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User participation

Research with and about user particiaption

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RESEARCH
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USER PARTICIPATION
Research with and about user participation

User participation in research is a field undergoing development → It might be about involving users in parts of a research process → Or jointly developing activities such as care services with users → It may also involve a scientific study of user participation in research → However, researchers and users face a number of challenges

SUMMARY

In recent years, user participation has been paid increasing attention as an important part of research. The scientific literature describes a range of benefits: Enhanced understanding of the research field in question. Identification of urgent issues. Richer, deeper data. Innovative dimensions in data analysis. And increased confidence in and improved dissemination of research results.

However, researchers face a number of challenges, not least ethical challenges. Users may feel that their contributions are not taken into consideration or that participation is stressful. User participation also involves time and requires additional resources. Consequently, user participation in research should have a scientific basis and be cost-efficient.

Research with and about user participation is being developed both nationally and internationally. One example is the use of research circles to enhance and develop user participation in research. Gaps in knowledge that urgently need filling include: better defined, more uniform terminology; theoretical support; better knowledge about which users should be involved, depending on the issue and the area of application; continued development of valid methods for evaluating research with user participation.

1. Definitions of research with and about user participation

User participation in research is not currently clearly defined. It may be about involving users in parts of a research process or in the development of activities in, for example, healthcare and social care (Reed, Weiner & Cook, 2004; Ross et al., 2014) or physical planning (Ståhl, Carlsson, Hovbrandt & Iwarsson, 2008). It may also be about scientifically studying user participation in research as such. Consequently, it is important to define whether it is about research with user participation or research about user participation.

Research with user participation concerns participation that goes beyond just providing, for example, blood samples, answering surveys and being examined, tested or interviewed. Instead of being a study object, the user is an active participant in various parts of the research process. Research with user participation may therefore be seen as an active partnership between the persons involved in a study and the researchers (Fudge, Wolfe & McKevitt, 2007). At the same time, it is not only users in terms of patients, clients or other private individuals who are involved in research. Representatives of trade associations, professional groups and public authorities and political bodies also frequently participate actively (Priestley, Waddington & Bessozi, 2010).

Research into user participation aims instead to enhance knowledge of the benefits and challenges of involving users in the research process. Such research may also involve ethical aspects or focus on the evaluation of research with user participation and its effects.

2. Starting points for user participation

The purpose of involving users in research has its origin in ideas relating to empowerment. The aim is to support the individual to take control over his or her own situation (Mockford, Staniszewska, Griffiths & Herron-Marx, 2012). This commonly involves a striving to shift power in the research process from the researchers to those the research concerns. The research process is characterised by being carried out with the users with continuous feedback for mutual reflection and action between the parties as an important principle (Cornwall & Jewkes, 1995).

The view of knowledge is an important aspect of research both with and about user participation (Nolan, Hanson, Grant & Keady, 2007). In order to guarantee and develop quality in healthcare and social care, there is a high degree of focus on evidence-based knowledge (Sackett, Rosenberg, Gray, Haynes & Richardsson, 1996). With this approach, scientific knowledge is generally assigned higher value than tried and tested experience.

However, with user participation in research this traditional view of knowledge is problematised and questioned. Users are seen as representatives of various groups of society and as experts on their own and others' situations and conditions. For example, this may concern a group's opportunities for activity, participation and health. In addition to evidence-based knowledge it is necessary, therefore, to take into consideration the experience and wishes of professionals, users and relatives as well as the relevance and benefit to the field of various activities (Sackett, Rosenberg, Gray, Haynes & Richardsson, 1996). Consequently, researchers must expand their view of knowledge and take more interest in the knowledge contributions that users, in their role as experts on their own situation and their own field, are able to make to research (Glasby & Beresford, 2006). Based on this perspective, it is also important to make scientific studies of user participation in research.

Table 1. Benefits of research with and about user participation

Field of research/ issues	The researcher is helped to identify and prioritise relevant research issues. The researcher receives pragmatic criticism on the design of the research and its suitability in relation to the user group.
Methodology	The researcher is helped to develop questionnaires, interview guides and information concerning language and understanding, thus facilitating communication between the researcher and the participants in the study. This may also have a positive impact on recruitment of participants.
Execution	The data collected is interpreted on the basis of the user's and the researcher's perspectives. The researcher is helped to identify gaps in knowledge in the field.
Implementation	Increased dissemination and implementation of research results. The results can be communicated in a clearer, more easily accessible manner.

Source: CASE, Lund University

Field of research/ issues	Scientific and ethical conflicts may arise on account of differences in understanding and expertise between researchers and users. May only give the appearance of involving users and create conflicts between researchers and users based on a power imbalance.
Methodology	Difficulties recruiting a representative selection of participants. Difficulties balancing scientific requirements such as reliability against participants' subjective experiences.
Execution	Users may influence each other, particularly in groups with a strong participant who underlines a certain type of problem. Groups risk being ensnared by individual, subjective experiences instead of conducting general discussions. For example in order to find relevant fields of research.
Implementation	Research results are disseminated fast, which may jeopardise scientific publication.

Source: CASE, Lund University

3. Challenges and benefits of user participation

Several studies discuss both the challenges and benefits of involving users in various parts of the research process (Staniszewska, Jones, Newburn & Marshall, 2007; Priestley, Waddington & Bessozi, 2010; Tritter & McCallum, 2006). Among other things, user participation is expected to generate better understanding among researchers of relevant and urgent fields of research and issues (Brett et al, 2012; Staniszewska, Jones, Newburn & Marshall, 2007). However, the change of role involved in moving from fighting for your rights to discussing research issues may represent a challenge for a user. It is important for the researcher to provide support. The challenge lies in conducting the dialogue on equal terms and converting the users' expressed problem areas or ideas into issues that can be studied with scientific methods (Erdtman, Tideman, Fleetwood & Moller, 2012).

As in all research, the recruitment of participants (in this case users) is important. Who should be asked, who

assumes the role of user and which group of individuals in society can they speak for and represent? This might involve the type of selection applied in qualitative research, where variation in experiences is important to reflect the situation of the user group as credibly as possible. However, it should be noted that the recruitment of participants to research concerning user participation differs from the recruitment of informants for qualitative studies. That is, a user should be able to represent a broader perspective than his or her own (Ståhl, Carlsson, Hovbrandt & Iwarsson, 2008). However, in qualitative research, it is important for informants to be able to share precisely their own, deeply personal experiences.

One common method of making contact with participants for studies concerning research with user participation is to approach interest groups (Boote, Baird & Beecroft, 2010). However, this entails a risk of only reaching users who are much too focused on their personal situation and are therefore unable to relate their own needs to the needs of other individuals or groups (Cornwall & Jewkes, 1995; Erdtman, Tideman, Fleetwood & Moller, 2012). There are also examples in which researchers have involved individual users as intermediaries in the recruitment of participants. The intention is to make contact with and have the opportunity to include participants from specific contexts and with a variety of backgrounds.

Circumstances that make it difficult to involve users in the research process include poor health, the length of time involved and the challenges of travelling from home to various meetings (Fudge, Wolfe & McKevitt, 2007). An example of ethical aspects for researchers to consider is the extent to which the experiences expressed may be used and reported (Barber, Boote, Parry, Cooper, Yeeles, & Cook, 2011). There is a risk of users feeling that their statements are not taken seriously. For example, in cases when a researcher's interpretation of the data collected does not reflect the views expressed. The time required for participation should also be taken into consideration. This is particularly important in relation to the expectations users have of their opportunities to influence and change their own situation and that of others (Boote, Baird & Beecroft, 2010).

Involving users in data collection has been shown to have both positive and negative impacts, both for those involved and for the results (Svensson & Hansson, 2006; Bengtsson-Tops & Svensson, 2010). In his or her role as data collector, a user can contribute to greater openness in terms of the experiences of the people interviewed. This type of involvement can pave the way for a deeper dialogue and also create greater confidence among interviewees in the person carrying out the interview. It can also contribute to richer data or a deeper level in the data collected. At the same time, there are challenges, not least of an ethical nature, when people with similar experiences meet in the roles of interviewer and interviewee in a research project (Svensson & Hansson, 2006). Individual life stories and accounts can be hard to bear and difficult to handle. Users

who participate in a role similar to that of the researcher may, therefore, need support in their task.

Moreover, it is important to consider how the material collected may be influenced by the person who collects it. Researchers and users do not usually share experiences and understanding of what it is like to live in a certain situation, which may create a distance between the parties (Priestly, Waddington & Bessozi, 2010; Staniszewska, Jones, Newburn & Marshall, 2007). Researchers and users may also make different interpretations based on their own knowledge and understanding of what is being studied.

Involvement of users in the analysis process may contribute to reinforcing the validity of the study as a user's subjective experiences are considered equivalent to a researcher's expert knowledge (Cotterell, 2008). Where a researcher's starting point is his or her formal knowledge, a user is able to contribute his or her own and others' experiences (Hewlett et al, 2006). Handled correctly, this type of contrast adds innovative dimensions to research. Collaboration between researchers and users in the analysis process may also make it easier to maintain focus on the aim of the study and not lose a user's experiences and area of interest (Horne & Costello, 2003).

In other words, user participation may entail active involvement throughout the research process (Brett, et al., 2014; Hewlett et al., 2006), which places demands on all participants. For example, different levels of education among participants may affect collaboration, both between researchers and users and within the user group. Where the researcher is concerned, it is important for he or she not to make use of his or her academic position but to be able to meet the user on the user's level. This is particularly important not least in educational contexts in which users need to be informed about and learn to understand and work on the basis of the various stages of the research process (Iwarsson, Jernryd, Rutström & Boqvist, 2000).

4. Effects of user participation

It is complex and complicated to evaluate the effects of user participation in research (Barber et al., 2011). Consequently, such studies are uncommon. Where evaluation initiatives are reported, they are usually based on anecdotal evidence (Fudge, Wolfe & McKevitt, 2007). A recently published literature overview limited to user participation in healthcare and social services with adults as the target group presents a large number of articles in which the effects of research with user participation are reported in different ways (Brett et al., 2014). Based on the literature reviewed, the authors identified effects on three levels: for the individual users, for the groups of citizens affected and for the researchers.

The positive effects for individual users are that they are appreciated and noticed, their self-confidence is increased and they are able to cope with the situation as patient or client better. Target groups affected become more aware of their situation, and their knowledge about the group's specific problems is enhanced. However, users would like more preparation and training for their tasks (Svensson & Hansson, 2006). Some users feel overloaded with work, which may lead to them thinking they are unable to contribute sufficiently or in the way they would like.

The researchers, for their part, develop increased understanding of their own research field, acquire more respect for the users and form stronger contacts with the groups of users with whom they conduct the research. At the same time, challenges associated with user participation in the research process are described. Not least as extra time is required and it leads to increased costs. In several articles (Mockford, Staniszewska, Griffiths & Herron-Marx, 2012; Stewart, Makwarimba, Barnfather, Reutter, Letourneau & Hungler, 2007) the authors point out the increasingly common requirements for user participation from research sponsors, which means that funds for user participation must be set aside in the project budget.

5. Current state of knowledge

A national and international survey shows that there are many initiatives driving the development of knowledge about research with and about user participation forwards. The degree and importance of user participation are illustrated and discussed in various ways in the literature (Barber et al., 2011; Staniszewska, 2009). As research both with and about user participation is often reported without any clear distinction, however, it is difficult to describe these perspectives in absolute terms.

The published studies represent a wide range of topics. For example: media and communication science, cultural geography, research into older people and ageing, medicine and medical science, traffic planning, architecture, industrial design, computer science, political science, sociology and social work. Many target groups are covered, including children and young people, older people, people with disabilities, people with abuse problems and immigrant groups.

Judging by the wealth of literature, developments have been particularly strong in the United Kingdom, which may therefore be regarded as something of a pioneering country. However, researchers in Sweden also publish method studies and results from projects focusing on research with and about user participation (see e.g., Svensson & Hansson, 2006; Erdtmann, Tideman, Fleetwood & Moller, 2012; Ståhl, Horstmann & Iwarsson, 2013). The majority of the studies are either qualitative or

literature overviews (Brett et al., 2014). Most of the published studies have been carried out on a small scale within a specific activity in a national context. However, there are also examples of studies on which researchers and users in different countries work together (Haak et al., 2015).

6. The research circle as an example

There are many procedures for developing research with and about user participation. One example is the research circle. The Forte-financed Centre for Ageing and Supportive Environments (CASE) at Lund University works continuously to develop the research circle as a method and a tool. The aim is to enhance research with user participation and contribute to developing research into user participation into a separate research field in which results are presented and published internationally.

The research circle can be adapted, depending on various starting points in research with and about user participation.

It may be about involving the residents of a specific area in planning to change the outdoor environment, developing a product or improving the dissemination of research results. Using seminars and publications, researchers can present and discuss experiences of the research circle as a method and contribute to identifying gaps in knowledge in relation to research with and about user participation. This can be done not only within their own fields but also in a broader perspective.

The research circle is a structured, practically oriented research method described by Härnsten (1994). The method aims to achieve change and is rooted in the Swedish tradition of study circles. Its theoretical basis was developed during the early twentieth century by the educationalists Ferrière, Ferrer and Freinet.

A research circle is led by researchers and consists of people with a common interest but with different backgrounds. The aim is for users and practitioners who represent different levels in society to jointly develop knowledge in a new way within the specific field. After having met on a number of occasions, the group must also agree on practical solutions to the problems that were the focus of the discussions. Three examples are given below of how the research circle was used by researchers linked to CASE and how the method can develop research with and about user participation.

6.1. Involving older people in a residential district

In the project 'Kom så går vi' (Let's go for a walk), a partnership between Kristianstad Municipality, Lund University and the Swedish Road Administration for Region Skåne, the research circle was used in its classic

Table 3. Facts about the research circle

Participants and topics	The group consists of user representatives and societal experts with a common interest in achieving results of some kind on a shared issue. The research circle is led by researchers. Each meeting, of which there are around 4-6, has a specific topic. The first is determined by the researchers. The subsequent topics depend on the discussions and are determined jointly by the participants from meeting to meeting.
Invited experts	The group has the opportunity to ask for additional expert advice to advance the discussions. Invited experts can give a presentation, for example, or participate in discussions.
Homework	The group discussions lead to homework which is done between the meetings. Homework may involve own reflections, talking to people nearby about a specific subject, etc. The homework is designed to make the participants active, creative and motivated and able to contribute additional information to the next meeting. This enhances the opportunities for more in-depth discussion of the shared issue or problem.
Analysis	Analysis contains two levels. The first level begins after the first meeting. Both participants and researchers participate. Each meeting subsequently begins with the participants giving feedback on the researchers' summary of the minutes of the previous meeting. The second level involves just the researchers. They organise the data collected. Categories emerge that are related to each other in a repetitive process. Participants and researchers jointly arrive at proposals for solutions to the shared issue or problem.

Källa: CASE, Lunds universitet

form. This means that it was used as a method of solving a shared problem (Härnsten, 1994). The aim was to use intervention to give older people in a selected residential district greater opportunities to live a mobile, independent life. This was to be achieved by involving them in the research process with the focus on designing an accessible, safe and secure pedestrian environment.

Surveys and accompanying observations were used to map urgent problems within and outside the district in question. The research circle was then put together on the basis of this mapping process. In addition to two researchers, the group included representatives of

older people in the area (eight people) and politicians, associations, the municipal administration, property owners, the public transport provider Skånetrafiken and the Swedish Road Administration (eight people). The research circle met on a total of six occasions over a period of six months. Its discussions led to the creation of the basis for an intervention. The action programme that was developed was then implemented by the municipality over a two-year period. Examples of its actions were moving parking spaces, smoother, wider pavements, bevelling kerbs, installation of benches and lower speed limits in the area (Ståhl, Carlsson, Hovbrandt & Iwarsson, 2008).

The project was evaluated on two occasions, in 2006 and 2011. The results show that the research circle as a method is effective and also highlight the benefit of involving older people in health promotion initiatives in their local environment. As a result of user participation throughout the research process, the older residents in the residential district had the opportunity to both influence and actually participate in decisions on the actions and measures to be implemented. The participants felt a personal responsibility for ensuring that the actions and measures were as good as possible for everyone in the area (Ståhl, Horstmann & Iwarsson, 2013; Hallgrimsdottir, Svensson & Ståhl, 2014).

From the point of view of the users, the method was also positive in the sense that users and representatives of the nonprofit, municipal and political worlds got to know each other. This proved to be of great importance to the older people in the residential district in question in their future contact with the municipality. From the point of view of society, the research circle broadened the view of the needs of older people among the municipality's politicians and civil servants. The group discussions made planners aware that it is not extensive infrastructure initiatives, for example signalized controls at pedestrian crossings, that make older people feel safe and secure in their residential districts. In fact, it was relatively cheap, simple measures that increased accessibility and mobility for them.

6.2. Developing a product
The research circle as a method is subsequently being further developed in several projects at CASE. For example in the project 'User-driven housing provision for senior citizens", which is part of the EU-financed project Innovage. The fundamental idea is to develop a computer-based, interactive tool in the form of an app to assess and identify accessibility problems in housing, based on scientifically tested methodology. Older people must be able to use the app themselves and assess the accessibility and suitability of housing on the basis of their needs. The idea is that this will also allow them to influence future housing design and provision by means of active demand for accessible housing.

Parties involved in providing housing can also use the app. It offers a valid, reliable picture of accessibility for different user groups in different housing stocks. Users

were involved in the project from the start. It is about older people with and without disabilities and parties involved in providing housing. Research circles have been conducted in Germany, Italy, Latvia, and Sweden. During 2013, participants met in the respective countries on four occasions over a three-month period. Five to eight people took part in each research circle, a total of 26 people, plus one researcher and one research assistant. The project produced experience and knowledge of research with and about user participation from an international perspective as well (Haak et al, 2015).

The research circles jointly prepared a specification of requirements for the design and content of the app. This specification of requirements was essential to the ongoing technical development of the app. Some of the participants in the research circles and other users have tested the app on repeated occasions in various ways, giving their views on its user-friendliness. When the project is completed in December 2015, the app will be available in a pilot version that can be used in research and relevant practical activities.

6.3. Disseminating research results
The research circle as a method is also being used in the project 'Development of user-driven models for implementation of research results in municipal activities and social planning'. It is financed by Forte and is an important part of the work to develop research with and about user participation. The focus is on how older people themselves and those who work with them value and prioritise research results and their thoughts on possible ways of disseminating and using new knowledge.

Two parallel research circles were used, one with participants from rural locations (ten people) and one with people who lived or worked in cities (nine people). One researcher and one project assistant also participated in each research circle. The research circles contained representatives of older people and various societal experts. Each research circle met four times over a four-month period in spring 2014.

The aim was to understand what older people and their interest groups think about new research results concerning housing and health as related to ageing. To find out what actions and measures are important, prioritise them and identify the most important. And develop a new action programme for implementation and knowledge transfer using an interdisciplinary team of researchers. In spring 2015, the participants in the research circles were invited in to provide feedback and to discuss the preliminary results. Other user representatives who have contacted CASE recently to provide their views on the research in progress were also invited to interactive sessions.

7. Gaps in knowledge

In summary, we can say that there is a significant volume of literature based on research with and about user participation. However, in the course of our work on this overview of knowledge, we have not found any publication in which a systematic approach has been taken to the challenge of defining more than a small selection of all the terms used. Closely related, similar terms are used to describe both research with user participation and research into user participation without any distinction between the two. This makes the research field hard to analyse and can lead to new research not being based on the total range of knowledge currently available. Accordingly, the research field makes a split impression. However, the recommendations and conclusions presented in extremely varied contexts have much in common, indicating that the range of knowledge is in the process of being consolidated.

The expression 'user' is a term that is particularly in need of analysis and definition. It is necessary to take a more deliberate approach to studying which categories of user should be involved, depending on the type of study, the issue and the area of application. It is also important to scrutinise more closely the problems associated with who can be said to represent groups of users. In our increasingly globalised world, various groups' experiences and needs, for example for healthcare and social care, are becoming increasingly complex. Consequently, both collaboration between various disciplines and professional groups and international collaboration are important (Stewart, Makwarimba, Barnfather, Reutter, Letourneau & Hungler, 2007).

There is a marked lack of theoretical support in the literature. However, a number of theoretical approaches are made, for example in implementation science, which could form the starting point for studies on research with and about user participation (Bertram, Blase & Fixsen, 2014; Fixsen, Naoom, Blase, Friedman & Wallace, 2005; Rycroft-Malone & Bucknall, 2010). In many cases, the fundamental approaches relating to the theory of the science also require clarification, not least as the methods described are often similar. Consequently, it is unclear to what extent the researchers use different terminology and to what extent the fundamental assumptions are unique or overlap each other.

Research with and about user participation is dominated by qualitative approaches. This type of research is valuable for developing in-depth knowledge, but there is a risk that the build-up of knowledge will be a slow process. Therefore, it is necessary to develop an even broader arsenal of methods that lays the foundations for the development of generalisable knowledge and cumulative knowledge building as well. There is also a significant need for more reliable, valid methodology for evaluation of research with user participation.

Research sponsors today often ask for user participation in their projects. It is therefore important to enhance the knowledge about the challenges of involving users in research and how to handle them best. For example, time and cost aspects need to be elucidated more thoroughly from the point of view of both users and researchers to create favourable conditions for future research.

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