



Patient Journey Value Mapping: Illustrating values and experiences along the patient journey to support eHealth design

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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.

CCS CONCEPTS

• **Human-centered computing** → **User studies**; • **Applied computing** → **Health care information systems**.

KEYWORDS

Patient journey map, value sensitive design, design method, user experience design

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1 INTRODUCTION

eHealth technologies aim to assist and enhance activities such as (remote) disease management [31, 32, 46], the development of support networks [10, 43], and the exchange of health information [2, 56]. Furthermore, eHealth solutions can support the collaboration between patients and healthcare professionals, for example, when choosing from different treatments [50]. 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 [38]. 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 [5, 6, 15, 17, 39, 61].

Value sensitive design (VSD) is a theoretically grounded approach that accounts for human values throughout the design process [23]. 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 [21]. Amongst others, these include value-oriented semi-structured interviews [19], value scenarios [11], and value-oriented coding manuals [22]. 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 [21]. 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 [21] and there are still open questions concerning theory, method and practice of VSD [20].

Firstly, while values seem to be somewhat stable, they may nevertheless be subject to change [5, 6, 45, 60]. 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 [5, 6, 14]. 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” [30, 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 [3, 9, 13, 16, 25, 62]. However, studies and methods have to be carefully crafted to avoid overburdening patients who already face a high disease burden dealing with their condition [34]. 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 [14, 27, 29, 37, 52, 55, 59, 65]. In patient journey mapping projects, patients' emotions and experiences along their encounters with health services are synthesised into visual or descriptive maps [35]. 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 [12]. 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 [36], the five most prominent types of maps that are used in current practice are: customer journeys [24], experience maps [41], mental model diagrams [48], service blueprints [47] and spatial maps [35]. 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.

2 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 1).

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.

2.1 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 [8], 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 [63], 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*.

2.1.1 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 [26]) 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 [18] and value-oriented semi-structured interviews [21]. 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

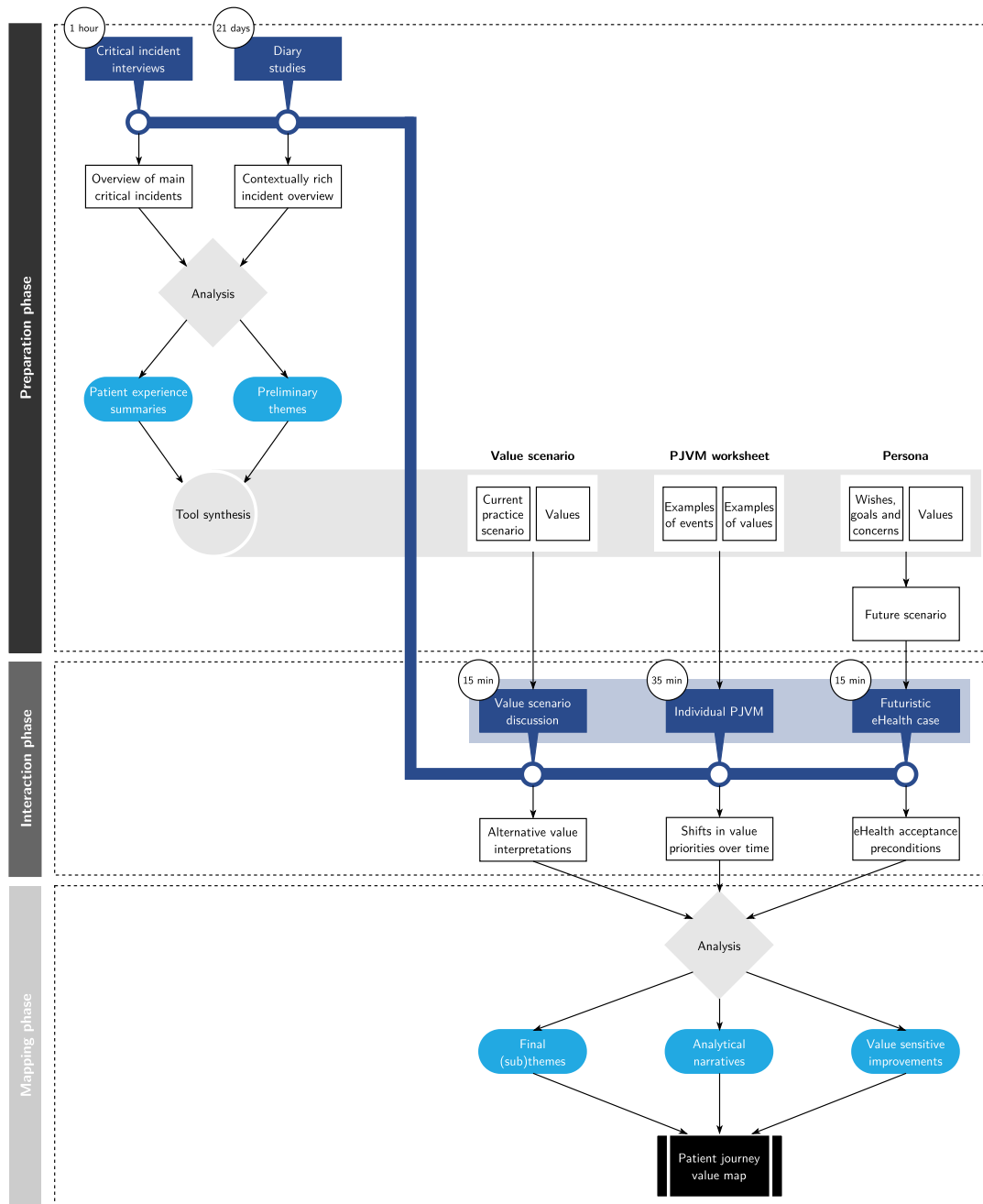


Figure 1: Overview of the methods proposed to perform patient journey value mapping and the respective data flows.

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, which can be found in the interview protocol in the Appendix, 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 [7, 20]). Instead, showing a list of values after participants already identified what is important to them (as suggested also by [20]) 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 [7]). 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 [21] 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.

2.1.2 Diary Study. Interviews and particularly the critical incident technique collect retrospective reports, which are drawn from participants' memories [18, 26]. 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 [33, 40]. Furthermore, diary studies have a low memory strain and a high ecological validity [64]. Complementing retrospective data with data collected via diaries helps determine the extent to which critical incidents characterise a typical or regular experience [4].

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.

2.2 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.

2.2.1 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 [51]. A value scenario [21] 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 [1] 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 [44].

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.

2.2.2 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 Figure 5 of the Appendix.

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.

2.2.3 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 [1]. 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 [49] (Figure 4 of the Appendix). 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 [58], 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.

2.3 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 [14, 65], 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.

3 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.

3.1 Recruitment

The study took place between July and November 2021 at Roessingh, a centre for rehabilitation 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.

3.2 Critical Incident Interviews and Diary Studies

All five patients participated in the critical incident interviews. The complete interview protocol is shown in Appendix. The interviews

Table 1: Examples of main events identified during the critical incident interviews.

Main event	Interview excerpt
Being able to act proactively by making suggestions about adaptations to the treatments.	<i>“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).</i>
Experiencing patient-centred care due to acts of tailoring.	<i>“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).</i>
Awareness creation due to confrontation with and reflection on own behaviours.	<i>“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).</i>
Discontinuity in care delivery due to insufficient involvement in the provision of eHealth aided rehabilitation options.	<i>“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).</i>

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 1.

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 [42].

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 2. 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 1, 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)*.

3.3 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

Table 2: Example of a single diary entry obtained from participant P1.

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".

following sections address the outcomes per workshop activity in further detail.

3.3.1 Value Scenario Discussion. Figure 2 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 2, 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.

3.3.2 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).



Figure 2: The value scenario used during the workshop. The preliminary identified values are coloured in blue.

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).

3.3.3 Futuristic eHealth Case. The participants read through a fictional newsletter from the future (see Figure 6 of the Appendix) 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.

3.4 Patient Journey Value Mapping

3.4.1 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.

3.4.2 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 3). 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 3, 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 3 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

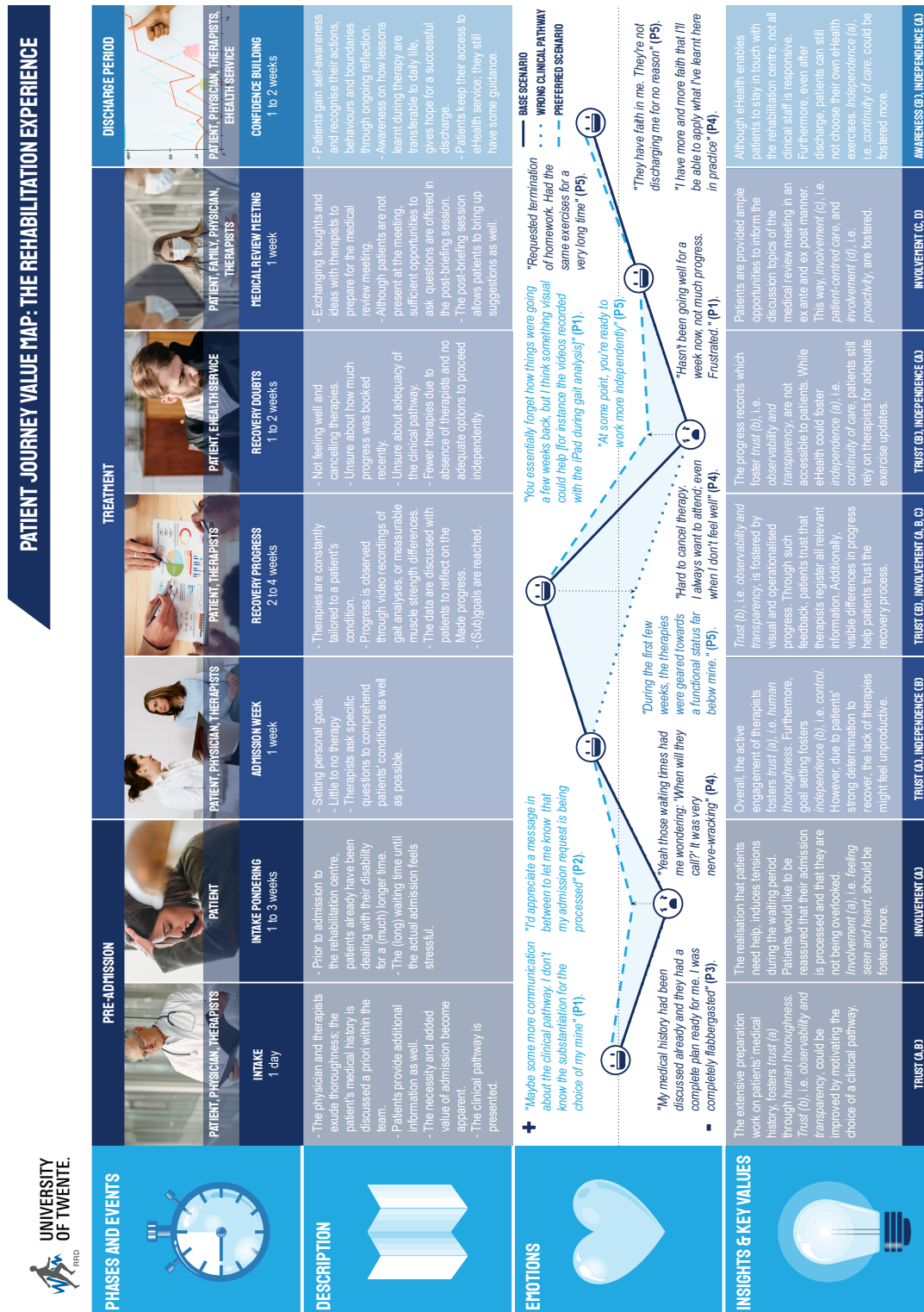


Figure 3: Final patient journey value map. Colour-coded quotes along the emotion curves represent the base, desired, and undesired scenarios. Capital letters in parentheses behind the listed key values are used to distinguish between the specific meanings of identically named values.

clinical outcomes. On the other hand, it was conceptualised as therapists' active involvement through tailoring of treatments to accomplish patient-centred care.

4 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 3.

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 [7], 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 [59], while evidence on efficiency and effectiveness of methodological pipelines is lacking [54]. 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 [4, 28, 53, 64], 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 [63], 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 [28, 59], and for VSD research in general [21], 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 3, 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 [59].

In case that it is feasible to pursue the preparation, interaction, and mapping phases, several adaptations 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 et al. [1] 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 [14]. 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 [57].

Table 3: Overview of strengths and weaknesses of research methods used in the PJVM approach.

Method	Strengths	Weaknesses
Critical incident interview	<ol style="list-style-type: none"> 1: Allows for the collection of main events along the patient journey. 2: Yields rich narrative content which can be unpacked further through follow-up questions. 	<ol style="list-style-type: none"> 1: Completeness of the data depends on the patient's recall.
Digital diary study	<ol style="list-style-type: none"> 1: Yields event descriptions which are often embedded in specific therapy contexts. 2: May reveal how frequent and embedded critical incidents are in the usual care delivery. 3: Allows experiences, sentiments, and patient values to be sampled jointly. 	<ol style="list-style-type: none"> 1: Could pose barriers to participation depending upon patients' digital literacy. 2: Comprehensiveness of the data fluctuates across patients. 3: The required longitudinal engagement makes data collection more prone to missing entries (e.g. due to health-related drop-outs).
Workshop	<ol style="list-style-type: none"> 1: The group setting allows for the identification of similarities between patients' views and experiences. 2: Enables researchers to verify whether analytical interpretations of previously collected data are representative. 	<ol style="list-style-type: none"> 1: Requires a high degree of engagement from patients, and should therefore comprise a limited number of activities to limit the burden. 2: Depending upon the task complexity, a substantial portion of the available time could be lost to providing explanations.
Patient journey value mapping	<ol style="list-style-type: none"> 1: Is able to capture the context and time dependency of priorities in patient values. 2: Allows patient values to be organised in relation to concrete events and feelings. 3: Is compatible with multiple data collection methods and therefore allows for a holistic integration of research findings. 	<ol style="list-style-type: none"> 1: Excludes patients' views on the researcher's interpretations of the final map. 2: Inherently assumes a linear progression of events, while care processes could be cyclical. 3: Currently only captures how value prioritisations vary between activities, but not how they vary within activities.

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 [57, 64]. 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 3. 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.

5 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.

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APPENDIX

CRITICAL INCIDENT INTERVIEW PROTOCOL

Motivation and expectations

What motivated you to participate in this study?

Have you (or someone you know) participated in a similar study before?

[If so, could you elaborate on it? *Prompts*: what kind of research was it, what was the study duration, what was your experience?]

What are your expectations regarding your participation in this study?

Patient journey

Could you first provide an overview of important events which have occurred during your rehabilitation? You could do this chronologically, or any other way that is comfortable to you. In the meantime, I will briefly summarise these events on post-its for later referral.

[Create an overview of important events.]

Critical incidents

Now that we have a nice overview of the important rehabilitation-related events, I would like to discuss several of them in more detail.

[During the conversation, pay attention to which events are noteworthy, for instance due to the subject's vivid storytelling or because it concerns drastic event. If the researcher is unable to identify an event of interest based on these criteria, allow the subject to select events.]

[Per event:]

[Start with a general question: could you elaborate on this event?]

[Additional questions, provided that they have not been answered yet:]

- What was the cause of this event?
- Who were involved? [technology/care providers/other]
- What were you doing? What were others doing?
- How did you feel about it?
- As a consequence of that, has anything changed for you or your treatment? What were the consequences?
- How could this be prevented in the future (in case of a negative event) or how could this be supported (in case of a positive event)?
 - Do you think that technology could assist you / improve the conditions?
 - Do you think that the rehabilitation centre could organise this differently?

Patient values

We are curious about the values that are important to you during your rehabilitation. With values, we mean the notion of what is desirable. Or to phrase it differently: principles which are important to you (personally), which should be accounted for during your rehabilitation.

Which value(s) do you recognise in the stories you have just told?
[How would you define this value / what does ... mean to you?]

We have prepared several examples of potential values. Are there any values on this list which you have not mentioned yet, which do apply to your experiences?

[Show list of values: safety, independence, conviviality, control, trust, efficiency, involvement, closeness, convenience]



Figure 4: Persona constructed based on interviews and diary studies. The persona guided the process of future scenario drafting.




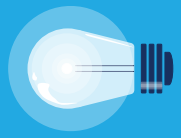
PATIENT JOURNEY VALUE MAP			
 TIMELINE	<p>Please describe the phases and relevant events along your rehabilitation. A phase describes a period in time. Examples of phases include: the start of the rehabilitation, period around the first medical review meeting and the period after the first medical review meeting.</p> <p>Examples of shorter phases include: morning, afternoon, evening, therapy week and outpatient testing week. An event on the other hand, occurs during a phase, such as: intake meeting, goal setting, attending therapy, gaining new insights, taking part in a meeting at home, of transitioning with therapists.</p>	PHASES	
 DESCRIPTION	<p>Shortly describe what the event lasted in the phase and where it may be written down in bullet points.</p> <p>In case you feel uncertain about what to write here, consider the following example prompts you could address:</p> <ol style="list-style-type: none"> 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? 	EVENTS	
 EMOTIONS	<p>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.</p> <p>On the gray bar, you may specify the corresponding emotion, such as happy, neutral, sad, stressed, inspired, frustrated, fearful, insecure, stressed, dissatisfied and disappointed.</p>	<div style="background-color: #cccccc; height: 20px; width: 100%;"></div>	<div style="background-color: #cccccc; height: 20px; width: 100%;"></div>
 VALUES	<p>For each event, write down the 5 most important values which apply to your experience on the line on the left-hand side of the box. Rank them from 1 to 5. Examples of values include: safety, control, independence, transparency, trust, awareness, efficiency, involvement and conviviality.</p> <p>Next, rank the values from 1 to 5 based on how positively they are experienced 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.</p>	<div style="display: flex; justify-content: space-between;"> <div> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </div> <div> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </div> <div> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </div> </div>	<div style="display: flex; justify-content: space-between;"> <div> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </div> <div> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </div> <div> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </div> </div>

Figure 5: Patient journey value mapping worksheet used during the interactive workshop.



Your treatment

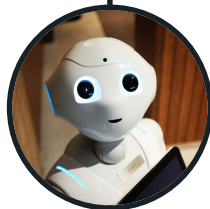
Therapy robot update 3 december 2051

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.



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.

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



Figure 6: Future scenario presented during the workshop.