# Who, When, How

## Guiding the active involvement of stakeholders in eHealth Action Research



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# WHO, WHEN, HOW – GUIDING THE ACTIVE INVOLVEMENT OF STAKEHOLDERS IN EHEALTH ACTION RESEARCH

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by

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# Contents

# Part 1

# State of the Art of eHealth AR

This first part introduces the main topics of this thesis: action research and stakeholder involvement. It also describes how action research and stakeholder involvement are currently done in eHealth project, and where there is room for improvement. This provides a basis for the next parts in this thesis.

# Chapter 1

# General introduction

Chapter 1

The way health care is organized and executed is of vast societal concern and greatly affects our quality of life. The use of eHealth is often suggested to mitigate rising problems like the ageing population, increased co-morbidity and health care staff shortage. The Covid-19 pandemic emphasized this necessity, and pushed the digital transformation in the healthcare sector (Guitton, 2021; Pauzi & Juhari, 2020). eHealth services and technologies cover a wide variety of topics (e.g. self-management, monitoring) and can therefore greatly benefit patients, professionals, and many other health care stakeholders. However, to gain the most from eHealth services, it is crucial that they are developed to fit what relevant stakeholders need in practice (van Gemert-Pijnen et al., 2011). To ensure such a match, van Gemert-Pijnen et al. (2011) suggest working together with these relevant stakeholders in all stages of developing the technology, implementing the study results in practice, and continuously evaluating the process. Action Research (AR) is a promising approach for the successful development and uptake of eHealth services in practice, as it includes all of these important elements.

## Action Research

AR is a collaborative approach, where people affected by the change envisioned in AR become active members of the research team (Williamson et al., 2011). According to Reason and Bradbury (2007), the key elements of AR are that this approach (1) involves stakeholders as co-researchers, (2) consists of plan, act, and reflect cycles, (3) makes a change in practice, while also extending scientific literature, and (4) evaluates the said changes in and with the community. These elements are visualised in Figure 1. Furthermore, AR in healthcare "seeks to (1) improve patient experiences and the health of populations, (2) reduce the per capita cost, (3) improve the work life of those who deliver care, and (4) bring healthcare providers into circumstances that allow for continuous learning together with patients" (Bradbury & Lifvergren, 2016). AR has been used as a research framework in nursing and healthcare, for example to improve the quality of patient care by implementing a new service, or to investigate the impact of policy changes in a department (Williamson et al., 2011).

AR is one among many participatory research approaches, and as we will see in the second chapter, the lines between these approaches can become blurred sometimes. For example, stakeholder involvement is a key element of AR, but also highly valued in other approaches like Citizen Science (for more information see Wiggins and Wilbanks (2019)) or Patient and Public Involvement (for more information see de Wit et al. (2018)). However, in AR there is larger focus on and need for reflection, as part of its cyclical nature, whereas this is not necessarily included in the other approaches. Other approaches that are similar to AR come from the field of design research, for example participatory design (for more information see Clemensen et al. (2017)). AR can include elements of design, but this is not always the case. In addition, AR differentiates itself from design research through its necessary situation in practice or within a community. Regardless of the differences between participatory approaches, they can borrow elements from one another (e.g., including reflection in a Citizen Science project, or design techniques in AR), and it can be useful for action researchers to learn from the other approaches and vice versa.

## Stakeholder Involvement as key element of AR

As Figure 1 depicts, the active involvement of stakeholders is a central element to AR. The stakeholder co-researchers are involved in all cycles, and they form the bridge to the practice or community where the projects aims to make a change. Hence, AR can not truly take place without stakeholder involvement. Stakeholder involvement will take different forms, and include different types of stakeholders, depending on the project. In the context of healthcare, involved stakeholder groups often include patients and healthcare professionals, and specifically eHealth projects will likely also include partners
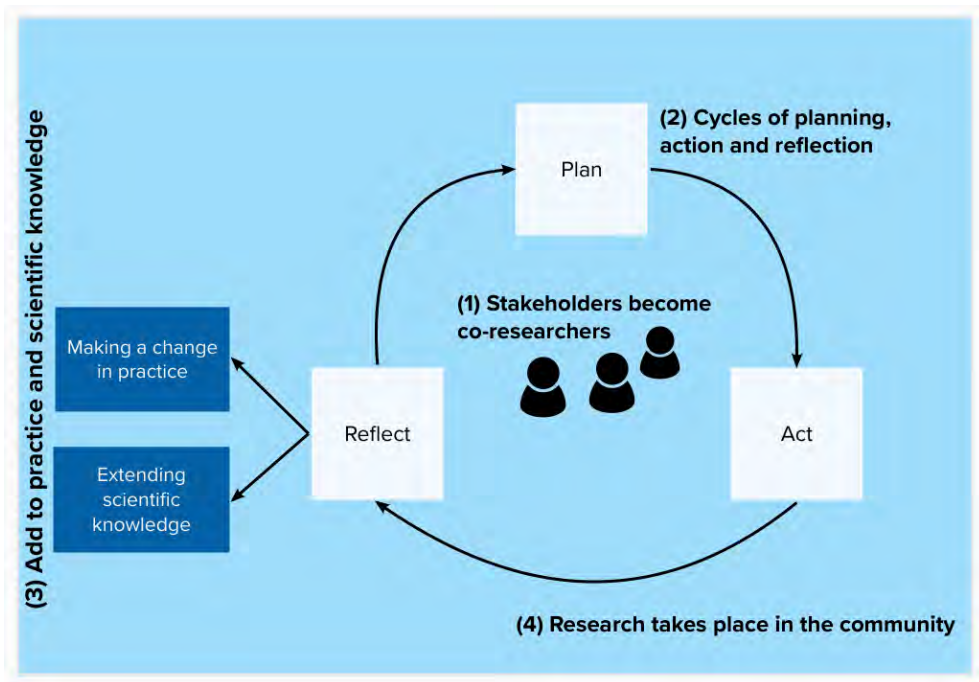
Figure 1: Visualisation of the AR elements based on the definition by Reason and Bradbury(2007)

with a technical background, like developers. Not only the background of the involved stakeholders varies, the level of involvement might also differ between stakeholders, or over the course of a project. Some stakeholders take on very active roles, for example acting as a so called 'champion', driving the project (Kirchner et al., 2012; Wade et al., 2014). Others might prefer taking part in meetings, or being participants in a study (James & Buffel, 2022). For many of the participating stakeholders, such involvement in a research project will be a new experience, and feel somewhat outside of their area of expertise. Therefore, it is crucial that they are adequately supported and enabled to take on a new role, for example through education (Connor, 1988). Similarly, researchers need to learn how to involve stakeholders, and learn from the involved stakeholders about their perspective and experience (Maaß & Buchmüller, 2018).

Ideally, projects should organically arise from within a community, naturally forming project teams (Callén et al., 2009). However, in practice, most of the time it is still researchers who apply for funding and search for stakeholder parties to involve in a project (Righi et al., 2017). Especially in such researcher-initiated projects there is a large need for stakeholder involvement. Researchers have to be aware of different power dynamics and roles within the group (James & Buffel, 2022), and be willing and able to hand over some of their responsibilities to stakeholder co-researchers (Corrado et al., 2020).

Chapter 1

## Reporting about AR

Extending scientific knowledge is a an important aspect of AR. However, the way in which knowledge about AR projects is shared often mainly includes anecdotal reporting of findings, i.e. how the specific project was conducted and what the outcomes were in the particular context. On the one hand, the format of research papers often necessitates such a focus and are specific norms and conventions on how to report research results. On the other hand, the goal of a project is usually related to the content of the project (e.g. implementing a new eHealth solution in a hospital), instead of focusing on the research process. However, this focus on content outcomes leaves out any findings about the process of doing AR and working with stakeholders. The fact that published descriptions of AR, and especially the involvement of stakeholders in AR are rather anecdotal and content-oriented makes it difficult to generalise findings and translate them to other projects. Specifically, others could benefit from concrete descriptions of what works well (best practices) and which problems others faced and how they dealt with them (lessons learned).

## Problem statement and research question

Currently, no clear overview of best practices and lessons learned for eHealth AR projects is available to support and guide researchers in conducting such a project. Therefore, the main research question of this thesis is *How can we guide active stakeholder involvement in eHealth AR projects?*, with the three sub-questions being *What is currently known about eHealth AR?*, *How can we motivate and engage relevant stakeholders?* and *How can we facilitate the communication and collaboration between stakeholders?*.

## Aim and thesis outline

The aim of this thesis is to develop a framework on stakeholder involvement in eHealth AR projects, by synthesising the answers to the research questions outlined above. With this framework I hope to support researchers in setting up and performing stakeholder involvement in their research, which in turn should lead to an overall improvement in the quality of AR generally, and stakeholder involvement specifically.

# Part 1 - State of the art

This background section answers the first sub-question, *What is currently known about eHealth AR?*, and thereby gives a better understanding of the context of my research. At the end of this introduction, I present an overview of the research projects in which I conducted my studies. Then, in CHAPTER 2 the results of a literature review on AR in eHealth projects are presented. The aim of this review was to get an overview of current eHealth AR, specifically looking at *how* the research is conducted, instead of focusing on outcomes. We investigated the context of these projects, how they define and conduct AR, and which best practices and lessons learned they draw. The section ends with some conclusions drawn from this first part, and how it relates to the following studies that were conducted.

## Part 2 - Engaging relevant stakeholders

The second part of this thesis looks at different levels or roles of involvement in research projects, independent of the type of stakeholder that fulfils each role. The sections starts by looking at researchers, as the leader and initiator of a project. After that, on a slightly less involved level, research champions are studied, followed by research participants, again less involved than the previous group. Finally, on the lowest level of involvement, we will look at reaching the general public and engaging them with a project. Together, the chapters in this section answer the second sub-question, *How can we motivate and engage relevant stakeholders?*.

The part starts by looking at researchers, as stakeholder involvement will not be initiated if they are unwilling to do so. Therefore, in the first chapter of this part (CHAPTER 3) we studied novice action researchers' attitude towards AR. The goal of this study was to understand how researchers new to AR perceive the approach and whether they are able to implement it in practice. We introduced AR to researchers, and asked them to identify benefits, risks and mitigation actions they foresaw for their project. The chapter outlines the methods that we used, as well as the novice action researchers' perceptions of AR.

In CHAPTER 4 we move on to look at 'champions' in AR projects. We followed the champions in several different pilots of a project over the course of the project, with the goal of investigating how they see their role and whether this changes over the course of the project. Based on the outcomes, we developed champion personas, and give recommendations for identifying and involving champions in research projects.

Next, CHAPTER 5 presents a study in which we investigated the motivation of stakeholders participating in long-term, time-consuming research projects like AR. The aim of this study was to identify ways of keeping participants motivated in such projects. We asked participants in two different research projects about their motivation for taking part in the study. The chapter includes a discussion of motivating factors and provides recommendations for keeping participants engaged and motivated during a project.

CHAPTER 6 looks at the involvement of the general public, as outsiders to a project. As opposed to the previous chapter, in this chapter our goal was to identify how to involve participants unplanned and spontaneously. We explored the usefulness of a specific method - the flash mob method: fast-paced and practice-situated studies. We tested this method in two different projects, and through observations and reflection, we provide recommendations for implementing the method in AR projects.

To summarize the findings from this part, I will give a brief overview of the main recommendations, and how they feed into the framework that will be presented at the end of the thesis.

## Part 3 - Facilitating interaction between stakeholders

The third part of this thesis looks at how the stakeholders involved in a project interact and communicate with each other, and how researchers can help facilitate this process. This part takes on several topics related to the communication and interaction between collaborating stakeholders, specifically looking at what researchers can do to facilitate such processes. In this way, sub-question 3, *How can we facilitate the communication and collaboration between stakeholders?*, is answered.

In the first chapter of this section CHAPTER 7 we studied the alignment of interests and needs of different stakeholders in a project, in terms of what they want to achieve from the project (content-wise). The aim of this study was to describe how stakeholders can be brought to agreement in a project. Following from a case study involving older adults, technology developers and researchers, the chapter proposes different recommendations for aligning stakeholders throughout the project.

CHAPTER 8 provides a reflection tool for collaborative reflection with stakeholders, both on content and process level. The aim of this work was to provide a structured way for researchers to reflect

together with project partners. We iteratively developed this tool with several pilots of an AR project, who tested the tool and provided feedback.

The focus of CHAPTER 9 is on the process of enabling stakeholders to be involved and interact with each other. Our aim was to investigated important elements of stakeholder skill training. This chapter discusses the outcomes of a workshop with researchers experienced in such training activities. We raise some questions that should be considered when planning stakeholder skill training.

The last chapter in this part, CHAPTER 10, describes an iterative method to involve patients, their perspectives and lived experiences in research. The goal of this method is to map patient values along the patient journey. The method is present together with a case study and reflections and recommendations for future use of the method.

As with the previous part, a summary of the main recommendations and findings is given, to relate this section to the final output of this thesis, the framework for stakeholder involvement in AR eHealth projects.

## Part 4 - Framework for future projects

The final part of this thesis synthesises the results that were described in the preceding chapters. First I present a framework for stakeholder involvement in eHealth AR projects that I developed based on the previous studies and the wider literature (CHAPTER 11). The framework describes important topics to consider in such a project, taking into account the recommendations made throughout this thesis. The chapter also includes a reflection on the development of the framework and its application in eHealth AR projects. In the final chapter of this thesis (CHAPTER 12), I discuss the results and give an outlook on future research.

## Context of this research

Several studies in different research projects fed into this thesis. Below, I will outline these projects, to give an idea of the context and goals in each case. A summary can be found in Figure 1. The largest part of my research was conducted within the Pharaon project. Two studies each were partially conducted within the SALSA project and the Task Force Project. Finally, part of one study was conducted within the Scotty project.

| Project name | Pharaon | SALSA | Taskforce patient values | Scotty |
|---|---|---|---|---|
| Topic | Technology supported healthy and active ageing | Healthy lifestyle, exercising | Patient values in rehabilitation care | Evaluation of a social robot |
| Target group | Primary: Older adults Secondary: healthcare professionals, relatives | Patients with COPD | Patients with stroke, chronic pain or spinal chord injury | Patients, older adults |
| Context(s) | Various (e.g., home, nursing home, hospital | Physiotherapist's office, rehabilitation centre | Rehabilitation centre | Rehabilitation centre, nursing home |
| Study aim within this thesis | Investigating attitude of researchers, finding and keeping champions, conducting stakeholder skill training, aligning stakeholder interests, guiding reflection meetings, building a framework for doing AR | Investigating participant motivation, testing the flash mob method | Investigating participant motivation | Testing the flash mob method |
| Chapter(s) | 3, 4, 7, 8 & 9 | 5 & 6 | 5 & 10 | 6 |

Table 1: Overview of the research projects in which I conducted my thesis research.

## Pharaon

The Pharaon project focused on technology-supported healthy and active ageing. Existing technologies (e.g. activity trackers, videoconferencing, dietary coaches) were integrated, to provide older adults with one interface from which they can access the various services. Pilot test of these technology platforms were conducted at seven pilot sites in five different countries (Italy, The Netherlands, Slovenia, Spain and Portugal). At each of the pilot sites, different stakeholders were actively involved in the project (e.g., older adults, healthcare professionals, technology developers). AR was used as approach guiding the collaboration of the different parties. The studies that I conducted within the Pharaon project were for the most part overarching, looking at the pilot sites and researchers as participants, to investigate how they conduct their AR.

## SALSA

The aim of the SALSA project was to support a healthy lifestyle for older adults. In the overarching project there were two different topics (community building and exercise), and the studies were conducted in three countries (Austria, Switzerland and The Netherlands). However, all studies that fed into my thesis were conducted in the Dutch Pilot for the exercising part of the project (SALSA Health). In this part of the research, and exercise gaming (*exergame*) technology was tested in practice. On the one hand, this was done in a physiotherapy practice with COPD patients for a period of six months. On the other hand, a short evaluation of the technology was conducted at a rehabilitation centre, involving different healthcare professionals and various patient groups.

## Taskforce patient values

The taskforce project patient values was a local project focused on determining patient values over time in a rehabilitation care setting in general, and with a focus on technology use specifically. Over the course of the project, patients were first interviewed, then asked to fill in an online diary questionnaire during three weeks, and finally they took part in a focus group.

## Scotty

In the Scotty project a social robot was tested in practice, to evaluate its usefulness for current healthcare settings. For the part of the project that relates to my thesis, two studies were conducted. In one case the social robot was situated in the outpatient clinic of a rehabilitation centre, while the other study was situated in different departments at a nursing home. In both cases, there was collaboration with the participating institutions to shape the research and research questions.

# Chapter 2

The literature review in the following chapter gives an overview of eHealth action research projects. The context of these studies is described, and best practices and lessons learned are highlighted. Many of the points discussed in this chapter are investigated in more detail in the next parts and chapters.

**Abstract**

**Background:** Action Research (AR) is an established research framework to introduce change in a community following a cyclical approach and involving stakeholders as co-researchers in the process. In recent years, it has also been used for eHealth development. However, little is known about the best practices and lessons learned of utilizing AR for eHealth development.

**Objective:** This literature review aims to provide more knowledge on best practices and lessons learned from eHealth AR studies. Additionally, an overview of the context in which AR eHealth studies take place is given.

**Methods:** A semi-systematic review of 44 papers reporting on 40 different AR projects was conducted to identify best practices and lessons learned in the research studies while taking into account the particular contextual setting and used AR approach.

**Results:** Recommendations include attention for the training of stakeholders' academic skills, as well as the various roles and tasks of action researchers. The studies also highlight the need for constant reflection and for accessible dissemination suiting the target group.

**Conclusions:** The literature review identified room for improvements regarding communicating and specifying the particular AR definition and applied approach.

## Introduction

The way healthcare is organized and carried out is of great societal concern, as it affects our quality of life. Hence, healthcare systems and eHealth technologies used to support healthcare should be designed in a way that meets the needs and expectations of their stakeholders. One way of doing this is Action Research (AR). According to Bradbury and Lifvergren (2016), AR in healthcare "seeks to 1. improve patient experiences and the health of populations, 2. reduce the per capita cost, 3. improve the work-life of those who deliver care, and 4. bring healthcare providers into circumstances that allow for continuous learning together with patients." AR has been used as a research framework in nursing and healthcare, for example, to improve the quality of patient care and to investigate changes in action (Williamson et al., 2012). AR is a collaborative approach, people affected by the change envisioned in the AR become active members of the research team. AR is often used in the design of eHealth systems. However, existing literature reviews of AR in eHealth predominantly focus on the development of new frameworks (Eyles et al., 2016; Greenhalgh et al., 2017; Moore et al., 2019), but not on how eHealth AR is currently carried out. Therefore, the contribution of this paper is a literature review outlining the state of the art of AR in eHealth design.

eHealth projects cover a wide variety of topics and technologies and can therefore greatly benefit patients, professionals and many other healthcare stakeholders. However, to gain the most from eHealth systems and technologies, it is crucial that they match with what is needed in practice (van Gemert-Pijnen et al., 2011). To ensure such a match, van Gemert-Pijnen et al. (2011) suggest, amongst other things, to work together with relevant stakeholders in all stages of the project, to implement the study results in practice, and to continuously evaluate the process. Similarly, co-design has been mentioned as a useful technique for creating eHealth that suits the needs of the end-users (Eyles et al., 2016). These ideas fit well with the principles of AR, which will be outlined below.

Definitions of AR have changed over the years. AR originated with Kurt Lewin et al. (1946), who described it as several consecutive circles of planning, action and reflection. These cycles are shown in Figure 2, which comes from Williamson et al. (2012). In later definitions, the cyclical nature
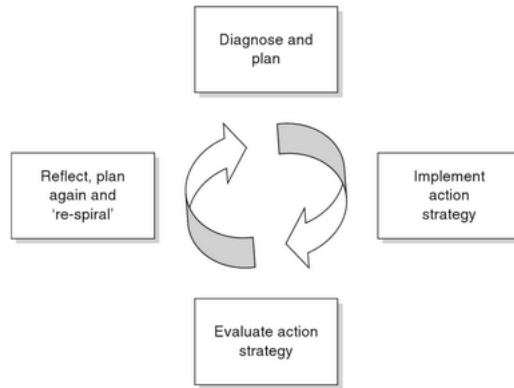
Figure 2: Action Research Cycles. Adapted from Lewin et al. (1946) by Williamson et al. (2012).

of AR remains one of its key features. Reason and Bradbury (2008), who build on Lewin's work, define AR as research that a) involves stakeholders not only as participants but as members of the research team, b) consists of (at least) one cycle of planning, action and reflection, c) establishes direct changes, and then d) evaluates those changes in and with the community. Their Handbook of Action Research (Reason & Bradbury, 2008) includes many interesting examples of AR from various fields. Furthermore, Bradbury and colleagues defined seven "choice points for quality in action research" (Bradbury et al., 2019), criteria which can be used to plan, conduct, report and assess AR projects.

Within AR, different variations exist, for example Action Design Research (ADR) or Participatory Action Research (PAR). Usually, there is agreement on the main principles of AR that were explained above, but some authors or groups emphasize some aspects over others. For example, as the name suggests, ADR incorporates elements of design research into AR (Sein et al., 2011), while PAR highlights the involvement of the community (Coghlan, 2019). For a more detailed overview of similarities and differences between some of these approaches, see for example Williamson et al. (2012) or Coghlan (2019).

AR in general, and AR approaches such as ADR specifically, are similar to participatory design (PD) approaches that are used in human computer interaction (HCI) research. However, AR emphasizes reflection on and learning from the process that was carried out, while the main aim of PD is to create a solution (Hayes, 2011). AR, as opposed to PD, does not start with a clear goal of what needs to be developed, but defines this throughout the process together with stakeholders. Additionally, AR is more immersive and calls for stakeholder involvement for a longer period of time, due to its iterative cycles (Foth & Axup, 2006). Still, in some cases, studies that are described as participatory design also meet Reason and Bradbury (2008)'s criteria for AR (Clemensen et al., 2017). Hayes (2011) argues that AR and HCI research can supplement each other, as both often provide solutions on a local scale.

As Hughes (2008) describes, there is no one standard way of doing AR in healthcare research due to the broadness of the field. Rather, there is a variety regarding the why, how and with whom AR in healthcare is carried out (Cordeiro & Soares, 2018; Hughes, 2008). For example, levels of stakeholder engagement and the context in which AR takes place can vary (Cordeiro & Soares, 2018). Other differences between AR studies include the topic, country, project duration, main target group, and

methods used. These aspects are therefore considered in this review.

The purpose of this review is to give an overview of the current literature on eHealth AR and to summarize the best practices and points of improvement that future eHealth AR projects can learn from. Special attention is paid to contextual variables of the research (e.g., setting, duration, amount of stakeholders) as this is expected to influence the outcomes, best practices and points of improvement of a study. To provide an overview of AR in eHealth, this literature review addresses the following sub questions:

1. What is the context of AR eHealth projects?
2. How do eHealth AR studies define and operationalize AR?
3. What are the best practices of conducting AR in concrete eHealth studies?
4. What are the lessons learned from conducting AR in concrete eHealth studies?

## Method

## Study selection and screening

The search was carried out in June 2020. PubMed, Scopus and Google Scholar were searched using combinations of the search terms "action research" or "participatory design" and "eHealth", "health technology", "digital health" or "telemedicine". PubMed was chosen for its extensive medical database, Scopus and Google Scholar were chosen as large scientific databases. Searching for "action research" turns up articles that include similar and related keywords like "participatory action research", "action design research" or "action-based research". "Participatory design" was included as a search term because PD has significant overlap with AR, and both are sometimes used to supplement each other. The list of synonyms for "eHealth", while not exhaustive, is expected to cover the various facets of the field. The initial search yielded 739 results. Articles were included if they 1) used and explicitly mentioned AR and 2) were about eHealth or health technology. Papers were excluded when they 1) were not written in English, 2) only included a study protocol but did not report results or 3) only included a review of other articles. Two authors (KO & CG) both did a full text screening of the same 15 articles and discussed whether to include them until an agreement was reached. After that, the first author screened the full text of the remaining articles, with some exceptions where a second opinion was necessary. These were again discussed between the first and second author until an agreement was reached. Ultimately, 44 articles were included, reporting on 40 different projects (see Figure 3 for the full inclusion flow).

## Data extraction

For each study, the definition of AR that was provided by the authors, and the related AR approaches they cited (if any) were extracted. Additionally, information about contextual variables of the study was derived. Specifically, we identified the topic, country, organisational context, project duration, types of stakeholders involved, the main target group of the research, and methods used. The types of involved stakeholders were grouped according to the framework described by Schiller et al. (2013), in which they define the main stakeholder categories as public, policymakers and governments, research community, practitioners and professionals, Health and social service providers, civil society organizations, and private business. Finally, best practices and lessons learned were derived. Both best practices and lessons learned were activities that could move forward and benefit the AR project, without necessarily being recognised as standard components of AR. The difference between what
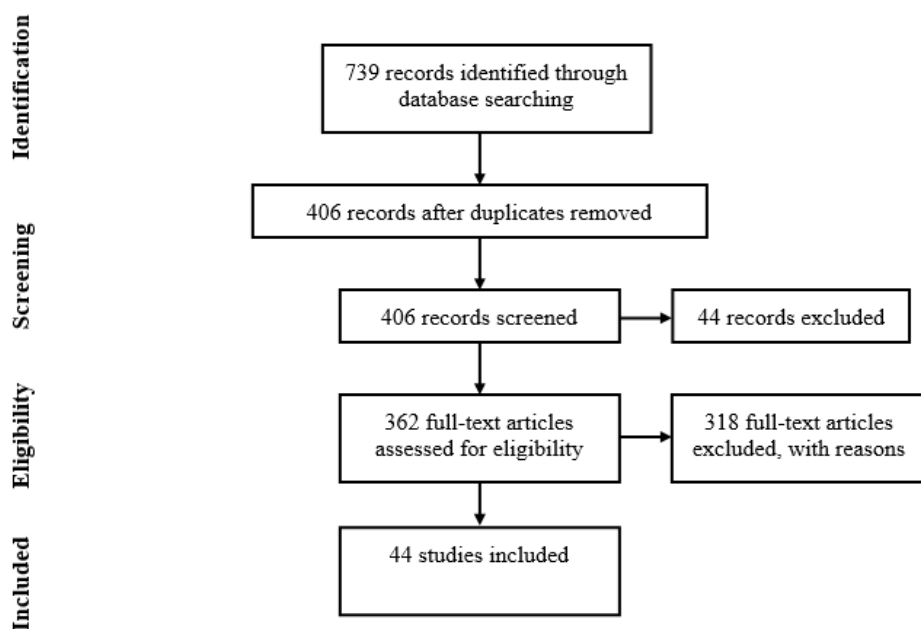
Figure 3: Inclusion flow for the literature review search and screening.

was seen as best practice and what as lesson learned was based on the timing and reporting of these actions. An activity was labelled as best practice if researchers already planned their project with this in mind (e.g. mention it in the description of methods). On the other hand, lessons learned were those points that researchers came to know during their project, which were reported mainly in the discussion section. Two authors (KO & CG) extracted best practices and lessons learned from the first five articles and compared their results. The remaining data extraction was done by one author (KO) in consultation with the second author where a second opinion was necessary.

Five authors published not one but two papers about their project. For these papers, the study context was reported as one, while the definition of and approach to action research and the best practices and lessons learned were reported separately, as these sometimes differed between the articles. One article included a reflection on two projects. In this case, each project context was reported separately while only one AR definition and approach as well as one set of best practices and lessons learned are outlined.

## Synthesis

A general overview of all included studies describing AR approach, AR definition and contextual variables was made. The contextual variables (topic, location, target group, stakeholders, duration and methods used) were categorised. Furthermore, the studies were mapped in a matrix based on study duration and the types and number of different stakeholders that participated in the study. The contextual data were coded and categorized inductively. To identify which AR approach was used most, the citation frequency of each approach in the included studies was counted. Furthermore, the cited AR approaches that were available were accessed and checked for cross-referencing. All cited AR definition were mapped to show the relationship between them. The AR definitions used, best practices and lessons learned were coded by one author (KO). Best practices and lessons learned were coded individually first and then combined for both categories.

## Results

## Context

The setting of the included studies was described based on six categories (topic, location, duration, involved stakeholders, target group and methods). A table showing all categories and the description of the setting for each study can be found in Appendix 2.1. The most common aspects for each category will be discussed below.

### Topic

Nine broader categories of research topics were identified (see Appendix 2.2 for full list). The most common were home care and telemonitoring, and health promotion and education (both n=8), followed by electronic medical records (EMR) and health information systems (n=7) and mental health services (n=5).

### Location

The studies were set in 21 different countries, Australia being the most common (n=5) followed by the United States (n=4) and Canada, Sweden and the United Kingdom (all n=3). Some studies from

non-Western countries, like Tanzania or Colombia were included, but no country was represented more than once or twice. Within the different countries, studies took place in various contexts, the most prevalent of which were rural areas (n=6) and hospitals (n=5). All countries and contexts can be found in Appendix 2.2.

## Target group

Two studies explicitly focused on two different target groups at the same time, while all other studies had one main target group. In most cases, the target group were patients (n=11). Of these, the most common group was patients with Cancer (n=3). There were six studies focused on clinicians, as well as six on youth, and five studies targeted older adults (see Appendix 2.2 for the full list of target groups).

## Stakeholders

In many cases, several stakeholders were included in the study, in some cases up to six different types of stakeholders. In sum, 20 different types of stakeholder were involved (see Appendix 2.2 for the full list). Health care workers (n=18) and patients and patient representatives (n=12) were involved most, followed by governmental bodies (n=9) and general, non-medical staff members (n=8). When clustering these stakeholder types according to the framework defined by Schiller et al. (2013), the biggest group consists of practitioners and professionals (n=48), followed by members of the public (n=38). Policymakers and government (n=13), research community (n=10), private business (n=6) and civil society organisations (n=3) were represented less often. The only group that was not represented at all are health and social Service Providers.

## Duration

Not all studies reported the duration of the project (n=7). Studies that did report the duration (n=33) lasted from a few months (n=5) to more than ten years (n=2). The majority (n=13) of these studies reported a project duration between two and three years and the average project duration was 2.7 years.

Figure 4 shows the distribution of the ten most frequently involved types of stakeholders for the different project durations in the 33 projects that reported project duration. Stakeholder types are shown in order of how many times they were involved in total, but since some studies did not report project durations the numbers in this graph differ from those described above. The two biggest stakeholder groups, health care workers and patients, were rarely, or in the case of patients even not at all, involved in long term studies.

In Figure 5 the study duration is shown mapped against the number of different stakeholders that were involved in each of the 33 projects that reported a project duration. Studies that did not report the overall project duration were not included in the figure. Most of the included studies lasted for up to two years, including two or three stakeholder groups. There are some examples of longer studies including more stakeholder groups.

| | Duration 0-1 year | Duration 1-2 years | Duration 2-3 years | Duration 3-4 years | Duration 4-5 years | Duration 5-6 years | Duration 6-7 years | Duration 7-8 years | Duration 8-9 years | Duration 9+ years |
|---|---|---|---|---|---|---|---|---|---|---|
| Health care workers | 5 | 2 | 4 | 2 | 1 | | | | 2 | |
| Patients and patient representatives | 2 | 1 | 3 | 3 | 2 | | | | | |
| Governmental body/local authority | 1 | 2 | | | | | | | 1 | 1 |
| Citizens | 1 | 1 | 2 | 1 | | | | | | 1 |
| Other staff members | 2 | | 2 | 1 | | | | | | |
| Specialists | | 2 | 2 | 1 | 1 | | | | | |
| Family/relatives | | | 2 | 1 | 1 | 1 | | | 1 | |
| Research team | | | | 1 | 1 | | | | 1 | |
| Nurses | | 3 | | | | | | | | 1 |
| Youth | 2 | | 1 | | | 1 | | | | 1 |

| Number of studies in each category | | | | | |
|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

Figure 4: Heat map showing the most commonly involved types of stakeholders against the project duration.

| | Duration 0-1 years | Duration 1-2 years | Duration 2-3 years | Duration 3-4 years | Duration 4-5 years | Duration 5-6 years | Duration 6-7 years | Duration 7-8 years | Duration 8-9 years | Duration 9+ years |
|---|---|---|---|---|---|---|---|---|---|---|
| 6 stakeholder groups | | | | | | | | | 1 | |
| 5 stakeholder groups | | | | 2 | | | | 1 | | |
| 4 stakeholder groups | 2 | 2 | 2 | | | | | | | |
| 3 stakeholder groups | 4 | 1 | 2 | | | 1 | | | | 2 |
| 2 stakeholder groups | 3 | 6 | 1 | | | | | | | |
| 1 stakeholder group | 2 | | 1 | | | | | | | |

| Number of studies in each category | 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|---|

Figure 5: Heat map showing the number of stakeholders involved against the project duration.

Chapter 2

**Methods**

As mentioned earlier, AR is a framework that does not advise the use of a single methodology, and studies can therefore include a variety of different research methods. Most included studies indeed used several methods, with some studies employing up to six different methods. Interviews were used most frequently (n=24), followed by focus groups (n=22), workshops (n=14) and surveys (n=13). On average, studies used nearly three different methods (average 2.8). All methods can be found in Appendix B6.

## AR definitions

Forty-four definitions of AR were given in the articles. They could be grouped according to four different aspects they emphasized. First, twenty-one studies emphasized that in AR projects practitioners and other stakeholders become (co-)researchers (n=21). Second, AR is a cyclical process that includes different stages (n=19). Third, fourteen studies described how AR includes both the focus on solving a practical issue and the aim to extend research knowledge. The fourth aspect was that AR takes place in a community setting (n=10). Two studies included three of these aspects in their definition, and only two other studies mentioned all four aspects. Most studies included either one (n=16) or two (n=17) of the aspects, while seven studies included none of these points in their definition, or did not at all define AR in detail. An overview of the number of mentions per aspect, including the reference, can be found in Table 1.

Table generated by Excel2LaTeX from sheet 'Tabel 1'

## AR approaches

Table 2 shows an overview of the AR approaches that were cited at least twice in the included articles. Four studies did not cite an action research approach. In some cases, different papers from the same authors were cited, but as these eventually described the same approach, the citation count was added up. The most commonly cited approach was proposed by Reason and Bradbury (2008). As described above, the key elements of this approach are that AR a) involves stakeholders as co-researchers, b) consists of plan, act and reflect cycles, c) makes a change in practice, and d) evaluates said changes in and with the community. Overall, most definitions share these main aspects, but differ in terms of which aspects are particularly emphasized. For example, Baskerville and Myers (2004) highlight the duality of practical work and scientific knowledge, whereas Baum et al. (2006) underline the need for reflective practice that includes all stakeholders. Figures 5 and 6 look at the cited approaches in more detail. There are three independent researchers or groups that are mentioned as being the origin of AR: Lewin et al. (1946), Trist (1976) and colleagues, and Freire (1970). Where an origin of AR was mentioned, some cases named two of these (see Figure 6). The cited AR approaches also frequently refer to each other and sometimes authors collaborate with each other, for example on books about AR (see Figure 7). There are no very distinct groups doing their own kind of action research, rather, the different AR groups are often connected and build upon each other's work.

## Best practices and lessons learned

As previously described, an activity was identified as "best practice" if researchers already planned their project with this in mind (e.g. mention it in the description of methods). Lessons learned were those points that researchers came to know during their project. These were mostly reported in the

| Aspect of the AR definition | Number of articles that define AR including this aspect (N=44) | References |
|---|---|---|
| Practitioners and other stakeholders are (co-) researchers | 21 | Asangansi and Braa (2010), Bishop et al. (2003), Byrne and Sahay (2007), Callén et al. (2009), Chipps et al. (2012), Dansky et al. (1999), Day et al. (2016), Fennell et al. (2017), Hansen et al. (2008, 2013), Heffernan et al. (2016), Katibeh et al. (2019), Lehto (2017), Molapo et al. (2016), Raij (2016a), Rendón et al. (2005), Rönkkö (2018), Taylor et al. (2015), Thobias and Kiwanuka (2018), and VanHeerwaarden et al. (2018) |
| Cyclical process including different stages | 19 | Alexander et al. (2015), Andersen et al. (2011), Callén et al. (2009), Chipps et al. (2012), Day and Kerr (2012), Day et al. (2016), Hansen et al. (2008), Lehto (2017), Molapo et al. (2016), Norman and Skinner (2007), Park et al. (2017), Phanareth et al. (2017a), Rendón et al. (2005), Rönkkö (2018), Simm et al. (2016), Street et al. (2007), Trondsen and Sandaunet (2009a), VanHeerwaarden et al. (2018), and Webb et al. (2018) |
| Aim to solve a practical problem and extend academic knowledge | 14 | Andersen et al. (2011), Byrne and Sahay (2007), Callén et al. (2009), Fennell et al. (2017), Gaur et al. (2017), Hansen et al. (2008, 2013), Heffernan et al. (2016), Lundberg et al. (2010), Park et al. (2017), Raij (2016a), Stensæth and Ruud (2014), Trondsen and Sandaunet (2009a), and Waterman et al. (2007) |
| Research takes place in a community setting | 10 | Berger and Peerson (2009), Bishop et al. (2003), Callén et al. (2009), Hansen et al. (2008, 2013), Holeman and Kane (2020a), Kimaro and Twaakyondo (2005), Lehto (2017), Taylor et al. (2015), and Thobias and Kiwanuka (2018) |

Table 2: Number of mentions and references for each aspect of the AR definition.

| Author(s) | # Author citations | References | AR Approach Paper(s) |
|---|---|---|---|
| Peter Reason & Hilary Bradbury | 8 | Day et al. (2016), Gaur et al. (2017), Lehto (2017), Street et al. (2007), Taylor et al. (2015), Trondsen & Sandaunet (2009) | Bradbury-Huang (2010), Reason & Bradbury (2013), Reason & McArdle (2004) |
| Robert N. Rapoport | 4 | Andersen et al. (2010), Day et al. (2016), Fennell et al. (2017), Gaur et al. (2017) | Rapoport (1970) |
| David Avison and colleagues | 3 | Gaur et al. (2017), Andersen et al (2011), Lundberg et al. (2010) | Avison et al. (1999) |
| Richard L. Baskerville and colleagues | 3 | Hansen et al. (2008), Park et al. (2017), Thobias & Kiwanuka (2018) | Baskerville (1999), Baskerville & Myers (2004), Baskerville & Wood-Harper (1996) |
| Jørn Braa, Eric Monteiro & Sundeep Sahay | 3 | Asangansi & Braa (2010), Holeman & Kane (2020), Kimaro & Twaakyondo (2005) | Braa et al. (2004) |
| Stephen Kemmis & Robin McTaggart | 3 | Bishop et al. (2003), Street et al. (2007), Waterman et al. (2007) | Kemmis & McTaggart (1988) |
| Fran Baum, Colin MacDougall & Danielle Smith | 2 | Berger & Peerson (2009), Molapo et al. (2016) | Baum et al (2006) |
| Bob Dick and colleagues | 2 | Day et al. (2016), Street et al. (2007) | Dick (2001), Shankar et al. (2002) |
| Max Elden & Morten Levin | 2 | Berger & Peerson (2009), Byrne & Sahay (2007) | Elden & Levin (1991) |
| Colin Robson | 2 | Hansen et al. (2008), Hansen et al. (2013) | Robson (2002) |
| Harvey A. Skinner, Oonagh Maley & Cameron D. Norman | 2 | Norman & Skinner (2007), Skinner et al. (2006) | Skinner et al. (2006), Skinner (2002) |
| Gerald I. Susman & Roger D. Evered | 2 | Hansen et al. (2008), Park et al. (2017) | Susman & Evered (1978) |
| Elizabeth Hart | 2 | Dansky et al. (1999) | Hart (1995), Hart (1996) |
| Gillian R. Hayes | 2 | Ferrario et al. (2016), Simm et al. (2016) | Hayes (2011) |

Table 3: Overview of the most cited AR approaches in the included articles per author, including the number of citations.
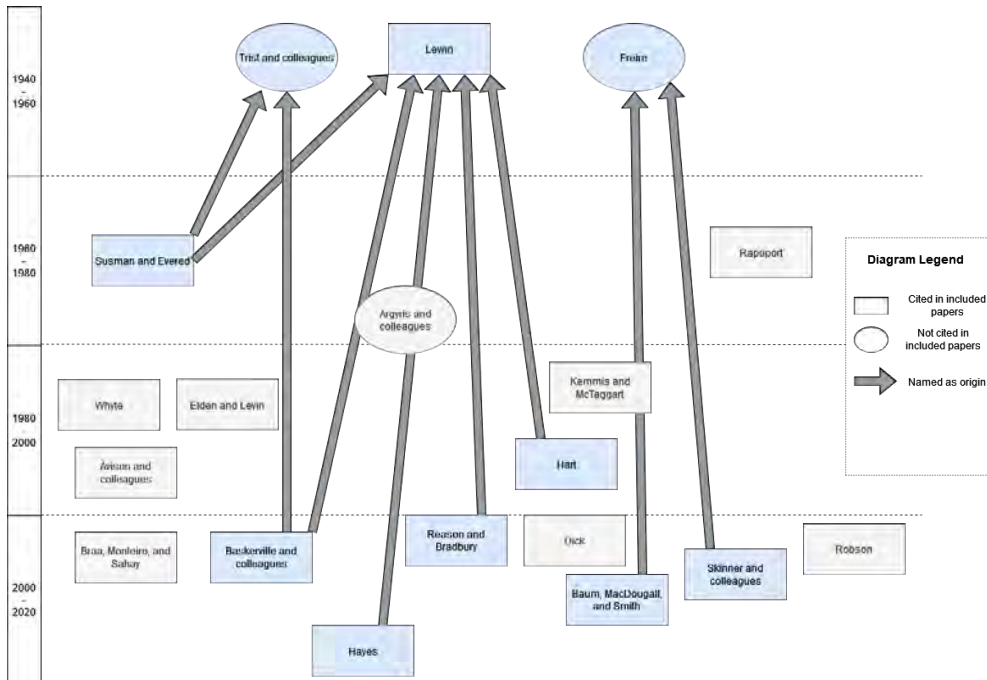
Figure 6: Overview of the AR approaches referred to in the included articles, indicating those papers that are mentioned as "the origin" of AR. Studies that either name an approach as being the origin of AR, or are being named as such, are highlighted in blue for better readability.
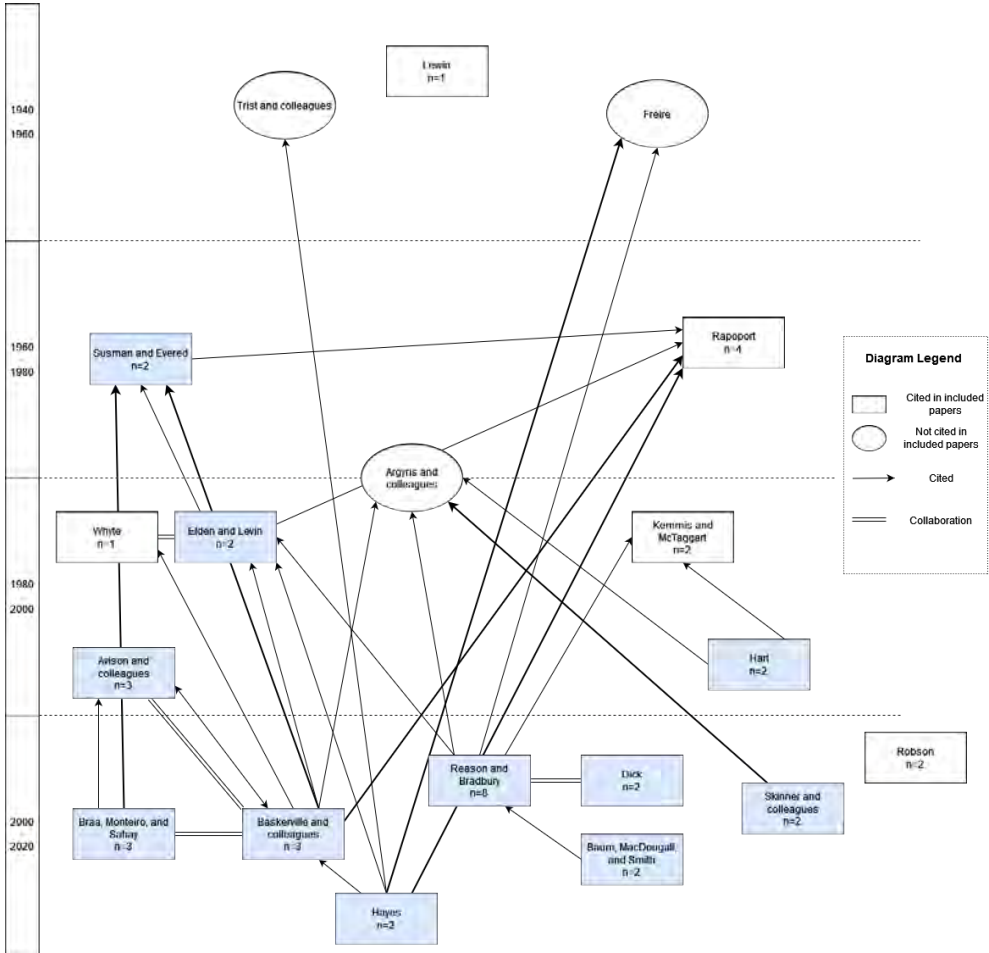
Figure 7: Overview of AR approaches referred to in the included articles. Arrows indicate citations between the AR approach papers; the number of how many of the articles included in this review cited each approach is indicated in the box). Different arrow thicknesses were used for better readability. Blue boxes indicated those papers that were available and checked for citations.

discussion section. In total, 85 best practices and 66 lessons learned were identified, which were clustered into 22 categories of best practices and 16 categories of lessons learned were. Three papers did not indicate any best practices that they followed, while twelve papers did not include any identifiable lessons learned. There were eight overlapping categories, identified as a best practice in some articles and as a lesson learned in others. These will be discussed in more detail below.

## Best practices

The identified best practices were most often related to the use of a specific method (n=9), namely personas (n=2), world café, journey mapping, role play, scenarios, case studies, design cards and mixing different types of data collection (all n=1). Other best practices were a continuous evaluation of the project and a reflection on the process by the research team (n=8). Seven studies emphasised the importance of establishing active contact between researchers and stakeholders, and raising confidence and skills of stakeholders. The improvement of stakeholder skills mainly referred to research and analytical skills, allowing stakeholders to set up their own studies or continue the work after the project has finished. There were several specific suggestions to improve the regular project team meetings, for example, to always use the same agenda or to share a common (office space) to make contact easier. Some other best practices concern the reporting and presentation of outcomes (n=6). The complete list of best practice categories can be found in Table 3.

## Lessons Learned

Next to the best practices, lessons learned from each study were identified. The most common lessons learned were increasing stakeholder knowledge and skills (n=8) and continuous evaluation of the project and reflection on the process (n=6). Both of these had been identified as best practices in other articles (more on this overlap below). Recommendations for the use of specific methods were also common (n=5). Lessons learned regarding reporting, adapting the project to fit the needs of stakeholders, fostering a welcoming environment and the questionable replicability of the research were each mentioned four times. All lessons learned are shown in Table 4.

## Overlapping best practices and lessons learned

As stated before, some aspects were identified as a best practice in some articles and as a lesson learned in others. In total, we identified seven of such overlapping aspects. Overall the most mentioned was the importance of raising stakeholder skills and confidence (Total (T): n=15, Best Practices (BP): n=7, Lessons learned (LL): n=8). Many articles reported the need of stakeholders to learn new skills, for example related to academic research, or the need to be convinced of their ability to perform these tasks. Almost all of the studies that reported this as best practice or lesson learned involved health care professionals as stakeholders. Other commonly mentioned points were recommendations for specific methods, even though the suggested methods differed (T: n=14, BP: n=9, LL: n=5) and the continuous reframing and evaluation of the project (T: n=14, BP: n=8, LL: n=6). Continuous reframing often referred to the iterations of planning, action and evaluation in the AR projects. Studies that described this mostly did not include this cyclical nature of AR in their definition of it. In total there were ten recommendations regarding the reporting and presentation of results (BP: n=6, LL: n=4), for example calling for open and accessible publishing of outcomes. Both best practices and lessons learned included recommendations about meeting regularly (T: n=9, BP: n=7, LL: n=2), adapting to the needs of stakeholders (T: n=8, BP: n=3, LL: n=5), and investing in the relationship between partners (T: n=6, BP: n=3, LL: n=3).

**Chronology of overlapping best practices and lessons learned**

When looking at the publication timeline, most of the overlapping aspects appeared as a lesson learned in earlier publications, and then as a best practice in papers published at a later point in time. This was the case regarding stakeholder skills (LL e.g. Dansky et al. (1999) published in 1999; BP e.g. Raij (2016b) published in 2016), continuous reframing of the project (LL e.g. Bishop et al. (2003) published in 2003; BP e.g. Trondsen and Sandaunet (2009b) published in 2009), having regular meetings (LL e.g. Skinner (2002) published in 2006; BP e.g. Rönkkö (2018) published in 2018) and adapting the research to stakeholder needs (LL e.g. Byrne and Sahay (2007) published in 2007; BP e.g. Ferrario et al. (2016) published in 2016). Such a clear timeline could not be seen for accessible reporting (LL e.g. Phanareth et al. (2017b) from 2017; BP e.g. Norman and Skinner (2007) from 2007) and the relationship between partners (LL e.g. Fennell et al. (2017) from 2017; BP e.g. Hansen et al. (2008) from 2008).

## Discussion

## Principal results

To identify recommendations on how to do AR in eHealth studies, this literature review looked at the setting, AR description and best practices and lessons learned of 44 papers. The most important recommendations from this review, which will be discussed in more detail below, are:

- Actively raising stakeholder skills and confidence
- Fulfilling multiple roles and tasks as a researcher
- Fostering constant reflection and evaluation
- Ensuring open and accessible dissemination
- Reporting in a more structured and extensive way

These recommendations are not exclusively related to eHealth, despite them being derived from a review of eHealth AR studies. So, it is possible that the recommendations are also relevant for AR in various other fields. Therefore, where possible, examples from different disciplines are shown below to explain or supplement a recommendation.

## Stakeholder skills and confidence

Being involved in a project as co-researcher can potentially increase a stakeholder's confidence, alongside teaching them new skills (Baldwin et al., 2018). However, this does not happen automatically. Similar to our findings, the narrative review conducted by Harrison et al. (2019) also identified education of the research team as the most important task when stakeholders are involved in healthcare research. Still, there is little research about how skill training for stakeholders could look like, and this can vary greatly between studies. Stakeholders in some eHealth studies might need to learn content-related information (Tomlinson et al., 2018), while other studies require methodological or statistical skills (Kimaro & Twaakyondo, 2005). Researchers should provide adequate training and material for their project, and encourage stakeholders to make use of it. The studies included in this review which recommended stakeholder skill training almost exclusively worked with health care professionals. The relation between recommending skill training when working mainly with health care professionals remains unclear. One explanation could be that other stakeholder groups in other studies already had the necessary skills and thus did not require any additional training. Another possibility is that other stakeholders were not given the same roles that health care professionals held, and therefore

| BEST PRACTICES CATEGORY | # MENTIONS OUT OF 44 | |
|---|---|---|
| **Process** | | |
| Recommends specific method | 9 | |
| Personas | | 2 |
| World Café (n=1); Journey Mapping(n=1); Role Play (n=1); Scenarios (n=1); Case Study (n=1); Design Cards (n=1); Abstract vs. personal methods of data collection (n=1) | | 7 |
| Continuous evaluation / reflection | 8 | |
| Report / present results | 6 | |
| Share resources and findings (online) allowing others to benefit from it | | 4 |
| Present findings to community / target group in a suitable manner | | 2 |
| Start with close examination of context (observation and literature) | 5 | |
| Agile development / scrum | 3 | |
| Combining AR with Randomized Controlled Trial (RCT) | 2 | |
| It is advisable to combine these two | | 1 |
| Keep line between stakeholder and researcher blurred, don't do RCT | | 1 |
| Gradual scaling up | 2 | |
| Immediately resolve problems / apply lessons learned | 2 | |
| **Stakeholder and Relationship** | | |
| Frequent / regular (face-to-face) meetings, active contact (e.g. shared space), same transparent agenda | 7 | |
| Raise stakeholder confidence and skills (e.g. analytical) (for example so they can set up own studies) | 7 | |
| Clearly define role of each partner (equal involvement is not always good) | 5 | |
| Find committed stakeholders with intrinsic motivation (that can carry on with the project after the researchers have left) | 5 | |
| Reference group (with technical, juridical and clinical expertise) | 4 | |
| Step in each other's shoes (experience other's tasks, familiarize with what the other does) | 3 | |
| Invest in relationship between partners (also non-work activities) | 3 | |
| Adapt method / schedule to needs of stakeholders | 3 | |
| Neutral position of the researcher (no steering or predetermined outcomes; rather communication link) | 3 | |
| Patient / Stakeholder generated content (e.g. persona's) | 2 | |
| Different disciplines | 2 | |
| **Context and Environment** | | |
| Living labs as context for AR | 2 | |
| Actively encourage pilot participation | 2 | |
| Attention for economic / business values | 3 | |

Table 4: Overview of all best practice categories and number of mention per category.

| LESSON LEARNED CATEGORY | # MENTIONS OUT OF 44 | |
|---|---|---|
| **Process** | | |
| Continuous reframing / renegotiation (flexibility), baby steps | 6 | |
| Recommend specific method | 5 | |
| Field work (n=1); RCT (n=1); Case study (n=1); Action circles (n=1); Fun methods (quiz, game, puzzle) as learning opportunity (n=1) | | 5 |
| Reporting | 4 | |
| Open source | | 2 |
| Higher level of sophistication necessary (n=1); Also include non-project target group (n=1) | | 2 |
| Integration of literature | 3 | |
| Regular meetings to check on progress and motivate the stakeholders ('reality check') | 2 | |
| Triangulation of data to decrease biases | 2 | |
| End of an AR project | 2 | |
| Accompany stakeholders until they find that the process is done (n=1); AR can lead to other collaborative activities (n=1) | | 2 |
| Commitment to AR necessary (e.g. through specific funding) | 1 | |
| Ethical restrictions | 1 | |
| Immediate reflection impossible | 1 | |
| **Stakeholder and Relationship** | | |
| Raise stakeholder confidence and skills, knowledge sharing | 8 | |
| Tailor to needs of stakeholders | 4 | |
| Include AR in work schedule (n=1); Researchers take over some of the stakeholders' usual tasks to make schedule less busy (n=1); Adequate feedback methods (n=1); Identify unique strengths (n=1) | | 4 |
| Invest in relationship between partners | 3 | |
| Accept that participation is different for everyone and can change over time | 3 | |
| Communication | 2 | |
| Language barrier (n=1); Find common language (n=1) | | 2 |
| Enthusiastic local 'champion' to start the project and help keep people motivated | 2 | |
| Involve authorities / local government (address issues at multiple levels) | 2 | |
| Actively break down power structure | 1 | |
| **Context and Environment** | | |
| Foster positive, welcoming environment for change | 4 | |
| Questionable replicability | 4 | |
| Researcher is actively involved and present in environment | 2 | |
| Draw attention to External influences | 1 | |
| Ethical issues | 1 | |
| Diffusion of innovation | 1 | |
| Organisational expectations | 1 | |

Table 5: Overview of all lessons learned categories and number of mention per category.

did not need the skills training. Finally, as we will discuss later on, reporting of AR activities was not always very extensive, so it could be the case that stakeholders from outside healthcare were trained, but that studies did not report on this. Generally, it should be noted that not all participants prefer the same level of engagement in a project and that the researchers should respect these preferences (McNeil et al., 2016).

## Tasks and roles of the researcher

Different aspects of the role and tasks of the researcher in an AR project were discussed. Brydon-Miller and Aragón (2018) describe the many different tasks that action researchers need to fulfil as their '500 hats'. These are not specific to eHealth studies, but can occur in any AR study. As researchers and stakeholders both have many varied duties, their roles are not fixed and might change over the course of the project (Bishop et al., 2003). One main task of the researcher that continues throughout the project is the need to foster a welcoming environment for all stakeholders Trondsen and Sandaunet (2009b). Researchers should also be present and actively involved themselves, more so than is necessary in other, non-AR projects (Hansen et al., 2008). Additional, AR specific tasks for the researchers include investing in partner relationships (Day et al., 2016) or breaking down power structures (Taylor et al., 2015). Generally, AR studies demand more self-reflection and awareness of the researchers than other projects and researchers should keep this in mind when entering an AR project.

## Constant reflection

The importance of continuous reframing and evaluation of the project was emphasized in several studies. While evaluation is one of the AR cycles, studies that made recommendations on this topic rarely included this in their definition of AR. Due to the lacking reporting of AR, which will be discussed below, it is unclear if they still followed the AR cycles without reporting on them. However, it seems that sometimes periodic planned evaluation is not enough. Rather, the participants need to regularly reflect on the current status of the project and their role in it. New AR projects should therefore create suitable spaces for evaluation and reflection, in ways that fit their project and stakeholders. This is especially important because reflection can get difficult once you are in the middle of the project (Lundberg et al., 2010). Holeman and Kane (2020b) emphasize that reflection should not only take place within the project, but should be explicitly reported to help other researchers. If action researchers take reflection seriously and include honest evaluations in their publishing, the AR community can learn from each other. Additionally, researchers and other stakeholders within the project also learn and benefit from this reflexivity themselves (Bradbury et al., 2019).

## Accessible dissemination

Another important aspect concerns the attention for open and understandable dissemination of results, both within the community and amongst researchers. Action researchers need to communicate findings to the academic world, while also finding ways to inform the target group about the project in ways that suit the target user's needs. An example of open source, accessible dissemination can be found in Canto-Farachala and Larrea (2022). They present the results of their AR project in territorial development on an interactive website, allowing others to learn from their work. However, it seems that accessible reporting is still not the norm in AR, as Avison et al. (1999) describe that generally, many AR studies are "published in books rather than in articles. Action researchers have large and complicated stories to tell". Future AR projects should make an effort to tell their stories in such a way that allows others to learn from them.

## Comprehensive reporting

The different way of describing AR studies also leads to another issue: incomplete and elusive reporting. While most studies did give at least a short description of what they saw as AR, seven studies provided no definition at all. Additionally, there were only four studies that included three or all of the four aspects of the AR definition in their description. Even the most mentioned aspects appeared in less than half of the included papers. Also, while most papers did cite an AR approach of definition, some did not. In combination with the often limited descriptions of AR, this makes it difficult to get a good picture of how AR is seen and performed in the particular study. This resonates with what Bradbury et al. (2019) describe as one of the quality points of AR, that "action research process and related methods [should be] clearly articulated and illustrated".

The best practices and lessons learned that were extracted from the included studies were seldom mentioned explicitly. Best practices were often hidden in the description of the project, without much reasoning. Similarly, lessons learned were often described as adaptions made during the project, or as plans for the future. While we saw that some lessons learned turned into best practices over time, we think that researchers could benefit more from each other's work by giving concrete recommendations. This review aims to take a step in that direction.

Both aspects show that the reporting of AR studies in eHealth can be improved to show more clearly what eHealth AR projects can look like and to help others in setting up such projects with specific recommendations.

## Limitations

Around a third of the included papers (14 out of 44) were published more than ten years ago. This also means that some of the technologies that are described in the older papers are relatively old. However, this literature review focuses mainly on the AR methodology and lessons learned about doing action research. Therefore, there was no exclusion criterium regard the publication date of the papers.

The search resulted in several papers from the participatory design literature. These papers could have been included, given that some definitions of PD are very similar to AR Clemensen et al. (2017), and fit Reason and Bradbury (2008) definition of action research. However, as our aim was to give an overview of how AR is done, these were excluded as the researchers of these studies themselves did not identify their studies as being action research (i.e. not referring to AR, mentioning or describing AR). While this gives a more clear picture of how researchers conduct AR, it also creates a potential limitation in that best practices and lessons learned could be enriched from PD literature.

The overview of AR approaches focuses mostly on interconnectedness among the approaches, without a more in-depth comparison of the content. Comparing the approaches with regards to the specific aspects of AR that they describe would be a review in and of itself, going beyond the scope of this current review. Rather, we decided to focus on the definitions that the authors themselves gave, even when they also cited AR approaches, as these are most likely to reflect their own vision on AR.

## Conclusions

This review illustrates how AR is conducted in eHealth literature. Studies that fulfilled the inclusion criteria mainly took place in Western countries and lasted for two to three years. Different stakeholders were involved, but the most commonly involved groups were health care professionals and patients. As for the methods used, most studies opted for focus groups and interviews. While many studies cited the AR approach by Reason and Bradbury (2008), their own definitions of AR were often not explicit on how they implemented AR. Future projects should report their AR definition as

well as best practices and lessons learned more clearly. Other recommendations include the attention for skills and confidence of the stakeholders, being aware of the changing role of the researcher, frequently evaluating the project and disseminating results in an adequate, understandable fashion.

# Part 2

# Engaging relevant stakeholders

This part focuses on the first question in the title of this thesis: 'who?' The chapters in this part look at the different roles and levels of involvement in a project. Based on the findings, recommendations are provided for involving different stakeholders on various levels in a project.

# Chapter 3

The engagement of stakeholders does not take shape if researchers do not involve them and share some of their power. Therefore, to begin this part we first look at how researchers perceive action research, and which benefits and risks they foresee. The chapter concludes with some recommendations to support researchers in their (first) action research project.

Chapter 3

## Abstract

Action Research (AR) is increasingly used as a participatory approach in eHealth research. However, many researchers in the field are new to the approach and AR can differ from the methodological frameworks they are used to. It is unclear how eHealth researchers who are new to AR perceive the approach and whether they are able to implement it in their research. In this mixed-methods study, novices' attitudes towards AR and their expectations about its risks and benefits were investigated. This was done in interactive workshops, followed by semi-structured interviews. In general, participants were positive about the approach, and were able to relate it to their research practices. Their perceptions of AR were in line with definitions of AR. Knowledge sharing was found to be an important factor in familiarizing them with AR, and a reflection on the methods used was included to help future projects structure such knowledge sharing.

## Introduction

Action Research (AR) is a form of participatory research, that is often said to have originated with the work of Lewin (1946). AR's key principles are that (1) there need to be several iterations of planning, action and reflection, (2) stakeholders are involved as co-researchers, (3) the action takes place within a community, and (4) a practical problem should be tackled while simultaneously adding to scientific knowledge (Reason & Bradbury, 2007). When doing AR and following these key principles, researchers need to be reflective of and flexible in their behaviour, as they have to fulfill many different roles and perform a variety of tasks, like educating, advocating or mediating (Brydon-Miller & Aragón, 2018).

Historically, AR has mainly been used in educational research. However, it is increasingly adopted in healthcare research, and specifically eHealth research, in recent years (Bradbury & Lifvergren, 2016; Hughes, 2008). Such eHealth AR projects differ a lot, but a recent literature review identified certain patterns (Oberschmidt et al., 2022). Firstly, most published eHealth AR studies were done in Western countries and typically lasted between two and three years, with a few projects lasting either only a few months or much longer (e.g., 10 years) (Oberschmidt et al., 2022). eHealth AR can involve a vast variety of stakeholders, but according to the literature review health care professionals and patients were involved the most, and patients were often the target group of the project. Usually, (combinations of) different and sometimes unconventional methods are used, but focus groups and interviews were the most common (Oberschmidt et al., 2022).

There are many benefits to implementing AR in eHealth research for the development, implementation and evaluation of new technologies. Because AR actively involves different stakeholders and aims to create change in a community, the outcomes of AR projects are usually more aligned with the goals and needs of the target group (Austin et al., 2021). This way, AR can achieve a positive change, both on a small community level and in a bigger context (Austin et al., 2021; Reason & Bradbury, 2007). Additionally, the hope is that the outcomes of AR projects (e.g., a changed practice) is sustainable and continues within the community or location where the project took place (e.g., hospital) even after the researchers have left and official funding has ended.

However, there are also drawbacks and challenges when doing AR in eHealth. A more general challenge that action researchers are confronted with is the lack of knowledge sharing about AR projects and inadequate theoretical descriptions of AR in publications. As for the lack of knowledge sharing, even though the extension of scientific knowledge is one of the key elements of AR, projects are not always published in scientific articles, and when this happens, "*many articles describe*

*a process, but few reflect on the research process or challenge underlying assumptions and ways of thinking*"(Kjellström & Mitchell, 2019). Both phenomena make it difficult for other action researchers to learn from the knowledge of their peers. Regarding the challenge of inadequate theoretical descriptions of AR, a review looking at how the key principles of AR are applied in eHealth AR projects found that the given definitions of AR were often lacking, and even missed essential key points (Oberschmidt et al., 2022). For example, stakeholders becoming co-researchers was mentioned only in half of the cases. The cyclical process (planning, acting and reflecting) was described second most frequently, while the duality of solving a practical problem while extending scientific knowledge was even less common (Oberschmidt et al., 2022). The least mentioned principle was that research should take place in practice. No conclusion can be drawn, whether the authors of these eHealth AR studies lack in-depth theoretical understanding of AR, or whether publication constraints have lead to the omission of these details. In any case, novice AR researchers who might be drawn to recent literature to develop their knowledge would miss out on key principles when relying solely on this type of literature.

On the other hand there are challenges for the individual researcher, directly related to their work and project. Those who are new to AR need to adapt their current processes of doing research in many cases. In AR there are different roles, politics and ethics that researchers have to deal with, like the hierarchy and dynamics in the organisation where their research is situated (Coghlan & Shani, 2005). Some researchers might be reluctant to share their power with other stakeholders (Grant et al., 2008). Additionally, AR often takes a lot of time (Grigorovich et al., 2022), not least because the various stakeholders have different notions of what needs to happen (Grant et al., 2008). In order to face these and other challenges that may arise during the project, a theoretical understanding of AR is not sufficient. Researchers who are new to AR need to be able and confident to apply AR in practice, and transfer the theoretical knowledge into concrete steps and actions in their projects.

While in some graduation programs, an introduction to AR is provided, little is known about how researchers in eHealth practice are able to adapt AR when confronted with it for the first time. To investigate this, we introduced eHealth researchers to AR and documented their theoretical understanding and initial ideas for implementation. By sharing findings we hope to support others who wish to learn more about AR and use it in their project. Additionally, in line with the focus on reflexivity in AR, we include a reflection on our activities in this project and how we facilitated knowledge exchange and understanding of AR. We hope that this can help others who introduce researchers to AR for the first time.

## Aim and Objectives

The aim of this study is to understand eHealth researchers' perception of AR, who have been recently introduced to the methodology (i.e., novice AR researcher) and to identify ways to guide novice AR in future eHealth projects. The study is situated in the context of active and healthy ageing research and its aim will be achieved through two connected objectives. On the one hand, we will investigate whether novice action researchers developed the right theoretical understanding of AR and what attitude towards AR they hold (RQ1). As part of this objective the following sub-questions will be answered:

- RQ1.1 How do novice action researchers define AR?
- RQ1.2 What attitude do novice action researchers hold towards AR?

Second, the novice researchers' ability to transfer the theoretical background to their current eHealth project, and how they deal with challenges specific to their research, will be studied (RQ2). Following from this main aim are these two sub-questions:

- RQ2.1 How do novice action researchers operationalise doing AR in their eHealth research practice?
- RQ2.2 Which possible risks and mitigation actions do they identify?

## Method

This study is part of a large European project on healthy and active ageing. Within this project, existing Active and Assisted Living (AAL) technologies are connected, implemented and tested in seven pilots spread over five countries. In the pilots, different stakeholders are involved, including technology providers, older adults, caregivers, and researchers. Due to its focus on stakeholder involvement and orientation towards change in the community, AR was chosen as a suitable framework for this project. The present study took place during the planning phase for the pilots and involved the researchers leading the pilot activities.

Researchers from all five pilot countries (Italy, The Netherlands, Portugal, Slovenia and Spain) were approached and agreed to participate in the study. These researchers had varying backgrounds and fields of work (e.g., psychology, computer science, healthcare). Similarly, their experience with AR and other participatory research methods was diverse, with some commonly working in a participatory way, while others had limited experience with such approaches. Last, in terms of research experience in general, the group consisted of PhD students and post-doctoral researchers as well as more experience researchers in (assistant) professor positions. There were also participating researchers who worked outside of academic institutions, for example at hospitals or companies.

A mixed-method study was designed consisting of semi-structured interviews and an interactive workshop (see Figure 8). In the semi-structured interviews, the researchers' definition of and attitude towards AR, as well as foreseen risks and benefits were evaluated (RQ1.1, RQ1.2, RQ2.2). The online workshop focused on the practical implementation of AR, mitigation actions and practical tips were gathered (RQ2.1, RQ2.2). The interactive aspect of the workshop facilitated knowledge exchange, so that participants could learn from each other.

According to Dutch law, the nature of this research did not require formal medical ethical approval. All interview participants gave their written informed consent prior to starting the study. Interviews were recorded, transcribed and then processed in coded form. The notes made during the workshop were processed and coded. More information on the specific method and analysis for both the interviews and the workshop is provided in the sections below.

## Interviews

Prior to this study, a webinar was held within the project, in which we introduced the participating researchers to AR and invited them to brainstorm about first ideas on how AR could be suitable for their project. Following this webinar, semi-structured interviews were conducted with the aim of assessing participants' attitude towards AR, how they would define AR and to learn more about risks and benefits that they foresee when conducting AR in their pilot (RQ1.1, RQ1.2, RQ2.2). 15 researchers from the project's pilot sites were approached and agreed to participate in an interview, which meant that at least two interviews were conducted for each of the involved pilot sites.

The interviews were semi-structured and discussed three main topics: (1) recapitulate what the participants remembered as being important about AR and its definition from the webinar, (2) their attitude towards AR, and (3) their perceived risks and benefits for using AR in their pilot. There were a few interviewees who had not participated in the webinar, for them the first set of questions was replaced by general questions about their AR knowledge.

All interviews were conducted online using GoToMeeting. All participants gave informed consent to (video-) record the sessions. The recordings were then transcribed by the first author who had also conducted the interviews. After all interviews had taken place and were transcribed the first author coded the data using ATLAS.ti. Codes were first developed inductively from the data. In a second step, the developed codes were collated into general categories, again by the first author. This lead to four categories: 'previous experience with (eHealth) AR', 'attitude towards (eHealth) AR', 'foreseen risks
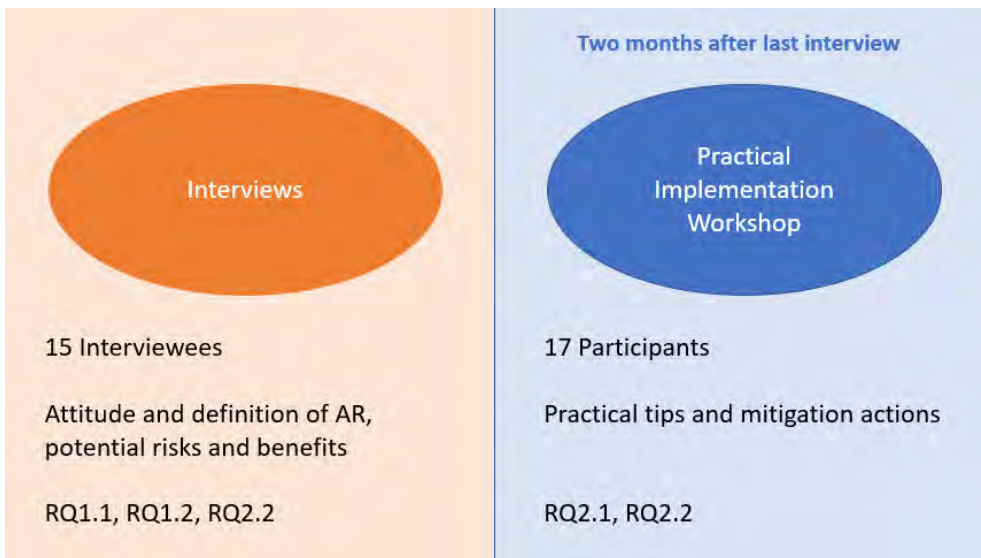
Figure 8: Overview of used methods, including the number of participants and answered research questions.

from doing (eHealth) AR' and 'perceived benefits of (eHealth) AR'. Especially for the risks and benefits, attention was paid to whether and how the mentioned points related specifically to the context of eHealth research (e.g., a risk that mainly occurs in eHealth projects). Furthermore, the sections where participants described their definition of AR were deductively coded based on the four elements of the AR definition ('iterative research', 'stakeholders as co-researchers', 'action within a community', and 'tackling a practical problem while extending scientific knowledge').

## Practical Implementation Workshop

The design and content of this workshop was informed by the results of the semi-structured interviews, and specifically the 'foreseen risks from doing (eHealth) AR' that were mentioned and coded after the interviews. The workshop took place about two and a half months after the last interview was conducted. In the meantime, participants had continued to plan their project, and some had made first steps with the implementation of AR. The aim of this workshop was twofold; (1) facilitating researchers to share ideas about the practical implementation of eHealth AR in their pilot, and hence supporting knowledge sharing as well as (2) jointly developing project specific mitigation actions for risks of doing eHealth AR, which had been mentioned by participants in the interviews (RQ2.2).

17 representatives from the seven pilots attended the second workshop. For a large part, these were the same participants who had been interviewed previously. The workshop lasted for 90 minutes, and Zoom and Mural were used to facilitate videoconferencing and digital brainstorming.

The overall agenda of the workshop was as follows:

- Short opening and outline of the agenda (10 minutes)
- Pilot presentations for knowledge sharing (50 minutes)
- Introduction to breakout session (5 minutes)
- Breakout session on risks and mitigation plans (20 minutes)
- Closing (5 minutes)

The first part of the workshop focused on knowledge sharing. Here, each pilot presented a slide on an aspect of AR that was currently going well in their pilot or that they had previous experience with. Pilots could choose any topic that was related to their AR activities or pick the one suggested to them by the first author, who had conducted the interviews and identified interesting aspects that may be useful for the other pilots to learn about. For example, one pilot was asked to present their work on training nurses to conduct interviews for the project. After each presentation there was a short time for questions from the other participants.

The second part of the workshop focused on risks and mitigation strategies. Here, the attendees were assigned to breakout rooms together with others from their pilot. In these small groups (2-4 participants) they discussed ideas to mitigate the risks that were mentioned the most during the interviews, which they saw in the Mural board. They made use of the Mural board to collect their ideas for risk mitigation on notes. Similar to the first workshop, these notes were used for analysis. Redundant notes and pictures were removed. The remaining notes were analysed within each of the risk categories (e.g. all notes related to the risk 'decision making is difficult' were analysed together). As in the interview coding, specific attention was paid to whether there were mitigation actions concretely related to eHealth projects. Again, the coding was done inductively by the first author.

## Results

First, the results of the interviews will be described, where information about the novice action researchers' knowledge, attitude and expectations towards (eHealth) AR was gathered. Then follow the

results of the practical implementation workshop, namely mitigation actions for commonly foreseen risk that were identified by the participants.

# Interview results

The interviews gave an in-depth insight into the participants' previous experience with AR, how they defined AR, their attitude towards it as well as the benefits and risks that they foresaw when conducting AR in the context of eHealth in their pilot. These five topics will be discussed in more detail below.

## Experience with AR

Of the 15 interview participants, most had no previous experience with AR (n=11), while four participants reported that they did have previous experience. However, of the eleven participants without previous experience, eight mentioned experience with similar methodologies or described how, without necessarily seeing it as AR, they already implemented some elements of AR in their work. Examples included collaborative or participatory research, stakeholder involvement and iterative research. 12 interviewees had joined the webinar on AR organised by the authors two months before the interviews took place.

## Key elements of AR

Prior to this study and the webinar, researchers in the pilots were asked what they thought constituted an AR project through a short online survey. Some of their answers captured aspects of AR, like "*the simultaneous process of taking action and doing research*" or to "*adjust your research according to latest findings in reflection with your stakeholders*". During the interviews, participants were again asked what they thought were the key elements of AR or how they would define it. Three of the four key principles described earlier were mentioned by participants: involving stakeholders as co-researchers (N=9), the cyclical nature of AR (N=7), and the fact that research should take place in practice (N=3). In contrast to the survey result, nobody mentioned the need to simultaneously solve a practical issue while adding to scientific knowledge.

## General attitude

Overall, participants talked positively about doing AR. Five participants were generally positive about AR, saying that "*the idea [is] satisfying because you are really doing something that is meant to help people*" and calling AR "*quite useful*". Another seven participants were even more positive and very enthusiastic about (aspects of) AR. Four participants described AR as being very important, and one participant said that they "*really love it because it's a way to involve older adults*", while another called AR "*wonderful*". Lastly, three participants mentioned that they were curious about AR and interested in learning more about it.

Some participants also shared some scepticism. All of the participants who were doubtful were completely new to AR and had no previous experience with the approach. One participant mentioned that they had been sceptical about AR before the workshop, but after finding out that it was similar to their usual work this criticism decreased. Another participant mentioned that in their opinion, researchers are biased against AR because they feel like they "*should have access to some untainted experience, some that you didn't ruin in any way*", whereas AR aims to change practice continuously

throughout the research. Therefore they mentioned that even though they knew about AR and its potential advantages, they would not have thought about it if it hadn't been for the webinar.

## Benefits

The benefits of AR that participants mentioned during the interviews fell into four categories: (1) benefits related to the broad, open nature of AR, (2) benefits related to the outcome of AR, (3) benefits related to the cyclical nature of AR, and (4) benefits related to stakeholder involvement.

Participants perceived it as a benefit that AR is such a **broad and open approach**, because this leaves room for creativity and leads to richer data. In addition, for one participant, the openness of the approach led to fewer risks and problems.

Other benefits that were mentioned related to the **outcome of AR**. Specifically, many participants highlighted that AR can really make an impact in a community and for various stakeholders, with one participant explaining that "*action research is not only focused on getting some results for publishing in journals, papers and so on. But also trying to show to the society that the money that they invest in research has a positive effect on them*". It was mentioned that the effects of AR are more likely to be adopted by the community, and higher sustainability of the changes can be reached because "*it's not something [that is] finished when the project comes to an end*". Lastly, participants mentioned the high ambitions of the AR outcomes as a great benefit which can be very motivating. As one participant put it: "*as long as you believe in that [ambition], that also motivates you to work on it*".

As for the advantages of the **cyclical nature of AR**, participants mentioned that by working this way, more and richer feedback could be gathered. Progressing continuously in small steps after each iteration was also seen as a benefit, especially because the agile methodology often used in technology development allows for quick changes. Allowing for constant adjustments was again a form of flexibility that was appreciated by the participants.

The **involvement of different stakeholders** and their perspectives in the project was named as a benefit of AR, because this adds a human perspective and many valuable viewpoints to the technology development. One participant described this: "*having different mindsets, different people from different backgrounds, sharing the knowledges and sharing their opinions about something [...] at the end we will have a more robust methodology and process. And at the end a more robust service*". Lastly, the stakeholder involvement was seen as a possibility for wider outreach as "*it's also a way to disseminate, to inform more people about what you are doing*".

## Risks

Five types of risks were identified: (1) the complexity of an eHealth AR project, (2) a lack of different resources, (3) methodological risks, (4) risks related to stakeholder involvement, and (5) a lack of structure.

Regarding the **complexity of doing AR**, participants described how a difficult methodology might scare stakeholders off. Participants feared that stakeholders expect too much from the outcomes of the project, while in practice these high expectations can sometimes not be met within the project. Since the goals of a project are iteratively defined with the stakeholders during the project, AR does not always start with a clear goal, which was seen as adding to the complexity of AR.

A **lack of different resources** was mentioned as well. The first example were time constraints, as AR demands a lot from stakeholders, especially medical staff, whose "*own duties are sort of first and foremost*". The second resource that was mentioned close relates to the other duties of involved stakeholders; participants saw lack of energy as a potential risk, because the workload from AR is very high.

Figure 9: Exemplary screenshot of part of the Mural board for the workshop.

The **methodological risks** the participants identified were related to the validity of the results in different contexts, the privacy of stakeholders who are very involved as well as the difficulty of obtaining ethical approval for a study that is not fully specified from the start.

Participants also mentioned risks relating to the **involvement of different stakeholders**. A concern was that decision making would be more difficult in AR with so many parties actively involved. Another risk was the unwillingness of stakeholders to change their behaviour and way of working, which one participant summarized like this: "*You can have an action research process but the problem is that if in the reflection step people want not to plan again [...] this [doesn't] work*". Furthermore, participants worried that researchers might not want to share the control over the project.

Finally, **lack of structure** was identified as a risk. Participants expressed on the one hand the need to balance structure and flexibility in the project. On the other hand, participants were missing a study protocol, but knew that this could not be fully implemented, "*because you are always adjusting*".

## Practical Implementation Workshop results

During the practical implementation workshop the participants went into breakout sessions with their pilot team and tried to identify mitigation actions for the most commonly mentioned concrete risks that were mentioned in the interviews: (1) lack of time, (2) difficult decision-making, (3) expectations being too high, and (4) AR being too difficult for stakeholders. Figure 9 shows an exemplary screenshot of part of the Mural board that was filled with notes during the workshop. Many of the notes that participants posted acknowledged the risk that was mentioned or gave concrete examples from the pilot. However, the participants were also able to think of some potential mitigation actions for each of the risks, which will be described below.

The **lack of time** for doing AR properly was a risk frequently mentioned during the interviews. In the workshop, participants came up with three mitigation strategies. The first was to prioritize tasks and then "*focus on the most relevant*". Additionally, participants suggested to combine activities where possible, for example, by doing measurements in groups or pairs of participants instead of individually. Finally, it was pointed out that remote meetings can be a way of saving (travel) time.

Interviewees were concerned that **decision making** would become very difficult if all stakeholders need to be involved, as discussions would become too complex. During the workshop three suggestions were made for the mitigation of this risk. The first was to differentiate between top-down and bottom-up decision making to then determine who should be involved when and how. Participants also emphasized the necessity of supplying stakeholders with all information that is needed to take the decision, which currently does not always happen. Lastly it was suggested that decision making might be indirectly supported when working collaboratively and involving relevant stakeholders (like older adults and policy makers) all at the same time, because in this way, the stakeholders get more familiar with each other.

During the interviews some participants pointed out that AR can create unrealistically **high expectations** among stakeholders, that the project is then unable to fulfil. Stakeholders assume that the project will fix problems they encounter, while this is not always feasible, and maybe only small steps are taken. Two mitigation actions were suggested in the workshop. The first was once again to prioritize tasks and then "*focus mainly on short term activities*", for which clear expectations can be set. Furthermore, specific activities like training sessions or workshops with the stakeholders were suggested to leverage their expectations.

The last risk that was frequently mentioned during the interviews was that doing AR was **too difficult for the involved stakeholders**, for example older adults. The workshop participants came up with two strategies to mitigate this risk. First, working with a clear task and role description during the recruitment of potential partners was suggested to give stakeholders an idea of what will be expected of them. Additionally, training and empowering the stakeholders was seen as a way to mitigate this risk.

## Discussion

This research investigated novice action researchers' understanding of and attitude towards AR, the benefits, risks and corresponding mitigation actions they foresee for their project as well as practical tips they share.

Part of this study investigated which elements of the AR definition researchers who are new to the methodology considered important. After introducing participants with a full definition and description of AR prior to the study, they were asked in interviews to share what in their opinion are the key elements of AR. The most mentioned aspects were the involvement of stakeholders as co-researchers and the cyclical nature of AR. These findings were in line with the most commonly mentioned definitions in AR eHealth literature (Oberschmidt et al., 2022). The fact that research should take place in practice and the combination of solving a practical issue and simultaneously adding to scientific knowledge were mentioned less, or not at all. Similarly, these two aspects of the AR definition were also described less often in literature (Oberschmidt et al., 2022). This shows that novice action researchers highlight the same key aspects that are presented in other studies. Of course it is debatable whether this means that some aspects are truly seen as more important, or a rather more prominent and easier to recall. However, for the sake of this study we made the decision to start an open conversation with participants to see what they would discuss.

While most participants had no previous experience with AR, they were positive about its opportunities for their research. Especially the real world impact of AR and the involvement of stakeholders were mentioned as being very valuable. Participants also identified concrete practical benefits of AR,

a lot of which were related to elements of the cyclical nature of AR and the active role of stakeholders. These are points that differentiate AR from other more traditional research methods, and are especially fitting within the field of eHealth development and human-computer interaction (Hayes, 2011, 2014). They also described the impact that AR has on practice as a benefit of AR, and one participant specifically pointed out that AR is not just focused on academic publications. While they perceived this as a benefit, a disadvantage of this lack of publishing on AR - especially the practical experiences - is, that it makes it more difficult for action researchers to learn from one another (Avison et al., 1999; Oberschmidt et al., 2022). With this paper we try to take a step to change this, and share our experience working with novice action researcher, as well as risks and mitigation actions for eHealth projects. However, overall many of the benefits mentioned by the participants are in line with commonly seen advantages of AR (see e.g. (Oberschmidt et al., 2022; Williamson et al., 2011). Similarly, many of the risks that they expected from doing AR in this project are reflected in literature (Brydon-Miller & Aragón, 2018; Grant et al., 2008). For instance, many participants foresaw the challenge that AR is a time consuming endeavour and a rather slow process, which has been pointed out by other studies as well (Grant et al., 2008; Grigorovich et al., 2022). Other expected difficulties that are mentioned by both the authors and the participants in this study, include the need to share decision making power and necessary (research) qualifications of the participating stakeholders (Grant et al., 2008). We see this as a sign that novice action researchers are able to understand AR, with its challenges, even without much experience. Being able to estimate risks can help them shape their project by taking mitigation actions.

This also became visible during the workshop, were participants collaborated to identify mitigation actions for their common risks of eHealth AR. While there were some difficulties with this task (as we will outline in our reflection below), the participants were able to identify concrete steps and actions that they could implement in their pilot in order to decrease some of the risks and challenges of eHealth AR.

The workshop also provided room to connect AR to activities and practices the researchers were already familiar with. Asking them to prepare a presentation where they share their knowledge that can apply to AR served as a way of facilitating this process. We think that knowledge sharing is crucial, not only for those new to AR. Therefore, we encourage others to not only implement elements of knowledge sharing between peers in their project (which we will also address in the reflection below), but to also emphasize sharing of practical, applicable knowledge in their publications so that others can also benefit.

## Reflection on methodology

In line with the reflexivity of AR, we want to look back on the process and activities within this project to find strong points and room for improvement in future projects working with eHealth researchers who are new to AR. The points discussed below are reflections by the authors, but are in some cases based on input and comments received from the participants over the course of this research.

As most participants had little to no previous experience with AR of course the information that was presented to them during the webinar, and how they saw AR in turn, was influenced by our view of AR. We tried to prevent this by providing literature and sources for finding more information, and encouraging participants to learn about AR on their own. Additionally, those participants who did have previous experience shared their knowledge with the others, which was perceived as very valuable. However, we acknowledge that this is a limitation of our research, and will go into more detail on this topic later.

The individual interviews with participants gave us good insights into each participant's view on an perception of AR. The combination of this more individual method and the group sessions during the webinar and workshop was very valuable to gather information on different levels. Additionally, one on one conversations can make it easier for participants to ask questions or discuss things that

they did not fully understand. Therefore, we see the use of individual and group activities as very beneficial when learning about AR, or new methodologies in general, and would encourage others to work in a similar way.

In the workshop, some new participants were involved compared to the initial introductory webinar that took place before this study. They did not receive any official introduction or additional information, but pilot leaders were encouraged to inform their colleagues about the previous activities. We noticed that for some participants it was hard to work on mitigation actions for risks when they had not been involved in the collection of those risks, or did not perceive them as relevant for their situation. For a future project, where participants can not be involved from the start, providing them with a more general, plenary introduction might be helpful. Even for participants who had joined the first workshop and the interviews, it was sometimes difficult to find practical mitigation actions to the common risks of eHealth AR. On the one hand this was due to their lack of previous experience, but because the pilots were in a planning phase, there were also no ongoing activities taking place within the pilots at the time of the workshop, which made it even more difficult to translate the AR theory into practice. This remains a challenge for future project as well. On the one hand you want participants to be informed ahead of time about what they need to do, but this simultaneously makes it more abstract for them to envision what this will mean for their practice.

An important lessons from this research in general was the value of exchanging knowledge between researchers (new to) doing AR. After the webinar and workshop, as well as during the interviews, many participants expressed their appreciation of the knowledge sharing activities. Hearing from others and learning from what they have done in the past was seen as very valuable, a finding that is also supported in literature (Crupi et al., 2020). AR eHealth projects should therefore aim to facilitate the sharing of knowledge and experiences. In this project, different spaces were created for doing so, combining interactive meetings, breakout sessions and presentations in the workshops, as well as working in shared documents asynchronously. Offering such opportunities for knowledge sharing and exchanging can be a useful, easily integrated tool, especially for multinational projects.

## Limitations

As mentioned, participants valued the possibility of learning from each other's practice and sharing knowledge between pilots, and we know that learning from peers can be beneficial to AR projects. However, in this case, most of the participants started to conduct AR for the first time, while having some experience with similar methodologies. Additionally, as the project is quite large and demanding and all participants had other tasks to fulfill as well, the time dedicated to learning about AR was limited. Arguable, having more mature action researchers present, and investing more time in learning about AR individually (as described for example in Arslan-Ari et al. (2018) and Schwartz and van de Sande (2015)) would have added to the discussion. Still, being able to learn together and from each other can already be a useful experience for the novice action researchers, and we feel that they were able to gain something from the process.

## Conclusion

This study investigated the attitude that eHealth researchers new to AR have about AR, what they perceive as important elements of it, and which risks and benefits they see from doing AR. Overall, even though few participants had previous experience doing AR, the general attitude towards AR was very positive. Additionally, participants made good estimations of certain risks or challenges they might face while doing AR in their eHealth project and developed mitigation strategies. This shows that while keeping their positive attitude, they were not overestimating the benefits of doing AR, but

were also realistic about its challenges. Participants emphasized the importance of sharing knowledge with peers and exchanging any best practices they have learned in their own work, and by reflecting on the methods we used, we were able to set up the sessions in a way that worked for the participants. Our findings are not only interesting for researchers new to AR who wish to implement it in their project, but also include our lessons learned from introducing others to AR, as we see knowledge sharing as an important element of doing AR.

## Acknowledgements

# Chapter 4

In action research, champions are highly motivated stakeholders who go beyond their role and drive a project. This chapter investigates the role of champions, and how this develops over time. We give recommendations for involving champions in a project, and keeping them engaged throughout.

Chapter 4

**Abstract**

Within Action Research (AR), champions are committed people in a project or organisation who drive change and enthuse their peers to participate in AR activities. More specifically, in AR projects about eHealth such champions can play a big role in implementing a new service or technology in practice. This study investigates the perceived and self-described role of champions in a large-scale eHealth project, as well as how their involvement changed over time. To do so, we asked researchers to identify champions in their AR eHealth project and rate their champion characteristics. Then 18 champions were interviewed, and a follow-up interview was conducted with four of them. We found that enthusiasm and the ability to connect people are important champion characteristics, both from the survey and the interviews. Additionally, interviews with champions showed that they valued freedom to decide upon their role, and maybe change it in the process. This gave them the chance to make a positive impact both in the project and in the organisation they work in. Future projects should facilitate the champions in this way to benefit most from their involvement.

## Introduction

eHealth research increasingly involves various stakeholders in the design and development of new technologies for healthcare. This leads to better alignment between the technology and the needs and preferences of relevant stakeholder groups (van Gemert-Pijnen et al., 2011). In health communication, the involvement of community members can increase engagement, and peers can act as an example for others (Lefebvre et al., 2020; Ruck et al., 2017; Warwick-Booth et al., 2013). Active involvement of stakeholders as co-researchers is one of the key elements of Action Research (AR) (Reason & Bradbury, 2007). AR projects work in cycles of planning, action and reflection, and situate research in the community that is affected by the change. To achieve this aim, involving stakeholders is not only important in the development of a new service or technology. During the implementation of a service or technology in practice, giving stakeholders an active role is crucial, to ensure the success of a technology within an organisation (e.g., hospital, rehabilitation centre, care facility, retirement home).

Research shows that stakeholders driving the AR project, so called champions, play a key role in making implementation a success (Miech et al., 2018), for example by supporting clinician acceptance of the technology (Wade et al., 2014). Champions are individuals within an organisation who "*have an intrinsic interest and commitment to implementing a change*" (Miech et al., 2018) and therefore drive a project from within the organisation. However, what makes somebody a champion in practice is not as clearly distinct as literature suggests (Kirchner et al., 2012). There are certain characteristics that are mentioned in relation to champions, like the fact that champions are often early adopters, respected by their peers and colleagues and are very enthusiastic (Kirchner et al., 2012; Miech et al., 2018). In health communication, the creativity of champions is also highly valued (Lefebvre et al., 2020). Champions also form 'teams', which might even be more successful than a champion working alone (Kirchner et al., 2012; Miech et al., 2018).

The way champions are usually described in literature gives the impression that they are not chosen but emerge within a project. In the review of Miech et al. (2018), in just four out of 199 studies, the presence of a champion was allocated. However, it was unclear how these champions were chosen. Therefore it might be possible that this role did not come naturally. Howell and Higgins found that allocating a champion "*may undermine their intrinsic motivation and commitment and hence jeopardize the innovation's ultimate success*" (Howell & Higgins, 1990). Instead, we expect that future projects can

benefit from guidance on finding champions when preparing their research. That way, hopefully, a champion can be proactively involved who fits this role, instead of waiting for them to emerge. To do so, more research is needed into the identification of champions and their characteristics (Greenhalgh et al., 2004; Luz et al., 2019).

Champions can be involved in a project from the start, and continue their engagement until the innovation is implemented and spread within an organisation. However, as Luz et al. (2019) point out, research that follows champions throughout this whole process is largely missing. In addition to that, Hendy and Barlow (2012) even suggest that the continued involvement of a champion can have negative consequences for a project. They describe how the project that is being driven by one champion can become extremely important to them, which can make it difficult to share the project with others. Additionally, they outline that a champion with too much control over the project and the way of working could make it impossible to implement the innovation more widely within the organisation. Clearly, more (longitudinal) research is needed to investigate the role and involvement of champions in AR projects.

The aim of this research is to find characteristics of champions that can be used to identify potential champions ahead of the start of an AR project. The main research question is *How can we identify and involve champions in eHealth AR projects?* To answer this question we will look at (self-)described characteristics of champions and their role and involvement over time.

## Method

This research was carried out in the European eHealth project Pharaon (Horizon 2020, No 85718) with seven pilots in five different countries (Italy, The Netherlands, Portugal, Spain and Slovenia). The main aim of Pharaon was to connect, test and validate different technologies and platforms to promote healthy and active ageing in older adults. AR (Reason & Bradbury, 2007) was used as a way of working at the different pilot sites. This included for example that a variety of stakeholders were actively involved in the project (e.g. healthcare professionals, older adults, informal caregivers, volunteers) and that continuous reflection took place at each site. In all pilots, there was a researcher as the main contact point (pilot lead). This study was conducted using mixed methods, at two points in time (between May 2022 and February 2023). At the first data point in the summer of 2022, pilot leads filled in a survey to identify champions, and the first group of champions was interviewed. At the second data point at the start of 2023, follow-up interviews were conducted with this first group of champions. Additionally, at the second data point, other pilot leads completed the survey and a new group of champions were interviewed.

## Survey with pilot leads

To identify pilot champions and get a view of some of their characteristics, the pilot leads were asked to complete a short survey. After being provided with a short definition of champions, they were asked to identify, based on their perception and understanding, whether there were any champions in their pilot. Then, for each of the champions they identified, the participants were asked to complete the scale for champion behaviour (Howell et al., 2005). The scale consists of 15 items, which are rated on a 5-point Likert scale ranging from 'Not at all' to 'Frequently, if not always'. There are three sub-constructs to this scale, *expressing enthusiasm and confidence about the success of the innovation, persisting under adversity* and *getting the right people involved.* Mean scores were calculated for each of the items on the champions behaviour scale, to determine whether any characteristics were especially common (or uncommon) in the involved champions. Participants had the opportunity to add additional characteristics of the champions that they felt were missing from the scale. Because some

pilots started their activities later on and were not yet able to determine champions at the time we initially sent this survey, the method was repeated a few months later with the other pilots.

## Interviews with champions

Following the survey, the first author had a brief conversation with the pilot leads to clarify the next steps; since the pilots were situated in several European countries, being able to conduct the next step of the research (interviews with the champions) online was a necessity. Additionally, interviews were conducted in English. If pilot leads estimated that either of these criteria would be a problem for the champion(s), they were asked to conduct the interviews themselves in their native language. In these cases, the translated transcripts were made available by the pilot leads. If pilot leads deemed the champions able to participate in an online interview in English, they were asked to establish the first contact between the researcher and the champions.

The main aim of the interviews with the champions was to learn about their role in the project, and how they see their position. The interviews were semi-structured and lasted between 15 and 30 minutes. All interviews (those conducted by the first author and those conducted by pilot leads) were analysed by the first author. The interviews were coded inductively, guided by the research question and overall aim. As with the initial survey, this method was carried out at two different points in time, to accommodate also those pilots who initially did not identify champions.

## Follow-up interviews with champions

Six months after the first survey, the pilot leads who responded to the initial survey, and whose champions were interviewed at the first data point, were contacted again. We asked them via email whether the champions in their pilot had changed, and whether any new champions had come forward. Then, all champions from the first set of interviews were contacted to schedule a follow-up interview. The goal of this session was to see if their self-described role and their activities and goals within the project changed over time. Again these were semi-structured interviews, this time lasting between 10 and 20 minutes. The questions were similar to those in the first interview, with the difference that in the follow-up we also asked the champions to reflect on the answers they previously gave, for example, whether desired changes they mentioned in the first interview had been achieved. Inductive analysis was performed.

## Results

An overview of the participating champions and their characteristics can be found in Table 6. As the overview shows, the champions fulfilled a diverse range of roles in their organisation or within the project. Both paid professionals, as well as study participants (older adults and volunteers) were mentioned as champions. In the following sections, the results of the different elements of the study will be described in chronological order, starting with the outcomes of the initial survey with pilot leads to identify champions. This section is followed by the results of the first interviews with the pilot champions, at two different time points. Then the outcomes of the follow-up interviews with the first group of champions are described.

| ID | Role / Background | Gender | Time | Follow-up | Interviewed by |
|---|---|---|---|---|---|
| C1 | Computer Science Engineer | Male | T1 | Yes | First author |
| C2 | Director of innovation and research | Male | T1 | Yes | First author |
| C3 | IT Technician | Male | T1 | Yes | Pilot lead |
| C4 | Telecommunications engineer | Male | T1 | No | First author |
| C5 | Medical doctor | Male | T1 | Yes | First author |
| C6 | Project Coordinator | Female | T1 | No | Pilot lead |
| C7 | Professional educator | Female | T1 | No | Pilot lead |
| C8 | Older adult | Male | T2 | n.a. | Pilot lead |
| C9 | Older adult | unknown | T2 | n.a. | Pilot lead |
| C10 | Older adult | unknown | T2 | n.a. | Pilot lead |
| C11 | Older adult | unknown | T2 | n.a. | Pilot lead |
| C12 | Volunteer | Female | T2 | n.a. | Pilot lead |
| C13 | Older adult | Female | T2 | n.a. | Pilot lead |
| C14 | Social Worker | Female | T2 | n.a. | Pilot lead |
| C15 | Sociocultural animator | Female | T2 | n.a. | Pilot lead |
| C16 | Medical doctor | Female | T2 | n.a. | First author |
| C17 | Volunteer | Female | T2 | n.a. | First author |
| C18 | Psychologist / Researcher | Female | T2 | n.a. | First author |

Table 6: Overview of participant characteristics for each champion

| Item | Mean (SD) | Min | Max |
|---|---|---|---|
| Enthusiastically promotes the project's advantages. | 3,57 (0.76) | 2 | 5 |
| Expresses strong conviction about the project. | 3,29 (0.91) | 2 | 5 |
| Expresses confidence in what the project can do. | 3,21 (0.80) | 2 | 4 |
| Shows optimism about the success of the project. | 3,07 (0.73) | 2 | 5 |
| Points out reasons why the project will succeed. | 2,86 (0.86) | 1 | 4 |
| Keeps pushing enthusiastically. | 3,43 (0.85) | 2 | 5 |
| Sticks with it. | 3,29 (0.99) | 2 | 5 |
| Shows tenacity in overcoming obstacles. | 3,21 (0.80) | 2 | 4 |
| Continues to be involved with the project until it is implemented. | 3,14 (0.77) | 2 | 4 |
| Knocks down barriers to the project. | 3,21 (0.89) | 2 | 5 |
| Does not give up when others say it cannot be done. | 2,86 (0.86) | 2 | 4 |
| Persists in the face of adversity. | 3,07 (0.83) | 2 | 4 |
| Gets problems into the hands of those who can solve them. | 3,21 (1.19) | 1 | 5 |
| Gets the right people involved. | 3,64 (0.92) | 2 | 5 |
| Gets key decision-makers involved. | 3,36 (0.92) | 2 | 5 |

Table 7: Mean, minimum and maximum scores for each item of the champion scale

## Survey with pilot leads

At the first data point, four pilot leads completed the survey, together identifying ten champions. Two of them mentioned three champions while the other two mentioned having two pilot champions. At the second data point, four new pilot leads completed the survey, together identifying seven champions. One of them mentioned three champions in the survey, but later also interviewed three additional champions. One pilot reported having two champions, while two participants mentioned having one pilot champion. The complete survey was filled in for six of these seven champions.

The mean scores per item of the champion behaviour scale varied between 2.86 and 3.64. The two items that were rated the lowest, with a mean of 2.86 for both, were *Points out reasons why the project will succeed* and *Does not give up when others say it cannot be done.* On the other hand, the two items with the highest mean scores of 3.64 and 3.57, respectively, were *Gets the right people involved* and *Enthusiastically promotes the project's advantages.* An overview of the mean scores across champions for each item can be found in Table 7. One participant at each data point provided an additional champion characteristic, namely that the champion "*keeps pushing toward the objectives no matter the adversity*", and that they had a "*positive attitude*".

## Role of champions in AR projects

Of the seven champions that were included in the first interviews, four were interviewed online by the first author, while three were interviewed by their pilot leads. In the following, champions' remarks regarding their own role as a champion, and the concept of champions in general will be discussed. Specifically, their self-perception, mentioned characteristics of the champions and their reasons for participating in the pilot, as well as changes they would like in their role will be described.

## Self-perception as being a champion

While we told the participants how they had been selected, we did not explicitly ask them whether they shared this perception. However, some participants chose to comment on this of their own volition.

Some participants hesitated on being called a champion. For example, C2 explained that at least they "*cannot maybe say this about myself*, but they did see how others might identify them as a champion. Another champion voiced a similar feeling when contacted about the interview, as they saw what they were doing as normal, but agreed to participate regardless. C17 also stated during the interview that they see their role as "*not such a terribly active role*", although the person who mentioned them as champions saw this differently. Similarly, one of the participating older adults said "*I wondered what criteria I was chosen on, because I'm not so bright anymore*" (C8).

To the contrary, there were two pilot leads who, based on the description of champions that we provided, mentioned their own names as being one of the champions. During the interview, C1 wanted to clarify why they self-identified as champion. In their opinion, they qualify as a champion because they "*want to move things forward in the project because I like it*" and "*tried to be enthusiastic too*".

One participant commented on the concept of champions more generally, voicing their criticism that working with champions means that a project is not truly embedded in the organisation, but rather involves only those who are enthusiastic and willing. In their opinion, relying too much on champions means that "*you have a problem [...] in your company*"(C5).

## Champion characteristics

When asked about their own role and tasks in the project, the champions brought up that they, as C2 called it, "*try to act [as] a glue*", making connections between other involved partners or colleagues. Some of them specifically mentioned making use of their network of contacts, or acting as a coordinator on a smaller scale, like C18 who said "*I'm the middle person and I have connections all over the place*". Others emphasized their appreciation for working in multidisciplinary teams, also as a way of learning from each other. Another participant expressed their general eagerness to learn from projects. This was also mentioned by several of the participating older adults who said "*I want to know even more, to learn new things*" (C9) and "*I still want to live, even though I am old. I wanted to learn something new.*" (C11) and even "*[what made me enthusiastic is] proving that things can be learned despite your age*" (C13). Both C9 and C11 also mentioned liking the social aspect of the project.

Enthusiasm was also mentioned as an important characteristic of champions, both as something they acknowledged in others and as something that the champions themselves tried to bring. In practice this translated to a desire to take the project further, as well as making others enthusiastic about the project and to "*convince people to do these kind of things*" (C2). One of the volunteers showed this enthusiasm and said that it was likely for that reason that "*if they [organising partner] need something they often know how to find us*" (C17). C12, another volunteer, highlighted "*I was impressed by the positive attitude, motivation and professionalism of the staff*", which in turn sparked their enthusiasm. On the other hand, C14 and C15 were motivated by the enthusiasm of the participating older adults.

C2 also described how they take on tasks that are not necessarily theirs in order to support their colleagues. In this way, they either hope to reduce the burden on their colleagues, or teach them their way of working, as "*this is also a good training for them*"(C2). C16 also described doing a lot of different tasks, whatever is needed for the project at a given time. As C17 put it, "*everything that comes your way, you just have to grab it*". Lastly, C6 reported that they "*feel partly responsible for the success or failure of the projects*".

**Reasons for participation in the AR project**

The champions usually got involved in the project through a previous connection, based on collaborations in the past. The project in which this study was conducted is rather large, including more than 40 partners, from more than ten different countries. The size of the project was mentioned by many of the champions, usually as a point of interest and a challenge at the same time. As C2 put it, "*I don't know if this is a source of enthusiasm or maybe should better generate fear, [...] the fact that we have a lot of partners*". However, the C2 later stated that "*given that we are a lot of partners, maybe something more can be generated that can last beyond the term of the project*". C1 said that for them "*the bigger [the project], the more effort I spend, the more attention I spend*". For one participant, the involvement of important organisations had been a big factor, which relates back to the previously mentioned activities of connecting people and making new connections.

Aside from the size of the project, participants also mentioned that the content had drawn them to the research, specifically aspects related to the use of technology. C9 stated, " *I'm interested in technology. It's hard to get to. That's why I joined the project, so I can have technology.*". Similarly, C10 said, "*I am interested in how technology has progressed and in what direction it is going to go*".

For the older participants, the fact that the project was interested in them and their opinion was another factor that lead to enthusiasm. As C9 was saying, "*I am interested in the questions that you are asking, that you want our opinion on every single thing, to help us.*". What made C10 enthusiastic about the project was "*That you are interested in the opinion of the older population. Finally, someone asks for your opinion. It brightens our day.*"

**Desired changes**

When asked what they would like to change about their involvement in a project, time and availability were important points. This could both refer to more time for themselves to invest in the project or the fact that other involved parties are not always able to invest as much time, as the champions would like them to. Referring again to the large size of the project, it was mentioned that reaching an agreement and aligning partners is very difficult, which can be less of a problem in smaller collaborations.

One champion had not been involved from the start of the project and remarked "*it was difficult for me to start after one year. To catch [up] with a lot of documentation, deliverables*" (C4). They would have preferred being included from the start, to not miss things and feel like they are behind on others. Finally, C5 felt no need for any changes in their work or role as they are "*very free to decide the way, the plan, the strategy*". However, they would like to see a change in their organisation rather than in their role or the project, namely to focus more on innovation.

Something champions emphasized was that they hoped for the continuation and sustainability of the implemented changes after the end of the project, or even "*extending the range of users and covering other pathologies*" (C2). C16 also had ideas to engage more with the participants, saying "*I think it could be better to engage the older adults in a different fun way*". Their goal was to extend collaborations with other parties and services.

# Follow-up

Of the seven champions that were interviewed at this first data point of the study, four were interviewed for a follow-up (three online, one by pilot lead). Of the other three, one dropped out due to being on leave, while the other two could not be interviewed by their pilot leads as it was a very busy period in their pilot, so none of them could make time for this activity.

## Role of champions over time

For most of the champions, there were only marginal changes to their role throughout the project. These changes were related to the different types of activities to be conducted at the different stages of the project (e.g. recruitment is done after a while). For C5 there was a bigger change, however. Their organisation set up a team to support their tasks, making the champion the leader of this team, instead of doing most of the work alone. C5 was happy with this change as it created less stress for them and gave the innovation and the project a more sound foundation in the organisation.

## Reasons for participation in the AR project over time

One characteristic that was mentioned a lot as sparking enthusiasm about the project was that of collaborating and "*being able to help people*" (C3), which was also highlighted in the first interviews. The project teams they were working in were greatly appreciated as well. C5 said about their project partners: "*You must be with people like this. Plausible, positive, ready to learn and to recover*". C2 mentioned that a change they would appreciate is to have more follow-up contact and conversations with people.

However, working with a new technology, which was previously also an aspect that made the champions enthusiastic had now changed to something they would like to change about the project. They felt this was because "*what is missing right now is a certain maturity level of the technology*" (C1), or because the technology was very rigid and not adaptable to their situation.

For some of the champions and their organisations, new ideas and opportunities opened up through the project, which they were enthusiastic about. In one case a call centre was set up to follow-up and support the use of technologies among patients of a regional public health service provider and their informal caregivers. The involved champion also saw this as a step towards a change they hoped for in their organisation, which they mentioned in the first interview: to have a more innovative culture. At the organisation of C1 and C2, a new collaboration was set up with a university for older adults "*to disseminate the project result and the spirit that animates [the project]*" (C2), sharing their knowledge and experience. Both of them mentioned this in their interviews as a point that sparked enthusiasm. This was also related to C2 mentioning that what made them enthusiastic was that "*the lessons that we learned can be applied*". The fact that the project was a learning experience and that this can be shared was also mentioned by others.

## Desired changes

In the initial interview, when asked what they would want to change about their involvement in the project, the champions mention aspects related to time and availability, both from themselves and others, as crucial. They, for example, wanted to spend more time on the project or hoped that others would be more available for work in the project. In the follow-up, they were asked whether these changes had been achieved in the meantime. For most champions at least some shift had taken place. New colleagues were involved in the project to help out with certain tasks, and as previously mentioned one organisation set up a call centre to facilitate innovative actions. For C2, the change in availability of their own time specifically happened because their involvement in another project ended and they had more time to spend on this project.

As for the goals that the champions still wanted to achieve at the time of the follow-up, most were related to finalizing and rounding off the project in a good way. C2 voiced that they would like to involve an additional care unit in the testing. C1 said, "*I would like to involve myself more in the research activities in the writing of papers [...] Maybe presenting a poster or maybe participating in one*

*of the conferences*". They stated that this had so far not happened because they needed to manage their time differently, not because the organisation was preventing this from happening.

## Discussion

The aim of this research was twofold, namely to find characteristics that can help researchers identify champions, and to investigate how champion involvement changes over time. Based on a discussion of our findings we will make some recommendations for champion involvement in future projects below.

## Enthusiasm and acting as glue

A big element of being a champion, both from the survey and from the interviews was enthusiasm. This is already mirrored in the definition of champions by Miech et al. (2018) saying that they "*have an intrinsic interest and commitment to implementing a change*", as well as in the survey by Howell et al. (2005) in statements like "*Enthusiastically promotes the project's advantages*" and "*Keeps pushing enthusiastically*". Not only were the champions rated highly on both of these items, enthusiasm was also a big topic in the interviews with the champions themselves. However, the reason for enthusiasm is very specific to the champion within a project, and can change during the project duration. For example, the size of the project was on the one hand mentioned as something they were excited about, while others pointed out the disadvantages of working in such a large team. They would prefer working in a smaller, more focused group. Additionally, for the champions with whom a follow-up was conducted, what initially made them enthusiastic - the use of innovative technology - changed to a more negative aspect over the course of the project because they found the technology not to be working as good as they had expected. Therefore, it is important to discuss what makes champions enthusiastic and pay attention to how the champion's enthusiasm evolves during the project.

A second important characteristic was their ability to connect different people with each other. Several of them mentioned that their role was to 'act as a glue' between different involved parties. Additionally, of the survey items by Howell et al. (2005), *Gets the right people involved* and *Gets key decision makers involved* were items that the pilot leads rated the champions highly on. Therefore, looking for well-connected champions, or that can easily make connections with people can benefit a project. However, when it comes to involving key decision-makers it is important to consider that not all champions are able to get access to this group of decision-makers.

## Champion or no champion

In this study, we could not identify a clear reason why some people can clearly identify themselves as a champion while others are reluctant to use that term even if somebody else described them in this way. We especially saw this reluctance to be seen as or called 'a champion' in the participating older adults. They emphasised being very happy to be asked for and involved in the project. However, these statements often went hand in hand with a diminishing of how they saw their own role and what they can add to a project. This portrays how elements of power, hierarchy and bias become important when co-researching with stakeholders, especially in the context of healthcare (Roura, 2021). Citizens, like patients or in our case older adults and their informal caregivers, might not see themselves as having the same legitimacy and role in a project as the researchers or participating healthcare professionals do. Similarly, from the perspective of researchers and other stakeholders that are perceived as more 'powerful', a bias exists towards those with a lived experience (e.g., of a disease, or being an older

adult), and what they can add to a project. We noticed that the volunteer and older adult champions frequently mentioned not seeing themselves as a champion, even though they were identified as such. Raising the stakeholders' confidence in this regard, so that they can fully take on this role could be a good action to take.

However, one of the champions (a healthcare professional) also made some critical remarks about what they called a 'culture of champions' because in their opinion this would mean that the work to push a project only relies on a select group. They thought that this was not something an organisation should strive for. This is similar to what Hendy and Barlow (2012) describe, champions being reluctant to share a project with others as it has become important to them. However, we also had several champions reporting at the second interview that they were happy to share responsibility with other colleagues who had joined the project. This did not diminish their role, but rather gave them room for other activities, or create a broader outreach in the organisation. It is possible that the champions in our studies perceived this differently as the involvement of other colleagues had been a desired change from their side from the beginning. From a project leading perspective, it seems that good communication about possible changes to the work and role of the champion, and the potential involvement of colleagues is a good strategy to employ.

## The role of a champion

There were some changes to the role of the champions that happened organically, because of shifting demands in the project (e.g. recruitment was finished, but other activities needed to be set up). However, that the activities changed did not affect their perceived role, as they were just doing what needed to be done at each point in time. Therefore, projects might be able to keep champions engaged without much re-negotiation of tasks, just because the champion's commitment to their role keeps them engaged in the project.

An important aspect of the champion's role related to the desired changes in their projects was their freedom and ability to schedule their own tasks. This not only made them feel good about their role in the project but also allowed them to take on new opportunities that can benefit the project. It seems that a good way to keep champions involved is to give them the freedom to make decisions and allow them to divide their time in a way that works for them. It should not be forgotten here that even though champions go beyond what is required of them in their work, they still have other tasks to fulfil that can't be neglected.

To help researchers facilitate longer-term involvement of champions as well, we found that it is especially important to provide an environment where champions can thrive and fulfil their role even better, to sustain their active involvement. Future studies could focus more on this aspect of connecting people within and to the project, to study how different champions fulfil this connecting task and whether steps can be taken to enhance these activities.

## Limitations

Where it was not possible to conduct an online interview in English, pilot leads were asked to either interview the champions themselves or pass on the questions and send an English translation of the answers back to the researcher. This might have influenced the champions' answers, especially regarding what they would like to change about their role and activities in the pilot, to which they provided very limited answers. In general, the answers provided in these interviews were less extensive than those conducted by the first author. Furthermore, while the first author was not directly involved in specific pilot activities, they were nonetheless a partner in the same overarching project (Pharaon). Therefore, champions might have been hesitant to be critical also towards the first author.

## Conclusion

This study looked at the involvement of champions in eHealth AR projects from the perspectives of AR project leaders and the champions themselves. We identified characteristics that are very prominent in champions and can be used to identify them, namely overal enthusiasm and the ability to connect people. Additionally, we saw that champions were able to make positive changes in the project and their organisation. They highly valued having the freedom to shape their work and schedule their own tasks. These findings can help researchers set up and shape the involvement of champions in their AR projects.

## Acknowledgements

# Chapter 5

Action research requires intensive involvement for a long period of time, which stakeholders need to be aware of and willing to commit to. We looked at what motivates stakeholders to take part in longer term, time-intensive research to identify factors that influence their involvement. Based on our findings we provide some recommendations to reduce the risk of dropout.

Chapter 5
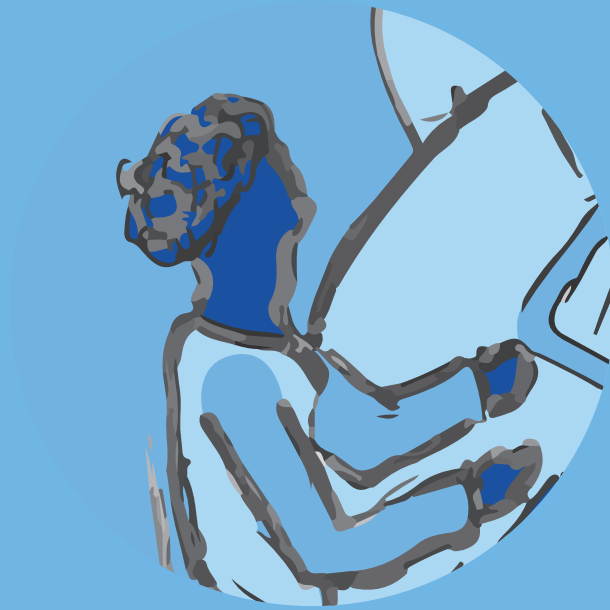
**Abstract**

Research on the development and implementation of technology in healthcare increasingly relies on the engagement and participation of various stakeholders. However, research participation can be burdensome, especially for patients with diseases that impact their daily functioning. This exploratory research investigates the motivation of patients for taking part in longer term or more demanding qualitative studies about evaluating health technologies. The participating patients were diagnosed with Chronic Obstructive Pulmonary Disease (COPD), stroke, spinal cord injury or chronic pain and participated in one of two different projects. During these studies, participants were asked in semi-structured interviews and focus groups about their motivation for and experience with these studies. Most participants were motivated by altruistic reasons, like wanting to please their therapist or to help the researchers involved in the study. In some cases, expected personal health benefits or improvements in future healthcare also played a role.

## Introduction

Early and continuous user involvement and engagement is one of the principles within the field of human-computer interaction (HCI) and user-centered design (Kujala, 2003). In the context of healthcare this means that stakeholders are increasingly involved in the design of eHealth services, and collaborating with patients in health and biomedical research is also becoming more common (Wiggins & Wilbanks, 2019). Such engagement in participatory studies can take a lot of time, so it is important to find people who are willing and motivated to continue participation for a longer period of time (Baldwin et al., 2018). Additionally, the activities and tasks that participants are asked to fulfill in participatory research can feel like a burden or require a lot of effort (Jongsma & Friesen, 2019), so researcher need to evaluate what they can ethically ask of participants. In this paper we define such burdensome studies as being 'substantial', that is, research that either (1) takes place for an extended period of time and / or (2) involves many activities that participants need to complete. Especially in such substantial projects, keeping up engagement of the participants is crucial. Yet, dropout is frequently experienced, especially when working with patients. Such dropouts can have different reasons. Participants might not be able to participate any longer due to health issues or other personal reasons (Braeken et al., 2017) or they do not like the study they are involved in, or the technology they need to evaluate (Lie et al., 2017). To avoid dropouts for these reasons, we believe that it is important to know 1) what motivates people to participate in research, 2) what keeps them motivated to continue participation and 3) how this is specifically for research with patient groups.

Previous research on the motivation for taking part in research showed that expectations of what the research entails and what participation means for the person play a crucial role. People are more willing to participate in research if the topic affects them personally, or one of their loved ones (for example if they suffer from the disease being studied) (Kabacińska et al., 2020; Soule et al., 2016). Additionally, if an intervention is tested in the study, the way the intervention is set up should fit the patients' preferences for receiving care (Skea et al., 2019). Besides such personal interests, participants might also be motivated to advance knowledge in general, for example, to help future patients (Soule et al., 2016). Also, having previously participated in research might increase participants' willingness to do so again (Kabacińska et al., 2020).

The initial motivations for enrolment described above were mainly found in limited, short-term research. However, keeping people motivated to continue participating in what we here call substantial research is additionally challenging due to the extra requirements of such studies. Suggestions

are made that personalized messages about the study can help keep participants motivated for their participation (Manea et al., 2019). However, no outcomes of such research have been published yet. Additionally, the personalized participation approach suggested by Manea et al. (2019) focused on healthy participants, which might not be sufficient when it comes to the participation of patients who are already dealing with their disease burden.

Participants can become demotivated if they have expectations that are not met by the research. Specifically for health-related studies, one of the main motivators for patient participants is that they expect an improvement of their health from an intervention (Kabacińska et al., 2020; Soule et al., 2016). However, this personal gain may sometimes be small or not immediately noticeable within the time frame of the research. Such a lack of visible health improvement was found to be a reason for dropout among patients with Chronic Obstructive Pulmonary Disease (COPD) (Sohanpal et al., 2015). Even more, there are studies that produce no direct personal gain at all, for example qualitative research focused on describing current treatment or patient journeys. Therefore, especially in the case of long-term studies and those that demand a lot from patients, it is possible that the burden of participation outweighs the immediate personal benefit. This makes it crucial to find participants who are motivated by something other than the potential direct beneficial health outcomes for themselves. Examples of such motivation could be the wish to enhance scientific knowledge or an altruistic reason to help others (Soule et al., 2016).

Alignment between the study's demands and the participants' capabilities is crucial, especially in studies that ask a lot from participants. Participants prefer to take part in studies that they can easily fit into their schedules or that require little to no additional effort outside of their daily routine (Kabacińska et al., 2020; Skea et al., 2019). Additionally, the complexity of a study can be a problem because not fully understanding the research scope and why it is done might lower the participants' motivation and engagement (Donnelly et al., 2018). If participants are not able to perform what is asked of them, they might be less motivated to continue participation (Skea et al., 2019). For patient participants, specific symptoms of their disease have an additional impact on research participation. Examples include persistent pain in patients with chronic pain (Treede et al., 2019), (sensory) impairments and/or physical disabilities in patients with stroke (Brady et al., 2013; Wolfe, 2000) or speech, cognitive and motor impairments in patients with spinal cord injury (Kabir et al., 2021), which might impact their ability to participate in research. Furthermore, a patient's condition can suddenly deteriorate, like so called exacerbations in COPD patients (Braeken et al., 2017; O'Neill et al., 2018). Due to the additional burden and time investments related to their disease, some patients find that they lack time or energy for research participation and need to drop out, or refrain from participating altogether (Burke et al., 2019; Sohanpal et al., 2012).

Some studies have investigated general motivation to participate in research, while others specifically looked at different patient groups and their participation in research. However, these studies usually look at short studies, where not a lot is required from the participants. In this exploratory study we therefore investigate patients' motivation for and expectations from participating in more substantial, qualitative research projects. We expect that aligning participant motivation and expectations with the planned research will decrease drop-outs.

The case studies described in this paper investigated what motivates patients to take part in extensive and substantial qualitative research projects. To do so, motivators and barriers for participation as well as characteristics of each case study are taken into account. Additionally, recommendations will be made on how to keep participants motivated in substantial qualitative research.

## Method

As the content and characteristics of a given study can have a big influence on the motivation to participate, we performed our research in the context of two distinct case studies: Exergame project

(project name anonimised for review) and TaskForce. While the data collection that provided input for this paper was done in the same way, the other activities, timeline and data collection in both case studies differed. One study evaluated an intervention, which held a potential benefit for the participants, while the other was a more exploratory study from which participants did not directly benefit. Table 8 provides an overview of both cases, which will be explained in more detail below. Then, we provide a combined description of the data collection and analysis, since this was done in the same way for both studies.

## Case study 1: Exergame project

The first case study called Exergame project focused on the qualitative evaluation study of an exercise system for patients with COPD who are under the treatment of a primary care physiotherapist. Participants were recruited by their physiotherapist. The system consisted of a TV screen and Kinect motion sensing device, installed at the physical therapy practice, by which therapists could schedule exercise programs in the form of small games for the patients to follow in their therapy session.

The evaluation study lasted for six months. An overview of the performed activities can be found in Figure 10. During the study, patients exercised with the system during their therapy sessions. For the evaluation of the exercise system, participants performed short physical tests and filled in questionnaires at different points in the study. The outcomes of these physical test and questionnaires were not relevant to the current study and are therefore not included in this paper. Each participant took part in 30 minute interviews at different points in time. Interviews were held face-to-face or online, based on the preference of the participant. The outcomes of (some of the questions in) these interviews will be reported in this paper. Besides motivation, the interviews discussed other topics that are reported elsewhere (Oberschmidt et al., 2022). Initially, the plan was to interview participants five times, with six weeks in between the interviews. However, around the time of the third interview a lot of participants were on holidays and therefore not using the technology. Moreover, several dropouts occurred around this period as well, and therefore the fourth interview was cancelled for all participants. The last interview took place as planned, six months after the start of the study. One participant dropped out before this last interview, due to health reasons.

| Characteristics | Exergame project | TaskForce |
|---|---|---|
| Duration | 6 months | 2-3 months |
| Target group | Patients with COPD | Patients with Stroke, Chronic Pain and Spinal Cord Injury |
| Recruitment via | Physical therapy practice | Rehabilitation center |
| Aim of the research | Evaluation of intervention (technology installed at physical therapy practice), embedded in treatment | Exploratory study of values implicated in rehabilitation care to inform eHealth and service design |
| Research activities | Interviews: 4x 30min, Use of technology during treatment Questionnaires and physical exercise test | Interview: 1x 1h, Diary: 5 minutes daily for 21 days, Focus group: 1x 1,5h |

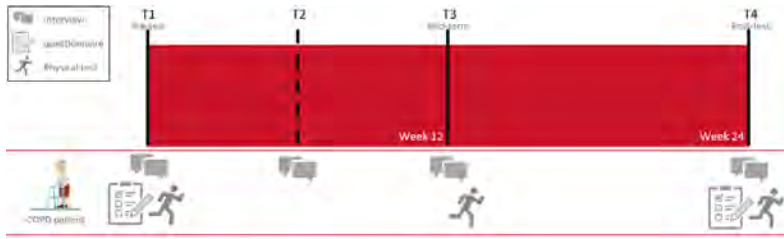Table 8: Comparison of the two cases based on study characteristics

Figure 10: Overview of the timeline and activities within the Exergame project

## Case study 2: TaskForce

The second case study was an internal project between the authors' research institution and an affiliated rehabilitation centre. The primary goal of this project was to learn about patient values in rehabilitation care in general, and specifically concerning the use of technology during treatment. Additional goals were (1) to develop patient journey maps and (2) to use insights from this project to improve care processes and technology use in rehabilitation treatment.

The project duration was between two and three months and therefore shorter than the Exergame project. However, participants were asked to take part in time-intensive, qualitative activities. Specifically, the research started with an intake interview of approximately one hour, a small part of which concerned the questions regarding motivation, next to a set of other questions about their rehabilitation treatment. The interview was followed by a three-week long diary study requiring daily input, which took roughly five minutes per day. The results of the diary were purely related to the rehabilitation treatment of the participants and are therefore not included in this study. The study involvement ended with a focus group of 90 minutes, which also included a small set of questions about their motivation, once again amongst other questions and exercises that will not be discussed here, but are reported elsewhere (submitted). Participants were recruited via their health care professional at the rehabilitation centre.

## Ethical approval

The medical-ethical committee of East Netherlands reviewed both studies and concluded that no medical-ethical approval was needed to conduct the study (reference number Exergame project 2021-7358, reference number TaskForce 2021-13032). All participants were provided with an information letter prior to the study, with at least a week to consider their participation. All gave their written informed consent prior to starting the study.

## Data collection

In both case studies, we utilized interviews and focus groups conducted as a small part of the original research projects to investigate participants' motivation to participate. To answer our research question, we asked a set of questions during each interview moment and focus group. Furthermore, data from the diary study in the TaskForce study was included in the analysis where information on participant motivation was given. In both case studies, we asked participants the same questions in the first interview. Specifically, participants were asked (1) why they had decided to sign up for the

research project, (2) whether they or anyone close to them had ever participated in similar research, and if so, what this research was about, (3) what they expected from participating in the study and (4) whether they had talked to anybody in their surroundings about the project, and if so with whom and what their reactions had been. The last question was included to investigate the effect of (peer) contact on research participation. In the follow-up interviews in the Exergame project case study, we reviewed the previous answers with the participant to see if anything had changed for them and whether their expectations were met. The diary in the TaskForce study included no specific questions related to motivation, but since participants also commented on their research participation in the diary, one author read these answers and coded and extracted any relevant quotes related to participant motivation. At the final contact moment with participants in each case study (interview for the Exergame project study, focus group session of the TaskForce project), we asked participants (1) how they had perceived their participation in the research, (2) what they liked about the study, (3) what they disliked or thought could be improved, and (4) whether they would consider participating in similar projects in the future.

## Data analysis

We made clean verbatim transcripts of the audio recordings from all interviews (Exergame project and TaskForce) as well as the focus group in the TaskForce project. Since participants were asked the same questions, and the idea was to distill overarching patterns, we used one coding scheme for the data from both projects. The first author developed this scheme inductively based on the initial set of interviews from the Exergame project, since these data were available first. When coding the data from the TaskForce project according to this scheme we found that it covered all new data, so no additional codes needed to be added. Additionally, we used the motivation factors described by Soule et al. (2016), namely altruistic, financial, health-related and intellectual, as underlying motivational categories to sort the codes.

## Results

After a brief presentation of the participants' demographics, the results from both studies are jointly described. The sections are structured based on the main topics that were investigated, namely the motivation to sign up, previous research experience, (peer) contact about the study, the participants' expectations and the overall research experience during the study.

## Demographics

Seven patients (five men, two women) with COPD started to take part in the Exergame project, but over the course of the six month study, five of them dropped out. In three cases this was due to medical reasons that no longer allowed participants to follow their physiotherapy as planned. The other two dropouts happened because the participants did not like the technology they had to use. As they all stopped using the technology, they were also no longer included for the rest of the study period. However, where the participants' health allowed this, and they were willing to do so, a final interview was conducted, also discussing their reason for dropping out of the technology use.

In the TaskForce project, five participants (three women, two men) were recruited by their healthcare professionals at the rehabilitation centre. The participants received rehabilitation treatment for different diagnoses (spinal cord injury n=2, chronic pain n=2, stroke n=1) Of these, all five took part in the initial interview. One participant with chronic pain dropped out during the diary study, and

two participants (one with spinal cord injury, one with stroke) dropped out before participation in the final focus group. In all three cases, health problems were mentioned as the reason for dropout. In this study there was no intervention that participants were using, so all dropouts were participants who were no longer able to take part in the data collection.

## Motivation to sign up

Most patients in the Exergame project gave altruistic reasons for their initial sign up. Specifically they either accepted the invitation to participate because their therapist asked them or they were interested in helping the researchers. The motivating factor of helping the researchers was also mentioned during the second interview as demonstrated by one participant: "*I also hope for you, that you can achieve some results with it, whether the system works*". Another patient mentioned at the halfway interview that they would continue using the system but that they "*would do it because I am asked to, not because I feel the need*", emphasizing the willingness to participate for somebody else's sake. Other participants were motivated by the possibility of improving care in general, or because they expected personal (health) benefits. Lastly, one participant stated that it was curiosity about the technological possibilities of the future that motivated him to sign up.

In the TaskForce project, one participant was motivated by their interest in the innovation of care their desire to improve treatment. They mentioned seeing evaluative research of the current treatment as a crucial element of rehabilitation care and felt it important to contribute to this. Similarly, another participant was motivated to share their experience "*so that people can benefit from it and take something from it so that other people [...] can function better in [their] daily life*". A third participant's motivation fell along the same lines, they participated because they found it important that treatment is aligned with the patients' needs and improved based on their values. In a later diary entry they also stated a personal change that the study had brought about, saying "*This research invites me to better think about the treatment and what it does to me. Every day I am stimulated to reflect on this and I notice that my awareness grows because of this*". One participant specifically mentioned that they had encountered particular issues in their treatment that made them more eager to participate, but did not go into more detail on this. Later during the interview they mentioned that certain aspects of the treatment they received did not align with their needs and wishes. During the focus group at the end of the study, one of the participants said that they would participate in similar research in the future because it is important that patients have their voice heard, saying that "*this is the only thing we can do*". They elaborated on this some more: "*if you don't give your opinion, you can't complain afterwards: oh, all those robots are here now*", referring to potential future scenarios about the digitization of care that had been discussed before.

As a reason for their participation, another participant described how they are a student themselves, and have experience from their own and fellow students' projects. Therefore they wanted to help out the researcher in this study because "*you can imagine how nice it is that people participate*". Similarly, another participant mentioned that they supervise student interns in their work and are therefore involved and interested in research.

## Previous experience

The Exergame project participants' previous experience with research varied greatly, both in terms of the content of the research and in their evaluation of the experience. For example, one participant frequently took part in online survey research, while another was previously involved in a long-term research at a hospital. Likewise, some had very positive associations and memories of research participation, while others had stopped their earlier participation immediately. One participant described a

previous study as follows: "*it was a bit simple, a bit always the same repetitions. At a certain point that gets boring, so it is 'again that exercise, again'. You have to see a bit of a challenge in it*".

In the TaskForce project, most of the participants had no previous experience with research, except for the participant who mentioned taking part in fellow students' research as part of their motivation to sign up. However, the studies they took part in were one-time interviews on different, non-health related topics.

## (Peer) contact about participation

A few of the participants in the Exergame project had discussed their participation in the study with other patients in their COPD treatment group. These groups are often rather close as experiencing the same disease and training together creates a bond between patients. Some participants stated that others in their group were interested in the study after seeing them use the intervention, and some even asked whether they too could participate. This interest from others continued throughout the project. Occasionally, participants also discussed the study with their friends and family, from whom they got mixed reactions. Some were positive and interested in the study whereas one participant stated that their daughter was worried that it would be too much. In the later interviews, participants told us about additional positive and interested reactions from their friends and family. One participant even invited their daughter and granddaughter to view the exercise system that was being tested and said that the daughter "*thought it was perfect, magnificent*".

Because the patients in the TaskForce project were treated and sometimes also living in the same facilities as other participants, some had discussed the research with each other, or with patients who did not sign up for the research, or they were at least aware of others that had signed up. One participant had told his wife and son about the study and said they responded positively because "*that's how we all look at these things*".

## Expectations

In the Exergame project, some participants expected either positive health outcomes for themselves, an improvement of treatment for future patients, or were curious to learn what treatments in the future might look like. However, there was also one participant who explicitly stated that they did not expect any health benefits for themselves from their participation. Others had no concrete expectations at the start of the study. Noticeably these were the three participants that had no previous experience with research. However, one of them did add "*I only expect that it is beneficial for me, that I get moving more. And being able to do certain exercises*".

Several participants who expected health benefits in the beginning, did not experience them throughout the study. Additionally, one participant had expected more guidance with the intervention and was feeling disappointed by the support they were receiving from the therapist. Conversely, one participant who went into the study expecting no positive health outcomes did see improvement after participating for a while, saying they were "*becoming more and more positive*". There was another patient who saw a mental health benefit from participation because they felt good about contributing to research and being part of the study. In the halfway interview one participant stated that they were expecting some sort of study evaluation or sharing of preliminary results. They had not voiced this expectation towards us initially but were slightly disappointed that this was not part of the study process.

None of the TaskForce project participants mentioned any concrete expectations, but some hoped that their participation might contribute to better care in the future. One patient terminated their participation during the three week diary period. They stated in a message to the researcher that they would have liked to "*be of more use*" but were "*far too busy with other activities*" which did not leave

any room for the research. In a later conversation in person, it turned out that in fact a decrease in health had lead them to drop out.

## Overall experience

In the last interview of the Exergame project, the participants were asked how they had perceived their overall participation in the study. Both remaining patients highlighted the good contact with the researchers. When asked whether they would participate in a similar study in the future, both said yes and mentioned their curiosity for new things. However, one patient added that for them this was only the case if the threshold to participate is low and if they are able to try out things for themselves. The other participant was very clear that they would take part in another study in the future as they "*love new things and research*" and enjoyed seeing "*young ideas, fresh ideas that contribute to innovation*". They explicitly mentioned the in-person contact with the researcher, which they appreciated.

In the TaskForce project, two participants took part in the final focus group session, as the other three had dropped out due to health reasons. When asked about their overall experience with the study, the participants agreed with each other that having this focus group together with the others "*makes it complete*". Both participants appreciated having a clear closing moment together in a group and with the researchers, since the rest of the study they had been one-on-one with one of the researchers, or by themselves when filling in the diary. One participant specifically emphasized liking the in-person-meeting, because doing the session online would have felt more distant to them. Both were enthusiastic about participating in similar research again in the future, with one saying that they were "*always open to these sort of things*" and the other adding that "*it was useful*".

During the session, some struggles were discussed as well. For one participant, using a smartphone to fill in the diary was sometimes difficult. Noticeable there had been another interested patient who in the end declined participation because they did not feel comfortable using an Android phone for the diary study. A focus group participant also mentioned that they sometimes felt bad when they forgot to complete the diary or hurried and stressed to still do it on time. However, both focus group participants mentioned that they felt capable to decide if a future study is interesting and doable for them or not and would then see whether or not to participate. When the researcher mentioned that it was difficult to find participants, this was very unexpected to one of the participants who expressed "*I thought: everybody wants to participate, right?*".

## Discussion

This paper discusses the outcomes from two substantial qualitative research studies with different patient groups. Over the course of the research, their motivation to participate and expectations for the project were investigated.

While participants often mentioned the 'kind request' they received as a reason for signing up, this is not a direct motivation. Rather, the good relationship with the therapist and wanting to please them acts as a circumstance that makes participants more likely to sign up, or rather less likely to decline participation. It is possible that participants mentioned an altruistic reason but were motivated by underlying other reasons. For example, the work by Wasan et al. (2009) described "*an initial altruistic reason for participation was often followed later in the interview by reasons of personal benefit*", like improved treatment or making a contribution to science. It would be interesting to investigate further if a kind request also leads to participation for research that does not suit the preferences of the participant. In both of the presented case studies, difficulties with the technology were pointed out by the participants. While in the Exergame project these were difficulties with the technology that was being tested, in the TaskForce project the comments referred to the diary app that was used

for data collection. Literature shows that research becoming more technical can be burdensome for participants or even make research less inclusive and open (Braun et al., 2020; Kabacińska et al., 2020). Participants said that for future participation they would need to see if the study suits them, but it is possible that a kind request from their therapist could still convince them to participate.

Participants signing up or joining a research study, is however only the first step. We found, in accordance with other researchers (e.g. Habibipour et al. (2018)), that eliciting and managing the various implicit and explicit expectations that participants have for the research is very important. In the Exergame project, where participants with COPD used an exergame technology, no expected results were communicated beforehand. This led some participants to expect more health benefits than they eventually experienced, while others who had expected no improvement in their health were positively surprised. In both studies there were participants who highlighted the mental benefits of the study, which had not been anticipated by the researchers or participants. Lakeman et al. (2013) describe research participation as being therapeutic for some participants. In their opinion, these potential benefits should be mentioned beforehand in the same way that risks are usually included in informed consent forms. However, they concede that it can be difficult to concretely describe these benefits and recruit participants on this basis. Our findings underline this, since the benefits did not occur, or were at least not mentioned, by all participants. Still, the mental health benefits of research participation, even if they are not planned for, can be an opportunity for engaging participants and keeping them motivated.

Another aspect of eliciting and managing expectations is related to the methodology and process of the study. Participants did not mention any expectations related to the study beforehand, but later mentioned activities they had expected (e.g., mid-term reporting of findings). In this sense, communicating with participants clearly and openly about the research is crucial (Habibipour et al., 2018). For studies where long-term participation is needed, it can be interesting to have a discussion on their expectations with participants and to specifically ask them about aspects of methodology and process. Repeating this discussion on expectations throughout the study can help continuously align the research to the participants needs and wishes.

Other studies have found that financial incentives can be a reason for deciding to participate in research (Cohen & Schleider, 2022; Fiore et al., 2014; Manea et al., 2019; Rochat et al., 2020; Soule et al., 2016). While at the end of each study, all participants (including dropouts) received a €25 gift card as a small compensation for their time, the information letter only mentioned that they would get a 'small reimbursement', without specifying what this would be. Therefore it seems unlikely that this largely influenced participant motivation to sign up in our case. Additionally, none of the participants mentioned this financial incentive when asked about their reason for participation.

Most of the participants in both studies had little to no experience with previous research. For those who did have experience, this was in some cases related to their own education (e.g. participating in studies of fellow students) or work (e.g. supervising students during their research). There were some patients who had previous experience with taking part in research and liked it. Literature shows that having participated in research before makes future participation more likely (Kabacińska et al., 2020). However, this is not the case for everyone, and participants without previous experience signed up as well. This is also beneficial as this means that the voices that are heard are not always the same. Related to this is the topic of peer contact. In both studies, participants mentioned discussing their participation with other patients who had been asked to join the study. Regardless of whether or not those eventually decided to do so, and for which reasons, for the participants it can be nice to have a peer, who experiences the same as they do to discuss the study with. A peer specifically, as opposed to family members, friends or healthcare professionals, more likely shares the same concerns and hopes regarding their health and condition. Therefore, even in individual studies, like interviews or diaries, getting participants in contact with others can enhance their participation in the research. In the case of the Exergame study, participants discussed the research with others in their treatment group, and made others curious about it. While in this case no additional participants were recruited through

such snowballing, this could potentially be a fruitful way of finding other motivated participants.

In both studies, patients had to drop out due to health problems. While some dropouts were expected, the low number of participants that completed the full study in both cases (2 out of 7 for Exergame project, 2 out of 5 for TaskForce) was not. As we have mentioned before, it is good to keep specific symptoms and aspects of a disease (e.g., risks of worsening) in mind that might limit research participation (see for example Brady et al. (2013) and Sohanpal et al. (2012)) and to find ways to deal with them (e.g., making remote participation possible, as will be explained below). In the case of substantial studies with patients it can be even more crucial to have a strategy for dealing with dropouts than in other research projects. This could include the recruitment of additional participants to replace dropouts or adapting data collection methods to make it easier for participants with health issues to keep contributing.

Due to the Covid-19 pandemic, participants in both studies had the option to participate online or via phone. When participants preferred face-to-face meetings, these were made possible in line with the government guidelines (e.g., keeping a distance, wearing face masks). A reflection on our results and these circumstances made us wonder, since the participants often had altruistic reasons for participation, whether the form of research conduction shaped their relationship with the researcher. While this was not remarked upon negatively by those participants who joined the research remotely, some of the participants who had had face-to-face contact with the researcher explicitly made positive comments about it. Naturally, this does not mean that all research should be conducted in-person. In general, online and phone studies can be an opportunity for research inclusivity, since participants can take place from their own home, reducing for example the effort and burden that can come from traveling to a research location (Masoli et al., 2021; Noonan & Simmons, 2021). However, others have described that setting a study in a more natural as opposed to atypical research setting could lead to more participants dropping out (Cohen & Schleider, 2022). Additionally, seeing that many participants appear to want to help the researchers and sometimes keep participating solely for that reason shows how important it is for researchers and participants to establish a good relationship. The importance of building rapport in qualitative research is also described in literature (McGrath et al., 2019). Taking the time on activities solely for building a relationship (e.g. conversations that are not related to the research project) can be especially important when doing research remotely, as these are more difficult to establish while carrying out online methods than when meeting face-to-face.

There are some limitations in the setup of this research. Since participants were talking to the researcher personally (either face-to-face or on the phone), they might have given socially desirable answers to some questions. This could for example be the case for their willingness to participate in future studies, or their general perception of the research. However, some critical remarks were made by participants regarding the difficulty with technology use and the high demand of the diary. This indicates that participants were at least to some extend open about potentially negative experiences within the research. However, a more anonymous setting (for example, using an online survey) could make it easier for participants to share criticism and concerns.

Especially in the Exergame project, a lot of participants dropped out, mainly due to health reasons. While health-related dropouts were to be expected in both studies due to the patients' serious conditions, important data is missing from those who did not complete the study. While exacerbations were the leading reason for leaving the study, it is possible that participants held other perspectives regarding research and motivation that they were not able to share with the researchers. For future studies, provided their health allows this, it could be valuable to have quick debriefing conversations with participants who wish to leave the study, to learn about their experience and potential issues other than their health that might have lead to the dropout.

From this research and our reflection on it we draw some recommendations for motivating patients to participate in future substantial research projects, similar to those we conducted:

- Making sure that participants do not just take part in the study out of kindness. Instead, check if the study fits their needs and interests.

- Thinking about the positive mental health benefits that participation might have, and how to describe them to potential participants.
- Starting the research by learning about and managing participants' expectations regarding the process, methodology and outcome of your project.
- Part of the research plan should be to develop a strategy for mitigating the risk of health-related dropout (e.g., are participants replaced or can they participate in an adjusted way in case of exacerbations?)
- For patients who decide to drop out of the study, try to have short conversations to debrief them and round off their participation in a nice way.
- Investing in building a good relationship with participants, especially when (most of) the research takes place online or via phone, and in the case of long-term studies.
- Establishing a way for participants to communicate with other participants, ideally peers in the same situation (provide participants consent to this).
- Thinking about involving participants for peer recruitment, for example, via their treatment group, as a way of including other motivated participants.

We are aware that some of our recommendations might be applied differently in different projects (e.g., mitigating drop-out is very project-specific). However, we see these as general pointers for other researchers to consider when setting up and conducting their research.

## Conclusion

This study investigated the motivation of different patient groups for participating in substantial studies. The results from two different studies were included. For the most part the findings in both projects were similar, participants sign up for the study out of altruistic reasons (e.g., being kindly asked by their therapist or wanting to improve care for future patients), they enjoyed the contact with the researchers and being able to communicate with other patients within and outside of the study about the study. A difference between both studies was that where an intervention was being tested, some participants expected and were motivated to participate by potential improvement of their own health, whereas in the other project, no direct benefit for the patient could be expected. Their participation was motivated by the drive to improve care in the treatment facility for the future. Based on our findings some recommendations were made for motivating participants in substantial projects and aligning the research to their expectations.

## Acknowledgements

# Chapter 6

The last role that we look at in this part is that of outsiders to a project, who might not be involved, but are still affected by a project. The relatively new flash mob method provides a fast and spontaneous way of investigating the opinion of outsiders, without a lot of commitment from their side. We end this chapter with some recommendations for others who want to use this method in their projects.

Chapter 6

**Abstract**

Action research (AR) is a participatory research approach that works in iterative cycles which are conducted in practice. However, some cycles of AR can take a long time, slowing down the speed of iterations. Therefore, in this study we investigate the use of a relatively new method for AR: the flash mob. Flash mob studies lend itself to spontaneous, unplanned participation, by collecting large amounts of data in a short time, while also analysing and reporting quickly on findings. To investigate the applicability of the flash mob as a method for AR in eHealth projects, we conducted three flash mob studies in two research projects and draw recommendations based on observations, reflections and short pre- and post surveys. Outcomes show that the flash mob is a potential method for AR, as it is situated in a practical setting, where stakeholders can easily be involved, and its pace could speed up the AR cycles. To further improve the applicability for AR, our main recommendations include; promoting the flash mob adequately to increase participation and improve the involvement of 'champions'; also tracking interactions outside the flash mob (e.g., comments and questions from bystanders); and choosing an accessible and visible location, taking into account the activities associated with the location.

## Introduction

Action Research (AR) is a framework for conducting participatory research. Its key elements are that (1) iterative research cycles are conducted (2) in practice, (3) together with relevant stakeholders, (4) while also extending scientific knowledge (Reason & Bradbury, 2007). AR is increasingly used in eHealth studies, which are about the development, implementation or evaluation of technology in healthcare. This can include a variety of topics, like the prevention of illness through the promotion of healthy lifestyles (e.g., through activity monitoring), self-management of disease (e.g., tracking of symptoms over time) or shifting of care from a clinical setting to the home of the patient (e.g., videoconferencing with healthcare professionals). Additionally, the types of technologies that are used for eHealth also vary greatly and include things like apps, virtual reality, sensors or robotic devices. Furthermore, what is specific in the context of eHealth is the involvement of various stakeholders with diverse backgrounds. Projects affect and commonly include stakeholder groups like patients, healthcare professionals or technology developers.

In eHealth research, the cyclical nature and close connection to daily practice provide many benefits (Hayes, 2014; Oberschmidt et al., 2022). Additionally, AR focuses on actively engaging stakeholders. Studies on *champions*, the drivers of a project who are exceptionally committed to it, show that such actively participating stakeholders can help the successful implementation of a new service or technology in daily practice (Miech et al., 2018) However, research also points out that AR often requires a lot of time and resources (Grant et al., 2008). Yet in some cases, through faster paced studies, it would be possible early on to quickly and easily determine whether a project has any potential benefit and is even worth pursuing further. Additionally, some specific research questions could be (partially) answered in a relatively short period of time to avoid unnecessary delays and disturbances of the work in practice.

Recent studies have suggested so-called flash mob studies as a way of quickly finding answers to questions in daily practice (Moons, 2021). Flash mob studies get their name from the social activities where large groups of people gather in a specific location for a brief period of time to perform an action together (e.g., dance). In research this means that data is collected on a large scale (e.g., in multiple

locations at the same time, or involving many participants) in a short period of time. Moons (2021) suggest that a core research team sets up the study (e.g., develops material, requests ethical approval), while local partners from daily practice help in recruiting participants and collecting data. Flash mob studies are most suitable for topics and research questions that are "*fun, hip, and playful, in order to gain enough interest*" (Moons, 2021).

There are only few examples of flash mob studies in eHealth literature so far, but their results and reflection on the method are promising. Schols and colleagues found the flash mob study they conducted as part of clinical diagnostic research to be resource - and time-saving compared to more traditional research (Schols et al., 2019). In their analysis of health record data, Van Nassau and colleagues used a flash mob study as a way to get an overview of a topic on a larger scale (van Nassau et al., 2021). In a large, qualitative flash mob study on what matters to patients after hospital admission it was mentioned that less data was missing due to the quick and easy approach (as not much is asked of participants, so they rarely skip a question) (van den Ende et al., 2021). Therefore, the research questions was answered in a better and more reliable way.

The flash mob is situated in practice, allowing for direct contact with and feedback from the community. Where AR projects are often time and resource consuming, flash mob studies promise fast results (Schols et al., 2019). Additionally, the immediate outcomes from a flash mob study (within a few weeks after data collection) allow for a quick progression to a new iteration and next steps within the AR project. Lastly, as flash mob studies are more creative and fun, they can attract more attention and involve participants that do not usually take part in research (Moons, 2021). This aligns well with the fact that AR aims to benefit a community, not just some involved individuals. Therefore, we consider flash mob studies to be very suitable for eHealth AR. However, to our knowledge, no studies have yet investigated the applicability of the flash mob as a method for AR ehealth projects.

The aim of this paper is to investigate the applicability of flash mob studies for AR eHealth projects. We will do so by carrying out flash mob studies in different research project settings in the health domain, reflecting on our own activities, and drawing recommendations for others who want to use flash mob studies in AR.

## Method

To investigate the applicability of the flash mob as a method for AR in eHealth projects, we conducted three flash mob studies, situated in two different research projects. While the content and structure of both projects differed, the data collection to evaluate the flash mob method was the same. Therefore, a short introduction of both research projects will first be given, followed by a combined data collection and analysis section. An overview of all three flash mobs can be found in Figure 11. While both research projects had elements of AR (e.g., making a change in practice), the projects were not specifically set up as AR. However, for our analysis we used AR as a framework, and relate our findings to the key elements of AR (cycles of planning, action and reflection; research in practice; stakeholders as co-researchers and extend scientific as well as practical knowledge).

## Exergame project

The first flash mob that we conducted was part of an Active Assisted Living (AAL) Exergame project [1]. Within this participatory research project, an eHealth program that offers exercise games was developed and evaluated at a rehabilitation centre. The flash mob study was conducted as part of the evaluation of the developed program. For the flash mob, a screen (approximately 1 by 2 meters),

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[1]https://www.salsa-project.com/

| Project name | Exergame project | Social Robot Project | |
|---|---|---|---|
| Technology to be evaluated | Exercise Game | Social Robot | |
| Target group | Patients, healthcare professionals | Outpatients | Nursing home residents, healthcare professionals |
| Location | Rehabilitation centre (entrance hall) | Rehabilitation centre (outpatient clinic waiting room) | Nursing home (different departments, common spaces) |
| Duration | 3 days | 2 days | |
| Data collected | Observation, reflection, pre- & post-survey | Observation, reflection | Observation, reflection, pre- & post-survey |

Figure 11: Overview of the three different flash mob studies that were part of the two research projects Exergame project (one flash mob) and Social Robot (two flash mobs)

including the developed program, was set up in the entrance hall and both patients and healthcare professionals could walk by, try out the system and then fill in a short survey about their perception of the exercise game. The tv screen was on at all times during the study, displaying the start screen of the program to draw attention. The survey that participants filled in included an informed consent form that needed to be filled in before the participants could answer the other questions. The answers to this survey (i.e. the data collected through the flash mob method) are not used or presented in this paper, as we focus on the method and process itself. The study was set up together with the innovation manager at the rehabilitation centre, who not only helped with practical matters within the centre (e.g., setting up technology), but also gave input and feedback on the study set up and survey questions. Participants could spontaneously join the flash mob, but to already make healthcare professionals aware that the study would take place, a message was put on the internal digital bulletin board a week before the study.

## Social Robot

The second eHealth research project in which we applied the flash mob method, was the Social Robot project, which aimed to evaluate the use of a social robot in rehabilitation and nursing care. In the project, new features were developed for a social robot, and these were tested and evaluated via the flash mob method. Within the Social Robot project, two different flash mobs were conducted. Both lasted for two days and focused on the evaluation of a social robot in a healthcare setting. The first flash mob took place in the waiting room of the outpatient clinic at the same rehabilitation centre that also participated in the Exergame project flash mob. The setup included the social robot, as well as a laptop to fill in the survey. In this flash mob, patients briefly interacted with the social robots before and after their appointment (e.g., answering questions about their appointment), and finally filled in a short questionnaire about their experience with the robot. after providing their informed consent at the start of the survey. Again, these content-related answers are not included in this paper, we only focus on the flash mob as a method. As in the Exergame flash mob, a message was posted on the bulletin board to inform staff about the flash mob. In the second flash mob, at different departments of a nursing home, both patients and healthcare professionals interacted with the robot (e.g., playing games) and filled in the same previously mentioned questionnaire. Like in the Exergame project, the studies were set up together with employees from the two healthcare organisations, who helped planning the flash mobs. In this flash mob, a schedule was created for when the robot would visit each department. The schedule was communicated with the healthcare staff internally.

## Data collection and analysis

Two types of data were collected. First, a pre- and a post-study survey was conducted to assess the perceived usefulness of the flash mob among the organising partners. The surveys were sent via mail, to the different contact persons at the participating organisations. Both surveys started with information about the research and participants had to provide their informed consent before they could continue the survey. In the pre-survey, next to some demographic questions, participants were asked (1) about their expectations for the flash mob and (2) what they would see as a successful conduction of the flash mob, as well as (3) whether they had any other remarks or questions up front. In the post-survey, we asked the participants (1) how they experienced the flash mob, (2) whether they saw this as a useful way of doing research and why (not), (3) whether the results were as they had expected and why (not), (4) what they would do differently in a future flash mob and (5) whether they saw more opportunities to apply the flash mob method in their organisation. The answers from the pre- and post-survey were thematically coded by the first author. The second type of data collected were

observations made by the researcher who was on site most of the time, and a reflection on these observations together with the co-authors after each flash mob. These were observations of passers-by who did not provide informed consent to participate in the study. However, when we noticed somebody looking at our study set-up we orally explained that we were performing a test of the technology, and of the flash mob method. When people then commented, for example, their opinion about doing a study in the entrance hall of the centre, we informed them in the conversation that this was also interesting for us to hear about. We did not take any notes about these passers-by except an aggregated summary of the general sentiment of all bystanders towards the flash mob to our field notes. This made it possible for us to reflect on the method and how it is perceived, while respecting their anonimity. The notes were structured in a specific way beforehand, and mainly records of what did not go well, what we noticed and which comments we received. The notes and reflections of the researchers were organized into themes. We discussed these outcomes and reflected on them especially in relation to the key elements of AR, but also to plan the next flash mobs within this study and potentially in the future. The reflections were done in conversation between the authors as well as individually by the first author who was present in all flash mobs. We generally think that reflection, and sharing the lessons learned from these reflections, are crucial to (participatory) research. Since the survey results represent the perception and opinion of the participating healthcare institutions and the observations reflect the researchers' perception of the flash mob, the results are presented separately, but combined conclusions will be drawn based on both outcomes.

## Results

Based on the researchers' observation notes, we identified four themes in relation to the applicability of the flash mob method for AR eHealth projects, based on the flash mobs we conducted. These themes, Initial hesitation, Interactions outside of the study, Help of insiders, and Purpose of the location, are described in more detail below. The description of the results from the pre- and post-survey, which represent the perspective of participating healthcare institutions, were analysed separately and are presented after the themes.

## Initial hesitation and expectations

In the three-day Exergame flash mob, there were five participants on the first day, eight on the second and thirteen on the last day. According to the organiser from the rehabilitation centre, this was unrelated to the day of the week, since they had actually expected the second day to be the busiest. So it seems that people needed some time after first seeing the flash mob set up, before they eventually got involved. There were also participants who explicitly expressed this initial hesitation, saying that after seeing the flash mob while walking by a few times they got curious and wanted to know more. Finally, there were also people expecting us to be there the whole week, instead of only three days, or saying that they would come back tomorrow while it was already the last day of the study.

## Interactions outside of study

In the Exergame project flash mob study we observed a lot of interactions, questions and attention from people who did not participate (both patients and employees). Some were interested but had no time to participate, others had questions about the eHealth program that was being tested but felt that it was not for them. There were also relatives and non-medical employees whose attention was drawn due to the unusual location of the flash mob. Therefore, from the first Social Robot flash mob on, we explicitly started to count interactions and made notes of remarks outside of the study

questionnaire, to gain insight into these additional interactions. In the two Social Robot flash mobs, part of the interaction with the social robot consisted of filling in a survey on the tablet of the robot. Some participants only completed this activity, but were not willing to fill in the questionnaire about their experience with the social robot.

## Help of insiders

In the Exergame project flash mob, a healthcare professional who participated in the study early on offered to send an email to his colleagues asking them to participate as well. Several participants later stated that they had already seen the flash mob and been interested but only decided to participate after the message from their colleague. There had been an announcement via the internal communication of the rehabilitation centre, but seemingly this had not had the same effect. Similarly, in the second Social Robot flash mob at the nursing home, there were some healthcare professionals who were interested in the social robot and, after participating themselves, motivated patients and other healthcare professionals to participate, in this case by calling them over. We noticed that they only invited specific participants (e.g., saying "This is something for you"), and were not pushing when somebody declined the invitation. While the researchers involved in the different flash mobs invited participants in, the snow-balling started by these insider participants reached people in a different way, and helped draw more attention to the flash mob.

## Purpose of the location

The three flash mob studies were conducted in different locations, serving different purposes (e.g., waiting room, living room, restaurant). The Exergame project flash mob took place in the entrance hall of the rehabilitation centre, which also served as waiting room for the occupational therapists, and as extension of the restaurant during lunch break. The first Social Robot flash mob was conducted in the waiting room of the outpatient clinic at the rehabilitation centre, while in the second Social Robot flash mob, the robot was brought to different departments of the nursing home. There, the flash mob usually took place in the communal space or living rooms of the departments, and in the lunch break the social robot was taken to the canteen. In the first two flash mobs, when people came across the flash mob, they sometimes did not have the time to participate, as they were on their way somewhere, or waiting for an appointment. We tried to make it possible to participate in the waiting time, but this did not always work out as some time was needed to familiarize with the technology and then for filling in the survey. Lack of time was less of a problem in the Social Robot flash mob in the nursing home where the robot was brought to the communal spaces where residents and healthcare professionals were spending time together. As was briefly mentioned before, the different locations also attracted different types of participants, as for example the entrance hall was open to everyone and a lot of people walked by, whereas the outpatient clinic waiting room was mainly populated by patients waiting for their appointment.

## Pre-survey

To include not only the researcher perspective, but evaluate how participating organisations perceived the flash mob, a short pre-survey was sent to the innovation manager at the organising party in the Exergame project flash mob and by two health technology advisors and a nurse in the Social Robot flash mobs. In both studies, the main expectation of the participating organisation was to gain insight into the usefulness and possibilities of the technology that was being tested. This was mostly mentioned in relation to the work of healthcare professionals, but in the Social Robot study, the usefulness for

patients was mentioned as well. There were also some expectations that differed between the studies. For the Exergame project, the organising institute was not only interested in the technology that was being tested, but also wanted to learn about the usefulness of a flash mob study as a way of testing technology in practice. One of the participants from an organising party in the Social Robot flash mob expected that the "*research can lead to possible inspiration in employees*".

Additionally, in the survey participants were asked when they would see the flash mob as successful. In the case of the Exergame flash mob, having more than five participants was seen as a success. This related back to the expectations regarding the flash mob as a method, rather than the evaluation of the technology, since the organising institution had mentioned being interested in carrying out more flash mobs if the initial study showed good outcomes. In the Social Robot flash mob, the main factor to make the flash mob a success was that it provided valuable insights to inform the decision of whether or not to implement (or further investigate) social robots.

There was also room for other comments or remarks at the end of the survey. Two participants in the Social Robot study added that they thought it was "*very nice that the flash mob makes it possible to conduct this study at our location in an accessible way*" and that they were "*very curious*".

## Post-survey

The post-survey in the Exergame project flash mob was again completed by the innovation manager of the organising institution. In the Social Robot flash mob, one of the health technology advisors completed the post-survey. When asked how they perceived the flash mob, both participants called it "*nice*", and one of them added that it was an "*open, transparent, spontaneous*" method. Similarly, both stated that they perceived the study as useful, with one of them saying that it provided "*nice insights*".

The outcomes in both studies were approximately as the participants had expected beforehand. In both cases, the technology was not yet ready to be fully implemented, and there was some scepticism about the usefulness of the technology from healthcare professionals. For the Exergame study, the "*good attendance*" was mentioned as part of the outcome.

When asked about things they would change in a future flash mob, only the participant from the Exergame study answered, saying that more shielding should be provided, as in this study some patients had felt awkward exercising in an open space where a lot of people passed by. Still, the same participant concluded that all eHealth innovations in their organisation could be tested in this way.

## Discussion

To evaluate the applicability of flash mob studies for action research and other participatory approaches in the healthcare and eHealth domain, we conducted three flash mobs, in which we identified the following themes: Initial hesitation, Interactions outside of the study, Help of insiders, and Purpose of the location. Data from surveys with organising institutions as well as observations from the researchers were reflected upon and are combined in the discussion to provide lessons learned for others who wish to implement the flash mob method in their projects. After a discussion of these more general findings, we will go in to more detail discussing the potential of flash mob studies in AR eHealth projects, and finally give recommendations for future flash mob studies.

## General findings

We conducted flash mob studies in two projects that both had the aim to see if a certain technology could and should be implemented in practice. For this use case, we found the method to be valuable,

as we were able to base the decisions on quickly gathered data from practice, and opinions from larger numbers of participants than are usually involved in such short studies. Based on our experience we also foresee a use to answer other (sub-) questions of a research project, like zooming in on aspects of a project that are still unclear, gauging attitude towards a project, testing the feasibility of ideas and generally raising awareness for a project (as a by-product of the flash mob). However, there are aspects to consider when planning a flash mob, as we will outline in the following sections.

From our study, we observed that people are hesitant to take part in the flash mob study and that clear visibility of the flash mob in terms of timing, duration and internal announcements within the whole organization are useful in overcoming the hesitation, especially for healthcare professionals. Other types of announcements, for example via newsletters or information screens might help to attract other participants, like patients, as well. Kersting and colleagues mention that flash mob studies should be used for "*popular and simple research topics*" (Kersting et al., 2022) as these potentially attract more participants. However, their research targeted the general population, whereas for patient groups, a research about their diagnosis could also be interesting. Therefore, future projects wishing to employ the flash mob should prepare a clear and suitable announcement strategy, including information on aim, duration, and target group of the study. In practice, this could for example mean having information posters near the location of the study, as we are thinking to implement in future flash mobs.

In our study, the aim of the flash mobs was not only to gather data, but also outreach, involving and inspiring different stakeholders. As was also mentioned by the organising healthcare institutions in the survey, giving attention to the subject of the flash mob (e.g., for a new eHealth technology, or general innovation policy) is an important goal that the flash mob can also fulfil. However, to our knowledge, previous flash mob studies in healthcare focused on the collection of large quantities of data, and outreach was a side effect at most, as it is expected that studies that draw attention also draw more participants (Moons, 2021). From the second flash mob we conducted, we started to track the number of interactions and made notes of comments or questions we received unobtrusively. It was important to us that our tracking of the outreach would not put an extra burden on participants, nor go against the idea that a flash mob should collect very limit data as "*the research question can be answered with a small data set per patient*" (Schols et al., 2019). In future flash mob studies, we are planning to continue using similar unobtrusive ways of tracking the outreach of the flash mob.

We as researchers were an outside party in all flash mobs and therefore not familiar to the healthcare professionals or patients. What really helped us, especially in the first, and to some extend in the third flash mob, were the efforts of insiders to convince others to participate. All of the healthcare professionals who did so were enthusiastic and motivated to drive the research, characteristics which are often attributed to 'champions' (stakeholders from within an organisation, who drive a project from an intrinsic interest, going further than just what is their job) (Greenhalgh et al., 2004; Hendy & Barlow, 2012). In both of our studies these champions became involved during the conduction of the study, although it would have been ideal to know them and involve them earlier on. Involving champions and other motivated stakeholders, for example for encouraging and inviting in participants, also aligns with the principles of AR, where stakeholders become co-researchers (Reason & Bradbury, 2007). However, it could be argued that recruitment via champions poses ethical issues, as some might be convinced to participate out of obligation to the champion. In our case, the champions were healthcare professionals, who either recruited colleagues (in both projects), or in the case of the Scotty flash mob patients. They only did so after completing the study themselves, therefore they were aware of what was expected. As the champions only asked others to participate but did not push further once somebody declines, we think that their involvement in our studies can be evaluated positively, but future studies should be mindful of whether nobody feels forced to participate, or unethical behaviour takes place. This is something that we and others should continuously reflect on.

A finding from our study was that the location in which a flash mob takes place can influence if and how people participate. For example, during the Exergame flash mob, some participants were

hesitant to try the exergame system while others in the entrance area could see them. Therefore, there are some aspects to consider when choosing a location[2]. First of all, thinking about the target group and their relation to the location is crucial. This can include questions like whether the target group actually comes to this location and whether they have the time to participate in a study while they are there (e.g., patients in a waiting room might have five to ten minutes if they come a bit early, but usually not much more). Similar considerations apply to locations that serve a purpose but might still work as a flash mob location. An example that we also experienced in our study is the canteen or restaurant at an institution. While patients and healthcare professionals come there with a different purpose, they might still be able to make time for the study. Another consideration is the fact that flash mob studies need to take place in open, visible spaces, as opposed to closed off lab settings. In our opinion this holds advantages (reaching different audiences, more attention for the study) as well as disadvantages (feeling ashamed of participation, privacy concerns), and researchers need to weigh these considerations for their study. Especially in studies where participants are asked to perform a task that involves the use of technology, they might feel awkward when others are (potentially) watching them. The importance of participants feeling comfortable in a location where research is taking place has been emphasized before (Fox et al., 2021), and we suggest this should be the primary consideration for studies that require actions from the participants. Additionally, in public locations, people other than those being targeted might be present. They might ask questions and might in some cases even want to participate. It is good to think of a strategy for dealing with such requests beforehand, and testing this in future studies. An example that we are thinking to include in future projects is to have a separate way for non-target group members to give their opinion and feedback (for example a notice board where they can place post-it notes). While it can be nice and information to have conversations with them, this should not distract from the main aim of the study.

As the data we collected in the flash mob studies was not very extensive, it was decided to leave the analysis to the involved researchers. However, in our reporting and dissemination efforts we included the involved institutions, and tried to make our findings understandable and usable for them. We produced fact sheets of the study outcomes, the rehabilitation centre prepared two vlogs (one for the Exergame flash mob and one for the first Social Robot flash mob) which they shared on social media, and we wrote a blog post that informally explained some of our recommendations for future flash mob studies. A key element of flash mob research is the quick analysis and reporting of results. However, in AR, stakeholder become co-researchers and should ideally be involved in the analysis and reporting. This means that they need to make time not only for the conduction of the study but also for data analysis. For some stakeholders, for example healthcare professionals, this can be challenging. Additionally, stakeholders might need additional training in order to be able to analyse data. A more accessible way could be to have focus group discussions with the researchers and stakeholders where the data is presented and discussed together to make meaning of it with the stakeholders.

A limitation of our study is that the flash mob studies in both research projects were driven by the involved healthcare institutions and researchers. Patients were not consulted in the planning of the studies, but only took part as study participants. This decision was taken due to the limited time frame in both projects, as the studies took place in the last months of the run time of the projects. This time-constraint made the flash mob, with its fast paced data collection, analysis and reporting, a very suitable method. However, we expect that involving participants in the conception of the study could have prevented situations like in the Exergame flash mob where participants were uncomfortable performing exercises in the entrance hall.

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[2]In this case, by location we mean the exact spot where a study is conduct, e.g., a waiting room. For selecting the institution or organisation where a flash mob takes place, other considerations are necessary.

# Linking eHealth AR and the flash mob method

To discuss the applicability of the flash mob method for eHealth AR, we will highlight several elements of AR and flash mob studies, and the connection between them. These are (1) AR being situated in a community, (2) AR actively involving various stakeholders, (3) flash mob studies being very fast-paced, and (4) flash mob studies involving large groups of people. Furthermore, we will explain how one of the challenges of flash mob studies that we mentioned earlier, namely (1) the involvement of champions, is mitigated in AR. Throughout this section we describe for which research questions, which stakeholders, and at which stage of an ehealth AR project, flash mob studies hold potential.

A key element of AR is the fact that the research takes place in a community, instead of being carried out in a lab setting for example. While situating a research in practice like that is a good first step, to make such a change last it is important to involve community leaders and for example local government organisations (James & Buffel, 2022). A flash mob study makes the changes brought about in a project very visible, and can be used as a showcase to convince local leaders. Additionally, drawing (media) attention emphasizes the outreach and importance of a project, which might convince local government. In our opinion, flash mob studies to support AR *in practice* work best for communities that have a clear (meeting) space, for example community centres. Of course, the previously mentioned considerations about how suitable a location is for the given flash mob still apply in this case.

In eHealth research in general, but also participatory approaches like AR, those with a higher education level are more likely to participate (James & Buffel, 2022). Furthermore, the decision of who gets to participate frequently lies with the researcher (Vines et al., 2013), and might be based on previous collaborations (Hand et al., 2019). This leads to a biased, select group of participating stakeholders. Flash mob studies can serve as a way of broadening who is involved and lowering the barrier of participation. By making research participation fun, engaging and spontaneous, people who might usually be reluctant or not interested to sign up for research projects can easily get involved. In the Exergame case for example, patients could join without referral from their therapist, who might make mistaken assumptions about whether or not somebody is able to use a technology and wants to participate (Wilderink et al., 2021). Our assumption is that flash mob studies can best support those AR projects (and sub-studies) where no previous knowledge or (digital) skills are required for participation, to allow for a very low barrier and also involve those without affinity with research.

Flash mob studies are meant to be carried out very fast-paced. This not only includes short periods of data collection, but also quick analysis and feedback of outcomes to the involved parties. In our experience, this worked very well. When everybody who is involved is aware of the fact that the analysis and reporting need to happen quickly they can schedule time for this. It is not uncommon for AR processes to take a lot of time (Grant et al., 2008). In our opinion, flash mob studies could be implemented to speed up cycles, and help make quick decisions. An example from our experience is to use a flash mob study to decide whether or not to adopt a new eHealth technology or device. This might also apply in other situations where short input from large groups is more valuable than having thorough conversations with a smaller group. However, we generally believe that the outcomes of a flash mob are more than a "quick and dirty" approach, as the study was quick, but the results were still somewhat detailed, and useful to answer the questions, making it "not dirty" in our opinion.

Another central point of flash mob studies is that large groups of participants can be involved. This is possible even in such a short period of time because the burden for participants, and the time investment required from them, are kept to a minimum. A problem of AR is not only that the process itself takes a lot of time, but because of that, participation in AR also becomes very time-consuming for stakeholders (Grant et al., 2008). We believe that flash mob studies can make research more accessible also for those groups for whom longer term involvement could be a burden, or too time-consuming. This can also be an easy, low threshold way of getting the target group in contact with a research project or with an eHealth technology still under development, which can be interesting at the start of (new phases of) the project.

A problem that we noticed in the way we carried out our flash mobs was that we had little involvement of 'champions' on the work floor. The innovation managers and technology advisors we worked together with helped set up and promote the flash mob, but peer contact (e.g., between physical therapists) worked much better for promoting the flash mobs. However, we expect this to be less of a problem in AR projects, where there is already good contact with some healthcare professionals, as they are likely involved as co-researchers. In our opinion, AR and flash mob studies supplement each other well in projects that already have some involvement from the work floor, but wish to receive additional input from peers.

## Recommendations for future flash mob studies

From our study we can conclude that flash mob studies are a potentially suitable method for eHealth AR projects. For setting up a flash mob study we suggest the following recommendations:

- Find 'champions' from inside the organisation who can invite peers to participate.

- Make people aware of your flash mob beforehand, for example through internal communication channels. This way, spontaneous participation is not excluded, but those who need to consider participation have the time to do so.

- Similarly, during the flash mob have materials present to inform and attract attention of potential participants.

- If general outreach is one of the goals, think about tracking for example the number of interactions (regardless of whether they eventually participated in the flash mob or not), or write down questions and comments you get.

- Consider which location is the most suitable for the purpose of your flash mob. Take into account aspects like accessibility, visibility and activities associated with the location (e.g., canteen).

## Conclusion

In conclusion, the flash mob holds a lot of potential for AR eHealth projects, as it is naturally situated in a practical setting, which also makes it easy to involve relevant stakeholders, even those that might not usually join a research project, by drawing their attention. The fast pace of the flash mob is suitable to speed up the often lengthy cycles in AR. However, as the method is relatively new, and has not been used in studies comparable to ours, there is still a lot to learn. For example, it would be interesting to study the effect of different locations, and promotion strategies, on participation in flash mob studies. Based on our lessons learned, we were already able to make some general recommendations, namely (1) promoting the flash mob on suitable channels ahead of time, (2) also tracking interactions, questions and remarks aside from the study, (3) finding a suitable location for the study and (4) involving insider champions to facilitate participation.

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# Part 3

# Facilitating interaction between stakeholders

The next part looks at the second and third question in the title of this thesis, 'when?' and 'how?' These questions are investigated at the same time because it is difficult to disentangle them; the activities that need to happen differ at the various stages of a project.

# Chapter 7

When various stakeholders work together in a project, it is likely that there are discrepancies between what each party wants and expects from the project. Therefore, this chapters discusses how alignment between different stakeholders can be facilitated. This is a crucial activity at the start of a project, but should also be repeated throughout to make sure everybody is still on the same page.

Chapter 7

**Abstract**

Technological innovations have the potential to support the ageing society, by providing tools to improve quality of life, overall health, preserving independence and reducing loneliness. Acceptance of such innovations and long-term user engagement, however, depends highly on a proper fit between the technology and different kinds of stakeholders (including end-users). In this article, we report on a co-design process with different stakeholders and the negotiation that ensued after the elicitation of their wishes. A first session was held with older adults (n=11, aged 64 to 88 years), leading to nine challenges and opportunities that older adults face. In a second workshop service and technology providers (n=8) jointly ideated new service concepts. This process laid bare the discrepancies between project objectives, end-user challenges, service providers' interests and researcher aims. This article outlines the difficulties when aligning stakeholder interests and suggests interest mapping and direct, iterative dialogue as a possible solution.

## Introduction

There are a variety of health related changes that occur in the process of ageing. Older adults can encounter problems like reduced mobility (Ebeling et al., 2019) or increased loneliness which can lead to decreased quality of life (Boss et al., 2015; Crewdson, 2016). Technological innovations have the potential to support older adults mitigating negative consequences of ageing. For example, technology can improve communication with family and friends for older adults (Blaschke et al., 2009), assist older adults in making it possible to live at home longer (Grossi et al., 2019), increase their physical activity (Cooper et al., 2018; Skjæret et al., 2016), decrease depressive symptoms (Harerimana et al., 2019), or monitor their health remotely (Malwade et al., 2018).

In a review on ageing and technology, Blaschke et al. (2009) conclude that research should include the older users in all stages of the development process. Involving the older adults increases the fit of the developed technology with their needs and practices (Botero & Hyysalo, 2013) and failing to do so can lead to a technology that is based on erroneous assumptions. For instance, in an interview study by Fleming et al. (2018), industry representatives assumed that older adults are less empowered and more passive when it comes to technology. Research is also often based on stereotypical images of older adults (Vines et al., 2015). Blindly trusting on stereotypes, without seeking older adults' input and/or feedback, could lead to the development of a service that is not useful for actual older adults. Durick et al. (2013) argue that low use of technology by older adults is not so much related to their age but rather related to the usefulness and benefits of the technology, as perceived by the older adult. Therefore, they reason that existing mainstream products should be made more adaptable for older persons and that older adults need to be included when such technologies are adapted.

One of the main elements of participatory design is the involvement of "partners as a major driver" (Bødker & Kyng, 2018). Researchers pass some of their control to other partners in order to make the power balance within the project more even (Frisby et al., 2005). In recent years the call for more involvement of potential end-users, for example older adults, has been growing (Kushniruk & Nøhr, 2016). At the same time other stakeholders, like service and technology providers or caregivers should not be left out of the development process (van Gemert-Pijnen et al., 2011). Therefore, older adults as well as service and technology providers are involved in this study. Reviews have shown that researchers tend to take on the perspective of one of the participating stakeholders, often those involved in the financing of the project (Clarke, 2016; Clarke & Davison, 2020). Researchers should be

conscious of this and try to equally involve the different stakeholders, for example by providing them with suitable information materials (Grönvall & Kyng, 2013). However, ensuring the involvement of different stakeholder groups is not enough. The involved stakeholders might have incongruent interest, as will be described in more detail below. In the worst case this could lead to discrepancies or even conflicts between them. Yet, how to deal with these conflicts has remained largely unexplored to date (Cajander & Grünloh, 2019).

This paper outlines a study that is part of a large scale European action research project for active and healthy ageing (Pharaon project) and describes participatory activities involving a variety of stakeholders. The aim is to shed light on views and interests of different parties that are rarely described in research articles but might be inherent in the idea of involving as many key stakeholders as possible. The paper contributes with an overview of congruent and incongruent perspectives, interests or priorities from older adults, service and technology providers, researchers and project management. Furthermore, there are specific points of attention when working with older adults. These will be outlined, together with common problems that older adults are facing regarding their health.

# Background and related works

## Stakeholder involvement and interests

eHealth projects can benefit from the involvement of different stakeholders, as they each bring in their own expertise (Ganesh, 2004; van Gemert-Pijnen et al., 2011). However, discrepancies among stakeholder perspectives can arise due to their different beliefs, intentions or concerns (Andersen et al., 2019; Askedal & Skiftenes Flak, 2017; Johnsen & Normann, 2004; Steen, 2011). Examples of such stakeholder conflicts in eHealth studies can concern topics like efficiency, personalization, willingness to change the current behaviour or enthusiasm about new technology (Askedal & Skiftenes Flak, 2017). Additionally, different stakeholder groups have conflicting motivations that can even lead to them following a hidden agenda when participating in a research project (Klöcker et al., 2015). Whenever these conflicts arise in a project, the goal should therefore be to try and find a solution or compromise to these conflicts. How easily stakeholders will cooperate to find such a compromise depends on different factors (Johnsen & Normann, 2004). According to Johnsen and Normann (2004), stakeholders are more likely to cooperate if a small alteration is necessary, rather than a substantial change. Furthermore, trust influences the stakeholders' willingness to compromise. Being open and trusting towards others is more likely to result in cooperation, while mistrust leads to everyone pursuing their own interest, creating more conflict and possibly endangering the project. Johnsen and Normann (2004) describe this as the difference between deliberation and power play, warning against the negative impact that power play has for the project. Therefore, finding a trusting, compromising relationship between stakeholders from the start is crucial, especially in large scale projects.

## Co-design with older adults

While there is an increased focus on designing products and services for older adults, acceptance is lacking as many products fail to fulfill their needs (Maaß & Buchmüller, 2018). Consequently, the importance of including older adults and care professionals in research processes has become increasingly relevant (Smits et al., 2014). Therefore, participatory design approaches such as co-design have been introduced (L. Sanders, 2012). When applied correctly, co-design allows the researcher to uncover the hidden latent knowledge of users (i.e. what they know, feel and dream) (Sleeswijk Visser et al., 2005) by providing them with tools to express themselves (E. B.-N. Sanders & Stappers, 2008).

These tools are used in generative sessions, where participants follow the framework of make-enact-tell, i.e. developing a vision, putting it into context and explaining it with words and gesture (Brandt et al., 2012).

Several researchers have conducted co-design sessions with older adults, such as Maaß and Buchmüller (2018), who jointly developed an online platform; Davidson and Jensen (2013), who prototyped mobile healthcare applications and Lindsay et al. (2012), who attempted future-scenario development. What becomes apparent from these cases, is that in some cases older adults must be facilitated differently than e.g. younger participants. Ideas can be to keep sessions short to maintain focus (Davidson & Jensen, 2013), to provide support with envisioning novel technologies (Lindsay et al., 2012) and to make the older adults feel valued as experts of their own lives (Maaß & Buchmüller, 2018). Techniques that have proven useful are e.g. cultural probes (Maaß & Buchmüller, 2018), video prompts (Lindsay et al., 2012) and scenario-building (Lindsay et al., 2012; Maaß & Buchmüller, 2018). Other examples of getting closer to the participants' everyday context were applied by Ambe, Brereton, Soro, Chai, et al. (2019) and Altay (2017), who both promote visiting older participants in their own homes.

## Concerns for older adults

Older adults face some challenges that - while not specific to older age - are more relevant to them than to younger users. The European Pharaon project aims to address several of these challenges, three of which will be discussed here in more detail, namely, loneliness, malnutrition and physical activity.

Loneliness has been defined as an aversive experience and reflects a person's subjective experience of deficiencies in their network of social relationships (Russell et al., 1984). Weiss (1973) distinguished social loneliness (occurring through isolation and caused by lack of social integration), and emotional loneliness (caused by an absence of a reliable attachment figure). In the process of ageing, parts of the social network are lost, for example because older adults stop working or because friends and family members pass away (Cornwell & Waite, 2009). The reduced social network can increase the older adults' feelings of loneliness. Reviews have found that loneliness in older adults is associated with lower cognitive function (Boss et al., 2015) and lower mental and physical health (Luanaigh & Lawlor, 2008; Ong et al., 2016). Thus, it is important for older adults to stay connected, and technology can offer different ways of connecting with others, for example through social media or video calls (Baecker et al., 2014).

Another problem that increases with older age is that of malnutrition. The European Society for Clinical Nutrition and Metabolism (ESPEN) defines malnutrition as lowered body mass and different body composition due to decreased nutritional intake (Cederholm et al., 2017). Cederholm et al. (2017) mention advanced age as one of the factors leading to malnutrition. It comes as no surprise that older adults, especially those that are institutionalized, are often malnourished (Kaiser et al., 2010). While good nutrition has a positive effect on different aspects of quality of life, malnutrition can lead to physical and cognitive decline and can even increase mortality (Amarantos et al., 2001; Volkert, 2013). Technology could support older adults in monitoring their nutrition, increasing their awareness of malnutrition and helping them improve their diet (Aure et al., 2020).

In older age, physical activity levels often decline due to the physiological changes that come with ageing, although there is some variability (Chodzko-Zajko et al., 2009). However, especially for older adults, regular physical activity can have psychological and cognitive benefits and can increase life expectancy. This is why physical activity in older adults is encouraged. Interventions that use technology, like for example accelerometers or pedometers, could help to increase physical activity in older adults by allowing them to self-monitor (Cooper et al., 2018).
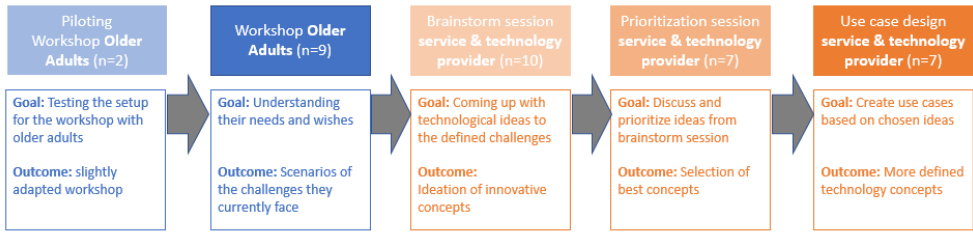
Figure 12: Overview of the sessions in this study, their goal and outcomes.

## Method

In this study, which is part of a European project on healthy and active ageing, different co-design activities were conducted, involving several stakeholders. After a brief description of the project, the sessions that were held with older adults and service and technology providers will be explained.

## Project description

The European project encompasses several pilot sites across Europe which address a variety of challenges related to the promotion of a healthy lifestyle in older adults. A key characteristic of the project is the aim to integrate existing technologies, which means that the partners in the consortium contribute to the project with their current technologies that already have a high technology readiness level (TRL). These technologies are then integrated into an overarching system, without deviating too much from the initial concept. The main aim in the Dutch pilot lies in reducing isolation and loneliness and promoting healthy eating and physical activity, through the use of digital tools.

In order to achieve these research aims, co-design sessions and workshops were held with various stakeholders (see Figure 12). First, a workshop was conducted with nine older adults, which was pilot tested beforehand in a session with two older adults. The aim of the workshop with older adults was to gain insights into the daily lives of older adults and to identify challenges they are facing. These challenges were then presented to service and technology providers in different sessions, to see how their services and technologies could support the older adults in dealing with the challenges and to develop and refine innovative concepts.

## Workshop with older adults

The goal of the first part of the workshop with older adults was to get a better idea of their daily lives and hear what, if anything, they would like to change or improve. The second part of the workshop focused on how the older adults thought they could bring about these changes. Ethical approval was requested and granted by the Ethical committee of the University of Twente, faculty of Electrical Engineering, Mathematics and Computer Science (Reference number: RP 2020-50).

At the beginning of the workshop, participants were asked to describe their typical day related to four categories (Food, Movement, Social Contacts, Outside Activities). The categories were based on the project aims (i.e., support the ageing society by providing tools to improve quality of life, overall

health, preserving independence and reducing loneliness). Participants wrote the elements of their day on differently coloured post-its, indicating the four categories, and attached them to a poster (Figure 13). This exercise is an example of context mapping, as described by Sleeswijk Visser et al. (2005) and is similar to the card sorting of daily routine used in a study by Herpich et al. (2017). After discussing the posters with the group, they received another poster and were asked to recreate the first exercise, this time including what they would like to change or do differently in their daily life. In the last exercise the participants were asked to write a short fantasy story describing how they could bridge the gap between the two days that were described. Instructions were left very broad, as to not limit the creativity of the participants. By drawing lots, participants formed four groups, each focussing (mainly) on one of the topics in their stories. The inspiration for this exercise came from a study by Ambe, Brereton, Soro, Buys, and Roe (2019) with older creative writers. There was room for participants to read these stories aloud at the end of the workshop.

Before the actual workshop took place, a pilot workshop was conducted with two participants (one female, one male; aged 63 and 72) from a research panel of older adults interested in eHealth services. Based on this pilot, some changes were made to the original plan for the workshop. First, it became clear that participants were immediately able to describe activities in the four categories that related to their daily life, without a separate warming up to this activity. Furthermore, the wording in the second activity was important. Both participants in the pilot found it difficult to improve their daily routine as they had accepted their life as it is. Therefore this exercise was rephrased more neutrally, by asking what aspects of the daily routine could be done differently. Lastly, because there were not many improvements participants saw for their daily life, writing a story about their situation was difficult. It was decided to also allow the participants to write about a peer.

The adapted workshop was then held with users of a 'BoodschappenPlusBus' (=GroceryPlusBus, BPB) in the east of the Netherlands. The bus is an initiative of the Dutch National Foundation for the Elderly (NFE), which offers more than a hundred of these busses throughout the Netherlands. Participants can go on diverse trips, for example to a museum or the beach, but also to the supermarket or a mall. The trips are organised by volunteers, who are mostly older adults as well.

For the workshop, seven participants (five female, two male participants; aged between 81 and 88, mean age 84) as well as two BPB volunteers (one male, one female, aged 64 and 73) were recruited. During the workshop, three researchers and two facilitators helped the participants with the exercises, but also stimulated talking, for example, by asking questions about their posters. While the participants were happy to share their answers in an informal way, none of the participants wanted to share the stories they had written in the second part of the workshop with the whole group. After the participants had left, the researchers and facilitators discussed their impressions and the main challenges that they perceived the participants were facing in their daily lives. Additionally, notes and minutes were shared among the researchers. Based on this discussion and the shared notes, challenges were identified and clustered.

## Sessions with service and technology providers

Five partners were involved in the initial phase of the project: an ICT company that supports processes in healthcare, a university spin-off company that develops movement sensors, a research institution that works on different projects related to eHealth and rehabilitation technology, a foundation representing older adults, and finally a (technical) university. Originally, a face-to-face workshop with these service and technology providers had been planned. Due to the national Covid-19 measures this workshop was cancelled. Instead, several online meetings were held, and information was shared digitally. Before the first online session all participants received slides and audio commentary about the outcomes of the workshop with the older adults, including the defined challenges.

Figure 13: Poster used in the workshop with older adults to describe elements of the their daily routine and possible changes to this routine, divided into the four categories.

Adobe Connect[3] was used to video chat and to split the group into breakout rooms during the workshop. The brainstorming activities in the smaller groups were documented using MURAL[4], a web-based tool for visual collaboration. The participants were able to add their own ideas, but could also just talk out loud, in which case the facilitator created notes on the MURAL. Information about the content of the workshop, the instructions on how to use the different tools and supplementary material were sent to all participants via email several days before the session. For each of the four partners, between one and three representatives participated in this first session. Additionally, two design students joined in, adding up to a total of ten participants. The workshop was managed by two university researchers and one researcher from the research institution, who each facilitated one group in the brainstorming sessions.

After a short introduction, the online workshop started with brainstorming sessions in a 'speed dating' style. This meant that the participants worked on different challenges and in different groups each round. A rotation schedule was prepared beforehand to make sure that every provider got to give input on each challenge and had the chance to brainstorm with a representative of each other partner at least once. The digital workspace in MURAL (see Figure 14) was prepared before the workshop and included

- Instructions
- Tips for creative brainstorming
- Areas for each breakout room. Each area consisted of space for 2-3 challenges of older adults, each of which was color coded. Each challenge was divided in three group areas, reflecting the different brainstorming rounds.

Due to time constraints and technical problems with Adobe connect (participants lost connections, had to re-enter the room or lost audio functionality), only two of the three rounds that had been planned were carried out in this first session. Therefore, the participants were asked to document additional ideas to the MURAL workspace themselves in the days after the workshop. During another

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[3]https://www.adobe.com/products/adobeconnect.html
[4]https://mural.co/

Figure 14: Digital Workspace in MURAL, screenshots during the session with post-it notes attached to challenges

meeting a few days later, all technology providers were asked to list the ideas that were the most promising for them.

Based on the selected ideas, use cases were developed by the researchers and presented to the service and technology providers in another online meeting. In the following weeks, several iterations of these use cases were produced, going back and forth between the researchers and the service and technology providers. During mostly bi-weekly online meetings where usually all partners were represented, they discussed their ideas and determined the next steps. Between meetings, these comments were integrated by the researchers, and the partners provided feedback on the new versions of the use cases. As all involved service and technology providers are partners in the project, the meetings with them were less formally structured workshops, but rather sessions to interact and discuss the outcomes.

## Stakeholder interests

During the sessions with service and technology providers, as well as in regular project meetings, there was much attention for the different partners' aims and interests. The aims of the researchers, project management, older adults and service and technology providers were summarized by the researchers and compiled in a matrix to show similarities and differences between the parties.

## Results and Discussion

In the following sections, the results from the stakeholder engagement activities will be described and discussed in relation to the wider literature, starting with the challenges that were mentioned by the older adults. Next, the concepts defined by the service and technology providers are discussed, leading to a reflection on the congruent and incongruent perspectives of the stakeholders and some lessons learned from the process.

## Challenges and opportunities identified from workshop with older adults

From the posters, the stories that participants wrote, and from personal discussions with the participants during the workshop, a set of challenges was identified. The researchers clustered these challenges into three categories: Challenges related to older age as a stage of life, personal circumstances and perception by others (see Figure 15). However, it became apparent that there were also opportunities with regards to healthy and active ageing. In the following, the challenges and opportunities are described and discussed in relation to the wider literature.
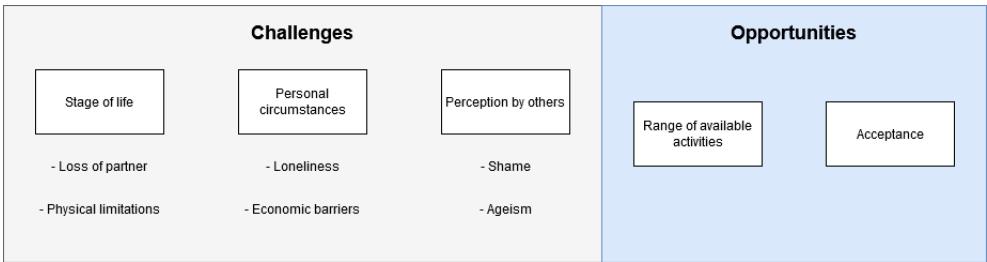


Figure 15: Categories of challenges and opportunities identified from workshop with older adults

### Stage of life

Some of the challenges that were identified can be seen as being directly or indirectly related to the process of ageing. Almost all participants had experienced the loss of a spouse, and some also talked about deaths of friends and family members. Second, participants experienced challenges related to their physical abilities, due to the ageing of their body.

**Loss of partner**    Some participants reported that it is very hard to go out after the death of a partner because usually they would go together but now have to do this fully by themselves. They also reported feeling sad after coming home from a trip, because there was nobody there to tell about their day. This is in line with Spahni et al. (2016) who found greater loneliness, more depressive symptoms and lower levels of satisfaction as a consequence of the death of a spouse. Furthermore, there are different responses to grief that require other forms of support, which should be taken into account in the development of interventions (Ott et al., 2007).

**Physical limitations**    Another recurring theme was increasing physical limitations. Some participants were no longer able to cycle or to go for long walks. While the older adults reported that they were usually able to adapt to this new situation, one participant got very emotional at the prospect of not being able to join the bus trips anymore if her physical abilities would decrease further. So, while physical decline is something to be accepted and dealt with in older age, these physical restrictions also have an impact on other aspects of the older person's life. Additionally, literature shows that

physical decline is related to mental decline (Furtado et al., 2018; Guo et al., 2018). However, technology can provide assistance for dealing with physical decline and the older adults do not have to accept physical restrictions (Tomšič et al., 2018).

## Personal and contextual circumstances

Another set of challenges can be categorized as being related to more specific personal and contextual circumstances. For example, some older adults might experience more loneliness because they are living by themselves, compared to a care home with frequent social activities. Similarly, economical barriers and therefore lack of money for certain activities is a problem for some of the older adults, but not for others.

**Loneliness**   Most of the participants lived alone, often still in their old house, though some had moved to apartments for older adults. Their children usually live far away and are busy, so there is less frequent contact with them. Furthermore, family and social circles are shrinking, because people move (e.g., to retirement homes) or pass away. As one participant put it, "*the group grows smaller and smaller*". It should be noted that this loneliness as described by the older adult is an emotional and subjective perception and not the same as more objective concepts like solitude or isolation (as described for example by Durick et al. (2013); <empty citation><empty citation>citeGray2018). A person who is or lives alone is not necessarily lonely, while somebody who has frequent contact with others can still feel lonely. This challenge should therefore be approached on a more subjective, personal basis.

**Economic barriers**   Even participants who were aware of the options that the bus offered for going out, were sometimes restricted from going. One of the main barriers that was mentioned was the price of, for example, going to a museum. That older adults may face financial challenges later in life is also reported in the wider literature. The cost for care increases with age, and this can lead to substantial expenses (Keating et al., 2014). Together with a small pension or housing costs this can mean that older adults have only little money to spend on activities and leisure time (Delfani et al., 2015).

## Perception by others

Three of the challenges that were mentioned fall into the last category: perception by others. First, participants mentioned that older adults can feel ashamed and judged by their peers or others if they engage in unhealthy or socially unaccepted behaviour. Another challenge regarding how others perceive the older adults is ageism.

**Shame**   Some participants mentioned that they might feel asham- ed when being in contact with others who might judge their behaviour. Specific examples they mentioned were unhealthy eating or alcohol consumption, but also lack of good eating manners. Next to alcohol consumption, literature also mentions eating difficulties as reasons for shame in older adults, but recently not much research has been done on this topic (Menninger, 2002; Nyberg et al., 2015).

**Ageism**   Participants emphasized that younger people sometimes underestimate them, and that they do not like being seen as 'old'. They stated that "*old people stay fitter in their head [...] and then the years do not count*" and that "*a 65 year old can sometimes feel older than a 87 year old*". These

experiences are examples of ageism, or assumptions that are held about a certain age group (Butler, 1969). Ageism is widely spread for example in our media and in healthcare (Sargent-Cox, 2017), yet a review by de São José and Amado (2017) found no studies on interventions to decrease ageism. Ageism is often related to technology use (Lenstra, 2017; Mannheim et al., 2019). Usually, young volunteers are recruited to support older adults in using technology, for example in community centers or libraries (Lenstra, 2017). It is often overlooked that there are older adults that are able to master technology use by themselves and are able to teach others as well. Maaß and Buchmüller (2018) also emphasize that instead of an intergenerational platform, as they had initially envisioned, older adults were more interested in sharing their skills and experiences with peers.

## Opportunities

While the focus of the workshops with older adults was to identify challenges in their daily lives, some of the aspects that the participants discussed in relation to healthy and active ageing were identified as opportunities and strengths.The most prominent ones were the many activities that are offered for older adults and their general attitude of accepting changes that come with older age.

**Wide range of activities for older adults**   While all older adults in the workshop went on trips with the bus, they also all had different other social activities that they joined. These ranged from church dinners and choir repetitions to different sports classes, like Tai chi or swimming. During the workshop some participants requested additional information about activities that they had not heard of and some made notes. This is an opportunity, as activities do not need to be set up from scratch. Rather, there is already a lot out there. The problem is that many people seem to be unaware of these options, or do not know how to approach them. A participant mentioned that it is mostly the same people that go on trips with the bus and asked: "*Where are the others?*" This notion that it can be difficult to engage people in new projects or to keep them engaged after initial contact has been reported before in other studies (Carucci & Toyama, 2019; Lee, 2019).

**Acceptance**   The changing social contacts, losing friends and family and physical decline all demand adjustments from the older adults. Still, the participants were very accepting of these changes that are part of ageing. This is in line with reports that have found older adults to be most content with their lives when compared to younger people (Durick et al., 2013). As one participant advised in her story: "*Don't throw in the towel. Keep doing things as best as you can*". Acceptance is generally positive, for example as a coping strategies to deal with loneliness (Kharicha et al., 2018).However, a danger is that older adults become too accepting and miss out on opportunities.

# Service and technology solutions

The brainstorm and subsequent discussion with service and technology providers initially resulted in three ideas for services that could help older adults solve their daily challenges by building on existing services and technologies. These three concept services were connecting older adults and volunteers, signaling when older adults might be facing health issues, and giving older adults the opportunity to share their experiences with others. Later the first and third concept were combined so that older adults can both share their experiences and be connected to others.

## Connecting and sharing experiences

The first idea that was brought up by the service and technology providers was to connect the older adults, both among themselves and with volunteers like those from the BPB. It was discussed that participants could be matched based on either a common interest or a (care) need, for example needing help with household chores. This idea makes use of the wide range of activities that are offered for older adults, which was seen as an opportunity. Connecting older adults in this way could be effective against the challenge of loneliness as the older adults could meet new people. Furthermore, having a shared interest (e.g., cross-stitching) would provide a topic to start the conversation. Lastly, an older person can be connected with a volunteer who can assist them with chores they are no longer able to do due to physical restrictions. The basis for this service could be provided by the ICT company, in collaboration with the elderly foundation who can reach many older adults and volunteers.

Connecting older participants with others digitally has been the aim in different projects. For example, "connecting with people" was one of the themes that Fronemann et al. (2016) found in their study on enhancing the wellbeing of older adults. In the Brelomate project (Rottermanner et al., 2018), older participants have the opportunity to video chat or play one-on-one online games together. However, this project only mentions the online connection between older adults, while one of the aims described by the service and technology providers is to use the online connection to facilitate offline contact.

The service and technology providers decided to integrate another idea in this concept: sharing experiences. This way, older adults would be able to reminisce together online after they had been on a trip with the BPB. As mentioned before the older adults in the workshop liked talking about trips they previously went on and fretted about not having anyone to share stories with after returning home from a trip. Therefore, the idea for a platform to share these experiences with each other was brought up. The use of such a system could help the older adults deal with their loneliness and the loss of a partner. It would also allow others to see the options that are available for older adults, and see how participants experienced activities like BPB trips. Lastly, if the experiences are also shared with others, for example with grandchildren, it could decrease the perception that older adults are inactive and in need of support. A similar idea to this platform for sharing experiences is already included in a technology that the participating research institution developed together with the elderly foundation and which was planned to be integrated. This could be supplemented with the ICT company's database and infrastructure.

Giving older adults the opportunity to share stories with others digitally is not a new idea. In the 'Historytelling' project (Volkmann et al., 2016), older adults are encouraged to document their personal history and link remembered moments to a time and place. These stories can be shared with other users and family members. More recently, a similar approach has been taken by Li et al. (2018). In their study, older adults are prompted to record audio fragments that they can then share with others, for example their grandchildren. While these two studies are focused on telling the older person's life story, the concept that the service and technology providers have come up with does not aim at the big picture in terms of a complete life story. Instead, the idea is to make smaller everyday events more visible and memorable.

## Signaling

Another concept that was seen as valuable by some of the service and technology providers was the signaling of potentially unhealthy behaviour, health risks or changes in the older person's life. By monitoring for example their eating and drinking patterns or their physical movement, any changes in their behaviour could be noted. Family members or caregivers can then be notified of these changes and choose to act. The way the service and technology providers saw it, this system would be adaptable to monitor a variety of different variables and could therefore also include concepts related to mental

health, like loneliness or grief. For this concept, existing technologies like movement sensors and a nutritional diary could be linked as potential sources of data, and integrated in a combined system.

The technology providers were enthusiastic about the opportunities for expanding this signalling service. Once the general structure is established it would not require much effort to include measures for other (mental) health indicators. Providing a variety of different variables that can be monitored would make the system more adaptable to the needs of each individual user. While for some older adults, diet and movement might be most important, for others loneliness and mental health could be the biggest concerns. Allowing for such personalization would fit in with the advice given by Righi et al. (2017) to design an infrastructure in which older users can make adaptations to have the technology accommodate their own situation.

## Additional interests

Next to the challenges that the older adults talked about and the concepts that the service and technology providers came up with, there were other factors influencing the outcome of this study. On the one hand there was the project aim to integrate existing services instead of developing completely new ones. Additionally, the influence of the researchers in the project should not be neglected. Both perspectives will be briefly elaborated before the discrepancies between the perspectives are outlined.

### Project aim

As mentioned before, this study is part of a larger project which focuses on the integration of existing technologies to help older adults age healthily. So, the goal is explicitly to work with existing technologies instead of developing new services from scratch. The project also emphasizes the participation of end-users and stakeholders as research partners and the need to involve them in co-design sessions. Monitoring overall health status and coaching people to healthier lifestyle is an aim of the project. Despite the fact that the older adults in our workshops did not mention this wish, it is something the project must deliver.

### Researcher

The research team in this project also brought their own interests to the table. One of the main aims for the researchers was to include the voice of the older adults and to focus on problems that they brought up. However, after the national Covid-19 measure became active, preventing face-to-face meetings with older adults, the researchers were more engaged with the service and technology providers, with barely any contact to older adults anymore. It was easier to keep in contact with the service and technology providers online, as these remote channels had already been established before. The researchers also brought in some interests with regards to the co-design methods. They were inspired by different creative design methods and tried to incorporate those in the different stakeholder and end-user workshops. Finally, as part of the research team worked for one of the service and technology providers, these interests sometimes overlapped.

## Congruences and incongruences between the different stakeholder interests

When aligning the outcomes from the previous sessions it became apparent that there was some dissonance between 1) the challenges that were described by the older adults, 2) the ideas that the tech-

| | Researcher | Older adults | Service and technology providers | Project aims |
|---|---|---|---|---|
| Researchers | | + Involvement of end-users | + Involvement of stakeholders | + Action research / participatory methodology |
| | | - Need to change<br>- Use of creative methods | - Older adults are starting point (not technology) | - Innovation vs. Integration |
| Older adults | | | + Supporting older adults | + Supporting older adults |
| | | | - Challenges vs. Concepts<br>- Contextual problem solving vs. technology driven approach | - Need to change<br>- Given challenges |
| Service and technology providers | | | | + Use existing technology |
| | | | | - Feasibility to integrate on large scale |
| Project aims | | | | |

Figure 16: Overview of congruent (green) and incongruent (red) interest between the four parties.

nology providers wanted to develop, 3) the researchers ideas and plans for the study, and 4) what was demanded from the overall project's perspective. Generally, such incongruences are neither unusual nor necessarily a bad thing, as the involvement of different stakeholders helps develop and implement a fitting technology (van Gemert-Pijnen et al., 2011). However, it is important to identify any potentially conflicting interests early on, especially because they are often not voiced explicitly, but remain rather implicit. The same was true in this project. While the meetings with the different stakeholders were harmonious and no conflicts occurred, some incongruences could be noticed when reflecting on the project. If such differences of interest are not acknowledged and discussed explicitly, they can become bigger problems and even endanger the completion of the project (Mysore et al., 2019).

It should be noted that different interests can also exist or arise within a certain group (e.g. service and technology providers have conflicting ideas, older adults emphasize different topics or researchers disagree over parts of the study). However, mapping these incongruences within parties goes beyond the scope of this paper, therefore only the differences between the four parties in this study (Researchers, older adults, service and technology providers and the project aims and guidelines) are described here. Figure 16 gives an overview of the congruent and incongruent interests of the different stakeholder groups. Overall, these points can be summarized in three different categories: interests regarding methodology, regarding content and ideas about what is feasible.

## Methodological interests

Overall, the different parties agreed on stakeholder involvement and participatory methodology as the starting point for this research. However, some differences in interest between the groups became apparent with regards to the methods of the research. The stakeholder participation in the different workshops, especially in the session with older adults, was rather low when it came to the envisioned

exercises. While the researchers had expected the use of creative methods to be beneficial to the outcomes of the workshop, the stakeholders seemed less interested in the creative exercises. This relates to what Braten (1973) describes as 'Model monopoly', "*in which the professional researcher dominates the conversation*" (Hayes, 2011). Steen (2011) suggests that researchers should deal with this tension by reflecting and becoming aware of their role in the project.

Additionally, not all parties shared the same idea on what the starting point of the research should be. The researchers were interested to first hear from the older adults as envisioned end-users and to use their stories as a basis. On the other hand, the service and technology providers and the project guidelines lay more emphasis on the integration of existing technologies, and were less interested in innovation.

## Content

While the partners overall agreed that the service should offer content that supports the older adults, their opinions differed with regard to what this content should be. The first incongruence became apparent between the challenges that were described by the older adults and the concepts that the service and technology providers suggested. None of the suggested concepts tackle the problems that were mentioned regarding economical barriers, shame, and acceptance.

Furthermore, ageism was only touched upon in the concept of "sharing an experience". In contrast, with the signalling concept the service and technology providers suggested a solution that did not directly target any of the challenges that the older adults had described. Additionally, some challenges had already been defined in the project guidelines before the workshop with older adults took place and these challenges only partially match those challenges that were mentioned by the older adults. There was also some disagreement about the 'need for change' of older adults. While the project and the researchers focus on changing some part of the older adults life to improve their health, the older participants generally did not see any need to change something in their lives. This was underlined by the challenge of 'acceptance'.

## Feasibility

The last category of incongruences concerns what is feasible within the project. On the one hand this is about the integration of the existing technologies, which service and technology providers and the project agree upon. However, but it is still unclear what this integration will look like. Furthermore, the technologies do not always fit well with the needs and challenges that were voiced by the older adults, and in some cases by other service providers. Therefore, addressing all proposed challenges with the technology at hand is often not feasible. Similarly, Peek et al. (2016) describe how it is not possible to address the various needs that older adults have in a single technology.

# Lessons learned

A positive aspect that had not been anticipated beforehand was the value of conversations outside of the exercises, both between researchers and participants, and among the older adults themselves. This became apparent right at the start of the workshop, when, as an icebreaker, participants were asked about the best trip they had had with the BPB. They were very enthusiastic when talking about these trips and interacted with each other a lot, for example, by asking questions, adding their memory of the day or just voicing their agreement. Later on in the workshop, the participants seemed to enjoy talking about their lives on a more abstract level, comparing their daily tasks to those of others. This also included discussing topics that they would usually not talk about, like the sadness upon returning

to an empty home after a trip with the bus. Even though some of the participants knew each other from trips with the bus they had never really had contact outside of the activities. At the end of the session, three participants exchanged addresses and phone numbers to stay in contact more. This experience shows that it is beneficial to include room for unstructured spontaneous conversations in a workshop, as these can be very informative.

While the older adults enjoyed participating in the workshop, and were overall very willing to share their experiences, they found it difficult to write a fantasy story that bridges the gap between their current typical day and the improved day. This was related to the fact that they saw little room for improvement in their day and therefore did not envision a clear situation to write about. However, writing stories seems to be a difficult exercise for some regardless. For instance, the older adults in the study by Ambe, Brereton, Soro, Buys, and Roe (2019) were (amateur) writers, and therefore more familiar with writing (fantasy) stories. Furthermore, Malmborg et al. (2016) mention that some older adults might generally dislike more 'creative' co-design methods.

Older adults specifically seem to be a group that is often misunderstood or judged wrongly by various other stakeholders. Literature points out different opinions or values between older adults and relatives, care professionals, local governments, businesses and service providers (Farmer et al., 2010; Huh et al., 2013; Kolkowska et al., 2017; Teles et al., 2017). However, Teles et al. (2017) argue that these conflicts can be overcome by collaborating with multiple stakeholders. Initially, the plan was to have a meeting including both service and technology providers and older adults to decide on the concepts together. However, the national Covid-19 measures made this impossible. Aligning the aims of the different stakeholders face-to-face and being able to directly respond to each other and ask questions might have led to other outcomes. This was also recommended by Greenhalgh et al. (2012), in that "*more effective inter-stakeholder dialogue must occur to establish an organising vision that better accommodates competing discourses*". As Greenhalgh et al. point out, however, consensus might be neither realistic nor a desirable goal, but such a dialogue can lead to accommodation in which other perspectives and practices are acknowledged and adapted towards (Greenhalgh et al., 2012).

This project has shown that the process of aligning stakeholder interests takes time and several iterations. Coming together in different groups (e.g. first within a stakeholder group, later combined), and using different methods for alignment (like the matrix suggested above, repertory grids (Buchan et al., 2017) or stakeholder tokens (Yoo, 2018)) can make needs more tangible, both for the stakeholders themselves, and between groups. This can be enhanced by including the relations that form between individual stakeholders or stakeholder groups (Dantec & DiSalvo, 2013). In the current situation it will be challenging to adapt these methods to make them work in an online setting. However, a positive side effect of the current pandemic is that most people, and especially older adults, have become more proficient using online tools (Morrow-Howell et al., 2020). Additionally, there are ways of letting older adults share their ideas in online research that were proven before, for example through blogs (Genoe et al., 2016) or discussion boards (Nahm et al., 2009). Therefore, our suggestion for future projects is to take some time to align stakeholder interests and to return to this point throughout the project. For example, our team has incorporated regular check-ins asking about each partners aim for the overall project, their goals for the coming period or even their wishes for the current meeting.

While stakeholder involvement is increasing, and different stakeholder groups like user, care professionals or technology developers are being included, researchers tend to see themselves as separate from these groups. However, as Steen (2011) describes, researchers have an important position in the project, which is sometimes in disagreement with that of users or other stakeholders. He suggests that researchers should therefore examine their own role and reflect on the decisions they made. By including our research team as one of the stakeholders in our analysis we tried to be reflective of our actions. This is an important first step to enable mapping out stakeholder interests and identify potential conflicts as was done in this paper. However, the stakeholder interests were identified and described by the authors of this paper and not articulated by each stakeholder during the mapping activity. The process of aligning stakeholder interests would benefit from following a participatory

approach in which stakeholders can represent their own interests and identify potential conflicts with interests of others. This could strengthen the role of other stakeholders and help equalize the power balance in the project (Frisby et al., 2005).

From the onset of the project the aim was to develop a technological solution that does not reinforce ageist stereotypes, which is why a co-design approach was chosen. Despite this overarching aim and being critically aware of our own implicit biases, the nature of the project (integration of existing technologies) and methodological decisions might still have some ageist assumptions embedded of which we were not aware at the time. For instance, by applying a problem-solving approach in the workshop with older adults, this activity focused on challenges not on strengths. It became apparent that ageism is not eradicated through self-awareness alone and sometimes the critical eye of an external party is needed. Researchers working with older adults should let their work be checked periodically.

## Limitations

One limitation of this study is participant bias. The older adults in both the workshop and the pilot were very active and outgoing. However, especially in the pilot study, the participants talked about others in their community or surroundings that are less active. Furthermore, the National Foundation for the Elderly that was involved represents a much broader group of older adults. Therefore, the challenges that were mentioned apply not only to active older adults, but also to those who are less involved in a community. Nonetheless the aim for future studies should be to also include other older adults, who might be harder to reach.

Due to the national Covid-19 measures, meetings between the older adults and the service and technology providers were not possible. Such a meeting had originally been planned to stimulate conversations between the stakeholders. As was stated above, such direct discourse between the stakeholders could have helped mitigate the discrepancies between the challenges put forward and the solutions ideated and might even have led to a consensus between them. The service and technology providers were included in online discussions on this topic, but it was expected that it would be too difficult to involve older adults in these online sessions. However, the online meetings included representatives of the National Foundation for the Elderly. Nevertheless, direct contact between older adults and service and technology providers would have been preferable.
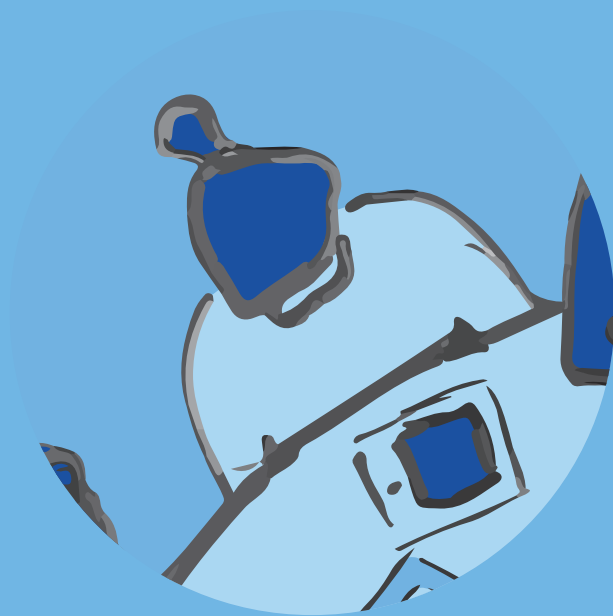
## Conclusion

This study describes the start of a large scale project that involves older adults and service and technology providers, as well as the researchers and overarching project aims. In this paper the different interests of these various parties are made explicit. Generally, opinions differed when it comes to methodological or content-related topics, or issues of feasibility. While such incongruences often remain implicit, mapping and discussing the different positions can enhance the cooperation between parties. Projects should pay attention to the interests of involved parties and foster open communication between them to prevent conflicts later on in the process. Furthermore, researchers should not shy away from reflection on their own role in the project and critically examine themselves as one of the stakeholders. Lastly, accidental ageism can happen even to those researchers who actively try prevent this. They should be reflective and engage in discussion with others to see where they might be overlooking their own ageist assumptions.

## Acknowledgements

# Chapter 8

Reflection is a key element of action research, and should take place frequently. This chapters describes a method for involving stakeholders in this reflection as well. The tool, consisting of questions to be answered with the project team, can help researchers make sure that all voices are heard, and steps can be taken that benefit the project in the future.

**Abstract**

One of the principles of Action Research (AR) is ongoing reflection on the process at different time points. This reflection includes all relevant stakeholders, who are actively involved in AR, and helps the team identify what went well and what did not in a previous project cycle, and based on these findings new plans can be formed for the next AR cycle. Reporting on lessons learned from such reflection also benefits other projects. However, there are limited resources to help researchers conduct reflection meetings. In this paper we describe how we iteratively developed a reflection guide for AR, which can help researchers shape their reflection meetings with stakeholders. The guide was developed in five phases within a large European eHealth AR project. Pilots used the guide and provided feedback on each iteration. Webinars and surveys were used to gather feedback. Additionally, we used the guide to prepare and conduct a cross-pilot reflection meeting. The outcome of these activities fed into the final version of our reflection guide for AR, which is presented in this paper. Our study shows that the guide facilitates reflection within an AR team, and makes it easier for projects to share their process related lessons learned with others.

## Introduction

eHealth research increasingly pays attention to the active involvement of stakeholders, and a methodology for doing so is Action Research (AR). AR is based on four key principles, namely (1) involving stakeholders as co-researchers, (2) situating research in the community that should benefit from it, (3) making a change in practice while also extending scientific knowledge and (4) doing research in an iterative, cyclical way that involves continuous reflection and changes made based on said reflection (Reason & Bradbury, 2007). Kjellström and Mitchell (2019) describe reflection as "*a process of learning from experience, where the individual considers, thinks and responds to a specific problem situation*". They distinguish between reflection and reflexivity, whereby the latter "*is a more ambitious and challenging process of thinking about your own way of thinking, assumptions and underlying patterns of values and world views*" (Kjellström & Mitchell, 2019). In AR, researchers should use both reflection and reflexivity throughout the project.

Bradbury and colleagues mention reflexivity as one of their quality choice point for AR (Bradbury et al., 2019). Similarly, based on a literature review of challenges in AR, to cope with these challenges Lake and Wendland (2018) recommend self-reflexivity as well as continuous evaluation and dialogue with stakeholders. Reflection has several benefits for a project, for example helping researchers decrease inequality and marginalization by raising awareness of these issues (Kwan & Walsh, 2018). Additionally, conversations and reflection with partners help determine a positive course for the project (Ollila & Yström, 2020). Finally, reflection offers opportunities for others to learn from previous AR projects and benefit from the experiences and lessons learned.

However, AR projects often lack a clear reporting on the reflection process and outcomes (Holeman & Kane, 2020; Kjellström & Mitchell, 2019; Oberschmidt et al., 2022). And even in AR studies where reflection was included and described, a "majority of the studies focused primarily on process and formative evaluation but not sustaining the practice or improving clinical outcomes" (Soh et al., 2011). Additionally, due to the very practical focus of AR, especially practitioners involved in the project might be more interested in concrete actions and activities following from the reflection, rather than in the activity of reflecting and evaluating (Ollila & Yström, 2020). So, while the benefits of reflection, like decreasing inequality and helping other projects, are generally known and acknowledged, in practice the reflective element of AR is often not well reported on, making it difficult for the researchers to bring their project further, and for others to learn from their work.

There are some existing suggestions for methods that researchers can use to reflect on their role in, and influence on, the project, like auto-ethnography (Lake & Wendland, 2018). Examples exist of collaborative auto-ethnography (Groot et al., 2019). However, oftentimes only the reflection and perspective of the researchers are included, while within AR, stakeholders become co-researchers, and should therefore be actively involved in the reflection as well. The process described by Gustavsson and Andersson (2019) can be seen as a way of reflecting with stakeholders, but it is rather specific to their project and does not include concrete steps to follow. Some action researchers have written self-reflectively about their AR, often spanning several projects (Boulus-Rødje, 2014; Hadfield, 2012; Luguetti et al., 2023). Again, what is missing is a structured way of collaborative reflection in research projects in order to not only improve the project and jointly develop lessons learned, but also to share

the outcomes with others outside the project. Costello et al. (2015) describe how structured reflection can make it easier to implement what was learned in practice. We therefore suggest a guide for structured reflection in AR projects. The aim of this research was to develop and evaluate a guide that researchers can use for collaborative reflection together with involved stakeholders in eHealth AR.

## Setting

This study was conducted within a large-scale European AR project that aims to integrate technologies for healthy ageing and implement them in practice. The project work was conducted in seven pilot sites, located in five different countries (Italy, The Netherlands, Slovenia, Spain and Portugal). Each pilot was coordinated by a so-called pilot lead, commonly a researcher from a participating research institution. These pilot leads largely had no or only little experience with AR. Two of the authors were responsible for the overarching coordination of these pilots, with one being the overall coordinator, and the other supporting this work as a PhD student. This meant for example that they had frequent meetings with the pilot leads, and supported them in conducting AR in their pilots and aligning the pilots with each other and the general project goals. One way of doing so was to respond to their questions and needs related to carrying out AR. This is how the idea for this reflection tool came about, as pilot leads were wondering how to carry out the reflections best to reflect within their pilot, and because as general coordinators, we wanted to find a way to synthesise and compare findings between the pilots on what worked or did not work for them. The pilots mainly had very practical questions and issues they faced, and were very action oriented in their way of working. Therefore, we focused on reflections on pragmatic aspects and the process of doing AR, which they could hopefully directly implement in their work. The first author took the lead for the activities around the reflection described here, supervised by the second author (directly involved in the project as pilot coordinator) and the third author (not involved in the project, but as promotor for the PhD of the first author). While the pilots were coordinated by a pilot lead, the team carrying out the activities in each pilot consisted of different types of organisations, for example, healthcare organisations (e.g., hospitals), representatives of stakeholder groups (e.g., foundation for older adults) and service and technology providers (e.g., developers). The pilot leads were our main contact point for this study, participating in the different research activities and providing input from their respective pilot. However, the whole pilot team made use of the reflection guide together during reflection sessions.

## Development of the reflection guide

The reflection guide was developed in five phases. Different methods were used at different stages of the process, depending on what we felt was the most useful at that time (e.g., individual vs. group activities). In a sense, the development of the guide was done through AR as well, as we worked in iterations, with stakeholders who used the guide in their practice during the development, and we continuously evaluated the process and used our own reflections to improve the guide. This allowed us to stay close to the needs and wishes of the pilot leads. It also meant that we started the process without a defined end-point, and open to suggestions or ideas from the pilots. An overview of this process can be found in Figure 17. In the sections below, the method and outcomes of each phase will be described, followed by a more detailed description of the final reflection guide.
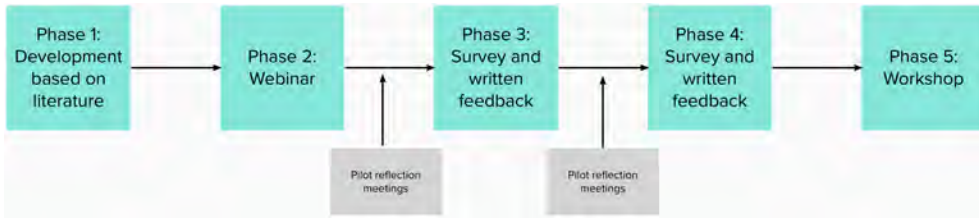
Figure 17: Overview of the different phases, including the methods used to improve the reflection guide

## Phase 1 - development based on literature

The initial version was developed based on a reflection guide for teachers as described in Madin and Swanto (2019). The pilot leads were interested in seeing concrete questions that they could answer in a reflection session. Therefore, this guide for teachers was a good starting point, as it included the type of practical questions that we were looking for. This guide for teachers focuses on individual reflection and consists of 39 questions. These questions are sorted into the following eight sections (with sub-aspects per section in brackets: Introduction (Overview and research context; Teaching and learning experiences), Research Focus (Selection of research focus; Initial data collection; Action), Research objectives and research questions, Research participants, Research implementation, Research findings, Reflections, Further recommendations. Each section or aspect contains between two and six open questions, for example, "What are my interpretations from the findings?". As this example shows, the questions are written from the perspective of the researcher.

As we wanted to facilitate discussions amongst participants in a stakeholder meeting, we made some adaptations to arrive at the first version of our guide. To allow for enough room for conversation, we decided that having fewer but more focused questions would be more useful. Therefore, the guide was shortened to ten questions (eight to be discussed in every meeting and two additional questions from the second reflection onward to look back at what was previously discussed). We also rephrased the questions from "I" to "You" or more neutral formulations without pronouns (for example: "What do these outcomes and reflections mean for the future?"). Moreover, as the reflection guide we referenced was focused on teachers, all questions related to the teaching process were removed. Similarly, some questions had to be revised to exclude references to teaching and the classroom (e.g., changing "From my teaching experiences, what specific issue(s) bothered me a lot? Why did the issue(s) arise?" to "What bothered you? Why / how did this happen?"). As these examples show, the language of the questions was generally simplified, to make the reflection guide accessible and easy to use for stakeholders of different educational levels. The initial version was developed by the first author, and briefly discussed with the second author.

The initial version of the reflection guide included four sections, namely questions about the GENERAL PROCESS (four questions), the RESEARCH PROCESS (two questions), a section on LOOKING FORWARD (two questions), and a section of questions to be answered from the second evaluation meeting onward (two questions).

## Phase 2 - adaptation based on webinar

To prepare a new iteration of the reflection guide, the guide was shared with project partners, specifically the pilot leaders who were expected to use it for collaborative reflection within the project. As they were the ones bringing the reflection guide into the project teams, we wanted to hear from them how they perceived the process, but also which feedback they got from the other partners in the project team. We shared a first version of the reflection tool in a webinar format, which was hosted on Microsoft Teams. Participants to the webinar (i.e. pilot leads) received the reflection guide beforehand so that they could already have a look and prepare questions. During the webinar, the first author gave a presentation that briefly described each section and provided some examples. Then, the sections were again shown one by one, and the pilot leads could make remarks or ask questions by using the chat or unmuting their microphone. There was also room for general discussions and questions. In total, the session lasted around 30 minutes.

During the session, one of the participants suggested to add some rules for how to behave during the reflection meeting (e.g., letting everybody talk and finish their point). Based on this suggestion, we discussed what could be included in such a set of 'ground-rules'. The list was then added at the start of the reflection guide to facilitate open and honest participation of all involved stakeholders. The ground-rules that were provided in the second iteration of the guide (based on input we got during the session) were the following:

- All participants need to be able to speak their mind freely and honestly. This includes any criticism of other parties that are present.
- Listen actively and respectfully.
- Do not interrupt each other but wait and take turns.
- Give everybody the chance to speak.
- Be constructive and polite.

Below the list of ground-rules, we added a statement encouraging users of the reflection guide to discuss and where necessary extend this list together with the participants in their reflection meeting. No additional ideas were suggested during the webinar, but pilot leads were curious to try the guide in practice together with stakeholders in their project team.

## Phase 3 - adaptations based on first survey

The third phase took place after pilot leads had the chance to use the proposed guide in a reflection meeting in their pilot. Instead of another webinar session to evaluate the guide, we decided to send out a questionnaire, to get more structured, individual responses. In this questionnaire, participants were asked if they had yet had a reflection meeting, and whether or not the used (an adapted version of) the guide during the meeting (closed questions). The options to use an adapted version of the guide was given to allow for a better fit with each given context (e.g. allowing for translation or an online format). Suggestions from pilots who used the guide in an adapted format were still included for the improvement towards a new version of the framework. Pilot leads were then asked to give their reasoning for not using the guide, describe how they had adjusted the guide, or share their experience working with the guide (open questions). We were aware that the pilots all worked in different contexts and with different stakeholders groups, and understood that this might necessitate an adjusted approach for using the framework. Therefore, we did not oblige them to strictly follow the guide as described, but rather tried to learn from the adjustments they made. There was also room for additional remarks or questions, or to make concrete suggestions for adaptations to the guide (open

questions). Pilot leads could also send an email with additional remarks and comments to the first authors if they wished to do so, but none of them did.

There were nine participants who filled in the initial survey because for some pilots, more than one person responded as they lead the activities collaboratively. Of these nine, six had already had a reflection meeting, while three had not. In those cases where no meeting had taken place, this was due to the pilot still being in an early stage, or due to stakeholders being unavailable because of the holiday period. Of the group that had already had a meeting, three did not use the provided reflection. One of them explained that they "*used the tool for inspiration*", but adjusted the meeting to the need they perceived in their pilot, focusing on some specific topics that were the most relevant to them at that time. One pilot lead mentioned that their pilot used an adapted version of the guide, performing 'informal' reflection on topics similar to those in the guide. Of the two pilot leads that incorporated the guide as suggested, one described their experience in detail. The reflection guide gave them "*a good opportunity to talk about organizational/logistic topics as well as other stuff*". Additionally they mentioned that they had sent out an online questionnaire containing the questions of the tool to prepare for the meeting, which gave a nice opportunity to also get feedback from those who could not attend the meeting. The pilot lead also shared a screenshot from the online collaboration tool that they had used. They structured the digital whiteboard based on the sections and questions from the guide, and participants added differently coloured notes (one colour per stakeholder) to each question. At a later stage, another pilot lead shared the approach they had taken, which involved oral discussions of the questions, with the pilot leads summarising and taking notes. These two examples show the flexible use of the tool to different groups and contexts.

There were two concrete suggestions regarding the content of the reflection guide. First, a pilot lead pointed out that they found it difficult to answer questions related to research questions if no researcher was present. Here, some concrete examples were added to make it more apparent what the question referred to. Additionally, the language was in some cases perceived as difficult, which was partially related to English not being the mother tongue of the participating parties. Some small changes were made to simplify these questions. As for overall remarks, both pilot leads who had, and those who had not used the guide remarked that it "*appears relevant, useful and adequate*" and that "*it seems understandable*".

While integrating the feedback we received from the survey, the authors also reflected on the aim of the guide, and whether this aim was fully achieved. It was at this point that we started to think that the guide could not only help projects to collaboratively develop lessons learned, but that this could also make it easier to report on reflection in a structured way. We therefore decided to add a question asking stakeholders to write down concrete recommendations in the Looking forward section. The idea behind this section was that writing down recommendations in a clear and structured way would not only be useful for the continuation of the project, but also be a first step towards later including these recommendations in publications and reports.

## Phase 4 - adaptations based on second survey

A second survey was sent out after pilots had conducted their second reflection meeting, using a newly iterated version of the guide that was improved based on feedback from the initial survey. The questions asked in the second survey were the same as previously, and once again, pilots could email additional comments to the first author. Furthermore, in preparation of the final iteration, they were asked to send us an anonymized summary of (the outcomes of) their reflection meeting. In this way we hoped to learn more about how they had conducted the meeting, and what kind of insights they got from using the guide.

In the second survey, one pilot representative commented that they were unsure how to use the reflection guide. They raised questions like "*How many people should do this exercise?*" and com-

mented that "*completing this document takes a lot of time*". It became apparent that this had been a misunderstanding as they also said "*everybody is sitting down completing a form rather than talking to each other*", which was not our intention. While we had discussed this during the webinar, this comment helped us understand that for use in other projects, instructions or suggestions for how to use the guide should be written down and added to the reflection guide document, much like the ground rules that were added in Phase 2. To prepare a 'suggested use' section, we made use of the comments and information we received from the other pilots. For example, several of them mentioned sending the questions to the participants of the meeting beforehand so that they could prepare. Whether or not they collected the answers beforehand differed. One pilot made use of an online collaboration tool (MURAL) to collect answers during the session.

During this survey, some pilot leads responded that the guide seemed complete to them, with one pilot lead saying "*The usage of this reflection tool was helpful for all our team. There were no missing questions*". Because of these comments, we decided to finish the development after one final iteration (Phase 5).

## Phase 5 - adaptations based on workshop

To demonstrate a way of using the outcomes of the reflection guide in practice, we organised a final workshop. The workshop had the additional aim of benefiting the project by sharing lessons learned and experiences between the pilots. This time, the workshop took place in person, during a project meeting. To prepare for the session, all pilots were asked to provide us with summarized outcomes of their earlier reflection meetings. The session focused on two specific elements: issues that the pilots were facing (and how to overcome them) as well as recommendations and best practices on what worked well for them. For the first part we prepared posters with issues on them that were common between the pilots (e.g., keeping up the engagement of study participants). During the first half of the workshop, participating pilot representatives walked around and discussed amongst each other and proposed solutions for the issues, which they added onto the poster with post-it notes. The second half of the workshop was focused on determining common best practices and recommendations. For this part of the workshop, we again took input from the materials provided by the pilot leads beforehand, and structured their mentioned best practices into different categories (e.g. making use of specific tools). The posters of these categories already included some post-it notes with recommendations from the collected information, to stimulate the discussions. Again, participants walked around, discussed, and this time added supplementary best practices to the posters. After the session had ended, all notes were digitized and sent around, without changing or structuring them in any way, so as not to bias the output. In this way, pilot leads were able to implement the proposed solutions and best practices from others in their own work. The aim of this session was to see how the outcomes of the reflection could be used outside of the isolated context of each pilot project.

This research took place in a rather unique setting, with different, but connected pilots taking place in several locations. As they were facing similar issues, and working in comparable ways, the workshop was very fruitful and lead to knowledge exchange and sharing of ideas. Participants to the session commented that they had gotten some new ideas to implement in their pilot, and generally saw the session as valuable. Additionally, one pilot suggesting writing a paper together to also present the lessons learned in the wider scientific community. Not only for this purpose, the session was well received, and pilots also went to share the outcomes of the workshop with others in their pilot team, to implement what they had learned from each other. We understand that using the outcomes of the reflection guide in such a way will not be possible in other projects, where there is no connection to similar projects, like that between the pilots in this case. However, we believe that there are other opportunities to achieve similar outcomes, which we will comment on in the discussion section of this paper.

## Final version of the reflection guide

The final version of the reflection guide contains the same sections as the initial version of the reflection guide (Phase 1): General process, the Research process, a section on Looking forward, and a section of questions to be answered from the second evaluation meeting onward. Except for the question about recommendations that was added to the Looking forward section in Phase 3, the amount of questions within each section also remained the same (four questions about the general process, two about the research process and two questions to be answered from the second meeting onward). There were only small changes to the phrasing of some questions (see Phase 3). Two additions were made to the guide, namely the set of ground rules added in Phase 2, as well as suggestions on how to implement and use the guide (see Phase 4). The full guide can be found in Appendix 8.1.

## Discussion

Reflection is an important element of AR, both for working together effectively within the project team, and for allowing (scientific) knowledge sharing beyond the research project. We developed a guide to support AR project teams in their reflection and to hopefully facilitate knowledge sharing within and between projects.

AR projects bring together various different stakeholders as co-researchers in project teams. This can include parties with very different backgrounds, and different aims within the project which might be incongruous and difficult to align (Oberschmidt et al., 2020). The reflective element of AR can help project groups solve conflicts that may arise during the project (Gozzoli & Frascaroli, 2012) and our guide aims to support such reflection. Eventually, AR should not only make a change in practice, but also make a scientific contribution. However, before being able to communicate about a project externally, it is important to consider whether the communication within the project is effective (Fischhoff, 2019). We think that the reflection guide, and the accompanying, structured reflective meetings, can help a project team to first sort out any questions or issues internally, providing a basis for broader sharing of the resulting knowledge. Some of the participants in our study also mentioned explicitly that the whole project team benefited from use of the guide, not only the researchers. The reflection guide therefore indirectly supports the active involvement of stakeholders in AR projects, by facilitating reflection and communication between the different parties.

Oftentimes, reporting of research projects is very much focused on the output and achievements of the project, which puts a lot of pressure on the project team, and specifically researchers, to have presentable findings (Knowles et al., 2021). Additionally, researchers expect that "deviation from the planned protocol [will] be reviewed negatively by peers and supervisors" (Knowles et al., 2021). However, actually explaining and reflection on such deviations might provide valuable input for similar projects (Knowles et al., 2021), yet such process-related lessons learned are rarely explicitly included in literature (Oberschmidt et al., 2022). The reflection guide facilitates and supports project teams to explicitly formulate their lessons learned, making it easier for them to share this knowledge with others, whether informally or in scientific publication. We experienced this ourselves in the final session that we held. Beforehand we collected the input from all pilots, and prepared the session accordingly. Then during the workshop, problems they were still facing, and recommendations they would make to others were discussed, sharing knowledge with each other in a very tangible and concrete way. One of the pilots also suggested turning the lessons learned and recommendations into a scientific paper together, thus ensuring that the knowledge was also available beyond the project.

While such knowledge sharing is very important, and can be valuable to the project at hand as well as to others, it can be difficult to integrate similar activities in a stand-alone project. Our project offered the unique structure of pilots working in different but related contexts, with one overarching aim, therefore allowing them to share knowledge within the project. For projects where this is not

the case, ideas for sharing one's own knowledge on the one hand, but gathering input from others on the other hand, could include organising knowledge sharing webinars as part of the project, or having open round table discussions (Asthana et al., 2020). Dissemination of results is generally included in the project plans, and could be extended to include such intermediate, process related forms of knowledge sharing.

In the development of this reflection guide, we not only based the changes in new iterations on the suggestions that we got from pilot leads. We were also continuously looking for ways to improve the guide ourselves. By gathering pilot leads' input in different ways (workshops, surveys, written feedback), we think that we were able to improve the guide in a better way overall. For example, after reading a comment saying that each stakeholder filling in the document would take too much time, we gathered information on how others had implemented the reflection guide and added guiding suggestions for how to embed the guide in a reflection meeting. This variety of methods, along with the fact that the guide was evaluated in different countries and contexts, is a strength of this work.

It should be noted that this guide, while expected to be used with different stakeholders, is likely going to be initiated and implemented by researchers. This influenced the choices we made when developing the guide. For example, as we noticed that the researchers in our project where less experienced with AR and reflection, we provided a very structured guide, knowing that it might not work in every context. To accommodate this, we gave room to the pilot leads to adapt the guide for their context (e.g., in terms of translations or format). In our experience, the pilots valued the structure introduced by the guide, but also the flexibility to adjust it to their situation. Similarly, we believe that as AR projects differ so much, others looking to implement the guide can have a critical look at how they would implement it in their case. For example, methods that allow for visual input rather than written or spoken comments could be included (e.g., photo-voice, as described in Povee et al. (2014)).

Overall, the feedback we got from the pilots who used and evaluated this guide, as well as from our own reflection on it, is that it can provide a useful directory for collaborative reflection, especially for those who have little experience with the topic so far. Researchers can initiate the use of the guide, but all stakeholders give their input, beforehand as well as during the session. In this way, the guide ensures that all voices are heard, and that stakeholders are further empowered to give their opinion, as is the aim in AR. Similarly, while the feedback on the guide came from the pilot leads, they experienced the sessions together with other stakeholders, and in some cases included what they had heard back from the stakeholders in their feedback to us (e.g., which questions had been difficult to answer)

While the reflection guide was evaluated with different methods and used in several pilots, it was the same group of people who were involved in all phases. This means that they got experienced in their use of the (different iterations of) the guide over the course of the project. As a next step, it would be interesting to evaluate whether researchers who are new to the use of the guide and were not involved in its development find it equally useful and comprehensive.

## Conclusion

Amongst other things, reflection is a key part of AR. When project teams reflect together, they can not only solve internal questions and issues, the reflection also allows them to get a better picture of what others can learn from their project. The guide that we developed in this study aims to support researchers in organising regular, structured reflection meetings together with their whole AR team. We found that the guide was not only perceived as useful by the project teams that made use of it, but the guide also served the purpose of facilitating knowledge sharing between pilots. We make suggestions for how others can implement the guide, and thus share heir own lessons learned, so that other projects may benefit from them as well.

# Acknowledgements

# Chapter 9

The project team in action research is multidisciplinary by nature, meaning that skill sets differ between the project partners. Therefore, researcher as well as involved stakeholders might need to learn additional skills. This chapter investigates important themes for stakeholder skill training, to support those setting up such activities.

Chapter 9

**Abstract**

Participatory health research requires the active involvement of diverse, multidisciplinary stakeholders from patients to health professionals. These stakeholders are often required to attain new research skills to actively participate, while researchers themselves must prove equally capable of gaining new skills and knowledge from practice. Stakeholder skill training (SST) is therefore an essential component of participatory health research. Yet little consensus exists regarding how to prepare and conduct SST. We sought to explore and clarify this activity by conducting a one-day workshop involving human computer interaction (HCI) - and health researchers of many and varied experience levels. In this article, we draw on insights gained through the conversations and activities of this workshop; to briefly outline what SST currently and most often looks like, to draw readers' attention to five key themes that were identified during this workshop, and to raise important questions for anybody preparing SST or wishing to learn more about it. This includes the value of attending to considerations spanning 'hierarchy, power and culture', 'mutual learning', 'common language', 'terminology' and 'accessibility'. We close the paper with suggestions for future research and collective reflection on the topic and promise of SST.

## Introduction

Many different participatory health research streams (e.g., action research, participatory design, citizen science) call for the active involvement of multidisciplinary stakeholders from patients to healthcare professionals in research (Bradbury & Lifvergren, 2016; Clemensen et al., 2017; Wiggins & Wilbanks, 2019). This means that stakeholders who are not researchers but experts in their own right (e.g., through professional expertise and lived experience) take on roles and tasks vital to the project's success. Such a shift in responsibility can prove challenging not only for the researchers involved, who are required to hand over some of their power (Corrado et al., 2020) but for those other stakeholders who may require additional support and training to feel sufficiently empowered to confidently perform their new and more active roles. This furthermore requires researchers to learn enough about the research setting and practical processes (Barry et al., 2017). Mutual learning and stakeholder skill training (SST) are therefore essential practices in the conduct of participatory health research.

The key stakeholders of participatory health research are most commonly patients and healthcare professionals, next to the researchers commonly leading a project. However, the SST provided to these groups can prove very diverse. In addition to general research competencies, these might be, for example, leadership training (Chen et al., 2007), training in interdisciplinary work (Lepore et al., 2023) or (medical) terminology (Thompson et al., 2012) training. The acquisition of new skills might furthermore alone prove insufficient to ensure active participation from stakeholders. Confidence raising, for example, is often equally crucial, particularly when patients are involved and required to discuss with (their) healthcare professionals (Hewlett et al., 2006). For researchers on the other hand, SST is more often about preparing them to work with stakeholders and includes topics like Patient and Public Involvement (PPI) (de Wit et al., 2018).

While previously studying projects involving SST, we perceived a significant need for more precise information and instructions regarding the preparation and conduct of training [reference excluded for blinded review]. In response to this essential gap in knowledge and practice, this study aims to develop further insight into current knowledge, practice, and knowledge gaps relating to SST.

## Study Context

The themes and topics discussed in this paper were derived from a full-day conference workshop [conference name and reference excluded for blinded review]. To ensure an informed basis for discussion, potential participants of this workshop were in advance asked to complete a survey detailing either their previous experience with SST (e.g., describing the content and recipients of the training) or, if they had no prior experience, explaining why they were interested in SST. Although the workshop was targeted at and advertised to a broad audience of researchers and others experienced in SST (e.g., patients and healthcare professionals), only research professionals applied to attend. Eight participants joined the session in addition to the ten organizers, for a total of 18 present on the day. The workshop was conducted in a hybrid form; some participants and organizers joined in person, and others online. This set-up was facilitated by enabling all participants to work in the same online environment, a MURAL board where each group made their notes, and a Microsoft Teams meeting where all participants joined with their cameras turned on, so that all could see each other. For group discussions, mutually exclusive in-person and online groups were devised, in order to mitigate the too often cumbersome and/or exclusory nature of mixed discussions, according to our prior experience.

The day started with a brief presentation of participants' answers to the pre-workshop surveys, including open questions and topics for discussion as suggested by the participants. Workshop participants then split into breakout groups to discuss any gaps or incongruencies they perceived in the varied descriptions of SST gathered through these surveys and own experiences in their research. Following a plenary discussion of the outcomes of this first breakout session, the group split into another round of breakout discussions, this time working to identify facilitators and barriers of SST. Where possible, groups attempted to generate links between these facilitators and barriers (e.g., this facilitator mitigates this barrier). The day concluded with a final plenary round to discuss the outcomes from each group's activities and any overarching open questions and recurring topics.

The discussion during this session, and our analysis of the notes made by participants during it, identified a number of open questions and key topics essential for researchers considering SST to take into account. These themes and topics for future research were inductively derived from the workshop notes by the first author and discussed amongst authors until agreement was reached. These identified key themes and topics are introduced in the following sections.

## Reasons for Conducting Stakeholder Skill Training

Workshop participants' reasons for conducting stakeholder skill training varied. Reasons commonly provided, however, included elevating understanding among research study participants and raising awareness of how participation in a study could benefit both the patient-public and the researcher. One participant added that SST is a key component of the participatory design process, and therefore critical to respectful and value-driven innovation. The survey also showed however that not everyone possessed such altruistic reasons for conducting stakeholder skills training. One person commented that training was often employed to increase compliance in relation to the use of devices, and another that it was included as a means of performing usability testing during the stakeholder skill training process. During the workshop, the point was often made that individuals are invited to take part in the co-design process to share their knowledge and expertise, and was therefore followed by questioning why they would need to be trained in research skills in particular. One reason offered by workshop participants in response was to note that other approaches, from citizen science to action research, stress stakeholders' involvement not as participants but as co-researchers, and that offering some form of training can lower the often significant barriers to their adopting certain roles in the project (e.g., training people to perform interviews or introducing more intuitive methods, such that people can start right away).

Chapter 9

# The Structure and Content of Stakeholder Skill Training

Through participants' comments and notes, it became evident that stakeholder skills training currently takes place during many different phases of the research and development process, from testing to development, validation, and during the first month of a pilot study. No one phase proved more popular nor prominent as the time for stakeholder skills training; the activity appearing across all stages of a project.

The methods used for SST were described as very varied, although many comprised human-centered approaches with a focus on exploratory and qualitative methods in particular. Several participants explained through the survey that they had employed stakeholder skill training as a means of educating participants on how to use a particular technology, and to share general digital skills including how to turn a system on and off, connect to the internet, access an application, and return to the home menu.

## Identified Themes

Through our analysis of the pre-workshop survey and notes made during the often vibrant discussions part of the workshop itself, we identified five major themes and topics for future research. These span Choice of the word 'Training', Hierarchy, Power and Culture; Mutual Learning; Common Language; and Accessibility — each of which we next describe below.

## The Choice of the Word 'Training'

The term 'training' is employed in many fields (e.g., in education, work organization, information technology, sports, etc.) to refer to an (often) prolonged process of learning, practicing, and acquiring certain skills. Different terminologies exist to describe such a process, depending on the precise context. In education, this process is often more commonly referred to as 'learning'. For this workshop, the title of 'stakeholder skill training' was chosen — a term critically reflected upon during the workshop by participants who debated whether 'training' was the appropriate term. One group discussed whether training is appropriate in the context presented here or whether terms such as learning or education might be more appropriate. The group suggested alternative terms, for instance, 'experimental learning' or 'experience-based coaching'. Distinct related questions were subsequently discussed, including; "Is it relevant to the training or learning process if somebody teaches specific skills, and these taught skills will be applied by all stakeholders (i.e., also the teacher)? Is the term 'training' more appropriate if more hands-on practices are conducted? Is there a difference between learning something collaboratively or alone? Are group dynamics essential in training (as in sports, for instance)? Is there a group goal that all participants can achieve through learned skills? Does one speak of training in such cases? And does one speak of learning (e.g., in the field of education) instead, when the teacher him- or herself does not conduct or use the skills, but only explains theoretically to the learners what needs to be done for applying these skills?"

Other topics of conversation surfaced spanned whether the appropriate terms could differ depending on the goal, content, skill or training method. Participants' responses to the pre-workshop surveys reflected the content and goals addressed through SST in each of their contexts, although most training methods mentioned in the workshop itself took the traditional form of lectures. Considering the literature, we conclude that both terms ('training' and 'learning') are most likely appropriate in our context and that the training process can be understood as an umbrella concept that includes the learning process. In the literature, "Kirkpatrick's Model of Training" (Smidt et al., 2009) is widely employed and often referenced as the basis for such training processes. This model consists of four

levels, the second of which comprises learning; "measuring what participants have learned in terms of both knowledge and/or skills" (Smidt et al., 2009).

Another relevant thread of prior research mentioned by participants focuses on the training of employees; "Training is an instrument to expand the knowledge base of the employees and allows them to transfer this on their jobs in the form of improved performance. It is generally defined as a systematic acquisition of skills, concepts or attitude that results in improved performance" (Sahni, 2020). A similar framing is expressed by Masadeh (2012) in defining 'employee training' as in particular "associated with on-the-job skills acquired for a particular role, while education is seen as relating to a more formal academic background".

The training process itself was the source of much discussion among groups, giving rise in turn to questions including; "When does training even start? Is it enough to explain a method theoretically or is it necessary to teach it so that stakeholders can conduct it or even gain the ability to teach it themselves?" Within the training process, it is then necessary to ensure a common language and the everyday use of terminologies. These considerations play a crucial role in participatory health research and skill training in particular given the frequent involvement of interdisciplinary teams (e.g., consisting of different researchers, patients and/or healthcare professionals). On the one hand, a skill is taught and on the other hand, it is learned. Creating a common base for sense-making discussion through the consistent definition of interdisciplinary specificities and vocabularies is therefore essential. Every participant needs to be, and feel, able to contribute.

## Hierarchy, Power and Culture

Actively involving stakeholders with different backgrounds and fields of research expertise was often described by participants as directly challenging long-established research and power dynamics. During the workshop, many different levels and challenges of power relations were discussed in the context of SST. On the one hand, power relations between trained researchers and research participants are evidently shifting when those same participants become co-researchers. In participatory research, stakeholders are furthermore attributed expert knowledge based on their experiences, which challenges the traditional knowledge hierarchy superordinating academic knowledge over other forms of knowledge. On the other hand, these precise power dynamics are often transferred to the research setting by the act of bringing together stakeholders and researchers from different fields and with varying levels of social or organizational power, including patients and healthcare professionals. As one workshop participant highlighted, power structures are inevitable, as part of human nature. Such power imbalances were identified during workshop discussions as a critical barrier to the success of SST. Creating a safe environment and flat organizational structure were yet discussed as possible means of addressing these power dynamics. During our workshop, one group suggested that SST facilitators should be trained outsiders, not stakeholders in the project. Thus, facilitators can more effectively mediate power imbalances and cultural differences. Literature adds that setting ground rules for the session and making use of narrative methods can help create safe spaces (Egid et al., 2021). However, Roura (2021) describes how the idea of 'safe' spaces is not always true in reality. The early involvement of stakeholders in the research process and the equal sharing of agency concerning decision-making were also mentioned as crucial facilitators in this regard. This latter factor has previously been considered essential for meaningful stakeholder engagement in participatory health research (Cornwall, 2008). Participants furthermore commented that the research process, SST, and its content function best when adapted to the prevalent cultural and social structures on which considerations of power and hierarchy hinge.

Across the literature on participatory health research, researchers describe similar ways of counteracting power imbalances. Authors suggest in particular, among other actions, involving stakeholders from the beginning of the research process (Abma, 2019), as a means of establishing equal

partnerships through mutual learning from the beginning.

At a sufficient scale, participatory approaches can be seen as striving to equalize input in the production of knowledge. And yet, power imbalances might equally reproduce the very inequities that these approaches were initially intended to address, for example, when the most disadvantaged bear the greatest share of costs given that participating can be extremely time-consuming (Roura, 2021). It is therefore essential to examine and understand the power dynamics present within any research project, to jointly reflect on subjective perspectives, interests, and assumptions (Roura, 2021) and to address tensions directly during SST.

## Mutual Learning

As previously noted, it was often emphasized during this workshop that stakeholders participate in health research in the first place precisely because they are already experts and possess valuable knowledge (e.g., of the lived experience of a specific condition). Researchers are, similarly, experts within their scientific domain (e.g., epidemiology, technology development, methodology) and yet can also learn from both stakeholders and other researchers. One of the questions put forward for discussion during the workshop via the survey asked; "How can we facilitate mutual learning between researchers and stakeholders?" The importance of creating a safe environment was discussed during the workshop as one means of mitigating power imbalances in support of mutual learning — as was fostering shared understanding and employing a common language, as will be discussed in greater detail in sections to follow.

The discussion engaged in by one group in particular framed the development of a joint base for sense-making discussion as a key motivation for stakeholder training. From this perspective, stakeholder training makes possible the common ground necessary for effective collaboration between stakeholders (i.e., the process) and outcomes (mutual learning). Members of this group furthermore commented that everyone needs to warm up to each other's ways of working and that by starting in a ridiculous way (e.g., by talking about a subject nobody is an expert in), knowledge might later be unlocked. When discussing effective facilitation, reiterating that everybody is an expert was seen to be beneficial — shared leadership supporting a change in roles enabling researchers to learn as much as research participants. On the other hand, it was considered a barrier that a) everybody is an expert in their own domain, and b) that there might exist a lack of awareness of one's own expertise. It was emphasized that we should refrain from assuming which skills others possess, and that a more effective first step is to instead "identify what skills are at the table and then see what we can learn from each other". Establishing mutual learning itself as a goal was furthermore considered by participants a valuable facilitator of SST.

The importance of remaining open to learning from others is often acknowledged in the co-design literature, in the context of which, relationships that are non-paternalistic and grounded in mutual learning are required to create systems capable of producing better outcomes for the people they serve (McKercher, 2020). A recent scoping review furthermore highlighted the creation of mutual learning opportunities as the most frequently reported benefit of patient engagement in preclinical laboratory research (Fox et al., 2021).

## Common Language

The task of warming up to each other's ways of working was highlighted in the prior section as a key challenge for SST. Another issue highlighted during this workshop relates to that of employing the same vocabulary between groups. Specifically, this discussion centered around the notion that researchers may implicitly use terms that carry different meanings for other stakeholders. Typically,

researchers come equipped with a considerable amount of theoretical knowledge grounded in the research literature. In contrast, stakeholders – possibly driven by intuition or experience rather than peer-reviewed research – may tend to use the very same terms to label very different "things". Participatory health research in the arena of digital health in particular furthermore commonly involves several different academic disciplines, each of which is likely to bring with them the unique vocabularies of their own academic communities (see e.g. the varying meanings of the frequently employed term "implementation" between the health and computing science communities (Blandford et al., 2018)). Similarly, some terms may carry heterogeneous meanings even across different communities of practitioners. Lastly, cultural differences have the potential to produce severe misunderstandings even in relation to the communication of simple concepts, as noted by both the participants of this workshop and the prior research literature (Barrett & Oborn, 2010).

The above differences in disciplinary, professional, and cultural backgrounds may result in a considerable level of terminological ambiguity during training and research activities. To solve this particular problem, workshop participants suggested clarifying the meaning of key terms in advance of exercises. While there are different ways of doing so, two specific approaches were mentioned during the session: using visuals to support the understanding of key concepts, and using collaborative tools to foster interaction. As others have noted, preference might furthermore be effectively granted to the use of "lay terms" rather than the "language of research" (Sieck et al., 2017). Finally, participants suggested that when discussing technological problems, concrete and relatable examples should always be provided to render potential issues tangible even for those stakeholders with less technical backgrounds.

## Inclusivity

Workshop participants noted that given the involvement of professionals and patients or end users is often desired and very valuable, attention should be given to inclusivity considerations. Participation in projects requires both knowledge and time. For some projects, stakeholders must acquire specific knowledge to join and obtain an equal voice in discussions. To ensure sufficient expertise on a specific topic – either process or content – training may be provided by the researchers or any other stakeholders. This training will however take time, which may burden stakeholders. And, there will therefore always exist a trade-off between knowledge sharing and time (Jongsma & Friesen, 2019).

Access to training demands special consideration in cases where time can prove very limited for participants, either due to symptoms relating to the condition under investigation (i.e., fatigue), the fact that research has to be engaged with in their spare time (i.e., for patients), a heavy workload (i.e., for healthcare professionals), or similar causes. In such cases, finding the right balance between providing relevant training and using more intuitive, less time-consuming methodologies requires more attention.

Inclusivity also warrants special consideration in cases where the knowledge or experience gap is substantial. For instance, people who have not previously come into contact with scientific projects or have not received higher education may feel less comfortable participating. The same goes for vulnerable groups. This requires on the one hand additional effort in the recruitment phase of projects, and on the other hand organizing the training in such a manner that participation can be easily achieved for this group. During the recruitment phase, researchers may consider using a 'third contact', for instance, their nurse or a neighborhood volunteer organization with whom a relationship and trust have already been substantiated. Researchers may also consider shorter and less formal, tailored, training sessions when developing such training.
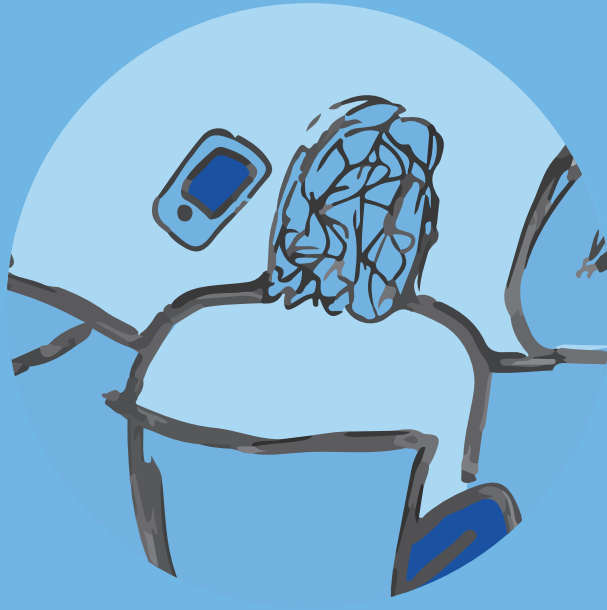
It can be necessary for some groups to ensure financial compensation for participation. For example, this can make a difference for some patients, as spending money to participate in research is not always an option. Inclusivity will frequently remain a challenge. It is, therefore, essential to consider

in advance of research which individuals or groups can contribute through their presence, and what their training needs are likely to be.

## Conclusion

This paper presents key topics and themes for future research in relation to the conduct of SST in participatory health research. Our findings, derived from a workshop with 18 participants, provide an overview of what can and should be considered in the planning and conduct of SST. In this context, our findings suggest, SST is likely to function most effectively when seen and implemented as a form of mutual learning, where there is not one trainer or teacher, but where each participant is an expert in their own right, and shares this knowledge with others. The terminology of 'training' might in this sense prove a misnomer, and yet we can also interpret this as an activity that includes 'learning' aspects. While setting up and starting the training process, it is essential to identify a language mutually understood among participants and to make the session as accessible as possible for all involved. Navigating both hierarchy and power dynamics is in this regard also a critical task. We make some suggestions for addressing these issues, and yet more research into SST, specifically in relation to healthcare, is needed. Developing and sharing best practices, potentially including clear guidelines for those developing and implementing SST, would be of significant future value to the field.

# Chapter 10

The final chapter in this part describes an iterative method that actively involves patients in the research process. By combining different methods, values are elicited and mapped along the patient journey. The iterations and involvement of stakeholders make Patient Journey Value Mapping fitting for action research projects.

**Abstract**

This paper introduces *patient journey value mapping* – an approach to capture experiences, emotions and values implicated in patients' care delivery. As patients' values (i.e., what's important to them in their lives) may change along their patient journeys, our approach aims to support designers to respond to patients' changing needs in the (re)design of eHealth, by mapping patients' values and their prioritisations over time. To substantiate the creation of the map, we propose two preceding data collection phases comprising complementary empirical methods. First, important care-related events and associated values are collected retrospectively through interviews, and in-situ through diary studies. Subsequently, the data are analysed to develop materials to elicit values and value tensions through deepening discussions in an interactive workshop based on which the maps are finalised. The approach is illustrated through discussions and reflections on its application in a case study investigating patient values in eHealth for rehabilitation care.

## Introduction

eHealth technologies aim to assist and enhance activities such as (remote) disease management (Hutchesson et al., 2015; Islam et al., 2015; Oh et al., 2005), the development of support networks (Cobb et al., 2011; Neuhauser & Kreps, 2010), and the exchange of health information (Baker et al., 2005; Skinner et al., 2003). Furthermore, eHealth solutions can support the collaboration between patients and healthcare professionals, for example, when choosing from different treatments (Ruland & Bakken, 2002). The collaboration between patients and their care providers can lead to a greater patient satisfaction, support patients to follow their treatment plan, and improve patients' health outcomes (Martin et al., 2005). Apart from supporting patients' needs, it is increasingly acknowledged that patients' personal preferences, experiences and values should be incorporated into care delivery and the design of healthcare technology (Bente et al., 2021, 2023; Dekkers & Hertroijs, 2018; Doyle et al., 2013; McCarthy et al., 2016; van der Wilt et al., 2015).

Value sensitive design (VSD) is a theoretically grounded approach that accounts for human values throughout the design process (Friedman et al., 2006). Different methods have been developed and proposed to elicit stakeholder views and values, to identify and/or resolve value tensions amongst stakeholders, and to subsequently translate the identified values into technical design decisions (Friedman et al., 2017). Amongst others, these include value-oriented semi-structured interviews (Friedman, 1997), value scenarios (Czeskis et al., 2010), and value-oriented coding manuals (Friedman et al., 2005). Rather than relying on a single method, it has been proposed to use a variety of VSD methods to identify and avoid blind spots, by accommodating for the expressive preferences of diverse stakeholders (Friedman et al., 2017). Despite the wide range of available methods in VSD, it is acknowledged that methodological innovation remains necessary as the existing toolset is not free of limitations (Friedman et al., 2017) and there are still open questions concerning theory, method and practice of VSD (Friedman & Hendry, 2019).

Firstly, while values seem to be somewhat stable, they may nevertheless be subject to change (Bente et al., 2021, 2023; Oberschmidt et al., 2022; van de Poel, 2021). Little is known about how to utilise, adapt and combine empirical methods to identify values and value changes along a patient's care path. Hence, to design eHealth technologies and services which support patients' values, it is crucial to investigate their experiences, preferences and values, which might differ depending on where they are in their patient journey (Bente et al., 2021, 2023; de Ridder et al., 2018). After all, healthcare comprises multiple stages such as onset of disease, treatments, and discharge from a clinical

institution, throughout which patients cope "with life's ever changing physical, emotional, and social challenges" (Huber et al., 2011, p. 2). To ensure that patients' values are taken into account for the provision of care and the design of eHealth technology, the experiences of patients throughout their patient journey need to be investigated.

Secondly, it may be challenging to engage participants in a variety of VSD methods for a longer period of time, especially in the healthcare context. There is a growing awareness that patients should be partners and involved in the design of eHealth (Barry & Edgman-Levitan, 2012; Clemensen et al., 2017; Davoody et al., 2016; Delbanco et al., 2001; Garne Holm et al., 2017; Vandekerckhove et al., 2020). However, studies and methods have to be carefully crafted to avoid overburdening patients who already face a high disease burden dealing with their condition (Jongsma & Friesen, 2019). Therefore, it is of importance to reflect upon experiences from the field to examine the suitability of study designs involving long-term patient engagement.

To take the time and context dependency of values into account, this paper utilises an approach based on patient journey mapping (de Ridder et al., 2018; Gregory, 2012; He et al., 2021; Ly et al., 2021; Schildmeijer et al., 2019; Simonse et al., 2019; Trebble et al., 2010; Westbrook et al., 2007). In patient journey mapping projects, patients' emotions and experiences along their encounters with health services are synthesised into visual or descriptive maps (Joseph et al., 2020). These maps can be used to develop a deeper understanding of a patients' experiences, to identify unmet patient needs, and to find opportunities for patient-centred improvements in healthcare (Davies et al., 2023). Depending upon the exact purpose of the patient journey mapping project, different maps can be created to emphasise different aspects of the patient journey. According to Kalbach (2016), the five most prominent types of maps that are used in current practice are: customer journeys (Følstad & Kvale, 2018), experience maps (Mulvale et al., 2019), mental model diagrams (Pillan et al., 2018), service blueprints (Paquet et al., 2003) and spatial maps (Joseph et al., 2020). While these maps allow researchers to focus on patients' end-to-end service experiences, cognitive processes, experiences from a systems view, or broad views of an organisation, they do not allow for an in-depth analysis of patients' personal values over time. Therefore, to make patient journey maps a helpful tool in VSD, methodological extensions are necessary.

In this paper, we present an exploratory investigation that introduces patient journey value mapping (PJVM) as a tool in VSD to identify patient experiences, emotions and values implicated in the delivery of care along the patient journey. It supports a critical analysis to capture which values are currently not supported, whether there are currently value tensions at play, and whether value tensions could arise if the care plan changes. To design the PJVM method, we build further upon previous work done in customer journey mapping and experience mapping by adding an additional value dimension. In the next section, the design of the PJVM approach is described in detail. To illustrate the usefulness of this approach, the outcome of a case study is presented which focused on the values implicated in rehabilitation care. Finally, strengths and weaknesses of individual methods used, as well as the synergy between methods, are discussed. This paper contributes to value sensitive eHealth design by sharing experience on the application of PJVM involving active participation of patients. Furthermore it provides valuable reflections and recommendations for combining and adapting methods when collaborating closely with patients.

## Design of the 'Patient Journey Value Mapping' approach

In this section, the PJVM approach is presented and the rationale behind the design choices of underlying research methods are described. The proposed methods were selected such that the strength of one method could overcome the weakness of the other as anticipated based on theory. The PJVM approach entails three phases (preparation, interaction, mapping) and utilises critical incident interviews, diary studies, workshop activities, and PJVM (see Figure 18).
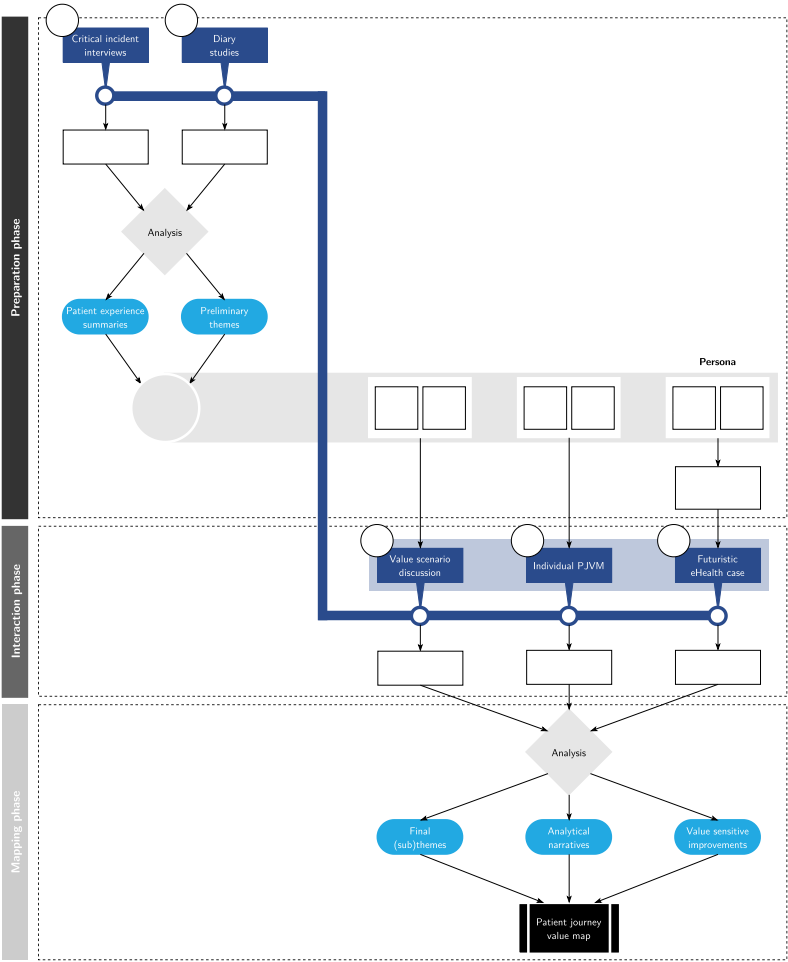
Figure 18: Overview of the methods proposed to perform patient journey value mapping and the respective data flows.

In the *preparation phase*, preliminary summaries of patient experiences and preliminary values are obtained through thematic analysis. These insights are used to prepare creative workshop materials for the interaction phase. In the *interaction phase*, patients participate in an interactive workshop to extend the interpretations of values obtained in the *preparation phase*. Finally, in the *mapping phase* the data from all research phases are combined to synthesise a comprehensive patient journey value map. The methods in each phase and the rationale behind their use, as well as the expected outcomes for each of the methods are reported below.

## Preparation Phase

In the preparation phase, an overview of important events and values along the patient journey is created. This is done using two methods: critical incident interviews and diary studies. The interview and diary questions were developed by all three authors (MB background in human-computer interaction and design, KO PhD student in eHealth action research, and CG senior researcher in human-centred eHealth design). The interview was conducted by the first author and the transcripts were merged with the diary data. Subsequently, patient values were identified from the combined data set through a reflexive thematic analysis performed by the first author (Braun & Clarke, 2006), and iterative discussions amongst all authors. An inductive approach is chosen to capture the implicit values underlying patients' statements, since explicit verbalisation of abstract values might be challenging. The generation of themes follows a constructivist ontology (Varpio et al., 2017), acknowledging the personal and context-dependent nature of patient values. The preliminary patient values are used to design creative tools to facilitate deepening value-oriented discussions in the *interaction phase*.

### Critical Incident Interviews

There are different ways to investigate the experiences and values of people. Narrative methods are particularly well suited to capture a holistic view of a person's experience. Storytelling methods (e.g., critical incident technique, narrative interviewing (Gausepohl et al., 2011)) encourage people to tell their story about their experiences, which often include important contextual factors (physical, temporal, task, social, information, and cultural context).

To investigate in-depth the experiences and values of patients, interviews in the *preparation phase* combine two approaches: critical incident technique (Flanagan, 1954) and value-oriented semi-structured interviews (Friedman et al., 2017). Within the PJVM approach, critical incidents refer to lived experiences which were of personal significance to the patient during their care. This way, critical incidents can function as a prompt to further unpack values implicated in healthcare. Patients are asked to provide personal judgements towards the events they described, along with motivations as to why these were critical. Orienting the interviews further towards values, patients are asked to report self-defined values which they associate with the criticality of the events. Afterwards, a list of values is presented to them, from which they can select additional values which apply to their stories. The presented values can be informed by research in the application domain, e.g. literature reviews or studies conducted in the hospital setting. We derived values from a previous internal report describing exploratory focus groups with patients at Roessingh Centre for Rehabilitation, ensuring contextual relevance to our case study conducted at the same centre. The list is shown afterwards to prevent the questions from being too leading, privileging or reifying certain values or claiming any universality (see more on the critique of heuristic lists (Borning & Muller, 2012; Friedman & Hendry, 2019)). Instead, showing a list of values after participants already identified what is important to them (as suggested also by Friedman and Hendry (2019)) can prevent to overlook important values and also invites them to reflect what a particular value means to them in their context (i.e., supporting contextualisation as suggested by Borning and Muller (2012)). Additionally, patients are asked whether there are any values that

are not on the list that would better describe their personal experiences. Finally, to study the values implicated in eHealth design, participants are invited to reflect whether technological support could improve the conditions described in their critical incidents. This is done to explore potential value tensions which may arise due to the introduction of technologies in healthcare (Friedman et al., 2017) associated with the acceptance or rejection of technological services.

The value-oriented critical incident interviews are expected to yield an overview of the main events which were of personal significance to participants during their care, and initial values associated with these events.

### Diary Study

Interviews and particularly the critical incident technique collect retrospective reports, which are drawn from participants' memories (Flanagan, 1954; Gausepohl et al., 2011). This can present a drawback in that some experiences might not be critical enough to be remembered on the spot when asked for in an interview. The solicited diary method accommodates for this limitation, as data are collected in the moment and over a longer period of time (Janssens et al., 2018; Meth, 2017). Furthermore, diary studies have a low memory strain and a high ecological validity (Verhagen et al., 2016). Complementing retrospective data with data collected via diaries helps determine the extent to which critical incidents characterise a typical or regular experience (Baxter et al., 2015).

To support the identification of values implicated in patients' experiences, the diary study follows a sequential elicitation structure. Firstly, patients are asked to describe a noteworthy event of that day, related to their patient journey, along with a description of how they experienced it (positively, negatively, neutrally). Secondly, using their sentiment as a starting point, patients are asked which values they associate with the event to further contextualise their experience. To guide the process and to keep the values within the scope of the research context, patients are presented with a list of values informed by exploratory focus groups which were previously conducted at the rehabilitation centre. Given that the presented list may be incomplete, patients are also given the option to define values themselves. Additionally, as identically named values may have different meanings to different people and in different contexts, patients are asked to explain how the values related to their stories specifically.

To conclude, due to the in-situ sampling and by avoiding a recall bias, the diary study can yield additional sets of contextually rich experiences and self-reported values, which may not be described during the critical incident interviews.

## Interaction Phase

By participating in the studies during the *preparation phase*, patients contributed individually. The *interaction phase* follows these activities with a workshop to see what lessons can be learnt from patients as a collective. That is, to reflect together with patients on the extent to which their views and experiences overlap or differ. Additionally, the interactive workshop allows them to extend and contextualise the preliminary interpretative analysis of the interview and diary study data carried out by the researcher. The workshop uses a tripartite approach, involving (1) discussions on current practices in healthcare using a value scenario, (2) an individual patient journey mapping activity to identify opportunities for improvements in the quality of care, and (3) a futuristic eHealth case to speculate about the added value and limitations of technology-aided care.

## Value Scenario Discussion

Given that activities such as patient journey mapping require patients to recall their experience alongside analytical tasks, the workshop commences with a priming activity (Sanders & Stappers, 2012). A value scenario (Friedman et al., 2017) is used to prompt participants towards the experiences they had previously shared along with the implicated values. The value scenario is constructed based on results from analysing interviews and diaries collected in the *preparation phase*. The identified experiences and values are used to create a value scenario, that narratively summarises the current practices (Anggreeni & van der Voort, 2007) and experiences reported by patients along their patient journey. To effectively represent and communicate the narrative concisely, a storyboard is used as a medium of expression as recommended by Nielsen (1990).

During the workshop, participants first read through the value scenario. Subsequently, they are asked to select two important events which they related to and to elaborate on them in a plenary discussion. These insights are used to extend the analytical interpretations acquired from the thematically analysed interview and diary study data.

The outcome of the value scenario discussion is to gain insights into the extent to which participants identify themselves with the analytical interpretations of data collected in the *preparation phase* which are presented in the storyboard. Furthermore, the interactive activity support patients in recalling noteworthy experiences, which are utilised in the individual PJVM activity, described in the next section.

## Individual Patient Journey Value Mapping

Individual PJVM is carried out to allow each of the patients to define their patient journey for themselves. The individual maps are then brought together in a plenary discussion to compare journeys, experiences, and values across patients. The activity is performed using a worksheet, which is customised based on results from analysing interviews and diaries collected in the *preparation phase*. The general worksheet comprises four main components: (1) a timeline in which phases and events along the patient journey can be named, (2), description boxes in which the phases and events can be described, (3) an emotional timeline in which the emotions experienced during the events can be described, and (4) boxes in which the associated values can be reported for each of the events. Data from the *preparation phase* are used to customise the worksheet to the specific application context, by providing supportive examples of potentially relevant phases, events, and values along the patient journey. These examples merely serve as prompts to inspire patients. They are free to construct the map as they wish, using their own examples and descriptions. The worksheet used in the case study is shown in Appendix 10.1.

During the interactive workshop, patients are asked to fill out the worksheet. They are given post-its on which they can write down relevant events. Subsequently, they are instructed to select the most critical or salient ones amongst these. Afterwards, the post-its can be rearranged in chronological order to describe the patient journey. Per event, patients are asked to report the emotions they felt and to list and rank the values that were of importance. Additionally, for each listed value, participants indicate whether they believe that the value is already sufficiently supported or not. The worksheet is designed such that these tasks could be performed consecutively, rather than simultaneously, to lower the cognitive demand. After the mapping activity, each patient selects one event to be addressed in a plenary discussion. Furthermore, participants are asked to respond to each other's stories to indicate whether they had similar or different experiences.

Due to the compartmentalisation of the patient journey into a series of consecutive steps, and the systematic elicitation of care experiences in terms of phases, events, emotions, and values, the individual maps enable patients to visualise changes in value prioritisations over time.

**Futuristic eHealth Case**

Apart from understanding which values are currently sufficiently or insufficiently supported, it is also of interest to study whether technologies can support the identified values, and whether value tensions could emerge upon implementing technologies which address the challenges identified along the patient journey. Hence, to understand the acceptance or rejection of future eHealth services, a futuristic solution-focused inquiry is pursued using a scenario-based approach (Anggreeni & van der Voort, 2007). The goal is not to present and evaluate a finalised concept, but to identify the conditions under which technological support would be accepted.

To focus on patients' goals, wishes, and concerns while drafting the futuristic eHealth case, interview and diary study data from the *preparation phase* are used to create a persona (Pruitt & Grudin, 2003) (Appendix 10.2). The persona is then used as a supportive tool to write a case which closely touches upon patients' reported experiences. It is assumed that embedding relatable experiential elements into the narrative facilitates discussions grounded in patients' lived experiences (Spaulding & Faste, 2013), even if the narrative is taking place in a future setting.

By imposing a futuristic eHealth solution into a narrative based on patients' current experiences, the futuristic eHealth case has the potential to uncover how potential innovations disrupt or improve patients' experiences. By discussing this further, value tensions can be uncovered along with preconditions for the acceptance of eHealth services.

# Mapping Phase

During the final *mapping phase*, results of the *preparation phase* and the *interaction phase* are synthesised and integrated to create an overall patient journey value map. Furthermore, similar to previous research (de Ridder et al., 2018; Westbrook et al., 2007), the mapping phase is used to systematically organise the overall research findings.

PJVM is performed by dividing the patient journey into a timeline of relevant phases, and describing the most critical incidents occurring within these periods. To identify these systematically, all excerpts from the *preparation phase* and *interaction phase* which are extracted for the thematic analysis, are labelled by the phase in which they were described. The diary entries are used as an additional separate resource due to their convenient data structure. Since all patients were asked to label each entry as a neutral, positive, or negative experience, the diary data structure allows for a convenient identification of relevant events and encounters with healthcare providers along the patient journey, by filtering entries by the self-reported sentiment.

For each event, the emotions, insights and key values are described. To contextualise the experienced emotions, fitting quotes are extracted from coded data and added to the map. The analytic narrative obtained through reflexive thematic analysis is subsequently used to translate the mapped experiences to insights for clinical practice, in relation to the key values with which the events were associated thematically. If the thematic analysis reveals substantial differences between patient experiences, additional journeys could be visualised along the emotion timeline to illustrate why and how these experiences differ.

Through integration of all data sources, the analysis in the final mapping phase results in a comprehensive patient journey that encompasses a holistic linkage between events, emotions and values. These findings can be used by designers to respond to patients' changing values and needs in the design or redesign of eHealth.

## Case Study

To illustrate the application of the proposed PJVM approach, this section reports in detail on the setup and outcomes of a case study on values related to eHealth in rehabilitation care for stroke, chronic pain, and spinal cord injury patients. All patients were offered eHealth services for mental and physical health through the same platform, but the respective exercises differed across patients based on their needs and symptoms.

## Recruitment

The study took place between July and November 2021 at Roessingh, a centre for rehabiliation care in Enschede, The Netherlands. Participants were recruited through their health care providers at the rehabilitation centre. According to Dutch law and supported by a ruling from the appropriate ethics committee (METC Oost-Nederland), no medical ethical approval was required for this research (ruling 2021-13032). All participants were provided with an information letter and gave their written informed consent prior to starting the study. Interviews and workshop were recorded, transcribed and together with the data from the diaries processed in coded form.

Initially, seven patients voiced interest in the study of which two decided to terminate their enrollment before signing the informed consent form. Reasons for early termination were only known for one case (here, the technological demand of the diary study). While the plan was to involve all remaining five patients throughout the complete study, three patients unfortunately had to drop out due to health-related reasons. The codes P1, P2, P3, P4, and P5 denote the patients who participated in the study.

## Critical Incident Interviews and Diary Studies

All five patients participated in the critical incident interviews. The interviews yielded an overview of main events which had left a lasting impression on patients. These included systemic aspects, such as how the interaction between therapists and patients was set up, and how the rehabilitation centre's eHealth service was integrated into the rehabilitation programme. Examples of incidents reported by patients included opportunities for patients to proactively steer the clinical pathway towards their own needs, and discontinuity in care delivery as a result of infrequent eHealth usage as a substitute for cancelled in-person therapies. Additional examples accompanied by supporting excerpts are shown in Table 3.

The diary study was conducted using a mobile application developed in-house by Roessingh Research and Development. If patients were unable to download the application due to device incompatibility, suitable mobile phones were supplied to them by the researchers. The diary study was performed through fixed daily assessment of seven questions, using both open and multiple choice questions. These inquired about whether any rehabilitation-related events had occurred, patients' stance towards these events, and which values were considered important during this experience. Both the experiences and the associated values were sampled momentarily across a time span of 21 days. While all five patients started with the diary study, one patient terminated the enrollment early on in the process due to health-related reasons.

A 24-hour response window was chosen to avoid recall bias, starting at 12 pm and ending at 12 pm the next day. The mid-day time window was preferred over a conventional day cycle, as it allowed participants to still fill in the diary of the day before, in case they had forgotten about it. Incidences of the latter were countered through daily reminders which were sent out at 6 pm. The daily workload was restricted to an estimated maximum of five minutes, since previous studies suggested that diary studies were perceived to be demanding and time-consuming (Myin-Germeys et al., 2009).

| Main event | Interview excerpt |
|---|---|
| Being able to act proactively by making suggestions about adaptations to the treatments. Experiencing patient-centred care due to acts of tailoring. | *"During the last medical review, it was me who brought [something] up: 'Well, perhaps it is sensible to make some adjustments, to get other things [exercises].' Because I saw that others were doing different things [exercises], which made me think: 'Yeah, that's also very functionally relevant to me"* (P1). *"They don't have a fixed programme, but act on- what I mentioned just now: 'The needs expressed by patients are considered most important.' Using this as a starting point, feasible solutions are sought for"* (P2). |
| Awareness creation due to confrontation with and reflection on own behaviours. | *"They are asking the right questions, due to which an enormous amount of awareness has been gained. [...] I would grant this experience to everyone. Simply for the awareness, as an added value for the rest of your life. [...] Also to get insights on patterns that you've been carrying with you your entire life"* (P4). |
| Discontinuity in care delivery due to insufficient involvement in the provision of eHealth aided rehabilitation options. | *"I had a lot of spare time in between [due to a lack of therapies]. [...] 'How about putting something [exercises] on the digital rehabilitation platform?', I asked. [...] Yeah, I received the same ones [exercises] for 14 days. That made me think: 'The same things again? Well, I am capable of doing that by now. That's not something I need to train further'"* (P5). |

Table 9: Examples of main events identified during the critical incident interviews.

| Diary question | Response |
|---|---|
| **Q1:** Has anything related to your rehabilitation happened today? This could be something neutral, positive (something that went well or that made you happy), or negative (something that went wrong or annoyed you). | *"Yes"* |
| **Q2:** Could you briefly describe what happened today and how you experienced this (positive, negative, neutral)? | *"Positive: Had a medical review meeting".* |
| **Q3:** Were there any technologies involved in this experienced? If so, how? | *"Yes, the new [rehabilitation] programme was registered in the [digital] system, which is subsequently sent to the planning department".* |
| **Q4:** Have care providers of the rehabilitation centre contributed to this experience? If so, how? | *"Yes, they brainstormed with me to set up an adequate follow-up programme".* |
| **Q5:** Which values would you associate with this event? You can select multiple options. If there any unlisted values which apply to your story, you can specify these separately. | *"Control, trust"* |
| **Q6:** Could you briefly explain how these values relate to your story? | *Control: My own contribution was also important to give shape to the follow-up.* *"Trust: Aligning with each other and eventually reaching a consensus, gives [me] confidence that the chosen path is the best one to follow for the rehabilitation process".* |
| **Q7:** Is there anything else that you would like to share with us regarding your rehabilitation or participation in this study? | *"A physiotherapist, who is not my main therapist, came to think along with the therapy and asked me about my emotional state. That was something I could really appreciate".* |

Table 10: Example of a single diary entry obtained from participant P1.

Through analysis of the diary study entries, it became apparent how frequent and embedded the critical incidents were in the usual care delivery. An example of a diary study entry is shown in Table 3. This entry illustrates that it was common for P1 to be regularly be involved in formulating plans for follow-up treatments. In particular, the diary entry revealed that this form of involvement was of importance to P1, as it fostered a sense of control. The explicit association with control as a personal value had not been made during the interview yet. As shown in P1's interview excerpt in Table 3, P1 gave suggestions for adjustments of the clinical pathway due to concerns regarding the optimality of the current approach. However, initiations of such critical inspections to safeguard optimal health outcomes were portrayed as the responsibility of clinical staff: *"So perhaps that's something they [physician and therapists] could look into more actively".* The diary entry however, demonstrated that it was not only the optimal health outcome that was valued. Being involved in the process leading up to the outcome was perceived important as well, to experience a sense of control.

Another noteworthy difference between the interview and diary study data, was the way in which rehabilitation experiences were described. Amongst the diary entries, emphasis was put on the individual contributions of the particular therapies in a context-specific manner. For instance, *"During ergotherapy, virtual reality goggles were used to enter a virtual environment in which I was told to execute some exercises. This was recorded with a phone. This [the execution of exercises] was discussed afterwards"* (P4). During the interviews, on the other hand, patients provided a broader perspective on their treatment, including the collaboration and interactions between different therapists to deliver integrated and tailored care. For instance, *"Whenever they do something, it always matches your [previous] treatments, regardless of who takes over [the therapy session]"* (P2).

## Interactive Workshop

Due to health-related drop-outs, only two patients could participate in the interactive workshop. Overall, the group setting allowed for the explicit identification of overlap between their experiences; even though the participating patients seemed to have very different experiences based on their interviews and diary studies. The following sections address the outcomes per workshop activity in further detail.

### Value Scenario Discussion

Figure 19 depicts the value scenario which was constructed based on preliminary analysis of the interview and diary study data. Upon asking the workshop participants to each select two important storyboard events to which they could relate, it was noteworthy that both participants chose one event which they had not previously mentioned in their interviews or diary study. This was indicative of a degree of overlap between patients' rehabilitation experiences.

For instance, P2 chose the fourth box of Figure 19, which was previously associated with the experiences of P3 and P4. They explained that *"Yes and well, what's very important, is awareness on habits that hinder you, because many of those seem normal to yourself. But during therapy, I was told that I need to stop in time. […] For example, it is very energy consuming if you walk to the seventh checkpoint, even though you only have energy to reach the first or second one."* Stated differently, P2 associated the process of awareness creation with discovering the boundaries of one's physical capabilities to deal more effectively with energy expenditure. P2's statement provided a complementary perspective on the insights gained from analysing the interviews and diary studies. While efficient energy expenditure had already been identified as an outcome of awareness, its association with finding one's own boundaries had not been identified yet. Overall, both P2 and P4 expressed that they recognised their experiences in the value scenario.

## Patient Journey Mapping

Both participants created a patient journey value map individually to share their experiences along the patient journey. However, due to time constraints, only one event of the patient journey could be discussed in further detail. Both participants discussed the waiting times during the intake period. It was noteworthy that these experiences were not mentioned previously during the other data collection phases by any of the participants. Both P2 and P4 expressed that there was a lack of transparency in the communication during the intake period. *"But in between, I'd appreciate, if there's such a waiting time you know, to receive a message like: 'You've been signed up. We'd also like to start the treatments, but...' Just a short description like: 'That's the reason [for the delay], have some patience'. Then you're aware that they're working on it."* (P2) Similarly, the other participant shared: *"If this clarity is present, then I can also adjust my expectations to it"* (P4).

Furthermore, the patient journey mapping exercise revealed which contextual and emotional factors made the waiting period hard to bear. Previously, we assumed that the patient rehabilitation journey commenced at the start of admission to the rehabilitation centre, based on the responses from the interviews and diary. However, the workshop participants expressed that their patient journey started in the period prior to admission. They described that the waiting experience was worsened due to the fact that they had been dealing with their disability for a much longer time already. *"But what I'm trying to say is: people often have been in this process for a much longer time, you know? And that could be months long and at some point, they'd like to proceed. Especially if you know you've been signed up but don't receive any follow-up news, that's just very unpleasant"* (P2).

Finally, similar to the value scenario discussion, the patient journey mapping exercise revealed overlap between rehabilitation experiences as well. During a brief impromptu discussion, P2 and P4 brought up several commonalities relating to the early stage confrontation with their disabilities. *"I mean... especially the moment you accept that you're no longer able to do some things and that you need a different approach. Or the complete change in general and having to confront your own family [with the disability]. I think everyone experiences this similarly"* (P4). *"I think that these experiences mostly coincide; there wouldn't be major differences"* (P2).

## Futuristic eHealth Case

The participants read through a fictional newsletter from the future (see Appendix 10.3) in which the rehabilitation centre announced that they were going to implement a therapy robot. Despite being against the hypothetical solution, the participants still engaged in productive discussions about alternative use cases in which the solution would be better accepted, along with preconditions for implementation. The participants suggested that therapy robots should not aim to fully mimic a human therapist. They mentioned that emotional support was of utmost importance during rehabilitation, which could not be outsourced to digital services in their opinion. While additional opportunities to independently proceed with treatments to ensure continuity of care delivery were valued, patients believed that this should not happen at the expense of therapists' involvement. Stated differently, the futuristic eHealth case elicited a value tension between independence and involvement. An alternative use case suggested by patients, was to employ the rehabilitation robot for after care post-discharge. This way, the robot would not be used at the expense of human contact during rehabilitation.

Chapter 10

# Patient Journey Value Mapping

## Abstractions Based on Previous Analyses

The construction of the journey map commenced with the identification of relevant phases. Data obtained through the interviews, diary studies, and workshop were analysed for this purpose. The earliest relevant phase along the patient journey, i.e. the waiting period prior to admission, was identified from the workshop data. The latest phase along the patient journey for which data was collected, was the discharge phase. Information regarding this phase was extracted from both the interviews as well as the diary studies. However, the treatment period in between was perceived to be challenging to characterise as a linear sequence of events in the patient journey map. The reason for this was that it was not uncommon for rehabilitation periods to be extended, resulting in a somewhat cyclical timeline. The cycle refers to repeatedly going through therapies and medical review meetings, until the health assessment at the medical reviews indicate that all rehabilitation goals have been accomplished.

The diary entries were filtered by sentiment (i.e., whether an event was experienced neutrally, positively, or negatively) to characterise which positive and negative events the rehabilitation care entailed. Most of the positive events were associated with making progress in recovery, while most of the negative events were associated with doubts regarding recovery. However, these experiences could not be pinned to characteristic timestamps along the patient journey, as they appeared to occur rather incidentally. Hence, to illustrate the events along the treatment phase, all accounts of experienced progress and all accounts of experienced doubts were merged into two separate events: recovery progress and recovery doubts. This simplification was made since it was assumed that understanding the factors that contributed to positive and negative experiences, was more important than knowing the exact timing of occurrence.

## Patient Journey Value Mapping

The patient journey was conceptualised as a sequence of three phases: pre-admission, treatment, and discharge period (as shown in Figure 20). Although all identified patient values were assumed to be important during rehabilitation, analysis of the patient journey value map revealed that the priorities between patient values differed depending upon the phase of the patient journey. Additionally, as shown in the insights and key values section of the map depicted in Figure 20, identically named patient values such as involvement recurred throughout the patient journey. However, the exact meanings of the values were dependent upon where they occurred along the patient journey, emphasising the time and context-dependency of values. To illustrate this, a walkthrough of the map shown in Figure 20 is provided below for two instances where the patient value of involvement was prioritised.

Firstly, as part of the pre-admission phase, patients described the waiting period during their intake to be a critical incident. As discussed previously, patients entering the rehabilitation centre have often been dealing with their disability for a longer time already. Amongst other reasons, this induces a stronger sense of necessity to receive help. Patients experienced this negatively and described the associated feelings as distress and anxiety, since they felt uncertain about their admission status due to a lack of communication from the rehabilitation centre. Hence, the key patient value corresponding to the described events and emotions was identified to be involvement. Here, involvement was conceptualised as an act of acknowledgement to ensure that patients would not feel overlooked. To better support this patient value, it was proposed to incorporate an e-mail system which would update patients on their admission status during the intake period, along with motivations for potential delays until admission.

Secondly, as part of the treatment phase, patients described the medical review meeting to be a critical incident as well. This is a periodic assessment of patients' progress, in which the decisions

regarding the termination, continuation, and adjustments of the treatment programme are made. Patients described that they valued the opportunity to exchange ideas with therapists to ensure that their concerns and wishes would be addressed during the meeting. Subsequently, as clinical staff acted on these ideas by tailoring the treatment programme accordingly, patients reported that they perceived the care delivery to be patient-centred. Patients experienced this positively and described the associated feelings as being taken seriously, and feeling reassured about the adequacy of care as their needs were put central. Hence, the key patient value corresponding to the described events and emotions was identified to be involvement, with a two-fold manifestation. On the one hand, it was conceptualised as a means for patients to leverage their own understanding of their clinical condition to be involved in adjusting their treatment programme, with the objective to achieve better clinical outcomes. On the other hand, it was conceptualised as therapists' active involvement through tailoring of treatments to accomplish patient-centred care.
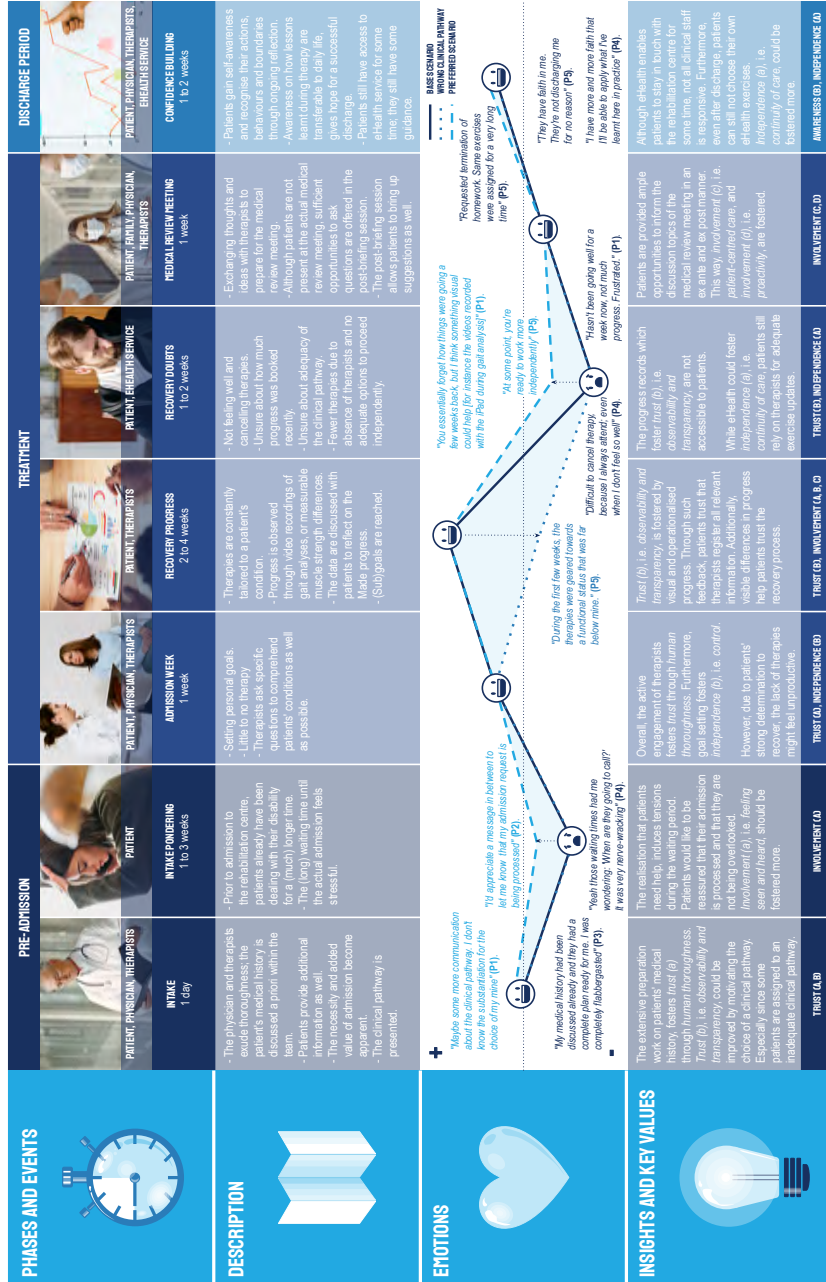
# Chapter 10

Figure 20: Final patient journey value map constructed from interviews, diary studies, and workshops. Colour-coded quotes along the emotion curves represent the base, desired, and undesired scenarios. Capital letters in parentheses behind the listed key values distinguish between the specific meanings of identically named values.

## Discussion

This paper discusses the design of the PJVM approach, which was developed and tested through a case study to capture the experiences, emotions and value prioritisations along the patient journey. To carry out PJVM, a combination of multiple empirical research methods was proposed. The study findings suggest that critical incident interviews, diary studies, and the interactive workshop jointly offer valuable insights to support PJVM. Over the course of the design process of the PJVM approach, strengths, weaknesses and opportunities for improvements of the empirical research pipeline were identified through critical reflections, as summarised in Table 4.

The primary strength of PJVM lies in its ability to define values and their prioritisations in a contextualised manner. We found that identically named values reported by patients could have different meanings depending upon where they occurred along the patient journey. Hence, in accordance with Borning and Muller (2012), there was a strong need to contextualise the exact meanings of values. Failing to do so might induce implicit claims about universality of values during the VSD process, leading to inadequate support of patients' values. PJVM addresses the challenge of contextualisation effectively, by tightly coupling values to the critical incidents they relate to, as well as the experienced emotions.

Several strengths of the data collection methods used during the preparation and interaction phases were identified as well. These experiences are important to reflect upon since a combination of multiple methods is generally advocated in patient journey mapping studies (Trebble et al., 2010), while evidence on efficiency and effectiveness of methodological pipelines is lacking (Sijm-Eeken et al., 2020). We postulate that our proposed combination of methods uncovers novel and complementary insights, even when used with the same study participants. In the healthcare domain, where it could be challenging to acquire large sample sizes due to the accumulation of disease and response burden, these findings could support researchers in increasing their information gain. Firstly, in accordance with Baxter et al. (2015), Halvorsrud et al. (2016), Shiffman et al. (2008), and Verhagen et al. (2016), we found that momentary sampling through diary studies enriched the insights gathered through retrospective critical incident interviews. Apart from identifying novel experiences, the diary entries illustrated how frequently and prominently critical incidents occurred throughout the usual care delivery. Secondly, as described in the constructivist approach towards member checking (Varpio et al., 2017), the workshop allowed analytical interpretations of the interview and diary study data to be extended further by discussing the results with patients. By pursuing such an approach, patient journey value maps can be constructed in a comprehensive manner to identify opportunities for value sensitive improvements along the patient journey.

While the combination of multiple research methods is idealised in literature for the characterisation of patient journeys (Halvorsrud et al., 2016; Trebble et al., 2010), and for VSD research in general (Friedman et al., 2017), the participation burden for patients cannot be neglected while designing a study. Based on the novel information uncovered by the complementary use of interviews, diary studies, and an interactive workshop, the three distinct phases (preparation, interaction, mapping) remain recommended for carrying out PJVM. However, the current study only tested one specific combination of empirical research methods to complete the preparation and interaction phases, based on their strengths described in literature. Future studies should assess whether the methodological pipeline described here is suitable, and whether it suffices to use methods that are more feasible for patients in the particular study and context to complete. For instance, as shown in Table 4, one weakness of the diary study is that the method is prone to health-related drop-outs due to the required longitudinal engagement. If long-term engagement is anticipated to be a high risk factor for early drop-out, researchers could for instance consider combining interviews and direct observations of the patient journey instead. This way, the sampling period could be shortened for patients, while still obtaining in-situ data (Trebble et al., 2010).

In case that it is feasible to pursue the preparation, interaction, and mapping phases, several adap-

| Method | Strengths | Weaknesses |
|---|---|---|
| Critical incident interview | 1: Allows for the collection of main events along the patient journey. | 1: Completeness of the data depends on the patient's recall. |
| | 2: Yields rich narrative content which can be unpacked further through follow-up questions. | |
| Digital diary study | 1: Yields event descriptions which are often embedded in specific therapy contexts. | 1: Could pose barriers to participation depending upon patients' digital literacy. |
| | 2: May reveal how frequent and embedded critical incidents are in the usual care delivery. | 2: Comprehensiveness of the data fluctuates across patients. |
| | 3: Allows experiences, sentiments, and patient values to be sampled jointly. | 3: The required longitudinal engagement makes data collection more prone to missing entries (e.g. due to health-related drop-outs). |
| Workshop | 1: The group setting allows for the identification of similarities between patients' views and experiences. | 1: Requires a high degree of engagement from patients, and should therefore comprise a limited number of activities to limit the burden. |
| | 2: Enables researchers to verify whether analytical interpretations of previously collected data are representative. | 2: Depending upon the task complexity, a substantial portion of the available time could be lost to providing explanations. |
| Patient journey value mapping | 1: Is able to capture the context and time dependency of priorities in patient values. | 1: Excludes patients' views on the researcher's interpretations of the final map. |
| | 2: Allows patient values to be organised in relation to concrete events and feelings. | 2: Inherently assumes a linear progression of events, while care processes could be cyclical. |
| | 3: Is compatible with multiple data collection methods and therefore allows for a holistic integration of research findings. | 3: Currently only captures how value prioritisations vary between activities, but not how they vary within activities. |

Table 11: Overview of strengths and weaknesses of research methods used in the PJVM approach.

tations are recommended. Firstly, regarding the *interaction phase*, it is recommended to omit the futuristic eHealth case from the interactive workshop and to allocate the respective time to individual PJVM. While the futuristic eHealth case provided a means to elicit value tensions which shed light on principles underlying the acceptance or rejection of eHealth solutions, the elicited tensions were rather specific to the depicted futuristic eHealth solution. Given that this fictional service did not represent a concept that was truly in development, the fruitfulness of the solution-specific value tensions could be questioned. It is noteworthy that similar applications of future practice scenarios described by Anggreeni and van der Voort (2007) were intended to explore emergent ideas which were viable candidates for implementation, rather than fully exploratory concepts. Therefore, the use of futuristic eHealth cases is deemed more suitable for summative rather than formative purposes. However, we believe that the other methods proposed in this paper remain valuable to inform the design or redesign of eHealth.

Secondly, re-designing the structure of the individual PJVM during the *interaction phase* could increase the richness of the elicited information. While an attempt had been made to design and facilitate the activity to minimise the cognitive burden of the task, the participants still felt rather overwhelmed. As a result, the individual PJVM activity could not be completed as intended due to time constraints. Future studies should not underestimate the analytical burden of journey mapping, as this task is conventionally performed by researchers to systematically organise and analyse events to identify opportunities for improvements (de Ridder et al., 2018). The process could be facilitated more appropriately by breaking down the analytical tasks into smaller actions, for instance by first asking participants to write down a set of critical incidents. Subsequently, these could be clustered based on a similarity criterion, and then organised in a chronological sequence.

Nevertheless, breaking down the PJVM activity into several sequential analytical tasks might increase the time required to complete the activity. To improve the quality of the data obtained during workshops and to reduce the experienced workload during workshops, others have proposed the use of sensitising activities (Sleeswijk Visser et al., 2005). These serve as preparation activities which participants can complete in their own time, prior to a workshop. Diary studies are intrinsically suitable for sensitising, as they require patients to repeatedly engage with the research topic of interest, resulting in a greater degree of familiarity and awareness (Sleeswijk Visser et al., 2005; Verhagen et al., 2016). While diary studies were used for data collection in the current study, their sensitising properties were not leveraged actively. At the end of the diary study, patients were for instance not asked to reflect upon what they had discovered about their patient journey based on their diary entries. At the start of the diary study, future studies could ask patients to express what they would like to achieve in their patient journey by the time the diary study has ended. At the end of the diary study, patients could be asked to revisit their diary entries to motivate which critical incidents contributed to, or worked against achieving their goals. Such a summary measure or endpoint of the diary study could be brought into the workshop to support the PJVM activity.

Aside from potential adaptation strategies to maximise the elicited information during a PJVM activity, it is recommended to always give patients the opportunity to define their patient journey themselves. Even though the individual patient journey value maps constructed during the workshop were incomplete in the current case study, important lessons were learnt from merely discussing what the start of the patient journey entailed. Based on solely the analysis of the interview and diary study data, we conceptualised the first critical phase in the patient journey to be the admission phase. However, the workshop participants reported the events associated during the pre-admission phase to be the first critical incidents in their patient journeys. If patients had not been given the opportunity to define the patient journey for themselves, the pre-admission phase along with the associated opportunities for improvements would have been overlooked.

Although PJVM provides novel contributions to the existing VSD toolkit, the approach has some limitations as shown in Table 4. While the current PJVM approach allows key values to be identified between events along the patient journey, identification of tensions and priorities between coexisting

values within the same event has remained limited. If the participation burden is still perceived to be acceptable, future studies should include an additional feedback session to allow patients to comment on the final patient journey value map. During this session, inquiries could be pursued to study the coexistence of values within the same activity to increase the granularity of the findings by further characterising value tensions and prioritisations.

## Conclusion

This paper presented the first steps towards developing PJVM as a novel approach in value sensitive eHealth design. Through a case study on values implicated in rehabilitation care, we identified critical incident interviews, diary studies, and interactive workshops to be suitable empirical methods to collect data for PJVM. Nevertheless, researchers could adapt the approach, by considering the methodological trade-offs between information richness and participation burden. The PJVM approach extends the existing toolkit of VSD methods by tightly coupling values to the critical incidents they relate to as well as the respective emotions patients experience, while describing how these dimensions may change over time. This coupled structure is a favourable representation, as the case study revealed that the meanings of identically named patient values could be highly dependent upon where they occur along the patient journey. Additionally, the maps offer a means to capture potential shifts in priorities in values over time. This way, the quality of care can be improved by pivoting the focus of care delivery and eHealth design to patients' preferences and values along the critical phases of the patient journey.

# Part 4

# Framework for future projects and synthesis
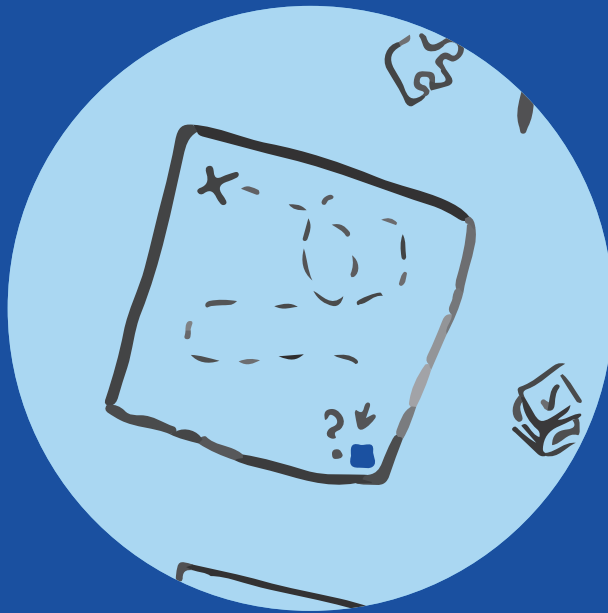
The final part of this thesis combines the findings and recommendations from the previous parts in the development of a framework for active stakeholder involvement in eHealth action research. This part ends with the general discussion of this thesis, which includes some reflections as well as topics for future research.

# Chapter 11

This chapter presents a framework to guide researchers in their action research projects and foster the active involvement of stakeholders. The framework was developed based on literature, and the findings from the earlier chapters in this thesis. After an evaluation with experts from the field and researchers from practice the framework was improved, and the final version is described in this chapter.

**Abstract**

The involvement of stakeholder groups, like patients or healthcare professionals, is highly valued in eHealth Action Research (AR) projects because it ensures a match between the project outcomes and the needs of the target group. However, few best practices or advices are available and no overview exists that describes the process of active involvement of stakeholders in the context of eHealth. Therefore, this paper presents the development of a framework for active stakeholder involvement in eHealth AR. The framework was developed based on several studies on stakeholder involvement in a project, as well as existing literature. To evaluate the framework, interviews were conducted with eight participants, who were either experts from the field or researchers currently working in practice in eHealth AR projects. Based on the suggestions made during the interviews, the framework was adjusted. The final version of the framework consists of 9 sections with a total of 56 questions, as well as material for additional reading. This framework can help researchers, especially those who are relatively new to AR and stakeholder involvement, shape their research process. A next step would be to further investigate how to operationalise the framework, for example in project meetings with stakeholders, and then, evaluate the framework in practice by implementation into an AR project from start to finish.

## Introduction

Healthcare research in general, and eHealth studies specifically, increasingly value and require the involvement of different stakeholder groups because this can increase the success of a project, through aligning the project with what stakeholders want. One approach that includes active involvement of stakeholders is Action Research (AR), where stakeholders become co-researchers of a project (Reason & Bradbury, 2013). Other elements of AR include that 1) the project is conducted in cycles of planning, action and reflection; 2) it takes place within the context that is studied (e.g., in a community); and 3) it aims to make a change in practice and to extend scientific knowledge at the same time. However, a literature review on eHealth AR projects showed that there is a lack of clear knowledge sharing, making it difficult for others to shape their project and to learn from others (Oberschmidt et al., 2022). Research frameworks can be a useful starting point for getting familiar with a certain field, approach or methodology. Such frameworks also support transferability of knowledge or comparability between studies, as they can support researchers to work in a more standardised way.

Stakeholder involvement has been the topic of various research frameworks outside the context of eHealth, each focusing on another discipline or aspect of the involvement. For example, one framework classified different objectives of involvement (Schmidt et al., 2020): the normative, substantive, social-learning, and implementation objectives. A framework also exists for the reporting of parameters of stakeholder involvement when performing a systematic review (Pollock et al., 2019). These parameters were: who is involved, how they are recruited, the approach and method used and the stage of involvement. Furthermore, five levels of involvement were defined: leading, controlling, influencing, contributing and receiving. The framework by Achterkamp and Vos (2006) described stakeholder involvement in sustainable innovation projects, based on the four pillars: when, who-inside, who-outside and what, and the three phases: initiation, development and implementation. Concannon et al. (2012), included six stages of stakeholder involvement in their framework: evidence prioritization, evidence generation, evidence synthesis, evidence integration, dissemination and application as well as feedback and assessment, next to describing Plan-Do-Study-Act cycles for researchers.

Several eHealth frameworks also included the involvement and roles of stakeholders, but not as key element of their framework. For example, van Gemert-Pijnen et al. (2011) mention the importance of involving stakeholders in all stages of the process for eHealth uptake and impact. Ammenwerth et al. (2006) focus on the *Fit between Individual, Task and Technology* (FITT) and an extension of this framework also exists for eHealth self-management (Kujala et al., 2020). Buccoliero et al. (2008) mention the impact of involvement on different stakeholders for the evaluation of eHealth projects.

There are several frameworks for AR available within other fields like education, information systems or management. However, the healthcare sector presents very specific challenges e.g., the specific relationship between patient and healthcare professional and potential vulnerability of patients as involved partners) making other frameworks less applicable for this context . Where frameworks do exist for AR in healthcare, these relate mostly to education. For example, in the praxis framework for health education developed by Nelson et al. (2004) values, assumptions, power, partnership, systems and action are the key concepts. Also the Sensitise, Take Action, Reflect (STAR) framework by McAllister et al. (2013) includes elements of AR, like reflexivity, and applies them in the context of healthcare professional training.

To the best of our knowledge, no frameworks are available that combine the specific context of eHealth (action) research and the process of active involvement of stakeholders. Yet the field of eHealth research can greatly benefit from AR in general, and stakeholder involvement specifically, to address some of the current problems in the healthcare sector. To facilitate knowledge sharing and support a more standardized approach, researcher could benefit from a framework that includes the main aspects of stakeholder involvement in eHealth AR. Therefore, the aim of this research is to develop and evaluate a practical framework for guiding the process of stakeholder involvement in eHealth action research.

## Development of the Framework

The development of this framework started from earlier AR and stakeholder involvement studies in different projects, which have been described in more detail in other publications (Oberschmidt et al., 2020, 2022). Based on these findings we started to create a list of important aspects for each phase of a project. The framework follows an abstract version of the timeline of a project, from (developing) the initial idea to sustaining the change in practice after a project ends. The initial version of the framework started with an introductory text as well as a figure to provide an overview. This was followed by nine elements, with a brief description and somewhere between three and nine pointer questions for each. These elements were: Project idea (4 questions), Plan - Roles and tasks (9 questions), Plan - Align interests and needs (6 questions), Ethical approval (3 questions), Training (5 questions), Act - Celebrate milestones (5 questions), Act - Dissemination (3 questions), Reflect (7 questions) and Sustain change (4 questions).[1]

A first draft version of the framework was presented to project members of a large scale European project, all doing AR in their different pilots. The session was attended by 20 project partners with different functions (e.g., researchers, stakeholder representatives, healthcare workers). After a short presentation of the framework, the participants worked in groups to discuss the framework, and as a group provide feedback, ask questions and suggest improvements. To structure the input, we gave each group a list of questions that they could use to stimulate the discussion (e.g., which elements are you missing?), but they were also free to add remarks directly onto a large printout of the framework that they received. Based on the input we received in this session, some small changes were made to the draft of the framework. These were mostly about adding some questions that the participants

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[1]To help visualise what this looked like approximately, final version of the framework in Appendix 11.2 can be consulted.

were missing (e.g., Which tools can be used for reflection?), and slightly changing some phrasing to improve the understanding of the framework for those new to the topic.

## Evaluation study of the Framework

To further improve the content and practical usefulness of the developed framework, the next step was to evaluate the framework with researchers from the field, who were not previously involved in the studies or the workshop that led to the framework.

## Methods

The evaluation was conducted with two different groups of participants: experts from the field, with experience in AR; as well as researchers who recently got involved in AR projects, without much previous experience. This twofold approach was chosen because we expected that the responses from both groups would complement each other. Experts are better able to evaluate the content of the framework based on what they have learned and experienced in previous projects. However, they are likely not going to be the ones using the framework because they rely on their own experience to set up projects. Researchers new to AR, on the other hand, can estimate whether this would be a useful tool for them in practice, but might not yet be familiar enough with the processes of AR the evaluate the content of the framework. Experts were identified from literature (i.e., publications in the field of AR and eHealth), supplemented with online searches for senior academics in the field. The experts were then contacted by mail by the first author. One of the experts who was not available for an interview made contact with one of their colleagues who was then interviewed. Inexperienced researchers were identified via convenience sampling, through two regional projects that the first author was (made) aware of, and were also contacted by mail.

All participants (both experts and researchers) were interviewed, either online or in person, by the first author. Before the interviews, participants signed an informed consent form, stating that the session would be recorded. They also received the link to the (English) framework, to familiarise themselves with the framework before the interview. However, this was not mandatory as there was sufficient time during the interviews to go through the framework. The interviews were semi-structured and started with a brief introduction by the first author of themselves and their work, followed by an introduction of the interviewee. Then, the participants had the chance to go through the framework and provide any remarks that came to mind (similar to think-aloud methods). Afterwards, the first author asked them a set of questions regarding their perception of the framework, and how they think it could be improved.

The answers were inductively coded as recommendations or requirements for the framework. While coding the answers, a distinction was made between answers related to the **content** (whether this was missing or unclear), the **language and structure** of the framework, the **presentation** (e.g., in terms of images) and any comments related to **additional materials** to be added.

## Results

The interviews were conducted with four experts who had longstanding experience with AR, as well as four researchers from practice currently getting started on an AR project. The AR experts had all previously worked in several AR projects. The domains of these projects varied but included studies from the healthcare, active ageing and public health domain. The participants from practice were

involved in (one of) their first AR project(s). Three of them worked as researchers at different academic or healthcare institutions, one as a healthcare professional. The interviews lasted on average 37 minutes (minimum 19, maximum 47 minutes). The evaluation interviews resulted in a total of 65 recommendations, of which 31 were related to missing content, 13 about unclear content, 12 about unclear language or structure, five about the visual presentation and four about background materials. Table 12 shows the distribution of recommendations across the categories.

Below, the resulting recommendations for each part of the framework are outlined, including how these were integrated in the second version of the framework. The full overview of all recommendations made by the participants, and the implemented changes based on these recommendations, can be found in Appendix 11.1.

## Introduction of Framework and Figure

The comments regarding the introductory text and figure at the beginning of the framework were mostly about unclear content. Participants were missing a clear explanation for the link between this framework and AR as a research approach, and between this framework and similar models. Additionally, participants commented that the cycles of AR are not as clear and structured as they are presented in the framework, and that a project might not have such a clear and defined endpoint. *To address these recommendations, more links to literature and other approaches were added in the introduction section. Additionally, a disclaimer was added to the figure to raise awareness that AR is rarely such a straightforward process and that it might not have such clear time- and endpoints.*

## Element: Project idea

Regarding the setting up of a project idea, there were several recommendations about content and pointer questions that were missing, for example, the fact that this process takes time, and that ideally the project should be initiated by the community or stakeholders. There were also some recommendations to adapt the phrasing of some of the questions, to make them more realistic and make sure that stakeholders are truly involved (i.e., replacing the word 'consulted'). Lastly, several participants commented on the fact that the word 'reimbursement' can be unclear, with the suggestion to specify that this can also be about non-monetary aspects, like time, meaning or recognition. *These recommendations were taken into account by adding some questions and explanations, and by changing the wording of some questions as suggested.*

## Element: Plan - Roles and tasks

For the section 'Roles and tasks' of the framework, participants again recommended some missing elements, like: risk analysis, defining clear metrics for evaluating change and creating space for renegotiations. Furthermore, a recommendation was made to restructure and re-phrase the questions to make sure they are all on the same level and in logical order. One participant asked for clarification of the word 'champion' in this context. *These recommended items were added to the framework. Also, a link to relevant information on this topic was added, along with links to other approaches and useful methods that were mentioned by participants.*

| | Content missing | Content unclear | Language & structure | Visual presentation | Background material |
|---|---|---|---|---|---|
| **Introduction & figure** | | 4 | 1 | | |
| **Project idea** | 6 | 1 | 2 | | |
| **Roles & tasks** | 6 | 2 | 1 | | 1 |
| **Align interests** | 3 | | 2 | | |
| **Ethical approval** | 3 | | | | |
| **Training** | 2 | 1 | 1 | | |
| **Celebrating milestones** | 2 | | 1 | | |
| **Dissemination** | 3 | 1 | | | |
| **Reflection** | 2 | 2 | 1 | | |
| **Sustain change** | 1 | 1 | 2 | | |
| **General remarks** | 3 | 1 | 1 | 5 | 3 |

Table 12: Overview of the amount of remarks in each category for the different elements of the framework

**Element: Align interests and needs**

Participants suggested making it clearer that the alignment of interests is not always possible, and that even subconsciously conflicts might exist. One participant recommended stressing here that being open requires some courage. Lastly, there were two recommendations related to language, suggesting sharper and more active phrasing. *Again, these suggestions were implemented as suggested by the participants.*

**Element: Ethical approval**

Regarding ethical approval, participants made some suggestions on what else should be considered. These recommendations referred to getting in contact with an ethics board early on to discuss procedures, including the European General Data Protection Regulation (GDPR) in this section and adding suggestions for what to do when participants do not (want to) give consent. *Questions related to all three topics were added to the section.*

**Element: Training**

Several participants pointed out that the wording 'training' might be misleading in this context and suggested renaming the section, for example to 'Mutual learning and skill development'. Additional questions were suggested, about which skills are needed and about didactics. One participant asked for clarification about what hierarchy means in this context/ *We renamed the section to 'Mutual learning and skill development', added the suggested questions and clarified what hierarchy means in this context.*

**Element: Act - Celebrate milestones**

Around the topic of celebrating milestones, participants pointed out that it is important to not only focus on the positive milestones but to also learn from failures and facilitate this process. Another participant added that milestones take a different shape in each project. *The section was renamed to 'Celebrate successes and learn from failures'. In this way, we also addressed the remark from one participant that 'celebrating milestones' sounded quite formal. Additionally, a sentence was added in this section to raise awareness that milestones can look different each time and for everybody.*

**Element: Act - Dissemination**

There were several suggestions for what to add to the section on dissemination, like including different ways of disseminating and thinking about the reasoning behind dissemination efforts. Additionally, one participant asked to specify which stakeholders are meant in this context, those within or outside of the project, and mentioned that this might be too broad currently. *Therefore, a clarification was added that this section referred to external dissemination as opposed to internal communication with stakeholders on the team. The other additions were implemented as suggested by the participants.*

**Element: Reflection**

Participants suggested adding some more information regarding reflection, like how to shape the reflection, and the different levels at which reflection can take place. There were also some requests for clarification, like making it clear what mitigations mean in this context, and adding more explicitly

that reflections should take place continuously, and at intervals that make sense for the project. Lastly, one participant suggested changing the order of the questions, to start with the tools that can be used. *The questions were reordered and the clarifications and additional information regarding reflection was added.*

### Element: Sustain change

An important element of sustaining change that was mentioned by some of the participants was to embed the project outcomes in policy-making, as this can ensure a more lasting effect. However, one participant highlighted that this might impact how flexible a project is to make changes. While 'Sustain Change' was presented as the final part of a project, participants recommended paying attention to this aspect much earlier. Lastly, a participant pointed out that wording in this section was inconsistent, and to make this the same across the whole framework. *In this section, a question regarding policy making was added, alongside a note that this might impact flexibility. We emphasized the importance of thinking about sustaining change early on, and made the wording consistent for this section.*

### General remarks

The general suggestions that participants made were diverse. Some recommended adding more figures and additional literature, as well as examples from practice. Additionally, researchers from practice mentioned that they would like a downloadable document that they could fill in for their project, maybe together with the team. One participant suggested thinking about other ways to present the framework, like through video or a (chat) forum. It was also mentioned that it might be more intuitive to add the headings 'Plan' and 'Act' as these had two sub-headings each while training and ethical approval were somewhat in between. One participant remarked that a challenge of this framework is to stay realistic by showing people the difficulties they might face without discouraging them. In a similar vein, one participant pointed out the balance between being specific and at the same time presenting something that can be applied in many contexts. Participants mentioned that they appreciated how compact and clear the framework was, however, sometimes they were missing background information and resources. One participant proposed to keep the main framework relatively simple, but to add a list of further reading and materials below the framework. This way, as another participant pointed out, the framework is easy to understand for practitioners. Lastly, one participant mentioned that in their context, an English language version would be less useful and that a translation in their local language would be better. *We have created a downloadable version of the framework, and included additional reading at the bottom. The suggestions regarding video or (chat) forum to present the framework will be explored further, but were not yet implemented. A disclaimer was added regarding the generalizability of the framework. We are currently looking to provide translated versions of the framework for download as well.*

## Final version of the framework for stakeholder involvement in eHealth AR

The final version of our framework for stakeholder involvement in eHealth AR projects consists of an introductory section, followed by descriptions and pointer questions for the nine different elements of eHealth AR. For each of these elements, some additional explanations and questions were added compared to the initial version, leading to the following overview of the framework: Project idea (6 questions), Plan - Roles and tasks (10 questions), Plan - Align interests and needs (6 questions),

Ethical approval (6 questions), Mutual learning and Skill development (5 questions), Act - Celebrate milestones (6 questions), Act - Dissemination (5 questions), Reflect (7 questions) and Sustain change (5 questions). A full version of the final framework can be found at https://www.rrd.nl/ar-framework/ as well as in Appendix 11.2.

## Discussion

The aim of this research was to develop and evaluate a framework for stakeholder involvement to be used in eHealth AR projects. This has resulted in a framework that includes some explanation, pointer questions and additional reading material to guide (novice) action researchers in their eHealth projects.

A specific characteristic of the eHealth AR context, which we again noticed in the current study, is its multidisciplinary nature. Stakeholders from health backgrounds meet those with technical expertise, and citizens are involved, for example, as patients or caregivers. In a project, these groups might need to overcome differences in language and experience (Blandford et al., 2018). Methods and ways of working that are obvious to some, because these are common in their field, might be new to others outside of that field. We hope that this framework, complemented by a collection of links to different methods and tools, can help researchers in other projects.

The main component of the framework we present are the pointer questions that researchers can answer, alone or with their project team, to investigate the stakeholder involvement in their project. Other frameworks have focused more on the stages (Concannon et al., 2012) or levels (Achterkamp & Vos, 2006) of stakeholder involvement. Generally, these frameworks are often kept rather clean and simplified. On the contrary, our framework is much more extensive and goes into detail on some practicalities of stakeholder involvement. This makes our framework more specific and practice oriented, and thus hopefully easier for researchers to apply it in their projects.

One of the main challenges in the development of this framework, which also was mentioned in several of the interviews, was finding a balance between keeping it simple and still providing enough information. Based on the results we have implemented a list of further reading and materials below the framework. We hope that this strikes the balance between too much and too little information.

Similarly, in our results, many recommendations were based on individual experiences and supplemented with specific examples from practice. Therefore, these are likely important points to consider, but not necessarily applicable to other projects. Similarly, readers and those using the framework might find points that are more or less specific to their project. Still, we believe that the way this framework was developed covers the most important general aspects of stakeholder involvement in eHealth AR. However, as we will also outline below, this framework should be seen as a living document that we would like to adapt based on input from those who use it in practice. This might bring up other elements that we did not consider general, but that apply to more eHealth AR projects.

The dual evaluation both with experts and with potential users of the framework (i.e., researchers from practice) was very valuable, as the feedback they gave differed, and we expanded our framework based on their recommendations. How the developers of other frameworks included the target users in the development and evaluation differs. Concannon et al. (2012) describe that they followed an iterative approach and involved a panel of (external) stakeholders to review their taxonomy for stakeholder involvement, however it is unclear how the feedback from this panel was implemented in their work. A good example of evaluating a framework is provided by McAllister et al. (2013), who evaluated their framework with members of their target group, health educators, and used different methods to collect data for evaluation. Schmidt et al. (2020) do not include an evaluation in the description of their framework, but encourage readers to share their experience with it. We have involved both experts and members of our target group for this evaluation, but would like to follow the example of Schmidt et al. (2020) and ask readers about their experience. This way we hope to

make this framework a living document, similar to the approach for communicating AR described by Canto-Farachala and Larrea (2022).

In our results the experts provided more of the input on what was missing, while researchers from practice asked more questions to clarify. However, the researchers from practice also added what they were missing from their practice and what they had learned so far. It would be interesting to hear the perspectives of involved stakeholders (e.g., healthcare professionals, patients) as well as experts for specific related topics (e.g., ethics, communication), which could add new elements to the framework as well. We generally believe that it is important to include several perspectives, especially also those of involved stakeholders, in comparable future studies, and would recommend such an approach to others conducting similar research.

The current evaluation of the framework was rather theoretical. Additionally, the interviews provide insights from a specific moment in time. Especially for the researchers from practice, with less experience in AR, it can be difficult to foresee how the framework could be used over the course of a whole project. Therefore, a logical next step to further develop and improve the framework is to implement it in a research project from start to finish, and evaluate this process. This can not only unearth missing content and unforeseen hurdles that a project faces but can also provide more insight into how best to operationalise this framework in practice. Some of the participants already thought about this during the interviews (e.g., would they use it as a checklist for themselves or share it with the stakeholders), but practical experience would allow us to give recommendations on the use of the framework as well.

A specific characteristic of the eHealth AR context, which we again noticed in the current study, is its multidisciplinary nature. Stakeholders from health backgrounds meet those with technical expertise, and citizens are involved, for example, as patients or caregivers. In a project, these groups might need to overcome differences in language and experience (Blandford et al., 2018). Methods and ways of working that are obvious to some, because these are common in their field, might be new to others outside of that field. We hope that this framework, complemented by a collection of links to different methods and tools, can help researchers in other projects.

## Conclusion

eHealth AR projects can benefit greatly from sharing knowledge, best practices and lessons learned. This can act as a guide for future projects, especially for researchers and other project partners who are new to working in such a participatory way. Through the presented framework we hope to support researchers in setting up and conducting projects together with stakeholders. Based on an evaluation with experts and researchers from practice we believe that this framework contains all important elements of eHealth AR and fits the needs of researchers in terms of presentation and content. Hopefully, the framework can continue to evolve based on future evaluation in practice, and from feedback by those who (want to) use the framework.

## Acknowledgements

# Chapter 12

# General Discussion

The aim of this thesis was to investigate *how* we involve stakeholders in AR, in order to learn more about the *process* of AR projects. Frequently, reporting of AR studies is focused on the outcomes of a project, whereas more attention for how the project was carried out would be important for others to learn from. Based on different studies, we developed and evaluated a framework for active stakeholder involvement in eHealth AR projects (Chapter 11). The framework aims to provide researchers with guiding questions to ensure a match between the stakeholders being involved, the stage of the project and the way and role in which they are involved.

The main research question guiding this PhD research was:

**Main research question:**
*How can we guide active stakeholder involvement in eHealth AR projects?*

Three sub-questions fed into answering this question, and into the subsequent development of the framework for active stakeholder involvement in eHealth AR:

1. *What is currently known about eHealth AR?*

2. *How can we motivate and engage relevant stakeholders?*

3. *How can we facilitate the communication and collaboration between stakeholders?*

In this discussion I will first answer these sub-questions, and from there move to my overall research question. To answer each question, I will not only rely on my findings and relevant literature, but also include some reflections from my perspective. As I have highlighted various times throughout this thesis, reflection is a crucial element to AR. Without reflection, it becomes impossible to draw conclusions from a project and identify lessons learned from which others can benefit.

## What is currently known about eHealth AR?

To investigate the state of the art of eHealth AR, a literature review was performed (see Chapter 2). We described the context, AR definitions, best practices and lessons learned from 44 eHealth AR papers. The main findings of this study were that it is important to raise stakeholder skills and confidence (this topic was tackled in more detail in Chapter 9), that researchers need to be conscious of the roles and tasks they need to fulfill (touched upon in Chapter 3 as well), that it is important to foster constant reflection (also discussed in Chapter 8) and that dissemination should be open and accessible (see the reflections below). Additionally, we found that reporting on AR definition used, best practices and lessons learned was very limited in the studies included in the review. This literature review showed that in general, more extensive reporting on eHealth AR is needed to optimally benefit from each other's work. While we included a variety of variables to characterise what eHealth AR looks like (e.g., context, methods), it would be interesting to be able to go into more detail on certain aspects, to find lessons learned for more specific situations. This could, for example, mean looking at differences in involvement between different groups, like patients or older adults, or focus on key elements of stakeholders involvement like hierarchies and power dynamics or multidisciplinarity. James and Buffel (2022) provide an overview of ways in which older adults can be involved in participatory research, and describe benefits and challenges of such involvement. However, many of the studies they include are about communities or understanding the perspectives of older adults in society, but do not study their interaction with technology specifically. Since technology brings about specific challenges and biases towards older adults (Mariano et al., 2022), the dynamic in participatory, technology-related projects with older adults is very interesting to look at. This way, future projects can learn to better address the challenges of working in this context. Similarly, the involvement of patients in participatory research (like AR, but also Patient and Public Involvement) requires specific attention. An

example of such collaborations, from the perspective of patients, who point out important pitfalls of patient engagement can be found in Richards et al. (2023). However, as we found in our literature review, aside from some positive examples, current reporting of AR lacks the reflexivity to be able to learn a lot about these processes. Even more so, in other participatory approaches like Patient and Public Involvement or Citizen Science, there is less focus on reflection compared to AR, rendering a literature review focusing on these aspects difficult if not impossible.

## How can we motivate and engage relevant stakeholders?

The subject of motivating and engaging different stakeholders is closely related to the first question in the title of my thesis, 'who'. Who needs to be involved in a research project? Who takes on which role? Whose perspective are we missing in our project team? Based on the research conducted, I believe that **looking at different levels of involvement in a project and ensure the role stakeholders fulfil in a project fits their needs** is the key to motivating and engaging them. One person might want to drive a project as a champion while another prefers to follow along from the sidelines. Additionally, somebody being a champion in one project does not make them a fitting champion for another project. While the different chapters in this part zoom in on specific roles in a project, and how to enhance engagement there, making the roles in a project a topic of discussion to me is what is most important here, and yet often forgotten. This will also be touched upon in the discussion of the third part of this thesis, because elements like reflection and alignment influence the motivation and engagement of stakeholders. There are four other important aspects about motivating and engaging stakeholders that I want to discuss: (1) the importance of the mindset of the researcher, (2) listening to stakeholders instead of deciding for them, (3) managing expectations, and (4) being aware of, and ideally avoiding, selection bias.

**Mindset of the researcher:**    In Part 2 of this thesis ('Engaging relevant stakeholders'), we looked at the perspective of researchers, and throughout this thesis also provide advice to researchers about involving stakeholders in their project. This may seem counter-intuitive as I advocate for active involvement and empowerment of stakeholders in the research process. However, this perspective is a conscious choice, as for the most part, researchers are the ones who set up and lead a project (Vines et al., 2013). Furthermore, even though researchers hand over some of their tasks, and eventually hope to hand the project over to the community, the role of the researcher is still crucial to AR projects. However, it is different from what many researchers are used to. As we have seen in CHAPTER 3 of this thesis, AR poses some challenges for researchers, and they need to be willing to face these challenges and adopt new practices. Luckily, we also found that researchers saw the benefits of AR. This makes me hopeful that researchers can embrace AR, which is a first step towards motivating and engaging stakeholders. Additionally, I believe that the framework provided in CHAPTER 11 can make it easier for those new to AR to work in such a way.

**Listening to stakeholders:**    Because AR projects require intensive, long-term involvement, it is important to ensure a fit between a stakeholder and the role they will play in a project. In the third part of this thesis ('Facilitating interaction between stakeholders'), we recommend to continuously align with and re-align between stakeholders, which can also be applied to the distribution of tasks and roles (CHAPTER 7). It is important to emphasize here that this is a collaborative effort, that should be done together with the project team. Wilderink et al. (2021) nicely reflect on this topic, highlighting that researchers should not be 'filling in' what they expect older adults (in this case) want. As mentioned in the previous paragraph, it is also commonly researchers who decide whom to invite to a project and how to involve them (Vines et al., 2013), which they should be aware and self-critical of. However,

there are tools to help researchers shape the process of dividing roles and tasks throughout the project, like the participation matrix (de Wit et al., 2018), which comes from Patient and Public Involvement but is applicable to the context of AR. The biggest lesson here is that to keep stakeholders engaged in a project, researchers and stakeholders should decide **together** how the stakeholders want to be involved.

**Managing expectations:**  When working with stakeholders, especially those who might not have previous experience with participation in a research project, it is crucial to manage expectations. We saw this in Chapter 5, where we looked at the motivation of research participants and found that unmet expectations can make them less motivated to continue their participation. In AR projects, disappointments can arise at different stages, beginning with funding not being granted for a project idea that was developed together, which can delay or even completely prevent the start of a project. During the project, the involvement can be different from what stakeholders expected, and the change envisioned for a project might not be achieved (Corrado et al., 2020). Lastly, when funding for a project runs out, researchers will at some point leave the site and if a project cannot be sustained at that point, this can again be disappointing for involved stakeholders. Therefore, continuously managing expectations, for example during reflection meetings, and being realistic about what a project may or may not achieve is important for the motivation and engagement of stakeholders.

**Selection bias:**  A challenge when it comes to the question of who to involve is that of selection bias. This applies across the levels of involvement, from champions to spontaneous participants in the flash mob studies. In this context selection bias means that those stakeholders who join the project, and ideally become co-researchers in it, may not necessarily the ones who would benefit most from a project. Often, stakeholders who decide to join a research project already have an affinity with research, for example because of higher levels of education (James & Buffel, 2022). This phenomenon is not exclusive to AR, but for example also seen in Citizen Science, where participating stakeholders are often more more highly educated and tend to have a higher income than the general population (Raddick et al., 2013; West & Pateman, 2016). Therefore, it remains important for researchers to ask themselves whether the involved stakeholders are a good representation of the target group of a project, and how a more diverse group of stakeholders might be involved. The flash mob method that was presented in Chapter 6 can be a step in this direction, as it brings the research right to the stakeholders. Generally, participatory projects should reflect on and be aware of whom they are missing, and look for strategies to reach these people. Again, listening to involved stakeholders from the target group can be a good starting point.

## Future research

In Chapter 6 I discussed how outsiders to a project can be involved on a rather low level through the method of flash mob studies. However, there is another level of more distant involvement in a project that is very interesting to look at in light of stakeholder involvement. As described in the literature review in Chapter 2, some AR projects involve stakeholder in so called expert reference groups. These groups consist of members with different backgrounds and expertise (e.g., ethical or juridical) and act as an advisory board for the project team throughout the project (see for example Trondsen and Sandaunet (2009)). The involvement of such a reference group is likely closely linked to other topics that were discussed in this thesis, like aligning the interests of stakeholders and providing skill training. There is limited information about how to form, shape and engage such a reference group throughout a project. Looking at this topic, either in literature, or by contacting projects who have worked in this way before, to gather their best practices and lessons learned, could be very valuable for future projects.

Another interesting dimension of stakeholder involvement that was outside of the scope of my thesis is that of government involvement. Local AR projects with actively involved stakeholders can lead to change in a community, but the involvement of municipalities and (local) governments can achieve changes on a higher level (Kleijberg et al., 2022; Lindner et al., 2021). However, in the projects described in this thesis we already saw that hierarchy and power dynamics play an important role in project teams. This effect might be even more prevalent when governments with large decision power are involved. It would be interesting to repeat activities like alignment and expectation management, collaborative reflection or skill training in projects with governmental involvement and study how this plays out.

## How can we facilitate the communication and collaboration between stakeholders?

Part 3 of my thesis looked at the facilitation of the interaction between stakeholders during a research project. This closely related to answering the 'when' and 'how' from the title of my thesis. I believe that these questions go hand in hand, because how stakeholders are involved can evolve and change during a project. Overall, it requires continuous effort to facilitate collaboration, which is supported by the framework developed and discussed in Chapter 11. The framework includes aspects like alignment between stakeholders (see also Chapter 7), mutual learning (see also Chapter 9), the celebration of milestones and reflecting on and learning from failures (see also Chapter 8), which are all activities that can facilitate communication and collaboration. The framework also mentions other activities that we did not elaborate on in detail in Chapter 11, but which are important to discuss here, as they influence the communication and collaboration with and between stakeholders. Specifically these are: (1) dealing with the unpredictability of an AR project, (2) dealing with the ethics of AR, (3) disseminating the project, and (4) handing over a project to the community.

**Unpredictability of AR:** Due to the iterative nature of AR projects, it is generally not known from the start how a project will play out as the direction of the project may change (for example, based on reflections, but also through policy changes). As this is different from what researchers and participants are used to, expectation management (also mentioned in Chapter 5) plays a big role here, and all involved parties need to be open to delve into such a process together. However, the fact that current funding and research structures are less applicable to AR does not help here. For example, when applying for funding project plans for three to four year need to be submitted that are thought out in high detail. This is impossible to achieve for an iterative process like AR, where reflections and changes in practice largely influence the next steps of a project. This also becomes apparent in structures like ethical review at institutions, as I will discuss in the following sections. All in all, researchers and stakeholders in an AR project will run into different barriers due to the ever-changing nature of AR, making it a difficult approach to follow, and one that requires much flexibility.

**Ethics of AR:** In terms of ethics there are some important considerations to be made when doing AR, both when in comes to conducting the research in an ethical way and about receiving ethical approval for the project. For example, there are hierarchical elements and power differences at play (e.g., between the researcher and participants, healthcare professionals and patients), which should not be neglected. This topic was touched upon in Chapter 9 about stakeholder skill training as well. More involvement from, and responsibility for, stakeholders likely places a higher burden on them. Another aspect that is often discussed in this context is that of reimbursement, as researchers are paid for their work, while this is not always the case for stakeholder co-researchers. As Pandya-Wood et al. (2017) mention in their ethical framework for stakeholder involvement, it is important to acknowledge

and reward the effort that stakeholders put into a project, be it in terms of financial reimbursement or in other ways like skill development (see also Chapter 11). As we have seen in Chapter 5, getting in contact with peers can be a rewarding experience for people as well. McKercher (2020) describes giving back an equivalent amount of time to the participants as they invest in the research, to spend on an activity of their choosing. Projects should determine fitting means of reimbursement together with the involved stakeholders.

Of course, what is most important is that research is conducted in an ethical way. However, another questions is how best to present an AR project to ethical review boards in order to get approval for a study. Ethical review boards do not always have an understanding of AR, making it difficult for them to judge and grant ethical approval because they expect a more 'traditional' research setup (Kwan & Walsh, 2018). The approval process is complicated by the iterative nature of AR, and the fact that stakeholder groups, especially those that are sometimes seen as vulnerable (e.g., patients) have an active role in a project, arguably placing a higher burden on them. It has been suggested, as was also included in the framework in Chapter 11, to have ongoing contact with ethical review boards (in line with the cyclical nature of AR) (Hand et al., 2019), and maybe even work to educate them about AR processes (Gelling & Munn-Giddings, 2011; Kwan & Walsh, 2018).

**Dissemination of AR:**    A key element of AR is that it not only extends scientific knowledge but also brings about practical knowledge and a change in practice. This includes an imperative to communicate findings not only in traditional academic formats (e.g., journal publications, conference presentations), which are generally less accessible to the broader public. During my PhD I have taken an interest in science communication, to search for ways of disseminating research findings in a more accessible way. For example, I have written blog posts to summarize research findings in a shorter and more accessible way, and given presentations to non-academic stakeholders involved in AR projects. Additionally, this thesis will not only be published in book format, but also as a magazine which distills the framework in a way that is most relevant for its target group (i.e., stakeholders that might become involved as co-researchers in AR projects). In this way I hope that to have a broader outreach with my findings.

While the above mainly refers to dissemination to non-academic audiences, the chapters of my thesis were of course written as scientific papers, with the aim of extending scientific knowledge. As we already discussed in the literature review in Chapter 2, it is still uncommon to publish reflections and lessons learned from AR projects. However, as this thesis and other authors have pointed out, reflections are crucial to build best practices (Boulus-Rødje, 2014; Cooper et al., 2022), and we received positive responses (e.g., from reviewers) to our openness to also report on things that did not go well. Therefore, not only should researchers be stimulated to be more reflective of their work, it would benefit scientific publishers to see that there is an audience keen to read about projects that did not achieve all they aimed for but are able to reflect and draw lessons from these 'failures'.

**Handing over a project:**    It is likely that the overall involvement of (some) stakeholders might increase over time. Most notably, as the framework in Chapter 11 also points out, the change in practice brought about by an AR project should hopefully be sustained after the project has ended. As researchers in most cases leave the project at this point, it is up to the stakeholders to take over. This necessitates that stakeholders are well prepared for this role and feel confident to fulfil it, which is related to the skill development discussed in Chapter 9. However, especially in projects that develop a new technology or service, there needs to be support that can be upheld by the community themselves (Taylor et al., 2013).

**Future research**

In Chapter 9 we explored the topic of mutual learning and stakeholder skill training in participatory health research. The themes we identified were based on the experiences of researchers who conducted stakeholder skill training in their projects. In our exploration we saw that there was a lot to be learned still in this regard, for example, looking at different ways to shape mutual learning activities, and again sharing lessons learned from practice. Here, AR can potentially also look at, and learn from, Citizen Science, where training stakeholders in scientific skills is equally important (Resnik et al., 2015). As skill development can be a step towards empowering stakeholders in a research process, it would be valuable to investigate this topic in more detail.

## How can we guide active stakeholder involvement in eHealth AR projects?

In the last part of this thesis, the findings from all previous studies were used to develop a framework for active stakeholder involvement in eHealth AR. The framework was evaluated with experts from the field and researchers from practice. Their recommendations were implemented in the framework, and the overall consensus was that this could be a useful tool, especially for beginning action researchers, to support them in their project. The framework is presented on an open access website [2], and translated versions are being added to make it easier for local projects to use the framework also with non-English speaking stakeholders. At the time of writing we are also looking to promote implementation of the framework locally, as we work to build a network for knowledge sharing about AR. Hopefully, the framework, as well as the reflection tool developed in Chapter 8, can be used and shared by (practice based) researchers, especially those who are new to AR. To achieve this, I have begun, and will continue to take action to present my framework at events in different relevant communities (e.g. citizen science, eHealth implementation). Additionally, within the Pharaon project we are currently developing a European standard for AR in large scale pilots, which includes many of the elements from the framework I developed, as well as a specific section on reflection.

Something that was seen throughout different studies in this thesis (e.g. Chapter 2, Chapter 8), and again remarked upon in the evaluation of the framework was the fact that AR projects will usually not go as smoothly as planned. Commonly, researchers perform a study on a certain topic (e.g., the implementation of a new eHealth service in a hospital) and report on the outcomes related to this specific goal. In AR, some reflections on *how* the project was conducted might be included, for example, the role that relevant stakeholders played in a project team. However, as the literature review in Chapter 2 showed, such reflections are still described only to a limited extent. But because not everything will work out as planned in an AR project, it is important to also discuss what did not go well, and draw lessons from it, which can also benefit future projects. Additionally, researchers have a responsibility to also be self-reflective of their own role and position.

For the most part, I was not directly involved in the eHealth research that I was studying. Instead, I looked at what was going on in the projects, what worked and what did not work, and how we can draw lessons learned from these findings and support this process in the future. I usually explained this as 'researching the research(ers)', or 'working from a meta-perspective'.

In my opinion, this perspective was beneficial, as I was able to look at the project somewhat more from a distance. As I was not directly carrying out the research in the project I think that my perceptions were sometimes more objective than those of the involved researchers, and therefore made it possible for me to extract recommendations for guiding projects. Randall et al. (2018) also highlight the benefit of having a meta-researcher in a project: "*In publicly-funded research schemes*

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[2]https://www.rrd.nl/ar-framework/

*there are typically not any resources designated for the role of a 'meta-researcher'. However, such research findings would be very helpful to improve the performance of practice-based research consortia. Honest and self-reflective empirical analysis could also be a permanent trigger for improving the mechanisms applied within the Central European approach to research funding."* With the different perspective of a meta-researcher comes the risk of them having limited insight into what is going on at a lower level, missing important aspects of the research process. I tried to defy this by being in contact a lot with the different researchers (e.g., joining in on meetings, conversations outside of my studies). Additionally, in some cases the researchers were co-authors on my papers, thereby including their perspectives as well. Still, I think it is good to keep in mind my distinctive perspective when looking at the outcomes of this thesis.

Working from a meta-perspective brought about another aspect to reflect on. Studying the process involved that my colleagues and project partners became the subjects of my research. In some way this was beneficial for my work, as I had a fixed group of (potential) participants to fall back on. The fact that people knew me from project meetings and activities may have also made them more willing to become a participant (and 'help me out', which we saw as an important motivational factor in Chapter 5). In this sense, my role allowed me to guide them throughout the project. However, there are also downsides to studying the work of colleagues. Next to my research work, I also carried out tasks in the project that were not part of my thesis. Whenever I collected data that was to become part of my research, albeit via email communication, I explicitly stated that the information provided to me might be used in a scientific publication. Still, there were sometimes assumptions when working on project-related tasks that I would make use of those also for my thesis. Being transparent is therefore crucial in meta-research, as you want to avoid unnecessary conflicts that might lead to a loss of access to the given context (Randall et al., 2018).

There are some examples of others who have taken a self-reflective stance and critically looked at their role as researcher in an AR project. Their approaches can act as inspiration for others who want to guide their projects from a meta-perspective. While usually, AR reflection is focused on the researcher, it does not need to be a solitary activity. On the contrary, Bjørn and Boulus (2011) describe their reflective conversations, which helped them in their project work and their own roles. Another example of self-reflexivity is the study by Randall et al. (2018), in which they describe a meta-research program to investigate how (design) research is being conducted, which is illustrated through two case studies.

## Future research

The studies in my thesis looked at different elements of stakeholder involvement (e.g., stakeholder skill training), as well as at different levels of involvement (e.g., as champions). Together, these form the bigger picture around stakeholder involvement, as it was presented also in the framework in Chapter 11. However, in the different studies these elements were investigated more or less in isolation, meaning that for example in the study about collaborative reflection, no specific attention was paid to the roles of champions etc. On the one hand, this approach allowed us to zoom in on a very specific part of stakeholder involvement. On the other hand, in practice these elements interplay and influence each other. In the framework we tried to make some links between the different elements, however as one of the participants in the evaluation of the framework in Chapter 11 also commented, AR is rarely so clearly structured and demarcated. As was already mentioned in the discussion of Chapter 11, an overall, holistic evaluation of the framework in a project in practice would be a useful next step to further underline the value of this thesis and its outcomes.

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# Appendix 2.1 Full overview of all categories and description of settings for each category

| Paper | Topic | Country | Context | Duration | Stakeholders | Target group | Methods |
|---|---|---|---|---|---|---|---|
| Alexander et al. (2015) | Electronic medical records | Canada | Family Health Teams | 8 months | Clinicians, Organization / local group, Managers | Clinicians | Interviews, Meeting data |
| Andersen et al. (2011) | Telemonitoring of chronic heart patients | Denmark | Heart Centre | 4 years | Specialists, Developers / IT, Patients and patient representatives | Clinicians | Observation, Interviews, Workshop |
| Asangansi & Braa (2010) | Health Information Systems | Nigeria and India, Norwegian researchers | Health Information System unit | 1+ years | Health workers, Govermmental body / local authority | Clinicians, government | Observations, Trainings, Interviews |
| Berger & Peerson (2009) | Physical activity | United Arab Emirates | Women's college | 8 months | School and university staff, Students | Young Muslim Women | Interviews, Focus groups |
| Bishop et al. (2003) | Digital library of health information | US | Local grassroots group of African American women | n.r. | Citizens, Healthcare professionals, Other staff members | African American women | Focus groups, Workshops |
| Byrne & Sahay (2007) | Health Information Systems children's health | South Africa, Norwegian researchers | Rural communities | 8 years | Clinicians, (Community) Health care workers, Govermmental body / local authority, School and university staff, Companies / SME | Clinicians | Workshops, Focus groups, Interviews |
| Callén et al. (2009) | Telecare for older adults | Spain | Red Cross Telecare service | 2 years | Operators, volunteers, relatives, caregivers, users (older adults) | Older adults | Focus groups |

| Paper | Topic | Country | Context | Duration | Stakeholders | Target group | Methods |
|---|---|---|---|---|---|---|---|
| Chipps et al. (2012) | Telepsychiatry services | South Africa | Four consultant hospitals | 3 years | Specialists, Other staff members | Psychiatric patients | Demonstration education, Testing |
| Dansky et al (1999) | Telemedicine in home care | US | Homecare | 1+ years | Nurses | Diabetic patients, nurses | Focus groups, Surveys, Anecdotal data |
| Day et al. (2016), Day & Kerr (2012) | Telemonitoring for long term condition management in outpatient clinics | New Zealand | Two urban hospital services, one rural primary care service, remote health service in outpatient clinics | 4 years | Healthcare care professionals, Patients and patient representatives, Family / relatives, Research team | Patients with different conditions | Workshop, Interviews, Documents, Survey, Observations, Focus groups |
| Faruque et al. (2019) | Digital healthcare platform for noncommunicable diseases | Bangladesh | Rural communities | 6 month pilot | Citizens, Clinicians, Managers | Community members | Survey, Interviews, Focus groups |
| Fennell et al. (2017) | Providing health information to cancer patients in rural community | Australia | Rural communities | 3+ years | Patients and patient representatives, Family / relatives, Health care professionals | Cancer patients | Survey, Interviews, Log data, |
| Ferrario et al. (2016), Simm et al. (2016) | Anxiety interaction in autistic adults | UK | Existing partnership | 2 years | Health care professionals, Citizens, Patients and patient representatives, Family / relatives | Adults with ASD | Workshops, Evaluation / reflection |

| Paper | Topic | Country | Context | Duration | Stakeholders | Target group | Methods |
|---|---|---|---|---|---|---|---|
| Gaur et al. (2017) | Crowdsourcing in telemedicine | Italy | Local policy making | 3 years | Governmental body / local authority, Citizens | Policy makers | Interviews, Log data, Survey |
| Hansen et al. (2008) Hansen et al. (2013) | Telemedicine for critical care | Australia | Intensive Care Units in two hospitals | 2,5 years | Specialists | Clinicians | Interviews, Workshops, Surveys, Log data |
| Head et al. (2009) | Telehealth for cancer patients | US | Cancer centre | n.r. | Patients and patient representatives, Clinicians | Cancer patients | Surveys, Interviews |
| Heffernan et al. (2014), Heffernana et al. (2016) | App to improve vitamin D status | Australia | Different groups in community | n.r. | Clinicians, Specialists, Research team. Developers / IT, Health care workers, Citizens | Young women | Survey, Focus groups, Testing |
| Holeman & Kane (2019) | Community Health Toolkit for various topics | Malawi, Kenya, Nepal | Hard to reach communities | 10+ years? | Citizens, Nurses, Managers | Community members | Log data, Documents, Observation, Interviews |
| Katibeh et al. (2019) | Prevention of avoidable blindness | Iran | Local health care providers in 4 districts | n.r. | Specialists, Research team, Governmental body / local authority, Health care workers | Residents above 50 | Focus groups, Testing |

| Paper | Topic | Country | Context | Duration | Stakeholders | Target group | Methods |
|---|---|---|---|---|---|---|---|
| Kimaro & Twaakyondo (2005) | Health Information System | Tanzania | Five districts | 2+ years | Health care workers, Managers, Other staff members | Health workers | Interviews, Focus groups, Workshops, Training, Observation, Documents |
| Lehto (2017) | Robots for older adults | Finland | Living labs | n.r. | Older adults, Health care professionals | Older adults | Focus groups, Demonstration / education |
| Lundberg et al. (2010) | Teleradiology | Sweden | Public health sector cluster | n.r. | Specialists, Developers / IT, Managers, Other staff members, Companies / SME | Radiology Units | Focus groups, Log data |
| Molapo et al. (2016) | Community Health Education | Lesotho | Health Centre | 1,5 years | Health care workers, Nurses | Community Health Workers | Meeting data, Observation, Focus groups, Workshops |
| Neuhauser et al. (2013) | Health Communication about Crohn's disease | US | University clinic | 1,5 years | Patients and patient representatives, Specialists, Nurses | Patients with Crohn's disease | Focus groups, Interviews, Trainings, Surveys |

| Paper | Topic | Country | Context | Duration | Stakeholders | Target group | Methods |
|---|---|---|---|---|---|---|---|
| Norman & Skinner (2007), Skinner et al. (2006) | Health Promotion for youth | Canada | Different community settings | 10+ years | Youth, School and university staff, Governmental body / local authority | Youth | Interviews, RCT |
| Park et al. (2017) | IoT based health service in hospital | Korea | General hospital | 11 months | Health care professionals, Patients and patient representatives | Patients in hospital | Interviews |
| Phanareth et al. (2017) | Integrated care | Denmark | Living lab | 3+ years | Health care workers, Companies / SME, Patients and patient representatives, Research team | Patients with long term conditions | Meetings, Focus groups, Training, |
| Raij (2016) | Interactive tv for elderly people | Finland | Care in home of elderly person | 8 years | Older adults, Family / relatives, Health care professionals, Research team, Developers, Companies / SME | Elderly people | Interviews, Focus groups, Workshops, Surveys |
| Rendón et al. (2005) | Telemedicine for rural public health network | Colombia | Rural health care centres | 4 month trial | Health care workers, Patients and patient representatives, Governmental body / local authority | Health workers | Workshops, Meeting data, Surveys |
| Rönkkö (2018) | Activity tracking, increasing exercise | Sweden | Care and accommodation home | 4 month trial | Youth, Other staff members | Youth | Interviews, Log data |

| Paper | Topic | Country | Context | Duration | Stakeholders | Target group | Methods |
|---|---|---|---|---|---|---|---|
| Sjölinder & Scandurra (2015) | Communication technology system for elderly people | Sweden | Nursing home | 2 years | Older adults, Health care professionals | Elderly people | Workshops, Interviews, |
| Stensæth & Ruud (2014) | Interactive technology in music therapy | Norway | School and Resource Centre | 5 years | School and university staff, Youth, Families / relatives | Children with disabilities / disorders | Video analysis |
| Street et al. (2007) | Palliative care website | Australia | Palliative care | 2 years | Citizens, Health care professionals | Internet users | Survey, Focus groups, Summary grids, Anecdotal data, Think aloud protocols |
| Taylor et al. (2015) | Telehealth in community setting | UK | Community health setting | 2 years | Other staff members, Patients, | Patients with different conditions | Interviews, Documents, Workshops, Focus group |
| Thobias & Kiwanuka (2018) | ICT to improve mothers' knowledge | Tanzania | Rural environment | 1+ years | Citizens, Health care workers, Specialists, Community leaders | Mothers in rural areas | Interviews, Documents, Focus groups, Observation |
| Trondsen & Sandaunet (2009) | Online self-help for breast cancer patients Online self-help for adolescents with mentally ill parents | Norway | Norwegian Centre for Telemedicine | 2 years 2+ years | Patients, Organisation Local group Youth, Specialists | Breast cancer patients Adolescents with mentally ill parents | Observations, Interviews |

| Paper | Topic | Country | Context | Duration | Stakeholders | Target group | Methods |
|---|---|---|---|---|---|---|---|
| VanHeerwaarden et al. (2018) | Mental health services for youth | Canada | University / college | 3 months | Students | Youth | Workshops |
| Waterman et al. (2007) | Publication of information about the performance of primary healthcare providers | UK | Two Primary Care Trusts, Two Local Health Boards | n.r. | Citizens, GP office, Managers, Research team | Patients | Interviews, Focus groups, Surveys, Observation, Documents |
| Webb et al (2018) | Screening app for mental health in youth | Australia | GP office | 2 month implementation | GP office, Other staff members, Youth | Youth / young people | Interviews, Focus groups |

# Appendix 2.2 Full list of categories per setting variable

| Topic | # |
|---|---|
| Health Promotion and Education | 8 |
| Home care and telemonitoring | 8 |
| Health Information Systems and EMR | 7 |
| Mental health services | 5 |
| Care for older adults | 4 |
| Community health network | 3 |
| Physical activity | 2 |
| Clinical setting | 2 |
| Integrated care | 1 |

| Context | # |
|---|---|
| Rural communities | 6 |
| Hospital | 5 |
| Specialized care centres | 4 |
| Health Centre | 4 |
| Homecare or nursing home | 4 |
| Governmental body | 4 |
| Community group | 4 |
| University / college or school | 3 |
| Living lab | 2 |
| Telemedicine / telecare service | 2 |
| Existing partnership | 1 |
| GP office | 1 |

| Country | # |
|---|---|
| Australia | 5 |
| US | 4 |
| Canada | 3 |
| Sweden | 3 |
| UK | 3 |
| Norway | 2 |
| South Africa | 2 |
| Tanzania | 2 |
| Denmark | 1 |
| Bangladesh | 1 |
| Colombia | 1 |
| Finland | 1 |
| Iran | 1 |
| Italy | 1 |
| Korea | 1 |
| Lesotho | 1 |
| Malawi, Kenya, Nepal | 1 |
| New Zealand | 1 |
| Nigeria and India, Norwegian researchers | 1 |
| Spain | 1 |
| United Arab Emirates | 1 |

| Target group | # |
|---|---|
| Patients | 8 |
| Clinicians | 6 |
| Youth | 6 |
| Older adults | 5 |
| Cancer patients | 3 |
| Community Health Workers | 3 |
| Community members | 2 |
| Policy makers | 2 |
| Young women | 2 |
| Adults with ASD | 1 |
| African American women | 1 |
| Internet users | 1 |
| Mothers in rural areas | 1 |
| Radiology Units | 1 |

| Method | # |
|---|---|
| Interviews | 24 |
| Focus groups | 22 |
| Workshops | 14 |
| Surveys | 13 |
| Observations | 9 |
| Documents | 6 |
| Log data | 6 |
| Trainings | 4 |
| Meeting data | 3 |
| Testing | 2 |
| Anecdotal data | 2 |
| Demonstrations / education | 2 |
| Evaluation / reflection | 1 |
| Video analysis | 1 |
| Randomized controlled trial (RCT) | 1 |
| Summary grids | 1 |
| Think aloud protocols | 1 |

| Stakeholder group | # |
|---|---|
| Health care workers | 18 |
| Patients and patient representatives | 12 |
| Governmental body / Local authority | 9 |
| Citizens | 8 |
| Other staff members | 8 |
| Specialists | 7 |
| Family / relatives | 7 |
| Research team | 6 |
| Nurses | 5 |
| Youth | 5 |
| School and university staff | 4 |
| Clinicians | 4 |
| Community health workers | 4 |
| Older adults | 4 |
| Managers | 4 |
| Companies / SME | 3 |
| Developers / IT | 3 |
| Organization / local group | 3 |
| GP office | 2 |
| Students | 2 |

# Appendix 8.1 Full version of the AR Reflection Guide

## Action Research Reflection Tool

### Provisions for the use of this Reflection Tool

- All participants need to be able to speak their mind freely and honestly. This includes any criticism of other parties that are present.

- Listen actively and respectfully.

- Do not interrupt each other but wait and take turns.

- Give everybody the chance to speak.

- Be constructive and polite.

*Feel free to add any other ground rules together with the participants at the start of the session.*

### Suggested use

#### Before the reflection meeting
- Share the questions with the participants.
- Inform participants what the process will be during the meeting and what is expected of them.
- You may choose to collect the input beforehand to streamline the discussion and make sure that no points are overlooked or forgotten. Alternately, ask participants to bring their notes to the session.

#### During the reflection meeting
- Make use of collaborative materials or tools (posters or similar for in person meetings, online brainstorming tools like Miro or Mural for online meetings).
- Use the format of the reflection tool as a basis for the material (e.g., one poster for each question)
- Keep the provisions mentioned above in mind, maybe even include them in your material as a reminder.

## General Process

1. Briefly describe the actions that have taken place since the previous meeting.
   o *[Example: Dissemination of results via social media campaign]*_____
   o _____
   o _____
   o _____
   o _____
   o _____
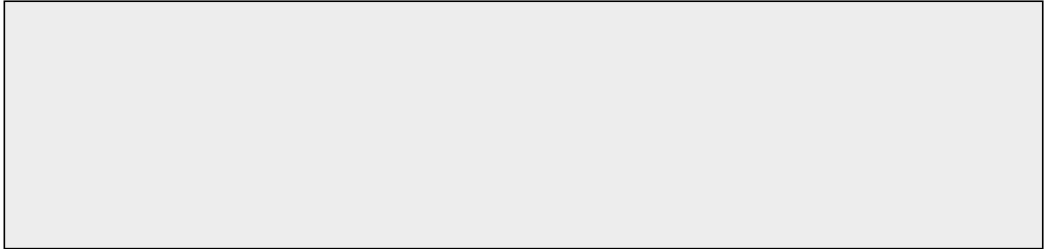
2. Thinking back to your initial plan, what worked out the way you had planned it?

3. What did not work out the way you had planned it? Why do you think this was the case?
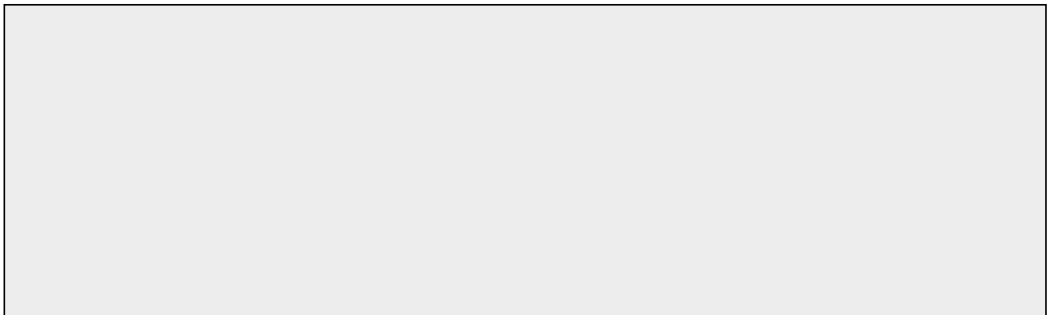
4. What bothered you? Why / how did this happen?

## Research process

1.  In what way do the findings answer the research question (e.g. regarding health improvements for the older adults)?

2.  What have you learned from the action research process (e.g. involvement of champions, collaborative work with stakeholders)?

## Looking forward

1. What do these outcomes and reflections mean for the future?

[ ]

2. What would you recommend to others starting a similar project? (think about both positive and negative experiences you had).
   o *[Example: Schedule meetings with the reference group at the start of the project}*
   o  _____
   o  _____
   o  _____
   o  _____


3. Has this process given you any <u>new</u> ideas for the future? Please explain them briefly.
   o *[Example: Reaching out to local community centre for collaboration]*
   o  _____
   o  _____
   o  _____
   o  _____

## From 2<sup>nd</sup> process evaluation meeting onward:

1. Look back at the things that bothered you the last time. Has anything changed? Briefly describe how and why.

2. Look back at the ideas that you had for the future. Have you implemented any of them?
   a. If Yes: How did it go?

   b. If No: Why not? Do you still want to implement these ideas?

# Appendix 10.1 Individual Patient Journey Value Mapping Worksheet

## PATIENT JOURNEY VALUE MAP

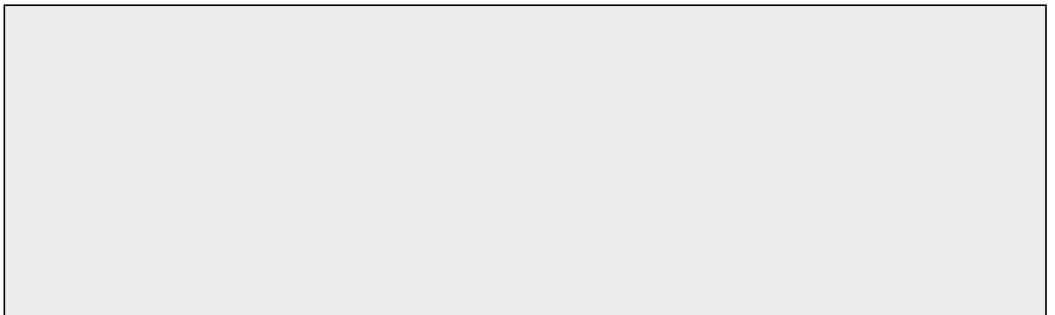| | PHASES | EVENTS |
|---|---|---|

**TIMELINE**

Please describe the phases and relevant events along your rehabilitation. A phase describes a period in time.

Examples of phases include: the start of the rehabilitation, period around the first medical review meeting and the period after extending the rehabilitation.

Examples of shorter phases include: morning, afternoon, evening, therapy week and out-patient testing week. An event on the other hand, occurs during a phase, such as: intake meeting, goal setting, attending therapy, gaining new insights, booking progress, exercising at home, off brainstorming with therapists.

**DESCRIPTION**

Shortly describe what the event listed in the timeline entails. Answers may be written down in bullet points.

In case you feel uncertain about what to write here, consider the following example prompts you could address:

1. Which steps or components does the event comprise?
2. Which actions did you perform?
3. Who was involved in the event?
4. Does the event occur often?

**EMOTIONS**

+

Please indicate how positively or negatively you experienced each of the events. You may draw a graph to illustrate how your emotions evolve over time across the different events.

On the gray bar, you may specify the corresponding emotion, such as happy, hopeful, proud, relieved, satisfied, relaxed, courageous, inspired, frustrated, fearful, insecure, stressed, dissatisfied and disappointed.

−

**VALUES**

For each event, write down the 5 most important values which apply to your experience on the line on the left-hand side. It is also fine to list less than 5. Examples of values include: safety, control, independence, transparency, trust, awareness, efficiency, involvement and conviviality.

Next, rank the values from 1 to 5 based on personal priority using the line on the right-hand side. In case you believe that the value is already supported well enough, you may tick the box. Otherwise, you may leave the box unticked.

# Appendix 10.2 Persona

> ❝ IF YOU DIGITISE CARE TOO MUCH, IT MIGHT BECOME TOO IMPERSONAL FOR A PATIENT. ❞

## MARCO VERSTEEG
### TEACHER

🎂 46 YEARS OLD

📍 ALMELO

MOTIVATED, SOCIAL, PROACTIVE CRITICAL

### GOALS

- Being able to walk independently at a normal pace **(P2, P3)**.
- Being able to cycle safely **(P2, P5)**.
- Recover as quickly as possible to re-integrate as an active member of society **(P5)**.

### WISHES

- Safeguarding safety during rehabilitation **(P2, P3, P4)**.
- Confirmation that therapists have the best intention for his recovery **(P1)**.
- Being able to monitor his progress **(P1)**.
- More transparency in the motivation behind chosen treatments **(P1, P3)**.
- Tailoring **(P1, P2, P3, P5)**.
- Being able to take his own initiatives in his rehabilitation programme **(P2, P3, P4, P5)**.

### PERSONAL INTERESTS

- Going out with his family.
- Various sports.

### CONCERNS

- Losing mobility and independence **(P3)**.
- Disappointing others due to the consequences of his health condition **(P4)**.
- Impersonal care due to excessive digitisation **(P1, P2, P3, P4)**.
- Insufficient supervision from experts during rehabilitation through eHealth, leading to increased exacerbation risks **(P2, P3)**.

### VALUES

| INDEPENDENCE | CONTROL |
|---|---|
| INVOLVEMENT | EFFICIENCY |
| SAFETY | CONVIVIALITY |

### EHEALTH SERVICE JUDGEMENT

FLEXIBLE ■■■□□
TARGETED ■■□□□
POTENTIAL ■■■■□
ORGANISED ■■□□□

### SCENARIO: THE CURRENT BOUNDARIES OF THE EHEALTH SERVICE

Marco is a 46-year-old teacher from Almelo. He is currently an outpatient at the chronic pain department of Roessingh centre for rehabilitation. He is actively working on his rehabilitation: both at home, through the eHealth service, and at the rehabilitation centre itself. He solely considers digital therapies to have a complementary function to care, rather than as a replacement of in-person therapies. In a recent study from the rehabilitation centre, 78% of the surveyed patients expressed that they do not believe that the current eHealth service is capable of replacing aspects of in-person therapies.

Additionally, Marco's physiotherapist expressed that they were reluctant to use the eHealth service in early stages of rehabilitation. His physiotherapist believes that it is essential to first acquire a good impression of Marco. Other therapists observed that digital therapies were mostly effective shortly after an in-person therapy. This enables therapists to check up on whether their patients have been executing the online exercises correctly.

While the pace of the in-person therapies can be increased since Marco has already been doing tailored exercises from home, there is also a risk of health exacerbation since Marco is inclined to continuously exercise to recover as quickly as possible.

# Appendix 10.3 Future scenario

**Your treatment**

# Therapy robot update 3 december 2051

On days on which no therapies are scheduled, or in case of cancellations, Roessingh centre for rehabilitation offers opportunities to continue exercising independently under the guidance of a therapy robot. The robot is able to instruct the exercises which are also accessible through the online rehabilitation portal. In the ergotherapy module for instance, the robot will ask questions about how much muscle tension you experience and whether you can execute the movements smoothly. Through audio recordings, the robot can record your spoken answers and save them to the online portal. With the use of artificial intelligence, the robot analyses your answers to deduce which exercises go well and which exercises still present challenges. This information is combined with video recordings to construct progress record. De videos can be projected as 3D holograms to showcase your movements comprehensively. The robot will give both you and your therapists faith in the complete registration of important health-related progress, even outside of scheduled therapies. This leads to a greater degree of involvement of your therapists, as they are now able to better tailor the treatments to you. Additionally, the robot can use the data to predict whether you are on track with completing your rehabilitation goals. Thanks to these insights, you are more in control of your rehabilitation, since your treatment can be adjusted timely by consulting your therapists.

## What is the function of the robot during rehabilitation in short?

**Talk to your therapist first**
Together with your therapist, determine which exercises are useful and safe to practice independently in the coming period.

**YOU HAVE FINISHED YOUR EXERCISES! WHICH RECORDS WOULD YOU LIKE TO SEE?**

PROGRESS  CHALLENGES  SUCCESSES

**Exercise with the robot outside of scheduled therapies**
Perform the exercises under the guidance of the robot. The robot can make video and audio recordings, and convert these into progress records.

**Receive better targeted treatments**
Discuss the progress records together with your therapist. This way, the upcoming scheduled in-person therapies can be tailored to your needs more adequately.

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# Appendix 11.1 Recommendations and implemented changes to the framework

## General remarks

| Type of recommendation | Recommendation | Mentioned by | Exemplary quote | Change to framework |
|---|---|---|---|---|
| **Content missing** | Make the headings more fitting to the content. | P5 (Practice) P8 (Expert) | *What I notice now, between training an then act celebration and dissemination, there is nothing separate for act, so to say. Even though in there there is a complex reality of change. [...] For me the question would be, aren't there any general things to say there?* (P5) | We now use sub-headings below Plan and Act, and included a short introductory text, to make the headings and phases clearer. |
| **Content missing** | Add the role that context plays in project. | P5 (Practice) | *For us, context played a huge role as well.* (P5) | A sentence was added to emphasize the influence of the research context. |
| **Content missing** | Make it clear who takes on the described tasks. | P8 (Expert) | *Who does this? Is it the researcher and are they aware of all these tasks that often come on top of all the other work?* (P8) | A sentence was added to mention that researchers can use the framework alone or together with other stakeholders. |
| **Content unclear** | Make the headings clearer. | Practice | *You have two times plan [...] and the same for act. I was thinking if visually that should be different, working with sub-headings.* (P1) | See above, sub-headings and short explanations were added. |

| Type of recommendation | Recommendation | Mentioned by | Exemplary quote | Change to framework |
|---|---|---|---|---|
| **Language and structure** | Be realistic in showing challenges, without discouraging people. | P2 (Expert) | *And then trying to point to challenges without trying to be too discouraging. [...] because the framework [...] makes it look quite easy [...]. And it's not.* (P2) | Throughout the framework, it was added that this is a challenging process that takes time and that there are not always clear solutions. |
| **Visual presentation** | Add a downloadable file that people can fill in. | P1 (Practice) P4 (Practice) | *In a table form, that you can take it with you and discuss the subject. And immediately fill it in, I would like that.* (P4) | A downloadable word file of the framework was added to the website. |
| **Visual presentation** | Add more figures throughout the framework. | P1 (Practice) P2 (Expert) | *It is quite wordy and starts with a figure but that is the only figure, so I don't know if there could be other supporting figures [...] that makes it more lively.* (P1) | We found it difficult to add more figures, but have included some examples in the recommended reading to make the framework more lively. |
| **Visual presentation** | Use other forms of presentation | P2 (Expert) | *Some more material is, I think a solution, marketed in different ways, is it possible to use short films 2 minutes about this. Like we do with patients or informal stakeholders. You do a chat forum, contact the expert advisor. There's a drop in here. I wouldn't know how you get funding for this. This is just wild ideas, but. (P2)* | We are looking into different forms of presentation. |
| **Visual presentation** | Decide on the focus and specificity of the framework. | P3 (Expert) | *It depends on how generic you want to make it. [...] Now the more you add to it, the more specific it gets and the more you leave out the more generic it is. (P3)* | A disclaimer about the context in which this framework was developed was added at the bottom. |

| Type of recommendation | Recommendation | Mentioned by | Exemplary quote | Change to framework |
|---|---|---|---|---|
| **Visual presentation** | Add translated versions of the framework. | P4 (Practice) | *For myself, I could not use it like this. I would need to translate it. (P4)* | We are currently working on translated versions of the framework. |
| **Background materials** | Add recommended literature at the bottom. | P1 (Practice) P2 (Expert) P8 (Expert) | *I think you could prevent that by adding consulted literature, or recommended literature, at the bottom, maybe just for the enthusiast. (P1)* | We have added several suggested references at the bottom and supplemented the list from our own experience. |
| **Background materials** | Add examples to each step. | P6 (Expert) | *Do you also have examples? That is always good, to refer to examples, look, we did it like this here and this worked or did not work and these were the problems. (P6)* | In the recommended literature, some examples were added |
| **Background materials** | Add references to other methods and ways of working. | P7 (Practice) | *I notice that I sometimes find it quite difficult, you sometimes have other ways of working or other ways of doing meetings. (P7)* | We have added recommended literature with other methods at the bottom of the framework. |

| Type of recommendation | Recommendation | Mentioned by | Exemplary quote | Change to framework |
|---|---|---|---|---|
| Content unclear | Add that projects don't always have a clear endpoint. | P1 (Practice) | You say 'Sustain change', but I can imagine that these cycles continue indefinitely. Especially with questions of implementation, right? (P1) | A statement was added to make it clear that project don't always have a clear endpoint. |
| Content unclear | Make clear how this relates to other models of AR. | P4 (Practice) | How is this [framework] different from action research? (P4) | The first sentence was rephrased to reflect that this is not different from AR, but an extension of it. |
| Content unclear | Make clear what 'n' stands for in the figure. | P7 (Practice) | The first thing I was curious about is what this n stands for. (P7) | An asterisk was added to indicate that the n stands for an undefined number of cycles in the AR project. |
| Content unclear | Make clear why these cycles were chosen. | P7 (Practice) | Wat you for example often see in PDCA cycles is that there are four steps. I was curious why this has three steps.(P7) | It was emphasized in the first sentence that these three steps are the core cycles of AR |
| Language and structure | Make clear that cycles are less explicit in practice. | P2 (Expert) P8 (Expert) | I mean, it could be this organised Plan, act, reflect, Plan, act, reflect, but it can also be quite chaotic [...] So maybe blur it a bit or make it an alternative which is not this well structured (P2) | A statement was added to emphasize that cycles are not this clear in practice. |

| Type of recommendation | Recommendation | Mentioned by | Exemplary quote | Change to framework |
|---|---|---|---|---|
| Content missing | Add that not all stakeholders will be in favour of a project. | P2 (Expert) | But then at the same time organisations are big and people don't have the same opinions so. So you can have this stakeholder agreement with management, but then if you talk to the others they don't agree. (P2) | A sentence was added at the beginning to explain that it is not uncommon that there are stakeholders who are against the project. |
| Content missing | Emphasize that ideally, the project idea should originate with community. | P2 (Expert) P3 (Expert) P6 (Practice) | The dogmatics say you shouldn't do anything if it does not come from the people themselves, so to speak. I think that is a bit too simple. (P6) | The first sentence was rephrased to put more emphasize on the fact that the project should originate with stakeholders. |
| Content missing | Add that time is needed, especially in the beginning, to build the team. | P4 (Practice) | Yes, and that took more time than I estimated beforehand. (P4) | A sentence was added at the beginning to explain that the process of developing a project idea takes time. |
| Content missing | Add that the project proposal should be written in collaboration. | P6 (Expert) | We invited some of these actors to write the proposal with us, so the project idea, I would recommend to add the proposal writing as a point. (P6) | In the first sentence we added 'co-writing' to the collaborative shaping of the project. |
| Content missing | Add a question to identify all stakeholders. | P8 (Expert) | Because then the first question of course it who are all the stakeholders? That one is not in there. (P8) | A question was added to evaluate whether all relevant stakeholders were identified. |
| Content missing | Add a suggestion to plan for supervision and exchange with others. | P6 (Practice) | So to think of booking a supervision, maybe we already included the means for that in the proposal already. (P6) | A question was added to think about supervision and exchange with others. |

| Type of recommendation | Recommendation | Mentioned by | Exemplary quote | Change to framework |
|---|---|---|---|---|
| Content unclear | Clarify what is meant by 'reimbursement' and that this need not only be financial. | P1 (Practice) P5 (Practice) P6 (Expert) | It also gave all sorts of things back to them in terms of involvement and meaningfulness. (P5) | A note was added that reimbursement can be, but is not only, financial. |
| Language and structure | Rephrase 'all relevant stakeholders'. | P3 (Expert) | That is a very large group of about 100 stakeholders, whom you can never contact all at once. So the consultation is via representation. (P3) | The sentence was changed to include 'representatives of' all relevant stakeholders. |
| Language and structure | Rephrase 'consulted'. | Practice | Language is also important here [...]We decide and they can add some things. Or we shortly consult them so to say. (P5) | The word 'consulted' was replaced by 'able to give their input'. |

| Type of recommendation | Recommendation | Mentioned by | Exemplary quote | Change to framework |
|---|---|---|---|---|
| Content missing | Add risk analysis and mitigation plans. | P2 (Expert) | I think also maybe something that's missing in this or somewhere, is some kind of joint risk assessment? (P2) | The question 'What are risk we foresee and how can we mitigate those risks?' was added. |
| Content missing | Add plans to evaluate changes. | P2 (Expert) | Also when you plan the roles, also try to discuss how you evaluate the change or how do we know that we reached the goal? Often these projects have a very meta level goal. Improve work environment or improve quality or systems and often it's impossible to measure. But at the same time, trying to measure and discuss that part in the beginning. (P2) | The question 'How will we evaluate the outcomes of our project?' was added. |
| Content missing | Add that roles and tasks are not always so clearly defined. | P5 (Practice) | I also have the feeling that in practice it's more fluent than you try to decide together. (P5) | A sentence was added to make clear that roles can be less defined in practice. |
| Content missing | Add to make a plan for dealing with changes in the (politics of a) project. | P6 (Expert) | That would be the point of politics. In which political context does it take place and [...] if we see this is going in a weird direction, which measures can we take, which instruments are available to us. (P6) | The question 'How will we deal with e.g. changes in leadership / politics? ' was added to the question about risk management. |
| Content missing | Add to find (digital) tools that work for everyone. | P6 (Expert) | Yes, you have to look carefully there. So which tool for communication is useful for which task? For us this was a huge problem, everybody had an affinity with email and then we wanted to switch to Telegram or Threema and we lost some who didn't feel like doing that. (P6) | A check questions was added to the question about communication to make sure the (digital) tools work for all involved parties. |

| Type of recommendation | Recommendation | Mentioned by | Exemplary quote | Change to framework |
|---|---|---|---|---|
| Content missing | Add to make room for (re-)negotiation spaces to document changes. | P6 (Expert) | I find that important, to have such negotiation spaces, wo how do we deal with changes that happen, how do we organise the negotiations [...] who takes which decisions and is this documented well. (P6) | A sentence was added to create space for negotiation, including documentation. |
| Content unclear | Explain what 'champions' are. | P1 (Practice) | Who are potential 'champions' in our project? (P1) | A footnote was added to explain what champions are, and additional literature was added in the section below the framework. |
| Content unclear | Add a reference to stakeholder analysis. | P3 (Expert) P8 (Expert) | Yes so, this is a sort of stakeholder analysis, I think? (P3) | A link to stakeholder analysis was added in the Additional Reading section. |
| Language and structure | Adjust the order of questions. | P8 (Expert) | The first question is who are you going to involve. Only then you get the question which roles and tasks will be taken on. Those are different levels. (P8) | The questions were re-ordered to reflect the different levels of stakeholder involvement. |
| Background materials | Add a reference to the ladder of participation or the participation matrix. | P5 (Practice) P6 (Expert) | Do you know the participation matrix [...] I think it's an important instrument for conversations. (P5) | References to both the ladder of participation and the participation matrix were added in the Additional Reading section. |

| Type of recommendation | Recommendation | Mentioned by | Exemplary quote | Change to framework |
|---|---|---|---|---|
| Content missing | Add that sometimes alignment might not be possible. | P2 (Expert) | So what do you do when you have a proper conflict of interests? So align interests. Yes, in the ideal world, but there's also lots and lots of research, [...] saying that aligning is not possible. (P2) | A sentence was added to reflect that alignment is not always possible. |
| Content missing | Add that conflict and resistance are normal processes that need to be dealt with. | P4 (Practice) | It is the implementation of something and basically that is a behaviour change, or change of culture, wo you always have to deal with resistance. (P4) | A sentence was added to reflect that conflict is normal, but important to address openly. |
| Content missing | Add that being open requires courage. | P5 (Practice) | Being open. That requires some courage. Yes, you have the topic courage, courage to bring up things, I think that is an important topic. (P5) | A sentence was added to emphasize that openness takes courage. |
| Language and structure | Rephrase 'ask the target group' to more active involvement. | P5 (Practice) | Ask the target group' [...] the task is, they are the goal. To formulate it in a way that they do it themselves. (P5) | The question was rephrased to a more active role for the target group in shaping the plans. |
| Language and structure | Rephrase goal and interest alignment to active wording. | P6 (Expert) | What are everybody's goals, interests in the project, I would phrase that actively, this is a task of the project. Those interests, to flag and map those. (P6) | The question was rephrased to reflect that this is an activity that needs to take place. |

| Type of recommendation | Recommendation | Mentioned by | Exemplary quote | Change to framework |
|---|---|---|---|---|
| Content missing | Add to contact the ethics board about procedures around iterative research and amendments. | P1 (Practice) P5 (Practice) | Yes, that you check beforehand whether it is possible to work with amendments. (P1) | The question 'Have we talked to our ethical committee and are we aware of procedures for this type of research (e.g., amendments)?' was added. |
| Content missing | Add that attention needs to be paid to GDPR, or similar laws. | P2 (Expert) | What we have in ethical approval here is also lots about data, GDPR. (P2) | The question 'Are we aware of all ethical guidelines that apply (e.g., GDPR)?' was added. |
| Content missing | Add how to mitigate when participants don't consent. | P3 (Expert) | If you want to present it in such a format, you could think of a 'what if', what if it does not go smoothly. (P3) | The question 'How are we dealing with stakeholders / participants who do not give consent?' was added. |

| Type of recommendation | Recommendation | Mentioned by | Exemplary quote | Change to framework |
|---|---|---|---|---|
| Content missing | Make explicit that the needed skills are context dependent. | P1 (Practice) | Because that was my question, which skills are we talking about? But is that very context specific or do you need all sorts of basic skills beforehand? (P1) | A sentence was added to emphasize that the skills that are needed depend on the given context. |
| Content missing | Make explicit that the training needs to be adjusted for each group of stakeholders. | P6 (Expert) | That one needs to be gentle, social learning and aspects like that, to pay attention to didactics and adjust the didactics to the people. (P6) | A sentence was added to pay attention to how to adjust the training. |
| Content unclear | Explain what hierarchies are in the area of training. | P7 (Practice) | And with hierarchies you mean... (P7) | The example of doctor-patient relationship was added. |
| Language and structure | Rephrase 'training'. | P5 (Practice) P6 (Expert) P8 (Expert) | Yes maybe you say 'mutual learning and skills development'. (P8) | The section was re-named to Mutul learning and skill development. |

| Type of recommendation | Recommendation | Mentioned by | Exemplary quote | Change to framework |
|---|---|---|---|---|
| Content missing | Add that not only should milestones be celebrated, but we should also learn from failure. | P2 (Expert) P5 (Practice) P6 (Expert) | I mean, the other aspect of this is to deal with failure. If you want to go with what they say in the leadership courses it's both celebrating milestones and dealing with failure, seeing failure as 'we're not there yet', as a learning opportunity. (P2) | The section was re-named to 'Celebrate milestones and learn from failures'. A sentence and question on this topic were added. |
| Content missing | Add that milestones can take on very different forms. | P6 (Expert) | We did a scientific study together and you were at conferences with us [...], it was fun for you and us. We had a good time, you met each other, so, what are the milestones? That's the question and you should be aware that it is not only what is in the proposal as a goal. (P6) | A sentence was added to reflect the different types of milestones that can exist in a project. |
| Language and structure | Rephrase in a way that it sounds less formal. | P8 (Expert) | Well, celebrate milestones, I fully agree, but you make it very official [...] even though often, if you are in a meeting or evaluating or discussing something, then it's often just mentioning as a success and shortly dwelling on it. (P8) | The sentence 'These do not have to be big, formal events, but can also be a small acknowledgement during a meeting.' was added. |

| Type of recommendation | Recommendation | Mentioned by | Exemplary quote | Change to framework |
|---|---|---|---|---|
| Content missing | Add a question about the way in which information is provided. | P1 (Practice) | And I would say and maybe add, how will we provide the information. [...] You ask two questions about dissemination and one questions about information. So I think you would put the same questions, who do we want to reach and how do we reach them and which information and how to we provide that information. (P1) | The question 'How can we best provide this information?' was added. |
| Content missing | Add that dissemination can take on many different forms. | P6 (Expert) | Yes, so that there can be various forms of dissemination. (P6) | A sentence was added to reflect how diverse dissemination can be. |
| Content missing | Change the questions from top down, to also include the reasoning for dissemination. | P8 (Expert) | This is a big think, and again thought very top-down. [...] But these are questions that are important, but also the questions behind those. Why should the project be disseminated? I don't see that here. What is the value for them? And which information can they provide? (P8) | The questions 'What is the goal of our dissemination? Why is it relevant to disseminate this?' were added. |

| Type of recommendation | Recommendation | Mentioned by | Exemplary quote | Change to framework |
|---|---|---|---|---|
| Content unclear | Specify who stakeholders are and what information you are disseminating. | P8 (Expert) | Yes but, that makes it a bit difficult, because you have stakeholders that are part of your research and stakeholders that are not. [...] And probably you mean that you want to disseminate on a bigger scale, and that for example if you have a project, others do that as well. But the question is, is it about the way of participative collaboration. That you want to disseminate that, because it works, or that you disseminate the results of a project and to whom? (P8) | In the beginning, sentences were added to emphasize that this is about stakeholders outside of the research team, and that the type of information that is disseminated can differ. |

| Type of recommendation | Recommendation | Mentioned by | Exemplary quote | Change to framework |
|---|---|---|---|---|
| Content missing | Add on which levels reflection can take place. | P1 (Practice) | You have reflection on different levels. You have reflection on the level of working together, the data that you collected in your research, reflection on your role. (P1) | A sentence was added at the beginning to highlight the different levels of reflection. |
| Content missing | Add a questions about ways to do reflection. | P1 (Practice) P5 (Practice) | You have to look at that very well. What is a good way of reflecting. (P5) | The question 'How are we going to structure our reflection?' was added and combined with the question about reflection tools'. |
| Content unclear | Add the frequency of reflections and emphasize that this is a recurring step. | P4 (Practice) P8 (Expert) | How often do you do these reflections? (P4) | The sentence 'Reflection happens continuously throughout the project, at intervals set by the project team.' was added. |
| Content unclear | Make clear what mitigation actions are. | P7 (Practice) | What do you mean by that? (P7) | The question was expanded to make it clearer what was meant by mitigation actions. |
| Language and structure | Change the order of questions. | P1 (Practice) | Which tools can we use for reflection, shouldn't that be the first question? (P1) | The question was moved up, and combined with a new question about ways of reflecting. |

| Type of recommendation | Recommendation | Mentioned by | Exemplary quote | Change to framework |
|---|---|---|---|---|
| Content missing | Add that projects need to find a balance between being flexible and making a sustainable change. | P6 (Expert) | There is a trade-off, on the one hand a community can be agile and flexible, and wants to keep it that way. On the other hand, a connection is needed, to the local authority, to political actors. (P6) | A sentence was added to reflect this balance and the fact that projects need to individually address this. |
| Content unclear | Make more explicit that this may include a change in policy. | P3 (Expert) P4 (Practice) | I don't know if we define success like that, but implicitly it is when the [project] outcomes become the basis of policy or of actions in a company, that they are being used. (P3) | The question 'Is it possible to implement the change in policy / regulations?' was added. |
| Language and structure | Use the same wording everywhere in the document. | P8 (Expert) | Why 'the team' and not 'the researchers' or 'the stakeholders'. So there is a new word again. (P8) | The term research team was added in several other places to indicate the collaboration between researchers and stakeholders. |
| Language and structure | Make more explicit that you should think about this early in the process. | P4 (Practice) | Things get mixed up a bit, so sometimes you already picked up this last thing at the start already. (P4) | A sentence was added to emphasize that this is the last step in the framework, but not an activity for the end of a project only. |

# Appendix 11.2 Final version of the framework after evaluation

Framework for stakeholder involvement in eHealth Action Research

This framework is an extension of other descriptions of Action Research, building on the core cyclical process of planning, action and reflection. It also includes the collaborative conception of a project idea, as well as steps to ensure sustainability of the change in practice after a project has ended. Additionally, activities are included within and between the steps of the action research cycles.

It should be noted that this is a very straight-forward and structured representation of a project process. In practice, cycles will be less distinguished and there might not be a clear endpoint to a project. Of course, the context of a research project and the involved stakeholders, play a large role in shaping the actual process of the project.
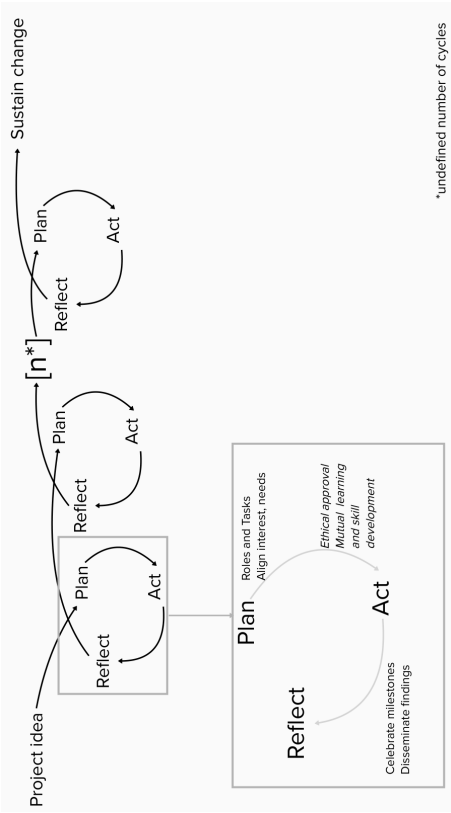


You can find more information about each of the actions below. After a brief explanation, pointer questions are provided, which you can answer in order to shape your research. This can be done by a researcher themselves, or together with the other involved stakeholders in the research team.

**Project Idea**

Ideally, the idea for a project should come from stakeholders or the community. At the least it should be shaped and co-written together with them. Still, not all stakeholders might be in favour of a project, and it will take time to settle on a project idea and build a project team.

- Did we identify all relevant stakeholders that need to be involved in this project?
- Were (representative of) all relevant stakeholders actively involved in setting up the project idea?
- Were the intended "users" able to give their input?
- Are stakeholders re-imbursed for their involvement in developing the idea? (note: while reimbursement can be financial, this can also mean e.g. having allocated (working) hours for a project, or receiving recognition)
- Are there ways to receive funding to further develop the idea?
- Have we planned and budgeted for project supervision / exchange with other project?

**Plan**

Every cycle of AR starts with a more or less defined planning phase. In this phase the next steps are set out, in many cases based on previous findings or reflections. Below, two important elements of planning a new cycles are outlined: dividing roles and tasks and aligning the interests and needs of all involved parties.

**Roles and tasks**

The role of the researchers is different in a project with involved stakeholders. They need to share power and hand over responsibility. Similarly, stakeholder take on more active and empowered roles. It is important to make these roles explicit and to discuss how tasks are divided, yet the roles might be less clear and distinct in practice. It is important to have leave room for such negotiations and document the decisions that are made clearly and accessibly.

- Who are the stakeholders involved in our project team? Who needs to be involved as participants? How will other stakeholders be involved and connected to the project?
- Who will take on which roles and tasks?
- Who are (potential) champions[1] in our project? How can we involve them?
- What can we do to keep all groups involved?
- How are we setting up communication between partners? Do these (digital) tools work for everyone?
- What are risk we foresee and how can we mitigate those risks? How will we deal with e.g. changes in leadership / politics?
- How will we evaluate the outcomes of our project?

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[1] Champions are stakeholders that drive a project and get beyond what is expected of them in their role. For more information, see the Additional Reading section.

At later stages ask:

- Is everybody still happy with their role? (ask individually)
- Are there new tasks that need to be divided?
- Are there new stakeholders that need to be involved? How?

**Align interests, needs**

Different stakeholder groups will bring their own ideas and needs into a project, which may sometimes conflict. This conflict is a normal part of the process, but one that should be acknowledged. Therefore, being open and trying to mitigate between stakeholders is crucial to do throughout the project. This openness requires a lot of courage from all involved parties. Still, it might be impossible to align interests, but a collaboration between the involved parties should still be made possible.

- How can we map everybody's goals for, and interests in, the project?
- What are our common values?
- Where do these needs conflict and how can we deal with that?
- How is the target group involved in setting our plans? Is there a good fit between the plans and the target group?

At a later stages ask:

- Are the needs still the same?
- Do we need to re-align?

**Ethical approval**

As the roles of stakeholder groups change, it can be difficult to explain the involvement of certain groups to ethical boards (e.g., patients are seen as vulnerable groups). Additionally, receiving ethical approval for iterative research can be more difficult as the research process changes continuously.

- Have we talked to our ethical committee and are we aware of procedures for this type of research (e.g., amendments)?
- Do we need ethical approval for this part of the research?
- Have we considered important ethical issues (e.g. compensation, burden)?
- Are we aware of all ethical guidelines that apply (e.g., GDPR)?
- Was the extent of the research clearly explained to participants?
- How are we dealing with stakeholders / participants who do not give consent?

**Mutual learning and skill development**

Both researchers and involved stakeholders might need additional skills to take on this new role in the research process. These can be general research skills, but will oftentimes be context dependent.

- Which skills are needed, and by whom?
- Who can provide the training? What do they need to do so? ('training the trainer')
- What will the training look like?
- How can we make the training accessible? How can we adjust the training to different stakeholders / stakeholder groups?
- Are there hierarchies and power dynamics we need to take into account (e.g. doctor-patient relationship)? How are we going to deal with those?

**Act**

In the action phase, the steps that were planned for are carried out. What this means will be highly different per project and per cycle, but below two important elements of the act phase are described: celebrating milestones while learning from failures, and disseminating of the project and its findings.

**Celebrate milestones and learn from failures**

A project may not achieve all it set out to do. Additionally, in the process, successes might get lost. Therefore, explicitly setting celebratory moments together with the whole team can help keep up motivation and show achievements. These do not have to be big, formal events, but can also be a small acknowledgement during a meeting. Milestones can take a variety of forms, not only related to project outcomes, but also to the experiences during the project. At the same time, failure to achieve a success provides a learning opportunity for the future, which should be made use of.

- How do we define success?
- What are our successes?
- How will we celebrate them?
- Who will be part of the celebration?
- How can we present the achievement?
- What can we learn from the things that did not go well?

**Dissemination**

As the project is set in practice and aims to make an impact, it is important that stakeholders outside of the research team, who are not involved in the project in any way, are aware of the project and its progress. There are many different forms of dissemination that will be useful to different degrees in a project. The information provided can also be different, e.g. about outcomes of the project versus describing the research process and lessons learned about that.

- What is the goal of our dissemination? Why is it relevant to disseminate this?
- Who do we want to reach with our dissemination?
- How can we reach them? What are suitable ways of dissemination?
- Which information should we provide?
- How can we best provide this information?

**Reflect**

Reflection is a central element of AR. By reflecting on the process, problems can be seen and fixed earlier. It is important to involve all relevant stakeholders in this process to not exclude their perspective. Reflection can take place on different levels, reflecting on the outcomes of the project, the way of working together, or the individual role, for example of the main researcher. Reflection happens continuously throughout the project, at intervals set by the project team.

- How are we going to structure our reflection? Which tools can we use for reflection?
- Did we achieved what we planned to do?
- What went well, and what did not?
- How will we address this in the future?
- Which mitigation plan(s) and ways of dealing with risks and challenges do we need?
- How can we plan for future sustainability of the change we are making?

At later stages also ask:

- Did our changes from previous reflections happen and work out?

**Sustain change**

The project should be beneficial for practice, even after funding has ended. Therefore, the team should make plans for sustaining the changes long before the project is set to end, so as to be able to make arrangements. So, while this is the last step in this framework, it should receive attention throughout the whole process. There is a balance between remaining flexible as project team and having a lasting impact through connections with for example policy makers. Each projects needs to weigh these options and find an individual solution to sustain the project.

- What needs to happen to sustain the change?
- Is there funding available?
- Is it possible to implement the change in policy / regulations?
- Who needs to be involved?

- Who can facilitate the change?

## Additional reading

To support you in your research project, we have compiled a list of recommended reading for the different elements of this framework. We try to update this list based on our own work, and input from users of the framework.

**Find an example of starting a project together with stakeholders:**

Hand, C., Rudman, D. L., McGrath, C., Donnelly, C., & Sands, M. (2019). Initiating participatory action research with older adults: Lessons learned through reflexivity. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 38(4), 512-520.

**Read more about stakeholder analysis:**

Franco-Trigo, L., Fernandez-Llimos, F., Martínez-Martínez, F., Benrimoj, S. I., & Sabater-Hernández, D. (2020). Stakeholder analysis in health innovation planning processes: a systematic scoping review. *Health Policy*, 124(10), 1083-1099.

**Read more about Champions:**

Miech, E. J., Rattray, N. A., Flanagan, M. E., Damschroder, L., Schmid, A. A., & Damush, T. M. (2018). Inside help: an integrative review of champions in healthcare-related implementation. *SAGE open medicine, 6*, 2050312118773261.

**Find an example of role definition (via the participation matrix):**

de Wit, M., Beurskens, A., Piškur, B., Stoffers, E., & Moser, A. (2018). Preparing researchers for patient and public involvement in scientific research: development of a hands-on learning approach through action research. *Health Expectations*, 21(4), 752-763.

**Read more about ethical issues in participatory research, including recommendations for dealing with these issues:**

Kwan, C., & Walsh, C. A. (2018). Ethical Issues in Conducting Community-Based Participatory Research: A Narrative Review of the Literature. *Qualitative report*, 23(2).

**Read more about how to disseminate AR findings:**

Smith, L., Rosenzweig, L., & Schmidt, M. (2010). Best practices in the reporting of participatory action research: embracing both the forest and the trees 1ʋ7. The Counseling Psychologist, 38(8), 1115-1138.

**Find recommendations for sustaining a project:**

Meurer, J., Müller, C., Simone, C., Wagner, I., & Wulf, V. (2018). Designing for sustainability: Key issues of ICT projects for ageing at home. *Computer Supported Cooperative Work (CSCW), 27*, 495-537.

## Disclaimer

This framework was developed for the context of eHealth action research. Projects can differ greatly, making it challenging to find a balance between specific information and general advice that is applicable on a broader level.

# Summary

Action Research (AR) is a collaborative research approach in which stakeholders play an active role as co-researchers. AR takes place in a community, in cycles of planning, action and reflection. While making a change in practice, AR also aims to extend scientific knowledge. AR fits the context of eHealth research well, as its key elements can hopefully ensure a better match between the technology being developed or implemented and the needs of relevant stakeholders. Ideally, stakeholders should take on a very active role and shape the research. However, oftentimes, neither the researcher nor the stakeholders are used to working in this way. Therefore, support is needed in terms of sharing knowledge, best practices and lessons learned between projects. Yet, in AR publications explicit reflection and description of these lessons learned is often missing. This makes it difficult for AR projects to learn from each other. To provide guidance for researchers setting up their project, and specifically to support the active involvement of stakeholders, **the aim of this thesis is to develop a framework on stakeholder involvement in eHealth AR projects**.

In the **first part of this thesis**, the **State of the Art** is described. The introduction provides some rationale for the aim of this thesis, and a description of the projects in which this research was conducted is given. In **Chapter 2** the results of a literature review on AR in eHealth projects are presented. The aim of this review was to get an overview of current eHealth AR, specifically looking at how the research is conducted, instead of focusing on outcomes. We investigated the context of these projects, how they define and conduct AR, and which best practices and lessons learned they draw. We found that oftentimes reporting on the conduction of, and reflection on, AR in eHealth projects is lacking. Other important findings were the need for stakeholder skill and confidence training, the various roles that researchers take on in AR projects and the importance of constant reflection.

The **second part of this thesis** looks at different levels or **roles of involvement** in research projects, independent of the type of stakeholder that fulfils each role. The part starts by looking at researchers, as stakeholder involvement will not be initiated if they are unwilling to do so. Therefore, in the first chapter of this part, **Chapter 3**, we studied novice action researchers' attitude towards AR. The goal of this study was to understand how researchers new to AR perceive the approach and whether they are able to implement it in practice. We introduced AR to researchers, and asked them to identify benefits, risks and mitigation actions they foresaw for their project. The chapter outlines the methods that we used, as well as the novice action researchers' perceptions of AR. Our main finding was that researchers have a positive attitude towards AR, while being able to foresee potential risks. Knowledge sharing sessions were perceived as useful and greatly valued.

In **Chapter 4** we move on to look at 'champions' in AR projects. We followed the champions in several different pilots of a project over the course of the project, with the goal of investigating how they see their role and whether this changes over the course of the project. Based on the outcomes, we give recommendations for identifying and involving champions in research projects. Enthusiasm and acting as a glue between parties were important characteristics of champions. They value having the freedom to shape their role and tasks, which enables them to make a change in their organisation or the project.

Next, **Chapter 5** presents a study in which we investigated the motivation of stakeholders participating in long-term, time-consuming research projects like AR. The aim of this study was to identify ways of keeping participants motivated in such projects. We asked participants in two different research projects about their motivation for taking part in the study. The chapter includes a discussion of motivating factors and provides recommendations for keeping participants engaged and motivated during a project, like continuing to monitor and manage expectations and enabling communication between participants.

**Chapter 6** looks at the involvement of the general public, as outsiders to a project. As opposed to the previous chapter, in this chapter our goal was to identify how to involve participants unplanned and spontaneously. We explored the usefulness of a specific methodology - the flash mob method: fast-

paced and practice-situated studies. We tested this method in two different projects, and through observations and reflection, we provide recommendations for implementing the method in AR projects. For example, attention should be paid to awareness raising and outreach through the flash mob, and insiders can help engage the target group.

The **third part of this thesis** looks at how the stakeholders involved in a project interact and communicate with each other, and how researchers can help facilitate this process. This part takes on several topics related to the communication and interaction between collaborating stakeholders, specifically looking at what researchers can do to facilitate such processes. In the first chapter of this section, **Chapter 7**, we studied the alignment of interests and needs of different stakeholders in a project, in terms of what they want to achieve from the project (content-wise). The aim of this study was to describe how stakeholders can be brought to agreement in a project. Following from a case study involving older adults, technology developers and researchers, the chapter proposes different recommendations for aligning stakeholders throughout the project. Specifically, open and explicit conversations and mapping the different interests can be useful activities.

**Chapter 8** provides a reflection tool for collaborative reflection with stakeholders, both on content and process level. The aim of this work was to provide a structured way for researchers to reflect together with project partners. We iteratively developed this tool with several pilots of an AR project, who tested the tool and provided feedback. The tool focuses on the general process, the research process and future activities, while also including outcomes from previous reflections.

The focus of **Chapter 9** is on the process level of stakeholder interaction. Our aim was to investigated important elements of stakeholder skill training. This chapter discusses the outcomes of a workshop with researchers experienced in such training activities. We raise some questions that should be considered when planning stakeholder skill training, for example how to deal with power dynamics and hierarchies, how mutual learning can be facilitated and how skill training can be made accessible.

In the last chapter of this part, **Chapter 10**, an iterative method for patient involvement is described. The aim of this study was to develop a method that other projects can use to map patient values along the patient journey. The method itself is described, along with a case study from the rehabilitation care sector. By combining different data collection methods in several phases, retrospective and in situ data is collected to give a more complete picture of the patient journey. This can help in the design and implementation of eHealth technologies, to ensure an even better fit with the context.

The **final part of this thesis synthesises the results** that were described in the preceding chapters. First I present a framework for stakeholder involvement in eHealth AR projects (**Chapter 11**). The framework describes important topics to consider in such a project, taking into account the recommendations made throughout this thesis. The framework includes short descriptions for each step in the process, questions that researchers can ask themselves and background material, for example links to potential methods. In the final chapter of this thesis (**Chapter 12**), I discuss the results and give an outlook on future research. The chapter also includes a reflection on my research and findings and their application in future eHealth AR projects.

# Samenvatting

Actieonderzoek (AO) is een vorm van collaboratief onderzoek waarbij stakeholders een actieve rol als mede-onderzoekers hebben. AO vindt in de praktijk plaats, in iteraties van planning, actie en reflectie. Terwijl er in de praktijk een verandering gedaan wordt, probeert AR ook wetenschappelijke kennis uit te breiden. AO past goed in de context van eHealth onderzoek, omdat de elementen van AO er hopelijk voor kunnen zorgen dat de technologie die ontwikkeld of geïmplementeerd wordt goed past bij de behoeften van de relevante stakeholders. Idealiter nemen stakeholders een zeer actieve rol aan en vormen het onderzoek. Echter, vaak zijn nog de onderzoekers nog de stakeholders gewend aan deze manier van werken. Daarom is er ondersteuning tussen projecten nodig in de vorm van gedeelde kennis, best practices en geleerde lessen. Toch ontbreken er in AO publicaties vaak expliciete reflectie en een omschrijving van de geleerde lessen. Dat maakt het moeilijk voor AO projecten om van elkaar te leren. Om onderzoekers in het opzetten van hun project te ondersteunen, en specifiek om de actieve rol van stakeholders te bevorderen is **het doel van dit proefschrift om een framework te ontwikkelen voor het actief betrekken van stakeholders in eHealth AO projecten**.

In **het eerste deel van dit proefschrift** wordt de **stand van zaken** beschreven. De introductie geeft onderbouwing aan het doel van dit proefschrift, evenals een omschrijving van de projecten waarin dit onderzoek plaatsvond. In **Hoofdstuk 2** worden de resultaten van een literatuurstudie naar AO in eHealth projecten gepresenteerd. Het doel van deze studies was om een overzicht te krijgen van het huidige eHealth AO, en daarbij specifiek te kijken naar hoe het onderzoek uitgevoerd wordt, in plaats van op uitkomsten te focussen. We hebben gekeken naar de context van de project, hoe zij AO definiëren en uitvoeren, en tot welke best practices en geleerde lessen zij komen. Daarbij hebben wij gevonden dat er maar weinig gerapporteerd en gereflecteerd wordt over de praktische uitvoering van AO. Andere belangrijke bevinden waren dat het trainen van vaardigheden en zelfvertrouwen van stakeholders nodig is, de diverse rollen die onderzoekers in een AO project op zich nemen, en het belang van continue reflectie.

**Deel twee van dit proefschrift** kijkt naar de verschillende niveaus en **rollen van betrokkenheid** in onderzoeksprojecten, los van het type stakeholder dat een rol invult. Dit deel begint met een blik op onderzoekers, omdat betrokkenheid van stakeholders niet geïnitieerd gaat worden als zij onwil vertonen. Daarom hebben we in het eerste hoofdstuk van dit deel, **Hoofdstuk 3**, onderzoek gedaan naar de houding van beginnende actieonderzoekers ten opzichte van AO. Het doel van deze studie was om te begrijpen hoe onderzoekers die weinig of geen ervaring met AO hebben deze vorm van onderzoek ervaren en of zij in staat zijn dit in de praktijk te implementeren. We hebben AO voorgesteld aan onderzoekers en hen gevraagd om voordelen, risico's en maatregelen te identificeren die zij voor hun project verwachten. Het hoofdstuk beschrijft de methoden die we gebruikt hebben, evenals de waarneming van AO van de beginnende actieonderzoekers. Onze belangrijkste bevinding was dat onderzoekers positief naar AO kijken, terwijl zij potentiële risico's kunnen voorzien. Sessies waarin kennis gedeeld werd, werden als zeer nuttig ervaren en gewaardeerd.

In **Hoofdstuk 4** richten we ons op 'champions' in AO projecten. We volgen de champions in verschillende pilots van een project gedurende het project, om te zien hoe zij hun rol ervaren en of dit tijdens het project verandert. Gebaseerd op onze bevindingen geven we adviezen voor het identificeren en betrekken van champions in onderzoeksprojecten. Enthousiasme en het verbinden van verschillende partijen waren belangrijke eigenschappen van champions. Ze waarderen het de vrijheid te hebben om hun rollen en taken zelf vorm te geven, en kunnen op deze manier een verandering in hun organisatie of project teweegbrengen.

Daarna presenteert **Hoofdstuk 5** een studie waarin we gekeken hebben naar de motivatie van stakeholders om deel te nemen in langdurige, tijdsintensieve projecten zoals AO. Het doel van deze studie was om manieren te identificeren om deelnemers in dergelijke projecten gemotiveerd te houden. We vroegen deelnemers van twee verschillende projecten naar hun motivatie om deel te nemen aan het onderzoek. Het hoofdstuk bevat een discussie van motiveren factoren en geeft aanbevelingen om

deelnemers gedurende een project gemotiveerd te houden, zoals het blijven monitoren en managen van verwachtingen en het faciliteren van communicatie tussen deelnemers.

**Hoofdstuk 6** kijkt naar de betrokkenheid van de algemene bevolking, als buitenstaanders van een project. In tegenstelling tot het vorige hoofdstuk was ons doel in dit geval, te identificeren hoe deelnemers ongepland en spontaan betrokken kunnen worden. We onderzoeken de bruikbaarheid van een specifieke methode – de flash mob methode: snel onderzoek in de praktijk. We hebben deze methode in twee verschillende projecten getest en geven, aan de hand van observaties en reflecties, aanbevelingen voor het implementeren hiervan in AO projecten. Zo is het bijvoorbeeld belangrijk om door de flash mob aandacht te besteden aan het vergroten van bewustzijn en bereik van een onderzoek, en kunnen insiders helpen de doelgroep te betrekken.

**Het derde deel van dit proefschrift** kijkt naar hoe stakeholders in een onderzoek met elkaar **interageren en communiceren**, en hoe onderzoeker dit proces kunnen ondersteunen. In dit deel worden verschillende thema's rondom communicatie en interactie tussen stakeholders opgepakt, en wordt specifiek gekeken naar de faciliterende rol van onderzoekers hierin. In het eerste hoofdstuk van dit deel, **Hoofdstuk 7**, onderzochten we de afstemming van interesses en behoeften van verschillende stakeholders in een project, kijkend naar wat zij (inhoudelijk) willen bereiken in het project. Het doel van dit hoofdstuk was om te beschrijven hoe stakeholders op een lijn gebracht kunnen worden in een project. Naar aanleiding van een casus met ouderen, technologie aanbieders en onderzoekers geeft dit hoofdstuk verschillende aanbevelingen om stakeholders tot overeenstemming te brengen. Specifiek zijn open en expliciete gesprekken, en het in kaart brengen van de verschillende interesses nuttige activiteiten.

**Hoofdstuk 8** biedt een handvat voor collaboratieve reflectie met stakeholders, zowel op inhoudelijk als ook op proces niveau. Het doel was om een gestructureerde manier voor onderzoekers aan te bieden om samen met project partners te reflecteren. We hebben dit handvat iteratief ontwikkeld samen met verschillende pilots in een AO project, die het handvat getest en feedback gegeven hebben. Het handvat richt zich op het algemene proces, het onderzoeksproces en toekomstige activiteiten, waarbij ook de uitkomsten van eerdere reflecties meegenomen worden.

De focus van **Hoofdstuk 9** ligt op het procesniveau van stakeholder interactie. Ons doel was om belangrijke elementen van vaardigheden training voor stakeholders te onderzoeken. Dit hoofdstuk beschrijft de uitkomsten van een workshop met onderzoekers die ervaring hebben met dergelijke trainingsactiviteiten. We stellen enkele vragen die overwogen dienen te worden wanneer vaardigheden training voor stakeholder opgezet wordt, zoals hoe met machtsdynamieken en hiërarchieën omgegaan wordt, hoe wederzijds leren gefaciliteerd kan worden en hoe de training toegankelijk gemaakt kan worden.

In het laatste hoofdstuk van dit deel, **Hoofdstuk 10**, wordt een iteratieve methode voor het betrekken van patiënten beschreven. Het doel van dit onderzoek was om een methode te ontwikkelen die andere projecten kunnen gebruiken om de waarden van patiënten tijdens de patiënte reis (Patient journey) in kaart te brengen. De methode wordt samen met een casus uit de revalidatiezorg beschreven. Door verschillende manieren van dataverzameling in meerdere fases te combineren wordt retrospectieve en situationele data verzamelt om een completer beeld van de patiënten reis te geven. Dit kan bij het ontwerpen en de implementatie van eHealth technologie helpen, om ervoor te zorgen dat de technologie bij de context past.

**Het laatste deel van dit proefschrift vat de resultaten** van de eerdere hoofdstukken **samen**. Eerst presenter ik in **Hoofdstuk 11** een framework voor het betrekken van stakeholders in eHealth AO projecten. Het framework beschrijft belangrijke onderwerpen waarmee in een dergelijk project rekening gehouden moet worden, waarbij de aanbevelingen uit de eerdere hoofdstukken meegenomen worden. Het framework bevat een korte beschrijving van elk stap in het proces, vagen die onderzoekers zichzelf kunnen stellen, en achtergrond materiaal, zoals referenties naar mogelijke methoden. In het laatste hoofdstuk van dit proefschrift (**Hoofdstuk 12**), bespreek ik mijn resultaten en geef ik een vooruitzicht op mogelijk toekomstig. Dit onderzoek bevat ook mijn reflectie op mijn onderzoek en bevindingen, en de toepassing hiervan in toekomstige eHealth AO projecten.

# Zusammenfassung

Aktionsforschung (AF) ist eine Form der kollaborativen Forschung, in der Stakeholder als Co-Forscher eine aktive Rolle spielen. AF findet im Kontext statt, in Iterationen von Planung, Handlung und Reflektion. Während eine praktische Veränderung im Kontext stattfindet, probiert AF gleichzeitig auch, zu wissenschaftlichen Erkenntnissen zu kommen. AF eignet sich zur eHealth Forschung, da die Elemente der AF im Besten Fall dafür sorgen, dass die Technologie, die entwickelt oder implementiert wird, gut zu den Bedürfnissen der relevanten Stakeholder passt. Idealerweise haben Stakeholder eine aktive Position und formen die Forschung. Trotzdem sind zumeist weder die Forscher noch die Stakeholder an diese Art des gemeinsamen Arbeitens gewöhnt. Darum ist es wichtig, dass Projekte sich gegenseitig unterstützen, in dem Wissen, Best Practices und gewonnene Erkenntnisse geteilt werden. Trotzdem fehlt in Publikationen zur AF häufige eine explizite Reflektion und eine Beschreibung der methodischen Erkenntnisse. So ist es schwierig für AF Projekte um voneinander zu lernen. Um Forscher bei der Planung ihres Projektes zu unterstützen, und speziell um die aktive Rolle von Stakeholdern zu fördern, **ist das Ziel dieser Doktorarbeit, ein Framework für das aktive Einbeziehen von Stakeholder in eHealth AF Projekten erstellen**.

Im **ersten Teil dieser Doktorarbeit** wird der aktuelle Stand der Wissenschaft beschrieben. In der Einleitung wir das Ziel der Doktorarbeit unterbaut, außerdem werden die Projekte beschrieben in deren Rahmen diese Forschung stattfand. In **Kapitel 2** werden die Ergebnisse einer Literaturstudie nach AF in eHealth Projekten präsentiert. Ziel dieser Studie war es, eine Übersicht heutiger eHealth AF Projekte zu bekommen und dabei im speziellen zu gucken, wie die Forschung stattfindet, statt nach den Ergebnissen zu gucken. Wir haben uns den Kontext der Projekte angeguckt, geschaut wie AF definiert und umgesetzt wird, und welche Best Practices und gewonnen Erkenntnisse beschrieben werden. Dabei haben wir gefunden, dass wenig über die praktische Ausführung von AF reflektiert und beschrieben wird. Andere wichtige Erkenntnisse waren, dass das Trainieren von Fähigkeiten und Selbstvertrauen der Stakeholder notwendig ist, welche diversen Rollen Forschende in einem AF Projekt auf sich nehme, und die Relevanz kontinuierlicher Reflektion.

Der **zweite Teil dieser Doktorarbeit** befasst sich mit den verschieden **Niveaus und Rollen des Einbeziehens** in Forschungsprojekte, unabhängig davon wer die Rolle erfüllt. Der Teil beginnt mit dem Blick auf Forscher*innen, da das Einbeziehen von Stakeholdern nur von ihnen effektiv initiiert werden kann. Darum haben wir im ersten Kapitel dieses Teils, **Kapitel 3**, die Haltung von beginnenden Aktionsforscher*innen zu AF studiert. Ziel dieser Studie war es zu verstehen, wie Forscher*innen mit wenig oder keiner Erfahrung mit AF diese Form der Forschung erfahren, und ob sie im Standen sind dies praktisch umzusetzen. Wir haben Forscher*innen AF vorgestellt und sie gefragt Vorteile, Risiken und Maßnahmen zu identifizieren die sie in ihren Projekten erwarten. Das Kapitel beschreibt die Methoden die wir genutzt haben, ebenso wie das Bild der beginnenden Aktionsforscher*innen von AF. Unsere wichtigste Erkenntnis war, dass Forscher*innen AF positiv gegenüberstehen, und gleichzeitig mögliche Risiken einschätzen können. Treffen, in denen Wissen geteilt wird, wurden als sehr nützlich erfahren und geschätzt.

In **Kapitel 4** schauen wir nach 'Champions' in AF Projekten. Wir folgen den Champions in verschiedenen Piloten eines Projektes, um zu sehen, wie sie ihre Rolle empfinden und ob sich dies während des Projektes verändert. Basierend auf diesen Erkenntnissen geben wir Ratschläge um Champions zu identifizieren und in Projekten einzubeziehen. Enthusiasmus und das Verbinden verschiedener Partner waren wichtige Eigenschaften von Champions. Sie schätzen es, die Freiheit zu haben um ihre Rollen und Aufgaben selber zu bestimmen, und auf diese Art konnten sie Veränderungen in ihrem Betrieb und dem Projekt erreichen.

Danach präsentiert **Kapitel 5** eine Studie in der wir die Motivation von Stakeholdern erforscht haben, um an längerfristigen, zeitintensiven Projekten wie AF teilzunehmen. Ziel dieser Studie war es, Strategien zu identifizieren, um die Motivation von Teilnehmern dieser aufrecht zu erhalten. Dazu haben wir Teilnehmer von zwei verschiedenen Projekten nach ihrer Motivation gefragt, um an dem Forschungsprojekt teilzunehmen. Das Kapitel enthält eine Diskussion motivierender Faktoren und

gibt außerdem Ratschläge, wie Teilnehmer während eines Projekten motiviert bleiben, zum Beispiel durch das kontinuierliche Überwachen und Verwalten von Erwartungen, und das Ermöglichen von Kommunikation zwischen Teilnehmern.

**Kapitel 6** befasst sich mit dem Einbeziehen der allgemeinen Bevölkerung, als Außenstehende in einem Projekt. Im Gegensatz zum vorherigen Kapitel war es in diesem Fall unser Ziel, zu identifizieren wie Teilnehmer spontan und ungeplant in ein Projekt einbezogen werden. Wir untersuchen die Möglichkeiten einer spezifischen Methode – der Flashmob Methode: schnelle Forschung, in der Praxis. Wir haben diese Methode in zwei verschiedenen Projekten getestet und geben, an Hand von Beobachtungen und Reflektion, Ratschläge für den Einsatz von Flashmob Studien in AF Projekten. So ist es zum Beispiel wichtig, durch den Flashmob die Aufmerksamkeit und Reichweite eines Forschungsprojektes zu vergrößern, außerdem können Insider helfen die Zielgruppe einzubeziehen.

**Im dritten Teil der Doktorarbeit** schauen wir, wie Stakeholder in einem Projekt miteinander **interagieren und kommunizieren**, und wie Forscher*innen diesen Prozess unterstützen können. In diesem Teil werden verschiedene Themen rund um die Kommunikation und Interaktion zwischen Stakeholdern aufgegriffen, und es wird speziell nach der unterstützenden Rolle der Forscher*innen dabei geschaut. Im ersten Kapitel dieses Teils, **Kapitel 7**, haben wir nach dem aufeinander abstimmen von Interessen und Bedürfnissen der verschiedenen Stakeholder in einem Projekt geforscht, um zu sehen was sie (inhaltlich) in einem Projekt erreichen wollen. Ziel dieses Kapitels war es, zu beschreiben, wie die Bedürfnisse von Stakeholdern in einem Projekt in Einklang gebracht werden können. Anhand einer Fallstudie mit älteren Leuten, Technologieproduzenten und Forscher*innen geben wir in diesem Kapitel verschiedene Ratschläge um zu Übereinstimmung zu kommen. Offene und explizite Gespräche, und das Aufzeigen der verschiedenen Interessen sind nützliche Aktivitäten.

**Kapitel 8** bietet ein Instrument für kollaborative Reflektion mit Stakeholdern, sowohl inhaltlich, als auch auf Prozessniveau. Ziel war es, Forschern eine strukturierte Methode anzubieten, zusammen mit Projektpartner zu reflektieren. Wir haben das Instrument iterativ zusammen mit verschiedenen Piloten in einem AF Projekt entwickelt, die das Instrument getestet und Feedback gegeben haben. Das Instrument richtet sich auf den allgemeinen Prozess, den Forschungsprozess und zukünftige Aktivitäten, wobei auch die Erkenntnisse aus vorherigen Reflektionen mitgenommen werden.

Der Fokus von **Kapitel 9** liegt auf dem Prozessniveau der Interaktion zwischen Stakeholders. Unser Ziel war es, wichtige Elemente des Trainings van Fähigkeiten der Stakeholder zu ermitteln. Dieses Kapitel beschreibt die Ergebnisse eines Workshops mit Forscher*innen die Erfahrung mit solchen Trainingsaktivitäten haben. Wir stellen einige Fragen für die Planung eines Stakeholdertrainings, zum Beispiel wie mit Machtdynamik und Hierarchie umgegangen wird, wie gegenseitiges Lernen unterstützt werden kann und wie Training zugänglich gestaltet werden kann.

Im letzten Kapitel dieses Teils, **Kapitel 10**, wird eine iterative Methode beschrieben um Patienten einzubeziehen. Ziel dieser Studie war es, eine Methode zu entwickeln, die andere Projekte nutzen können um die Werte der Patienten an der Patientenreise (Patient journey) abzubilden. Die Methode wird gemeinsam mit einer Fallstudie aus der Rehabilitationsmedizin beschrieben. Durch verschiedene Arten der Datenerhebung in unterschiedlichen Phasen, konnten wir retrospektive und situationelle Daten zu einem kompletteren Bild der Patientenreise kombinieren. Das kann bei dem Entwurf und der Implementierung von eHealth Technologie helfen, um dafür zu sorgen, dass die Technologie in den Kontext passt.

Der **letzte Teil dieser Doktorarbeit** fasst die Ergebnisse der vorhergehenden Kapitel zusammen. In **Kapitel 11** präsentiere ich einen Framework für das aktive Einbeziehen von Stakeholdern in eHealth AF Projekten. Dieser Framework beschreibt wichtige Themen, mit denen in einem solchen Projekt umgegangen werden muss. Dabei sind die Ratschläge aus den vorhergehenden Kapiteln mitgenommen. Der Framework enthält eine kurze Einleitung jedes Schrittes im Prozess, Fragen die Forschende sich stellen können, sowie Hintergrundmaterial, beispielsweise Referenzen zu möglichen Methoden. Im letzten Kapitel dieses Teils (**Kapitel 12**) bespreche ich meine Erkenntnisse und mögliche künftige Forschungsansätze. Dieses Kapitel enthält auch meine Reflektion auf meine Forschung und Erkenntnisse, und die Anwendungsmöglichkeiten für zukünftige AF eHealth Projekte.

# Dankwoord / Acknowledgements / Danksagung

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Large parts of my research were conducted within the Pharaon project. My role required me to study the work that the other researchers in the project were carrying out. This means that they were frequently my participants. I am grateful to all who let me interview them, or took part in our focus groups and workshops. The pilot leads played a significant role in this, and were my first access point. Therefore, to you I want to say: Grazie, Dankjewel, Hvala, Gracias and Obrigada! Mateja, thank you for being my PhD buddy, and for being the positive and supportive person that you are. Our chats were often related to the struggles and not so bright sides of academic life, but I always felt good afterwards. Good luck finishing your thesis, I know you can do it!

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## About the author

Kira Oberschmidt was born in Melle, Germany, on 16 November 1994. After completing her bachelor in Psychology at the University of Twente in 2017, she pursued two master degrees at the same university. In 2019 she graduated from the masters in Health Sciences and Health psychology and Technology. For her theses she studied the possibilities of eHealth to decrease student stress and burn-out. Part of this work resulted in a report on student wellbeing at the University of Twente. During her masters, Kira worked as teaching- and research assistant. She was involved in a project about technology use in forensic mental healthcare, which resulted in a journal publication that she co-authored. After her studies, Kira started working at Roessingh Research and Development (RRD) as a junior researcher. Initially, she was mainly involved in the Pharaon project, which formed the basis for most chapters in this thesis. During her time at RRD Kira got involved in other projects, both local and international ones. Some of these have also fed into this thesis. At the time of writing, Kira is coordinating a project on the implementation of wearables at Roessingh Rehabilitation Centre, and setting up a local network for action researchers, while finalizing her work in the Pharaon project.

## Publications

### Journal Papers

Kip, H., Oberschmidt, K., & Bierbooms, J. J. (2020). eHealth technology in forensic mental healthcare: recommendations for achieving benefits and overcoming barriers. International Journal of Forensic Mental Health, 20(1), 31-47.

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Oberschmidt, K., Grünloh, C. & van Velsen, L.. Novice action researchers' theoretical understanding and practical implementation of action research in eHealth. (submitted)

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Oberschmidt, K., Grünloh, C. & Tabak, M.. Supporting Collaborative Reflection: Development of a Reflection Guide for eHealth Action Research. (submitted)

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Oberschmidt, K., Grünloh, C., Tunç, S., van Velsen, L., & Nijboer, F. (2020, December). You can't always get what you want: streamlining stakeholder interests when designing technology-supported services for Active and Assisted Living. In Proceedings of the 32nd Australian Conference on Human-Computer Interaction (pp. 649-660). [Included as Chapter 7]

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Bui, M., Oberschmidt, K., & Grünloh, C. (2023). Patient Journey Value Mapping: Illustrating values and experiences along the patient journey to support eHealth design. In Mensch und Computer 2023 (pp. 49-66). [Included as Chapter 10]

# Conference Contributions

Jansen-Kosterink, S.M., Hurmuz, M.Z.M., Broekhuis, M. & Oberschmidt, K. Het belang van het betrekken van ouderen bij het ontwikkelen van eHealth. Workshop at De Geriatriedag 2021.

Jansen-Kosterink, S., Broekhuis, M., Hurmuz, M. & Oberschmidt, K. Solving the paradox: When usable eHealth applications are not used by the target population. Workshop at Medical Informatics Europe Conference 2022.

Oberschmidt, K. (2021). How can we facilitate the active involvement of stakeholders in eHealth action research projects?. Doctoral Consortium at the European Conference on Computer-Supported Cooperative Work 2021.

Involving older adults in the development of digital (caring) communities. Oberschmidt, K. & Grünloh C. Invited presentation and panel participation at EURECO Online Conference 2021.

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Oberschmidt, K., Grünloh, C., Doherty, K., Wolkorte, R., Saßmannshausen, S. M., Siering, L., ... & van Den Driesche, K. (2022, October). How To Train Your Stakeholders: Skill Training In Participatory Health Research. Workshop at the 2022 Nordic Human-Computer Interaction Conference.

Guiding active stakeholder involvement in eHealth action research projects. Oberschmidt, K. Doctoral Consortium at the 2022 Nordic Human-Computer Interaction Conference.

Using Action Research to incorporate Wearables in Rehabilitation care. Oberschmidt, K., Rinzema, R., Bartali, V., Flierman, I., Dijkstra, A., van Vliet, R. & Tabak, M.. Presentation at Supporting Health by Technology 2023.

Stimulating researchers to more actively involve stakeholders in their project. Oberschmidt, K. Position paper for a workshop at Mensch und Computer 2023.

Framework for active involvement in participatory eHealth research. Oberschmidt, K., Grünloh, C. & Tabak, M. Showcase at Citizen Science for Health Conference 2023.

Taking the next step: How to face the challenges of moving towards Citizen Science. Te Braake, E., Oberschmidt, K., Hurmuz, M., Jansen-Kosterink, S. & Grünloh, C. Solution room at Citizen Science for Health Conference 2023.

# Book chapter

Oberschmidt, K. Action Research for Smart and Healthy Ageing. In Rethinking Smart and Healthy Ageing in Europe. (accepted)

# Progress range

The following publications have been published in the Progress range by Roessingh Research and Development, Enschede, the Netherlands. Copies can be ordered, when available, via info@rrd.nl.

1. J.W.G.A. Pot, H. Boer, W.H. van Harten, H.J. Hermens, E.R. Seydel. Comprehensive Need-Assessment. Ontwikkeling van een meetinstrument voor zorgbehoeften en kwaliteitsbeoordeling door patiënten. September 1994, ISBN: 90-25452-01-2

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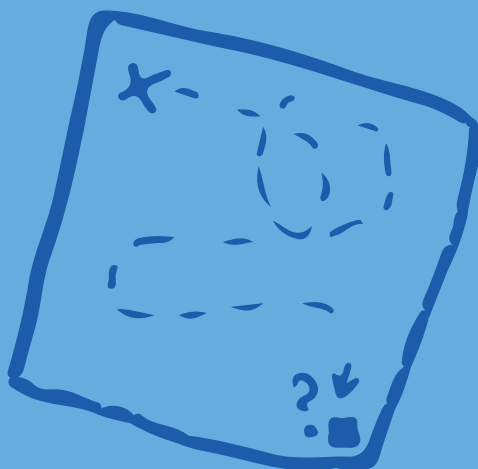
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