

A Model for Reflective Participatory Design - The Role of Participation, Voice and Space

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Abstract

This paper aims to contribute to the participatory tradition in health informatics by presenting a model for reflective participatory design emerging from qualitative fieldwork in a participatory project aimed to improve the health and wellbeing of older people in the northern periphery regions of Europe, through new mobile services. The model brings together two established processes in novel ways: systems development and user participation. Within each process three concepts are presented to facilitate discussion and reflection at the concept level, the process level and the integrated process level.

Keywords: Participatory Design, Space, Voice, Reflective model

Introduction

Participation has been a recurring theme in health-care practice since the 1960s (Katz et al., 2000, White, 2000). Implementation of participatory approaches in areas such as rehabilitation practice makes the patient a dialog partner and instead of being a passive receiver of care she/he can influence the design of services and products in health care (Katz and Alegria, 2009). Exploring the scope and extent of involving older people in research, age per se is not a barrier (Fudge et al. (2007) and participation can empower older people to become active in policies. The popularity of participation in academic circles varies depending on trends and policy endeavors, yet there is vagueness regarding what participation represents, its purpose and result, and how it has been stimulated (Gulliksen et al., 2003, Iivari and Iivari, 2010). This ambiguity is reinforced as traditional concepts of citizen, patient and user become replaced by those of customer, consumer and collaborator (Christensen, 2006, Clarke and Newman, 2005). This conceptual shift is partly related to the movement of person-centered care including features such as the extension of patient informed consent and balancing power inequalities between health professions and patients. However, concepts often come with baggage and “to be consumers, patients must have the necessary information to choose, and their choice must change service provision” (Tritter and McCallum, 2006, p. 161). It is important to be conscious of the connotations of concepts to avoid patient-centred care turning into the opposite - whereby citizenship becomes confused with consumerism (ibid). Therefore, it is crucial to take the concept of participation in all its different forms seriously (Bergvall-Kåreborn and Ståhlbröst, 2008, Ghaye et al., 2008) and reflect on its diversity when applied in practice.

This paper aims to contribute to the participatory tradition in health informatics by presenting a model for reflective participatory design emerging from qualitative fieldwork in a participatory project aimed to improve the health and wellbeing of older people in the northern periphery regions of Europe, through new mobile services. The model brings together two established processes in novel ways: systems

development and user participation. Within each process three concepts are presented to facilitate discussion and reflection at the concept level, the process level and the integrated process level.

In the subsequent section the user participation process with its three concepts, participation, voice and space are introduced, followed by a description of the MyHealth@Age project and the systems development process. Given the rich history of participatory projects in systems design (Bjerknes et al., 1987, Iivari and Iivari, 2010) the concepts, conceptualization, realization, and use, oriented within the IS discipline, are presented from an applied rather than a theoretical perspective. Next, the model for reflective participation is presented before ending with a summary and conclusion.

Participation, Voice and Space

In this section we discuss the concepts of participation, voice, and space, presenting various dimensions aimed at clarifying and conceptualizing the concepts.

Dimensions of Participation

The phenomena of user participation is renowned for diverse and multidimensional illustrations (Karat, 1997), which can result in a lack of clarity, thereby opening up the potential for misunderstandings. Over the years attempts have been made to reduce this confusion by building theoretically sound and verified concepts such as ‘participation’ and ‘involvement’ (Barki and Hartwick, 1989).

Some researchers such as Gulliksen et al. (2003) and Cavaye (1995) aim to clarify participation and its practice by defining the concept using a number of features or dimensions. In her analysis of published studies (1982-1992) Cavaye (1995) identifies six dimensions of participation: type of participation (the proportion of users that participate in the development), degree of participation (the level of responsibility), content of participation (the design focus), extent of participation (the type of system development activities the users participate in), formality of participation (the organizing approach), and influence of participation (the effect participation has on the direction and outcome of the process).

Since participation can be seen as the basis for related concepts such as involvement and influence, we apply the framework from Cavaye as a foundation for understanding user participation in the MyHealth@Age project. We have updated some of these dimensions to reflect contemporary changes in ICTs and to enable the conceptual framework to become more workable in a real-world setting. This provides the following six dimensions of participation:

Contributors of participation

More recently, the user concept has expanded and the boundary between user and developer become more permeable (Mackay et al., 2000, Millerand and Baker, 2009). Given the increased heterogeneity of user participants (Axelsson et al., 2010) it is important to reflect on the contributions that are expected from this stakeholder group (Brockhoff, 2003, Enkel et al., 2005). Therefore, Cavaye’s dimension “type of participation” will become “contributors of participation” to reflect these changes and allows us to consider participants as stakeholders and change agents (Markus and Mao, 2004).

Motivation of participation

There is one significant dimension that is absent from Cavaye’s research: motivation. While there can be numerous reasons why users participate, mainstream literature has focused predominantly on a management perspective (Brockhoff, 2003). Taking this perspective three common categories can be identified: 1) democracy, 2) learning and cooperation, and, 3) system quality and acceptance (Greenbaum,

1993b, Ives and Olson, 1984, Schuler and Namioka, 1993). However, the pervasive nature of ICTs, means users that voluntarily contribute are growing in number. If we hope to encourage participants to contribute based on personal incentive, it is important we understand what motivates people (Brockhoff, 2003, Ståhlbröst and Bergvall-Kåreborn, 2011, 2013). Examples of motivations here are: reimbursements, early access to future products and services, recognition for contributions, interest in innovation, new technology, or the application area. We therefore add a further dimension to Cavaye's framework: Motivation of participation.

Responsibility of participation

This was named "degree of participation" by Cavaye and refers to the level of responsibility of contributors. Since degree of participation can refer to many different things such as the activity level of participants, the degree of involvement, or the initiative and driving force of participants (Bergvall-Kåreborn and Ståhlbröst, 2008) we have renamed this dimension Responsibility of participation to better encapsulate its meaning.

Activities of participation

We have merged "content of participation" and "extent of participation" since the different MyHealth@Age project activities in which the contributors participate signals whether the content leans towards technical or social design. Following Markus and Mao (2004) we name these dimension activities of participation to indicate its focus on activities carried out by different contributors and the methods used. Clear demarcations regarding who contributes to which activities facilitates reflections on how this affects system success criteria.

The two remaining dimensions: **Formality of participation** and **Influence of participation** follow Cavaye (1995).

Dimensions of Voice

Communicative actions are the foundation for shared and mutual understanding (Habermas, 1995) and the basis for human interaction. Communication is essential for self-understanding as well as understanding the life-world and civic society that we live in. For this understanding to take place we need to invite different voices and facilitate the communication process in diverse ways. Reflecting on how to facilitate the communication process is important in systems design where professionals/experts interact with people who often lack expertise.

It is also important to reflect on how project contributors listen to the 'voice in the crack' (Mezzei, 2009, p. 48), i.e., the critical voices raised, the voices we do not understand or contradictory views and perspectives. If the distinct voices are not listened to and respected there is a danger that one single voice, seen as representing one single truth, becomes dominant (Guba and Lincoln, 2005). Hence the importance of reflecting on how the communication process can assist understanding between multitudes of voices.

Within ISD communication between stakeholders has long been identified as crucial for successful development (Churchman and Schainblatt, 1965, Martin and Fuerst, 1984). Despite this, Gallivan and Keil (2003) argue that the communication process between different contributors, especially developers and users, remains under-researched. Few studies have focused on how to facilitate communication where heterogeneous user contributors have been replaced by a purely need-based and use-oriented context, and where the possibilities for preparatory education are limited. As new types of development situations emerge, the importance of effective communication between developers and users is more crucial than ever. Wood & Wright (2011) suggest that many older people want to be involved, have their voice heard and to work in partnership with service providers.

Dimensions of Space

Both participation and voice are shaped within a certain space, so approaching participation democratically means creating and fostering a space where users can express their voice and be heard (Greenbaum, 1993a). To facilitate this, shared multi-dimensional spaces for emergent relations and

knowledge creation need to be designed (Nonaka and Konno, 1998) and can be in the form of physical space, virtual space, design space, or mental space.

Each space has its own boundary which includes two dimensions: placement, which involves a positional change in a boundary; and permeability, which represents the ease with which relevant information, behaviour, or presence leaks across a boundary (Shapiro, 1998).

One example of placement related to design space and mental space is the change occurring with participants' *weltanschauung* (Checkland and Davies, 1986) or worldview during the development process. Reflecting on hidden assumptions and value systems among the participants through structured dialogue is one effective way of uncovering peoples *weltanschauung* (Checkland and Scholes, 1999), giving project participants, including the older persons, a sense of "what matters" in their local moral worlds (Katz and Alegria, 2009).

The MyHealth@Age Case

The aim of the MyHealth@Age project (2008-2010) was to improve the health and wellbeing of the ageing population in the northern periphery regions of Europe (Sweden, Norway and Northern Ireland) by co-creating ICT-products and services that make it possible for them to sustain autonomous living and take a more active role in their own well-being. Drawing on Nolan et al. (2006) and their research on 'relationship-centered care', three key areas were identified for the project: mobile safety alarm, prescribed healthcare, and social networking. However, social networking never developed as a service (Bergvall-Kåreborn et al., 2010) and will therefore not be described in this paper. Following recent trends in health services (Tritter and McCallum, 2006) emphasizing public involvement and influence in development processes and decision making, the project invited potential users of the MyHealth@Age system as fully active participants, to enable them to influence healthcare and medical treatments relating to their well-being.

Project participants included: the project leader; older persons, health care professionals; ICT professionals from industry; and a multidisciplinary researcher team. Some of the older persons had been involved in previous projects; some were formally active in older peoples' organizations, and the majority had relevant medical history. The latter represent the target group of the proposed system and criteria included: age (55-85); gender mix, living conditions, location of living; stable physical and mental health; diversity in physical status such as high blood pressure, diabetes, history of or fear of falling and/or osteoporosis, transient ischemic attacks (TIA), overweight, and heart problems. In this respect, all the different user groups can be categorized as representative users (Mumford, 1979, 1981).

The Methodology and the Development Process

A methodology was required that placed patient/user needs as a central focus throughout, rather than involve users for the (early) system requirements. We also wanted to avoid using a methodology that was simply problem-oriented since the project aimed to find new products and services that could improve and support the lives of older people. Based on these criteria and our experiences from other project work, we selected the FormIT methodology (Bergvall-Kåreborn et al., 2008, Bergvall-Kåreborn et al., 2010).

FormIT is based on three key values which guide the development process. Firstly, change can occur only through changes in mental models, which implies the need to understand the various worldviews, interpretations, and the basis on which they are made. Secondly, recognize the possibilities embedded in the current situation and take necessary action to positively engage with others, so that outcomes unfold from the generative aspects of the current situation. Thirdly, ground system requirements on human needs, and keep a focus on needs throughout the development process.

Conceptualization of the System

To provide participants with an opportunity to shape the initial aims and scope of the project, three of the older participants were invited to participate in the writing of the research funding application with the academic partners. Through this we could initiate partnership and power sharing from the start of the project and move away from seeing the older persons as being *consulted* towards a model of greater *collaboration* (Robinson et al., 2012).

Following project approval, the first development activity focused on developing user needs, system requirements, and mock-ups to illustrate the basic functionality of the system. We continued with an open approach where the older persons were invited to participate in workshops and interviews to discuss their lives, needs and difficulties, as it is relatively easy for people to talk about their everyday experiences rather than suggest potential technological solutions (Patnaik and Becker, 1999). We also introduced cultural probes (Gaver et al., 1999) to enable the older persons to express themselves in different ways in their everyday context. This resulted in a collection of needs, the majority of which were related to health and well-being, but safety was also raised. These needs, together with needs identified in previous research studies, were verified and prioritized by the project group. To create transparency between user statements, defined user needs, system requirements, and system functionality, for all stakeholder groups, we created a diagrammatical representation linking the aspects together.

Realization of the System

As the project progressed the role of the older users shifted from boundary setting to content assessment. The different actors took on traditional roles and tasks (Axelsson et al., 2010, Cavaye, 1995), with the researchers and system developers translating the user needs into system requirements and the users assessing the requirements. At these meetings an initial boundary or space had already been created, but the users could modify this space by answering questionnaires researching the relevance, importance and functionality of the developed requirements and through active participation in the meetings.

Use of the System

The IT-based enhancement system developed for the project includes three services: prescribed healthcare support data collection of preventive health activities; medication support; and own medical diagnose measurement results. The data are visualized and shared between the elderly person and the healthcare staff. With the mobile safety alarm, alarm calls can be made wherever mobile network coverage is available and assistance staff can locate the person through GPS positioning. Alarm calls are made automatically via a fall sensor or by pushing an alarm button on the mobile phone.

At the end of the project the users tested the prototype for a few months and evaluated usability and usefulness. Users were very positive towards the usefulness of the prescribed health care and mobile safety alarm, suggesting they contributed to enhanced feelings of safety and well-being, with some creating daily routines around the health service. This is seen in statements like “using the system is like having your yearly check-up every day” and “I get up in the morning and that I go the round with myself and for myself”. Since the mobile safety alarm could not be used in full this service did not result in daily use and routines in the same way.

Finally, when the project results were presented publicly, many of the project participants, including older persons, researchers, care professionals and developers took part to showcase the results. The project was awarded a national prize for the user involvement process and the resulting services of the project.

A Model for Reflective Participatory Design

Reflection involves both projection and review and partly entails looking towards achieving our future goals as well as assessing past achievements. It is also important to reflect and respond in the moment, which is why improvisation is the third aspect of reflection (Ghaye, 2010).

Combining the two processes of systems development and user participation generated the model of reflective participatory design (figure 1). The model assumes that a change in one dimension will affect all the other five dimensions, as well as the central kernel. Using the metaphor of a kaleidoscope means that as each change is made, the central picture also changes. Disentangling important dimensions of the design and participation process facilitate reflection and debate about past and future activities and directions of a project. In the following sections three vignettes are selected to illustrate different types of participation.



Figure 1 A model for Reflective Participatory Design (the RPD model)

Testing the model for reflective participatory design

Using the RPD model for reflecting on and critically examining the project highlights a number of issues related to participation, including some persistent challenges and new lessons.

Integrating the two processes of development and participation

While numerous methods integrate the development and participatory process, the RPD model helped us reflect on how different concepts related to each other. For example, conceptualizing space as design space, we tried to open up the design process by inviting all participants to define the system boundary. One important aspect was the methods selected for the development and collaboration and so we strived to focus on ones that 'opened up' and 'broadened' opportunities for older people to authentically engage in decisions about mobile solutions affecting their health. This also meant that we placed voice in the wider communication context and reflects on different methods where users could express their voice in different ways. Therefore workshops and group interviews were mixed with individual interviews, questionnaires, and home assignments in order to take account of diverse preferences, communication media, and activity contexts.

Reflecting on the relation between space, voice and participation confirmed the importance of carrying out selected development activities in realistic contexts. Some of the needfinding activities were carried out by users in their everyday contexts since this is where they experience different needs, wants and challenges. We also wanted the use of the system to be realistic. There were also clear differences between the use of the prescribed health care and the safety alarm services due to differences in their realistic use and test situation.

Users as participants or users as partners

Initially, when the research group invited three of the older participants to participate in the writing of the research funding application, we hoped to initiate partnership and power sharing from the outset by facilitating the voice of the older people to be raised and heard (Robinson et al., 2012). Reflecting on this through the lens of the RPD model an alternative image also appeared since the older people participating in the application development were known to us from previous research projects. They were familiar with this type of project, the systems development process generally, and had developed relationships with some of the researchers. In this respect, they could be seen as expert user participants contributing to the conceptualization of the project. Had we considered this from the start of the project we would probably have also involved professional users in this activity.

Striving to regard the older participants as partners with equal voice and space in the project, we realized that had raised challenges due to the personal rather than occupational use context of the system, and the non-employment situation of the users. Considering the research application with the RPD model in mind

it became clear that older users were described as passive participants with no authority or responsibility assigned. There were no formal contracts developed with the older users clarifying their roles, responsibilities, provision of resources, or IPR rights. This meant that the older users had advisory responsibility in all development activities, except the purely technical tasks such as system integration. They also had a team-based, informal sign-off responsibility, but no juridical authority or responsibility. On a project level this meant that many sign-off responsibilities were treated in an informal, team-oriented manner. This resulted in the unspoken assumption that older users would not have time or interest to participate in this task and so were not invited to participate in some activities, such as requirements formulation. These examples illustrate the importance of considering the history inherent in different concepts when we move from design for users to design with or by users (Bergvall-Kåreborn and Ståhlbröst, 2008).

Who's voice is spoken

In our study there was a *tendency among the older persons to refer to the population of older persons rather than voicing their own needs and experiences*. This raises interesting questions such as whose voice different people listen to, the rationale for this, and the strengths and weaknesses of doing so. In our case this became problematic since we had invited different contributors' to secure multi-voices. We therefore encouraged the potential end-users of the system to speak of their own lived experience to "move beyond stereotypes" (Katz et al., 2000, p. 859) and adverse attitudes (ageism) towards older people (Katz et al, 2000) as well as facilitate accurate representative account of the older users, their user needs and system requirements.

The relation and conflict between system conceptualization and realization

Reflecting on whose voice was heard and *the space that different voices are allowed* was discussed in relation to the needfinding activities where the researchers wanted the older users to talk broadly about their living situation, their needs and experiences, while the project leader and system developers felt that this was not as relevant as defining the functional activities. Once the frustration had settled this resulted in a fruitful discussion about the project boundary, the difference between needs and requirements, the significance of context, and the importance of giving the users an accurate picture of the project.

Professional health and well-being activities permeating into the home

Reflecting on space also highlighted the permeability between the older persons' home and the health care organizations. With the MyHealth@Age system technology, routines and knowledge traditionally placed within health organizations now permeated the home environment. The project and the system also altered existing relations between health care professionals and their patients in the older user group. They also felt that the common virtual space created by the services reduced the distance between themselves and their doctor.

Conclusion

In this paper we have presented a model for reflective participatory design with the purpose of strengthening the participatory tradition in health informatics, by clarifying the concept of participation, and facilitating discussion and reflection on its practice. Illustrating the development process and the partaking process in two separate but integrated processes enabled us to move between the parts and the whole. It made it possible to understand the individual dimensions of the design and partaking process and relate these to each other and the development process as a whole. Disentangling important dimensions of the design and participation process facilitate reflection and debate about past and future activities and directions of a project.

Furthermore, reflecting on the three concepts: participation, space and voice in relation to ISD we see that while both participation and voice are concepts well represented in existing literature, space has received limited attention, except in relation to context (Beyer and Holtzblatt, 1997). Space is largely treated like a one-dimensional concept focused on physical space in the form of context. As we have illustrated, space - as well as participation and voice - needs to be designed. It is therefore important to start contemplating

issues such as the different dimensions of space, how they integrate in design situations, and how different types of space can facilitate or hinder participation and voice.

By amending some of Cavaye dimensions of participation we address Markus and Mao's call for a much finer grained conceptualization of users and actors (Markus and Mao, 2004) and facilitate reflection on the who and how of selecting contributors, motivational drivers for participating and expected contributions from different types of contributors. We also stressed the importance of reflecting on who should participate in which activities and what methods to use when carrying out these activities.

The model for reflective participatory design has mainly been used and tested among the Swedish project partners and might therefore include limitations from an international perspective. Had we used and tested the model on a project level, different perspectives could have surfaced. Taking an international perspective is probably most important in relation to space since this is less researched, so considering how space can be elaborated and incorporated in the design process is an important topic for future research.

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