prevent me from doing ordinary things, I think I would talk to a doctor…their advice is more valuable" [P2-F]. However, she also verifies online information, trusting that which "really looks orderly and precise" [P2-F] rather than a blog post or obvious opinion.
"We are in an era where science has been questioned. And some things that were worshipped religiously have been questions like, for example, BMI. Well, BMI works on the large scale. But then you look into ethnicity, and amount of exercise, and healthy feeling, and how your heart works, and everything..." [P2-F].

Digitally dependent health user Some participants relied on online health information and health and wellness apps as ways to maintain their health or self-manage chronic conditions. This narrative was personified by stories of participants whereby the themes of *technology experiences* and *technology beliefs* were connected to a *personal history* or *health history* of necessity and experienced benefit.

Participant 3 was a non-binary (NB) transgender individual (P3-NB) who had recently relocated to Northern Norway. They predominantly focused on how their reliance on technology (*technology experience*) was born from the necessity to manage their own *health situation*, due to lack of healthcare support, and how the positive *technology experience* reinforced their positive *technology beliefs*.

The tone of their interview was somber and focused on the context of their situation rather than an emotional response to their experiences and challenges in health. They described their health situation as a case in a greater context of transgender healthcare, rather than depicting themselves as a patient. They portrayed acceptance and explained taking action to self-manage their health situation. As such, we perceived them as emotionally intelligent, self-aware and self-informed.

While they did practice some yoga and light, formal physical activity, their health focus was to live comfortably by achieving "harmony" between the mind and body, rather than following standard recommendations. They were very proactive and relied heavily on digital health technologies; when asked about what they considered "health", they immediately responded,

"So the health for me… something like an app that tells me what is going on with like myself generally… it's like making an inspection so when something, I have pain somewhere, so…I need to fix something now." [P3-NB].

Apps were especially helpful to take away some of the burden, *"it's really cool that I do not need to keep all this stuff in the mind"* [P3-NB], and for specific health needs including sleep and mindfulness. They detailed the usefulness of a specifical app,

"for trans people to look after the like evolution of transformation because there you can put like the info about like your first injection like your surgery… like diary more but it's with a notification about like you need to get pills or some stuff and as well it's really useful it's like oh so it's now five years so then I'm doing this" [P3-NB].

Due to their choice to undergo gender reassignment, they were not only required to take hormone therapy but also to take responsibility to become an expert in the treatment - in most cases, far and beyond that of healthcare providers. They used online information and articles, virtual consultations with specialists, other people's experiences and their own to learn about their needs,

"So for me to use some like internet…articles or text or apps or wherever it's really important because I am the only one who can like you know lead through all this stuff…so it means that sometimes I'm more responsible for my health and how I will be treated than doctors." [P3-NB].

This need to become an expert was prompted by their experience in their home country,

"It's really difficult to get the medical care for transgender man [in home country]. Because of the laws and blah blah blah but as well because there aren't a lot of people who has competence in such questions… and that means that all the time I need to educate doctors" [P3-NB].

The illegal status of such hormone therapy coupled with their move to Norway - an unfamiliar healthcare system and protocols- has meant stopping their hormone treatments for the time being. Even so, they perceived the Norwegian healthcare system as "*really easy breezy*",

when using common healthcare services such as a family doctor and dentist. Despite warnings that the

> *"Norwegian health care system can be a little bit tough because sometimes you need to prove that you need help", they understood the need for lengthy protocols "when you are going to have some treatment from government…it's like free or wherever, so of course you need to like prove that you need this." [P3-NB].*

They were positive about the integration of health technology into the healthcare system, likening it to a tool to be used in "*this game of detective*",

> *"I don't feel that it's really dangerous to put it in the health field… when it's about…analyzing or making the work of doctors easier one…Of course it can be useful to uses to diagnose some really like like easy breezy like cases and…for example like ok we tried to look through all the stuff and didn't find anything so we need like some extra help" [P3-NB].*

While their explanation of health technologies had been only positive to this point, with the mention of AI, *"I have really doubled opinion on it" [P3-NB].* Personal experience with AI was limited to using ChatGPT like a

> *"cool game…I wasn't really serious about that" [P3-NB]*

and programming websites through previous jobs. They argued that while simple tasks can be allocated to a computer, it is scary to consider technology that is meant to perform more creative tasks without human intervention. Their concern about how AI would be used stemmed from the belief that

> *"as in politics or in like general stuff…it's really complicated …because everything is depends on how people are thinking about this stuff" [P3-NB].*

However, they also suggested that

> *"when it's like in combining both like human being brains and like technologies and machines…it can work really I guess cool" [P3-NB]. The potential of AI in the healthcare setting as a tool for healthcare providers was seen in the same way as for themselves, as a sort of external memory, "because sometimes it's a lot of about human factor that like ok I didn't think about it or didn't remember about it…but artificial intellect…it remembers all the time…it really can improve some stuff" [P3-NB]. However, the human factor was also the reason that, "we can't let like AI to kick out people who are doing this like artist or scientist or wherever because it's like about human being" [P3-NB].*

Participant 4 was a woman in her early 40's (P4-F) who has immigrated from South America to Gran Canaria. Her story revealed a conceptual relationship between a structured approach to her *health status and management* and the benefits gained from *technology experiences*. This relationship formed the foundation for her positive *beliefs about AI and technology* that it is a tool to improve one's knowledge and understanding of their health.

Health was a priority, and she considered herself to be

> *"predisposed to being healthy" [P4-F].*

While she focused on maintaining a balanced diet and taking care of her skin, she did admit to

> *"neglecting her physical activity" [P4-F].*

She was strategic in her approach to health, "If I have *programmed all my tasks along the hours I feel better" [*P4-F*].* Her ability to maintain healthy habits was linked to time and routine,

> *"I don't have any time to do many things along the day. I feel like I need to have a routine or a habit" [P4-F]. However, she also valued having different schedules that allowed for some flexibility in her day with her work as a formal carer.*

Her experience with the healthcare system in Gan Canaria was indirectly based on the experiences of her family members who have higher health needs than herself and who had seldom used it,

> *"but when I have the necessity to go to the doctor it has been fine." [P4-W].*

Her work as a carer often was aided by using health technology,

> *"when I'm taking care of people with some diseases, I search for the medication so I could be informed if it has any secondary effects." [P4-F].*

For her own health, she used the mobile phone and computer to search for information online but preferred the computer because it

"is easier to use and I can see the website pages better. I feel like the mobile phone is limited" [P4-F].

Consistent with her proactive approach to health,

"I search for symptoms that I have or some things that I watch on the TV. When I have any concern or I don't know anything about, I always try to search for it." [P4-F].

Her perception of AI is similarly positive. She seemed very familiar with the concept as it was

"a topic that I listen [to] every day" [P4-F].

AI was associated with innovation and the potential to *"replace people"*, which was met with some uncertainty

"I don't know if there is a paradigm [theory] or if it could work" [P4-F].

When it came time to scan the QR code to complete the WARIFA app questionnaire during the interview, she had questions about how to enter some of the parameters. Referring to the number of questions and the amount of time to complete it, she thought,

"it was easy. The extension of the questions was great".

However, she also admitted that

"it depends on the person who complete this because some of them could be difficult to answer it" [P4-F].

Not currently on my radar Some participants were aware but uninterested or less knowledgeable about health technology and instead focused on other responsibilities or more personal connections with others. This narrative was characterized by the interaction between the themes of *technology experience*, *health status* and *technology beliefs*. While this interaction may seem similar to the first narrative – "not for me but good for you"-, for this narrative, participants valued, *social networks*, not *societal context* in relation to technology support. Also, in the first narrative, *societal context* was strongly related to *technology belief* and *technology experience*. However, in this narrative, *social networks* were independent or less conceptually connected to these two themes.

Participant 5 was a young man in his 20's (P5-M), native to northern Norway. The themes related to technology and health were connected in the past, but not in the present. Instead his story focused upon the influence of their *social networks*, *personal history* and *health status and management*. Technology was not the answer to health problems, nor was the healthcare system. Lack of in-depth understanding left them more open to the possibility of trying health technology in the future, but no need for it now.

He began his story by describing his interests and importance of people in his life,

"number one is the people around me. I prioritize… people other than myself, but I'm directly behind". Health was always on his mind, "I think of my health 24/7 - mental health and physical health, mostly my physical health. Because I've had pretty bad injuries… I do weightlifting, cause I want to prevent from being like, when I am older-older, I won't like be like, stuck in a wheelchair" [P5-M].

There was a tone of matter-of-fact acceptance in his responses – a normalization and simultaneous disconnect between himself and his physical and mental challenges. He chronologically listed health challenges, noting that he often took months or over a year to seek treatment for these chronic conditions. Identifying and coping with acute and chronic health concerns was dictated by the role of his mother, friends and healthcare providers. His perception of the healthcare system was dichotomous, as was his family's support for his health. Both his mother and healthcare system were more active, supportive and present during physical health challenges, yet lacked emotional or practical support for mental health challenges.

"It's absolutely horrible. I think it's absolutely horrible. I've had like a past with like, suicidal thoughts… talked to them, maybe like for 30 minutes. They said, «don't do it again, Promise me» and pushed me out the door… They put me on the waiting list for a psychologist …And they told me it will take one-two years… And then it happened again…And the doctor send like a note to [psychiatric department of hospital] and to be like «he needs a psychologist as fast as possible». And I still haven't gotten that…that was like a month ago…My mom is like shit ….she's like a double edged blade. The first time it happened was on the 23rd of December Yeah, um…we had like arguments and she said I have ruined Christmas… My family has not been supportive of my health… I didn't complain or anything. But now I'm older, I see that…it's pretty mean…it don't effect me now… but other than that, my mom has always been there when it comes to like my health…My mom even now offers to go to the doctor with me" [P5-M].

He attributed this disconnect in part to the Norwegian culture,

> *"we aren't that social of culture…we'd rather like avoid social situations… I think that's like a big factor in…the mental health thingy - we aren't prepared to talking about anything that big…on a day to day" [P5-M].*

While youth has been associated with high tendency toward technology use, P5-M was more familiar with AI in games than in health technology.

> *"So I never used that burden… that I have not used any, like health apps…I use this one jogging app that like tracks like how far run… I think it was Strava I cant remember the name of it" [P5-M].*

Warnings from friends that diet apps may contribute to an eating disorder, steered him away from such technologies. He explained similar trends amongst his non-health related technology use as well, acting more as an observer than a participant. However, he did have a more engaged perspective toward AI. He was introduced to AI through gaming and while discouraged by its original functionalities, he applauds its development.

> *" People got like super scared…I just sat there thinking it was really cool…but I don't see as scary because it's something we have like 1000s of people studying… AI because it's just such a new and like, interesting topic" [P5-M]. As long as the health AI takes it a step further than the pre-programmed and limited response of gaming AI "to like to help you with your health…I think I'd trust a lot" [P5-M].*

Participant 6 was a woman in her late 40's (P6-F) who had immigrated from South America to Gran Canaria for work. Her perceptions of health more strongly related to *social networks* rather than health technology. In fact, previous *technology experience* demonstrated little to no positive impact on their health, meant the devaluing of technology as a means of health support.

She lived with chronic physical illnesses which made her work as a cleaner difficult, forcing her to be on partial disability. Her primary health goal was to be physically and emotionally healthy, which was associated with financial stability,

> *"I would like to find a job where I don't clean. That's why I'm studying. So that could help me to be healthier and be fine with myself. I would like to increase my salary and savings." [P6-F].*

Financial motivation was reinforced by her strong interest in the gift-card compensation for participating in the interview.

She also believed that being around family would mean better health. Her relationships with her health and healthcare system improved dramatically since moving to Gran Canaria. Even though she does not appreciate the waiting list for consultations, and not being able to reach the nurse when she needs,

> *"I call the medical center and nobody pick up the phone. So, I need to go to the emergency services" [P6-F], she "would like to thank God and the national health system" [P6-F].*

Her description of her health prior to moving to Gran Canaria reinforced the connection she made between her health and non-health priorities like work and family,

> *"When I was in [home country], I was feeling unwell, but I didn't give it a thought. I thought it was stress… If I was walking a lot, my feet started to being in pain. But I didn't know that I was having a disease. When I came here, I was diagnosed because I had a swollen toe and heels. But nowadays I'm feeling better than then. I'm taking pills so I'm feeling better." [P6-F].*

While she only went to the doctor in Gran Canaria "*if I need to*", she contradicted herself by saying, *"I go every three months for a blood analysis" [*P6-F*].*

Her relationship with technology was limited - based on the mobile phone and computer, which she found difficult but *"I always try to learn" [*P6-F*].* While she had used the Canary Health App to access the local healthcare system, she stopped using it because she had problems with the password. She used AI during work to ask it questions and called it "*fashionable*" [P6-F]. Her tone suggested that because health technology was not a well-known concept, it was seen as potentially useful, however, she did not currently see a place for it in daily life.

When asked to scan a QR code to enter the WARIFA app and answer the questionnaire during the interview, she needed assistance to complete it.

> *"I don't know it any person above 65 years old could understand this questionnaire. I think that it depends on the level of study. And with the cognitive level. But for me it's okay." [P6-F].*

Her overall perception of the recommendations the app produced were positive yet were redundant when it came to diet recommendations,

"I read that I need to reduce the sugary drinks, but I only drink a juice for lunch. But I like the way it tells me" [P6-F].

She was also confused about what the app meant by "protection clothes", in reference to recommendations for reducing one's risk of skin cancer. In fact, she noted that

"But in summer you don't wear that kind of clothes, only in winter. But I don't use sun protection" [P6-F].

This highlighted a disconnect between standard recommendations and realistic expectations and norms of those who live in warmer climates – that these extra steps for skin cancer prevention were not so natural.

Discussion

The in-depth narrative analysis provides evidence of the complexity that shapes a person's relationship with their health and technology. Interviews were characterized by dichotomies that challenged our presumptions of lay persons' and seldom heard groups' needs for health and health technology. We have characterized the participants' relationships with health and health technology into three main narratives. The first narrative, "not for me, but good for you", described participants who already had established positive health habits and expressed a nuanced and comprehensive understanding of the potentials and dangers of technology. While they did not have a specific health need or reason to use health technology themselves, they did see the potential for others with specific needs. The second narrative, "digitally dependent health user", demonstrated the opposite plot. Participants' positive perceptions of digital health were the result of having a specific health condition, needing assistance to manage that health condition and subsequent benefits. The third narrative, "not currently on my radar", described those who had specific health issues and thereby a potential need for digital health. However, this group had not considered digital health as a solution to their needs. In fact, participants considered the topics of health and technology as distinct and separate categories of life.

Relationship between narratives, stories and established theory

There are several takeaways from these stories and narratives that may be useful for developers and policy makers. The narratives also overlap and add to established theories of health technology acceptance and common practices of participatory design.

The FIST model, described above, emphasizes a person's agency or autonomy, perceived self-efficacy and health motivation in choosing to use health technology and describes the role of technology in the relationship between a person and an existing task [28]. This model was appropriate for the development of the interviews and WARIFA prediction and prevention app because it focused on predicting, rather than explaining, a person's choice to use digital health as a consumer good. The cited study by Ruyobeza et al. was the only one identified regarding the FIST model as it applied to a person's use of a assistive health technologies [28]. No other studies existed for predictive and preventive health technologies addressing multiple conditions at the time of the presented WARIFA project. Other established theories such as the Technology Acceptance Model (TAM), Unified Theory of Acceptance and Use of Technology (UTAUT), with insights also from TAM2, and Theory of planned behavior (TPB) [43–46], provide complementary explanation about the relationship between individuals and health technology, including: perceived ease of use (PEOU) and usefulness (PU), performance expectancy (PE), autonomy, attitude, behavioral intention (BI), and actual use (AU) [46, 47]. Recent adaptations of these theories have evolved to include job relevance (JR), output quality (OQ), and results demonstrability (RD) can impact PU and PEOU [43, 45, 48]. Furthermore, Elske Ammenwerth argues that health technology exists at the intersection of healthcare, technology, social and cultural systems, bringing the impact of external factors, or facilitating conditions (FCs) into the equation [47]. FCs refer to the previous experience with, need for, and expected availability of health services as well as infrastructural and technological factors [47, 51, 52].

FCs accounted for some of the dichotomous perspectives within participants' stories. For example, one participant had a cautious attitude toward technology's impact on society, including what she called lack of trustworthy infrastructure (FC) negatively impacted her personal BI and AU. Yet, she recognized the potential of technology to positively impacted PE and PU for others and serve specific health purposes (FC). Our analysis also revealed that P1-F's health habits and/or non-technological BIs impacted her technology-related AT and AU. Her AT also stemmed from previous knowledge of the potential benefits and dangers of data security (FC), and effectiveness of the technology to address her own and other's needs (FC).

The third narrative challenged relationships between factors presented in TAM and UTAUT. The narratives illustrate that participants separate their beliefs and use of technology from their personal or health needs. Instead, they considered personal relationships and financial stability to be more closely connected with health and happiness. This "gap" or disconnect can also be explained if we consider P6-F's concern with financial stability as a reflection of JR (TAM2), or, similarly, FCs (UTAUT). In

other words, even in a conversation that she knew would be about health and technology, she expressed a lack of relevance between technological usability as it applied to her occupational and financial goals, and health goals. P5-M and P6-F similarly expressed a lack of control related to their health, which could represent the impact of control beliefs on perceived behavioral control (TPB), thereby precluding the potential of using technology as an option to gain control of their health (UTAUT and TPB).

Ethics research: balancing innovation with values and needs

The Responsible Research and Innovation (RRI) approach was initiated by the EU in 2011 and encourages partnerships between the public and research, amongst others, to align knowledge and innovation production with the values and needs of society [49]. Too often, the agendas and expectations of the public and those involved in research and development of digital health do not align. These can include unrealistic expectations and priorities of innovating to benefit the individual vs. the greater good resulting in unintended negative consequences. The COVID-19 pandemic highlighted the simultaneous benefit and harm that can result from digital health [50]. For example, global shelter in place orders assumed that everyone had a shelter, while, in reality, large portions of the population, e.g. those without permanent homes, were left to fend for themselves [51].

The kernel of ethics is human dignity, encompassing autonomy, respect, justice and the balance between beneficence and maleficence [52]. Because digital health encompasses several areas of society, it is both difficult and necessary to understand whether pushing for digital health to solve a problem would do more harm than good [53], and for whom. In the first narrative, the stories included acute awareness of the potential threat that digital health would pose to, not only on data privacy and ownership, but also on social relationships, our capacity to learn, and the risk of harm due to improper programming or use. P5-M also suggested that he would only trust digital health if he were confident in the efficacy and transparency of the programming. However, all stories included some benefits of outsourcing specific and simple tasks to technology, such as a learning and tracking tool, which would facilitate rather than challenge human autonomy. Several joked that public perceptions of AI were that it would "take over" or replace humans, suggesting that it would violate their rights to autonomy, beneficence and justice by taking power away from the individual. While in jest, the pervasiveness of this dramatization indicates the skepticism toward digital tools and AI for health, as well as the need for clearer and more transparent knowledge about the personal and societal consequences of digital health implementation.

Inclusive development

One of the most understood and discussed ethical risks in digital health is AI bias based on large pools of skewed data. Such skewing can be traced back to assumptions, for example, of who can, and will use or benefit from digital health technologies. Most digital health research bases innovation on the voices of the few who are already engaged in their health and/or technology. These individuals are considered "easy to reach" because of their high socio-economic status and education, strong social networks and the capacity to take on the responsibility of health self-management. As such, they are also often those who have the greatest access but no the greatest need for health services. Those with the greatest need often do not have the access or capacity to fulfill those needs. A common explanation is that social inequality, material or resource deprivation and marginalization to a limited access, use for, and benefit from, health technology [54–57]. Those in the healthcare industry consider those in these circumstances to be "hard to reach" or "seldom heard". It is often accepted that the challenges of engaging these individuals, including the additional time, effort and money required to facilitate their involvement in research, justify their exclusion. As a result, health technology is built for the few, not the many, thereby challenging us to consider whether our approach to health technology development is in line with ethical principles.

The narratives and individual stories provide examples to challenge this assumption that "seldom heard" may have more difficulty engaging in development research or more barriers to using digital health technologies. The first narrative points to the inaccuracy of this common connotation, especially as it applied to an individual's barriers. Participants noted barriers of distrust, apprehension and lack of interest and needs despite, which are commonly considered "pro-technology" factors, including their high level of access, education, and experience and engagement in their health. Similarly, the second narrative challenges accepted ideas of who "seldom heard" groups are by presenting stories of one who could be considered socially marginalized not only due to their relationship with gender (P4-NB) but also the revelation in both stories of a history of inadequate healthcare treatment in their home countries. In these stories, participants may have been expected to have fewer resources, yet they both were positive and even enthusiastic towards the use of digital health technologies. These stories and narratives demonstrate that a reliance on terms such as "seldom heard" or "hard to reach" users limits research.

Another misunderstanding of needs and intention of individuals compared to clinicians, researchers and health authorities is related to differing connotations of "prevention". The WARIFA app is intended to identify risk of specific diseases and provide recommendations for preventative action. This intention is largely based upon clinical guidelines and policy recommendations for the general public. However, for most participants, prevention was related more generally to health. Instead of preventing a specific common morbidity, participants were concerned about their ability to stay active as they aged. It is, therefore, an ethical obligation to employ strategies as participatory research to identify where and how to address misalignments in agenda, priorities and goals as well as provide updated, reliable and accessible knowledge through iterative public involvement.

Strengths

Our approach to recruitment was inclusive of those who may be considered seldom heard or "lay persons" based on their perceptions and experiences of health and health technology. The broad inclusion criteria allowed us to identify similarities between those who may otherwise be considered "separate groups" and those who are not typically considered to be seldom heard.

The study was unique in its democratization of recruitment and data analysis [37, 38]. As such, we offered more comprehensive and foundational explorations of what may influence participants' willingness to engage with health technology. The openness of the interview and interviewers to learn from each participant encouraged in-depth and unexpected insights.

Limitations

A challenge of this analysis was the fact that there was no requirement for common experiences or perceptions of health or health technology. The only requirement was response to non-digital recruitment materials, chosen to be more accessible to those who may be considered "seldom heard", i.e. less engaged with technology, health technology and/or local healthcare services, in both northern Norway and Gran Canaria, Spain. However, this did not presume that participants had to be underserved or dis-engaged in all three realms.

Differences in recruitment approaches could explain the differences in participation numbers. While the research team in Gran Canaria used a more targeted approach at a social aid office to recruit those who they presumed to be "seldom heard", the approach used in Tromsø, Norway used an open and digital-free recruitment strategy with the aim of allowing us to reach lay persons, with respect to digital and health related topics. In Gran Canaria, the research team had also attempted to recruit participants in-person at a supermarket. However, people generally did not stop or stopped and were not interested. Non-digital methods, including posted flyers like those used in Tromsø, were also used but were not as successful. While the Norwegian research team intended to visit local community centers in-person, capacity constraints prevented us from doing so.

Conclusion

Participatory research can correct assumptions and redirect research focus according to the needs and preferences of the public [53]. The more we understand people's perceptions and beliefs in digital health, the greater chance we have of supporting their real-world needs. Allowing participants to lead the conversation allowed us to identify nuances and correct some prevalent assumptions and provide real-world application of theory to model participants' attitudes and decisions. Participants' stories demonstrated the nuances within narratives by presenting a wide range of, and interplay between, factors that affected participants' perceptions of, intentions to and actual use of digital health. Therefore, digital health development and intervention studies need to encourage as great a diversity of people as possible to participate. In doing so we can better understand how to make more flexible, broadly relevant technologies - that may be used by an individual for when, how and how long they find useful.

Abbreviations

AI	Artificial Intelligence
AT	Attitude
AU	Actual use
BI	Behavioral intention
FC	Facilitating conditions
FIST	Fit between Individual, Skill, and Task model
HCD	Human-centered design
HITAM	Health Information Technology Acceptance Model
ISO	International Organization for Standardization
JR	Job relevance
NOK	Norwegian Kroner
OQ	Output qualitaty
PE	Performance expectancy
PEOU	Perceived ease of use
PU	Perceived usefulness
QR	Quick response code
RD	Results demonstrability
TAM	Technology Acceptance Model
TPB	Theory of planned behavior
TTF	Task-Technology Fit
UCD	User-Centered Design
UTAUT	Unified Theory of Acceptance and Use of Technology
WARIFA	Watching the Risk Factors

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s44247-025-00211-2.

Supplementary Material 1: Supplementary file 1. COREQ checklist.

Supplementary Material 2: Supplementary file 2. WARIFA interview guide.

Supplementary Material 3: Supplementary file 3. Analysis method

example.

Supplementary Material 4: Supplementary file 4. Summary of transcript data.

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Author credentials
MB (F) is pursuing a postdoc about the digital divide and seldom heard groups in health research, with a PhD in mHealth development and Master of Business Administration. KD (F) is a department leader, senior research and an associate professor, with a PhD in sociology and focus in health and digital inequalities. MLAM (F) is a practicing medical psychologist focusing on obesity and nutrition AMCW (F) is a medical doctor specializing in endocrinology and nutrition.

Authors' contributions
MB and KD conceptualized and designed the study for both countries and performed interviews in Norway, collaborated on narrative analysis, interpreted the data and drafted the manuscript. MLAM performed the interviews in Spain, contributed to the interpretation of data and the manuscript text. AMW contributed to the management of the study and manuscript text. All authors read and approved the final manuscript and agree to be personally accountable for the author's own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

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Data availability
Data is available in the manuscript and supplementary files. Complete interview transcripts from are not publicly available. Participant privacy is of utmost importance. Given the small geographic areas and the discoverability of participants based on specifics offered by the participants in their interviews, raw data of the interviews will not be available.

Declarations

Ethics approval and consent to participate
The Northern Regional Committee for Medical and Health Research Ethics (REK-Nord) through the University Hospital of North Norway (UNN) found this study to be exempt from their purview (ref. 559412). Further approval was sought and granted by the Personal Data Commissioner (PVO) at UNN (ref. 2022/7611-12). In Spain, the Provincial (Biomedical) Research Ethics Committee of Las Palmas declared the study exempt from assessment because they are not defined by Royal Decrees 1090/2015 or 957/2020 and therefore fall outside the health research legislation. The presented study involving humans and/or human data adhered to the Helsinki Declaration. Participants received study information, were given time to read this and ask questions of the researcher. Written consent was collected by each participant before each interview.

Consent for publication
All participants received a printed version of the informed consent form, including the right for any information shared during the interview sessions to be anonymized and used in our research and scientific publications. Participants read and signed the forms in front of interviewers prior to the beginning of the interviews.

Competing interests
The authors declare no competing interests.

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