

Collaboration and co-ownership in research: dynamics and dialogues between patient research partners and professional researchers in a research team

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Abstract

Background Different strategies by which patients can be involved in research include consultation, control and collaboration. This article focuses on collaboration within research teams and considers this with reference to a research project about setting a social–scientific agenda for health research from the perspectives of patients with a chronic kidney disease (CKD).

Objective To examine the dynamics and dialogues in a collaboration between patient research partners and professional researchers.

Design 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.

Results 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.

Conclusion and discussion The 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.

Introduction: consultation, control and collaboration

Recently, the involvement of patients in health research has been gaining ground. Besides qualitative, pragmatic and political considerations, normative arguments lie at the core of this development. Patients are the end-users and are thus considered stakeholders in research. Their perspectives and experiential knowledge can contribute to the research process¹⁻⁴ and thus lead to research that better relates to patients' needs and expectations.⁵⁻¹¹ Arnstein's¹² participation ladder discusses the different levels at which citizens gain increasing control or decision-making power in policy and practice. In health research, this ladder has been adapted to encompass patients' degrees of involvement.¹³ Three levels of participation can be distinguished: consultation, control and collaboration.

Consultation is one of the commonest strategies for patient inclusion. In some research agenda-setting projects, patients participated in advisory-type roles, sharing their views with researchers or research committees. They also nominated research topics, for example in the areas of ulcerative colitis,^{14,15} cancer,¹⁶ asthma and COPD.¹⁷ In other studies, patients were consulted on the design of clinical trials.¹⁸⁻²¹ Some studies point at mismatches between the topics that patients nominate for clinical research, those that clinicians and clinical researchers find important for further research, and current research practice.²²⁻²⁴ In the United Kingdom, the James Lind Alliance was established to address such mismatches (<http://www.lindalliance.org/index.asp>). The participation of vulnerable, often marginalized or underrepresented groups in research breaks new ground. In research involving elderly people and people with learning disabilities or mental health problems, there is a trend towards incorporating their views and experiences into the research.²⁵⁻³⁰

Control means that patients have the prime decision-making power over all strategic choices in research. In some studies, patients help for-

mulate a research bid and decide on the research and methodologies.^{31,32} Patients or their family members also act as entrepreneurs, for example in the Duchenne parent project (<http://www.Duchenne.nl>) and PXE International (<http://www.pxe.org>) by raising money and setting up blood banks.

Although consultation and control differ in the degree of participation, in both instances, there is one party that takes the lead in the interaction. Either the researchers are in charge by formulating questions to which patients can respond (consultation), or the patients are in charge by determining the research (control). This is not to say that iterative contacts between patients and researchers do not exist. There are situations where patients control some research, and engage with researchers who conduct the work, under guidance of the patients. The point is that the ownership lies in the hands of one actor and that dialogue and interaction are kept to a minimum. This is quite different in the case of collaboration, where patients are as 'coresearchers' involved in all stages of the research process, sharing control and co-labouring on an equal basis with academic researchers in a going process of dialogue and interaction. Few studies describe this degree of participation. Examples are studies on migraine,³³ cancer,^{34,35} learning disabilities,³⁶ schizophrenia,³⁷ spinal cord injuries³⁸ and rheumatic disorders.³⁹⁻⁴¹ Some examples also exist outside health research, for instance involving community members as research partners,⁴² especially members of particular linguistic groups⁴³ and former sex workers.⁴⁴ However, most of this literature focuses on the substantive results; less attention is paid to the process of participation from the perspectives of the insiders.

The aim of this article is to specifically examine the dynamics and dialogues that emerge in the collaboration between patient research partners and professional researchers within the research team, where different perspectives, experiences and opinions are brought to the table. Instead of rigidly adhering to the dominant scientific paradigm and academic jargon, the team members find themselves searching for

and probing new ways of collaborating. In this process, dialogue can be seen as a force and forum for democratization;^{45–48} that is, an open, deliberative and inclusive dialogue improves the democratic quality of decisions about the research process and interpretation of results. It can also serve as a forum for reconsideration and reflection.^{45,49}

In this article, these notions of dialogue are examined further via the case of a research agenda-setting project in which patient research partners and professional researchers co-operated. The ‘research partners’ we refer to were involved in the project because of their personal experiences with chronic kidney disease (CKD), whilst the ‘professional researchers’ were involved by virtue of their employment at the university. The goals of the project were to formulate an agenda for social–scientific research from the perspective of patients with CKD and to develop a methodology to involve patient research partners in all stages of the research process. First, we describe the background of the research project and the methodology. We then focus on the collaboration in the research team, examining how a dialogue emerged, what was discussed and what added value this dialogue brought about. By doing so, we shed light on both the enhancement of the quality of the data as a result of the collaboration between patients and professionals, and the relational dynamics of their collaboration.

Case study: an agenda for social–scientific research on chronic kidney disease

The agenda-setting project, aiming at formulating a research agenda from the perspectives of patients with CKD, was carried out in Maastricht University and the Dutch Association of Kidney Patients (Nierpatiënten Vereniging Nederland) from December 2005 until February 2007. The patient association was established in 1977 to protect the interests of patients who underwent dialysis and kidney transplant as well as their partners and families. It has approximately 7200 members when compared with the 13 176 patients who received renal replacement

therapy – i.e. dialysis or a kidney transplant – in 2008 in the Netherlands (Dutch Renal Replacement Registry, Renine). It is largely run by volunteers who are patients with CKD and their partners or families. The Dutch Kidney Foundation (Nierstichting Nederland), which initiated and funded the project, was established in 1968 and financially supports the patient association. Its other main tasks include financing biomedical research on nephrology, improving patient care, and treating and preventing kidney disease.⁵⁰

The premise was that the involvement of patients with CKD would enable the setup of an agenda for social–scientific research that legitimately reflects the experiences of patients in their daily lives. The result was indeed an agenda related to 27 critical moments in the lives of patients with CKD and questions for research.

Responsive research

The research design was based on the responsive methodology originally developed as an approach in evaluation studies. It aims to enhance personal and mutual understanding of a situation by fostering dialogue about relevant issues among various stakeholders.^{46,51–59} It was adopted for this project to involve patients with CKD in developing a research agenda and to establish a dialogue between professional researchers and patients. The methodology was refined and validated in other research agenda-setting projects, for example on spinal cord injuries.^{1,2,13,38}

A responsive methodology follows an emergent design and often integrates qualitative and quantitative research methods. In the project here, we chose to use only qualitative techniques to elicit the research agenda from the perspective of patients. Both the patient research partners and the professional researchers were actively involved in every research activity (Table 1). The co-analysis of the in-depth interviews and group interview resulted in a list of possible research topics, which were then further discussed and prioritized in focus groups of patients with CKD. Additional focus groups later translated

Table 1 Methods used for data collection stage and the involvement of patient research partners

| Method for data collection | Number of respondents/participants (total) | Involvement of patient research partners |
|---|---|--|
| In-depth interviews | 27 respondents | Co-interviewer, analyst and writer |
| Group interview | 1 group interview; 3 participants (teenagers) | Comoderator, analyst and writer |
| Focus groups for prioritizing research topics | 2 focus groups; 19 participants | Comoderator, analyst and writer |
| Focus groups for formulating research questions | 5 focus groups; 36 participants | Comoderator, analyst and writer |
| Participant observation | Observations and informal talks at two dialysis centres | Coparticipant observer, analyst and writer |

the prioritized topics into concrete research questions. To facilitate contact with difficult-to-reach respondents (e.g. elderly people, very ill patients), observations and informal interviews were held at two dialysis centres. The patient research partners also collaborated in the writing process.

An inductive, content analysis of the interviews was performed in line with the Grounded Theory approach.⁶⁰ First, each entire interview was read to identify emerging (sub)themes. Labels were attached to the text parts related to a specific (sub)theme. Any new emerging themes were added to the process of labelling and analysis and adopted to the interviews analysed previously. In a next step, the data of the different interviews were grouped into clusters based on the main emerging (sub)themes in the interviews. Given the participatory aims, we actively involved the participants of the focus groups in this process of categorization and clustering by presenting them the themes from the interviews, asking them to further deepen and broaden the initial set of themes, and inviting them to search for relations between the themes. This cyclical, hermeneutic-dialectic process helps to prevent bias and adds to the validation of findings.⁵⁴

A responsive methodology is related to participatory research approaches, but places more emphasis on dialogue and relational empowerment. In participatory research, collaboration in the research process with patients, consumers or 'users' can be characterized in terms of control

over that process.^{61–63} In contrast, a responsive methodology emphasizes the use of dialogue to facilitate collaboration between patients and professionals. It creates space for the exchange of perspectives, opinions and experiences, and for possible controversies, contradictions and ambiguities.^{13,45} It values this diversity, rather than expecting a priori agreement between parties.

Participatory research often aims at empowering vulnerable and marginalized groups.^{64,65} A responsive methodology shares this goal, but regards empowerment as a mutual process. 'Relational empowerment'⁶⁶ should not be understood as a transfer of control from the 'empowerer' to those in need of empowerment. Rather, it demands mutual acknowledgement that everyone is involved in constructing knowledge in research and that everyone enters with an open mind and can change during the process.⁶⁶ All are both object and subject in the empowerment process.

Finally, in participatory research, the professional researcher acts as a coach or facilitator who delegates power and supports patient research partners in carrying out the research activities themselves.^{61,67} Ultimately, patients are in control. A responsive methodology, however, places more emphasis on the exchange of perspectives between patients and professionals to bring about a mutual learning process. The professional researcher, far from being a distant party, is also involved in this dialogical process, not solely as the coach of a vulnerable

Table 2 Central methodological notions in a responsive research design (based on 2, 13, 54)

| Central notion in a responsive methodology | Translation to the collaboration with research partners |
|---|--|
| Start with stakeholder group with least influence | Patient research partners are involved in the design of the research, and in the way, the research activities are organized |
| Focus on experiential knowledge | Patient research partners share their experiential knowledge with the professional researchers throughout the research process |
| Interaction of stakeholders | The interests of patient research partners are included in the process. The research design can be renegotiated according to their needs and expectations |
| Mutual learning | Both patient research partners and professional researchers change and develop new thoughts and ideas by interacting and listening to each other's stories |
| Openness and respect | Respect, openness, trust and involvement are stimulating for a dialogical process in which patient research partners and professional researchers mutually learn from each other |

party, but rather as a facilitator of the dialogue between all who are involved in the process.^{49,58} Patients and professionals thus share control and collaborate.

Table 2 summarizes the central notions of a responsive methodology and translates them into the collaboration with research partners.^{2,13,51}

The university's Research Ethics Committee indicated that the project did not need ethical approval as it did not involve invasive medical research. The respondents' prior permission was asked to record the interviews and focus groups, and the transcripts were anonymized. At the start of the interviews, respondents were informed that they could choose not to answer questions or take a break if and when they wanted. At the start of the focus groups, participants were also asked to treat the information shared by their peers as confidential. Reports that were made of the individual interviews and focus groups by the research team were sent to the respondents and participants, in order to give them the opportunity to respond. Such member checks are considered as central in collaborative action research as they do not only help to consensually validate findings, but also prevent exploitation and hand over some ownership and control to the participants.⁶⁸

As pointed out, extra critical ethical issues arise in the case of collaborative action

research.⁶⁹ Especially when it concerns the evaluation of partnerships. Relationships and team work are complicated and a sound evaluation even more sensitive. In our study, we dealt with this through the creation of open, equal and honest relationships, broad sharing of information and creating space for every voice to be heard.⁶⁸ In all our meetings, we had moments when we reflected on the dynamics within the team. This was not obligatory, but we spontaneously shared experiences and emotions and analysed them together. No external researchers were present at these meetings or in the evaluation of the research process.

Later we jointly decided to publish these findings. First in our research report and later in an ethno-drama with one of the research partners as first author.⁷⁰ A member of the Patient Association (who had a kidney disease herself) wrote a brochure about the research findings, which was especially aimed at patients.⁷¹

This article was also a coproduct of the whole research team although it was written up by academic researchers. The research partners did however actively participate in the writing process and gave feedback on earlier versions and stated that the dynamics and dialogue as described in this paper are recognizable to them.⁵⁴ Part of the discussion was also whether or not to use real or fictive names. We all felt that we could be open about our team work and

that it made no sense to use pseudonyms as we worked so closely together. We felt that the co-authorships reflected the partnership within the research team, and that it stimulated all members of the research team to be open and willing to share their vulnerabilities, insecurities and personal learning experiences during the research process.

Preparations within the research team

The research team initially consisted of three professional researchers, including the project leader. The patient association then recruited potential research partners from among its own members who did not hold an active role in the organization. It made clear that the research partners would be expected to provide an 'authentic' contribution (i.e. to share their own authentic experiential knowledge equally and freely rather than pursue an advocacy role for the association). The project leader expected the research partners to be interested in research, preferably involved in all research phases, and aware of the experiences of other patients with CKD besides themselves. The latter was considered important as it would enable the research partners to better approach the research and interpret the results from a broader intersubjective context. No other specific competences or educational qualifications were required of the research partners. They did not receive a formal research training beforehand.

Job interviews were organized for three candidates. These interviews were informal in nature, dealing with the candidates' personal stories and their expectations of the project. After the interviews, the project leader agreed with the patient association to admit two (instead of one as planned) research partners to the research team. In this way, they could support and complement each other and their experiential knowledge could be shared more prominently within the team. Both research partners expressed an interest in doing research, were able to invest the necessary time and maintained many contacts with other patients. One was a mother with a background in edu-

cation and a young child who had been diagnosed with kidney failure postbirth. The other was a woman with a background in psychology who had been diagnosed with a hereditary kidney disease and whose mother had CKD.⁷² Although both were university educated, neither had research experience.

The third interviewee was not selected because she had become ill recently and was very occupied with her own situation, especially because she also had to take on care assignments for her family apart from the job. It was concluded with her that there would be a high risk of becoming overburdened.

The job interviews provided the research partners with a sense of being taken seriously and persuaded them of the relevance of their experiential knowledge for the research project. One research partner later described this as follows:

The job interview was quite surprising for me. It wasn't like 'the standard interviews' I had before. We spoke a lot about my situation, my experiences, my feelings, my expectations, my ambitions and my life. It was all about me and my family! The project leader was really interested in my experiences [...] Telling my story and the story of my family raised my awareness and helped me realize I might have an added value for the research project given these experiences.

This illustrates that for a genuine dialogue to emerge, research partners have to be made aware of their unique complementary role. In addition, certain fears or insecurities have to be addressed, for instance in relation to emotional and psychological (and possibly also physical) over-involvement.⁷⁰ It is therefore important that the research partners feel safe and empowered to speak up.

The location of research team meetings should provide an environment conducive to dialogue between its members.³⁹ The research team thus jointly decided to hold these meetings at a central location close to the homes of the research partners, so that they could be organized frequently.

During the initial meetings, the team made concrete plans for research activities, including

the recruitment of patients and the formulation of an interview topic list. Informal talks and personal stories proved very instructive during this stage; they helped the researchers gain an understanding of what it means to live with a kidney disease. The professional researchers were able to move from detachment and ignorance to involvement and awareness; they could better relate to the problems of patients with CKD and were better prepared for the interviews. Based on their experiences, the research partners nominated new interview topics, like the possibility of being bullied at school, the impact of CKD on other family members, and insecurities related to hereditary kidney diseases. This also raised the researchers' awareness of the diversity of the patient population.

In this stage, presentations were also held to inform active members of the patient association about the project and gain feedback on the research proposal. During these presentations, members took on the role of advisers, adding interview topics such as comorbidity. The presentations were delivered jointly by a research partner and professional researcher, which added to the credibility and legitimacy of the project. This is important in a project that aims to involve and engage patients as co-owners. The research team further established contacts with the patient association's regional offices, in order that they might help recruit members for the interviews and focus groups. In sum, the dialogue between the research partners, patient association members and professional researchers resulted in genuine co-ownership of the project.

Paired interviewing

In the next phase, all the possible topics and questions for social–scientific research were inventoried and prioritized. Individual interviews, a group interview and focus groups were held, and participant observation was carried out (Table 2). The dialogue within the team took on a different dynamic in this stage. For the interviews, two pairs were formed consisting of a professional researcher and a patient research

partner. These continued as intimate partnerships during the data collection phase.

Concerning the recruitment of respondents, the research partners again stressed the importance of taking into account various dimensions of diversity, such as age. One suggested interviewing the parents of young children with CKD as well as teenagers, as their perspectives might differ from those of adults with CKD. She made it clear that conditions for dialogue with teenagers would require adjustments, relating to asymmetry, possible distrust, hesitation about speaking up and school commitments. The team therefore deliberately decided to organize a small group interview of girls (as the presence of boys might inhibit them). The research partner contacted parents in her own social network and asked them if they were willing to approach their daughters with CKD participate in a group interview. The research partner took the lead in arranging this group interview and created a climate in which the girls felt secure about sharing their personal experiences, like their sensitivity concerning their body image. The email contacts that the girls had established beforehand, the luxury lunch and the personal gifts (earrings) that they received all contributed to an open atmosphere in which they felt appreciated. This should not be mistaken for the research partner having influenced their participation in the research, as the lunch and gifts were a surprise to the girls. It also helped that the research partner could relate to their problems, given her son's experiences.

A dialogue within the team also emerged on how to conduct individual in-depth interviews with adult patients and parents of young children with CKD. Before the pilot interviews, arrangements were made among the pairs about the introduction to the interview, the explanation of the interviewers' backgrounds and involvement of the patients as research partners, and the reassurance that both parties would equally engage in asking questions. For the research partners, these pilot interviews served as a means to learn by doing (i.e. to practise technical skills like asking questions and probing for answers). For the professional researchers,

the pilot interviews were important in that they heard the patient's entire story, with all the emotions, insecurities, hopes and fears that it entailed. As a consequence, the pairs built up a partnership that proved very useful in the later stages of the research process.

As in the meeting with the teenagers, the participation of the research partners as interviewers also created an open atmosphere in which respondents felt their experiences were recognized. On occasion, respondents even directed questions to the research partner, as illustrated by this interview fragment:

Respondent: [My son is] a bit behind cognitively, for example in his perception of risks and of things that might happen. ... But how is that with [your son]? Does he attend a regular school or a special school?

Research partner: He attends a regular primary school, but [as a parent you notice] that he knows his body very well and when something happens, he can start worrying tremendously ...

Professional researcher: About the kidney transplant. Did either you or your husband ever consider donating one of your own kidneys to your son?

Respondent: We were both screened, but we initially wanted to keep this option open for emergencies. So we later have a possibility to donate one of our kidneys ... if his health really gets worse and he really needs it. And you?

Research partner: We also decided to save our kidneys.

Respondent: Yes [...] if his transplanted kidney is rejected [...] we'll have something to fall back on.

This interaction created a somewhat confusing situation for the professional researcher, who felt left out in this turn of the interview, and the research partner, who felt insecure about how to answer the respondent's questions. On the other hand, this dynamic also shows that the relationship between the research partner and the respondent became one of equals, in which both could exchange personal experiences and perspectives. During the interviews, respondents appeared to experience no barriers in explaining their stories when research partners were involved. In fact, they seemed to feel open, at

ease, and understood by someone who had shared the same experience.

Co-analysis and cowriting

After the interviews, which took place at the respondents' homes, the research partner and researcher usually travelled together by bus or train. During this time, they shared their impressions and experiences of the interview, which gave rise to the first 'informal' analyses of the interviews. Both researchers were able to start identifying the main issues from the interviews and checking whether they agreed on or could add to these. This fostered a mutual learning process. Later, the transcripts were read independently by the other members of the research team (i.e. the other interview pair and the project leader). This form of check-coding,⁷³ meaning that more researchers were involved in the process of data analysis, helped prevent possible over-identification with the respondents' story.

On one occasion, an interesting dialogue emerged during an informal conversation between the research partner and the professional researcher after visiting a dialysis centre. There they had seen patients at their most vulnerable, mainly older people and people of non-Dutch ethnic backgrounds, hooked up to a dialysis machine and experiencing increasing fatigue as a result of the treatment. When reflecting on their observations afterwards, the pair talked about the patients' frailty, and how they had connected with the patients in light of this. The researcher felt that her basic interviewing skills had helped her to make contact with people and ask open questions about their situation. The research partner found it helpful that she knew what dialysis was and how burdening it can be for patients. It became clear that both researchers felt empowered to approach patients in this setting as a result of each other's presence. They shared the difficulties of starting conversations with vulnerable patients, and views on the sober atmosphere and lack of interaction between the nursing staff and patients. The research partner could place this in

perspective; she knew other centres which were less depressing. The professional researcher could relate the conversations to her previous experience of interviews.

After finishing each interview, either the research partner or the professional researcher undertook the first full analysis of the interview. These analyses were subsequently discussed in the team meetings. The team jointly developed a framework for analysis, in which attention was paid not just to derive themes that would eventually constitute research agenda topics. The research partners stressed the life context in which respondents had mentioned various issues, and in doing so drew attention to the critical moments in patients' lives and illnesses, the accompanying feelings and emotions, and the values that were at stake at these moments. They could relate to the patients' personal circumstances and often provided a richer, more metaphorical interpretation of the patients' stories. For example, they explained the importance for many patients of celebrating the day of their kidney transplant as a birthday, the day of a 'new beginning'. The research partners were able to assist the researchers in exploring the meaning of living with CKD. They also pointed to the interrelatedness of critical moments, especially between issues in daily life and issues related to the medical aspects of kidney disease. For example, they further elaborated on the difficulty of dealing with a limited daily fluid intake when on dialysis and of maintaining social contacts. Mere lists of themes would be hard pressed to illuminate this complexity in the lives of patients with CKD. The team therefore decided to include short life stories in the final report, such as an insider's story of a kidney patient receiving haemodialysis, and a mother's perspective of her young child's life with CKD. These were written entirely by the research partners.

The dialogue that emerged during the analysis phase contributed to a research agenda which was not just a dry enumeration of research topics and questions, but encompassed a more holistic perspective that was recognizable for patients with CKD. This was later confirmed by

comments from patients with CKD and members of the patient association who had become committed to the research project. For example, a member of the patient association wrote a short, accessible version of the final report, financed by the Kidney Foundation and distributed among members.

Discussion and conclusion

Patient participation often means interviewing patients in an effort to bring their views to the table. The researcher predefines the questions, directs the analysis and draws conclusions, safeguarding the scientific quality of the research. However, assembling patient views necessarily means neither that they genuinely influence the research process nor that the outcomes are relevant for patients. Although consultation is a preferred alternative to mere objectification, patients' unique perspectives and voices can easily get lost in the researcher's interpretation of the outcomes, resulting in conclusions that are no longer recognizable for patients. Researchers tend to overlook the complexity and capriciousness of living with a chronic disease, reducing the meaning of life experiences to abstract themes and models. Researchers can also easily overlook the practical applicability and acceptability of the research outcomes in patients' daily lives, or take this for granted.^{14,20,74} As an alternative, patients and their family members have themselves taken up the role of researchers^{74,75} or are striving for more control by initiating and sponsoring research.

In our project, we aimed to empower patients, not by handing power over to them, but by including them as research partners in the entire research process. By fostering open, inclusive and deliberative dialogue, patient research partners as well as professional researchers can learn from one another's experiences and perspectives. A responsive methodology facilitates such a dialogue, because it is flexible, focuses on the involvement of patients, and stimulates mutual learning.

In this article, we showed how a dialogue emerged within the research team, and how the

interaction and dynamics in the team shaped that dialogue. In the preparations of the research, this implied that the professional researchers had to invest in giving the patient research partners ownership in the research process, by making them aware of the value of their experiential knowledge and addressing insecurities as well as expectancies of the research. In the stage of collecting data, the interaction between the patient research partners and professional researchers was fostered by the paired interviewing and discovery that both could learn from each other.

The collaboration of patients in the team contributed to the quality of the substantial findings as they noted the diversity within the patient population and related to the lives of patients in the interviews, using their experiential knowledge to probe. In the analysis of the data, dialogue between professional researchers and research partners resulted in more insights, and further emphasis on the context of the life world of patients with CKD, their values and emotions. This yielded fuller, holistic and meaningful interpretations which showed the interrelatedness of topics on the research agenda. In sum, this dialogic process resulted in new perspectives on social aspects of living with CKD, laying the groundwork for a research programme that can help to meet patients' needs.

The research partners did not receive any formal research training but instead learned by doing. One could argue that this set them back in the research process. Our experience in this project, however, showed that this prompted professional researchers to pay deliberate attention to their specific ideas and approaches. Yet, further research on training research partners is useful. Training could also increase the empowerment of patients as research partners in a team, but we note that this should not stop professional researchers from educating themselves on the life world of patients.¹³

An issue for discussion is whether the inclusion of patient research partners will lead to over-involvement or over-identification. As shown, respondents connect with the research partner, sometimes by directing questions at

them, other times more implicitly by simply sharing their personal experiences. Epistemologically, one can argue that patients will 'go native' if they over-identify with fellow patients and lose the necessary detachment to generate objective information. A hermeneutic perspective – on which our responsive methodology is based – sheds a different light, emphasizing that prejudices are inevitable and can be made productive through questioning and scrutinizing them in dialogue.⁵³ This is exactly what we saw; the research partners brought their experiences and standpoints into play, and sometimes adjusted them in the conversations with fellow patients. Bias due to over-identification was reduced through the interaction with the professional researchers, which resulted in reflection on the process as well as on the content of the interviews and focus groups. Bias was also reduced because the interviews and focus groups included many different patients in terms of stage of illness, age, sex and ethnicity; the research partners themselves also differed in background and experience. Bias was finally prevented by way of a member check, check-coding and the hermeneutic dialectic process.

Another issue for discussion concerns the backgrounds of the research partners. We selected candidates with experiential knowledge as well as knowledge of and a social network among patients. Both had academic backgrounds, which facilitated collaboration with the researchers. We were cautious that their professional and university background would not overshadow their contributory expertise as both sources were important for the project. In our team, we prevented this by constantly addressing their personal experiences ('How is your son lately?') in team meetings. This appealed to their contributory knowledge and created conversation room for the integration of both knowledge bases. The whole team thus became more skilled in their ability to build bridges between science and society.⁷⁶

Finally, one may question whether the inclusion and collaboration of patient research partners is not restricted to qualitative, practical and service-oriented research. We contend that even

in the case of fundamental research, it is worthwhile working with research partners, as they can help to frame questions, set goals and interpret findings. Yet more research into this is needed. It is important not to take advantage of patient research partners simply for the invisible work behind the scenes, such as recruiting patients and holding interviews. Collaboration means that patients and researchers work together, jointly in control. It is the dialogue between the parties that enriches research, produces new and unexpected outcomes and increases the co-ownership of findings.

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