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# Patients as Partners in Responsive Research: Methodological Notions for Collaborations in Mixed Research Teams

Tineke A. Abma
Christi J. Nierse
Guy A. M. Widdershoven
*VU University, Medical Center, Amsterdam*

Patients are increasingly actively involved in research. We depart from an approach that understands patient participation as dialogue. This idea is grounded in hermeneutic philosophy and responsive research. Patients are engaged in research via dialogues with other stakeholders. New is the inclusion of patients as research partners. Several methodological notions underpin responsive research. In two health research agenda-setting processes (intellectual disability and kidney disease), 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.

***Keywords:*** *Chronic illness; empowerment; hermeneutics; knowledge construction; participatory research; relationships, researcher–participant; research, collaborative; responsive evaluation*

Recently, mismatches have been reported between research topics of patients and clinicians, and those of researchers (Chalmers, 2006). Participation of patients is promoted to bridge this gap. It is expected that active involvement of patients in research will increase the relevance and implementation of medical knowledge (Oliver & Gray, 2006).

There are many ways to involve patients. We are familiar with patients as objects of research in a clinical trial or randomized controlled study, and as respondents to semistructured questionnaires. Their involvement enhances qualitative research. Open interviews and focus groups create room for patients to bring in their issues. Patients are approached as subjects when researchers try to understand their life-world experiences. Yet, in most cases, patients remain information-givers and their level of participation in research remains low. Emerging is the role of the patient as research partner. Patient research partners are patients who join research teams on an equal basis with professional researchers. They share decision-making power with professionals, and their degree of involvement is closer to the patient as advisor or the patient as research principal.

Several challenges complicate the collaboration between researchers and patients. Most prominent are the asymmetrical relationships between the parties. This asymmetry relates to the high status of scientific

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knowledge in relation to experiential knowledge (Abma, 2005; Blume, 2006; Caron-Flinterman, 2005). The input of patients is easily overruled by researchers, even if unintended. Patients have no training in scientific research, and are not familiar with the technical language and jargon. They often feel uncertain about the value of their input (De Wit, 2004). Since patients are not natural partners in research, they have to gain a position as authoritative knower (Blume, 2006), which is at least partly complicated by the personalized, narrative, situated modes of their communication (Aakster, 1999). The diverging scopes of research (short- vs. long-term; contextualized vs. decontextualized understanding of problems) further complicate the interactions (Abma, 2005; De Wit, 2004; Hewlett et al., 2006). Prejudices and stereotypes also play a role; patients are often considered to be too emotionally involved and subjective to be included in research.

To attend to these problems several methodologies have been developed and translated to the field of health research. Arnstein's (1969) "participation ladder" is among the best known. This model is helpful to understand various degrees of involvement in policy or research processes. We explain its use in the second section of this article to position the patient research partner. The model also has its limitations, however, because it focuses solely on the shift of control to those with the least influence and decision-making power. We depart from an approach that understands patient participation as dialogue. This idea is grounded in hermeneutic philosophy and responsive research (Abma & Widdershoven, 2005; Greene & Abma, 2001; Guba & Lincoln, 1989; Stake, 1975). Patients are seen as stakeholders who are involved in the research process via dialogues with other stakeholders such as researchers, caregivers, and funding agencies. This dialogical approach also has implications for the role of and collaboration with patient research partners in the research team. Currently, not much is known about the conditions, pitfalls, and challenges of mixed research teams. The modest amount of literature reports about teams of professionals bringing in the experiences of patients or family members (Austin et al., 2008), or teams in which patients acted as advisors or prime investigators (Belam et al., 2005; Buckley, Grant, Firkins, Greene, & Frankau, 2007; Hewlett et al., 2006; McClimens, Grant, & Ramcharan, 2007; Schneider et al., 2004; Staniszewska, Jones, Newburn, & Marshall, 2007; Wright, Hopkinson, Corner, & Foster, 2006). Systematic inventories of mixed research teams in which professionals and patients act on an equal basis are still rare. In this article we aim to fill this gap through a detailed portrayal of the dynamics within mixed research teams and the presentation of a responsive methodology to handle these dynamics. We start by identifying the role of patients as partners in mixed research teams.

## From Object to Research Partner

There are many ways to involve patients in health research. In the literature, the "participation ladder" is used to indicate degrees of participation in policy-making processes (Arnstein, 1969). Only the highest three rungs (partnership, delegated power, and patient control) imply real shifts in decision-making power and are considered "real" forms of participation. In partnerships, patients and professionals make decisions jointly. Delegated power takes this one step further, and implies that patients are taking full responsibility for some part of the decision-making process, whereas patient control refers to a situation where decision-making power is transferred from professionals to patients. We have adjusted Arnstein's model to position the patient research partner in relation to other patient roles in research. Table 1 gives an overview of the roles and tasks of patients in research, and their degree of involvement, ranking from low to high participation.

The patient as participant in a clinical trial and as respondent are quite common in research. Clinical researchers are interested in the (clinical) effects of a medical intervention, such as blood measures. Outcome measures are preordained by researchers. When patients act as respondents to surveys, questions and answers are again predefined by researchers; the level of participation is therefore minimal. Semistructured interviews leave some room for patients, but the degree of participation is still low. Open, in-depth interviews and focus groups offer respondents more space to control and structure the conversations. Yet, patients have no decision-making power. There is a duality between the researcher as expert and the patient as source of information. This relationship is quite different in the case of a patient research partner: Then patients are becoming experts, too, as their experiential knowledge is actively used in the research team. Researchers and patients are both experts, and this enables them to relate more equally.

In terms of the degree of involvement, patient research partners are much closer to patients as advisors. Patients are increasingly invited to act as referents, because they take other evaluation criteria into

**Table 1**
**Overview of the Roles and Tasks of Patients in Health Research**

| Roles | Tasks |
|---|---|
| Object or respondent | Cooperating in clinical trial; sharing information in interview or survey |
| Advisor | Bringing experience; discussing new developments; evaluating scientific articles and research proposals (as referent); advising; managing research projects as member of scientific commission |
| Interviewer/ moderator | Jointly composing surveys and topic lists; conducting interviews with patients; preparing and/or leading a focus group |
| Research partner | Jointly developing a design; gathering, analyzing, and presenting data; writing publications; evaluating articles and research proposals; participating in scientific congresses |
| Research principal | Initiating research; developing and maintaining a knowledge base; joining established research networks |

account, such as relevance and patient-friendliness. Notable is the Alzheimer Society in the United Kingdom, which has set up a network of 150 patients and family carers who assess the value of research proposals (Train, Nurock, Manela, Kitchen, & Livingston, 2005). Recommended projects obtain funding from the society. Patients might also join medical research commissions, which offers them the opportunity to influence what should be investigated and by whom, and to manage, evaluate, and control the output of research programs. Another advisory role is the inclusion of patients in scientific networks. Within the field of rheumatology, patients regularly join the Outcome Measurement in Rheumatoid Arthritis Clinical Trials (OMERACT) conferences. With their help, a new, patient-defined outcome indicator was identified, namely fatigue (Kirwan et al., 2007). Also worth mentioning are initiatives by the James Lind Alliance in the United Kingdom, which are aimed at encouraging patients and clinicians to work together to ensure that uncertainties which affect everyday clinical practice are addressed by research (James Lind Alliance, 2005). As advisors, patients might use their knowledge to influence long-term, strategic decisions in health research. Patient research partners will also influence crucial decisions regarding research (aim, questions, design, data collection and analysis, dissemination, and implementation), not in the role as advisor to decision makers, but as co decision makers in a research team.

As members of a research team, patients conduct operational research tasks, such as doing interviews and moderating focus groups. This has advantages, because patient-interviewers are less threatening, which leads to more valid information. This already happens in several research projects. In the Netherlands and the United Kingdom, for example, people with an intellectual disability (ID) are trained to interview other people with an ID, using semistructured questionnaires on the quality of life (Emerson, Malan, Davies, & Spencer, 2005; McClimens et al., 2007; Zomerplaag, 2003). Patients might also act as moderators of focus groups. This has advantages during the preparation because patients are better able to assess the acceptable workload, the appropriateness of methods, and use of resources (Wright et al., 2006). It can also support the recruitment of participants, because patients have better knowledge of groups that come together on a regular basis. Finally, patient-moderators are sometimes better able to ask the right questions and engage the participants (Balch & Mertens, 1999). One of the main differences between patient-interviewers or moderators and patient research partners is that the scope of their tasks is much broader, including not only data collection, but also data analysis and negotiations over methodological decisions. The degree of involvement of the research partners is therefore higher; they do not just carry out invisible work, but are engaged in intellectual work and strategic decision making.

Still another role is the one of the research principal. As research principals, patients might instigate research projects which are grounded in their own illness experiences. For example, Kay Redfield Jamison's work on depression takes into account her own medication history (Jamison, 1995). Worth mentioning here also is the participatory project undertaken by a group of patients with schizophrenia (Schneider et al., 2004). The group defined the main research theme (communication between patients and their medical professionals) and designed the whole study with the help of an academically based research assistant. Although the patient research principal is the core and single decision maker, the patient research partner shares decision-making power with professional researchers in a team. The degree of involvement of the patient partner is therefore somewhat more limited than the research principal.

Besides the degree of involvement, there is still another important distinction between the research partner and the other patients' roles. This distinction cannot be understood with the help of Arnstein's model, because this model is solely focused on degrees of involvement and control, and not on the quality of interactions and relationships. As object the patient has almost no control; as advisor the patient has a greater degree of control over the research. Yet, in all these roles the patient stands in a one-way relationship to others; there is no engagement, interaction, dialogue, or mutual learning: the relationship is monological. The patient research partner we envisage is involved in an interaction and relationship; he engages with researchers in a mutual learning process that changes both parties. This vision in grounded in a responsive approach to research.

## Responsive Research

In the late 1970s, Stake coined the term *responsive evaluation* to promote an approach aimed at enhancing the understanding of a situation from a variety of perspectives (Stake, 1975, 2004). This was prompted by the idea that a phenomenon has various, sometimes conflicting meanings for different stakeholders (Abma & Stake, 2001; Stake & Abma, 2005). With the focus on meaning processes, responsive evaluation is rooted in hermeneutic philosophy. Politically it is based on the notion of plurality; stakeholders have different interests and values. Instead of assuming consensus, Stake (1975 and 2004) acknowledges the plurality of interests and values to prevent the exclusion of certain issues. Methodologically, this means that researchers cannot preordain the variables of a design. Stakeholder issues (expectations, concerns, controversies) are not known in advance, but emerge in the conversation with stakeholders. The design has an emergent character. To generate stakeholder issues the researcher acts as a "social anthropologist;" he engages himself in the practice and familiarizes himself with the daily activities and social relations among people. A certain intimacy, prolonged collaboration, and personal engagement are required to illuminate the perspectives of others.

In line with Stake's ideas, Guba and Lincoln (1989) proposed not only to enlarge the scope of perspectives, but to foster a "negotiation" between stakeholders to reach consensus or a shared understanding of a phenomenon. The researcher not only interprets the issues of stakeholders, but acts as a facilitator of the negotiation process between stakeholders. We have connected this line of work with dialogical ethics and narrative psychology (Abma & Widdershoven, 2005). Instead of negotiation, a term associated with formal bargaining between groups, we speak of dialogues with and among stakeholders. Dialogues, from a hermeneutic perspective, are mutual learning processes in which all change in the interaction (Widdershoven, 2001). In dialogues people engage as unique persons with names and faces, as opposed to parties with interests that need to be protected. People make sense of their world through stories, and as storied beings we easily relate to others' stories (Josselson & Lieblich, 1999). Stories reflect a personal experience and standpoint, emotions and feelings, and an evaluation of a situation. Meaningful dialogues take these stories as a point of departure (as opposed to a list of issues).

Responsive methodology presumes an active participation of all stakeholders in the research process. The process starts open, and the stakeholders are the ones who define the research issues and topics. They are also actively engaged in ongoing dialogues among and between themselves to construct and reconstruct meanings and interpretations. As such, there are linkages with participatory research; it is not research on, but rather with people. Other parallels include the role of the researcher as facilitator rather than expert. Instead of the hierarchic distance in traditional research, there is a more horizontal relationship between the researcher and participants in responsive and participatory work (Heron & Reason, 1997). So far the similarities between responsive evaluation and participatory research. Differences relate to the degree of participation of the participants. In participatory research, the main goal is to enable participants to carry out the research themselves (comparable to the highest spot on Arnstein's ladder). The participants are in control, and the facilitator acts as a coach to assist them. Within responsive research, the stakeholders act as partners: they share decision-making power with the researcher, whose task it is to create conditions for dialogues between stakeholder groups.

The prime responsibility of the responsive researcher is not to delegate power to participants, but to enhance the quality of the dialogical process between stakeholders (both in terms of its meaningfulness and its relational quality). For a genuine dialogue to take place, the responsive researcher is sensitive to power imbalances and the subtle process of exclusion (Mertens, 2002). Although ownership and decision-making power is not fully delegated to patients in responsive research, we do think that this approach can be empowering for patients and other research participants. Yet, reasoning from a dialogical perspective, empowerment is not a one-way process of giving or taking control, but rather a process of mutual learning. This relational approach to empowerment means, as VanderPlaat notes, that "everyone [is] both an agent and a subject in the empowerment process. . . . All of us have a lot to learn. In a truly empowering process, everyone changes. Empowerment always is mutual" (1999, p. 777). This implies that responsive research does not just focus on the empowerment of those with the least power; it rather engages all stakeholders (researchers included) in a process of learning with regard to their capacities and incapacities to gain a hearing, to construct meanings, and to engage in meaningful dialogues. If consensus and mutual agreements are developed in dialogues, this might lead to actions to change situations. However, from a responsive perspective, practice improvement is not a linear process; it cannot be completely planned in advance, but rather emerges in the conversations between stakeholders. Dialogues are not conceived as means to take action (instrumentally), but as mutual learning processes. Actions, therefore, are not predefined in responsive research—as they are sometimes in action research—but might emerge as part of the process. Below we describe the underlying notions of our responsive approach.

*Need to start with the stakeholder group of least influence*. A responsive process starts with the stakeholder group with the least influence—in health research, the patients—to give them a "say" in the research process. In many instances researchers and policy makers have decided on health research and health research agendas; their wishes and preferences are known, and only need to be actualized. By contrast, the experiences of patients have not often been systematically investigated previously, and require extra attention.

*Focus on experiential knowledge*. Experiential knowledge refers to the often implicit, lived experiences of individuals. Experiential knowledge does not only concern personal opinions, but also learning experiences, emotions, and feelings. Patients' stories portray a holistic image of the impact and meaning of an illness or disability on daily lives and biographies. Apart from focusing on curing a disease, illness narratives show the importance of paying attention to the symptoms of a disease, the day-to-day activities, the need to cope with the illness or disability, and to give it a place in one's life history. As such, illness narratives are often illuminating for those reasoning from a purely biomedical or therapeutic model (Abma, 1998; Mattingly, 2007).

*The interaction of all stakeholders*. In a responsive approach, the interests of all stakeholders are included in the process. Engagement of patients and other stakeholders throughout the whole process implies frequent communication with their interest organizations, including patient organizations. The design will emerge in conversation with the stakeholders, and be renegotiated during the process.

*Mutual learning*. Dialogues are mutual learning processes. Concrete experiences and informal oral communications are most appropriate to foster these processes. In face-to-face meetings, participants ask questions, probe, argue, and deliberate about their experiences and opinions, and this might lead to adjustments of existing prejudices and ideas that cannot then be disregarded. This process can be compared with the fusion of horizons; participants extend their perspectives and broaden their horizons (Widdershoven, 2001). Dialogue is also a democratizing method. Through the engagement of stakeholders, but especially of groups in a vulnerable and/or marginalized situation, power relations shift.

*Openness and respect*. Genuine dialogues require openness, respect, trust, and engagement of all stakeholders. These conditions are not always in place, and need to be actively created and maintained throughout the whole process. The key to the creation of good social conditions is frequent, informal communication with all stakeholders. Interactive communication—ranging from informal contacts by telephone and e-mail to participation at meetings and conversations via interviews and focus groups—is most appropriate. This form of communication enables participants to engage in the process, to give advice, and to deliberate with each other.

## Case Examples

The above methodological notions were applied and refined in a series of health research agenda-setting processes (spinal cord injuries, neuromuscular diseases, kidney disease, and intellectual disability [ID]). These projects were aimed at developing a patient-defined research agenda and fostering the collaboration between patients and researchers. Another objective was to develop a participatory methodology in a dialectic between theory and practice. This dialectic was repeated several times, and spread over a longer period of time (2003 to 2007). Each of the health research agenda-setting projects were coordinated by the first author, who fostered the collaboration between the stakeholders. In three of these projects the first and second authors worked with patient research partners. In an earlier article, we reported about a health research agenda-setting process with spinal cord injury patients (Abma, 2005). Here, we present the latest such projects with patient research partners.

The research project with kidney patients was initiated by the Association for Kidney Patients (NVN) and funded by the Kidney Fund in the Netherlands (NSN; December 2005 to February 2007). Soon thereafter, the patient organization contacted a few of their members, and the project leader selected the candidates for the team. "Job interviews" were held with three potential research partners. Two of them proved eligible: a patient and a mother of a son with kidney failure. Both had personal experiences with the disease, were well informed about the illness experiences of other patients, and had a social network among patients and members of the Kidney Association. Together with three professional researchers (including the project leader), the two research partners formed a mixed research team. The mixed team started conducting in-depth interviews with renal patients and parents of young children with kidney failure. Furthermore, focus groups were conducted to prioritize research themes and to formulate research questions. The interviews and focus groups were tape-recorded, transcribed, and analyzed by the team. A dialysis unit was also visited and observed. The team collaborated in all these activities. Every activity was carried out by at least one professional and one patient partner (see Table 2 for a more detailed overview of the research activities and specifications of the role of the research partners).

The project resulted in a description of the critical moments in the illness and lives of kidney patients, and the uncertainties patients faced at these moments (Abma, Nierse, van de Griendt, Schipper, & Van Zadelhoff, 2006). This report was a coproduction of the whole team. A public-friendly brochure for patients was also written. This was done by a member of the patient organization, a journalist, and the editor of a magazine, who developed an interest in the project. The short, accessible brochure was funded by the Kidney Fund and distributed among members of the patient organization, respondents, and others with an interest in the project.

**Table 2**
**Data Collection and Involvement of Patients in the Project With Kidney Patients**

| Method of Data Collection | Respondents/ Participants | Involvement of Patient Research Partners |
|---|---|---|
| In-depth interviews | 27 respondents | Preparations (topic list, recruitment), interviewer, analysis |
| Open focus group | 1 focus group (3 teenage participants) | Preparations (topic list, recruitment), moderator, analysis |
| Focus group for priority setting | 2 focus groups (19 participants) | Preparations (protocol, recruitment), moderator, analysis |
| Focus groups for formulating research questions | 5 focus groups (36 participants) | Preparations (protocol, recruitment), moderator, analysis |

The second project under consideration was completed with people with an ID. It was initiated and funded by the Netherlands Council for Medical Research (ZonMw; December 2005 to September 2006). With the help of the Federation of Self-Advocate Organizations (LFB) and the Federation for Parent Organizations of People with an ID (FvO), the research team was composed of two persons with a minor ID, the mother of a son with a severe ID, and five professional researchers (including the project leader) with various disciplinary backgrounds.

People with minor IDs, parents of young children, and people with severe IDs were interviewed first. Subsequently, focus groups with clients and parents were organized to get more in-depth knowledge about their issues. In the last focus group, clients were asked to prioritize research themes. Parents of young children and people with a severe ID prioritized research themes by completing a questionnaire. Again, all the research activities were jointly carried out by the team. Table 3 presents an overview of the research activities and the tasks of the research partners.

The project resulted in a research agenda from the perspective of people with an ID (Abma, Nierse, Caron-Flinterman, Broerse, Heuvelman, van Dijk, et al., 2006; Nierse et al., 2007), which was placed (in Dutch) on the Web site of the Netherlands Council for Medical Research (see www.zonmw.nl/nl/programmas/

**Table 3**
**Data Collection and Involvement of Clients in the Project With People With an ID**

| Method of Data Collection | Respondents/ Participants | Involvement of Client Research Partners |
|---|---|---|
| In-depth interviews | People with ID: 7 interviews<br>Parents: 6 interviews | Preparations (topic list, recruitment), interviewer, analysis |
| Focus groups | People with ID: 9 focus groups (81 participants)<br>Parents: 4 focus groups (24 participants) | Preparations (topic list, recruitment), moderator, analysis |
| Focus group for priority setting | People with ID: 1 focus group (10 participants) | Preparations (protocol), comoderator, analysis |
| Questionnaire | Parents (17 respondents) | Construction of questions, analysis |

verstandelijke-beperking/startbijeenkomst.html). The research partners made an "easy-to-read" version of the report, using pictures so that people with reading problems could get an idea of the study and its results. The research partners were also involved in the dissemination of findings. One of the research partners and a researcher (Nierse) presented together at a national conference about research on ID. When preparing this presentation, they jointly decided on the presentation in the form of a "live" interview; this creative format embodied their equal collaboration.

The clients and patients in these projects were approached via the membership of the participating client/patient organizations. In the Netherlands, research projects with clients/patients who are not institutionalized is not legally required to undergo a formal evaluation by an ethical research commission; the project proposals were therefore not scrutinized by such a commission. We informed the members of the patient organizations via Web sites, and all the respondents by letter about the project, and gained their agreement to join the studies. At the time of the interview, we again checked whether or not they were still willing to participate. None of them refused to join the interviews or focus groups; on the contrary, most of them were glad to share their stories, and liked being involved in the projects. In the project with the participants with an ID, we also informed the coaches of the local client organization. To protect clients/patients from emotional distress or overburdening, we observed their well-being and introduced breaks when needed. The data gathered were anonymized. Before further dissemination, every respondent received an analysis to check the credibility of our interpretation. This was also prompted by the idea of preventing feelings of exploitation.

Whereas the first author coordinated these projects, the second author worked closely with the patient research partners. Both of these authors critically reflected on their experiences within the teams throughout the process. The two of them met monthly to discuss the proceedings in the teams and their own roles within them. In addition, the complete research teams regularly evaluated how the teams were functioning (twice a month). These informal, oral evaluations were recorded. The findings are thus grounded in a participant observation of dynamics in the mixed teams. Furthermore, each of the research partners was interviewed at least twice by the first two authors—at the very beginning to investigate their expectations, and at the end to gain an understanding of their learning experiences. During the process many informal conversations took place with each patient partner. We still keep in touch with all of them, and one of the research partners is currently a PhD student in our university. In the next sections we share these experiences.

## Methodological Notions for Mixed Teams

In this section we provide a description of the methodological notions for the participation of patients in mixed research teams on the basis of our experiences in the projects, and some of the benefits of these equal collaborations.

### Need to Start With the Stakeholder Group of Least Influence

From former projects with patient organizations, we knew it was important to include them from the very beginning; otherwise they might have the idea that the most crucial decisions had already been made. This notion was re-established in these projects. When writing the research proposals, the patient organizations were consulted to discuss the aim, research questions, feasibility of the project, and collaboration with research partners. Because the teams had not yet started, and some researchers had not worked with each other before, the research partners were included in the process of team building.

The notion that a participatory process should start with those with the least influence also appeared to be applicable to the formation of the mixed teams. In the beginning, a lot of attention was paid to the needs of the research partners; in the first encounters it became clear that they required a lot of support. They felt uncertain and insecure about their "surplus value," and doubted whether they really would have a "say." These feelings are related to a lack of experience with scientific research and the idea that science is about numbers, figures, and abstractions (rather than about lived experiences). Furthermore, there is a tendency to look up to experts, and to question one's own experiential knowledge (De Wit, 2004). Support entails such activities as making time to have a cup of coffee to listen to their concerns, providing reassurance, adjusting time schedules, and helping them with difficult tasks. The research partners in our teams emphasized how important it is to create a safe and respectful working environment, especially in the beginning. A woman with a kidney disease noted how the first encounter helped her feel more confident:

> I had a lot of doubts and fears before I had my job interview. But it wasn't like the standard interviews I had before. We spoke a lot about my situation, my experiences, my feelings, my ambitions in life. It was all about me and my family. . . . Telling my story and the story of my family raised my awareness and helped me realize I might have a surplus value for the research project. . . . As a daughter I had seen from very nearby how it was for my mother to have polycystic kidney disease, and I knew what it all meant for me and my family. I had reflected and talked a lot about my experiences, feelings and thoughts. . . . All this, I started to realize, gave me a lot of knowledge.

This woman's doubts came back for while a when she was going to meet one of the professional researchers: "What if she thinks she is more valuable than I am?" Yet, these feelings disappeared when she felt respected and when her knowledge base was validated.

A more practical, but often ignored need concerns the compensation of patient research partners. Others have argued that honoraria for respondents are part of a reciprocal research approach (Salmon, 2007). Compensation offers participants a benefit from research in a "tangible and meaningful way" (Salmon, 2007, p. 566). The importance of offering a reimbursement for traveling and other expenses is also more or less self-evident. In our projects, the research partners received a small salary acknowledging and expressing appreciation for their efforts. In the project with kidney patients, the research partners were offered a contract as a temporary worker at the university, since it was a short-term research project. In the ID project, an arrangement was made with the research partners to prevent reductions in their allowance from the government. Nonmonetary arrangements were also made; for example, library access was provided.

With respect to the prevention of overburdening the research partners, we learned that attention should be paid to travel time and the duration of meetings. Patient partners can become fatigued easily, or lose their concentration when working continuously for a long time. This necessitates negotiations over the planning of breaks, acceptable work periods, and work schedules for the research partners. Patient research partners might fear the emotional impact of interviewing other patients, or it might cause them to recall painful moments in their own lives, and the confrontation with the suffering of others might evoke feelings of powerlessness and pity. Sometimes counselors are appointed to provide emotional support (Wright et al., 2006). In our projects, the intimate and stable collaborations between a professional researcher and a research partner helped both to express their feelings and cope with tensions. The research partners reported no signs of overburdening.

Finally, we further elaborated on our ideas about the education and training needs of research partners. Education and training increases the expertise of the research partners, which might enhance their self-confidence and feelings of security. They might also foster communication with professional researchers. Yet, the more professional the patient research partners become, the greater the chance that they will lose touch with their fellow patients. One might even question whether a "professional" patient is still able to represent other patients. In the worst situation, the patient research partner will not feel at home among researchers or fellow patients. Another issue is whether purely technical scientific training is sufficient. It might give patients the impression that one will only be taken seriously if one speaks the language of professionals. As such, technical training might even disempower patients. The research partners in our projects reported how important it was, especially in the beginning, to have their own knowledge base validated. Training should therefore focus on the empowerment of patients and offer them the opportunity to learn by doing (cf. Schneider et al., 2004), preferably as an "apprentice" to an understanding and knowledgeable researcher, in a climate of support and encouragement.

We note that asking research partners to educate themselves is unfair; one might expect that professional researchers also educate themselves. Courses on participatory, empowerment, and community-focused research approaches, and courses on journalistic writing will broaden their scope of research. Patients might also educate and train professional researchers. They might, for instance, explain the needs of patients as respondents in the research process, which methods are appropriate for certain patient populations, how to approach certain hard-to-find populations, and how to deal with patients as advisors or research partners. Finally, we should consider developing courses for both groups (patients and professionals), so that they can learn with and from each other.

## Focus on Experiential Knowledge

We had sensed previously that it is important to appreciate the experiential knowledge of patients. In these projects we learned how patient research partners can help to get in touch with this type of knowledge. In both studies experiential knowledge was collected in several ways. First, we held a series of open interviews. The research partners shared their experiences when preparing the interviews, and together we considered what topics could be brought up during the interviews. Especially in the ID project, we talked about formulating appropriate questions and how to open a conversation with a respondent. The research partners added topics that researchers did not think of, such as "hugging," and helped to make topics more concrete. For example, instead of talking about "social contacts," they suggested we speak of "making friends." During the interviews, in which the interviewers operated in teams consisting of a patient research partner and a professional researcher, we followed an open, conversational interviewing style. This appeared to be the most appropriate way of collecting life stories and experiences. During the interviews, it was the respondents who could decide which way the interviews were going, using their experiential knowledge to inform the interviewers.

Second, in both research agenda-setting projects, focus groups were organized. The patient research partners played an important role in preparing, organizing, and facilitating the focus groups with patients/clients and parents. It became apparent that the research partners asked questions that invited participants to relate their experiences. For example, in a focus group with people with an ID, the discussion was about going to a doctor. At a certain point, the research partner asked the group, "Do you ever feel that your general practitioner takes you seriously?" Although the group had been somewhat passive up to that point, this question triggered a more animated response from the participants. The group responded immediately, and many participants started talking about instances in which they felt they were not taken seriously. It was clear that the research partner connected with the group, bringing in her own experiential knowledge. By asking this suggestive question, the team gained more in-depth knowledge of others' experiences.

Third, the patient research partners were actively encouraged to bring in their own experiential knowledge throughout the entire process. They did so informally in the team meetings, but also during interviews, focus groups, and the data-analysis process. It proved essential to guard this specific input, and to keep addressing the research partners on their experiential knowledge, because sometimes they would take a professional perspective; for example, explaining patient behavior. The mother of a son with a severe ID had a background in pedagogy (PhD), and sometimes relied on her professional knowledge. Especially in the beginning, she tended to fall back on her professional expertise. She would, for instance, focus on the distinction between various groups of clients and explain problematic behavior in terms of coping problems. Given her academic background, she was not accustomed to sharing her emotions and feelings; the team, however, was much more interested in her experiences as a mother. What were her main concerns, what were the problems her son experienced? To prevent her from "going professional," the project leader asked her specifically about her experiences (e.g. "How is your son lately?"). This evoked personal stories, for instance, about the difficult choices she had to make for her son because he was having more epileptic events.

These stories kept us focused and attentive to what the projects were really about, and enabled us to develop embodied knowledge. As we coalesced in a team, we developed a climate of trust in which emotions and feelings could be shared; each one of us knew it was safe to talk about his or her experiences, and that these were not excluded as being unprofessional. Austin, Park, and Goble (2008) emphasize how important a trustworthy relationship is in transdisciplinary research, to overcome what they call “disciplinary chauvinism” (p. 562), and to become open to the perspectives of others.

It can be challenging to include experiential knowledge in the research process, because experiential knowledge is sometimes considered secondary or “inferior” to scientific knowledge. However, from a pragmatist approach, experiential knowledge can contribute to the quality and validity of research processes (Caron-Flinterman, 2005). We experienced this, for example, while interpreting and analyzing stories of patients. To illustrate the relationships between issues that emerged from their stories, abstract figures like a “mind map” (a global scheme) and a “problem tree” (a detailed scheme with a strong emphasis on causal relations between issues) were made. During the analysis it proved important to involve the research partners. Whereas the researchers tended to take a reductionistic view—analyzing in detail the separate themes—the research partners tended to emphasize the interrelatedness of the themes (cf. Salmon, 2007). Ultimately, this resulted in an integration of various sorts of knowledge in the form of a combination of personal stories, thematic analyses (critical moments in the lives of patients/clients), and a condensed research agenda.

## Interaction and Mutual Learning

Interaction and mutual learning are core methodological notions in responsive research. We discovered that these notions are also relevant for the conceptualization of the relationships within a mixed research team. One of the research partners aptly described this as a process of naturalization. This catchy metaphor emphasizes that the research partners were the ones who held a lot of essential knowledge about a world unknown to us as professional researchers. They prevented us from asking silly, or even unintentionally belittling questions in the interviews and focus groups. The patient research partners advised, for example, not to talk about levels of intelligence or disabilities, because they predicted that people would walk away or not talk openly. Yet, the client research partners also learned a lot from us, imitating our behavior. While the research partners with an ID initially found it difficult to conduct open interviews, they gradually learned to ask open questions. Although instructions and training sessions did not work very well (the research partners interviewed each other and got feedback from the researchers, but both groups felt this was not very productive), cointerviews with researchers helped the research partners to develop the right attitude (genuine curiosity, openness) and skills (listening, probing) for open interviews.

In the research project with kidney patients, the research partners made us aware of the specific language, symbols, and rituals that surrounded people with kidney failure. For example, when talking about their health, kidney patients often referred to the value of their “creat” (creatinine). The patient research partners explained the importance of the symbolic value of the “creat;” its value had become an indicator of people’s health. When the “creat” was high or had risen, their kidney was not functioning well and their health was in danger. This indicated that the “creat” could make a difference in the lives of people who had a transplanted kidney, and revealed feelings of insecurity about a possible rejection or malfunctioning of the kidney. This intimate knowledge helped the researchers understand the illness narratives.

The research partners of both projects also increased our sensitivity to the issue of diversity. The research partners had outspoken ideas about which patients/clients we should consult to gain a broad spectrum of experiences. They helped us to identify and acknowledge the dimensions of difference that matter to particular patient groups. For example, in the project with people with an ID, we learned that age and housing situations were considered to be as important to diversity as the severity of the cognitive impairments. One of research partners introduced us to a group of homeless clients, a vulnerable group that we might otherwise not have reached (cf. Benoit, Jansson, Millar, & Phillips, 2005). In the project with kidney patients, the research partners prompted us to include patients at different stages of the disease, but also patients of different age categories—older people and children. The mother of a young boy with kidney disease, for instance, was very to keen to organize a roundtable discussion with teenage girls. Based on her experiences and contacts with other parents, she knew these girls experienced particular problems, such as being absent from school, being bullied, and feeling ugly or “different” because of their medication. The other research partner was the daughter of a woman with a hereditary kidney disease, and emphasized the particular issues and insecurities relating to the dimension of genetics within a family. Although we worked with a mix of clients/patients and proxies (parents of clients or patients), we became more aware of the notion that diversity should also find expression in the research team.

The interactions and mutual learning process proved to be crucial for the development of a shared understanding (cf. Austin et al., 2008). In the team meetings we were all engaged in searching for the best way to cooperate during the interviews and focus groups; this had not been preordained in a research plan or design. Together, we formed ideas about how to interview the respondents and how to organize and prepare focus groups. As the process proceeded, we felt more at ease with each other, and developed a sort of working routine; later on the research partners took over more tasks, with some even chairing a focus group.

In this process, several unforeseen challenges arose. We discovered that the team could handle these issues, because the members were committed, open, and willing to listen to each other, and to adjust their attitude and behavior. Humor also helped to reduce tensions. For example, in the project with people with an ID, tensions arose about the quality of the end product. One of research partners put things in perspective when she remarked, "Don't be too perfectionist! The report is meant for people with an ID and people should be able to notice that." In another instance, a professional team member openly wondered what it meant for the research partners when she took over a lot of the work so as to be able to complete research activities within the preset time frame. This confession created conversation space to talk about the interests at stake (i.e., sticking to the time schedule, exercising the patience to include patients in all activities). Research partners began to share experiences (e.g., they felt they were not taken seriously, got bored, and as a result felt less committed to the project), and this prompted a response from the professionals: "We feel bad about this. It should not have happened that way." The researcher who started the discussion explained the various interests she tried to serve. This communication did not solve the dilemma, but enhanced mutual understanding within the team, and stimulated members to think of ways to handle similar situations in the future. This experience resonates with Austin's work (2008) on transdisciplinary teams that emphasizes that respect, trust, dialogue, and time are required to work out conflicts when collaborations do not run smoothly.

## Openness and Respect

Social conditions receive special attention in a responsive approach. Social conditions such as respect, openness, trust, and involvement are stimulating for a dialogical process in which parties mutually learn from each other. These conditions cannot be commanded, but must be actively stimulated during the research process. This notion also enhances the dialogue within the research team. To encourage integration in the mixed research teams it was important to decide on a set date and location for the research team to meet. Austin and colleagues (2008) also note the importance of a shared space to meet for transdisciplinary research. Providing structure in the form of planning and working schemes proved to be important in making the research partners feel they were being taken seriously. We also learned that working with more than one patient research partner established a balance within the team. Research partners supported each other and felt "at home" in the team. As researchers, we felt more obligated to pay attention to research partners; it is harder to ignore the presence of two research partners than a single one. It also prevented the research partners from becoming overburdened.

It proved to be essential to actively search for the specific qualities of each research partner, and to adapt the working schedule to these qualities. We wanted to involve the research partners in every step of the design, but also acknowledge that everyone has particular interests and qualities, which should be made explicit in the research process. We decided that each research partner should be uniquely involved. For example, during the research project with people with an ID, it became clear that one of the research partners could not read well; as a result, we chose not to overburden him with tasks and questions that involved reading. His strength was connecting with people. He could easily initiate a conversation with others. For example, a professional researcher had difficulty approaching a person with autistic behavior who was completely involved with his collection of toys. The research partner simply said, "Shall we have a seat?" which caught the attention of the individual and began the conversation. The other research partner explained that she could "put out her feelers" and empathize with others; this was her strength. When leading focus groups she managed to engage quieter participants in the discussion.

Finally, we learned that prejudices should not be ignored, but should be worked out. Each researcher should be willing to bring their personal prejudices into the open, and adjust them if necessary. In both projects we recall instances in which we had to acknowledge that we were wrong about the capabilities of patients; for example, people with an ID turned out to be capable of leading focus groups. The patient research partners also recall moments when they realized that their idea of researchers proved to be wrong. One woman with an ID bluntly said to the facilitator in her first encounter with the team, "So, you are clearly from the university," suggesting that she was a prototypical, cold, and detached researcher. Later, she openly acknowledged that the facilitator was not at all what she expected her to be. From that moment on they could communicate openly in a horizontal, even friendly relation.

*Benefits of collaboration*. Collaborating with the patient research partners generated additional benefits to the research process:

- Revealing prejudices: Patient research partners confronted us with our own prejudices (and vice versa).
- Bringing in experiential knowledge: Patients are experts based on their illness experiences, and these experiences helped us to ask the right questions, and to better understand the perspectives of patients.
- Translating jargon: Patient research partners helped us find simple words to replace complex, abstract language. This helped us reach out and contact patients. It increased the response and improved the validity and dissemination of findings.
- Gaining entree and access: Patient research partners had social networks and knew the health care field, including types of available services and care arrangements, and helped us gain access to their patient organizations and other institutions.
- Establishing trust: Respondents appreciated the presence of a patient research partner in interviews or focus groups. The patient research partners were often the ones who established trust, especially among patients who felt uncertain, suspicious, skeptical, or vulnerable.
- Acknowledging the patient's perspective: Joint analysis of data with patient research partners helped us to genuinely acknowledge the perspective of patients. The coanalyses better reflected the capriciousness of the illness experience and practical problems in daily life, and minimized risks of misrepresentation.
- Developing new perspectives: Dialogues and mutual learning processes within the teams and among stakeholders resulted in new perspectives.

Patient research partners also experienced benefits, such as increased knowledge and skill, self-esteem, and meaningfulness. A research partner with a minor ID said,

> I have never learned so much in my life as [in] the last six months. Half a year ago you [could] not have asked me about a problem tree or mind map. Right now I am using these methods in my work as an advocate for patients. They always treated me as if I could not learn things, and I believed that. Now I know I can become educated.

She built on her own strengths and used the project to develop a new perspective on her future. Her ambitions increased and she started attending school. In 2008 she was to begin working as a client assistant in a care institution for people with a minor ID. She found she was capable of much more than she previously believed.

One patient partner with a kidney disease also commented on her personal development and growth:

> The interviews gave me the opportunity to get a better understanding of my life and situation . . . the whole project gave me a more realistic view of living with a kidney disease. . . . I was able to make my experiences more profound and to connect these to the experiences of other people. When people asked me before if I had a kidney disease I always responded with, "I seem to have a kidney disease," or "They have told me I have a kidney disease." The disease wasn't part of me. It was an enemy, something negative, not part of me. . . . During the project I [became] more and more aware of the fact that I really have a kidney disease. The disease became part of me and gave me the power to develop myself.

As researchers, we also went through a process of empowerment. We had already noticed that the research partners held up a mirror to us; we became aware of our own prejudices, and the fact that we are part of a dominant culture that often underestimates and stigmatizes groups of clients/patients. We have to confront the fact that we might reestablish patterns of oppression. Yet, recognition of one's internalized domination and resistance to change is a particular responsibility of those in a superior position, as VanderPlaat (1999) rightly notices. She argues that it forms the basis for mutual and social change. We also learned more about our own sometimes vulnerable positions; following an unconventional approach—building on narratives, working with patients in our teams—sometimes put us in a position in which we had to defend ourselves within academia. We had to stand up for ourselves, and this involved personal struggles.

The researchers and patients both reported on the value of developing new friendships.

## Discussion and Conclusion

The participation of patients in health research is an emerging trend, but a phenomenon which is still in a developmental stage. More detailed descriptions of actual experiences and evaluations of experiments, in all phases of the research process (from agenda-setting to evaluation), and in all kinds of research (clinical, biomedical, social scientific, policy, and so forth), will be helpful in gaining a better understanding of the dynamics and tensions in the process of feasible participatory methodologies, and the benefits and costs of a joint partnership between patients and professional researchers.

The case examples and methodological notions presented in this article are meant as nuggets of knowledge, adding to this emerging body of knowledge. Our projects underscore the importance of trustworthy relationships in preventing a one-sided focus on professional knowledge in mixed teams. Our findings also coincide with the notion that in transdisciplinary research not everything can or should be planned in advance. There should be room (literally and figuratively) in mixed teams to jointly develop, negotiate, search, and build a sense of co-ownership. What our case studies bring to the fore more explicitly is the need to deliberately focus on experiential knowledge, to foster mutual learning, and to cherish the value of openness and respect. Although not a panacea, a balanced composition of professionals and patients on the team might help to prevent the domination of professional expertise. Our findings indicate that one should not underestimate the insecurity and uncertainty felt by patients working on a par with professionals.

Responsive research and the inclusion of patients in research teams are especially appropriate when questions relate to the experiences and priorities of patients, and the integration of various stakeholder perspectives. Yet, we contend that researchers should always consider the possibility of working with patient research partners or patients as advisors. Even clinical research and basic or fundamental research might profit from the input of patients. Think of the patients who added fatigue to the core set in rheumatology (Kirwan et al., 2007). Patients might not have the expertise to carry out the actual research activities, but in the role of advisor they can help to define fundamental and clinical research questions, and help interpret data. Research institutes can stimulate their workers to collaborate with patients, implementing checklists for patient participation. Patient organizations can set up pools of research partners and referents, develop appropriate training courses, and appoint coaches to support research partners and referents. Sponsors of research might adjust their application procedures and formats to include another set of evaluation criteria (adding relevance and feasibility), set up a pool of patient–referents, and include patients as advisors of scientific programs. Governments might also foster these developments. The United Kingdom is notable for developing structural approaches through INVOLVE. This authoritative body advises the government on consumer issues in medical research (see http://www.invo.org.uk). In short, a variety of implementation strategies is required to make patient participation more sustainable over the long term.

Despite the need to promote patient participation, we should be alert to improper reasons for participation and improper forms of participation. Collaboration with a patient organization can be based on instrumental (versus normative) reasons; for example, when the organization is involved to enhance the compliance of patients in a clinical trial. Research partners might likewise be appointed to develop informative promotion material for a clinical study (Marsden & Bradburn, 2004). These considerations and forms of pseudoparticipation will negatively affect all parties. Participation is more than just involving patients for external and aesthetic reasons. It requires a lot of action, alertness to many potential pitfalls, and an attitude of openness and respect, as well as the creation of appropriate conditions for collaboration (such as sufficient resources and time). When the collaboration between patients and professionals runs smoothly, this can be rewarding for both individual patients and the patient organization. Patients/clients can be stimulated in their personal development and ambitions. Patient organizations might learn to collaborate and negotiate with professional researchers, and join or build research networks. As researchers, we can learn with and from patients to be empowering and to be empowered. If tensions in the process are acknowledged and shared, this might lead to a greater mutual understanding between researchers and patients, and an enrichment of ideas for health research attuned to the lives and perspectives of patients.

## References

Aakster, C. W. (1999). *Patiëntenperspectief in onderzoek* [Patients' perspectives in research]. Rapport ten behoeve van de gelijknamige Tijdelijke Projectgroep van ZON [Report for the temporary working group on patient perspectives]. Den Haag, The Netherlands: ZorgOnderzoek Nederland.

Abma, T. A. (1998) Storytelling as inquiry in a mental hospital. *Qualitative Health Research, 8*, 821-838.

Abma, T. A. (2005). Patient participation in health research: Research with and for people with spinal cord injuries. *Qualitative Health Research, 15*, 1310-1328.

Abma, T. A., Nierse, C., Caron-Flinterman, F., Broerse, J., Heuvelman, C., van Dijk, J., et al. (2006). *Onderzoek met en voor mensen met verstandelijke beperkingen* [Research with and for people with an ID]. Maastricht, The Netherlands: Caphri onderzoeksinstituut/UM, Athena instituut/VU, FvO, LFB Onderling Sterk. Retrieved (2008), fromhttp://www.zonmw.nl/fileadmin/cm/langdurende_zorg/Verstandelijke_Beperkingen/VRAAGSTURING.eindrapport_def_september_2006.pdf

Abma, T. A., Nierse, C., van de Griendt, J., Schipper, K., & van Zadelhoff, E. (2006). *Agenda voor sociaal-wetenschappelijk onderzoek naar nierziekten vanuit patiëntenperspectief* [Agenda for social-scientific research kidney disease from a patients' perspective]. Bussum, The Netherlands: University of Maastricht/Kidney Association and Kidney Fund. Retrieved, from http://www.professional.nierstichting.nl/onderzoek/swo/onderzoeksagenda%20Leren%20over%20lijf%20en%20leven.pdf

Abma, T. A., & Stake, R. E. (2001). Stake's responsive evaluation. In J. Greene & T. A. Abma (Eds.), Responsive evaluation. *New Directions for Evaluation, 92*, 7-23.

Abma, T. A., & Widdershoven, G. A. M. (2005). Sharing stories. Narrative and dialogue in responsive nursing evaluation. *Evaluation & the Health Professions, 28*(1), 90-109.

Austin, W., Park, C., & Goble, E. (2008). From interdisciplinary to transdisciplinary research: A case study. *Qualitative Health Research, 18*, 557-564.

Arnstein, S. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners, 35*(4), 216-224.

Balch, G. I., & Mertens, D. M. (1999). Focus group design and group dynamics: Lessons from deaf and hard of hearing participants. *American Journal of Evaluation, 20*(2), 265-277.

Belam, J., Harris, G., Kernick, D., Kline, F., Lindley, K., McWatt, J., et al. (2005). A qualitative study of migraine involving patient researchers. *British Journal of General Practice, 55*(511), 87-93.

Benoit, C., Jansson, M., Millar, A., & Phillips, R. (2005). Community-academic research on hard-to-reach populations: Benefits and challenges. *Qualitative Health Research, 15*, 263-282.

Blume, S. S. (2006). *Grenzen aan genezen: Over wetenschap, technologie en de doofheid van een kind*. [Boundaries of healing: About science, technology and the deafness of a child]. Amsterdam: Bakker.

Buckley, B., Grant, A., Firkins, L., Greene, A., & Frankau, J. (2007). Working together to identify research questions. *Continence UK, 1*(1), 76-81.

Caron-Flinterman, J. F. (2005). *A new voice in science. Patient participation in decision-making on biomedical research.* Amsterdam: Vrije Universiteit Amsterdam.

Chalmers, L. (2006, October 26). Nutteloos bewijs [Useless evidence]. *NRC Handelsblad*. An interview by Wim Kohler.

De Wit, M. (2004). "Bemoei je met je eigen zaken!" Partnerschap in onderzoek: een positiebepaling binnen de reumatologie ["Mind your own business!" Partnership in research: A position statement within rheumatology]. *Medische Antropologie, 16*(1), 21-33.

Emerson, E., Malan, S., Davies, I., & Spencer, K. (2005). *Adults with learning difficulties in England 2003-2004*. NHS Health and Social Care Information, Department of Health.

Greene, J. C. (1997). Participatory evaluation. In L. Mabry (Ed.), *Evaluation and the post-modern dilemma. Advances in program evaluation* (Vol. 3, pp. 171-189). Greenwich, CT: JAI Press.

Greene, J. C., & Abma, T. A. (Eds.). (2001). Responsive evaluation. *New Directions for Evaluation. 92*, 1-105.

Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation*. Thousand Oaks, CA: Sage.

Heron, J., & Reason, P. (1997). A participatory inquiry paradigm. *Qualitative Inquiry, 3*(3), 274-294.

Hewlett, S., de Wit, M., Richards, P., Quest, E., Hughes, R., Heiberg, T., et al. (2006). Patients and professionals as research partners: Challenges, practicalities, and benefits. *Arthritis & Rheumatism, 55*(4), 676-680.

James Lind Alliance. (2005). *An introduction to the James Lind Alliance: Tackling treatment uncertainties together.* Oxford: James Lind Alliance.

Jamison, K. R. (1995). *An unquiet mind: A memoir of moods and madness*. New York: Alfred A. Knopf.

Josselson, R., & Lieblich, A. (1999). *Making meaning of narratives: The narrative study of lives* (Vol. 6). Thousand Oaks, CA: Sage.

Kirwan, J. R., Minnock, P., Adebajo, A., Bresnihan, B., Choy, E., De Wit, M., et al. (2007). Patient perspective: Fatigue as a recommended patient centered outcome measure in rheumatoid arthritis. *Journal of Rheumatology, 34*(5), 1174-1177.

Marsden, J., & Bradburn, J. (2004). Patient and clinician collaboration in the design of a national randomized breast cancer trial. *Health Expectations*, *7*(1), 6-17.

Mattingly, C. F. (2007). Acted narratives. From storytelling to emergent dramas. In D. J. Clandinin (Ed.), *Handbook of narrative inquiry* (pp. 405-425). Thousand Oaks, CA: Sage.

McClimens, A., Grant, G., & Ramcharan, P. (2007). Looking in a fairground mirror: Reflections on partnerships in learning disability research. In M. Nolan, E. Hanson, G. Grant, & J. Keady (Eds.), *User participation in health and social care research* (pp. 104-119). Berkshire: Open University Press.

Mertens, D. (2002). The evaluator's role in the transformative context. In K. E. Ryan & T. S. Schwandt (Eds.), *Exploring evaluator role and identity* (pp. 103-119). Greenwich, CT: IAP.

Nierse, C. J., Abma, T. A., Broerse, J. E. W., Caron-Flinterman, J. F., Heuvelman, C., Smit, J., et al. (2007). Partners in wetenschap. Mensen met een verstandelijke beperking doen mee in onderzoek [Partners in research. People with intellectual disabilities are involved in research]. *Nederlands Tijdschrift voor de Zorg aan Mensen met Verstandelijke Beperkingen, 33*(2), 84-96.

Oliver, S., & Gray, J. (2006). *A bibliography of research reports about patients', clinicians' and researchers' priorities for new research.* London: James Lind Alliance.

Salmon, A. (2007) Walking the talk: How participatory interview methods can democratize research. *Qualitative Health Research, 17*, 982-993.

Schneider, B., Scissons, H., Armey, L., Benson, G., Derry, J., Lucas, K., et al. (2004). Communication between people with schizophrenia and their medical professionals: A participatory research project. *Qualitative Health Research, 14*, 562-577.

Stake, R. E. (1975). To evaluate an arts program. In R. E. Stake (Ed.), *Evaluating the arts in education: A responsive approach* (pp. 13-31). Columbus, OH: Merrill.

Stake, R. E. (2004). *Standards-based and responsive evaluation.* Thousand Oaks, CA: Sage.

Stake, R. E., & Abma, T. A. (2005). Responsive evaluation. In S. Madison (Ed.), *Evaluation encyclopaedia* (pp. 376-379). Thousand Oaks, CA: Sage.

Staniszewska, S., Jones, N., Newburn, M., & Marshall, S. (2007). User involvement in the development of a research bid: Barriers, enablers and impacts. *Health Expectations, 10*, 173-183.

Train, G. H., Nurock, S. A., Manela, M., Kitchen, G., & Livingston, G. A. (2005). A qualitative study of the experiences of long-term care for residents with dementia, their relatives and staff. *Aging & Mental Health, 9*(2), 119-128.

VanderPlaat, M. (1999) Locating the feminist scholar: Relational empowerment and social action. *Qualitative Health Research, 9*, 773-785.

Widdershoven, G. A. M. (2001). Dialogue in evaluation: A hermeneutic perspective. *Evaluation, 7*(2), 253-263.

Wright, D. N. M., Hopkinson, J. B., Corner, J. L., & Foster, C. L. (2006). How to involve cancer patients at the end of life as co-researchers. *Palliative Medicine, 20*, 821-827.

Zomerplaag, J. (2003). *Eindrapportage Zeg het ons! Mensen met een verstandelijke beperking over de kwaliteit van hun bestaan* [Final report Ask me! People with intellectual disabilities about the quality of their lives]. Utrecht, The Netherlands: NIZW.

**Tineke A. Abma** is an associate professor and research coordinator, Autonomy and Participation in Chronic Care, in the Department of Medical Humanities, EMGO institute, VU University, Amsterdam, The Netherlands.

**Christi J. Nierse** is a junior researcher in the Department of Medical Humanities, EMGO institute, VU University, Amsterdam, The Netherlands.

**Guy A. M. Widdershoven** is a professor in Bioethics and Philosophy in the Department of Medical Humanities, EMGO institute, VU University, Amsterdam, The Netherlands.