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The Design Process of an mHealth Technology: The Communicative Constitution of Patient Engagement Through a Participatory Design Workshop

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Abstract: The aim of this article is to allow for a better understanding of how patient engagement is progressively constituted through interactions during a participatory design workshop. We will present a research project (based on a Participatory Design Approach) with the objective of creating an mHealth technology to encourage post-myocardial infarction (MI) patients to manage their condition, and learn more about their sudden cardiac death risk. The analysis will allow us to reveal the communicative constitution of patient engagement during the design process. We will illustrate patient engagement "in-the-making" by revealing 3 interactional processes: (1) the collective constitution of "experiential knowledge", (2) the enaction of a "mutual learning space", and (3) the co-creation of a prototype that embedded the patients' voices.

Keywords: health technology, mHealth, participatory design, dialogical space, patient engagement

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Le processus de conception d'une technologie mHealth. La constitution communicative de l'engagement des patients lors d'un atelier de conception participative

Résumé : Le but de cet article est d'avoir une meilleure compréhension de la façon dont l'engagement des patients dans le design d'une technologie de e-santé se constitue progressivement au cours des interactions s'accomplissant lors d'un atelier de conception participative. Nous présenterons un projet de recherche (fondé sur une approche de conception participative) dont l'objectif est de créer une technologie de e-santé visant à encourager les patients ayant subi un infarctus du myocarde à mieux comprendre leur maladie et gérer leurs facteurs de risque. L'analyse nous permettra de révéler la constitution progressive de l'engagement des patients au cours du processus de design. Nous illustrerons l'engagement des patients « en train de se faire » en révélant 3 processus interactionnels : (1) la constitution collective d'un savoir expérientiel, (2) l'émergence d'un espace d'apprentissage mutuel et (3) la co-création d'un prototype matérialisant les voix des patients.

Mots-clés : e-santé, application mobile, design participatif, espace dialogique, engagement, patient

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Introduction

The design of health technology (such as health information systems, telehealth, telemedicine) is not new (Fitzpatrick & Ellingsen, 2013)[1]. However, there has been growing interest in healthcare design research for so-called mobile health applications or mHealth (Cajita, Hodgson, Budhathoki, & Han, 2017; Davis et al., 2017). As stated by Zapata, Fernandez-Alemàn, Idri, & Toval (2015):

> The release of smartphones and tablets, which offer more advanced communication and computing capabilities, has led to the strong emergence of mHealth on the market. mHealth applications are being used to improve patients' lives and their health, in addition to facilitating communication between doctors and patients. (p. 1)

In the last decade, the number of mHealth technologies for managing patients with chronic diseases has increased. Devices for self-monitoring imply new responsibilities for the patients, as well as the healthcare professionals (Oudshoorn, 2011). In this new "geography of responsibilities", the patient becomes a "diagnostic agent" (Oudshoorn, 2008). In other words, "patients are not just users of a new technology that requires instrumental skills, but should be considered as agents who have to perform all manner of articulation work required to carry out the responsibilities delegated to them" (Oudshoorn, 2011, p. 149). In this context, what

[1] For an extensive overview of design research in healthcare see Fitzpatrick & Ellingsen (2013).

role does the patient play in the design of mHealth technology? There is a growing consensus that patient participation or patient engagement in the design of mHealth tools is a crucial factor for improving the implementation of the technology (Pagliari, 2007).

1. Patient engagement in the design process: From testers to design partners

We note that numerous health technologies are developed without any real form of patient involvement (Oudshoorn & Somers, 2006; Vosbergen et al., 2013). Historically, the design process in telemedicine and telecare has rested mostly on top-down approaches that can be characterized as "technocentrically oriented" (Bonneville & Grosjean, 2008). The end user, i.e. the patient, is conceptualized as a "human factor"—at most an informant—rather than a real stakeholder, partner in the design process (Kanstrup, Bertelsen, & Nøhr, 2015). Patients do not play an equal role to software developers, engineers, and healthcare providers who make crucial decisions regarding the form and content of health technologies. Consequently, patients are consulted by the developers to give their opinion on a technology already designed. Often, patient involvement is sought to validate an already preconceived design to give it further legitimacy. Patients are perceived as testers of the prototype (Pagliari, 2007).

As suggested by Lundin & Mäkitalo (2017):

> A new kind of relation has been claimed urgently required between health services and the persons with whom they have long-term relations. What has been suggested is for health "users" to become more actively involved as "co-producers" at all levels and in all aspects of health system development and functioning. (p. 18)

In the past years, there has been a growing interest in the integration of patients in the design process, from user-centered design to the co-design of devices (Sanders, 2003; Bjerkan, Hedlund, & Hellesø, 2015; Kanstrup et al., 2015; Span et al., 2018). Patient-centered care implies fundamental changes in the way that mHealth technologies are designed. The involvement of the patients (as real partners) is considered vital to achieve this goal (Lundin & Mäkitalo, 2017).

However, several researchers pointed out the various conceptions of patient engagement[2] or patient participation in the design process (Bélanger, Bartlett, Dawes, Rodríguez, & Hasson-Gidoni, 2012; Andersen, 2010; Demiris et al., 2008; Yuan, 2016). For example, Das & Svanæs (2013), based on the work of Druin (2002), established a distinction between 4 types of end users:

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[2] In this paper, the term patient engagement is used to illustrate the active role played by patients in the design process. In the literature, various terms are used such as: patient involvement, patient participation, patient collaboration. We will use the term "engagement" to emphasize two elements: (a) the processual dimension of patients' participation and (b) the agency of patients in the design process.

> (…) user, tester, informant and design partner. In the role of *user*, end-users contribute to the research and development process by using technology, while the researcher may observe, videotape or test for skills. This is done to try to understand the technologies' impact on the user with the aim that future technologies can be changed or future environments enhanced. In the role of *tester*, end-users test prototypes and are observed with the technology to capture their experiences, and observation of participants with existing technologies or they may be asked for input on design sketches or low-tech prototypes. In the role of *informant*, end-users have an important part in the various stages of the design process, based on when the researcher believes that the participants can inform the process. This may involve observation of participants with existing technologies or they may be asked for input on design sketches or low-tech prototypes. In the role of *design partner*, end-users are considered to be equal stakeholders in the design of new technologies throughout the whole process. (p. 1077)

But patients are much more than "users", much more than their relation to a technology (Bannon et al., 2012). If we want to understand the complexities of the "figure of the user" (Suchman, 2007) in the design process, we must understand the multiple practices and experiences by involving patients as co-designers. In this context, design requires engagement, participation and creativity, as well as methods and techniques to transform needs and ideas into concrete solutions (Simonsen & Robertson, 2012).

For many authors, a participatory design approach appears to be the most effective way to include patients in the design process (Bjerkan et al., 2015; Noergaard et al., 2017; Sparud-Lundin et al., 2013). Participatory design is not only a technique to gather input, but a holistic approach that entails multiple steps through which patients are considered full-fledge partners (Smith, Bossen, & Kanstrup, 2017). In the same vein, patients are regularly invited to share their ideas, opinions, and views on the design of the technology. Patients are seen as a fundamental resource in the design process because of their first-hand experience with specific diseases and treatments. These patients develop an "experiential knowledge" (Blume, 2017) specific to their daily life with their condition. It must be stressed that this knowledge should be considered as important as the healthcare provider's biomedical expertise, and should consequently be included in the design process. This can be done by establishing a real and durable partnership between patients as end users on the one hand, and healthcare providers on the other. "The partnership paradigm credits patients with an expertise similar in importance to the expertise of professionals. This paradigm implies that while professionals are experts about diseases, patients are experts about their own lives" (Bodenheimer, Lorig, Holman, & Grumbach, 2002, p. 2470). However, the current lack of focus in contemporary work on the role of the patient as an expert (i.e. as possessing useful

knowledge to design health technologies) signals an underestimation of the patient's capacity to fully contribute in the design process (Kanstrup et al., 2015).

As researchers who participated in the conception of an mHealth application for post myocardial infarction (post-MI) patients, we adhere to the principle of engaging patients as partners. The patients (as future users of a technological solution) should "have a say" in the design of the mHealth. As stated by Bratteteig (2017), having a say is more than having a voice. It implies a real involvement throughout the design process, and the power to make a difference. However, in practice, the degree of patient engagement or patient participation (the two notions are used in the literature) varies throughout the development of mHealth technologies (Grosjean, Bonneville, Redpath, Mayère, & Marrast, 2017). How patients are involved, and the meaning of engagement or participation differs in the literature (Anderson, 2010; Bratteteig & Wagner, 2016) and "there is little explicit analytical attention directed at what constitutes participation" (Anderson, Danholt, Halskov, Hansen, & Lauritsen, 2015, p. 253).

1.1. *The purpose of the paper*

As suggested previously, the notions of patient engagement or participation are somehow taken-for-granted in the literature. What this engagement process might look like at the empirical level, and how patients may participate and contribute to the design process in concrete ways remains unclear. As mentioned by Lundin & Mäkitalo (2017): "Although users (such as patients) have been recognized as part of the design collective in the development of medical innovations, the interaction in design meetings with patients has not been explored to any extent" (p. 20). The role of patients and their involvement in the design process of mHealth is gradually becoming an important issue, but we must gain an in-depth understanding of how patients could contribute to the development of mHealth technologies. This points to a need for empirical studies of the design process, where patients' contributions are looked into thoroughly.

In order to address this knowledge gap, we aim to understand patient engagement by focusing on the communicative constitution of various acts of involvement that occurred during interactions in a participatory design workshop. This implies, as we will illustrate, that we conceptualize patient engagement as an ongoing and communicative process throughout the design of an mHealth application. We will clarify our approach in the next few pages. We will present our research project of designing an mHealth application—in which post-MI patients were actively engaged from the initial phase as experts sharing their experience of the illness, thereby co-constructing collectively a prototype. We will focus on a participatory design workshop for describing the ongoing process of patients' engagement through the interactions. We will follow patients' engagement "in-the-making" by revealing 3 interactional processes: (1) the collective constitution of "experiential knowledge", (2) the enaction of a "mutual learning space", and (3) the co-creation of a prototype that embedded the patients' voices.

2. Participatory Design: A communicative and collaborative approach

2.1. *Participation and communication at the heart of Participatory Design*

Originally, Participatory Design was developed by researchers in Scandinavia to support the development of technologies and information systems in the workplaces (Greenbaum & Kyng, 1991; Gregory, 2003; Bødker, Kensing, & Simonsen, 2009; Halskov & Hansen, 2014). "The dominant driving forces were the aims to focus on democratic approaches, including the user perspective, and to ensure that new technology enabled people, rather than constrained" (Bjørn & Østerlund, 2014, p. 20). The workers were involved as co-designers and the focus was to embrace an end-user perspective by understanding the work practices in which the technology should be used.

This approach was applied to new contexts, such as the design of technology for healthcare professionals or patients (Ackerman et al., 2018). Participatory Design is grounded in a democratic vision of empowering users by having them participate in the design and development of technology. The main purpose of the Participatory Design approach is to create a collaborative partnership with the people destined to use the technology.

> [This approach] refers to a set of theories, practices, and studies on how to include the end users as active *design partners* in the design process (Muller, 2009). The purpose of including the future users is to ensure that the final product is usable and meets the users' needs. [So] in PD, the research and design work are done *with* the users, while in related approaches within user-centered design, this work is done on *behalf* of the users. (Das & Svanæs, 2013, p. 1077)

The notions of collaboration and engagement are at the heart of the participatory design approach, and may be understood as the complex process that combines doing, talking, thinking, feeling, and sharing experience and knowledge. For Muller and Druin (2012), Participatory Design is described as the enactment of a "third space", maybe the space of the participatory design workshop (Muller, 2009); a dialogical space where participants are involved in the collaborative construction of a prototype (Béguin, 2003). Various tools and techniques are developed to involve users in co-design dialogues (Sanders, Brandt & Binder, 2010). These tools and techniques combine 3 elements (Brandt, Binder & Sanders, 2013): telling (e.g. sharing experiences, challenges and dreams), making (e.g. sketches, mock-up for externalizing and embodying ideas in an artefact) and enacting possible futures (e.g. imagine and act out future solutions, scenarios of use).

The participatory design process implies a succession of activities to stimulate interaction between the participants and to support users' involvement in producing interpretation, sharing knowledge and making choices and decisions. In a book on Participatory Design, edited by Simonsen and Robertson (2012), the authors state

that at the heart of participatory design is the user's voice in the design process, through interaction with humans (various stakeholders) and non-humans, such as prototypes (Rice, 2018). Participatory Design is also defined by mutual learning through collective "reflection in action" (Bratteteig & Wagner, 2016). Many authors describe design as a communication process or dialogical process (Béguin, 2003). For Lawson (2005), design is a conversation between participants, but also a conversation with the situation (involving space, objects). For Schumacher (2016), the design process is an ongoing process of communication between various actors and a "dialogue with the situation" (Schön, 1988).

2.2. *A theoretical framework to study patient engagement in the design process*

As suggested previously, various authors assert that communication in participatory design is constitutive of an organization involving heterogeneous actors (humans and non-humans), and design practices are constituted by both discursive and material practices (Jackson & Aakhus, 2014). Some authors use the term "sociomaterial-design" (Bjørn & Østerlund, 2014) to describe the entwined nature of the social and the material in the participatory design process. "The two are inseparably, constitutively entangled. Sociomateriality highlights the nexus of doings, materialities, and discourses that people carefully enact" (Bjørn & Østerlund, 2014, p. 8). As mentioned, various tools and techniques (such as CARD sorting, personas, mock-ups, etc.) are used to facilitate the generation and communication of ideas between participants and stimulate collaboration and engagement in participatory design. Various techniques of facilitation, tools and artefacts are needed to conduct the design activities in order to support all the participants in both creating collective understanding and supporting participation. For example, Brandt, Binder and Sanders (2013) have highlighted the performativity of tools used in participatory design that contribute to engaging users in enacting solutions.

Therefore, the CCO framework[3] will be useful to understand the constitution of patient engagement through the design process by studying the "constitutive entanglement" between discourse and materiality (Ashcraft, Kuhn, & Cooren, 2009; Orlikowski & Scott, 2015). This theoretical framework could contribute to the study of patient engagement "in-the-making" (i.e. in a processual perspective), by offering a way of understanding how patient engagement is being made and shaped through material-discursive practices.

[3] For further information on the Communicative Constitution of Organization (CCO) approaches see Cooren (2015) and Brummans, Cooren, Robichaud & Taylor (2014). The CCO frameworks "do not focus solely on human interactions and sensemaking activities; they extend the concept of communication to what non-humans do" (Giordano, 2015, p. 323)

3. Methodology

3.1. *Context of the research project*

In this research project, we followed the development of an mHealth application aiming to empower post-MI patients in tackling their cardiac risk factors.

Over seven million North Americans are MI survivors and have a fourfold higher risk of sudden cardiac death (SCD) compared to individuals without prior MI (Kannel, Gagnon, & Cupples, 1990). A recent meta-analysis emphasized the fact that β-blockers reduced the risk of SCD for post MI patient by 31% (Al-Gobari, El Khatib, Pillon, & Gueyffier, 2013). Randomized trials indicate that implantable cardioverter defibrillator (ICT) therapy reduces the risk of SCD by over 50% and increases overall survival by more than 25% in individuals at risk of SCD due to severe left ventricular (LV) systolic dysfunction, which is generally defined as a LV ejection fraction (EF) <30%. Despite strong evidence that knowledge of one's ejection fraction is beneficial to the patient's health, LVEF is poorly understood, infrequently measured, and SCD prevention therapies (β blockers and ICDs) remain underused (Chew et al., 2013).

To address this need in terms of patient education, the main objective of this project was to create an mHealth application that would encourage patients to learn more about their SCD risk following an MI event. We collected data relative to the generation of system requirements specifications; we sought to first understand the context of use through patient engagement in the design process of a healthcare device.

3.2. *Data Collection*

Our participatory design approach involved multiple methods such as semi-structured interviews and a participatory design workshop (Figure 1). Various tools and techniques were employed during the workshop as a means to directly engage patients in the design of the mHealth technology they will later use (Sanders & Stappers, 2014). Post-MI patients were invited in the early stages of the design process to share their experiences managing their medical condition, and to generate the features of the technology.

To understand the experience of post-MI patients with a high risk of SCD, we recruited a specific group of patients to participate in semi-structured interviews and in a design workshop. Our sample includes post-MI patients over the age of 18 years with an ejection fraction of less than or equal to 40%. To have a better understanding of the post-MI patients' needs, we also recruited healthcare professionals (through purposive sampling) to participate in semi-structured interviews.

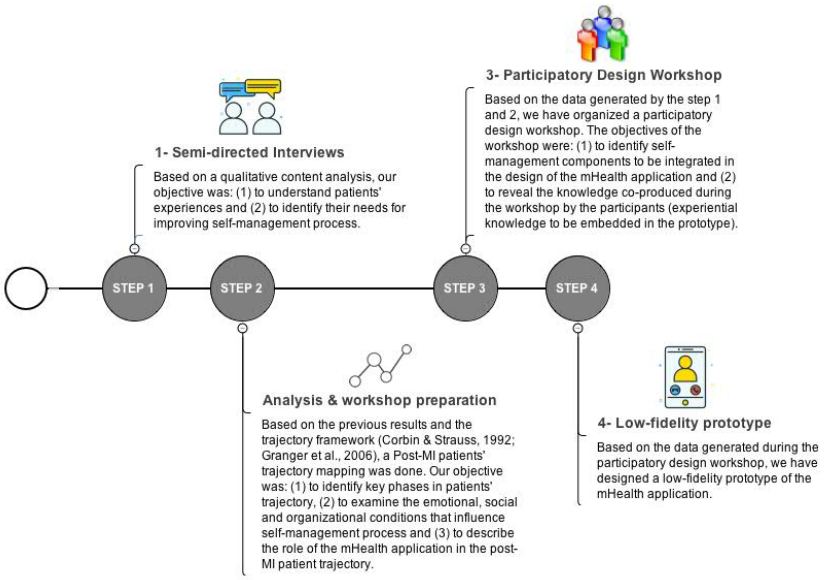


Figure 1. *Overview of the Participatory Design Approach*

After conducting interviews and gaining preliminary insight, we organized a three-hour participatory design workshop. Participants included post-MI patients (N=7), software designers (N=3), and one nurse. The objectives of the workshop were: (a) to understand the patient expectations (needs) in terms of support, information, and knowledge; (b) to identify the effective components of an mHealth application. The workshop was facilitated by a moderator; facilitation techniques were used to encourage the expression of individual needs, but also to contribute to the creation of a prototype that embedded patients' expectations to support self-management (Table 1). Consequently, the goal was to generate ideas for self-management resources and tools to be added in the design of an mHealth application to be used by post-MI patients. The workshop was audio recorded; notes and pictures were taken by two of the researchers.

Table 1. *Tools and techniques used during the participatory design workshop*

Tools and techniques	Instructions to participants
CARD sorting activity The goal of this activity was to identify the most important	***1- Small Group (20 minutes)*** Keep in mind the following question: What topics/content would people who have had a heart attack like to see on the mobile application?

information and resources for post-MI patients. Participants collaboratively combined cards in order to capture a sense of priorities, and to identify resources and tools necessary to support the self-management of the disease. This process was initiated by a discussion in which participants established a shared understanding of the cards' meaning and relevance.	We suggested 3 topic areas: (1) Medical information and advice to understand my disease (2) Tools and resources to manage my disease and (3) Support/communication to assist me with my disease. Each card represents a piece of information which could be important for understanding and managing your condition over time. 1) Select 10 cards for each topic areas; the most important in your opinion. 2) Rank the cards in order of importance (the most important on the top). ***2- Plenary session (15 minutes)***
Paper prototyping The goal of the second task was to gain further insight on the users' preference regarding the interface. Patients designed paper prototypes during the workshop. We asked participants to project themselves using the broad features/components they previously identified as relevant, by placing them onto a separate screen that would represent the final interface of the mHealth application.	***1- Small Group (40 minutes)*** Papers representing screens are placed on the table. Each paper has been designated as one screen. Your role: (1) To identify the components/information to include under each screen (2) to describe the organization of the content and the desired "look" of the user interface you would want to see on the screen. ***2- Plenary session (10 minutes)***

All the interviews were transcribed, and a qualitative content analysis was done in order to identify categories and themes. We used the trajectory framework (Corbin, 1998; Granger, Moser, Germino, Harrell, & Ekman, 2006) to inform our thematic analysis and to map the post-MI patients' trajectory in the healthcare system and throughout their recovery at home. Two complementary types of analysis were conducted with the data collected during the workshop: a) a qualitative content analysis, and b) the analysis of interactions. As mentioned by Brassac & Gregori (2001), there is logic underlying this type of analysis: it is possible to describe human cognitive processes by analyzing speech patterns produced through an interaction, in the context of a given situation. A fine-grained description of the interaction contributes to revealing the production of knowledge by the participants, and understanding patient engagement in the design process (Grosjean, Fixmer, & Brassac, 2000). For the purpose of this article, the analysis presented will solely focus on the participatory design workshop.

4. The participatory design workshop: A dialogical space revealing patient engagement "in-the-making"

In this section, we will present how patients contribute to the design of an mHealth application by revealing various acts of involvement that characterize patient engagement in practice. The analysis focused on how patients' expertise and knowledge were produced, shared, and finally integrated in the first prototype of the mHealth application. As mentioned previously, we will analyze the communicative constitution of patient engagement by revealing 3 processes: (1) the collective constitution of experiential knowledge, (2) the enaction of a mutual learning space and (3) the co-creation of a prototype that embedded the patients' voices.

4.1. *The collective constitution of experiential knowledge*

Engaging patients in the design process is a means to enact "experiential knowledge" (Blume, 2017). The concept of patients' experiential knowledge describes a unique type of knowledge that can only be gained through direct experience. Post-MI patients acquire knowledge and develop their own techniques to interpret their symptoms and shape their daily routines after having been diagnosed with a cardiac disease. This "knowledge of everyday life" needs to be expressed to be fully appreciated as such (Das & Svanæs, 2013).

During the workshop, patients explained to us the different ways in which they attempt to manage their symptoms or make sense of what is important for them to properly manage their condition. To stay motivated and sustain changes over time, some even go as far as sharing their new lifestyle with their partner (e.g. exercise every day, set realistic goals, reduce salt intake). Other patients doubted their ability to avoid worrying or experience strong emotions. They displayed an "embodied knowledge" which involved an apprehension of their sensory perceptions inflected with their own understanding of their symptoms and their capacity to manage them. However, experiential knowledge encompasses not only personal knowledge, but also the shared knowledge emerging from patients' discussions during the workshop. When patients share their own experience or practical advice with others, they become resources for one another, as well as for software developers. The excerpt below is typical in this sense:

Excerpt 1: Collective Experiential Knowledge about Symptom Interpretation

Note: P1, P2, P3=Patients; R=researcher, D=software developers

The group negotiates the ranking of some CARD related to the topic, "Medical information and advice to understand my disease".

P2: Yeah, I think it's important to know how symptoms could be interpreted. When I came to the hospital (Inaudible). I've never had a heart attack before. So, at that time, I broke out before it was too late. […]

P1: Yeah. I don't know about you guys.

D1: It's actually down here. [reference to the card]

P1: On three or four occasions, I had the exact same symptoms at home. I just had enough. This is acid reflux or indigestion. Or, but nothing…

P2: Yeah.

P1: … that I thought it was. I think, I think. I said to myself it never happened. I never had any heart issues at all. Originally, I went to the hospital thinking I had the flu. Because I had arthritis and all (Inaudible).

P1: It takes me all… Five seconds and all they said: "It's a heart attack." This one is probably, it's the most talked about with friends. Which brings your mind about, you know […] So, this honestly would do more…

P3: For people who didn't have a heart attack.

P1: Exactly! Because what you had, you guys, you need to understand the symptoms, right?

P2: Well, that's the best you can get. I mean. So, what you get, I don't think… I mean, this is more of an education tool. This should be more of a problem.

In this excerpt, patients with different backgrounds are sharing their experiences; common sense beliefs crystallize into knowledge that will later be translated into expectations or needs, and recommendations for the design. Patients are sharing their experiences of symptoms of a heart attack and discuss their inability to interpret them. At the end of this exchange, they conclude that interpreting the symptoms is not an easy task since they vary for everyone. This leads them to make the recommendation of developing training tools to empower patients so that they can better interpret their symptoms. Indeed, as patient experience is shared and interpreted, it progressively comes to make sense to all those involved in the design process.

We can see the importance of material setting (CARD) as a resource and medium of interaction and sense making. The cards are specifically designed to be manipulated and discussed by the patients. This technique of facilitation encourages patients to discuss existing practices applying to their experience, challenges and needs. Therefore, the cards are "cognitive artefacts" (Norman, 1993) playing a role in the co-construction of collective experiential knowledge by stimulating patients to talk about their own experience. This process, entangling discourse and materiality, takes place in a participation framework, and experiential knowledge is distributed among patients.

4.2. *A "mutual learning space" enacted*

Patient engagement in the design process means putting in place a mutual learning space (Béguin, 2003). This is a space where patients, designers, and healthcare providers negotiate points of view, share information, and present ideas. Interactions between patients and designers enable the co-production of useful

knowledge. Again, this knowledge is constituted in and through the interaction. Sometimes, during this process of co-creating knowledge, roles are reversed: patients become designers, making suggestions regarding technological choices, as illustrated in the following excerpt 2. Here, a patient is making suggestions for the design of the user interface and features.

Excerpt 2: When the Patient Becomes a Designer

> An iPhone, for some people could be… Information, that way. But at the same time, other people could maybe be more confused about… I'm thinking my elderly parents, I'm thinking something like that. We thought of a list of things that could be clicked and perhaps, like a balloon, would pop up, showing the graphical information and disappear. (Workshop—Patient)

When engaged in the participatory design workshop, patients play an active part in the discussion and decision-making processes; the boundary between designer and patient is blurred (Luck, 2003). The workshop opens up a space of dialogue to foster mutual learning. Knowledge is shared between patients, but also between patients and designers.

In the following excerpt 3, during the CARD sorting activity, patients prioritize the topics that are important to them. They take some time discussing a card on which is written: "Interactive lessons to help you learn what you need to know (i.e.: Your Ejection Fraction Explained)". However, the term "ejection fraction" does not appear to make sense for everyone here; some post-MI patients have never heard of it.

Excerpt 3: Knowing More About Your Ejection Fraction

P7: The ejection fraction. What in the world is that? Ejection fraction. Sounds like something important, I suppose! It could also be how effective the ejector seat is. For a pilot! (Laughter)

P4: Would you like to know what your ejection fraction is?

P7: I've never heard the term!

P4: You haven't? I'm surprised.

R: It's normal, because it's a technical, medical term.

P5: Exactly. I had no idea.

R: It's possible…

P3: So, you knew about it?

P4: I did, yes.

P3: You knew your success rate in having a heart attack.

P4: It's also not … easy to measure.

P7: A lot of patients don't know about it.

P5: So, what is it?

P4: Maybe it is exactly that. It's the percentage of blood that your heart actually pushes out every time it contracts.

P5: Oh!

P4: There's a hole that contracts through which leaves the blood inside of your heart when it pumps. Does it send out half of that? Does it leave 25%? Does it send out 75% of it? Cause it doesn't contract and push all of it.

P5: Right.

P4: So, it's gonna push a portion of it. How much is that portion? A normal person, you need to have something over 50. Closer somewhat to 70…

P7: The ventricle.

P4: Yeah. People have…

P7: I didn't know that! For a weak heart, it's gonna be low.

P4: Well, exactly. If it's weak, it's gonna be low. It's explaining the damage.

P7: How would they measure?

P4: Sorry?

P7: How would they measure that?

P4: Ultrasounds.

P5: Well, that's important.

P7: And it would go into this?

P4: Exactly, of course.

R: How many? I-2-3-4-5-6. OK.

P7: Did you get the first one? You need the first one.

P5: Yeah, he did.

In this exchange, at first, patient P4 is committed to explain to the other patients the meaning of this medical term (*It's the percentage of the blood that your heart actually pushes out every time it contracts*). Thus, during this conversation, a shared understanding of the ejection fraction is progressively constituted; information is provided about the severity of one's heart damage after an MI event. Then, another patient asks a question about how they can measure the damage; he wants to know what kind of test makes it possible to measure one's ejection fraction accurately. These patients finally make the collective decision to assign to this card a level of

first importance. By participating in the design of this mHealth application, some of them improve their knowledge of the concept of an ejection fraction, which contributes to a better understanding of their own medical condition. This decision will later influence the design of interactive tools that will allow other patients to better understand this medical concept, which is deemed essential to self-management of the disease. During the CARD sorting activity, both collective knowledge and understanding are co-constructed in the exchange.

The dialogue initiated during this activity reveals many knowledge gaps that can be addressed later in the design process. Patients share their doubts, interrogations, and experience in order to collectively make decisions about the design of a low-fidelity prototype. In the next excerpt, they debate which medical terms are important enough to be integrated in the mHealth application. During the workshop, participants share personal experiences related to medication side effects; they try to anticipate the future uses of the mHealth application by other patients, and thus they negotiate priorities among stakeholders (e.g. learning topics, self-tracking tools). In excerpt 4, patients discuss the importance of obtaining more information on their treatment, as well as why they are taking specific medications.

Excerpt 4: The Emergence of Collective Agreement Among Patients

P3: It's important, it's important. Why do I need to take that? That's pretty important.

P1: Well I can get you a little bit of reassurance. You know that it's important, that pill that I'm gonna take. But I think, you know, this… I know that if I don't take it…

P3: Bad things could happen. That's pretty important.

P1: Yes. So, you think that's important?

P3: Most important, yes.

P1: Because it's a cure, right.

Patient 3 deems it essential to know why one is taking certain medications. Patient 1 argues that it is a matter of reassurance. This dialogue showcases the importance of the sharing of impressions and opinions: patients emphasize the importance of having access to specific information, which could be integrated in the design of the mHealth application. They believe this could help them better manage their disease. By engaging patients in the design of the mHealth application, designers and patients gain a better understanding of each other's perspective. By manipulating and interacting with the cards, communication is enabled and supported between the participants in the workshop.

4.3. *The co-creation of a prototype*

The collaborative prototyping activity (paper prototype) empowers participants to cooperate to create an mHealth design based on their own expectations and needs.

In that regard, the prototyping activity appears to be a form of mediated communication (Lucero, Vaajakallio, & Dalsgaard, 2012). The discussion centered around the prototype constitutes a "third space" where points of view are discussed, solutions are shared, and collective decisions are made. Consequently, during the prototyping session, the patients' voices are embedded in the design process (as illustrated by Figure 2).

Progressively, the patients are engaged to imagine a solution and materialize ideas. The utilization of various materials helps to concretize ideas and build artifacts. In this context, the design process is a reflective conversation between patients and the materials of the situation (Schön, 1988). By manipulating different types of materials (wireframes, icons, etc.), the patients explore, during the workshop, potential solutions (e.g. "thinking by doing"). The materials created (paper prototype) by the patients make sense progressively and encourage patients to reflect on functionalities or future uses of the technology. This dialogue with the materials takes form through sketches and paper prototypes, and patients are involved in a way of exploring potential future design concepts.

By using different techniques such as dialogue and interactive activities to co-create design prototypes, patients become progressively engaged in the design process, and are treated as real partners (rather than end users). The radical shift from consultation to engagement entails not only giving a voice to the patients but creating a space where patients "have a say" (Bratteteig, 2017). Yet, the ideas generated, the solutions proposed, and the decisions made about the future solution must also be embedded in the prototype that is co-created. In other words, patient engagement is incarnated and materialized in the prototype that speaks in their name.

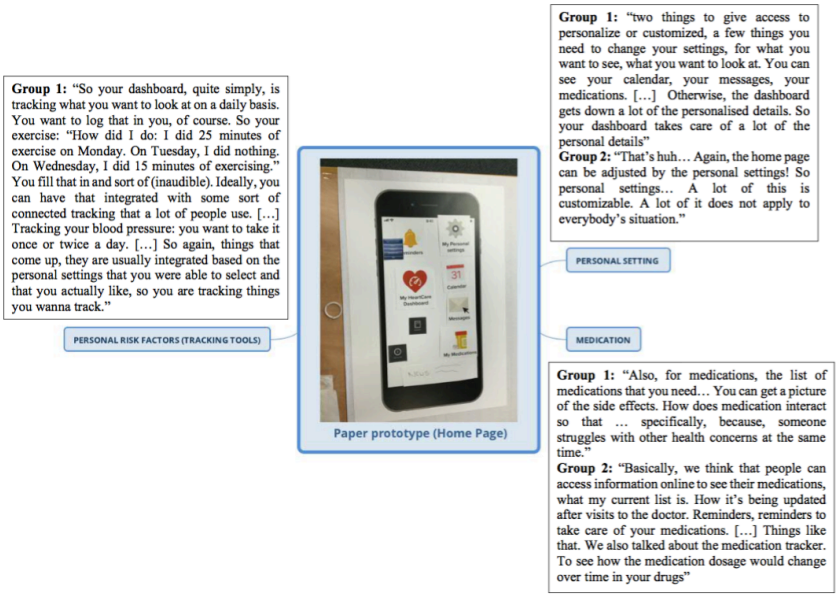


Figure 2. *Patients' voices embedded in the paper prototype*

Conclusion

In this study, our goal has been to describe patient engagement as an ongoing process throughout the design of an mHealth application. Specifically, we wanted to focus on communicative aspects of engagement. We use the term 'patient engagement in-the-making' to underline the progressive constitution of engagement through communication. Engagement is not a pre-existing state, we must be enacted during the workshop by using various tools and techniques. By talking, doing and making, the patients perform various acts of involvement during the workshop (e.g. sharing experiential knowledge, co-producing knowledge, making collective decisions, formulating requirements, creating solutions). The activities evolve from simple exercises (such as CARD sort) stimulating discussion to more demanding ones materializing ideas or future solutions (such as paper prototyping), which allows patients to take part in the design process, and to solidify their role as co-designers. By engaging in activities that rely on discursive and material practices, the patients are able to explore ideas and generate solutions.

Another finding from this study was that patient engagement evolved during the participatory design approach (from sharing lived experiences to producing collective knowledge and co-design prototypes). In the spirit of a participatory

design approach, patients were considered as co-designers[4]. Through the participatory design workshop, patients did get more and more involved by sharing their point of view and negotiating their preferences. They communicated their information needs based on their experience of surviving an MI event. As researchers, we were able to learn a lot from them: who they are, what their needs are, the emotions they experience on a daily basis, the concerns and preferences they have, etc. As mentioned above, patient engagement allowed us to better understand one's personal understanding of the disease. We did so by inviting participants to exchange with each other in a welcoming atmosphere, which involves a symmetrical relationship between stakeholders at the interpersonal level. As suggested by Lievrouw (2006), "Participatory design is both the means of designing usable and meaningful technologies as well as the outcome of successful systems. Participation and co-creation result in collaborative and distributed solutions tapping into people's perceptions, expectations, desires and motivations" (cited by Arslan 2016, p. 3). In Participatory Design, patient engagement has not been considered a prerequisite, but must be encouraged in different ways: by talking, doing, making and enacting.

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[4] Participatory or co-design approach is implemented by researchers from different countries (i.e. US, Canada, UK, Australia and European Countries) and is based on a fundamental principle: to create a collaborative partnership with the people destined to use healthcare services or eHealth technologies.

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