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Collaborative user involvement in health research agenda setting

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2019

document version

Publisher's PDF, also known as Version of record

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citation for published version (APA)

Nierse, C. J. (2019). *Collaborative user involvement in health research agenda setting*.

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SUMMARY

Within health care research it has become clear that on many occasions, the best available evidence is actually not available or even overlooked in research processes, stemming from a mismatch between agendas set by the research community and questions that arise from the perspectives of users of health services. As a result initiatives have been set up aiming at improving the applicability and legitimacy of research by including the experiential knowledge of users. In these initiatives users can take on more active roles in all phases of research processes, for example participating as research partners in research teams or being involved as an advisor in research committees. In the Netherlands several patient associations and funding agencies have shown an interest in promoting user involvement in setting agendas for research. However, the growing attention for users' needs and perspectives raises the need to develop methods for incorporating them in developing research agendas. Especially when it comes to involving vulnerable or marginalized groups in research, knowledge on how to facilitate this is lacking.

Three approaches for user involvement in setting an agenda for health research can be distinguished: user consultation, collaboration and control. In the approach focusing on consultation, users provide information about topics that they find important. The initiative of becoming involved does not come from users themselves, but rather researchers decide they want to collect the views of users about possible research topics. When taking on a collaborative approach, users' voices are being heard and they are also actively involved in decision making processes in order to make an agenda for health research. A collaborative approach thus focusses on dialogue, interaction and the exchange of perspectives between users and researchers. In the third approach, users are empowered and in control of the research agenda. They determine by themselves what topics they want for health research. Researchers have a facilitating or supporting role in this approach.

Three case studies in this dissertation focus on setting an agenda for health research using a collaborative approach, aiming for a dialogue in order to identify and prioritize topics. Users were involved from the beginning of these agenda setting processes. The case studies shared a two-fold goal: user involvement in establishing an agenda for research, and fostering

research partnerships during the agenda setting process. The case studies focussed on collaboration with three groups of people with a disability or disease: people with chronic kidney disease (CKD); people with intellectual disabilities (ID); and people with neuromuscular disease (NMD). The following research question was formulated: *How do users and researchers experience their involvement in research agenda setting through collaborative practices and what issues do users place on the research agenda?*

The research design was grounded in a constructivist and transformative paradigm, in which knowledge is socially constructed, influenced by different perspectives and reflecting social relations within societies. A responsive methodology with an emphasis on establishing dialogues was used during the agenda setting processes in these three case studies. This methodology is characterized by a cyclic and emergent research design, in which the research activities are not set beforehand, but are gradually developed in collaboration with stakeholders. A responsive methodology also facilitates the inclusion of users as research partners and generally consists of four phases: 1) an exploratory phase; 2) an inventory phase; 3) a priority setting phase; and 4) a dialogue phase.

Chapter 2 focusses on two health research agenda-setting processes (on ID and CKD). These studies depart from an approach that understands user participation as dialogue. This idea is grounded in hermeneutic philosophy and responsive research. New is the inclusion of patients as research partners. Several methodological notions underpin responsive research. In these two health research agenda-setting processes, these notions have been applied and refined for collaboration with research partners in mixed research teams. The findings demonstrate that equal partnerships include involvement in all research activities from beginning to end, a focus on experiential knowledge, mutual learning, openness, and respect. Mutual learning processes help to overcome stereotypes and handle tensions. Other experiences include the financial reimbursement of research partners, and the necessity of an acceptable workload and scheme. The collaboration might then have a surplus value for the research process and for those involved.

Chapter 3 further describes collaboration within research teams and considers this with reference to the case study about setting a social-scientific agenda for health research from the perspectives of patients with CKD. The objective in this chapter was to examine the

dynamics and dialogues in a collaboration between patient research partners and professional researchers. A responsive methodology was used in the research project. Two patient research partners participated in the research team. Twenty-seven patients with CKD and parents of young children with CKD were interviewed, seven focus groups were organized and observations were held at a dialysis centre. During the collaboration, the research partners and professional researchers engaged in a mutual learning process in all stages of the project. The professional researchers gave the research partners a sense of ownership in the research process. The research partners could relate to the lives of patients by using their experiential knowledge. In the context of collaborative working, this helped shape an agenda for research. The conclusion in this project was that active involvement of patients as research partners can add value to a research strategy, especially when research partners and professional researchers engage in a dialogue that is open, inclusive and deliberative. Issues for discussion include the possibility of 'over-involvement', the research profile and training of research partners and whether participation of patients is restricted to certain types of research.

Chapter 4 describes the case study about participation of people with ID in a research agenda setting process. Although people with ID are increasingly consulted in research, participation in research agenda setting processes is limited. This is not surprising as their voice can easily be dominated in consultations with researchers. The aim of this chapter is to explore the potentials of enclave deliberation as a first step towards broad consultation in research agenda setting. The research agenda setting process followed a responsive methodology, which is characterized by a cyclical and emergent design. Two persons with ID and one parent participated in the research team. Seven persons with ID and six parents were interviewed individually. Subsequently, 10 focus groups were organized with people with ID and four focus groups were organized with parents. Also, a questionnaire was sent to parents. The process towards involvement of people with ID was characterized by several steps that guided enclave deliberation. First, stories of people were collected that reflected their intimate voice. Then, a political voice was further developed through dialogue and interaction in focus groups. This process resulted in a prioritized list of nine potential topics for research. The process of developing intimate voice and political voice can be regarded as a concretization of enclave deliberation among disempowered groups. These steps are necessary to initiate a process

towards establishing a broad consultation between different stakeholders about research on ID.

Chapter 5 describes the case study in which patients with NMD were engaged to list top-priorities for scientific research in order to complement the researchers' agenda. A dialogic model for research agenda setting was used. Interviews, focus groups and expert meetings with patients were held to identify research topics. Research topics were prioritized via a questionnaire. Agendas were integrated in a dialogue meeting with professionals and patients. The research agenda of NMD patients is divided in four research domains, with a total of 24 research topics. These domains include 1) health; 2) quality of life; 3) quality of care and support, and 4) basic issues. Among the research domains highest priority was given to research on health, followed by research on quality of life. Both patients and professionals agreed a proper balance needs to be found between fundamental research and research on symptomatic treatment and quality of life. They concluded that more attention is required for research on the effective treatment of symptoms, quality of life and implementation of knowledge about NMD in regular care.

The purpose of chapter 6 is to indicate how a dialogue in the context of research agenda setting can be established to create an integrative research agenda. Creating a participatory research agenda on NMD was one of the aims of the case study on NMD. A multi-stakeholder and multi-phased dialogue model was used to work toward an integration of perspectives. Critical steps to establish equal partnerships between patients and researchers consisted of building trust among a mixed team composition, deliberation with and empowerment among patients, active collaboration with a core group of experiential experts and fostering an open-minded dialogue to create personal and mutual understanding. Structural adjustments are required to create more enduring partnerships between stakeholders in the science and public policy domain.

In the last chapter, the main findings over all of the case studies are described, with a reflection and discussion on the research agenda setting processes. First, I reflect on the issue of representation and expertise of users when they participate as research partners during agenda setting processes. It was not feasible for research partners to act as representatives for all users and the case studies showed that it was not necessary for them to be educated

about research beforehand. Rather, enclave deliberation and sharing contributory and interactional expertise were important aspects for collaboration and mutual learning and empowerment. Second, I reflect on the importance of inclusion, empowerment and dialogue in collaborative approach to user involvement in research agenda setting. A collaborative approach for user involvement in research agenda setting proved to be helpful to involve users as research partners from beginning to end in an agenda setting process. The dialogues within the research team facilitated relational empowerment, by interacting with each other and sharing decision making power. Third, I describe recurring issues that users place on a research agenda, especially values, identity and relationships. In the three case studies a broad range of issues was formulated by users on an agenda for health research. The research agendas could be characterized as holistic, because of the interrelatedness of the themes and the various life domains to which the themes are connected. Overall these research agendas showed that research themes formulated by users were not exclusively linked to their chronic disease or disability, but also reflected important issues relating to identity and relational aspects of their lives.

Recommendations include research on prolonged user involvement in agenda setting and in the stages of research programming and implementation; assessing the societal impact of user involvement; and evaluating decision making processes and power relations within research agenda setting processes. Directions for the practice of healthcare research include educating healthcare researchers on collaborative, participatory and emancipatory approaches in research; maintaining actions and initiatives towards including users in research agenda setting; and continuing and updating research agenda setting projects by patient associations.