Dialogue and deliberation: New approaches to including patients in setting health and healthcare research agendas

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Abstract
Collective participation of patients in health and medical research is an emerging trend. The literature falls, however, short on process descriptions focusing on the power dynamics when sharing power with patients in the research process. This article therefore aims to generate knowledge on how to involve patients and redress power imbalances in health research agenda setting. The context for the study was health research agenda setting on Parkinson’s Disease in The Netherlands. The dialogue model was used: a multistakeholder and multiphased process for the coproduction of research agenda. Patients with Parkinson were involved in all stages of the agenda setting. It appeared to be crucial for people with Parkinson to create a free, protective, and communicative space of mutual encouragement to develop power from within and to articulate their voice. This prepared them for meaningful deliberations with healthcare professionals, researchers, and funding agencies. Ultimately, these deliberations resulted in a relevant and useful research agenda that better enable health-care services to meet the needs and expectations of patients.

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Keywords
Health research, agenda and priority setting, patient involvement, coownership, dialogue, relational empowerment

Introduction
Increasingly, patients have a say in research and research agenda setting (Entwistle, Renfrew, Yearley, Forrester, & Lamont, 1998; Tallon, Chard, & Dieppe, 2000). The latter being of strategic importance to patients, as research priorities are still mostly guided and controlled by researchers or funding agencies, and may not cover the issues that matter to clinicians and patients (Chalmers, 2017). Research agenda setting processes with patients are regularly guided by the notion of consultation. In consultation, patients give information about their lives and illnesses and vote for research priorities (Nilsen, Myrhaug, Johansen, Oliver, & Oxman, 2006; Tong et al., 2008). Alternatively, patients can be approached as equal partners and become coresearchers to generate an integrative agenda with researchers (Abma, Nierse & Widdershoven, 2009). While consultation accepts power differentials and inequalities, collaboration and coownership work actively toward more equal power relationships through dialogue and deliberation.

The strive for coownership is justified with reference to the democratic right to influence decisions affecting one’s life (Thompson, Bissell, Cooper, Armitage, & Barber, 2013). Also, it is assumed that a more relevant and useful research agenda will be generated if patients become coresearchers (Cook, 2012). If patients act as coowners, they may be actively involved in the whole process of research agenda setting; from the formulation of questions, design, and research implementation to the dissemination of findings. They will breathe their unique experiential perspective, which is often complementary to that of researchers. Gillard, Simons, Turner, Lucock, and Edwards (2013) have shown how “nonconventional research voices”—if they are given a communicative space—can challenge what is conventionally known. In other words, the unique perspective of patients can only lead to new insights and innovation if they have an influence and are heard throughout the research process.

Handing over control and ownership to patients requires methodological flexibility, and interactive methods which give room for the voice of patients (Williamson, 2010). An example is the dialogue model (Abma & Broerse, 2010), which resonates with action research (Reason & Bradbury, 2008) and inclusive research (Kral, 2014; Oliver, 1992). The dialogue model is an interactive, multi-stakeholder, and multiphased process for the coproduction of a shared research agenda. It entails six phases including the consultation of patients and researchers and the integration of their agendas (see Table 1). The dialogue model strives for equal dialogue and deliberation and recognizes power asymmetries. The dialogue model is well established in The Netherlands and has been previously used in
several projects, for example, in fundamental psychiatric and burn research (Baart & Abma, 2010; Broerse, Zweekhorst, Van Rensen, & De Haan, 2010), and evaluated in terms of its impact (Abma & Broerse, 2010; Abma et al., 2014).

One of the major issues when using the dialogue model concerns the fact that the voice of patients is easily dominated via subtle processes of in- and exclusion (Elberse, Caron-Flinterman & Broerse, 2010). For example, limiting the amount of conversation time for patients, negative responses from researchers, and use of medical and scientific jargon. Power differentials in current research relationships indicate that patients need to develop a strong, self-conscious position before they are ready to participate and enter into a dialogue with researchers about their agenda. Although patients may be very knowledgeable, their voice is not automatically considered as a valid source of information in the context of setting research priorities. Patients may not be identified as credible knowers (Fricker, 2007), and unintentionally patients and researchers may reproduce traditional knowledge hierarchies due to internalized oppression (Tappan, 2006). Internalized oppression relates to patients holding negative images about themselves. They are used to being told by medical experts about their health, and often feel insecure when approached for research (Schipper et al., 2010).

The current literature on health research agenda setting focuses on outcomes in terms of research priorities, less on the process. We lack insights in how both patients and other relevant stakeholders can be facilitated in a fair dialogical process challenging hierarchy. This article therefore aims to generate knowledge on how to involve patients and redress power imbalances in health and medical research agenda setting. I will use the research agenda setting process on Parkinson in The Netherlands as a case example. From a power perspective, this is an interesting group. People with Parkinson may feel alone and alienated due to communication problems, are usually associated with old age and marginalized in society (Van der Bruggen & Widdershoven, 2001). In the Dutch health-care system, which is characterized by a regulated market-driven system, Parkinson patients experience not much influence and control over decision-making processes affecting their lives. Before turning to the Parkinson project, I will first sketch the

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**Table 1. Phases of the dialogue model.**

1. **Exploration.** The project team is established; key stakeholders are identified; an initial list of issues, perspectives, and ideas of patients and other stakeholders is drawn up; and the social conditions for collaboration are created.

2. **Consultation.** The different stakeholder groups are consulted separately to develop a list of research topics from the perspective of each stakeholder group.

3. **Prioritization.** The stakeholders prioritize the research topics identified in the previous phase.

4. **Integration.** The prioritized research topics of each stakeholder group are integrated into one integral research agenda.

5. **Programming.** The integral research agenda is translated into a funding program or plan.

6. **Implementation.** The research agenda is actively used, action is taken, and results are evaluated.
theoretical notions underlying the dialogue model. Subsequently, I will present a process description mirroring the six phases of the dialogue model, lessons relevant for the AR community and conclusions.

Theoretical background

The dialogue model actively engages patients in research agenda setting to balance power. It provides guidelines to develop a shared research agenda among patients and other stakeholders (Abma & Broerse, 2010; Abma & Widdershoven, 2014; Guba & Lincoln, 1989). The dialogue model is grounded in various theoretical notions. Dialogue and deliberative democracy being central ones as well as power and empowerment.

Dialogue is seen as an ethical and fruitful way for research agenda setting as it helps researchers understand the societal impact of their research and integrates patients’ experiential knowledge and voice. Ideally in dialogue, various perspectives come together to search for mutual understanding. Dialogue can foster mutual learning processes, leading to a new shared perspective that is acceptable and recognizable for all involved (Gadamer, 1960; Gergen, McNamee, & Barrett, 2001). The notion of deliberative democracy (Barnes, 2008) emphasizes the importance of deliberation to reach an informed decision. Deliberative democracy is a more direct form of democracy, that is, to say that people speak on their own behalf, which creates room for a diversity of voices and interests. Epistemologically deliberative democracy is grounded in the idea that experiential knowledge—knowledge gained via reflection on experiences—is necessary in addition to technical or expert knowledge to reach solutions that acknowledge context, value, and meaning (Barnes, 2008; Caron-Flinterman, Broerse, & Bunders, 2005; Yanow, 2003).

Habermas (1987) provides a useful framework to understand the role of power and hierarchy in deliberations. He emphasizes the importance of communicative action in the production of knowledge. Crucial is the critical awareness toward and balancing of hierarchical relationships, and the use of language that facilitates all participants to understand the arguments and values that support various validity claims, and the free expression of experiences and opinions. Only then, a genuine dialogue will be possible in which participants through deliberate argumentation will be able to contest validity claims, gain insight, and join in collaborative meaning-making. Ideally then the best, that is, most true and authentic, arguments will prevail. Some political scientists have criticized the rational overtones in Habermas’ work, and argued that such deliberation can be exclusive as well, particularly for groups not familiar with these rational forms of deliberation (Young, 1990). Patients, for instance, typically express themselves in stories, which tend to be considered subjective, emotional, and self-interested by researchers who enact a neutral, distanced discourse. A rational dialogue may privilege experts over patients, and thus implicitly reestablish unequal power relations, leading to a situation of epistemic injustice (Fricker, 2007). Therefore, other
collective, nonrational forms of expression need to be incorporated in the concept of deliberation, such as personal anecdotes, stories, dairies, photographs, movies, and theater (Barnes, 2008; Williams, LaBonte, & O’Brien, 2003; Young, 1997).

Furthermore, a process of mutual engagement may support minority groups, like patients, to develop their own voice and agenda (Karpowitz, Raphael, & Hammond, 2009). Through dialogue, minority groups can become more aware of their own situation. Via conversations with peers, they may become more critical of disenabling environments and processes of exclusion in society. This critical awareness can prevent the reproduction of internalized oppression and existing knowledge hierarchies (Tappan, 2006). We might assume that jointly patients can develop a sense of power among themselves to realize their goals via group solidarity and joining of forces. Here the concept of relational empowerment is relevant (Christens, 2011; Freire, 2000; Hyung Hur, 2006; Sprague & Hayes, 2000; VanderPlaat, 1999). It regards empowerment as a mutual supportive process mobilizing the strengths of participants through storytelling with others (Rappaport, 1995; Zimmereman, 2000).

Method

The study aimed to develop an integrative research agenda for Parkinson and was commissioned by the Dutch Parkinson Association. Identified stakeholders included the Parkinson Association (members, staff, board, and committees), people with Parkinson and their families, researchers and research centers, health-care professionals, and funding agencies (both governmental and charity foundations). At the time of the study, there were no structural contacts between these stakeholders regarding Parkinson research. The design followed the phases of the dialogue model (see Table 1). Data were collected and analyzed in the period between April 2010 and December 2011. After that, the Parkinson Association took over the responsibility for the project from the facilitating university. Currently, the university and association keep each other updated via informal contacts.

During the exploration phase, information about the project was widely disseminated to association members and other stakeholders through various means ranging from a kickoff meeting to presentations and newsletters. Interviews were completed with all stakeholders \((n = 9)\) to become familiar with their ideas on patient participation and research priorities. The consultation phase started with interviews about illness experiences among persons with Parkinson and their family members \((n = 27)\), who were recruited via the association and selected purposefully (see Table 2 for participants’ characteristics). The interviews were held at participants’ homes, lasted 1.5 to 2 hours and were recorded and transcribed. The interviews were carried out by two members of the project team: a coresearcher with Parkinson and an academic researcher. A topic list was used and the interviews focused on the life history and illness trajectory in all its facets. In addition, health-care professionals and researchers \((n = 17)\) were interviewed,
following the same procedures. The focus was on current Parkinson research, future research, and expectations of patient participation in research. Findings from the interviews formed the input for four focus groups with patients (respectively: 6, 6, 9, and 9 participants) held at a central location, lasting four hours with a long lunch break in between (see Table 2 for participants’ characteristics).

During the prioritization phase, research topics identified in the focus groups were used to develop a survey. Research topics were prioritized per domain (fundamental, medical, psychological, societal, and care-related research) and between domains. The association distributed 4059 digital questionnaires to its members and the questionnaire was completed by 1235 respondents. As not all members had access to the Internet, a postal questionnaire was sent to 495 members and completed by 130. In total, 1320 patients returned a completely filled-in questionnaire. Subsequently, in the integration phase, two dialogue meetings were organized to reach consensus among all parties over the research agenda. Both meetings included patients, researchers, health-care professionals, and funding agencies. The outcomes were related to the qualitative findings and discussed with patients. The programming and implementation phase were coordinated by the association.

Prior to the study, the research team contacted the local university Research Ethics Committee. The study was deemed exempt from an internal review board perspective. In addition to principles of informed consent and confidentiality, our

Table 2. Characteristics interview (n = 27) and focus group (n = 30) participants.

| Age division                  | Interviews                              | Focus groups                           |
|-------------------------------|-----------------------------------------|----------------------------------------|
|                               | 5 < 56 years old                        | 11 < 56 years old                      |
|                               | 22 ≥ 56 years old                       | 19 ≥ 56 years old                      |
|                               | 11 < 56 years old                      | 19 ≥ 56 years old                      |
| Gender                        |                                          |                                        |
| Interviews                    | 15 male                                 | 20 male                                |
|                               | 12 female                               | 10 female                              |
| Focus groups                  |                                          |                                        |
| Time since diagnosis          |                                          |                                        |
| Interviews                    | 7 ≤ 3 years                             | 11 ≤ 3 years                           |
|                               | 20 > 3 years                            | 19 > 3 years                           |
| Focus groups                  |                                          |                                        |
| Setting                       |                                          |                                        |
| Interviews                    | 25 living at home                       | 30 living at home                      |
|                               | 2 living in a nursing home              | 0 living in a nursing home             |
| Focus groups                  |                                          |                                        |
approach was guided by an ethics of care, adopting the virtues of attentiveness, responsibility, competence, responsiveness, and trust (Kral, 2014; Ward & Calahan, 2012).

**Process description**

The findings will be organized mirroring the six phases of the dialogue model, how patients were involved, and how they developed their voice among themselves and in dialogue with other stakeholders.

**Exploration phase (months 1–5)**

Traditionally, the Dutch Parkinson Association focused on peer support, advocacy, and information sharing. They noticed, however, that research projects did not always fit the needs and interests of patients. In 2010, the Association Board therefore commissioned a project to develop a research agenda in concordance with patient’s needs. The research proposal was developed by an academic team in close collaboration with the Science and Ethics committee members of the association. Patients were thus actively involved from the very first step of the research process.

After the proposal was accepted by the Board of the association, a research team was formed. The academic team was led by myself as a senior researcher and three junior researchers, all social scientists. One of them being a mother of a daughter with a brain injury who was particularly sensitive to the disabilities of patients and their perspectives. In dialogue with the advocacy organization, it was decided that the team should also include several patients and family members as coresearchers (Abma, Nierse & Widdershoven, 2009; Schipper et al., 2010). The coresearchers were selected from 12 patients and one spouse responding to a call on the website of the association. Eligible participants were:

a. able to look from a distance to their illness experiences;
b. familiar with experiences of fellow sufferers; and
c. motivated to participate in research.

Three coresearchers were added to the team: one female patient aged 47 doing voluntary work, one male patient aged 51 who runs a business, and the husband of a patient, a retired psychologist. Reasons for them to participate were:

- to be a part of a team again and
- the opportunity to deliver a meaningful contribution.

The coresearchers had neither been involved in designing the study nor had they been involved in research in the past. To build trustful relationships and to engage all in the process, a teambuilding session for the whole team was organized.
The teambuilding included a short training into the key issues of participation in scientific research. Next, roles and tasks were negotiated in the research team. It was jointly decided to collect data in duos. This has advantages like greater depth, more openness, emotional recognition, and trust on the side of participants (Abma, Nierse & Widdershoven, 2009; Nierse, Schipper, Zadelhoff, Van Griendt, & Van de Abma, 2011). Later on, the coresearchers were included in the focus groups as comoderators.

Although not planned, the research team formed a “voice-over group” of patients who applied for the coresearcher position and who dearly wanted to join the project. The name “voice-over” was chosen to signify that the voice of patients was central in the whole project and that interpretations of the researchers were commented on by the voice of this group. The voice-over group developed its own rationale, and met face-to-face among each other and later with the research team. Initially, a group of 15 persons gave feedback to our data, analysis, and reports. During the process, a core group of eight patients stayed actively involved. Also, an advisory group was installed, consisting of seven professionals (health-care professionals and researchers) and six patients recruited via the association, meeting three times. While the voice-over group only represented the voice of patients, the advisory group had a mixed composition. Their specific role consisted of keeping an eye on the relevance and usefulness of the findings for research practices and the dissemination and implementation of findings. All these activities helped to form a broad commitment and social base for the agenda setting and dialogue among patients and professionals.

Consultation phase (months 4–8)

The aim of this phase was to generate themes for Parkinson research. The consultation phase included the consultation of patients and other relevant stakeholders.

Dialogue with and among patients. During the consultation phase, the duos held interviews and focus groups with patients. In the interviews, patients would not immediately come up with a list of research themes. They rather started to reflect on their illness experiences. The open character of the interviews in the safe environment of the respondent’s own home, and the connection felt with the coresearcher stimulated patients to explore the meaning and impact of their illness on their lives. This can be illustrated with the following fragment:

Coresearcher: Can you give examples of social contacts?
Patient: Yes, they mean a lot. Lost my best friend. She couldn’t deal with Parkinson. We knew each other since we were young. But she was all well, never had had any trouble in her family, illnesses and so on. She didn’t understand that I couldn’t go shopping a whole day long.
Coresearcher: Lost her.
Patient: Actually, I also played a role in that. We talked a lot, but once I said I can’t live up to your norms, so I give up. It made me sad for a long time. I didn’t fit into her world anymore, so to say.

This fragment shows that the patient developed an understanding of the impact of the illness on her social contacts, and loss of friendship, through the dialogue with the coresearcher. By acknowledging experiences, patients developed self-confidence to articulate their voice. Coresearchers created trust and rapport. The following quote from a patient during an interview illustrates this:

I just know you will understand me.

Later on, the focus groups were particularly suitable for exchanging stories about Parkinson and its impact on daily life. The atmosphere in these meetings was open and even topics usually surrounded with taboos were discussed freely. The freedom to speak up was important and fostered by the decision to compose the focus groups of the members from the voice-over group. They had already a trustful relationship and dared to discuss intimate topics and taboos, like losing urine, shame, fear for loss of face, and societal disapproval. Among peers, these experiences could be shared without others withdrawing from the conversation or downplaying experiences. An excerpt of a focus group transcript:

Participant 1: I personally find it difficult to talk about incontinence. People don’t know about losing urine. It feels like a loss.
Participant 2: Yes, it is a loss, and a taboo, and it is related to sexuality [...] For me, talking about, telling that I have Parkinson is a taboo. Then I am very emotional. I don’t want talk about anything related to Parkinson with other people. Not at all.
Participant 1: This summer I lied on an inflatable bed, very difficult. Then he [my husband] said: “You should think about going to the toilet.” But I am incontinent! Then sometimes I noticed I didn’t like to talk about it with him. That’s just how the environment responds.

This fragment shows the deliberative character of the conversations. A core issue appeared on the daily basis on which patients experienced their disabilities. They did not realize this before, and felt this was a crucial insight. Critical awareness of the influence of the environment also appeared an important insight that was developed in their open, encouraging conversations. Participants started to realize how our contemporary culture sometimes makes it harder to deal with their limitations. An illustration is as follows:

The environment speeds up, always: hurry, hurry... ,while I become slower, in movement, in thinking, in responding. As a result, many daily activities become problematic, even minor things like shopping. Standing in line in a shopping mall is a very frustrating and very stressful event. It is hard to get money out of my pocket, and I feel bad if it takes longer.
In this phase, the analysis of findings was an ongoing, cocreative process in the research team aimed to formulate inductively themes for research grounded in lived experiences. Besides words, visuals were used because everyone could work with this material. The engagement of the coresearchers was especially high when using visual material like drawings and collages from focus groups. For example, someone made a painting reflecting feelings after hearing the diagnosis (see Figure 1), and collectively patients made collages in the focus groups reflecting the impact of Parkinson on their lives (see Figure 2). Another example is that participants of the third focus group explained that it was not possible to differentiate between themes for research, because they were all interrelated. A participant used the metaphor of a radar wheel to illustrate this and other participants recognized it. Findings were then regrouped in line with the radar wheel metaphor, resulting in a figure embraced by all participants, and shared with the advisory group, health-care professionals, and

*Figure 1. Painting by a patient: feelings after hearing the diagnosis.*
research community (see Figure 3; Dauwerse, Hendrikx, Schipper, Struiksma, & Abma, 2014). Quality of life forms the inner circle, influenced by the next circle referring to relational aspects of functioning (coping, stress, etc); the third circle refers to health-care services (diagnosis, medication, good care), and the outer circle to societal issues (culture, services, social position).

**Consultation of other stakeholders.** In this phase, the research team also talked to health-care professionals and researchers to get their perspective on the research agenda. For these groups, it was easier to come up with a list of research themes than of patients. Fundamental research was considered important to search for causes and solutions to cure the disease, but there were also participants who were cautious to raise high expectations among patients:

> Patients expect often more than can be expected, and sometimes express critique that is not right. And that is a discrepancy that is exaggerated by the media. I really think that needs adjustment.

Furthermore, participants emphasized that research findings should become available to clinical practice and improve patients’ quality of life. Professionals and researchers stressed the psychological impact of Parkinson and agreed on the relevance of psychological research and topics like initiation problems, stress, emotionality, coping, psychoses, and lack of illness insight. In addition, health-care research topics, like the role of the nurse and communication, were mentioned. Future research should also include the societal aspects of living with Parkinson, because not much is known about the impact of the disease on societal participation, for instance, work and school. When it comes to patient involvement, researchers expressed some doubts:
For many people, it is not clear what science is. Science determines science. The patient does not determine what science is.

Prioritization phase (months 6–11)

In the phase of prioritization, the social base for the research agenda was further enlarged via a survey among a large group of patients. The consultation phase revealed that patient’s research themes were broad and covered a whole spectrum of fundamental, medical, psychological, social scientific, and health-care research (Schipper et al., 2014):
fundamental research on the causes of Parkinson and prevention or reduction of symptoms;

• medical research on the diagnosis, medication, and side-effects and physical functioning (freezing, shaking, slowness);

• psychological research on coping styles and effects of Parkinson on psychological functioning;

• societal research on social and family relations and societal responses and taboos; and

• health-care research including medical and psychological care, autonomy, and communication.

In this phase, priorities were set by a larger group of patients. Fundamental research gained the highest priority, followed by medical, psychological, societal, and health-care research. Almost 57% of the participants placed fundamental research on number 1. See Table 3 for more details.

The voice-over group had an important role interpreting these priorities in relation to the qualitative data from the consultation phase. Voice-over members explained that the high priority given to fundamental research was related to the “hope” and “high expectations” of recovery and the wish of leading a “normal” life among many patients. Voice-over members believed that getting grips on and finding a cure for an “uncontrollable” disease was also triggered by the medical and societal attention paid to chemical processes in the brain. Another explanation voice-over group members gave was the association of scientific research with lab research. In the voice-over group, members emphasized how important dialogue and deliberation are to discover what is important and needed:

What is important, that is something we all learned in this voice-over group, is that the results of the survey not always reflect what is really important to people with Parkinson. For example, quite some people ticked the box stress and energy-levels as not important. While when we talked about it within our voice-over group, we discovered this is of utmost importance. These energy levels are really a core aspect, that is why it sometimes all blocks or stifles. That one needs a real dialogue to get to a deeper level.
Integration phase (months 12–20)

In the integration phase, dialogue took place between the voice-over group/patients, researchers, health-care professionals, and funding agencies. We included a variety of researchers, both medical and paramedical but also health-care professionals like nurses, because we expected that the latter could more easily identify with patients’ needs and priorities. We included funders into the dialogue, because we hoped they could adopt the integrated research agenda. The dialogue meeting itself was carefully prepared by sharing information to all about the aim of the meeting and program. The voice-over group and research team discussed prior to the meetings who should introduce which priority, also bringing in their voice.

Initially, the dialogue focused on the current research agenda setting. In order to create an open dialogue with enough room for lived experiences, patients began sharing a story from their own life illustrating a larger topic/priority. These short stories invited others to put oneself in the shoes of a patient. Participants carefully listened and then brought in their perspectives, and together they further critically explored why, for example, fundamental research gained more priority than other types of research. From there, participants began to jointly search for ideas and solutions. All underscored the importance of fundamental and medical research, and from this common ground consensus grew that many questions related to the here-and-now also deserved attention. Patients gave examples of questions bothering them:

*My emotions are not as they used to be. I think it has to do with the illness?
I'm postponing, postponing, postponing... Is it the Parkinson?*

These questions illustrate there was a spirit of inquiry, participants searching for answers to issues bothering them instead of attacking, blaming, and disrespecting the lives and work of others. In this open constructive atmosphere, all were willing to transgress traditional knowledge hierarchies. Funders acknowledged that research into the psychological, societal, or care-related topics was important but hardly got financed:

*In practice, we do indeed fund more fundamental basic and translational research than applied research.*

Critically investigating this matter resulted in researchers openly acknowledging they lacked expertise when it came to the design or appraisal of applied research and other than medical issues:

*I do not feel myself capable to set that up, I need someone else for that. I do want to join in to recruit and select patients, but other disciplines should do that. A very clear, recognizable theme is mastery. I think it is good to prioritize that as a separate research topic. But when you start to think about research you wonder: What kind of research is suitable to study and promote mastery?*
Jointly, participants also came to an understanding that scientific boards assessing proposals often used criteria that matched fundamental research, and as a result not many research proposals from other domains were submitted or granted. For the future, all agreed that a change was needed in the proportions of money going to fundamental and applied research, including psychological, societal, and health-care research, and that this required structural adjustments in terms of the composition of review boards, appraisal criteria, and training of both researchers and patients as coresearchers.

**Programming phase (months 20–32)**

In this phase, the aim was to translate the agenda into a program for research. The Board of the Parkinson Association approved the research agenda and focused on staying in control of its programming. This ownership was unique, because often the programming is coordinated by the funding agency, without active involvement of patients (Abma et al., 2014). In this instance, a meta-study was commissioned on one of the research priorities, namely minor psycho-cognitive problems. After several years, the Parkinson Association is still using the research agenda to evaluate research proposals and grants.

**Implementation phase (months 32–ongoing)**

The aim of this phase is to implement the research agenda. As part of this phase, a coordinator was appointed at the Parkinson Association to recruit and train a pool of coresearchers to foster patient involvement. A call on one of World Parkinson Days resulted in a group of 20 coresearchers. Currently, the coordinator and coresearchers are actively visiting all the clinical research units across the country to disseminate the research agenda. The coordinator says:

> To promote the research agenda, we go on a tour with two or three coresearchers to visit all the universities and medical centers. We also discuss the studies in which we are involved. At the moment, approximately 20 studies. The research agenda helps us to set priorities, also when it concerns grants.

**Reflections on the process from participants**

The coresearchers and voice-over group members experienced their involvement as very positive, special, and intensive. After the meetings, they said they were tired and “empty” of the hard work and thinking. They liked working with peers to inquire, deepen, name, and describe experiences. One of them noticed the mutual and emotional recognition:

> You are doing that with peers and you feel that other persons exactly know what you’re talking about.
Participants in the interviews and focus groups also stressed the importance of mutual contact, and the possibility to talk about topics like addiction, which were normally hardly discussed. Till that time, many patients thought of Parkinson as a brain disease. Conversations offered people with Parkinson a new understanding of their disability, stating that the disability was not a result of an impairment of an individual’s mind or body, but of the social environment. This helped people with Parkinson to reframe their lives, to undo oppression and internalization of oppression. Almost seven years later, the Parkinson Association considered the agenda setting project as one of the major events in their organization over the past 10 years and devoted in their 40th anniversary special issue newspaper two pages on the merits of patient involvement in research. Both voice-over group members as well as researchers and health-care professionals emphasized how important it was to meet and exchange perspectives on research priorities for Parkinson.

**Lessons learned**

This article addresses the issue of how to involve patients in the codesign and prioritization of a research agenda. The following lessons can be relevant for the AR community: the importance of ownership; the value of dialogue for personal and mutual understanding; relational empowerment and critical awareness raising among patients; the importance of responsibility, responsiveness and trust; support in working with coresearchers; and the issue of representation. These lessons are derived from field notes and minutes of team meetings.

**The importance of ownership**

In this process, patients have been involved in all phases of the process, from beginning to end. This is quite unique compared to other similar processes, where patient involvement often stopped during programming and implementation (Abma et al., 2014). A lesson is that making the patient association owner of the agenda, instead of a funding agency, helps to guarantee that the topics of patients are implemented and patients remain involved in research. This ownership can be facilitated by involving patients in all phases, adjusting ways of working to ensure that they can participate (e.g., using creative methods), making sure that their perspective and voice are not glossed-over, staying close to their life-world and emic perspective, like the radar wheel metaphor as a central element in the analysis (compare Kral, 2014), and by acknowledging their input, for example, via coauthorships of publications.

**The value of dialogue for personal and mutual understanding**

Another lesson is how important dialogue was to come to a personal and mutual understanding of their lives (patients) and practices (health-care professionals, researchers, and funders). Research priorities grew out of patients’ lifeworld experiences. In the consultation phase, patients needed dialogues with coresearchers
and fellow patients to discover the impact of the illness of their quality of life. In retrospect, the voice-over group members emphasized how important dialogue was to discover what was important and needed. In a similar way, researchers developed an understanding starting sharing their experiences with Parkinson, and from there inductively defining research topics. When reflecting on the mixed dialogue session, all participants stressed the importance of exchanging perspectives.

**Relational empowerment and critical awareness raising**

This study shows that patients can empower themselves when brought in a situation of mutual encouragement (Karpowitz et al., 2009). Through storytelling and dialogue, people with Parkinson became more aware of their voice (Rappaport, 1995). Via conversations with peers, they became more critical of disenabling environments and processes of exclusion in society. This critical awareness prevented a reproduction of internalized oppression (Tappan, 2006). Jointly, they developed a sense of power to realize their goals via group solidarity and joining of forces. The dialogues and “deep” deliberations among the patients resulted in a broad array of research themes that were grounded in their lifeworlds. Patients explicitly stated that deliberation was as a meaningful and empowering process to develop their voice and priorities. To a lesser extent, internalized domination/privilege was challenged, but professionals did admit funding was one-sidedly invested in fundamental research and limited knowledge to appraise applied research.

**Importance of responsibility, responsiveness, and trust**

Another lesson relates to the responsibility of the voice-over group; this group emerged over time and took responsibility for the process and outcomes. They became the coowners of the agenda. Although we had some initial ideas on how to involve patients, like working with coresearchers, we were open, responsive, and flexible to develop new forms of participation that suited the needs of the patients with Parkinson. This led to the voice-over group; this group of patients guided themselves, and developed and expressed a strong voice in the whole research process. It was this group that kept an eye on the patient’s perspective, and the complexity of living with Parkinson (compare Gillard et al., 2013). The decision to include the voice-over group members in the focus groups appeared to be essential to deeply engage them, and reach a depth not possible with people who do not know each other. Participants felt the freedom to speak up, which is an important aspect of communicative action (Kemmis, 2008). Trust enabled patients to speak up, and to be critical, also of the research process and the researchers (compare Kral, 2014).

**Support in working with coresearchers**

Despite cognitive impairments and stress, we experienced that patients were skillful to bring in their experiential knowledge. Yet, within the research team at times tensions occurred. It was sometimes difficult to divide activities in the team.
Sometimes, the coresearchers were not able to complete research work, like reading (large) reports. Time, patience, and effort were needed to support them. This was done by continuously involving them, making them aware of the importance of their contributions and inviting them to share their experiences, insecurities, and expectations. The academic researchers, as facilitators, also created conditions to promote equal participation. It appeared important to give coresearchers concrete tasks, to explain the research process, and to discuss mutual expectations. Besides good preparation and empathic understanding, flexibility proved essential. Also, practical matters like reimbursement and a home-like meeting place appeared to be essential for those involved to feel acknowledged. One coresearcher felt, for example, not welcome when there was no time to chat and have coffee with cake. “Being part of the team,” she said, was crucial for her.

**Representation**

In the process, the team included members of the Parkinson Association as information-givers. This group might be more articulate and active than other patients. However, participants in the interviews were severely disabled as a result of Parkinson. As a consequence, they were, for example, dependent on the help of their spouse for activities of daily living. Even participants of the voice-over group often felt disabled and experienced serious limitations due to their illness. Some could not participate in the focus groups since they were too ill to travel and/or participate within a group conversation. A possible exception was the participants of the focus groups, who felt relatively healthy and had mild disablement (although also focus group members had severe difficulties with communication and mobility). This indicates that flexibility is needed to involve people with various disabilities and it requires support, for example, enabling travelling.

**Conclusion**

Many questions and issues of patients remain unmet as long as researchers set and prioritize the research agenda. If patients and other stakeholders are included in a process of agenda setting power relations may change if handled with care. Patients, being a relative new group without established power, should first develop their own voice in the relative safe space of their own group. Through dialogue, they begin to understand their common issues and impact of the disease on their lives. The development of relational empowerment and critical awareness of both patients and researchers is necessary to prevent the reproduction of internalized oppression, normative frameworks, and knowledge hierarchies (Tappan, 2006). Dialogues among stakeholders need to be facilitated to enhance the personal and mutual understanding of all. This can lead to a relevant and useful research agenda, and mutual transformative power.
Acknowledgements
I would like to appreciate the engagement of all participants in the process. Special thanks to Maria Goedegebuur, Chris Struiksma, Hans Delebeke, Willem Leedekerken, Lisette van de Moosdijk, and Rob Hagen (Parkinson Association), and Linda Dauwerse, Joeri Tjitra, Karen Schipper, and Annette Hendriks (VUmc). The author(s) would also like to thank Dr. Svante Lifvergren for leading the review process of this article. Should there be any comments/reactions you wish to share, please bring them to the interactive portion of our blog on the associated AR+ | ActionResearchPlus website: http://actionresearchplus.com.

Declaration of conflicting interests
The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding
The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The research was funded by the Dutch Parkinson Association.

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