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# USER INVOLVEMENT IN DESIGN OF HEALTH CARE SERVICES

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## ABSTRACT

During the last decade, industrial designers have entered the arena for design of health care services in cooperation with health professionals. Parallel to this, user involvement has been recognised as an important part of quality improvement work in health care, acknowledging that users have their own type of expertise. This has resulted in an increased focus on involvement of users in both evaluation and design of new services. User involvement is an important aspect in both a health care and a human-centred design context. However, neither of the fields have "one good reason" nor do they have "one best way" to do it. This article explores and compares user involvement in the two fields.

*Keywords: Health care design, service design, health technology, user involvement, consumer involvement, design for welfare, patient involvement, user-centred design.*

## 1 INTRODUCTION

There are several factors calling for changes in health care services. Global shifts in population demographics make people question how it is possible to deliver health care services of good quality within the national budgets. The views on health and what defines good quality of health care are changing from disease-oriented models to more holistic approaches focusing on factors that support human wellbeing[1]. At the same time politicians world-wide want to increase the user-friendliness of the health care services and give the users a voice in the development process [2]. Design thinking and "designerly" ways of working have been announced as approaches that could find new and creative solutions in health care [3, 4]. This has resulted in an increasing number of designers participating in projects in the health care context. Designers and health care professionals share a focus on the users, but the views on users and how they should be involved differ considerably. But for effective multidisciplinary cooperation it is important to have a common understanding of central concepts, like who are the users, how should they be involved in the process, and are there other equally important stakeholders. This article seeks to answer these questions based on a literature review in two different fields, human-centred design and health care.

## 2 USER INVOLVEMENT IN A HUMAN-CENTRED DESIGN CONTEXT

User involvement is often used synonymously with terms like: "focus on users", "consulting end-users", "contacting with system" and "participation of users" [5]. It is not a question of involving users or not, the focus in literature seems to be on understanding when and how the users have a place in the process, and which role the designer should take[6]. In a design context, the term "user" would commonly refer to people using a product or a service [1, 6]. In the case of health care services this might refer to patients, as well as carers, relatives, and health professionals. In order to differentiate between types of users, one often refers to primary, secondary and tertiary users. Primary users are the ones hands-on with the products or services. Secondary users use the product/service through a mediator. Tertiary users are people affected by the product/services and who might influence the purchase [6]. In business inspired approaches, users may be classified as lead users and end users. Similarly customer and consumer refer to users as purchasers of the products/services or at least the ones choosing between alternatives.

## 2.1 Why user involvement in a human-centred design context?

A simplified overview over user involvement in a human-centred design context is given in Figure 1. highlighting critical questions in different phases of a design process. Most designers do involve users to some extent [6], especially in the early stages of the process. Though it is debated to which degree processes with user involvement could lead to disruptive innovations as opposed to incremental innovations [11], research also indicates that users need to be far more involved in cases of high task or system complexity [7]. Verganti [10] proposes that designers should only know the existing context and solutions to a limited extent in order to be truly creative and create something new. Users do not necessarily know their own need or would know how to create something new and visionary. This is often referred to as design without users.

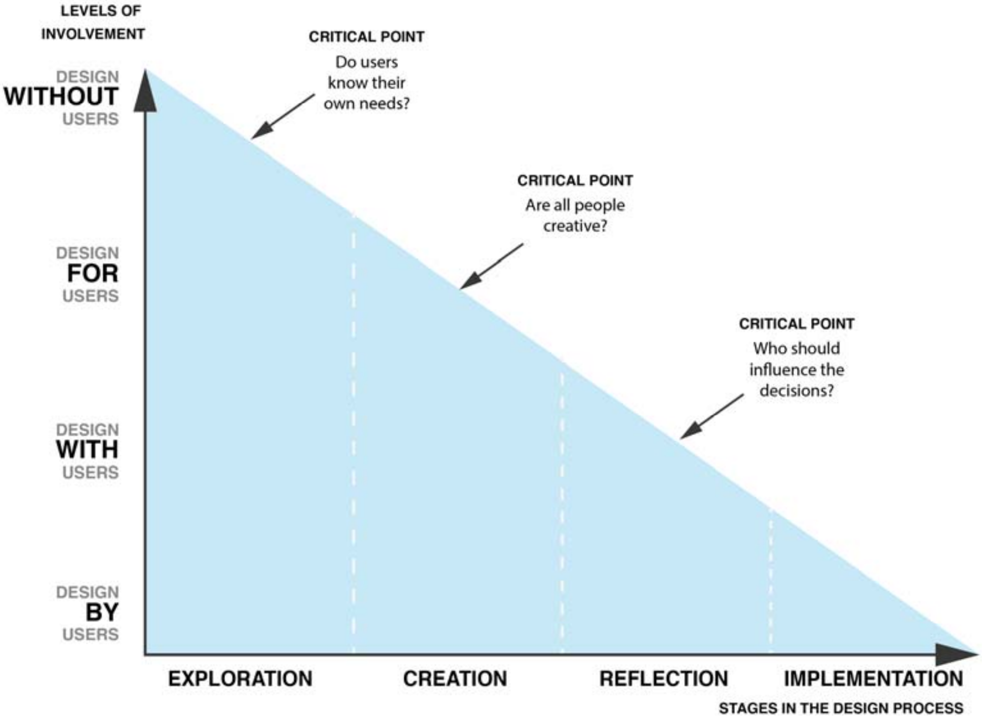

*Figure 1. Simplified illustration of user involvement in a human-centred design process.*

User-centred design approaches aim to make useful and usable products [7], and in order to do so they have an early focus in their process on users and tasks. The intended users are observed both in their real settings, confronted with prototypes, and to some extent interviewed by the designers. This could be seen as design for users. Designers differ in their view on whether people that are non-designers could be creative [6,8], and to which extent they could envision and create new solutions. As well as some believe that non-designers cannot envision future alternatives and solutions, others see everyone as creative. Approaches that see non-designers as creative would often invite users and stakeholders into the design process. This could be seen as design with users. To some extent it might even be the users that eventually design the product, resulting in design by users. One approach that embraces all people as creative is participatory design. “All people are creative, but not all people become designers”[8]

Co-design involves methods where different type of users and stakeholders can cooperate creatively and explore new opportunities [6]. Users are treated as experts with their own experiential knowledge and thereby an important asset in the design process [8]. The designers would support the user by providing tools for ideation and expression. The designer would still play a critical role in giving form to the ideas. Some take the co-creation process even further and suggest making toolkits that make lay people able to develop, modify and customize their own products [12]. Even though user involvement is considered to be somehow costly initially in a project, there are several economic benefits seen in these kinds of projects [5]. Further on it has shown to decrease training costs as well as the need of user support in the implementation stages. When designing services it is thought to ease the change process if the new solutions are proper anchored in the culture and organization [13]. The communication between developers and users may be challenging some times, and in some cases users has begun to request that changes be made to the system after being involved in development projects.

### 2.2 How is user involvement practiced today in a human-centred design context?

A design process typically starts with exploration of existing solutions and context. In order to understand users implicit and non-verbal needs field studies could be effective [8]. Some are concerned that designers will get prejudiced about user need when involving them to frequently [9], and that paying too much attention to the user may erode designer abilities to envision creative solutions [14]. A central question in this stage is to balance the individuals experience to what is relevant for all people, as well as balancing need of existing users with future users. Polaine et al emphasize the importance of using qualitative methods, together with quantitative methods. Qualitative methods often zoom in on a few individuals, while the quantitative methods may give you a better overall picture [15].

The next step is to create possible solutions based on the insight from the exploration. In order to reflect around the new solutions it is possible to test and prototype them. A central concern is to envision these solutions in a realistic and future context. Physical products can be tested by users with prototypes, but prototyping services is more complicated. When it comes to decisions, power is exercised and some actors have more agency in the decision-making process than others [6]. Implementation of new solutions is not the stage with most focus in design literature. When the new design is a service this could imply both changes in organizations and in technology [13]. Involving users earlier in the process, as well as using the insight when creating new solutions it is believed to give higher acceptance [13].

## 3 USER INVOLVEMENT IN A HEALTH CARE CONTEXT

The importance of user involvement in health care services is widely recognized. This applies to all levels: from the individuals own right to influence the treatment or care they receive, to the development of policies on national and global levels [16]. The methods used and reasons to for user involvement are diverse [19]. Most western governments emphasize the involvement of service users in their policies, but there seems to be a gap between these expectations and the work which is carried out on a service level [4, 18]. This might be due to lack of research on impact and actual outcomes of user involvement [18]. As Arnstein, put it more than 30 years ago: “ The idea of citizen participation is a little like eating spinach: no one is against it in principle because it is good for you. “ [19]

The users of health care services are named by a range of labels according to the context [17]. Generally “user” refers to persons on the receiving end of health care services. In literature their labels are linked to the underlying models and research frames [17]. Patient is widely used [20], as well as consumer and service user [16]. This article will refer to all these groups as “user”.

### 3.1 Why user involvement in design of health care services?

Involving users is believed to increase the quality of care and lower the cost[20]. Give more accessible services through simplifying appointment procedures, extending opening hours, improving transport to treatment units and improving access for people with disabilities [20].

The two main approaches to user involvement in health care services are termed the “democratic” and the “consumerist” model [21]. Internationally consumerism is a model that is getting widely recognized in health care. The central idea is that everyone knows what is best for him or her, and when provided with choices on which services to choose they would spend their resources on the best possible option. The consumerist model is closely connected to “patient-choices” which encourages welfare states to let the users themselves choose between treatment options and thereby making the users consumers. The users do not always want these choices, and the critics point out that health systems are based on needs not on wants [22], but these arguments and beliefs seemed to be central in legislations world-wide. The democratic model sees user involvement as a democratic and ethical right. The health services are for the public, and as their users you have the right and duty to participate [23].

The last decade user involvement has been recognized as a central part of quality improvement work [4]. This is based on the belief that health care users are in a possession of an experiential knowledge that is essential for understanding and improving quality of health services. This knowledge is something you possess after a direct and personal experience with the services [17]. Research also shows that health professionals and service users differ in their view on what are the most important indicators for good quality of care [16]. In order to enhance the quality of the services it is pointed out that user involvement should not be carried out as a separate activity, but should be linked together with the other quality and assuring systems [16]. User knowledge should not be considered a rival, but a part of the overall evidence system [17]. Incorporating the user view on good quality of care could be seen as a power shift from the health care professionals towards the patients, but the responsibility of choosing the right measures and solutions is still with the service providers. Involvements of users have also been thought to improve the actual health outcome, and thereby giving still another reason for user involvement.

### 3.2 How is user involvement practiced today in design of health care services?

WHO classifies measures to support user involvement into three categories: choice, voice and representation [23]. Choice is the individual's opportunity to choose between service providers and treatment options. Voice are measures that give groups and individuals the possibility to provide feedback and engage in redesigning services. Representation means user representatives in boards and committees.

Relating to Figure 1, user involvement in health care development is usually carried out in the first phase of a development process and with the aim of gaining insight in order to design for users in mind. Mainly by letting service developers get insight into user views by user satisfaction surveys. User satisfactions surveys have a long history in the health care context [16]. This tool makes it possible to get quantitative measurements on larger groups of users. It is however questioned what these surveys actually measure. [16]. Whether users are evaluating their own health outcome or the service provided, or whether they are reporting their services or rating them in a way and not all institutions have the adequate systems for coordinating survey data with their quality improvement work[4]. It is considered a common failure that there is an inability to use the findings to improve services [16].

Whilst user satisfaction surveys could be considered insight material for service developers, the level of involvement also increases, by including user representatives in projects and board meetings [20]. User representatives are users with experiences from the health care services themselves, and often with chronic or long-term conditions. Often the same persons represent users in more projects and boards and there are concerns whether they take over the health care professionals' worldview after a while [24]. Some places user representatives receive training in order to get a broader understanding of the services. There is little evidence that the inputs from the users are used in the actual decision-making, and they are usually asked questions about pre-existing agendas. It has been questioned whether user input only is used to legitimise decisions that would have been made without them [24]. It is also claimed that managers and health professionals are "drawing selectively and strategically on user views" arguing with their assumption that only some of the user views are relevant do to the questions around representativeness. Health conditions may make it difficult to be involved [16] and some users do not even want to be involved. Other times it is ethically questionable to involve users if they e.g. do not have much more time to live. There is still a gap between policy makers' expectations and the actual involvement that take place today. In order to close that gap there is a demand for new knowledge and culture to support user involvement and tools to use user experience in quality improvement work [4].

## 4 DISCUSSION

User involvement is an important aspect in both health care and human-centred design, but for effective cooperation reflections around the different views and reasons to practice it are important [5]. Neither of the fields have "one good reason" nor do they have "one best way" for user involvement. Whilst the user in a health care context usually refers to the person receiving care, whether named patient, client or consumer, the designers' user relates to a broader range of people. Designers seem to have a stronger tradition on a more active user role in their projects. Both in levels of involvement and in which stages the users are involved. This is especially true in approaches that embrace the user as not only an important expert in their fields and context, but recognize them as egalitarian partners in the creation process. However there are some interesting nuances that are visible when we look closer at which “users” that would normally take an active part in e.g. service design project [25].

In health care there is considered to be a lack of knowledge on how to bring user research into service development [3]. Designer’s on the other hand emphasize on the creation and reflection stages in the process, areas that are not covered in health care literature. Designers do not agree whether the user can be the one having ideas on the future alternatives, or whether they could only be involved as a source of inspiration. This has a parallel in health care where there are different views on whether the user should be consulted, be considered partners or even the ones in charge in the service development process. As well as designers have to balance their own knowledge and ideas with the users’ knowledge and ideas, health professionals have to balance their knowledge with their users’ knowledge. Some of the main concerns of user involvement in practice are shared between the two fields. First of all it is a balance between understanding the broader perspective by listening to individual experiences, and secondly to ensure that insight from exploration could be used in development of new services. Thirdly is to decide which voice to listen to in decision-making, and fourthly the entire process depends on the willingness in the organization to accept and put-to-life the proposed changes.

The health care context is considered evidence demanding. You might question how tools as storytelling and sharing of individuals stories will be seen by health professionals already annoyed by users being too subjective [6]. In health care user involvement is not only a tool and a method of improving the quality of services, it is also a right by law, and governmental legislations are emphasizing a more active role of the user – here the patient. Would this have any impact on how we as designers should approach user involvement in a health care context? When designers enter the health care context with own approaches to user involvement it is helpful to them to understand the existing traditions and approaches that are in use today. This might even facilitate the reflectiveness around your own role as designer and which methods and tools to use, as Steen asks for [6].

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