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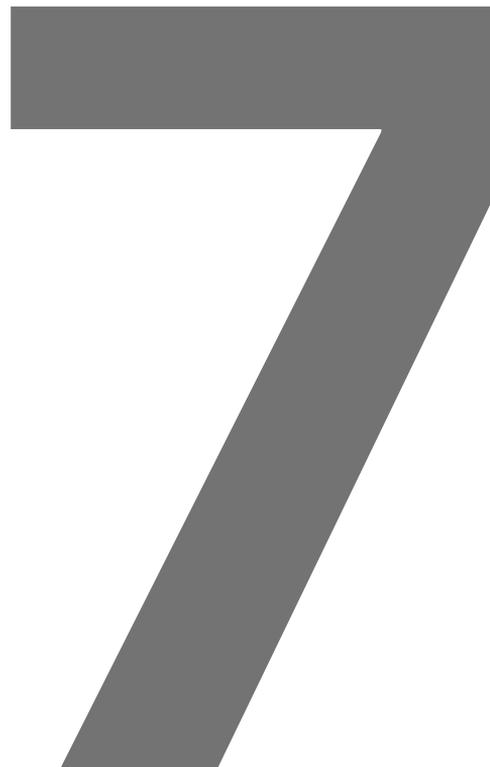
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DISCUSSION AND CONCLUSION



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This dissertation is grounded in three case studies in which people with a chronic disease or a disability were involved as partners through collaboration in health research agenda setting processes. The aims of the case studies were twofold: first, to formulate and reflect on methodological notions that guide agenda setting processes in which users are involved, and second to generate agendas for research in which users were actively involved.

These case studies all followed a responsive dialogic design (Abma & Broerse, 2010). In this approach, the interaction and dialogue between various stakeholder groups, in this case researchers and users, is central. To be able to respond to the stakeholders, an emergent design is used. The methodology is not preordained but rather follows the context and issues that stakeholders bring forward (Abma, 2005). The methodological notions that were guiding during the agenda setting processes, regarded the importance of starting with the stakeholder group with least influence; maintaining a focus on experiential knowledge; fostering interaction of stakeholders; engaging in mutual learning; and openness and respect (Abma & Broerse, 2010). These notions are explained in chapter 2.

In all case studies users were involved from the beginning of the agenda setting processes. Establishing partnerships and collaboration between healthcare users and professional researchers (i.e. both researchers involved in agenda setting, and researchers focussing on specific health issues) was the main focus of these case studies. In line with this, users were involved in the agenda setting processes in different roles, varying from being interviewed to participating as research partners in the team or becoming active members of expert groups and engaging in a dialogue with researchers in health care. The first case study focussed on people with chronic kidney disease (CKD), and resulted in learning how to establish co-ownership of a joint research project and in an agenda for social scientific research (chapter 3). The second case study involved people with ID, and resulted in learning how to develop a broad research agenda for research from the perspectives and experiences of people with ID (chapter 4). The third case study focussed on people with neuromuscular disease (NMD), and resulted in learning how to establish a dialogue with researchers in the field of neurology and rehabilitation (chapter 6) and an agenda for research from the perspectives of patients (chapter 5).

In this dissertation, the following research question was formulated:

“How do users and researchers experience their involvement in health research agenda setting through collaborative practices and what issues do users place on the research agenda?”

This research question regards both the experiences of users, as well as healthcare researchers and researchers facilitating research agenda setting. Below I reflect on the main findings of these case studies concerning the development of a collaborative approach for dialogical research agenda setting. I also address the quality and strengths and weaknesses of these studies. Finally, I describe implications for future research on user involvement in research agenda setting and practice of healthcare research.

7.1 MAIN FINDINGS

The main findings consist of formulation of and reflection on methodological aspects of user involvement in research agenda setting and on the content of agendas for research from the perspectives of users. I first address issues of users as representatives and their expertise needed when users and academic researchers engage in a collaborative agenda setting process. Secondly, I elaborate on the importance of inclusion, empowerment and dialogue in collaborative approach to user involvement in research agenda setting. Third, I describe recurring issues that users place on a research agenda, especially values, identity and relationships.

7.1.1 RECONSIDERING REPRESENTATION AND EXPERTISE IN COLLABORATIVE AGENDA SETTING PROCESSES

In two of the three case studies in this thesis (the studies with people with CKD and with people with ID) users were involved from the beginning as research partners in the process of agenda setting. This led to questions concerning the representation and the characteristics of users who are involved as research partners. Should they have a background or a strong affinity with research, and should they be representative for all users with the same illness or disability (Calnan, 2004)? These issues of representation and expertise came up in relation to the process of recruiting research partners for a research team, as this might entail a selection

of research partners that hold the most knowledge about research. Obviously, users can have gained extensive knowledge about research methodology, academic jargon or the latest developments or discussions in the research arena and have become equal discussion partners in academic conferences and in publications (Epstein, 1995). However fully adapting to the jargon of researchers and no longer reflecting on research based on experiential knowledge, can be a signal of proto-professionalism. This means that users are no longer involved through experiential knowledge but rather through their expertise on research (Hogg & Williamson, 2001; Mayer, 2012; Thompson, Bissell, Cooper, Armitage, & Barber, 2012). Consequently it may be doubted whether the users who collaborate as research partners represent all users with that particular illness or disability.

The case studies showed that expertise on research or even basic knowledge about research processes were not at all necessary for the research partners to be members of the team. Important aspects were curiosity and willingness and enthusiasm to participate in a collaborative project. Affinity with research proved not so much an essential characteristic beforehand, since for instance in the case study with people with ID, the research partners did not hold any knowledge about research methods but instead gradually learned during the process of doing research. For example, they had no previous knowledge of qualitative interviewing, but after taking part in the team meetings and after starting the initial interviews they understood that they could ask questions about things they wanted to know and use follow up questions like asking for examples from their daily lives. In team meetings they also shared critical reflections, for example about the final focus group that was organized for prioritizing research topics. An important characteristic was, however, being active as advocates before the project started; they were knowledgeable about issues that mattered to people with ID and were also willing to share their own experiences in life with other members of the research team.

The essence of their involvement as research partners was not so much being (statistically) representative of a large group of users, but rather being able to share their experiences stemming from diverse backgrounds and being able to reflect on their own experiences. For example, in the case study on CKD, one research partner was a mother of a son who had received a kidney transplant and the other research partner was a woman who was diagnosed with a hereditary chronic kidney disease. In team meetings they were not asked to represent all parents or patients with CKD, for that would be an unrealistic demand. Instead, they were

able to contribute using their various experiences with CKD during the research process. For example one research partner wanted to organise extra focus groups with teenagers with CKD and the other suggested to include diverse patients' stories in the final research report.

In sum, there is no such thing as "the patient". The patient organizations were involved, using their own expertise on collecting patients' stories and organizing peer groups, were able to describe what aspects of diversity among patients were important to take into account when selecting and recruiting patients as research partners or for interviews or focus groups during the agenda setting process. As a researcher or facilitator at the beginning of a research agenda setting project, one does not always know what differences among patients are relevant. The research partners gradually learned about research methods and the academic researchers learned about lived experiences of users that they would not have found otherwise (chapter 3).

A characteristic for research partners is sharing experiences with other members of the research team and with other users during the process. This is especially important for enclave deliberation, in which critical thinking and questioning among users are encouraged in an "enclave" of users in order to share and develop new ideas and perspectives on a topic or situation (Karpowitz, Raphael, & Hammond, 2009). In agenda setting processes, this concept is particularly useful to describe the process in which users take specific steps in order to formulate a research agenda, before engaging in a dialogue with researchers (chapter 4). In the case studies, people with CKD, people with NMD and people with ID shared their experiences and exchanged perspectives, for example in focus groups. This proved to be an important starting point for the research process, since it delivered the basis for a mutual learning process within the research team, but also laid the foundation for mutual learning among users. It proved therefore important that users are involved from the beginning, i.e. from the moment of writing the research proposals (also: Buckley, Grant, & Glazener, 2013; Staniszewska, Jones, Newburn, & Marshall, 2007). When they join a research team or project in later stages, their involvement can become a means to an end, in the sense that they are employed in order to gain answers on the questions that researchers have posed in the first place. In this way users cannot achieve ownership of a research agenda. The process of enclave deliberation prevents that their perspectives are overlooked or ignored and it

provides them with the foundation which they can build on during further dialogue meetings and interaction with researchers.

When users are involved as research partners in the agenda setting process, sharing experiences is, however, not sufficient (Ben-Ari & Enosh, 2013; Lloyd, Preston-Shoot, Temple, & Wu, 1996; VanderPlaat, 1999). Collins and Evans (2002) describe different types of expertise that are relevant for users as research partners. They distinguish interactional and contributory expertise. Interactional expertise creates possibilities *“to interact interestingly with participants”* (Collins & Evans, 2002, p. 254). Users and academic researchers use this type of expertise to exchange perspectives during team meetings, but also to facilitate focus groups where interaction and dialogue between users is essential in order to collect or prioritize topics that users find important for the research agenda. Users who are involved as research partners can show interactional expertise when they ask questions to other users in a way that academic researchers could not have come up with. Chapter 4 describes the example of a research partner asking participants in a focus group *“whether they ever felt they were taken seriously or not.”* When an academic researcher would ask this, the question might be considered as subjective or biased. However, when a research partner uses her interactional expertise when asking participants this question, she creates space for interaction and dialogue. Research partners possess more knowledge about their own community and cultural aspects within that community, which will help them probing questions and establishing rapport with members of their community (Björnsdóttir & Svendsdóttir, 2008).

Contributory expertise is expertise to contribute to the science of the field being analysed (Collins & Evans, 2002). Relating to user involvement in research agenda setting processes, users need their own dialogic process in which they formulate a research agenda from their own perspectives. This is important, because otherwise their unique input can easily be overshadowed during meetings with researchers who are leading in the field of research, ultimately resulting in tokenism. In one of the case studies, this was countered by starting the dialogue meeting between users and researchers with the research agenda that was formulated by people with NMD. This agenda (chapters 5 and 6) then provided the basis for users to exert their contributory expertise in explaining why certain topics mattered from their perspectives on living with a NMD for the research agenda.

Users who are involved as research partners may not possess interactional or contributory expertise from the start of an agenda setting process they are involved in. They may gradually develop these when they join research activities and take up responsibilities within research activities, for example facilitating focus groups, analysing qualitative data and discussing dissemination strategies. Researchers with an academic background can provide the opportunity to develop these kinds of expertise. They can do so by organising team meetings that are open and where ideas can be exchanged freely and by taking time for informal talks in which they share their own doubts and vulnerabilities and take care that research partners are involved in the decision making processes from the start (Mayer, 2011). In such cases, users' experience are not approached as "an obstacle to be surmounted", but as "a resource to be used" (Mayer, 2011, p. 71). The danger here is, that users are involved for opportunistic reasons (e.g. to gather research funds or support dominant research interests (Zipursky Quale & Droller, 2007)), instead of being involved based on an ongoing normative commitment of researchers with inclusiveness and engagement (Greene, 1997; Mertens, 1999). Involvement in research agenda setting then becomes an instrumental endeavour or a methodological issue, whereas collaborating and fostering partnerships from the start implies a process of co-creation and co-ownership between users and researchers.

When engaging in a dialogue with users about formulating an agenda for research, healthcare researchers (both health care researchers and researchers who facilitate agenda setting) in turn have to show interactional and contributory expertise, in order to involve users and create a space for joint learning. In a dialogue meeting between users and healthcare researchers about formulating a joint agenda on NMD, both parties used their contributory and interactional expertise to exchange perspectives and develop new ideas for research topics (see chapter 6). Furthermore, during the team meetings of mixed teams for research agenda setting (i.e. consisting of users and facilitating researchers), both types of expertise proved important when creating equal involvement in deciding how to plan the agenda setting activities and how to proceed in presenting and disseminating the findings of the research agendas (chapter 3).

When a joint research agenda is achieved, both parties, users and healthcare researchers, have delivered input in formulating the agenda. In some approaches a joint research agenda was formulated consisting of topics for research that are nominated by researchers and users

separately (Elberse, Caron-Flinterman, & Broerse, 2011; Rafie, Zimmerman, Moser, Cook, & Zarghami, 2019). Thus, the research agenda is a combined agenda, which can be regarded as the result of a multidisciplinary approach that leads to a broader research agenda with additive topics (Austin, Park, & Goble, 2008). In our studies, we aimed to go beyond this, and to engage users and researchers in collaboration ending in a dialogue about research agenda setting, they end up with a joint agenda which consists of newly discussed topics. The case study about setting an agenda on NMD ended with a dialogue meeting in which users and researchers explained their perspectives and formulated new, integrated topics for research (chapter 5). People with NMD discussed the wish for finding a cure for NMD, but also for treating symptoms and complaints that proved difficult in their daily lives. Researchers in turn explained the value of ongoing research about finding the causes of NMD, hoping that this will - probably in the long term - result in curative treatments. However, on the short term, more attention could be paid to finding symptomatic treatments of different types of NMD. Thus, in this dialogue meeting one of the resulting integrated research topics became “symptomatic treatment of NMD”. This type of research agenda can be viewed as a result of an interdisciplinary process, since there is an integration of knowledge (Austin et al., 2008), resulting in a co-production of topics for a joint research agenda. In this interdisciplinary process both parties were able to clarify their perspectives and interpretations on what they considered as valuable research topics. Engaging in a joint process of dialogue and mutual understanding prevents that parties have to choose between research topics that were formulated from their own perspectives and topics from the perspectives of the other party. In a dialogue it does not matter so much which topics are considered more valid or more important on a the research agenda. Rather, by illuminating the different perspectives on the topics, new and shared topics can be formulated which imply a “redefinition of the research agenda” (Liberati, 2011, p. 1778).

7.1.2 INCLUSION, EMPOWERMENT AND DIALOGUE IN COLLABORATIVE RESEARCH AGENDA SETTING

In the introduction of this dissertation, three approaches for user involvement in agenda setting were distinguished: consultation, collaboration, and control. A collaborative approach was presented as more promising than user consultation and user control in agenda setting processes, because it gives more opportunity to joint learning.

The case studies were carried out using a collaborative approach. This meant that users collaborated with researchers in order to set an agenda for research, being involved in all phases of the agenda setting process and sharing in decision making. In this approach users are research partners and have a shared ownership of the resulting research agenda. In comparison, when adopting a consultation approach for user involvement, users would be asked about topics for a research agenda, but would not be able to exert any influence in decision making, prioritization or in actions undertaken during the agenda setting process. On the other hand, an approach based on user control implies that users set the research agenda themselves, taking full control of the agenda setting process, making all decisions themselves and owning the research agenda. As a result, researchers can only be involved within the boundaries that users have set beforehand and can only react on topics formulated by patients.

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. This entailed a normative choice, because it values inclusiveness, mutual empowerment, reciprocity, deliberation and dialogue and social change (Abma et al., 2001; Abma & Stake, 2001; Greene, 2001; Mertens, 1999; VanderPlaat, 1999). In the field of ID “inclusive research” describes research that involves people with ID as active participants (Björnsdóttir & Svendsdóttir, 2008; Kramer, Kramer, García-Iriarte, & Hammel, 2011). In a collaborative approach, inclusiveness is also important, and translates in users developing ownership over the research agenda, involving them from beginning to end as equal partners. In the cases studies, in order to “getting to know each other” it proved important to set a first meeting which was not (only) dedicated to setting out goals and actions. Instead, the initial meeting was dedicated to sharing expectations, explaining one’s backgrounds and asking each other questions. These preliminary meetings set out a path for dialogue and reflection in other meetings during the process. This helped in sharing new insights, creating new ideas for the development of the project and interpretation of the results.

Empowerment is strongly associated with both emancipatory and participatory approaches in research methodology in the social sciences and evaluation (Fetterman, Rodríguez-Campos, & Zukoski, 2018; Patton, 1997; Ramcharan, Grant, & Flynn, 2004). In an emancipatory approach, empowerment and altering power relations within research is the main feature. In

participatory approaches, being involved in research is also considered as potentially empowering for users, but the aim is first of all to get their voices heard (Patton, 1997). Both approaches are valuable for user involvement in research agenda setting, where it is also expected that this will lead to empowerment of especially vulnerable groups who are often overlooked or excluded from research. Empowerment is associated with fostering improvement in the lives of people, with self-determination and with freedom of choice (Fetterman et al., 2018). However, in a collaborative approach for research agenda setting, relational empowerment is a more fitting term in order to describe what happened in the research teams during the different case studies. During dialogues about research agenda setting, there is not so much a transfer of power from the one person to other. Instead both parties, by interacting with each other, share decision making power and recognize that empowerment is a mutual process where everyone involved contributes to the construction of knowledge (VanderPlaat, 1999). Thus, relational empowerment acknowledges that empowerment is always mutual, and that there is a process of joint learning, not one person teaching the other. As a researcher I developed interviewing skills in which my questions complemented the questions posed by the research partner, who was asking questions from her own experiences. This also meant that users as research partners decided on how to organize the research activities. For example, users who were involved as research partners decided on organizing extra focus groups with specific groups of people that they found had been overlooked in research proposals. In the project on CKD, this was a focus group with teenagers and in the project on ID, this was a focus group with ex-homeless people with ID. As a consequence professional researchers had to be flexible in creating space in the research plan and not considering the research plan as a blueprint.

In the case studies a collaborative approach for research agenda setting was adopted from the start. However, a collaborative approach allows for flexibility and this proved important during the agenda setting process. Using elements from the other approaches for research agenda setting (i.e. through consultation and through control) proved beneficial. In a collaborative approach, taking recourse to consultation and control requires dialogue and in mutual agreement between all parties involved in the process. There can be phases or situations in which users indicate that consultation of other users would be better suited in the agenda setting process. On an individual level, involvement through collaboration can be

too taxing or time consuming for users, especially when they are in a particularly vulnerable place in life. This was the case in the study on NMD, when it was decided that asking people with the diagnosis ALS (a highly progressive NMD) to contribute in a dialogue meeting with people with other NMD diagnoses would not be feasible for the people involved. Other studies, for example in the field of palliative care, have shown that involvement through consultation is a better approach for research agenda setting (Wright, Hopkinson, Corner, & Foster, 2006). On a collective level, involvement in research agenda setting through collaboration can be too taxing for patient organizations, for example when they struggle to find resources or lack capacity to get their members actively involved in research agenda setting (Abma, Pittens, Visse, Elberse, & Broerse, 2014; van de Bovenkamp, 2010). If adhering to a collaborative approach in fact would lead to the exclusion of users during the agenda setting process, because they are not capable or willing to be involved in a collaborative endeavour, it is necessary that all parties can engage in a dialogue on how to incorporate consultation of users within a collaborative project. Thus, active involvement of users should not be accomplished for dogmatic reasons, but emphasis should be on the needs and wishes of the people involved and on feasibility and benefits of inclusion (Banks & Brydon-Miller, 2019; Ward & Gahagan, 2010).

In conclusion, within a collaborative approach a variety of strategies can be followed (Kramer et al., 2011). It is important that all parties involved must engage in a dialogue on user involvement in a way that follows their needs and capabilities. Users obviously have different identities, and in turn their involvement may even lead to reconfiguring their identity and finding a greater sense of agency (Thompson et al., 2012). As was found out in the case studies, some users prefer to be consulted only about research topics and others are committed to engage in a dialogue with researchers or become active members in recurring focus groups about a research agenda. In an approach based on consultation existing structures for decision making remain intact, while an approach based on collaboration or control challenges existing power structures within research agenda setting. The case study with people with NMD (chapter 6) most clearly showed that there can also be a growing collaboration in research agenda setting. In this case study a core group of active members of the patient organization showed an increasing commitment during the process. This core group was initially consulted in focus group meetings, but later, upon their own request, commented on the concept

version of the priority setting questionnaire and gave their input on interpreting the findings of this questionnaire and actively took part in the dialogue meeting with researchers. This showed an increasing ownership not only over the research agenda, but also over the agenda setting process.

7.1.3 RECURRING ISSUES FROM USERS ON RESEARCH AGENDAS: VALUES, IDENTITY AND RELATIONSHIPS

In the three case studies, a broad range of issues was formulated by users to be put on an agenda for research. The case study about agenda setting with people with CKD delivered a range of themes that reflected critical moments in the lives of people with CKD. These were further refined in themes about critical moments in the daily lives and in their illness history. For example, people with CKD prioritized themes relating to regaining or maintaining autonomy in their lives and also demanding more attention for issues that emerged after having received a kidney transplant and having to deal with side effects of medication or chronic fatigue (Schipper, 2012).

The case study about research agenda setting with people with ID not only resulted in themes for research but also made visible values that were crucial in the lives of people with ID (chapter 4). For example, friendship was prioritized in a focus group meeting with people with ID, who considered this a theme that impacted their lives most radically and that should receive more attention. They also mentioned the importance of coaching and receiving support in their lives which helped them deal with overcoming difficulties and being able to stand up for themselves when they felt not being treated equally with others.

The case study about research agenda setting with people with NMD resulted in themes on four main domains: health, quality of life, quality of care and support and foundational themes (chapter 5). Within these domains, themes relating to finding a cure for NMD, maintaining a healthy partner relationship, ways of preserving mobility, possibilities for movement and training and self-management, were prioritized.

The research agendas can be characterized as holistic, because of the interrelatedness of the themes and the various life domains to which the themes are connected. Because of this interrelatedness, users and research partners mentioned that prioritization could be difficult. For example, experiencing chronic fatigue impacted various aspects of social life of users. In

the final reports on the case studies this resulted in the inclusion of users' stories in order to show the connection and interaction of different themes in the daily lives of people.

Overall these research agendas show that research themes formulated by users are not exclusively linked to their chronic disease or disability, but also reflect important issues related to identity. Learning how to live meaningful lives when experiencing limited or decreasing possibilities, coping with prejudice or ignorance, sometimes having to find a new sense of self are themes underlying various themes on the agendas.

The themes were not necessarily related to the lives of individual users, but also reflect relational aspects of their lives, as interactions with others (e.g. partner, friends, children) were threatened by having to deal with a disease or disability. Users expressed their concerns about being able to maintain balanced relationships while at the same time being dependent on support from others. These themes deliver an added value to more specific medical or treatment related themes, because they provide a context for how people continuously translate and implement treatment related decisions into their daily lives (Teunissen, Visse, & Abma, 2015; Visse, Teunissen, Peters, Widdershoven, & Abma, 2010). The prominence of social themes on the research agendas (especially the agendas for CKD and NMD) show that this is a struggle according to users should be addressed more in research. For example, specific instructions on exercising in order to gain a better overall physical condition can be difficult when all energy is spent on getting back to paid work. For researchers it is important to attune to this by engaging in an ongoing dialogue with patients and patient organizations.

In the case study on NMD the prioritized themes from the perspectives of people with NMD was the starting point for a dialogue meeting with researchers in the field. This dialogue resulted in new, broader formulated research themes which also contained the reaction and contribution of the researchers on the agenda (chapter 6). Other studies show that prioritized themes after a joint agenda setting process indeed can have a broader scope (Buckley et al., 2013; Rafie et al., 2019). A broader definition of a research agenda can be advantageous because it offers researchers more possibilities for multidisciplinary collaboration (Abma et al., 2014). On the other hand a research agenda with more concise topics more specifically highlight the needs and wishes of users (Buckley et al., 2013). In other words, a research agenda with specific topics can be viewed as needs-oriented (Abma & Broerse, 2010).

7.2 REFLECTION ON QUALITY, STRONG AND WEAK POINTS OF THE RESEARCH

Guba and Lincoln (1989) formulated several criteria for discerning quality in qualitative research. I will use these criteria to reflect on the strengths and limitations of the three case studies. As described above a responsive, emergent design was adopted during the studies, which allowed for flexibility and responsiveness to the needs and wishes of the users who were involved as research partners. Often qualitative inquiries follow a meandering route (Zeni, 1998), adhere to a constructivist paradigm and use inductive analysis rather than a pre-set theory as a source for deductive analysis (Manning, 1997). With this in mind, the following criteria have been found relevant in order to establish rigor in qualitative research: fairness, ontological authenticity, educative authenticity, catalytic authenticity and tactical authenticity (Guba & Lincoln, 1989; Manning, 1997; Mertens & Ginsberg, 2008).

Fairness relates to the researcher's efforts to include stakeholders respectfully and meaningfully in the research process (Guba & Lincoln, 1989; Mertens & Ginsberg, 2008). Fairness in qualitative research is also described as the researchers making sure that all participants have an equal chance to express their voices during the process (Manning, 1997). In the case studies fairness was achieved by engaging users in a process of enclave deliberation (Karpowitz et al., 2009), in which they could exchange their experiences and views on possible topics for research. This also allowed users who were less assertive or active members of patient organizations to take part in focus groups in order to engage in a dialogue with other users about formulating a research agenda. Enclave deliberation proved important for achieving fairness, because it helped users to find a collective voice on what they found important for a research agenda. Also the active involvement of users as research partners during the agenda setting processes was a way of achieving prolonged engagement, which gave both the users and the researchers time to build understanding of each other's perspectives, way of life and culture (Manning, 1997). The focus on the empowerment of users sometimes leads to a lack of attention for professional researchers and their expectations of user involvement in research. This is a weak point also described by de Wit, Elberse, Broerse, and Abma (2015), stating that researchers are needed to adjust the health research practice. Developing an agenda from the perspective of users is one thing, but implementing such an agenda is only possible if researchers are willing to do so. Transforming a research culture

requires active engagement of researchers in the process of developing a joint agenda (Abma & Broerse, 2010; Abma et al., 2014; Majid, 2018).

Ontological authenticity refers to the construction of knowledge that users generate during the processes which can make a positive contribution to their well-being (Guba & Lincoln, 1989; Mertens & Ginsberg, 2008). Did the agenda setting process improve the users' conscious experiencing of the world (Manning, 1997)? Users who were actively involved as research partners did express that they experienced personal growth during the agenda setting process. In the words of one of the research partners in the case study on ID: *"I learned (from the agenda setting project) that I am able to learn new things"*. They recognized that their experiential knowledge helped them for example to ask relevant and valuable questions during interviews and focus groups, or to reflect critically during qualitative analysis of the data (chapter 3). Some research partners have published on this topic (Schipper et al., 2010; Teunissen et al., 2015). They also became aware that they held specific interactional and contributory expertise that they could share within the team, which gave them in turn confidence and ownership. However, not only their involvement in the agenda setting process empowered them (Björnsdóttir & Svendsdóttir, 2008). Maintaining friendships, being actively involved in patient organizations also contributed to their well-being or them feeling empowered.

Educative authenticity means that knowledge is shared between stakeholders during the process (Guba & Lincoln, 1989; Mertens & Ginsberg, 2008) and that users' understanding, also of other users' perspectives, is broadened by being involved in the agenda setting process (Manning, 1997). This became apparent in the dynamic between users who were interviewed or who took part in focus groups and the research partners who interviewed them (individually or in focus groups). The contribution of the research partners and their active role in agenda setting for research encouraged other users to learn from the experiences they shared. For example, in the case study on CKD during conversations respondents would in turn ask questions to the research partners about how they had handled certain choices they had made in their lives (chapter 4). Educative authenticity could also be noticed in the dialogue between users and researchers in the NMD case study, as both sides learned about topics they had prioritized for research and why. For agenda setting processes in general, it is important

to foster this type of authenticity, because it benefits mutual understanding and increases chances for gaining new insights and ideas on research.

Catalytic authenticity occurs when the results of the research prompt stakeholders to take action (Guba & Lincoln, 1989; Manning, 1997; Mertens & Ginsberg, 2008). Can knowledge developed during setting the research agendas can be applied by users in the stages after research agenda setting, i.e. in research programming and implementation (Abma et al., 2014; Manning, 1997)? Catalytic authenticity can be accomplished when users have gained capacities to exert influence on these later phases of the research process. On the one hand, several users expressed in the case studies that they felt better equipped to engage in dialogues with researchers, knowing that they had a thorough and reliable research agenda from the users' perspectives to rely upon. Widespread dissemination of the research agendas in the patient organizations who were involved in the case studies helped in this regard. For example, in the case study on CKD, a member of the patient organization with a background in journalism made a user-friendly brochure about the research agenda of users with CKD. On the other hand, only the case study on NMD ended in a heterogeneous dialogue between users and researchers, whereas the two other case studies resulted in a homogeneous dialogue among users about a research agenda. This can be considered a weak point in terms of changing a research culture and has later been described by others as well (Abma et al., 2014; de Wit, 2014; Elberse, 2012). In the case study on ID, timing proved to be an important factor, since in retrospect the moment of finishing the users' research agenda did not coincide with the start of the new funding program. This is a weak point in terms of implementation. Catalytic authenticity could have been improved by organizing multiple dialogue meetings between researchers and users, for example with different topics from the users' agenda as a point of departure in the dialogue. This might lead to a more specific research agenda in which users, researchers and research funds would have co-ownership. In further phases of the research process, this might facilitate the uptake of co-constructed topics into research.

Tactical authenticity means that participants in research develop the skills to use research results to confront oppressive structures in society (Guba & Lincoln, 1989), and that researchers create opportunities for participants to remain involved in research and to be able to communicate and interact with other stakeholders, especially those in power positions (Manning, 1997; Mertens & Ginsberg, 2008). In the case studies, it would mean that after the

research agendas were finished, users and research partners had developed the skills to use the research agenda in order to change research practice and to have become equal partners in research agenda setting, programming and implementation (Abma et al., 2014). After the case study on setting a research agenda for CKD had finished the Kidney Foundation used this research agenda for their program on social-scientific research on CKD. In other words, this research agenda delivers input for researchers to take into account when they submit research proposals. Other research funds have integrated the research agenda into programs and developments within the funds (Teunissen et al., 2013). For example, ZonMw (The Netherlands Organisation for Health Research and Development) has taken several initiatives stimulating the involvement of users, or asking researchers to clarify how their research proposal is relevant for users. In the field of NMD, after the case study ended, individual researchers who were actively involved in the agenda setting process, have incorporated topics from the research agenda in new research projects. Also they have reflected on the relevance of their research for people with NMD in proposals and publications (Cup et al., 2011; Voet et al., 2014; Voorn, Gerrits, Koopman, Nollet, & Beelen, 2014).

When considering the position of the users who were actively involved as researchers in the case studies, the process of relational empowerment has helped them to pursue new activities, mainly aimed at for education. It is a weak point in this dissertation that there is not enough evidence to claim that the case studies, which were carried out separately, contributed on a whole to tactical authenticity. In order to improve tactical authenticity, including users in advisory committees for research funding could have increased the chance of more active involvement of users in the formal programming and implementation of the users' research agenda (Abma et al., 2014). On the side of the patient organizations that were actively involved in the case studies, it is not entirely clear if they have become more involved in research agenda setting, programming and implementation. More initiatives around capacity building for patient organizations are probably beneficial for increasing tactical authenticity for user involvement in research.

7.3 RECOMMENDATIONS FOR FUTURE RESEARCH ON USER INVOLVEMENT IN RESEARCH AGENDA SETTING AND PRACTICE OF HEALTHCARE RESEARCH

Based on the experiences in the projects reported in this dissertation, some recommendations can be formulated. I first describe implications for future research on user involvement in research and in research agenda setting. Secondly, I describe implications for research practice in healthcare, specifically for collaborative approaches in the practice of healthcare research.

Directions for future research on user involvement:

- Prolonged engagement of users in research and research agenda setting is not self-evident. Following research projects on a longer term can give insight into factors that enable (or limit) prolonged user involvement in agenda setting, and in consequent stages of research programming and implementation.
- Societal impact of user involvement needs to be assessed. Societal impact should be operationalized, preferably in collaboration between users, policy makers and researchers. It should be evaluated in the longer term, since it is likely that the effects of user involvement will take longer to become apparent.
- Decision making processes and power relations in research agenda setting require attention. The process to establishing a national science agenda (De Kenniscoalitie, 2015), initiated by the Dutch Ministry of Education, Culture and Science might be evaluated, in order to clarify how citizen participation in research can be facilitated and implemented further and whether this project also instigates shifts in power relations within the research arena.

Directions for the practice of healthcare research:

- In educating healthcare researchers, more attention should be paid to collaborative, participatory and emancipatory approaches to research in healthcare. This education should be evaluated from a user perspective.
- Research funds should maintain actions and initiatives towards including users in research. The Dutch Kidney Foundation is an example of a research fund that has

shown continuous efforts in familiarizing researchers with a research agenda from the perspectives of users.

- User organizations and patient associations should continue research agenda setting projects and also strive at establishing partnerships with researchers from the early stages of exchanging perspectives and writing new research proposals.

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