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Patient participation as dialogue: setting research agendas

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Abstract

Background Collaboration with patients in healthcare and medical research is an emerging development. We aimed to develop a methodology for health research agenda setting processes grounded in the notion of participation as dialogue.

Methods We conducted seven case studies between 2003 and 2007 to develop and validate a Dialogue Model for patient participation in health research agenda setting. The case studies related to spinal cord injury, neuromuscular diseases, renal failure, asthma/chronic obstructive pulmonary disease, burns, diabetes and intellectual disabilities.

Results The Dialogue Model is grounded in participatory and interactive approaches and has been adjusted on the basis of pilot work. It has six phases: exploration; consultation; prioritization; integration; programming; and implementation. These phases are discussed and illustrated with a case description of research agenda setting relating to burns.

Conclusions The dialogue model appeared relevant and feasible to structure the process of collaboration between stakeholders in several research agenda setting processes. The phase of consultation enables patients to develop their own voice and agenda, and prepares them for the broader collaboration with other stakeholder groups. Challenges include the stimulation of more permanent changes in research, and institutional transitions.

Introduction

Involving and empowering patients in health and medical research is increasingly accepted as an important goal and route to enhance the practical relevance and quality of medical knowledge. [1–5] Arguments for engaging patients in research include an increased legitimacy and rationality of decision making, and an increased quality and applicability of outcomes. This development is supported by the rise of a negotiation culture in Western societies, and trends towards public accountability and empowerment of vulnerable and marginalized groups. The emerging trend to involve patients in research has led to a variety of initiatives.

The UK is notable for developing structural approaches through various organizations. For

example, the intermediary organization INVOLVE (http://www.involve.org.uk) aims to stimulate and support active participation of citizens in medical and health research, while the James Lind Alliance fosters discussions between patients and clinical researchers over the effectiveness of medical interventions (http://www.lindalliance.org). As a result, the UK has a wide network of citizens and organizations aiming to realize patient participation in research.

Within academia, experiments with patient participation have stimulated the development of participatory methodologies to envisage how patients can be included in research. Patient participation in health research can take place in all phases of the research process –from research agenda setting and research design to research evaluation and dissemination of research results. In this article we specifically focus on patient participation in research agenda setting.

The range of models for patient participation in research agenda setting is still rather limited. Patient participation in agenda setting usually concerns consulting patients about their problems and needs through a questionnaire, interview or focus group (see for example a study of cancer patients' opinions and priorities for research),[6] or including patients as members in a research programming committee.[7]

To analyse patient participation initiatives, the 'participation ladder' model, based on the ladder of citizen participation developed by Arnstein (1969),[8] can be used to assess the level of patients' decision-making power. The model has been helpful to show researchers that patients can be involved in many ways and that involvement is more than consultation or membership in a committee: it may also include 'partnership' (patients and researchers take decisions jointly) or 'delegated power' (patients take full responsibility for at least part of the decision-making process). Furthermore, the model indicates that the forms most commonly used do not involve shifts in decision-making power to patients. Professionals still determine whether or not and in what way the inputs of patients are used.

Abma[9] and Caron Flinterman *et al.*[7] have argued that 'partnership' between patients and researchers has a high potential for leading to effective patient participation in the sense that the inputs of patients lead to new perspectives and have a real impact on research agendas. This is preferred over delegated power, even if this is not the highest step on the participation ladder envisioned by Arnstein. Participation can result in substantial enrichment, but is hard to imagine without the mutual learning processes between various stakeholders (patients, family, researchers, caregivers). Participation is basically a relational, deliberative and dialogical process. Moreover, it is difficult to see how the perspective of patients will be accepted and utilized by researchers if control is simply shifted from the established party to the marginalized party.

The participation ladder model does not answer the question 'how' to involve patients as partners.[10] In 2000, when we started our investigation, no examples could be found of initiatives in which patients were involved as partners in research agenda setting. There were, however, strategies being used in other domains that successfully realized partnership between 'users' and other stakeholders, including researchers. Examples include participatory approaches in the field of agricultural development in developing countries,[11–13] and sustainable development.[14,15] Furthermore, interesting examples of partnership models between citizens and professionals were found in the field of interactive policy making[16,17] and responsive evaluation.[18–21]

Building on the strategies and experiences in these other fields, we have developed and tested a methodology for patient participation that is radically dialogical in its orientation and offers clear prescriptive guidelines on how to consult and integrate the issues of various stakeholders, including patients, in research agenda setting. In this article the Dialogue Model, including its underlying notions and methodological guidelines, is presented and illustrated with a case example. We conclude with a discussion and reflection on the limitations of our model.

Study design

To validate a methodology for patient participation in research agenda setting projects, we firstly developed a preliminary Dialogue Model on the basis of existing literature on interactive and participatory research (see Table 1). The translation of these approaches to the health field was not particularly complicated – the models are surprisingly similar in their theoretical concepts (focus on dialogical interactions and social learning) and guidelines for activities (cyclical and iterative), and the fields share many characteristics with the health sector. In the various contexts where these approaches originate there typically is an asymmetry between professionals and clients/users, a politicized tension between the interests of the stakeholders, and an absence of consensus over the desired goals and means of a practice/service. The approaches anticipate a high degree of ambiguity through the articulation of various, sometimes conflicting, perspectives.

The first version of the Dialogue Model was checked in a small research project. The expected relevance and feasibility of the model was investigated among patient organizations (January – March 2004). Expert interviews with the staff and board members of six patient organizations (10 participants) demonstrated that there was a need for systematic methods to consult their members; till that time they relied on ad hoc information, often based on personal complaints and website discussions. The respondents expected that a systematic investigation of patient's preferences for research would strengthen negotiations with other stakeholders. The unique combination of consultation and collaboration was considered relevant. The expected feasibility of the methodology was related to resistance among researchers and charity funds to finance agenda setting projects and to implement integrative agendas. Some patient organizations also observed that internally there was not a shared sense of urgency to join research projects; within some organizations the board chose to concentrate on the traditional roles of advocacy and information/support.[22]

Table 1 Key principles and guidelines for process design

Key principles	Process guidelines
-Active engagement of stakeholders -Good social conditions -Respect for experiential knowledge -Dialogue between stakeholders -Emergent and flexible design -Process facilitation	-Structured process: Exploration Consultation Collaboration Prioritization Programming Implementation -Large variety of tools and methods

To further develop and validate our Dialogue Model for research agenda setting, we conducted seven case studies over a 5-year period (2003–2007) in relation to: spinal cord injury,[9] neuromuscular diseases,[23] renal failure,[24] asthma/COPD, [25] burns, [26] diabetes[27] and intellectual disabilities.[28] The iterative multiple case study approach enabled us to work with different patient populations, different types of diseases, various patient organizations and research fields.

The cases were not selected *a priori*. The sample rather emerged on pragmatic grounds. The projects were coordinated by independent academic researchers who fostered collaboration between the stakeholders. In some of the cases the project teams also consisted of patient research partners or staff members of a charity fund or patient organization. The projects lasted between 5 months (the minimum time required to identify and prioritize the research opinions and wishes of patients) and 1.5 years. Several of the projects were financed (partly) by the Netherlands organization for health research and care innovation (ZonMw) and others by charity foundations (Asthma Foundation, Kidney Fund, Dutch Diabetes Foundation, and Dutch Burns Foundation). For more details about the different cases, see Table S1 (online).

Our Dialogue Model was developed in dialectic between theory and practice. Initial theoretical notions derived from partnership approaches in other fields were translated to the practice of health research agenda setting, and

experiences in case studies were then related to the theory, which led to adjustments of the initial notions.[29] The dialectic between theory and practice was repeated several times.

Our model was, thus, not tested in a classical hypothetic–deductive sense, using an experimental design. The theory was rather gradually refined and modified in conversation with practice. In that sense, we worked according to the ideas of the hermeneutic circle; this is a cyclical process of defining theoretical underpinnings and research activities in various contexts.[29] The whole (theory) is translated into parts (the case studies in various contexts), and the parts are then integrated into the whole. After each case study we reflected as to what extent the key notions and methodological guidelines were relevant. We considered what kind of specific adjustments were required to make the theory applicable in practice, and to what extent these local adjustments had implications for the model.

Reflection on the model was conducted systematically. The facilitators wrote an end report for each case study. This report presented substantive findings (integral research agenda), relational changes (new interactions and collaborations between parties), and also learning experiences with the model. Gradually the facilitators discovered and adjusted the model.

A draft version of a book that analyses and integrates the experiences with the Dialogue Model was reviewed by a group of experts with various disciplinary backgrounds (patients and professionals).[30] The feedback of the expert group helped to further refine the model.

Phases in the dialogue model for patient participation

Our Dialogue Model consists of six phases. In this section, we describe the phases and provide some of our learning experiences. We illustrate these with activities and some outcomes from one of our latest case studies. The case concerns the BhURN project ('Brandwondenonderzoek heeft Uw Reactie Nodig' – burns research needs your response).[26] The project took place from January 2006 to February 2007 and consulted burn survivors as well as professionals in research, health care and prevention about their priorities with respect to burns research. The project team consisted of the research coordinator of the NBS ('Nederlandse BrandwondenStichting'), a staff member of the NBS, two masters students and two academics who gave advice on the research design and acted as facilitators. All staff members were involved part time.

Exploration (phase 1)

In a dialogue approach various stakeholder groups deliberate and negotiate about their practice. The aim of the exploratory phase is to create good social conditions for the dialogical process and to gain a first understanding of the stakeholder issues. The project team identifies and contacts patient and professional organizations, and informs and motivates potential participants about the project. In this phase the team also considers the engagement of patient research partners.[31] A literature search, document analysis, internet fora and informal conversations with representatives of the stakeholder groups provide initial information about the stakeholder issues.

Examples of our learning include that it is helpful for the creation of commitment to engage patient organizations right from the start of the project, preferably in the stage of writing a research proposal. Even if the circumstances are constraining, for example a rigid call for proposals with tight deadlines, it is worthwhile to create room for negotiations. Early inclusion enhances the feeling of ownership. Another example of our learning concerns the fact that not every patient organization has a research orientation and tradition. Researchers are sometimes seen as insensitive to the needs and preferences of patients, and this perception is projected on the facilitators. In these instances, the project team may devote extra time and energy to build trust. In addition, more weight was given to the development of a social

infrastructure and empowerment of the patient research partners in the exploratory phase. Mutual trust, safety and openness foster the development of self-confidence among patient research partners and helps them to discover and trust their practical wisdom.[31]

Phase 1 of the BhURN project (January–March 2006)

One of the first activities in the BhURN project was to attend a meeting of the committee of the Dutch Association of Burn survivors (VMB – 'Vereniging Mensen met Brandwonden') to present the draft project design, to ask feedback, and to assess their willingness to support the project. Subsequently, a literature study was conducted using scientific literature, as well as (autobiographic) articles and books of burn survivors. In addition, ten semi-structured interviews were held with: burn survivors (three), a clinical psychologist, a coordinator care provision of the NBS, the director research of the Association of Dutch Burns Centres (ADBC), a burn surgeon of one of the three burns centres (also professor of burns care), a professor of applied psychology, a physiotherapist, and the chair of the Scientific Advisory Board of the NBS (also professor of plastic surgery). These interviews were held (a) to obtain insight into topics that are relevant for the project, (b) to assess the level of support for the participatory process, and (c) to create commitment for the project. The attitude of most of the interviewed professionals was characterized as sceptical, but not unwilling, while burn survivors were enthusiastic about the initiative. This phase ended with the publication of the first newsletter –the BhURN letter– that was widely distributed among burn survivors and professionals to inform them about the activities and (interim) results of the project.

Consultation (phase 2)

The aim of this phase is to identify the research agendas of the relevant groups. The different stakeholder groups are consulted separately. Usually asymmetries between stakeholders prevent meaningful interaction right from the start; researchers and health professionals are likely to dominate discussions and patients –not having had the opportunity to form an opinion yet – may easily be seduced to go along. Patients first need to go through a process of empowerment to prepare them for a more equal interaction with professionals. At the same time, professionals need to be sensitized to respect the experiential knowledge of patients.

Since less is usually known about the priorities of patients, project teams may need to give more attention to these stakeholders. Initially a broad overview of experiences needs to be obtained. It is important to pay attention to diversity (sex, age, SES, ethnicity) within the patient population and differences that matter to the specific patient group.[6] For instance, within the group of people with spinal cord injuries the height of the lesions is crucial.[9] Patient organizations are often able to indicate relevant differences. The project team will consider which methods are most appropriate to consult patients and professionals, often choosing a variety of methods to combine the strengths and weaknesses of each. To integrate data, it can be useful to create a mind map or argumentation tree in which issues are related. In all instances analyses are fed back to participants to see whether they recognize the interpretation (member check).

Examples of changes made following pilot work include the notion that care should be taken to choose appropriate consultation methods to contact and get meaningful input from a diverse patient population. When patients will or can not join a focus group one needs to apply other methods to reach out to that group (for example visiting people at home in case of mobility or acute health problems). Sometimes specific adjustments need to be made for different groups, such as fresh air for asthma patients. The composition of focus groups also requires attention. For instance, many youngsters are not interested in joining a group with adults, while they do find it attractive to attend a special group. Also in the case of interviews we

found that more tailoring to certain groups is needed. For example, people with intellectual disabilities felt uncomfortable with the setting of a formal interview. When we switched to narrative conversations respondents opened up. These experiences were relevant for the refinement of methodological guidelines as part of the consultation phase.

Phase 2 of the BhURN project (April–May 2006)

The consultation started with focus groups among burn survivors. Patients were invited through announcement in the VMB journal and on websites of VMB and NBS, by a letter and distribution of brochures. In total, 37 burn survivors participated in five focus groups. The meetings began with identifying bottlenecks and questions via post-its. Topics were then placed on a time table (before accident, first aid, intensive care, hospital care and afterwards) and discussed. Next participants gave priority to three topics using stickers. Finally, the facilitator asked participants to explain their priorities. The focus groups were lively and constructive, but also emotional. Since many burn survivors experience coping problems, a coach from the VMB was present during each focus group to provide assistance to participants, if necessary. A few weeks later a report was sent to the participants for member check. Since children and adolescents did not participate in the focus groups, two interviews were held with nurses working with children at a burns centre. All data were integrated and visualized in an argumentation tree and discussed in two feedback meetings. The analysis was adjusted on the basis of these meetings.

To list the themes for research of professionals, a policy document (2004) concerning pre-clinical, clinical, psychological and epidemiological research was used. In addition three thematic focus groups (with six to seven researchers and health professionals) were organized on prevention, rehabilitation and basic research. Data were analysed, visualized in argumentation trees and returned to participants for member check.

In May 2006 the second BhURN letter was published.

Prioritization (phase 3)

The aim of the third phase is to prioritize the research themes per group. A questionnaire is an appropriate method to identify the priorities of patients; the method is time consuming, but seen as legitimate, since it represents a large part of the patient population. A focus group with (representatives of) patients is often needed afterwards to help the team to analyse the outcomes of the questionnaire. Among other stakeholder groups a questionnaire can also be used. However, when it concerns relatively small populations, a Delphi technique (repeated written responses) may be more appropriate.

An example of a learning experience in this phase was the involvement of patients in both the design and analysis of a questionnaire. The consultation of patients about the questionnaire led in all cases to substantial adjustments in terms of its length, structure and formulations. Additional 'thinking out aloud' sessions with respondents for subsequent pre-testing of the questionnaire were also helpful. In the co-analysis of the outcomes, it proved to be important to relate the qualitative data from the interviews and focus groups to the quantitative results from the questionnaire. Sometimes one finds gaps between these sets of data, which help to trigger and deepen discussions. An example: in the project with neuromuscular patients the team was unsure how to interpret the high priority given to basic medical research. The qualitative data clearly showed a different outcome (need to pay more attention to the reduction of symptoms, and quality of life issues). An expert group from the patient organization explained that most patients want to go back to a 'normal life'. They have high, and sometimes unrealistic, expectations from medical research. If patients become more aware of the fact that solutions will not be available within their life time, they might shift their priority to research on the reduction of pain and other symptoms,

and social scientific research on the impact of the disease. This explanation was grounded in the vast amount of experiences of the patient representatives and legitimated the analysis.[23]

Phase 3 of the BhURN project (May-August 2006)

The prioritizing of research themes started with the preparation of a questionnaire for burn survivors. Important issues and questions derived from the literature study, interviews and focus groups were translated to 60 research topics and then clustered to ten themes. These themes and topics formed the backbone of the questionnaire, which was piloted during two feedback meetings (previous phase) and subsequently amended. The questionnaire consisted of three parts. One part concerned relevant characteristics of the respondents. The second part focused on the prioritizing of three research topics within each of the themes and the selection of four research themes. The third part of the questionnaire concerned evaluative questions and invited the respondents to make remarks. The VMB and NBS distributed 801 questionnaires to their members. In addition, questionnaires were distributed via a rehabilitation centre (59), the Foundation Child and Burns (52), and at holiday camps for adolescents with burns (46). Two weeks after distribution a reminder was sent. In total, 224 burn survivors returned a completely filled in questionnaire (response of about 25%). Beforehand the NBS had decided that the priority list of burn survivors would consist of 15 topics; this was 25% of the total and considered a manageable number. Per theme it was calculated which topics ended up in the top 15.

The priorities of professionals were clustered by the project team based on the data of the focus groups in phase two. This resulted in three lists: one on (pre)clinical research (11 topics), one on psychosocial and rehabilitation research (10 topics), and one on prevention (five topics). The first two lists were sent out to a larger group of professionals to reach consensus in two rounds (Delphi technique).

Early July 2006 the third BhURN letter appeared.

Integration (phase 4)

The aim of this phase is to integrate the agendas via dialogue. A dialogue meeting with representatives of all relevant parties is organized to foster a negotiation about the research agendas. Given the asymmetries between stakeholders the dialogue should be carefully prepared to give each stakeholder group a 'say'. An equal number of patients and professionals, the selection of participants with an open mind, the use of non-technical language, the reservation of conversation time for patients, the assistance of patients in advance of the meeting, and collaboration about an appropriate time and location help to create a fair and meaningful process.

Examples of changes made following pilot work include the organization of fair dialogues. Initially in the asthma/chronic obstructive pulmonary disease (COPD) project, the dialogue was organized with the same number of people from each stakeholder group. This resulted in a situation where patients were underrepresented. It became clear that a balance (in numbers) between professionals (whether researchers, caregivers or other stakeholders) and patients is essential to prevent domination of professional knowledge. In one of the latest projects, on neuromuscular diseases, a dialogue meeting was organized with two professors (neurology and rehabilitation) and five patient representatives. All participants were open minded. The patients were carefully prepared before the meeting, and jointly decided how they would present the patients' research agenda. Instead of presenting a list with research themes, they started with a personal account exemplifying each of the research themes. Also, it was decided that the researchers would be invited to respond to the research themes brought in by the patients. New perspectives emerged during the dialogue, which could not be reduced to the research themes of both parties.[23]

Phase 4 of the BhURN project (June 2006 – February 2007)

A dialogue meeting was organized to integrate and further prioritize the priorities of the different stakeholder groups. Thirty-six participants (18 burn survivors and 18 professionals) previously engaged in the process were invited to attend a dialogue meeting. A week prior to the dialogue the project team discussed the outcomes of the questionnaire among burn survivors, and prepared them for the dialogue. The dialogue was attended by 15 professionals and 14 burn survivors. After presenting the separate research agendas, participants split up in three mixed groups. The groups discussed and explained the agendas to gain a better understanding of each other's preferences. Next the groups were requested to integrate the four priority lists into one list with research topics. Results were presented and discussed in a plenary session and agreement was reached on one integral priority list. Finally the integral list was prioritized individually. The end product was an integrated list with research themes and topics prioritized as high, medium or low. 15 topics were categorized as having a high priority (top 15).

Research topics of the initial agendas appear in the top 15 (see Table S2). Participants at the dialogue meeting partly, but not exclusively, prioritized 'own' topics; participants also prioritized topics of other stakeholder groups. For example, some professionals prioritized the topic 'itching and oedema on scars and donor places' that was put forward only by burn survivors. In that sense the dialogue was successful; participants tried to persuade each other, and were willing to adjust their own perspective in the process of deliberation and negotiation. This is what is meant by openness; not just giving up one's perspective, but a readiness to acknowledge the limits and shortcomings of one's own perspective in the light of unknown experiences and better arguments.[32] Yet, the general voting behaviour of burn survivors was substantially different from that of professionals. Within the top four of both groups there were no overlapping topics.

Programming (phase 5)

The aim of this phase is developing a program based on the integral research agenda, and to keep all groups engaged in this. Learning includes the mismatch between time frames of the agenda setting process and programming phase. In several instances the programming phase had already been started in its usual form, and before the agenda setting process had ended. This mismatch and the fact that patients were not always included in the programming committee complicates the integration of the agenda in the programming phase. For example, in the project with persons with an intellectual disability (ID), the programming committee of the funding agency pre-ordained the program agenda, stating that ethics and behavioural research would not be part of the programme. What clients with an ID considered most important – research on basic values in life and research on friendship relations – were, as a result, not included in the programme.[28]

Phase 5 of the BhURN project (February 2007)

The end report was rewritten into a research program by the research coordinator of the Foundation.[26] The top 15 of research topics was compared with current research funded by the Foundation. Various topics coincided with current research, particularly research on tissue regeneration and scar management. 'New' topics in the top 15 included itching and oedema on scars and donor places, and topics in the field of rehabilitation. The proposal to pay more attention to topics that were hardly researched at that time was approved by the director of the Foundation.

Implementation (phase 6)

The final phase in the process aims to implement the research programme. This can be realized through 'calls for proposals' by the sponsors of research, by matching research themes with research groups or by stipulating some key topics. Stimulation of research networks may

also be part of this phase. Furthermore, sponsors may chose to include patients and their representatives more structurally in their research programs and commissions, to adjust the formats for grant proposals, to adjust criteria for selection of proposals and to start working with patient reviewers. Patient organizations can also implement new procedures. They may, for example, add patients to their scientific advisory boards. Finally, research institutes can create conditions to stimulate patient participation, for example, by adding societal impact as an indicator to assess research output. The implementation of more enduring forms of participation and interaction is a complex part of agenda setting. Since there is a tendency to go back to 'business as usual', alertness to this tendency is warranted.

Underlying notions

The methodology presented above is grounded in the assumption that participation is in principle a dialogical process between stakeholders, including patients. Instead of conceptualizing participation in terms of shifting control from one group to another (power dimension), our approach emphasizes the mutual learning between stakeholders by means of ongoing dialogues. The combination of consultation and collaboration seems a fruitful way of approaching patient participation, because it does not offend researchers and other professionals, and includes the voices and perspectives of all parties whose issues are at stake more effectively in the research process. The underlying notions of the Dialogue Model in research agenda setting, which are drawn from participatory approaches in other fields and adjusted on the basis of our empirical research, are presented below.

Active engagement of stakeholders, including patients

The Dialogue Model for patient participation in research agenda setting is grounded in participatory and interactive approaches. The issues of relevant stakeholders – particularly including vulnerable and marginalized groups – are taken as a starting point for dialogues about the value of practices. The underlying idea is that all stakeholders have a unique and relevant perspective and that dialogical exchanges will result in mutual understanding and shared action agendas supported by the different stakeholders. Stakeholders will not only serve as information-givers, but are actively involved in the process of designing, data gathering, interpretation and dissemination.[33] They are preferably consulted right from the beginning when the research proposal is written, while crucial methodological issues (such as sampling, choosing appropriate methods) are renegotiated throughout the process. Since stakeholder issues are not known before hand, the design emerges in conversation with the stakeholders. To create ownership and use the contextual knowledge of the stakeholders, findings are jointly analysed. The stakeholders can, for example, help to explain the meaning of certain findings. Stakeholder issues emerge in the process, and are grounded in experiences.

The participatory process often starts with the stakeholder group with the least influence – the patients – to give them a visible 'say' in the agenda setting process. In many instances researchers and policy makers have determined the research agenda in the past; their wishes and preferences are relatively well known and only need to be actualized. The experiences of patients have often not been investigated systematically before and require extra attention. Engagement of all stakeholders in the process implies frequent communication with their interest organizations, including patient organizations.

Good social conditions

A participatory approach aims to foster genuine dialogues between stakeholders. This requires openness, respect, trust and commitment of all stakeholders. These conditions are not always in place, and may need to be actively created and maintained throughout the whole process. In research agenda processes, both patients and

researchers often have strong feelings and prejudices about each other and the desirability of patient participation. These emotions are often grounded in prior experiences. These mutual opinions are made explicit and addressed during the course of the process. The key to the creation of good social conditions is frequent, informal communication between stakeholders groups. Face-to-face communication – ranging from informal contacts, participation at meetings and conversations via interviews and focus groups – enables participants to engage in the process, to give advice, to negotiate and to deliberate with each other.

Respect for experiential knowledge

The perspective of patients on research is grounded in their daily experiences with the illness or disability. In their day-to-day activities patients often encounter various uncertainties concerning medication, diet, physical exercises, mobility, work, social relations and many other aspects of life. Research may reduce these uncertainties, and to gain an understanding of these uncertainties, it is important to start talking about patients' daily experiences in an open dialogical conversation. Through careful listening and probing one gradually gains an understanding of the questions and concerns of patients. This approach also strengthens the self-image of patients; they start to see they are credible knowers.[31,34]

Dialogue between stakeholders

A dialogue between stakeholders is an essential part of our Dialogue Model. A genuine dialogue implies that participants change in the process; they will listen to each other, learn about each other's experiences and frustrations, and add new experiences to their existing repertoire.[35] Concrete experiences and informal oral communications are more appropriate to foster this mutual learning process than abstract knowledge.[21] In a face-to-face meeting participants ask questions, probe, argue and deliberate about their experiences and opinions, and this may lead to adjustments of existing prejudices and the development of ideas that cannot be reduced to existing ones. This process can be compared with the fusion of horizons; participants extend their perspective, broaden their horizon.[32,35,36]

Dialogue is a democratizing method.[37] Through the engagement of groups in a vulnerable and/or marginalized situation power relations shift. Bringing all stakeholders to the table does, however, not automatically imply equity and symmetry. Communication between patients and researchers gets complicated by diverging expectations and scopes, language barriers and the low status of experiential knowledge. To foster a genuine dialogue among asymmetric groups facilitators may prevent ways of exclusion through a careful preparation of dialogical meetings.[25]

Emergent and flexible design

In a dialogue approach, a radical openness for the stakeholders' perspectives implies that the design emerges gradually in conversation with all parties. However, the basic cyclical and dialogical ground pattern and separate phases of the methodology are preset. This means that input of one participant or stakeholder group forms the input for the other participant/stakeholder group, so that information gets redefined and deliberated during the process. To assist the various stakeholders to develop their own understanding, issues will first be investigated and discussed per stakeholder group, next the issues of the various stakeholder groups will be brought into a heterogeneous dialogue. Flexibility and creativity is required in selecting research methods to prevent the exclusion of certain populations.[38] For example, an interview may be inappropriate to reach psychiatric patients.[39]

Process facilitation

Our approach is based on the democratic notion that each and every stakeholder should be able to have 'a say' in the dialogical process to acknowledge the diversity of interests and

perspectives. As relations between stakeholders are rarely symmetrical, collaboration is fostered by an independent process facilitator who has no stake in the outcome but who creates the conditions for successful participation and dialogue. The facilitator has interpersonal skills and knowledge of group dynamic processes and develops a multiple partiality; the issues of each stakeholder are understood. The facilitator is not only an advocate of patients as this could prevent the engagement of other stakeholders. The facilitator also has a teaching responsibility, helping to explain the different perspectives to the various stakeholders. When stakeholders re-establish their own perspective, the facilitator acts as a Socratic guide, questioning certainties and taken for granted assumptions.[40] At the same time the facilitator will – when consensus is absent – act as a mediator and help to create mutual agreement. A process facilitator both keeps an eye on the fairness of the process and meaningfulness of the dialogues. Substantive knowledge is required to some extent to be able to ask the right questions, and to value the substantive quality of the process.

Conclusion and discussion

In this article, the Dialogue Model for patient participation in research agenda setting was presented. The model was developed and validated in seven research agenda setting projects among various diseases and patient populations. Findings of the separate case studies are connected to the particular contexts of the studies. Readers may, however, translate the local findings from the studied context to their own context on the basis of detailed case descriptions, like the one presented in this article (the BhURN project). This is called a 'naturalistic generalization'.[41] Yet, over the years we have formulated some general notions on the basis of the various projects. We call this a 'petite generalization' (vs. a grand generalization).[41] These general notions offer guidance, but always need to be translated to the particulars of the context at hand. We expect that the notions developed will also be of use for other research agenda setting projects, but invite readers to actually transfer knowledge.

Issues that arise from attempts to adopt the Dialogue Model in different situations include the question whether this approach is also feasible for clinical research or basic research. We think the key notions – to interactively engage patient groups with other stakeholders – are also useful for other kinds of research. Our notions find reflection in, for example, IMI/U-BIOPRED and IMI/PROactive, two large biomedical research programs on COPD funded by the Innovative Medicine Initiative of the European Community and the European Federation of Pharmaceutical Industries and Associations (EFPIA) where various actors (academia, industry, patient groups, regulators) jointly develop biomarkers for COPD.

Another issue is the implementation of research agendas (phase 6) in contexts other than those involving condition-specific research funders and patient organizations [42,43] How to interest those funders to take responsibility for some more general themes that have been raised? The answer must lie in developing commitment among representatives to accept the research agenda and to negotiate early on what general themes might fit in their policy aims.

Limitations of the Dialogue Model relate to the application in politicized and asymmetrical contexts. An issue for discussion is then whether it is possible to realize a genuine dialogue. Asymmetrical relationships between stakeholders, morally sensitive topics and strategic issues complicate the process.[44] There is always a risk that groups in vulnerable positions will be dominated by more established groups, and that the knowledge input of patients gets 'lost' in the process. Although there is insight into the subtle mechanisms of exclusion of vulnerable groups in conversations, we need to develop knowledge about effective ways to prevent exclusion, to stimulate fair inclusion and to empower patients. From a dialogical perspective empowerment is a two-way, mutual social learning process as opposed to a process of giving or taking power;

both patients and researchers need to be subject and agent to empowerment. Transdisciplinary research teams embody these dynamics.[31]

Criticism may be raised with respect to the validity of the Dialogue Model, particularly concerning patient priorities. To what extent are the research priorities of patients, identified through the Dialogue Model, representative for the entire patient population? The Dialogue Model uses a convenience sample, which is fine as long as the research is qualitative and explorative. However, since the status of the outcome is to increase the legitimacy of the research agenda, some may argue that the issue of a representative sample becomes highly relevant. This discussion touches upon epistemological groundings as to what counts as evidence. Many scientific disciplines are dominated by the post-positivist paradigm in which the issue of representation is central (in addition to criteria as reproducibility and internal and external validity). The Dialogue Model is, however, grounded in the constructivist paradigm. For constructivist inquiry different quality criteria have been formulated: credibility and fairness.[18] Credibility refers to the extent that participants recognize the results, and is enhanced through member check and triangulation. Fairness of a dialogical process is enhanced when relevant stakeholders are enabled to participate in the process in an open and respectful way and their voice is visibly included. Credibility and fairness can be checked by asking the participants about their satisfaction. Do they feel they have been sufficiently engaged in the process? Was the process transparent and were methods used clear? Is the result more broadly supported by relevant stakeholders who were not actively involved in the process?

Another challenge is to develop ideas how to interest researchers and other professionals in joining these processes; how do we stimulate them to open up for patients' perspectives? What kind of structural changes are required? Engaging patients in a research agenda setting is only a first step to more enduring, ongoing dialogues between patients and researchers. In our approach dialogue is more than a means for gaining adequate information, reaching high quality decisions or formulating an integrated research agenda. It is not only the product (an integrated research agenda) that is important, but also the relational process itself,[45,46] communication between stakeholders who did not previously discuss health research, and the mutual learning that occurs. As new relations develop, research practices may start to change more permanently through the interactive engagement of a new voice in science. Consultation complemented by dialogical collaboration breeds new partnerships. However, this is still rather speculative and requires more thorough research on the long-term impact of the case studies presented in this article. This may give better insight as to whether the current Dialogue Model is effective in achieving the aim of an increased quality and relevance of health research.

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Supporting information

Additional Supporting Information may be found in the online version of this article:

Table S1. Overview of the seven projects involved in the multiple case study.
Table S2. Research topics with high priority in the BhURN project.

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