Why should patients participate in research?

Patient participation is a key element of health policy design. Today, requirements for patient participation also apply to research. The experience of patients and users shall be acknowledged and help create practically relevant knowledge. In its calls for proposals, the Research Council of Norway requires applicants to provide valid grounds if service users are not to be included. But how does user participation affect the research process?

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User participation was introduced as a key public instrument in Report no. 41 (1987–88) to the Storting, *Health policy towards the year 2000: National health plan*. The health policy goals included increased democratisation, user empowerment and legal safeguards. Questions regarding how services could be developed to meet patients with respect and empathy were highlighted, giving rise to a need to collect user experiences. In turn, this helped acknowledge user experiences as valuable knowledge for the health services, and included the patients' subjective knowledge, their perspectives and perceptions of reality. In medical and health research, this may help supplement the perspectives of clinicians and researchers. This has led to new forms of knowledge production: participant-based research, user-involving research, co-research, collaborative research, user-controlled research. Instead of undertaking research on or about patients, research is undertaken jointly with them (1).

We feel, however, that there is a need to discuss what this kind of knowledge production implies at the level of philosophy of science. By way of an introduction, we will therefore elucidate some viewpoints regarding where and how such knowledge is produced. We will then proceed to discuss how user participation may affect knowledge production.

User participation and research

Participation can be ranked on a scale the lowest point of which is consultation. The users are asked, they are consulted about what they feel are important topics to be studied, but their advice is not necessarily acted upon. The next step is collaboration, which can take many forms, from membership of steering groups to collaboration on the research process itself, and involve one or many persons, depending on what has been agreed or areas of competence. The highest level is user-controlled research, where the users decide the research topic and approach. This is controversial, for instance with regard to the question of whether the users should do everything themselves or whether the research process should be left to professionals.

User participation in research is frequently associated with participatory forms of studies in which the research questions and objectives emerge «from within». This could be practice-oriented research, for example based on the clinicians' need for knowledge about their ordinary practice, or it could be action research. The latter is characterised by a consensus among the participants that change is desired, and that a joint effort will be undertaken not only to produce knowledge about the world, but also to change it.

However, the way in which user participation affects the scientific research process has been debated within research. These discussions address questions of the validity of knowledge produced when patients and users are to be involved, and whether this approach to research is applicable to all disciplines and projects. To understand the kind of value the user perspective may have for knowledge production, we need to look at the history of science and how the view of knowledge has changed.

From the ivory tower to the marketplace

In industrial society, the objective was to reveal eternally valid truths that could explain how the world was constructed and functioned. Theory and practice represented separate spheres. Research was charged with producing knowledge for others to convert into practical applications. The process of knowledge production was regarded as an exalted activity; researchers conducted their studies freely and independently for the sake of knowledge alone.

Our present age is referred to as the «knowledge society» and is characterised by globalisation, complexity and uncertainty. Science no longer has unconditional legitimacy to define «true knowledge». Society increasingly requires that the knowledge which is produced should be geared towards application and actual utility value.

This shift changes the relationship between society and science, and the traditionally sharp delineation is upset. In terms of philosophy of science, the discussions have addressed what we should consider useful knowledge, as well as where and how knowledge should be produced. In their book *Re-thinking science – knowledge and the public in an age of uncertainty* (2), the social scientists Nowotny, Gibbons and Scott argue in favour of a new understanding of knowledge production, implying that the researchers needed to leave their «ivory tower» and listen more closely to those around them. This requires a recognition that knowledge is produced in arenas other than academia. They refer to this as a movement from Mode 1 to Mode 2 societies, in which Mode 2-type knowledge has attained more influence and has more significance attached to it.

Mode 1 implies a notion of knowledge in which theory and practice represent different spheres, and where research is undertaken within a relatively secluded environment in which legitimacy is derived from the community of researchers itself. The task of research is to produce knowledge for practitioners to apply. An example of this might be randomised, controlled studies of the efficacy of drugs.

Mode 2 involves a new form of knowledge production in which clinicians, patients, next of kin, managers etc. are included in the research process. From being an object of research, the patient can now become a co-researcher in a team that jointly formulates the goals and methods of the research project. The applied purpose becomes evident. The research results can be discussed by and among various parties that have different competencies, interests

Illustration: Ørjan Jensen/Superpop

and perspectives. This model emphasises interdisciplinarity, collaboration and a given context.

On the other hand, Mode 2 has implications for the way in which the quality of the research is controlled. When the knowledge is produced in collaboration between researchers and practitioners in the field, it is no longer taken for granted that the traditional academic community should assess the quality. When the research is produced in other contexts and with other participants, traditional measures of quality may no longer be seen as applicable or relevant. Will this reduce the reliability of research?

Nowotny and collaborators do not believe so. Instead, they refer to «socially robust knowledge». They claim that such knowledge will have more impact, precisely because it is produced in collaboration with others and because it is discussed in public – in what they refer to as «the marketplace» (2).

The introduction of Mode 2 knowledge should not, however, be taken to mean that Mode 1 knowledge should be rejected. We wish to point out the importance of having both types of knowledge available in medical and health research. At the same time, an increased awareness of positions in terms of philosophy of science may provide new opportunities associated with research design and the implementation of patient participation.

The contribution of user participation to knowledge production

Much research (1, 3–8) points to advantages of user participation, not least that it provides access to knowledge that the research communities do not possess, such as the first-hand experience of patients. This type of subject orientation may increase the relevance of research. User participation is also linked to empowerment; the fact that the voice of the users is recognised in knowledge production may have an invigorating effect on them.

Some challenges remain, however. Researchers, clinicians and managers may be uncomfortable with relinquishing or sharing power and influence in collaborative projects, which may cause the users to be sidelined and kept from participating in major decisions regarding the project (3). Other challenges may include expectations, time and resources. Users may have unrealistic expectations with regard to the outcomes of the research effort. The projects are resource-intensive in terms of time and money. Such issues must be discussed openly at the initial project stage. The objective of this article, however, is to focus on the challenges and opportunities of user participation for the scientific process and knowledge production. We would like to mention research quality, representativeness and possible bias.

One essential impact is how patient participation implies an opportunity to learn «from the inside». However, this insider knowledge must be regarded and used as something more than mere isolated stories. The patients' knowledge may have a potential for adjustment of the objectives, research questions and implementation of the research effort. Epistemic cultures need to be challenged.

One pitfall consists in presuming that the patient who tells his or her story also understands it – that a description presupposes understanding. This may happen if the researchers fail to critically question the patient's narrative or to see it in a larger social context, because they are apprehensive of being perceived as not recognising or believing in it. However, the researcher cannot disregard the social, cultural or political issues that envelop the user's notions of reality – this would mean losing essential contextual information and the opportunity to see the patient's knowledge in a wider perspective (4).

It is frequently claimed that user participation can enhance data quality. Qualitative interview projects underscore how informants reveal more when users interview users, because they perceive the power relationship in the interview setting as more equal (5). Research results may also be different from when the research is undertaken by traditional researchers; for example, it may be perceived as more relevant for practitioners and users.

One challenge, however, consists in the question of representativeness – of whom is the user representative? Which patients express interest in participating as co-researchers? This underscores a key point: recognition of the patients' experiences must not cause personal insider knowledge to be granted a special position. Regarding the narrative of one patient as representative of a group of patients may help produce a new homogenisation, as well as undercommunication of complexity, different identities and relationships, thus risking a new form of «essentialism».

Users may have their own agenda and help produce generalisations on the basis of their own experiences. Subjective experiential knowledge may consist of widely varying experiences, and this may give rise to bias in the knowledge base. In other words, the strength of user participation – its recognition of individual user experiences – may also represent a challenge for the scientific process. One solution could be to rethink how the user should participate and reconsider the amount of personal experience he/she needs to have gained with regard to the research topic in question. For example, a user representative could participate in research in places other than the institution in which he/she has been a patient (4).

Another objection could be that the users possess no knowledge or skills in the scientific procedures of the research process. Several countries have therefore developed special courses for users who need more competence (6). However, this could also be linked to the question of representativeness – does this mean that the user's perspective develops to become more convergent with that of clinicians and researchers? If so, is this user participation genuine?

Balancing discipline requirements and creativity

In the development of the research design, views on the user and the degree of involvement will tend to be influenced by the researchers' perspectives in terms of philosophy of science. Action researchers and some practice researchers prefer to develop projects where patients are included at a high level and even as co-researchers. Research projects that only want to consult with users will continue to be controlled by researchers and/or clinicians.

However, to comply with the demands for user participation in research we need to remain open to questions and objections. Is user participation always feasible? Medicine as a research discipline undertakes research which is more distant and detached from the everyday life of users, such as biomedical and laboratory-based studies. Randomised, controlled designs are also highly relevant for knowledge production in this area. This research is based on positivist ideals of science that may be less compatible with contemporary trends towards negotiated Mode 2 knowledge. Nonetheless, researchers at the University of Glasgow have developed standard procedures for how patients can be involved at all stages of randomised studies (7), and it has been argued that outcomes other than statistically required primary outcomes could be granted higher status, for example if the data indicate other and unintended effects that might be meaningful to users (8).

There is consensual agreement that the patient perspective helps supplement the perspectives of clinicians and researchers. Patient participation cannot be regarded as a mere alibi, but as equivalent in knowledge production to produce better health services through research. Here, we have emphasised that participation can be graded, and only the highest levels imply co-research. There must be room for a variety of approaches in research, and different stages of the project may be suitable for consultations as well as for collaboration (or even management).

An increased awareness of the many forms of user participation may help researchers see new opportunities for patient participation in the production of knowledge. If we explore the terrain, many opportunities may reveal themselves on the road from the ivory tower to the marketplace.

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