

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. In these processes, concern for the users is central, but the views on users and how they should be involved differ considerably. Traditionally in development of health care services there are two main approaches to user involvement; the “democratic” and the “consumerist”. User insight is based on “user satisfactions surveys” or by having user representatives in boards or similar management functions. The last decade, however, user involvement has been recognised as an important part of quality improvement work, acknowledging that users have their own type of expertise. This has resulted in an increased focus on involvement of users in evaluation and design of new services. In a design process the users tend to be more directly involved and even considered creative partners in the design process. This may lead to a tension between understanding the existing conditions contra exploring and envisioning alternatives. 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, user involvement, consumer involvement, design for welfare, patient involvement, human-centred design

1. INTRODUCTION

There are several factors calling for a change in health care services. Global shifts in population demographics make people question how it is possible to deliver health care services of good quality without eating up too much of the national budgets [1]. The views on health and what good quality of health care would be are changing from disease-oriented models to more holistic approaches focusing on factors that support human wellbeing[2]. At the same time politicians world-wide wants to increase the user-friendliness of the health care services and give the users a voice in the development process [3]. This has resulted in an increasing demand for new answers to these complex and wicked problems.

Design thinking and “designerly” ways of working have been announced as approaches that could find new and creative solutions in health care [4, 5]. This has resulted in an increasing number of designers participating in projects in the health care context.

As an industrial design student I have been focusing on health care services in my latest projects. Recently I got the opportunity to be part of a multidisciplinary team working with technology and service development. Despite the diverse background of the team-members; all seemed to share my belief that people are at the core of the health care services. But after discussions about «user needs» and «user involvement», terms close to my heart, I realized that we had quite different understandings of

what this would imply. This complicated our process and when discussing how to approach this project I found myself at a loss of good arguments. Their “users” weren’t even the same as mine. Did we at all have anything in common?

As illustrated in the story above, designers and people working with health care services have a shared focus on the users, but the views on them and how they should be involved differ considerably. But for effective multidisciplinary cooperation it is important to have a common understanding of central concepts[6], like who are the users, how should they be involved in the process, and are there other equally important stakeholders. In this article I seek to answer these questions based on a literature review in two different fields, human-centred design and health care.

2. USER AND USER INVOLVEMENT IN A HUMAN-CENTRED DESIGN CONTEXT

User involvement in a human-centred design context can be seen as the general term describing direct contact with users and are approached in many different ways. It most often relates to direct contact with users during the design process [7]. This is often used synonymously with sentences like: “focus on users”, “consulting end-users”, “contacting with system” and “participation of users” [8].

Whilst the question of whether or not we should include the user at all in the process seem to be non-existing in human-centred design approaches, the focus in literature seems to be more on understand when and how the users have a place in the process, and which role the designer should take[9, 10].

2.1 Who are considered the “users” in a human-centred design context?

The term “user” in a design context would most commonly be referring to people using a product or a service [2, 10]. In health care services this might both refer to patients, as well as carers,

relatives, health professionals and other stakeholders. In order to differentiate between different types of users, some may refer to them as primary, secondary and tertiary users. Primary users are the ones hands-on the products/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[11]. In business theory related approaches, users may be classified as lead users and end users. Lead users are pioneers for a product/service, whilst end users are all people ending up on using the product/service later on [12]. Other terms used in a business related context are customer and consumer. Referring to users as the one buying products/services [13] or at least choosing between alternatives.

2.2. Why user involvement in a human-centred design context?

Lack of an adequate understanding of people’s needs and preferences is considered a key factor in the failure of innovation[14, 15]. As mentioned earlier most human-centred designers embrace the involvement of users in their process. Their ways to do this depends on several factors like motivation and understanding of the user, and this is resulting in different levels of involvement, as well as differences in where in the process user involvement are considered essential. Different products and services may demand different approaches. A simplified overview over user involvement in a human-centred design context is given in illustration 1, and the terms used there would be explored further on.

Some design approaches, as described by Verganti (16) believe that designers should only look upon the existing context and solutions with limitations 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**.

Most designers do involve users to some extent[10], especially in the early stages of the

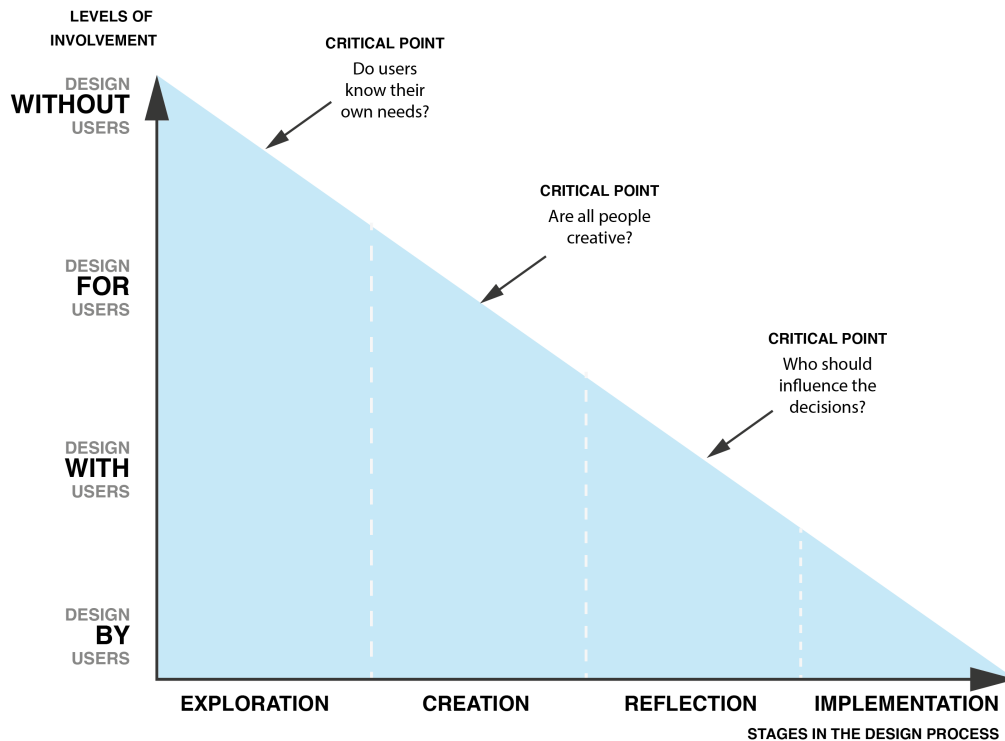


Illustration 1: Simplified illustration of user involvement in a human-centred design process

process. Though it is debated to which degree processes with user involvement could lead to disruptive innovations as opposed to incremental innovations [17]., research is indicating that users need to be far more involved in cases of high task or system complexity [8].

User-centred design approaches have the goal to make useful and usable products [8], 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 as well as with prototypes, and to some extent interviewed by the designers. The designers use this information to create new solutions. This could be seen as **design for users**.

The designers also differ in their view on whether people that are non-designers could be creative [10, 13], 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. However not all of them takes the roles as designers. As Sanders and Stappers (13) sees it: “All people are creative, but not all people become designers”. Participatory design is typically oriented towards concerns for democracy and emancipation [10]. Three different motivations for user involvement are mentioned in participatory design literature: pragmatically it helps to get the job done better, theoretically it is needed in order to facilitate communication and cooperation, and politically it is considered desirable that “people have the right to influence their own life” [18].

Co-design methodology have a focus on methods where different type of users and stakeholders could cooperate creatively and explore new

opportunities [10]. Users are treated as experts with their own experiential knowledge [19], and thereby an important asset in the design process [13]. 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.

In approaches that are related to commercial and business concerns you often meet lead users [10]. Lead users are at the leading edge of an important market trend and companies can invite these lead users to help in the design process [20].

Some take the co-creation process even further and suggests making toolkits that make lay people able to develop, modify and customize their own products [21]

User involvement may be motivated on **expected outcomes** of such processes. In a more pragmatic view, there are number of reasons to implement user involvement. A large part of the research done on the actual outcome of user involvement in design processes are mostly subjective opinions stated by the people carrying out the project, and report the benefits with statements such as “we feel confident that the methods has proved useful” and “valuable insights were gained” [8]. However there are some studies showing some more quantitative and measurable benefits of user involvement.

Muller and Carr [8] found that with less than 100 hours of user research they improved their understanding of the problem, and where redirecting their effort into better ways. Decisions of software development are also more likely to match the needs of the user. User involvement in the exploration stage has also shown to result in the need of lesser iterations, faster cycle times in development processes and improved productivity.

Even though user involvement is considered to be somehow costly initially in a project, there are several economical benefits seen in these kinds of projects [8]. As found in the review of Kujala

[8]: There is research showing that interfaces developed with user involvement are increasing the users’ productivity by the reduction in time to complete tasks. There is also evidence that it might lead to less time in change control meetings discussing design changes because of the credibility of the sources. Further on it has shown to decrease training costs as well as the need of user support in the implementation stages. Usability-engineered systems had 25% higher sales the first year. Witell [22] found that ideas generated through customer co-creation are more original.

When designing services it is thought to ease the change process if the new solutions are proper **anchored in the culture and organization [23]**. Rowley found that clients usually viewed visits as a form of respect and appreciation [24]. 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. Grudin (25) suggests that in order to make more positive conditions of direct user involvement in product development, it may be beneficial to alter the structure of organization and product development processes.

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

The design process typically goes through different stages. Despite that models often present this process as linear, that is seldom the case [23]. These processes are carried out in an iterative way [17], meaning that you often go through these stages several times in a project and hopefully learn something from the earlier cycles[23]. One model to illustrate these stages is using the terms: exploration, creation, reflection and implementation[23]. These stages are the ones used in the illustrations in this article. Shortly described **exploration** is the stage where the goal is to gain a understanding of the existing conditions as users, stakeholders and the context. **Creation** is the stage to envision new

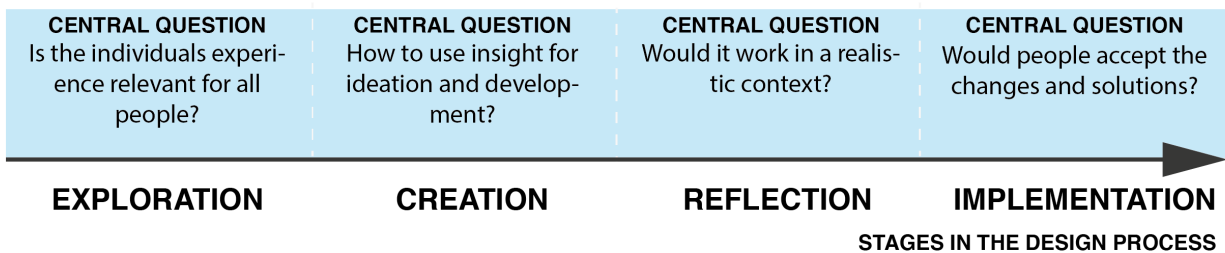


Illustration 2: Illustration of stages in the design process and central questions of concern.

solutions and alternatives. **Reflection** could be done by getting feedback, testing and reflect around this, often making decisions on which changes that should be made. The **implementation** stage is where the solution actually is implemented in the market or a context.

The different approaches may have different ways to **explore** the existing solutions and context. Emphatic design tools could help to understand the users' view, by increasing the empathy with the user and their context. This can be done by activities such as observing users, role playing and playing with prototypes. People may be unaware of their needs, unable to articulate them and unwilling to share them [26]. In order to understand users implicit and non-verbal needs field studies could be effective [9]. Some are concerned that designers will get prejudiced about user need when involving them to frequently [15], and that paying too much attention to the user may erode designer abilities to envision creative solutions [27]. 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. Some are concerned on over-emphasizing findings from a small number of users [28]. 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 [29].

The next step is to **create** possible solutions based on the insight done by exploration. The goal is to envision future alternatives, and it is a central concern to understand which existing

conditions to preserve as well as to understand how to use this insight for ideation and development. This could be done by designers or together with other co-creators. Co-creation could be seen as any act of collective creativity, whilst co-design is co-creation activity applied across the whole span of the design process [13].

In order to **reflect** around the new solutions it is possible to test and prototype them. A central concern is to understand how these solutions in a realistic and future context. Physical products could be tested by building prototypes which could be tested by users, services could make this more complex. Testing service concepts in reality or in circumstances close to reality helps to understand them. This could be done by roleplaying, storytelling or trying them out in the existing environment [23]. When the project comes to decisions, certain people is privileged over knowledge of other people [10]. Steen (2011) emphasizes the importance of reflection and reflexivity in the decision-making process during projects. With each decision power is exercised and some actors have more agency in the decision-making process than others.

What to do when you are about to **implement** the new solutions is not the stage with most focus in design literature. The new design often results in changes, and when this new product is a service this could imply both changes in organizations and in technology [23]. This results in a central concern about whether or not the people relating to the product or service would accept it. By involving users earlier in the process, as well as using the insight when creating new solutions it is believed to make this changes more easily [23].

3. USER AND USER INVOLVEMENT IN A HEALTH CARE CONTEXT

The importance of user involvement in health care services is widely recognized. This is on all levels: from the individual's own right to influence the treatment or care they receive; to the right to form and design services; to the development of policies on national and global levels [30, 31].

The methods used and reasons to implement user involvement are diverse [32]. Most western governments emphasize the involvement of service users in their policies, but there seem to be a gap between these expectations and the work which is carried out on a service level [5, 33]. This might be because of the lack of research on impact and actual outcomes of user involvement [33], or stakeholders' experiences with decision making processes that may be slower because users are involved, or a lack of tools to coordinate the users' view with the existing quality improvement work. As Arnstein, the creator of a much-referred model of user participation in public services, 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." [34]

3.1 Who are considered the "users" of health care services?

The **user** of health care services is named by a range of labels according to the context they are mentioned [32]. Generally **user** is referring to the person on the receiving end of health care services. In literature their labels are closely linked to the related models and research frames [32]. Patient is widely used [35], as well as consumer [30] and service user [32]. This article will refer to all these users of health care services as "user".

3.2 Why user involvement in design of health care services?

Approaches to user involvement in health care have diverse origins and are closely connected to the historical development of the health care services [36]. Despite different backgrounds, they

are aligned in their aim to increase user involvement [32].

Involving users is believed to increase the quality of care and lower the cost [35]. Give more accessible services through simplifying appointment procedures, extending opening hours, improving transport to treatment units and improving access for people with disabilities [35]. The most frequently mentioned effect of involvement is new or improved sources of information for patients [30, 35].

The two main approaches to user involvement in health care services are termed the "democratic" and the "consumerist" model [36]. 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 [37], but these arguments and beliefs seemed to be central in many legislations world-wide.

The democratic model sees user involvement as a democratic and ethical requirement. The health services are for the public, and as their users you have the right and duty to participate [38].

The last decade user involvement has been recognised as an important part of **quality improvement work** [5]. 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 [32]. 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 [31]. 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 [31]. Forbat et al emphasize that user knowledge should not be considered a rival, but a part of the overall evidence system. 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 are still on the service providers. Involvements of users have also been thought to improve the actual health outcome, and thereby giving another reason to why user involvement is increasing the quality of health care.

3.3 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 [38]. 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.

As illustrated in illustration 3, 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 to user views by user satisfaction surveys.

User satisfactions surveys have a long history in the health care context [31]. This tool makes it possible to get quantitative measurements on larger groups of users, making it possible for both managers and users to compare services against each other and over time. It is questioned what these surveys actual measures [31]. 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[5]. It is considered a common failing that there is an inability to use the findings to improve services [31].

Whilst user satisfaction surveys could be considered insight material for the developers to design services for the users, the levels of involvement are also increased when including representatives in project and development projects.

Users are also often **represented in projects and board meetings** [35]. User representatives are users with experiences from the health care services themselves, and often with chronic or long-term conditions. These users are often the same representing in several projects and boards and there are some concerns whether they take over the health care professionals' worldview after a while [39].

Some places **professional service users** are representing the user groups in projects and boards. These users have received training in order to get a broader understanding of the services. According to Greengalgh et al (2011) the users need a certain level of understanding of the organisation and how it works in order to be effective [39].

For practical reasons the user has to be represented in some way. The user groups are usually diverse and the **representativeness** of the chosen users is often questioned, as the critique on users being too subjective and addressing their own agenda instead of thinking what is common good for all the users of the services.

Where user involvement is being implemented it is largely in the capacity of **consultation** [32]. Of some this is considered as mere tokenism, meaning that it is just for show and that they do not really have any impact. 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

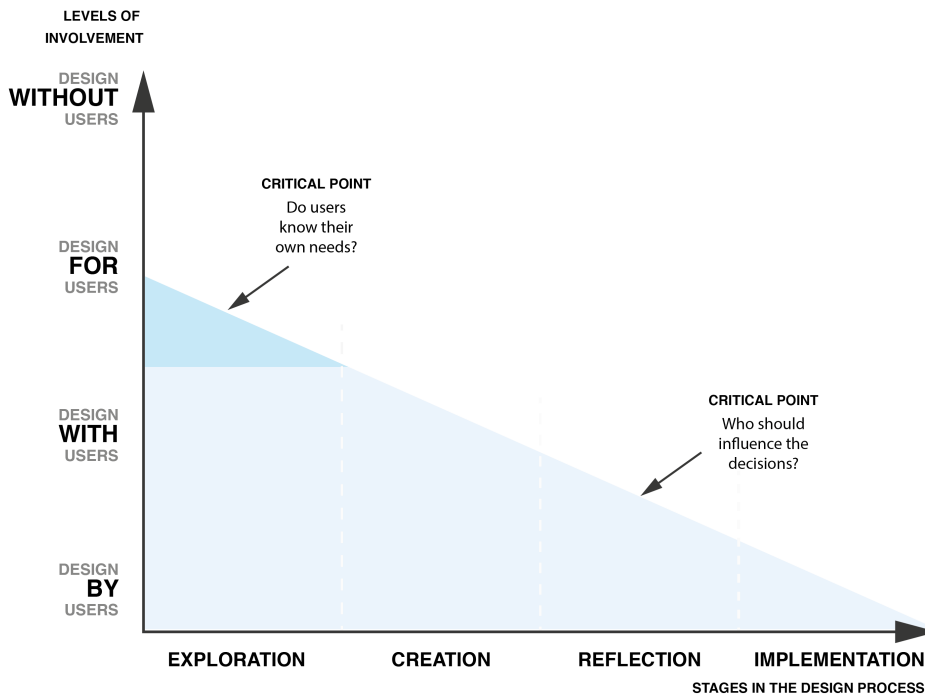


Illustration 1: Simplified illustration of user involvement in a human-centred design process

would have been made without them [39]. 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. Where there is considered to be a large power differential between health care users and staff changes due to user involvement is less likely to happen [39].

There are also other **practical and ethical issues** that may be challenging. Health conditions may make it difficult to be involved [31]. Some users do not even want to be involved. Other times it is ethical questionable to involve users if they e.g. do not have much more time to live.

Lately there have been some examples on giving the users more active roles in design of health care services [3-5]. **Co-design methods** with user interviews have been used to map the users’ needs. This is considered as a new lens with methods, tools and techniques that may help close the 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 [5].

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 is important [6]. Neither of the fields have “one good reason” nor do they have “one best way”, but here are some of the observations done when reviewing literature in both fields.

4.1 User ≠ user

Whilst the user in a health care service usually refers to the person receiving care, whether named patient, client or consumer, the designers’ user may relate to a broader range of people. This could be a user as according to the health care definitions, or it could be other stakeholders such as carers, relatives, health professionals and administrators.

Designers seem to have a stronger tradition on a more active user role in their projects. Both in

levels of involvement and in which in the 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. Segelström et al found that there are more traditions to include clients and stakeholders other than service users, in service design projects. And even they are a bit reluctant to be included in such ways [40]. In this context this may imply that it is more likely to include managers and health professionals rather than patients and carers. Would that be sufficient?

4.2 Process ≠ process

In health care there is considered to be a lack of knowledge on how to bring user research into service development [4]. This could be seen as a gap from using insight in the exploration into creating new services, as shown in illustration 4. Designer’s one the other hand emphasize on the creation and reflection stages in the process, areas that are quite uncovered in health care literature.

As mentioned earlier there’s indications that users need to be far more involved in cases of

high task or system complexity. Many health care services could be said to be both. Designers differ in their understanding of 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 question 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. In health care service design projects this would imply quite some balancing, and one way to try to handle this might be by inviting all these people into the process using co-creational methods.

4.3 Shared concerns

Some of the main concerns of practising user involvement 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 is depending on the willingness in the organization to accept and put-to-life the proposed changes.

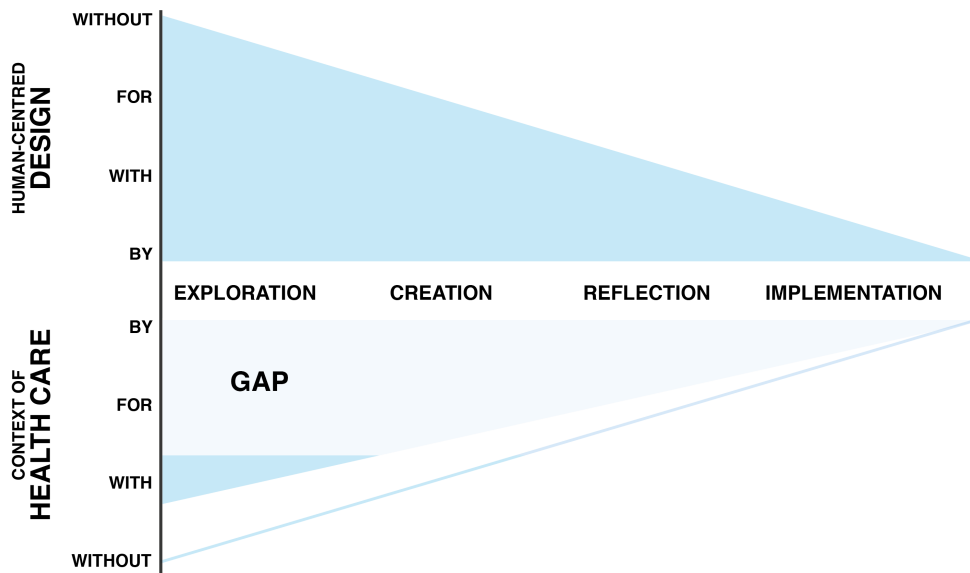


Illustration 4: A illustrative comparison between user involvement in human-centred design versus health care

4.4 Future topics of exploration

The health care context is considered evidence demanding. They like facts and statistics. 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[10]. Polaine and Bate emphasize the importance of using qualitative methods together with quantitative methods, and this would probably help the process of increasing the influence of the users.

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?

This article would give an overview of some of the central approaches and terms in both of the related fields. 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 [10]. However this article is based on literature, and there are a lot of practices on both national and global levels that aren't covered by research and literature today. How to best design services in health care is still an interesting design field to explore, and research such as case studies could give interesting knowledge to the design community.

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