

# Participatory Approaches for Digital Public Health: Giving Voice to Values



Rehana Shrestha, Anke V. Reinschluessel, and Jasmin Niess

**Abstract** This chapter discusses the need for community involvement and stakeholder engagement in the development and implementation of digital public health tools. The advent of digitalization in public health has necessitated an exploration of how to design tools that meet the needs of the community they serve. This can be achieved through a participatory approach that incorporates the voices and perspectives of all stakeholders in a democratic manner. Specifically, this chapter discusses two participatory approaches: participatory design and participatory research. These approaches originate from different intellectual traditions but share a vision of incorporating everyone from the community affected by the intervention or technology. Additionally, this chapter presents application examples from the literature on how the development of health-related applications benefited from participatory research and participatory design to illustrate the added value of integrating these approaches.

**Keywords** Participation · Digital public health · Participatory design · Participatory research

---

R. Shrestha (✉)

University of Bremen, Social Epidemiology, Bremen, Germany

Leibniz ScienceCampus Digital Public Health Bremen, Bremen, Germany

e-mail: [rehana@uni-bremen.de](mailto:rehana@uni-bremen.de)

A. V. Reinschluessel

Leibniz ScienceCampus Digital Public Health Bremen, Bremen, Germany

University of Bremen, Digital Media Lab, Bremen, Germany

HCI Group, University of Konstanz, Konstanz, Germany

e-mail: [anke.reinschluessel@uni-konstanz.de](mailto:anke.reinschluessel@uni-konstanz.de)

J. Niess

Leibniz ScienceCampus Digital Public Health Bremen, Bremen, Germany

Design of Information Systems (DESIGN), University of Oslo, Oslo, Norway

e-mail: [jasminni@uio.no](mailto:jasminni@uio.no)

© The Author(s) 2025

H. Zeeb et al. (eds.), *Digital Public Health*, Springer Series on Epidemiology and Public Health, [https://doi.org/10.1007/978-3-031-90154-6\\_4](https://doi.org/10.1007/978-3-031-90154-6_4)

59

## Abbreviations

DEMOS	DEMOKratiske Styringsstemer
DHIS	District Health Information Software
d-MH	Digital mental health
d-SWEB	Digital social and emotional well-being
DUE	Demokrati Udvikling og Edb
HCI	Human-Computer Interaction
HISP	Health Information Systems Program
IAP	International Association of Public Participation
NHS	National Health Service
PLWH	People living with HIV
SES	Socio-economic status
WHO	World Health Organization

## 1 Introduction

In this chapter, digital public health is defined as using digital technologies to work towards achieving public health goals (Iyamu et al. 2021; Odone et al. 2019). Thus, digital technologies and concepts can be applied to restructure and reimagine processes and knowledge acquisition and distribution in the context of digital public health. For example, the health data collected by fitness trackers (e.g., heart rate, steps taken) can be used to inform public health policies or personalize public health interventions. Both policymakers and researchers argue for the potential that digital public health holds. However, despite the increasing interest in digital public health, open challenges such as ethical questions, a lack of clear standards regarding the design of digital public health interventions, and challenges concerning access to technologies remain (Iyamu et al. 2022). To illustrate, not everyone in the world has the same access to digital public health interventions and has comparable technical infrastructures available. This, in turn, can lead to or exacerbate health inequalities. For instance, people in rural or low socio-economic status (SES) areas may not have access to (high-speed) internet or smartphones, which will naturally limit their ability to access and use digital health technologies. Consequently, this potentially reinforces inequalities as it gives people different levels of access to health information and resources than people in more affluent areas.

To address open challenges in digital public health and establish structures that facilitate societies' long-term health and well-being, the participation of all stakeholders is crucial. Participation of the community, as well as other stakeholders, including consumers and end-users, youth, individuals from marginalized

communities, developers, and practitioners, among others, is widely recognized as essential for building a healthier society. The World Health Organization (WHO) regards participation as a “means of organizing action and motivating individuals and communities” to “shape policies and projects to meet their priorities” (World Health Organization 1992). On another note, the importance of community participation in health research was formally recognized by the 1986 Ottawa Charter, which defines health promotion as “the process of enabling people to increase control over and to improve their health” (World Health Organization 1986). Emphasizing community participation as a cornerstone to achieve health for all and reduce health inequalities, the Charter indicates “working through concrete and effective community action in setting priorities, making decisions, planning strategies, and implementing them to achieve better health” (World Health Organization 1986). “Increasing control over one’s health” includes control over digital public health strategies, initiatives, personal health technologies, and digital public health systems.

In other words, in the context of digital public health, participation can foster a closer fit to user needs, improved service experiences, integration of values, facilitating change from within, and supporting uptake and long-term use of the digital public health system.

Although participatory approaches have a high potential to promote and support digital public health in a meaningful way, the concrete ways to actually apply them in digital public health contexts are still underexplored. Along similar lines, participatory approaches are not yet widely used in Europe (with a few notable exceptions). Whereas participatory approaches are already frequently applied in smaller (research) projects focusing on the participatory development of health applications for individuals or small groups, participatory approaches in the area of public health are rarely observed on a societal level. This chapter aims to discuss the potential of participatory approaches for digital public health. Positive examples are used to illustrate the potential of participatory approaches in this context. However, challenges and potential conceptual ambiguities will also be discussed, which can be partly attributed to the inter- and multidisciplinary in the field of digital public health.

Consequently, this chapter aims to discuss definitions and approaches of participation and their relevance to the digital public health field. It is important to note that this chapter is not meant to be a complete account of all existing participatory approaches. Instead, it is intended (with the help of examples) to provide inspiration and starting points for interested readers and to demonstrate the potential of participatory approaches for the field of digital public health. The structure of this chapter is as follows: First, it will give an account of participatory approaches such as participatory research and participatory design. Then, it will outline a few cases of participatory approaches in the context of digital public health. The chapter then concludes with a short summary and outlook.

## 2 Participatory Approaches

When conceptualizing, designing, evaluating, and refining digital public health interventions, many different groups are involved (e.g., designers and end users). This is the case for the majority of technologies developed and available today. In the field of digital public health, however, the situation is somewhat more complex since several different users can potentially be counted towards the group of end users (e.g., patients, clinicians, and politicians). There are efforts and a demand to integrate all relevant groups into the design and research process of digital public health interventions. However, in practice, there is still considerable potential for improvement (Mucha et al. 2022). To address the needs of relevant stakeholder groups in designing solutions, two different participatory approaches have emerged in different intellectual traditions. On the one hand, *Participatory Research* is emerging from Kurt Lewin's "northern tradition" of social action research and Paulo Friere's "southern tradition" of emancipatory theory and practice (Macaulay 2016) and on the other hand, there is *Participatory Design*, which has its roots in Scandinavian action research and what was then often called cooperative design (Bødker and Kyng 2018). These approaches have some similarities and differences. In the following sections, we describe both approaches briefly and highlight their similarities and differences.

### 2.1 *Participatory Research*

Participatory research finds its origins in social action research and emancipatory philosophy, thereby promoting that research be undertaken with or by society's marginalized people, or having people as full participants in inquiry, enabling them to determine their own needs to improve their own lives (Macaulay 2016). It is considered a research-to-action approach that engages those who are usually not trained in research. Vaughn and Jacquez (2020) defined participatory research as an umbrella term for "research designs, methods, and frameworks that use systematic inquiry in direct collaboration with those affected by the issue being studied for the purpose of action or change." The main premise of participatory research is to ensure the active roles of stakeholders, community members, and end users in the research process and shared decision-making while also including those with insider knowledge and lived experience or those belonging to or representing the interests of the people who are the focus of the research (Jagosh et al. 2012). As pointed out by Cook (2012), participatory approaches do not merely ask participants to comment on what "is" but engage them to work together to design what "could be." As such, the approach intends to build positive working relationships and meaningful interactions to harness the dynamic interchange of knowledge and understanding, bringing together contextualized understanding, practical experience, wisdom, and reasoning.

Many variations of participatory research are used across disciplines (see Vaughn and Jacquez 2020 for an overview). Among the approaches included within the field of public health are, for instance, community-based participatory research (Minkler and Wallerstein 2011), participatory action research (Kemmis 2006), participatory rural appraisal (Chambers 1994), cooperative inquiry (Reason 1999), participatory evaluation (Cousins and Whitmore 1998), etc. As suggested by Vaughn and Jacquez (2020), the breadth of terms describing the participatory research orientation is vast, spreading across disciplines. Nonetheless, they share a common mission of inclusivity, valuing the direct engagement of those who are beneficiaries, users, and stakeholders of the research rather than considering them mere subjects of the research. This integrates researchers' theoretical and methodology expertise with nonacademic participants' real-world knowledge and experiences (Balazs and Morello-Frosch 2013; Cargo and Mercer 2008; Vaughn and Jacquez 2020). Thus, participatory research is an orientation rather than a method, and research designs and methods used in participatory research are highly diverse, including both qualitative and quantitative methods. Instead of single-event data collection methods, participatory research uses methods that engage people in each step of the research process. These methods include tools, tasks, structured activities, networks, that facilitate shared decision-making, and mutual learning. In this respect, Duea et al. (2022) provide an overview of participatory research methods that are organized into five domains: (1) engagement and capacity building, (2) exploration and visioning, (3) visual and narrative, (4) mobilization, and (5) evaluation. Rather than supporting a specific stage in the research process, these categorizations intend to link each method to a collaborative goal.

Participatory research approaches are suggested to have a direct effect on both participants as well as researchers. In the case of participants, the approach holds the possibility to shape their thoughts, knowledge, and practices, whereas researchers are influenced by making them to reflect on the theories they draw upon, the design, rigor, and trustworthiness of the process that is adopted, as well as knowledge about practice and policy (Cook 2012). Thus, according to Cargo and Mercer (2008) the presence of mutual respect and trust among those involved in participatory research is essential to support capacity building, empowerment, and ownership, and these are the aspects that separate participatory research from other forms of research that are collaborative or action-oriented but not participatory.

Similarly, Bergold and Thomas (2012) propose fundamental principles or distinctive features of participatory research that guide researchers to make greater use of participatory research elements. These principles include (1) democracy as a precondition, (2) creating a "safe space," (3) defining "community," and (4) determining degrees of participation. As participatory research aims at an equitable research process for both the participants and researchers, forging a democratic working process is one of the key aspects. Achieving such a democratic working process, however, demands a higher level of involvement of participants as co-researchers (Unger 2013). Creating a "safe space" is another crucial aspect that needs consideration, especially while working with vulnerable groups (Duarte et al. 2018). Since participatory research requires a strong willingness on the part of participants to contribute

their personal views, opinions, and experiences, a sufficient degree of openness and trust between researchers and participants is necessary for participants to dare to share their thoughts. Such a “safe space” becomes even more important in a participatory research process seeking to co-produce knowledge amidst dissenting views. Instead of creating a conflict-free space, ensuring a space where such conflicts can be jointly discussed, solved, or at least accepted as different positions can bring different perspectives on the subject under study (Bergold and Thomas 2012). Another vital element to be considered in participatory research is defining the “community” or, in other words, identifying groups to be involved. Bergold and Thomas (2012) put forward two fundamental dichotomies observed in participatory research. While there are a number of studies in which researchers and practitioners collaborate and in which practitioners are either involved, or they themselves carry out research with the support of researchers, several other studies directly involve the affected groups in research. The former category of studies has been referred to as “practice-partners” and the latter as “community-partners” research (Von Unger et al. 2012). Nonetheless, it remains rather challenging to define, identify, and include representatives of all groups affected by a problem, and, as suggested by Le Dantec and Fox (2015), the decision on who is involved should be made at the beginning of the research.

Following the question of which groups will be collaborators, another question arises as to what degree these groups should be involved, i.e., the degree of participation. Discussions are ongoing regarding which activities or research processes the participants should be involved in and whether there should be different degrees of participation for different groups. To determine the degree of participation, several participation models exist currently, such as the model developed by Wright et al. (2010), and by the International Association of Public Participation (IAP2) (IAP 2014), all drawing upon the seminal work of Arnstein’s “ladder of participation” (Arnstein 1969). Ideally, as mentioned above, to achieve a democratic working process, it is suggested to involve participants in all stages of the research process as equal partners, such as research design, data collection, and data analysis. Yet, the degree of participation may vary depending on their particular situation and interest (Duarte et al. 2018). While on the one hand, Unger (2013) suggests involving at least some members of all affected groups across all stages of the research process with sufficient flexibility according to the conditions, Wright et al. (2010), on the other hand, do not demand the involvement of the same group across all stages. In this respect, as Bergold and Thomas (2012) suggested, it is important to specify “who, with what rights, at what point in time, and with regard to what theme” can participate in a decision. For example, in the development of community-based digital mental health (see Sect. 3), the researchers seek to involve local indigenous community members, organizational representatives, researchers, and others in all elements of a research project from the outset of the project. Through this, the researchers aim to develop culturally relevant digital health interventions. Whereas in most participatory sensing research (see Sect. 3), researchers often seek to integrate the participants’ subjective perception, thereby engaging participants during the data collection phase.

## 2.2 *Participatory Design*

As mentioned in the introduction of this section, one way to integrate the user directly into the design process is through *participatory design* (Simonsen 2013). The field of Human-Computer Interaction (HCI) generally centers the user in its research and development. Therefore, concepts like human-centered and user-centered design exist, which consider the users' needs and capabilities. Nevertheless, the users do not actively participate in each stage of the design process. They are "simply" kept in mind when designing interfaces and tools. In contrast to this, in participatory design, users are "active, first-class members of the product design team" (Shneiderman et al. 2018), meaning participatory design is used to gain insights into the user's tasks and work life, inviting them to take on the role of the designer themselves (Muller and Druin 2012; Dix et al. 2004). Therefore, they *participate* in the design process by taking an active role in the overall process. Simonsen (2013) defines it in their handbook of participatory design as the following:

a process of investigating, understanding, reflecting upon, establishing, developing, and supporting mutual learning between multiple participants in collective 'reflection-in-action'. The participants typically undertake the two principal roles of users and designers where the designers strive to learn the realities of the users' situation while the users strive to articulate their desired aims and learn appropriate technological means to obtain them.

In this context, 'users' are the participants who will interact with the technologies of interest, and the 'designers' are professionals responsible for the design. Yet, these roles are simplified because many more stakeholders are involved in a participatory design process (as mentioned in the beginning of this section), and the distinction between them blurs throughout the application of participatory design (Simonsen 2013).

Participatory design, then often referred to as cooperative design, emerged from Scandinavian action research in the early 1970s when computers were slowly integrating into everyday work life (Bødker and Kyng 2018). Bødker and Kyng (2018) describe three projects that can be seen as the first participatory design projects: the first is the *NJMF*, which was initiated by and named after the Norwegian Iron and Metal Workers' Union; the second is the Swedish *DEMOS* project (DEMOKratiske Styringssystemer); and the third is the Danish *DUE* project (Demokrati, Udvikling og Edb) (Bjerknes and Bratteteig 1995). The early projects all shared the goal and ideal of "promoting visions of democracy" as part of the joint effort in the research projects. According to the authors, the aspect of (workplace) democracy and changing the practice was one core element of participatory design—also because the first projects were initiated and executed together with trade unions, who wanted to contribute to a more democratic society.

In line with this vision, Simonsen (2013) states that participatory design has four central concepts: (1) take a stand, (2) participation, (3) practice, and (4) design. As participatory design prioritizes human action and people's right to participate in creating the world they will live in, one crucial aspect is always where they *take a*

*stand* in designing their future. Therefore, in the methodology of participatory design, there is the understanding that design has to be ethical as it is accountable for the design of the world it creates and the lives of those who inhabit it. With *participation* being the core aspect of participatory design, it asks for integrating the participants (or ‘users’) into the design process on an equal level as the designers and other stakeholders. This form of end-user participation requires acknowledging the users’ interests as fully legitimate elements of the overall design process. The concept of *practice* is important to participatory design, as there tends to be a difference between how people really work—how their practice actually is—and how others describe the work or, how the work processes are designed in the form of workflow diagrams and similar representations. Therefore, understanding practice is inevitable for a successful participatory design process.

The last central concept is *design*. In the early days, participatory design was primarily used for small-scale and custom-made systems, but since technology use has grown and off-the-shelf systems have become more configurable, the application area of participatory design has expanded. The availability of technology to use during the system design made it possible not just to investigate anticipated use but also unanticipated, unforeseen use. This also incorporates the so-called “designing for design after design,” which refers to the fact that the design explicitly supports the potential for unanticipated use.

When applying participatory design, researchers and designers have many methods available to engage users in the design process encompassing dramatic performances, photography exhibits, games, or sketches and written scenarios (Shneiderman et al. 2018). Among those methods are paper prototyping, sketching interfaces, and creating low-fidelity prototypes with the material at hand, e.g., paper, pieces of plastic, and tape. Furthermore, a scenario walk-through using high-fidelity prototypes or simulation can also help elicit user requirements. Further methods to engage the users as active collaborators include workshops, in which (future) users take part in the design process and actively contribute to shaping representations of their tasks and work-life (Dix et al. 2004). The method of providing sketches was used, for example, by Wadley et al. (2013). They created four different design sketches of an online platform to deliver therapy content and support therapies and used them during a co-design workshop to seed discussions.

### ***2.3 Summarizing Participatory Design and Participatory Research***

Participatory research and participatory design share a similar ideological stance in incorporating the participants’ perspectives and promoting empowerment, democracy, inclusivity, and equality. Both approaches stress that incorporating stakeholders is essential to create a beneficial outcome for everyone. As the approaches originate from different backgrounds, they differ slightly in their methods and dominant application areas. This is particularly visible in the way technology is incorporated into both approaches. Participatory design emerged as the advancements in

technology slowly but significantly integrated and changed the work life of many, with a strong focus on supporting worker in shaping how these technologies were introduced and used. Therefore, most participatory design approaches have some form of technology (design and use) as one of their main objectives. Participatory research, by contrast, was developed to engage all types of stakeholders in the research process. It highly values the community's involvement, independent of the research objective. It emphasizes the collaboration between researchers and practitioners, allowing them to develop and adapt specific research elements, e.g., research questions, objectives, methods, data analysis, and outcomes. As technology is becoming omnipresent, participatory research also adapts technology-focused methods, and both approaches show more and more similarities; however, due to their significantly different origins, both stand on their own as useful approaches to foster participation.

### **3 Participatory Research and Participatory Design in the Context of Digital Public Health**

In this section, we will present how participatory research and participatory design can be and are used in the context of digital public health. We will offer insights on how technology is integrated into participatory research and report on application examples from the literature where participatory design was employed to develop and advance the knowledge and the applications for digital public health.

#### ***3.1 Participatory Research***

Digital technologies change how researchers engage participants in participatory research to collect more adequate and relevant data. Similarly, participatory research is also being increasingly applied to engage participants in the development of digital public health interventions tailored to the community. In the following sections, we present these two strands of participatory research where (1) digital technologies are applied to engage participants in the research process and (2) a participatory research approach is employed to develop digital public health interventions.

##### **3.1.1 Application Example 1: Community-Based Digital Mental Health Program**

Bennett-Levy et al. (2021) demonstrate how bottom-up community-guided processes and locally-generated advocacy played a key role in developing and implementing digital mental health training programs into training that was far more culturally relevant, thus impacting not only locally but nationally in Australia. This has been possible through grounding community-based participatory research from

its inception. The project opted to involve local indigenous community members, organizational representatives, researchers, and others in all elements of a research project in collaborative and equitable partnerships from the outset. Thus, it proved useful in building indigenous capacity from the outset and enhancing community confidence in the project. The authors further describe how local indigenous guidance on re-framing the project from a mere focus on digital mental health to encompassing the indigenous Australian framework of social and emotional well-being led to the transformation of the project from a “top-down” government-funded project into a community-guided bottom-up project. By doing so, the project reported several unexpected and notable outcomes. At the beginning of the project, digital mental health (d-MH) was limited to the conventional understanding that it consisted of evidence-based online therapy programs. However, the iterative reflective processes of the learning circles and constant feedback from participants ensured that initially conceived non-indigenous d-MH programs were culturally inappropriate. This led to the development of indigenous-specific digital social and emotional wellbeing (d-SEWB) and digital mental health (d-MH) resources that were culturally relevant. The d-SEWB adopted a multidimensional concept of health that includes not only mental health but encompasses domains of health and well-being as the connection to land or “country,” culture, spirituality, ancestry, family, and community and is firmly grounded in the impact of colonization on the well-being of Indigenous Australians through political, historical, social and cultural factors. As a result, the original d-MH program underwent significant expansion and was included as a subset in the d-SEWB, which included different types of digital resources across a wide range of cultural domains from indigenous connection to land and sea, community and kin, as well as the individual domains of body, mind, and emotions. Additionally, the project was able to successfully advocate for an Aboriginal-specific online therapy program and the development of a dedicated one-stop-shop d-SEWB website, Wellmob. Thus, in this project, a participatory research approach such as a community-based participatory research approach is especially valued for promoting equitable partnerships with community members in defining problems and seeking solutions, focusing on public health concerns within a local context, disseminating knowledge and sustainable support for interventions, and focusing on how race, ethnicity, racism, and class shape health outcomes.

### **3.1.2 Application Example 2: Participatory Sensing in Environmental Health Research**

Increasing participatory research in the public health field nowadays employs digital methods to engage participants in certain stages of research, particularly to collect more adequate and relevant data for them. Such use of digital technologies is vivid in participatory sensing in environmental health research. The emergence of environmental monitoring and mapping technologies, the increasing use of mobile devices, and the growth of online data-sharing platforms are now supporting the

involvement of diverse citizens and communities in participatory research approaches, such as citizen science and crowd-sourced science. These approaches are increasingly reliant on digital technologies such as smartphone-based apps and sensor technologies as research instruments to promote community/citizen involvement in neighborhood documentation and representation, foster greater data accessibility, democratize science, and mobilize diverse people and communities. For example, a smartphone-based assessment was developed within the CITI-SENSE project to study the acoustic environment of urban spaces (Aspuru et al. 2016). The project is based on three fundamental concepts: (1) technological platforms for distributed monitoring, (2) information and communication technologies, and (3) societal involvement. The solution comprises a smartphone allowing the post-processing of acoustic signals, an external microphone for measuring noise levels, a smartphone app with an embedded questionnaire that allows citizens to provide their perception of the area, and a protocol for making the observations that includes clear instructions for the participants.

Overall, the project intended to empower citizens to collect and share perceptual analysis of the surrounding acoustic environment, thereby promoting citizens' contributions as active participation in environmental governance.

The participants involved were the general public, who were contacted through civic associations. Within the project, they received the smartphone and instructions to perform the observations, including both the acoustic measurement and the questionnaire to be filled in. Before the launch of the observation event, participants were invited to a specific workshop where the objectives of the exercise, the tool, and the protocol were presented, and attendees' expectations were noted concerning the observations of urban places and initiatives. Those participants engaged in making the observations were then provided with a training workshop on how to use the CITI-SENSE kit that included the tool and protocol for making observations. The observations for four places were made for 1.5 weeks. In the end, participants were invited to the feedback workshop, where they were asked to identify areas and provide suggestions for improvement. Furthermore, they assessed their experiences of using the tool and protocol for evaluating environmental quality in urban areas. One of the aims of this project was the simultaneous collection of objective and subjective data on-site and the empowerment of participants as active citizens in environmental governance. In this line, participants found the project and its results useful to educate and raise awareness of these issues and the importance of improving comfort in public spaces. However, some doubts and difficulties in generalizing the use of devices were raised as they are not available to a significant number of people. Moreover, an evaluation of technical solutions showed that while older participants thought the tool and protocol were complex, younger people considered them to be practical, user-friendly, manageable, and intuitive. Nonetheless, researchers argue that such solutions can be applied to develop empowerment initiatives such as evaluating quiet areas and collecting ideas for their improvement, identifying priorities for Noise Action Plans, including citizen perception, and participatory co-design of action within the Noise Action Framework.

### 3.1.3 Application Example 3: Digitalization of Participatory Research Methods

The use of visual methods in the form of photo and video-voice is a commonly practiced research method in participatory research. Major benefits related to such methods in participatory research in health include (1) enhanced community engagement in action and advocacy, (2) improved understanding of community needs and assets, which in turn could have community or public health benefits, and (3) increased individual empowerment (Catalani and Minkler 2010). The adoption of smartphones and social media has further changed the way these visual methods can be used innovatively for engaging participants in collecting and sharing photographs and videos for research purposes. For instance, Earnshaw et al. (2022) demonstrate how the online asynchronous photovoice method presents a promising alternative to work with key populations such as transgender women, female sex workers, and people living with HIV (PLWH). Their research project focused on understanding key populations' and PLWH's experiences of stigma in healthcare settings in Malaysia. Photovoice projects traditionally involve in-person, synchronous interactions between facilitators, participants, and other stakeholders such as community members and policymakers. Yet, this format may not always be feasible and acceptable due to participant locations and, importantly, concerns related to confidentiality (e.g., in places with strong HIV-related stigma) or safety (e.g., during COVID-19 surges). Thus, a project website was set up that facilitated the project introduction to participants and an informed consent process, provided photography skills and an understanding of visual literacy, and enabled the collection of photovoice submissions from participants. The authors leveraged online and asynchronous photovoice methods via the website, which could be accessed online at any time, as an alternative to engage more members of key populations and PLWH confidentially and safely. The results suggest the feasibility and acceptability of online, asynchronous photovoice methods to engage with key populations and PLWH in research. Amongst a number of positive comments, participants especially enjoyed expressing themselves through photography, learning new skills, and the anonymity maintained by the website. One participant even stated that they appreciated “expressing who we are without revealing ourselves.” In this line, the authors argue that online, asynchronous photovoice methods may enhance participant safety and address confidentiality concerns in a case study context with pronounced stigma towards key populations and PLWH, as in this project. As the methods do not require participants to physically gather at a study site, they can remain anonymous to other participants. In another example, Volpe (2019) argues that the use of mobile phones among young people is increasing, and they are already engaged in showing and sharing their pictures or videos on social media. Thus, these actions can provide insights into the movements and mobilities of young people in online spaces, creating “digital diaries” of the “everydayness” of their lives through the pictures and videos they share on social media. As young people are already producing digital representations of their real, lived experiences, with participants' permission, they can provide a diarized inspection of their daily lives

(Volpe 2019). Not only does it produce rich visual and narrative data on experiences of participants guided by participants' interests and priorities, but it also puts the methods in the hands of the participants.

## 3.2 *Participatory Design*

Participatory design has a stronger focus on technologies as it emerged when computers became more common in the workplace (see Sect. 2.2). In participatory design, all parties are influenced by the technology—e.g., the users—or can influence the technology either because they are designers, for example, or hold a position—e.g., in a government—that impacts the rules and the roll-out of the technology. There are various examples throughout research where participatory design was used in a health context, such as the work by Wadley et al. (2013), van Hierden et al. (2021), Bowen et al. (2013), Reeder et al. (2014), and Schmitt and Yarosh (2018).

Bowen et al. (2013) worked with nurses in the UK National Health Service (NHS) to understand and develop participatory methods for designing health services for the NHS. Reeder et al. (2014) followed a participatory design approach to engage public health nurses and nurse managers in the design process of an information system to enable analysis, visualization, and sharing of data between and across public health jurisdictions for different stakeholders to support public health work. Wadley et al. (2013), Schmitt and Yarosh (2018), and van Hierden et al. (2021) focused more on applications for supporting individuals with drug problems and mental health issues. Some of these projects would be described by Bødker and Kyng (2018) as focusing on the “small issues.” They use participatory design mainly to facilitate direct collaboration between users and designers through co-design and being able to “engage with everyday issues of use, through technology”, rather than aiming for broader or systemic transformation in practices or institutions.

In the following two sections, we will present two examples of participatory design, one by Wadley et al. (2013) focusing on designing an online therapy platform in Australia and the other being the Health Information Systems Program (HISP) project (Braa and Sahay 2012; Bødker and Kyng 2018), which started in 1994 in South Africa, and aimed to provide equity in health service delivery.

### 3.2.1 **Application Example 4: Designing an Online Therapy Platform**

In this section, we will briefly describe the work of Wadley et al. (2013), who used participatory design to design a platform for adolescents between 15 and 25 years old who received treatment at a local clinic. They describe how they ran co-design workshops with potential users of an online therapy platform, which included patients of a collaborating clinic and the clinicians of the same clinic, as treatment involves both parties. They used sketches and mock-ups of the potential online platform to spark and facilitate discussions in the co-design workshops.

Generally, the feedback on an online therapy platform was positive. However, the potential for (increased) anxiety was also mentioned, as reading about psychosis online can trigger an individual's anxieties. One reported benefit was the exchange of experiences among patients with similar experiences on digital platforms such as social networks (e.g., Facebook). The digital format of an online therapy platform was also perceived as possibly helpful as long as there were no "'corny' computer-generated messages." The workshop with the clinicians revealed that they were concerned that socio-economic factors could impact the accessibility of an online therapy platform and that some patients may benefit from actually leaving their homes to attend face-to-face therapy. Also, they mentioned that direct communication between patients could be helpful but should be moderated and thus wondered about the availability of the required human resources.

The three main design decisions resulting from the workshops are, first, that the platform will feature psychoeducational content accessible to the clients at times, places, and at a pace that is convenient to them. Second, it will allow for peer-to-peer social interaction inspired by social media. And last, the client interaction will be moderated by professional clinical staff who can also provide advice.

Based on the insights provided by the participants, the researchers developed the platform and refined it during sessions with the participants. After this step was finished, they started a trial run with clinicians and patients of the collaborating clinic and did post-trial interviews with the participants to understand the use of the platform. Based on the results, such as that the patients wanted to have more freedom in selecting therapy modules, the researchers proposed various changes to their system, which was planned to be tested in a larger trial. Still, the researchers already found a positive impact on the participants' mental health within the 6 weeks trial phase. For further details, we refer to the publication by Wadley et al. (2013).

### 3.2.2 Application Example 5: The HISP Project

In contrast to the relatively small scope of the presented study in the section above, the *HISP project*—“HISP” stands for Health Information Systems Program (Braa and Sahay 2012)—has lasted for several decades and has expanded to other communities. The HISP project started as an initiative in South Africa. It was initiated in 1994, just after apartheid ended. Among its aims was to provide equity in health service delivery and to develop and empower those communities and groups that were most disadvantaged under apartheid. The project aimed to build a flexible local data processing system enabling a local collection and delivery of health data requested from various health care providers such as hospitals, clinics, school health, or NGOs (nongovernment organizations). Due to political changes, the focus shifted slightly during the early phase of the project, and the goal to integrate the processes and information systems from the Department of Health was added to the original list of objectives. The software developed in the HISP project is the District Health Information Software (DHIS). It allows its users to access their information immediately. During the pilot phase, the software was developed and piloted at two

universities in Cape Town and three health districts nearby (Braa and Hedberg 2002). University staff, activists from the health sectors and NGOs, and two Norwegian researchers built a team to identify information needs and support the interim district management teams. By providing this, it was possible to implement and test the “information cycle” hands-on, leading to further improvements as users urged for “better information, analytical tools, and graphs.” This shows that if participatory design is deeply integrated into all processes, there exists an ever-changing system that will constantly adapt to the requirements and therefore is never ‘finished.’

One of the benefits of the HISP project is its linking of the South African community with the University of Oslo, where educational programs helped disseminate the participatory design approach on which the project was based. HISP has been successfully expanded to various countries, such as Cuba, India, and Mozambique, in the first phase of expansion. Thereby the team of developers, health professionals, and government officials working on and informing the project has increased. The expansion also led to the network becoming even more extensive, creating linkages for more collaboration in health information system development, implementation, and scaling.

Following this first expansion, the HISP project underwent some major concept changes, such as explicitly changing from a standalone application to a networked application within the health systems of developing countries. Furthermore, as the open-source technologies were gaining momentum, the technologies had matured enough that “the entire web-based technology stack could be provided as Free and Open-Source Software.” Following this change, after the civil war in Sierra Leone ended in 2002, their health systems needed extensive rebuilding, and in 2008 DHIS (in version 2) was introduced there. Participatory design was and is still a core element. The general process followed is, first, to implement the software as it is and enrich it with datasets to enable a hands-on experience for its users. In a second step, this allows users to prototype *their* version of the software and discuss what the revised system should look like. As a third and last step, the original system is adjusted to meet the users’ needs, which includes paper forms and data standards. In Sierra Leone, the traditional chiefdoms were facing systemic disadvantages and were eager to use the new system to demonstrate this. Therefore, they were part of the design process and even competed to produce “the best-quality data on health services and produce tables ranking their achievements, in both their local and their national contexts.” The HISP project continues, and with participatory design at its core, it confidently faces new challenges like the rapid improvement of mobile networks, enabling many online web-based services and cloud computing in developing countries.

Bødker and Kyng (2018) highlight the HISP project as one of the projects that inspired a “new” participatory design in the spirit of its roots. It is a long-sustained project (running for 20+ years now), and it has kept its continued focus on developing approaches to collecting and using data while supporting local action. Furthermore, it contributed to an ongoing participatory process of data standardization to support cooperation on a local-to-local and local-to-central level, including

the scaling up. They also highlight that HISP has created a “self-sustaining organizational network which handles the technological core and the processes of continued development, deployment, and use.”

## 4 Outlook

As digitization is advancing in nearly all areas of life, it also gets integrated into the domain of public health, thereby offering considerable potential to support and improve various health issues such as mental health, obesity, and chronic diseases. Despite the possibilities, research mentions significant challenges regarding the uptake of or adherence to digital interventions. The failure to ensure culturally and logistically appropriate digital public health interventions has been reported, among other reasons. In our understanding, the integration of participatory approaches, such as participatory research and participatory design, can address these reasons for failure.

The research presented in the previous section shows that participatory research and participatory design are valuable approaches for designing, developing, and implementing technologies and interventions for the health domain. In the examples mentioned, different methods were used to engage the users, such as focus groups, co-design workshops, cultural probes such as photos or videos, diaries, smartphone recordings, and questionnaires. The application examples are similar in that they want the development or research to be undertaken with or by society’s marginalized people, thereby having people as full participants involved throughout the process to determine their own needs to improve their own lives. This highlights that although participatory research and participatory design have different historical origins, they share similar ideologies of empowerment, democracy, and inclusivity.

Participatory research has a strong focus on the research process itself. It may focus on establishing an equitable community partnership process to design digital interventions to develop co-ownership and co-decision-making (cf. Application Example 1). Sometimes participatory research may be limited to just documenting or studying a problem or the needs and requirements of a community by involving participants in certain stages of research activity. In this case, digital technologies provide a research instrument for involving participants in research activity (cf. Application Example 2). Furthermore, the ubiquitous use of digital technologies such as smartphones, online platforms, and social media is opening up new possibilities and new ways to utilize existing participatory methods to involve research participants, especially in data collection processes (cf. Application Example 3).

While participatory research helps to understand the circumstances and context of the user group by involving them into the process, participatory design can help design and understand newly developed technical aspects brought into society. With its history of giving a voice to the people affected by the beginning of the digital age, participatory design can be a useful tool in supporting the design, development,

and integration of technology into the public health context. Among the most important questions for new technology—be it a device or a piece of software—are the questions “Is this useful and usable for the target group?” and “Does this meet the needs of the target group?” This was nicely illustrated by Application Example 5—where the requested features of the HISP project and resulting software changed several times over the course of its long-term development. It was designed hand in hand with its users and the relevant stakeholders and thereby focused on their needs.

Overall, the objectives of participatory research and participatory design complement each other well. Thus, harnessing the strengths of participatory research and participatory design not only improves the functionality of technologies used by participants but might also ensure that participants use these technologies more effectively in research and practice to improve health and well-being. Their vision of empowering the people affected, establishing a democratic process, and striving for inclusivity is highly relevant for creating a future in which digital public health is accessible and beneficial for everyone.

## References

- Arnstein SR (1969) A ladder of citizen participation. *J Am Inst Plann* 35(4):216–224
- Aspuru I, García I, Herranz K et al (2016) Citi-sense: methods and tools for empowering citizens to observe acoustic comfort in outdoor public spaces. *Noise Mapp* 3(1)
- Balazs CL, Morello-Frosch R (2013) The three Rs: how community-based participatory research strengthens the rigor, relevance, and reach of science. *Environ Justice* 6(1):9–16
- Bennett-Levy J, Singer J, Rotumah D et al (2021) From digital mental health to digital social and emotional wellbeing: how indigenous community-based participatory research influenced the Australian government’s digital mental health agenda. *Int J Environ Res Public Health* 18(18):9757
- Bergold J, Thomas S (2012) Participatory research methods: a methodological approach in motion. *Hist Soc Res* 37(4):191–222
- Bjerknes G, Bratteteig T (1995) User participation and democracy: a discussion of Scandinavian research on system development. *Scand J Inf Syst* 7(1):1
- Bødker S, Kyng M (2018) Participatory design that matters—facing the big issues. *ACM Trans Comput Hum Interact* 25(1):1–31. <https://doi.org/10.1145/3152421>
- Bowen S, McSeveny K, Lockley E et al (2013) How was it for you? Experiences of participatory design in the UK health service. *CoDesign* 9(4):230–246
- Braa J, Hedberg C (2002) The struggle for district-based health information systems in South Africa. *Inf Soc* 18(2):113–127
- Braa J, Sahay S (2012) Health information systems programme: participatory design within the HISP network. In: *Routledge international handbook of participatory design*. Routledge, London, pp 235–256
- Cargo M, Mercer SL (2008) The value and challenges of participatory research: strengthening its practice. *Annu Rev Public Health* 29:325–350
- Catalani C, Minkler M (2010) Photovoice: a review of the literature in health and public health. *Health Educ Behav* 37(3):424–451
- Chambers R (1994) The origins and practice of participatory rural appraisal. *World Dev* 22(7):953–969. [https://doi.org/10.1016/0305-750X\(94\)90141-4](https://doi.org/10.1016/0305-750X(94)90141-4), <https://www.sciencedirect.com/science/article/pii/0305750X94901414>

- Cook T (2012) Where participatory approaches meet pragmatism in funded (health) research: the challenge of finding meaningful spaces. *Forum: Qualitative Social Research, Forum Qualitative Sozialforschung* 13(1):Art-18
- Cousins JB, Whitmore E (1998) Framing participatory evaluation. *N Dir Eval* 80:5–23. <https://doi.org/10.1002/ev.1114>
- Dix A, Finley J, Abowd GD et al (2004) *Human-computer interaction*, 3rd edn. Pearson, London
- Duarte AMB, Brendel N, Degbelo A et al (2018) Participatory design and participatory research: an HCI case study with young forced migrants. *ACM Trans Comput Hum Interact* 25(1):1–39
- Duea SR, Zimmerman EB, Vaughn LM et al (2022) A guide to selecting participatory research methods based on project and partnership goals. *J Participatory Res Methods* 3(1):32605
- Earnshaw VA, Cox J, Wong PL et al (2022) Acceptability and feasibility of online, asynchronous photovoice with key populations and people living with HIV. *AIDS Behav* 27(7):2055–2069
- IAP (2014) *Public participation spectrum*. International Association for Public Participation-IAP2 Federation, Wollongong
- Iyamu I, Xu AX, Gómez-Ramírez O et al (2021) Defining digital public health and the role of digitization, digitalization, and digital transformation: scoping review. *JMIR Public Health Surveill* 7(11):e30399
- Iyamu I, Gómez-Ramírez O, Xu AX et al (2022) Challenges in the development of digital public health interventions and mapped solutions: findings from a scoping review. *Digit Health* 8:20552076221102255
- Jagosh J, Macaulay AC, Pluye P et al (2012) Uncovering the benefits of participatory research: implications of a realist review for health research and practice. *Milbank Q* 90(2):311–346
- Kemmis S (2006) Participatory action research and the public sphere. *Educ Action Res* 14(4):459–476
- Le Dantec CA, Fox S (2015) Strangers at the gate: gaining access, building rapport, and co-constructing community-based research. In: *Proceedings of the 18th ACM conference on computer supported cooperative work & social computing*, pp 1348–1358
- Macaulay AC (2016) Participatory research: what is the history? Has the purpose changed? *Fam Pract* 34(3):256–258. <https://doi.org/10.1093/fampra/cmz117>. <https://arxiv.org/abs/https://academic.oup.com/fampra/article-pdf/34/3/256/17695896/cmz117.pdf>
- Minkler M, Wallerstein N (2011) *Community-based participatory research for health: from process to outcomes*. John Wiley & Sons, New York
- Mucha H, de Barros AC, Benjamin JJ et al (2022) Collaborative speculations on future themes for participatory design in Germany. *i-com* 21(2):283–298. <https://doi.org/10.1515/icom-2021-0030>
- Muller MJ, Druin A (2012) Participatory design: the third space in human–computer interaction. In: *The human–computer interaction handbook*. CRC Press, Boca Raton, pp 1125–1153
- Odone A, Buttigieg S, Ricciardi W et al (2019) Public health digitalization in Europe: Euph vision, action and role in digital public health. *Eur J Pub Health* 29(Suppl 3):28–35
- Reason P (1999) Integrating action and reflection through co-operative inquiry. *Manag Learn* 30(2):207–225
- Reeder B, Hills RA, Turner AM et al (2014) Participatory design of an integrated information system design to support public health nurses and nurse managers. *Public Health Nurs* 31(2):183–192
- Schmitt Z, Yarosh S (2018) Participatory design of technologies to support recovery from substance use disorders. *Proc ACM Hum Comput Interaction* 2(CSCW):1–27
- Shneiderman B, Plaisant C, Cohen M, et al (2018) *Designing the user interface: strategies for effective human-computer interaction*, Global edn. Pearson Deutschland. <https://elibrary.pearson.de/book/99.150005/9781292153926>
- Simonsen J (2013) *Routledge international handbook of participatory design*, vol 711. Routledge, London
- Unger H (2013) *Partizipative Forschung: Einführung in die Forschungspraxis*. Springer, Berlin

- van Hierden Y, Dietrich T, Rundle-Thiele S (2021) Designing an eHealth wellbeing program: a participatory design approach. *Int J Environ Res Public Health* 18(14):7250
- Vaughn LM, Jacquez F (2020) Participatory research methods—choice points in the research process. *J Participatory Res Methods* 1(1):13244
- Volpe CR (2019) Digital diaries: new uses of photovoice in participatory research with young people. *Childrens Geogr* 17(3):361–370
- Von Unger H et al (2012) Participatory health research: who participates in what? *Forum Qual Soc Res* 13(1)
- Wadley G, Lederman R, Gleeson J, et al (2013) Participatory design of an online therapy for youth mental health. In: *Proceedings of the 25th Australian computer-human interaction conference: augmentation, application, innovation, collaboration, OzCHI'13*. Association for Computing Machinery, New York, pp 517–526. <https://doi.org/10.1145/2541016.2541030>
- World Health Organization (1986) *Ottawa charter for health promotion, 1986*. Tech. rep. World Health Organization. Regional Office for Europe
- World Health Organization (1992) *Our planet, our health: report of the WHO Commission on Health and Environment*. World Health Organization, Geneva
- Wright MT, Von Unger H, Block M (2010) Partizipation der zielgruppe in der gesundheitsförderung und prävention. *Partizipative Qualitätsentwicklung in der Gesundheitsförderung und Prävention* 1:35–52

**Open Access** This chapter is licensed under the terms of the Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>), which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license and indicate if changes were made.

The images or other third party material in this chapter are included in the chapter's Creative Commons license, unless indicated otherwise in a credit line to the material. If material is not included in the chapter's Creative Commons license and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder.

