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## Use of participatory design in the development of person-centred web-based support for persons with long-term illness

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### Abstract

**Background:** E-health solutions are increasingly being developed to meet patients' preferences and promote their participation in healthcare. Few studies have explored the participatory design process from the perspective of person-centeredness, including how it becomes materialized in technology. This paper explores how applied participatory approaches and the design of 4 web-based interventions directed towards long-term illness correspond to key areas of person-centeredness.

**Methods:** Data were collected during 2009 to 2012, from 4 Swedish research projects. The analysis followed an inductive approach involving a step-wise cross-case analysis. The purpose was to create shared knowledge and understanding of each separate case and to generate relevant categories.

**Results:** A number of question areas describe the dialogue with the case participants. Results of the dialogue are categorized into 4 support areas: psychological/emotional, personal, information and technical. Person-centeredness becomes visible in the participatory design process as the approach promotes the development of a holistic view of the person and the illness and a partnership between patients and carers. The use of communication technology exemplifies concrete materialization of person-centeredness in the design of the web-based supports. The purpose of the web supports and the shaping of the actual use of the functionalities are more abstract forms of materialization.

**Conclusions:** Our results contribute to a central development area within eHealth involving increased opportunities for patients to contribute actively in real time, obtaining access to information and sometimes interacting with carers. However, neither participatory approaches nor technology for online information and communication, can guarantee person-centeredness in isolation.

### Keywords

Communication technology, cross-care analysis, design process, e-Health, long-term illness, participatory design, patient empowerment, person-centered care, shared decision-making, therapeutic alliance, web-based support

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Accepted for publication: 16 January 2013

## Introduction

Recent scientific discussions about future eHealth development emphasize technology solutions that increasingly meet stakeholders' preferences, adding value to the patient's care trajectory [1,2] and serving as a more efficient resource in healthcare and to patients and their close friends and relatives. Part of this discussion concerns the development of web-based resources for patients with long-term illness [3,4] and how developers can capture peoples' needs and experiences to guide the specific design requirements [5,6]. Commentators have particularly stressed that patients themselves should be given the opportunity to participate in the development and with "such design approaches we are better able to customize the technology to individual preferences and user profiles" [7].

Lately, participatory design (PD) approaches have been shown to be a useful instrument in applying a more patient-centric design. In the development of web-based support for patients with chronic health conditions, PD has, for instance, successfully been used to design web-based self-care for patients with type 2 diabetes [7], peer-support on the web for patients with rare diagnoses [8], web resources for social support for breast cancer patients [9] and in development of e-therapy for patients with schizophrenia [10].

Even though earlier work is characterized by the intention to use PD to capture patients' needs, few studies analyse the development process and design results in relation to the emerging ideas of person-centered care (PCC). In short, the purpose of PCC is to capture the patient's subjective view of the illness in order to shape a care process and partnership with the patient based on the person's preferences [11,12]. In the search for more efficient and flexible web based support that can promote patients' own resources, the ideas of PCC become highly relevant. In addition, as PCC is a developing field mainly concerned with clinical settings, the presented work also contributes to PCC with examples from the diverse context of web support design.

Moreover, eHealth solutions are increasingly pointed out as key resources for healthcare to meet future challenges [1,2,13], the technology simultaneously being viewed as an opportunity to provide services that are more geared toward personal preferences [13]. In technological terms, it can be described as a carrier of person-centered ideas and, as such, calls for careful analyses from a PCC perspective in terms of how the design of technology and its use are shaped.

Consequently, the aim of this paper is to explore how the applied PD approaches and the developed web-based supports correspond to key areas of PCC. Two questions guided the analysis: 1) How can person-centeredness be materialized in the PD process? and 2) How can person-centeredness be materialized in the web-based supports? Further, while most studies of web support development in healthcare settings are single cases studies, this paper involves research work from 4 Swedish cases that includes

a variety of diagnoses, symptoms and ways of providing web-based support. This, we argue, contributes to a synthesis of experiences on a meta-level not yet described.

## Conceptual framework

The following introduces the conceptual areas of PD and PCC and how their specifics are applied in this paper.

### Participatory design

Participatory design originates from the idea that increased involvement of those affected by a particular change (social or technical) gives a more useful and accepted design outcome [14,15]. Central aspects of PD therefore concern increased democratisation and participation in decision-making for employees in workplaces. It is also believed that by actively involving the user in the change and development process, 'tacit knowledge' is more likely to be captured [15]. The involvement of the users and the drive to capture their true knowledge and ideas makes empowerment a core theme in PD for the design process as well as for the design outcome.

The role of empowerment in PD can take different expressions and focus on different aspects of the design process [16]. For instance, when design outcome is central, empowerment might concern ideas on how to improve the life conditions of a specific group of people through a PD approach. In other cases, empowerment is related to the design process and focuses on actual participation. Additional aspects of empowerment in PD that have been identified [16] concern the designers' possibilities to negotiate conditions for a participatory process.

In this paper, the ideas of PD are related to the design of web-based support for long-term illness. Here, we relate to empowerment firstly as a way of strengthening the position of the patients by involving them in the design process and, secondly, as a way of increasing the possibility of obtaining a highly useful result adapted to a specific health context. A core issue therefore concerns involving the people who will use the web support and learning about their needs and own resources in order to design solutions that meet the requirements of people with long-term illness.

The nature of user involvement in PD can, however, vary a great deal. At one end of the scale there is direct participation, in which the user is deeply involved not only in the design process, but also in the decision-making of the project. In such cases, the users become very active and the designers act more as participants who carefully guide the process [15]. At the other end of the scale, users are given a more consultative role and the main purpose is to check the design process.

In the work presented in this paper, user involvement is closer to the latter description, albeit with the user in a stronger position and there being several methods for collecting their views as well as particular focus on iterations in the design process.

## Person-centered care

In an effort to keep our focus on the person and on the idea of moving beyond the illness, we approach the use of participatory design in web support development from the perspective of PCC. This means focusing on the person from a wider perspective, but also being interested in reflective communication between patient and caregiver [17].

PCC is emerging as a field [11], but studies have been conducted with positive outcomes for elderly people with long-term illness and their relatives [18,19]. Due to its developing status, there is no consensus on an absolute definition of PCC. However, several commentators have captured what can be described as key areas or dimensions of PCC [20-23]. Common to these is the need to highlight the person and to consider him or her from a broader perspective than in terms of medical status alone. It is more about understanding the person's perspective and special needs and acknowledging that the person, despite health related limitations, is self-reflecting and capable of decision-making [23]. A key element, therefore, is to ensure understanding of the person's biography and everyday life, as well as their view on illness and health. This means that the illness and the ill person are considered from a larger and more holistic view, contrasting with a narrow (bio) medical perspective [22,23].

Other core issues involve shared power and responsibility with patients and efforts actively to involve them in the care process. Here, PCC focuses attention on issues relating to patients' empowerment and the nature of their participation in the development of their care process. The fostering, but also the maintenance of mechanisms for shared decision-making, is thus central to achieving the necessary conditions, from a holistic view of the person, for agreed decisions about treatment and care. This necessitates a dynamic, ethical relationship between the patient and the carer, where both parties are considered important in the process [23]. In the literature on person-centered care this is described in terms of the therapeutic alliance. Often the focus is on the relationship between the patient and healthcare professionals. However, in this paper, we use the term more broadly to involve not only healthcare professionals, but also others (such as peers, close friends and relatives) involved in the use of the web-based support.

This basis of PCC forms a useful background for exploring the usefulness of participatory design (PD) approaches in the development of person-centered web support. However, to guide the understanding of person-centered care further in this paper, we expand the concept and add work lately presented by Ekman and colleagues [11]. They emphasise the partnership with the patient and present thoughts on how to initiate, work with and safeguard the patient partnership in healthcare. Initiating the partnership refers to efforts to capture patients' stories of themselves and their everyday lives, as well as their personal views on health and illness and their expectations of care. Capturing the patient's narrative "constitutes the starting point for PCC and lays the ground for a

partnership in care" [11]. Working with the patient within such a partnership is about finding ways for collaboration between the patient and caregiver to establish shared decision-making based on the knowledge the patient has personally and the generic knowledge possessed by the carer. The patient narrative and outcomes of the shared decision-making should then be documented to secure the patient perspective throughout the care process. In this way, the documentation of the person-provider interplay becomes a means to safeguard the patient partnership.

This view of PCC is closely related to clinical practice and in-patient care and it focuses on the role of healthcare professionals as carers and their relationship with the patient. In contrast, we take the work of Ekman and colleagues into a new context characterized by the use of technology in everyday life. In this context, there are elements of prevention, emotional support, learning and long-term use of web-based support by patients and healthcare professionals, as well as by peers and close friends and relatives.

In summary, to capture the ideas of person-centered care, we depart from the existing realm of PCC work, expanding it with recent ideas about partnership in care and bringing it into the emerging field of web-support development. In our efforts, we identify 5 key areas of PCC that serve as an analytical tool for our exploration of the usefulness of PD in the development of person-centered web-based supports. In this paper, we understand PCC to be about creating conditions to initiate, work with and safeguard a patient partnership in order to: (i) Apply a holistic view of illness; (ii) Capture a holistic view of the person; (iii) Create shared decision-making; (iv) Develop and maintain a therapeutic alliance & (v) Document person-provider interplay.

## Methods

Data for this paper were collected from 4 Swedish regional and national research projects, also called 'cases'. Together, the cases form a larger joint project aiming to develop and evaluate a person-centered model of web-based learning and support for people with long-term illness. The presented work follows an inductive approach involving a gradual step-wise analysis [24,25] of the results from the included cases. This section presents the cases followed by a description of the step-wise analysis.

### The cases

Each case (Table 1) focused on a specific target group with long-term illnesses to investigate how interventions with person-centered web-based support can facilitate learning and increase wellbeing. The cases involve people of different ages (children, young adults and adults) and in different phases of life. The different groups were: 1) Pre-school children aged 4-6 with bladder dysfunction and urogenital malformation; 2) Women who have undergone surgery for breast cancer; 3) Women with diabetes type 1 who are pregnant or in early motherhood (up to infancy of

**Table 1 Characteristics of the four Swedish cases included**

	Case 1	Case 2	Case 3	Case 4
<i>Target group</i>	Pre-school children (age 4-6) with bladder dysfunction and urogenital malformation.	Women who have undergone surgery for breast cancer.	Women with Type 1 diabetes who are pregnant or in early motherhood (up to infancy of 6 months).	Young adults (age 16-25) living with mental illness.
<i>Participatory methods/approach</i>	<ul style="list-style-type: none"> <li>• Interviews and conversations</li> <li>• Dialogue with patients' association, stakeholders</li> <li>• Web-based survey</li> <li>• Text formatting/reviewing</li> </ul>	<ul style="list-style-type: none"> <li>• Focus-group</li> <li>• Dialogue with patients' association, stakeholders</li> <li>• Professionals, other researchers</li> <li>• Text formatting/reviewing</li> </ul>	<ul style="list-style-type: none"> <li>• Interviews</li> <li>• Focus group</li> <li>• Dialogue with stakeholders</li> <li>• Web-based survey</li> <li>• Text formatting/reviewing</li> </ul>	<ul style="list-style-type: none"> <li>• Interviews</li> <li>• Focus group</li> <li>• Dialogue and co-design with stakeholders</li> <li>• Web-based survey</li> <li>• Text formatting/reviewing</li> </ul>
<i>Web support</i>	Web support with specially developed themes of pictures and stories. Communication between children and a "web teacher" using Skype.	CD disk and web support with information and expert lectures on different topics (medical facts, and social and psychological aspects)	Web support for information, self-management tool for documentation and peer-support.	Web support for treatment, learning and self-care as well as peer and professional support.
<i>Design</i>	Consecutive selection with matched controls	Randomised controlled trial	Randomised controlled trial	Randomised controlled trial

6 months) and 4) Young adults (age 16-25) living with mental illness.

Common to the cases and their respective interventions was the provision of patients/users with information and opportunities for contact with peers or with healthcare professionals. Some interventions also support forms of documentation, such as health documentation for self-management or documentation in forum-logs.

A participatory design approach characterizes the development process, the idea of capturing the patients' own resources, needs, habits and experiences being central. To ensure a broad approach and to increase the opportunities to collect adequate design ideas, families, close friends and relatives and healthcare professionals participated in the process.

The applied PD approach involved the use of several methods for data collection [15,26]. Each one aimed to support the idea of involving the user to reach efficient and relevant person-centered web support. The following methods for data collection were applied:

- Focus-groups (involving patients and professionals)
- Interviews and dialogues with stakeholders (patients, close friends/relatives, professionals, patients' associations)
- Web-based survey (target group/presumptive users)
- Text formatting/reviewing

### Procedure for data collection and analysis

Since this research reports from a multiple case study [25], researchers from the various projects participated in the stepwise analysis. The purpose of the analysis was twofold. Firstly, it was about creating shared knowledge and understanding of each separate case. This was particularly important in order to identify differences and similarities, as well as to create a mutual understanding of key aspects. Secondly, the aim was to generate relevant categories (of the results and of the conceptual ideas of PCC) to support further work. This was performed by means of a cross-case analysis that involved the following 5 steps: 1) A first summary of the cases was developed. This was accomplished by interviews and data collection with researchers, in each case performed by a coordinating researcher not involved in any of the 4 cases. The description focused on target group, intervention and research design. 2) A tentative outline of the research material was then developed focusing on the applied PD methods, the used question areas (in interviews, surveys, focus groups and conversations), involved participants, types of identified support areas and how these areas become materialized in the web support design. The tentative description formed the basis for generating categories of question areas, support areas and design features of the web supports. The categories were developed, discussed and negotiated among the authors. 3) In the third step, refined project descriptions were developed that allowed a last adjustment of the categories and gave them their final labels. 4) The fourth step

included a description of the meaning of each category with key characteristics, scope and examples. 5) In the final step, the applied PD approaches and the actual design outcome of the web-based supports were analysed against key areas of person-centeredness.

## Results

The following section presents the types of questions used in the dialogue with patients to capture their requirements and expectations of web support, the areas of support revealed by the questions and, finally, how these areas materialize in the design of the web-based supports.

### Question areas to capture "the patient as a person"

The participatory design methods involved different forms of dialogue with the participants (such as semi-structured interviews, focus groups and conversations) and a number of themes describe the question areas that were used to fuel the dialogues (Table 2). The themes derive from the idea of capturing and understanding the participants' perspectives and their necessary requirements. This means the methods draw on the users' expressed knowledge, as well as their 'tacit knowledge' [15]. In addition, the choice of question areas was influenced by clinical experience of the various patient groups and from previous research exploring their needs. The following question areas were used:

- The person and relationships
- Everyday life, living with illness
- Current situation
- Emotions
- Body functions
- Experiences and consequences of illness in everyday life
- Wellbeing
- Information-seeking habits (online/offline)
- Desired information (in relation to illness and everyday life)
- Communicative support
  - Emotional
  - Social
  - Appraisal
- Design issues (for best online support)
- Future of daily living

Some of these question areas aimed to capture personal resources, preferences, relationships, feelings and experiences of the body and illness, as well as issues of daily life and wellbeing. Here, examples of questions the researchers asked were: "Can you tell us about your family?", "How does it feel when you get sad [or happy, or angry]?", "Can you describe your wellbeing during this time?" and "Can you describe your experiences (of the disease) and its consequences in daily life?"

**Table 2 Main question areas used in the four cases**

Case 1	Case 2	Case 3	Case 4
<ul style="list-style-type: none"> <li>• The person and relationships</li> <li>• Everyday life, living with illness</li> <li>• Emotions</li> <li>• Body functions</li> <li>• Illness experiences/Consequences of illness in everyday life</li> <li>• Information needs (in relation to illness and everyday life)</li> </ul>	<ul style="list-style-type: none"> <li>• Information-seeking behaviour (online/offline)</li> <li>• Information needs (in relation to illness and everyday life)</li> <li>• Design issues (for best online support)</li> </ul>	<ul style="list-style-type: none"> <li>• Everyday life, living with illness</li> <li>• Illness experiences/Consequences of illness in everyday life</li> <li>• Wellbeing</li> <li>• Information-seeking habits (online/offline)</li> <li>• Desired information (in relation to illness and childbearing)</li> <li>• Need of support (emotional, social)</li> <li>• Design issues (for best online support)</li> </ul>	<ul style="list-style-type: none"> <li>• The person and relationships</li> <li>• Everyday life, living with illness</li> <li>• Current situation</li> <li>• Emotions</li> <li>• Illness experiences/Consequences of illness in everyday life</li> <li>• Information-seeking behaviour (online/offline)</li> <li>• Need of support (emotional, social)</li> <li>• Information needs (in relation to illness and everyday life)</li> <li>• Design issues (for best online support)</li> <li>• Future</li> </ul>

Other areas of enquiry involved patterns of activities in relation to managing illness (such as information-seeking, web-based communication and strategies and habits for self-caring). To learn about this, the researcher asked questions such as “Who, or what is your main source of information?”, “How do you use the Internet - for information seeking or discuss with others?”

Further, questions were asked about different kinds of needs such as medical, social, psychological, or in relation to care. To capture this, participants answered questions such as “What might be the most difficult issue and what do you think is needed?”, “What might be the best help for you?” and “What are your needs for information and communication after surgery?”

Additionally, the researcher asked questions related to design and technical functionalities. These questions aimed to capture expectations of web support for illness management and included: “If you search for information online, how would you like the information to be presented?” and “To what extent do you find the 3 main functions (information/forum/documentation device) usable in managing your illness?” Some questions asked were a part of the iterative design process and involved questions about the ongoing development of the web-based support.

A final question area concerned future related issues and questions, such as “What do you think of the future?” or “What kind of support or help would be best for you?”

By means of the described question areas, a detailed picture of the participants was captured and the results can be described in terms of support areas further explained in the following section.

## Identified support areas

A multitude of different needs, expectations, ideas, resources and requirements became apparent and categorisation was required in order to manage the large volume of results. This led to 4 main categories describing central support areas:

- Psychological/emotional - related to the self and to the illness
- Personal - related to the specific everyday life situation of living with illness
- Information - related to illness and everyday life, living with illness
- Technical - related to technology use for contact (with healthcare professionals and peers), self-management, knowledge development, social/emotional support, and shared decision-making

The support areas are not fully separated as they sometimes include needs, experiences and resources, *etc.*, that extend across several categories. Nevertheless, the categories serve as a useful instrument in this paper to structure important areas for web-support development aiming to take the participants' experiences into account, meet their needs and strengthen their own resources. A relevant question, however, is how the supportive areas

materialize in the design of the web-based support. The next section elaborates on this.

## Support areas materialized in the web design

In general, it is noted that several technical functionalities in the developed web interventions serve multiple support areas and that the actual use and purpose of the functionalities determine what kind of support they provide. For instance, the web-based supports contain information resources such as web pages containing health specific information, links, or frequently asked questions (FAQ). Some of these resources are designed to meet psychological/emotional and personal needs, while others focus on generic knowledge development and increased empowerment (information).

In similar ways, functionalities for contact with peers or with healthcare professionals such as chat or discussion forums, online video/audio contact and e-mail serve different support areas. For example, online discussion with peers can provide emotional support (psychological/emotional) or recognition of everyday life experiences of living with illness. At the same time, the discussions can provide useful information on more practical and tangible topics.

Moreover, online contact with healthcare professionals may serve different purposes. This means that contact may sometimes be focused primarily on healthcare issues (information), while in other cases it may be more about issues of a psychological and emotional nature.

The needs for specific technical functionalities were materialized in 2 ways. One way, as described above, was through technical solutions that may now be considered common in supporting online contact and information. Another way was that the support area of technical functionalities became visible through specifically developed functionalities such as a self-care diary for illness management and visualization of measures.

However, it should be noted that some needs expressed by study participants were not possible to meet. To illustrate, in one of the cases, the researchers identified a need to allow care providers access to the patients' homepage. Due to strictly regulated laws on transferring patient data, this need could not be met and the patients were therefore encouraged to open their website themselves when visiting the clinic to discuss and evaluate the self-care documentation. In another case, the idea of conducting a discussion forum was not possible, as moderating the discussions was too demanding on resources.

## Discussion

Two main research questions guide the exploration of web-support development in this paper. The following provides an analysis of the questions in relation to the ideas of PCC as presented earlier.

Table 3 Summary of how the identified support areas become visible in the design of the web-based supports

Support areas	Case 1	Case 2	Case 3	Case 4
<b>Psychological/emotional</b>	Healthcare information from a child perspective and participation based on 3 themes: relations, integrity and body SKYPE conversation with web-teacher	Cancer specific information on the theme psychosocial support Support by professionals (study nurses and when needed by psychologists)	Diabetes specific information in relation to childbearing, divided into 3 childbearing phases: <ul style="list-style-type: none"> <li>• Being pregnant</li> <li>• Labor and childbirth</li> <li>• Life as a new mother</li> </ul> Links to other relevant sources	Health promotion Mental health information Chat with peers in relation to mental health. Facilities for contact with professionals
<b>Personal</b>	Healthcare information from a child perspective and participation based on 3 themes: relations, integrity and body SKYPE conversation with web-teacher	Cancer specific information Support by professionals (study nurses and when needed by psychologists)	Self-care diary Discussion forum divided into 3 childbearing phases: <ul style="list-style-type: none"> <li>• Being pregnant</li> <li>• Labor and childbirth</li> <li>• Life as a new mother</li> </ul>	Mental health information Chat with peers in relation to mental health. Facilities for contact with professionals
<b>Information</b>	The preschool web platform Library with different sections of themes; relations, integrity and body. SKYPE conversation	Cancer specific information divided in themes: early stages, what happens next, and psychosocial support and rehabilitation Information resources like world list, books, links and contact information to relevant healthcare providers Facilities for contact with the study nurses at each centre.	Diabetes specific information in relation to childbearing, Forum for frequently asked questions (FAQ) Contact information to relevant healthcare providers Links to other relevant sources	Online mental health information from the views of the participants in relation to their own functioning and to the surrounding social network.
<b>Technical</b>	The preschool web platform Library. Using pictures with a voice telling. SKYPE conversation	17 online lectures (power point slides) with an expert voice (patient, physicians, nurses, social worker and physiotherapist. The lectures range 10-20 minutes, total lecture time of 4 hours. Facilities for contact with the study nurses at each centre. Links to chat forum	Self-care diary Visualisation of measures and notes as support for self-evaluation and decision-making	E-mail contact with professionals Chat forum with peers Question-answering function.



## Person-centeredness materialized in the PD process

The first question concerns how person-centeredness can be materialized in the PD process. In order to meet the fundamental principle of user participation in PD [14,15], the cases at the centre of this paper applied different approaches such as semi-structured interviews, focus groups, surveys and conversations (Table 1). The overall aim was to capture and understand the patient/person situation from a broader perspective than mere diagnosis, the various forms for dialogue making visible participants' own resources, needs and experiences and evolving the picture of "the patient as a person" [21]. Different forms of support areas (such as emotional, social, practical, technical, or needs related to healthcare or daily life) were captured and the picture further developed by the involvement of additional stakeholders such as healthcare professionals, close friends and family.

On the one hand, these approaches can be described as adequate tools for capturing a *holistic view of illness and person* involving a larger perspective of illness and everyday life. On the other, in order to support person-centered ideas, PD demands careful formulation of the purpose of the web-based support, taking into account the target health context, since this affects the way the methods of PD could be applied. To illustrate, in one of the cases, the purpose was to create a web support for pre-school children (with bladder dysfunction/urogenital malformation) focusing on their emotions, self-esteem and experience of the body. In another case, the web support focus was pregnant women (or women in early motherhood, with type 1 diabetes) and how to provide them with adequate information and communication tools. Working with (small) children or adults placed different demands on the PD procedure. In the pre-school case, traditional interviews or focus groups were not an option and the developers had to find other ways to communicate with the children and to win their confidence. The importance of health context is further accentuated as the children suffered from illnesses that are stigmatizing. This implies that the specific context and diagnosis, as well as the purpose of the web support, exerted demands on adjusted PD approaches in order to form a detailed person-centred picture. In other words, PD does not create person-centeredness *per se*, but is more dependent on the design of the methods to capture a detailed and holistic view of illness and person.

In the cases under scrutiny, PD was also used to *create shared decision-making* between the person and carers. This is related to the idea of PD as a means to accomplish conditions for increased patient empowerment and influence [15,16]. The PD approaches were applied as a way of strengthening the patients' position, both in the development processes and by means of the design outcome. Technical functions for information and communications were worked out by applying the methods for dialogue and in this part of the process other stakeholders were also involved to further add detail to the

picture. The actual design of the web supports varied among the cases, however. For instance, in Case 2, the basis for shared decision-making is the patients' learning process and their need for information. The web design in this case thus focuses on facilities such as lectures and other forms of information on different subjects related to the illness. In Case 4, the information resources were combined with provision for online contact with the support team by chat forum or e-mail. In Case 1, the target group was pre-school children and here developers had to work with alternative ways for communication such as specifically designed pictures and online contact using both audio and video (Skype). The need and ability actively to participate in decision-making varied among the cases, demonstrating that PD placed high demands on developers to adequately adjust methods to capture different perspectives and varying preferences.

As a component of PCC, shared decision-making is closely related to the ideas of the *development and maintenance of the therapeutic alliance*. In the reviewed cases, the overall aim was to create web-based support that would strengthen the patient in his or her contact with carers (and others) in different ways. Nevertheless, the specific idea pertaining to creating necessary conditions for the therapeutic alliance varied by case, where the carer becoming more of a mentor/supporter for the patients at one end of the scale, or being guided by the idea of teaching the patient at the other. The types of questions asked during interviews, in focus groups, or in conversations therefore varied. Again, this brings attention to the importance of the design of the PD methods to serve person-centered ideas.

Shared decision-making and the maintenance of the therapeutic alliance are part of the partnership with the patient. As a way of safeguarding the partnership, Ekman *et al.* [11] stress the need to *document the person-provider interplay*. As PD approaches provide for user involvement, the researchers and developers in each case have captured how the documentation could be designed to meet the needs of the different patient groups. At the same time, the purpose of each web support and the target diagnosis has guided the design of support for documentation. For instance, in one of the cases, documentation was particularly important due to the characteristics of the diagnosis (type 1 diabetes), demanding daily documentation. In this case, the various PD approaches used, involving patients and other stakeholders as well, revealed a need for several functionalities for self-care documentation. In other cases, patient needs and the purpose of the web support were somewhat different, leading to the design of more traditional forms of patient documentation in electronic patient records (Case 1).

In summary, the results of the 4 cases propose that person-centeredness can be materialized in the PD process by different forms of dialogue, carefully considering the target group, as well as the actual purpose of the web-based support.

Table 4 How person-centeredness is implemented in the web-based supports

	Case 1	Case 2	Case 3	Case 4
<i>Apply a holistic view of illness</i>	<ul style="list-style-type: none"> <li>Through the purpose of the web-based support</li> </ul>	<ul style="list-style-type: none"> <li>Through the purpose of the web-based support?</li> <li>Links to chat forum</li> </ul>	<ul style="list-style-type: none"> <li>Through the purpose of the web-based support</li> <li>Discussion forum</li> <li>Tools for self-management</li> <li>Links to other sources</li> </ul>	<ul style="list-style-type: none"> <li>Through the purpose of the web-based support</li> <li>Chat forum</li> <li>E-mail</li> </ul>
<i>Capture a holistic view of the person</i>	<ul style="list-style-type: none"> <li>Communication online (Skype) supported by pictures on different themes.</li> </ul>		<ul style="list-style-type: none"> <li>Tools for self-management</li> <li>Discussion forum</li> <li>Links to other sources</li> </ul>	<ul style="list-style-type: none"> <li>Chat forum</li> <li>E-mail</li> <li>Link to other sources</li> </ul>
<i>Create shared decision-making</i>	<ul style="list-style-type: none"> <li>Communication online (Skype) supported by pictures on different themes.</li> </ul>	<ul style="list-style-type: none"> <li>Tools for information on different themes</li> <li>Contact information to relevant healthcare providers</li> </ul>	<ul style="list-style-type: none"> <li>FAQ</li> <li>Question/answering tool</li> <li>Tools for information on different themes</li> <li>Tools for self-management</li> </ul>	<ul style="list-style-type: none"> <li>Tools for information on different themes</li> <li>Chat forum</li> <li>E-mail</li> <li>FAQ</li> </ul>
<i>Develop and maintain a therapeutic alliance</i>	<ul style="list-style-type: none"> <li>Communication online (Skype) supported by pictures on different themes.</li> </ul>	<ul style="list-style-type: none"> <li>Tools for information on different themes</li> <li>Contact information to relevant healthcare providers</li> </ul>	<ul style="list-style-type: none"> <li>Tools for self-management</li> </ul>	<ul style="list-style-type: none"> <li>E-mail</li> </ul>
<i>Document person-provider interplay</i>	<ul style="list-style-type: none"> <li>Notes in the patient record</li> </ul>		<ul style="list-style-type: none"> <li>Tools for self-management</li> </ul>	<ul style="list-style-type: none"> <li>Chat forum</li> <li>E-mail</li> </ul>

## Person-centeredness materialized in the web support

The second research question of this paper concerns how person-centeredness can be materialized in the developed web-based supports (Table 4 provides an overview of each case). Here, this is considered from a concrete as well as a more abstract perspective. For example, different functionalities for communication (such as the use of Skype, chat forum, e-mail, or discussion boards) make person-centeredness visible in a concrete and tangible way. These technology features give the patients (and others close to them) the opportunity to express themselves and share experiences. At the same time, the picture of the “patient-as-person” emerges. Here, the idea of applying *a holistic view of the person and the illness* becomes visible. When the functionalities for communication include contact with healthcare professionals, they materialize person-centred ideas of *shared decision-making and development and maintenance of the therapeutic alliance*.

Further, the web based supports contain a lot of information on different themes related to the illness and everyday life. This supports learning and knowledge development in various ways and adds tangibly to the patients’ abilities to participate in shared decision-making in the care process.

Other examples of concrete person-centeredness in design relate to tools for self-management. These functionalities relate to the idea of *documenting person-provider interplay*. At the same time they contribute to the ideas of *shared decision-making and development and maintenance of the therapeutic alliance*. Together, these design features become important tools to safeguard the partnership with the patient [11].

Further, the examples of concrete materialization of person-centeredness in the cases are characterized by the use of commonly employed technologies for information and communication (e.g., e-mail, discussion forums and chat forum). Technologies meeting specific person-centered needs (e.g., self-management tools and tools for communication with small children) were more rarely developed.

The abstract dimension of how person-centeredness is materialized firstly relates to the specific purpose of the web-based support. This means that even if person-centered ideas have permeated the development of the web-based supports, it is the purpose and actual use of the functionalities that determine the person-centeredness. To illustrate, having the purpose of supporting participants’ learning and knowledge development is likely to engage a stronger focus on person-centered ideas related to shared decision-making and somewhat less focus on functionalities capturing a holistic view of the person. Similarly, the materialization of person-centeredness is affected if the web-based support aims to promote the person’s own resources by strengthening self identity and understanding of body functions.

Secondly, the abstract dimension concerns the actual use of the technology. This means that the shaping of the use of the functionalities need attention. For instance, in

using e-mail or a Skype connection for communication between patients and carers, it is what people talk about and how they do it that determine the person-centeredness, not the technical functionality itself.

Moreover, there is a risk of capturing person-centered needs that cannot be materialized for some reason. Regulations, technology, limited resources or other reasons can sometimes reduce the possibilities to materialize person-centeredness in the design. This indicates that development of person-centered web based support requires special attention in managing limitations of the person-centeredness and communicating them with the stakeholders involved.

To summarize, the work in this paper suggests that person-centeredness materializes in concrete as well as in abstract forms of the design. Both forms are, however, guided by the specific purpose of the web-based support, as well as the actual use of the technology.

## Conclusion

PD approaches provide possibilities to move beyond the illness and increase our understanding of people’s experiences of illness in a more holistic manner. However, PD *per se* is not a guarantee for person-centeredness. The work presented in this paper shows that in order for person-centeredness to materialize in the PD process, different forms of dialogue are required. In these dialogues, developers need carefully to consider the target group, as well as the actual purpose of the web-based support.

Further, the work suggests that the use of certain information and communication technology to support patient participation and illness management does not bring person-centeredness by itself. The use of e-mail, discussion forums, chat forum and web technology for video and audio exemplifies concrete materialization of person-centeredness in the design of the web-based supports. The purpose of the web supports and the shaping of the actual use of the functionalities are more abstract forms of materialization.

A limitation of the work presented here is that the 4 separate cases have slightly different starting points, directions and stages. Bringing together the outcomes puts demands on the meta-level analysis of the results. This paper is a first attempt to manage this precision which might affect the depth of the analysis. Nevertheless, the paper highlights important aspects of the emergence of person-centeredness outside clinical practice and inpatient care, an area in need of further investigation. In addition, the work presented here points to a central development area within eHealth, involving greater opportunities for the patient to actively contribute in real time, getting access to and adding information and interacting directly with carers.

## Acknowledgements & Conflicts of Interest

This work was supported by the University of Gothenburg Centre for Person-Centred Care (GPCC). IS, MB, A-LH, AR, MJN, CS-L, IK, and UJ were responsible for identifying the underlying structure of the paper. CS-L and UJ drafted this manuscript, which was reviewed by all authors. All authors read and approved the final manuscript. The authors declare that they have no competing interests.

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