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Patient involvement in research programming and implementation. A responsive evaluation of the Dialogue Model for research agenda setting

Under embargo
Chapter 9 – Patient involvement in research programming and implementation.
A responsive evaluation of the Dialogue Model for research agenda setting.

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Abstract

This research studied how the Dialogue Model can be optimised by focusing on programming and implementation, in order to stimulate the inclusion of (the perspectives of) patients in research. A responsive evaluation of nine agenda-setting projects was completed following the Dialogue Model. 54 semi-structured interviews were held with different actors (patients, researchers, funding agencies). Three focus group discussions with patients, funding agencies and researchers (16 participants) were organized to validate the findings. Patients are barely involved at all in the programming and implementation phases of the Dialogue Model. Optimization of the model is possible by attending to the nature of the agenda and its intended use in earlier phases. Attention should also be given to the ambassadors and intended users of agenda topics. Support is needed during programming and implementation to organize patient involvement and adapt review procedures. In all phases the attitude to patient involvement, actor participation and formal and informal relationships between parties need to be addressed to build a strong relationship with a shared goal.

Submitted as:

9.1 Introduction

Scientists and funding agencies have, for a long time, been the ones to set research agendas for medical and health research. They were seen as the experts and in the lead to prioritize research themes. The research process itself – from design to implementation – was also mainly controlled by scientists. Patients were merely the objects of study. This is something that started to change some two decades ago when patients (clients, consumers), governments and research councils became more aware of patients’ rights to be heard and respected. The origins go back to the campaigning of the disability movement over control of the process of knowledge production (Oliver 1992). Transitions in society, including consumerism, public accountability and democratisation of science, further prompted openness towards the patient perspective (Fuller 2000; Nowotny et al. 2001; Chopyak and Levesque 2002; Scott 2007; Broerse et al. 2010). Besides normative arguments, it was believed that patients’
experiential knowledge would complement scientific and expert knowledge and lead to more relevant research (Telford et al. 2002; Abelson et al. 2003b; Caron-Flinterman et al. 2005).

In the field of research-agenda setting, also referred to as priority setting, various models and strategies have been developed, ranging from reasonably well structured approaches, from a one-off consultation to regular advice from beginning to end (Mitton et al. 2009; Stewart et al. 2011). The James Lind Alliance (James Lind Alliance 2010) uses a number of different methods to engage patients and clinicians in dialogue about uncertainties in medical treatment. Transparency and proportional inclusion of parties are the guiding principles. The Delphi Method is a structured form of consultation of various parties by e-mail, going through several rounds until consensus is reached (Owens et al. 2008; Malcolm et al. 2009). The Delphi Method uses the positive aspects of group interaction, and attempts to avoid conflict. As there is no face-to-face interaction, fewer ideas may emerge than in direct deliberation (Owens et al. 2008). The Nominal Group Technique is a combination of the Delphi Method and focus group discussions (Jones and Hunter 1995). Participants are invited, in a structured manner, to identify, discuss and prioritize topics. The Dialogue Model for research agenda setting was developed (Abma and Broerse 2010) in the Netherlands. It operationalizes consultation of and collaboration among various actors, and is grounded in the notion that involvement is an interactive process between actors. The methodology was developed and validated over the course of seven agenda-setting projects with charity/government funding agencies and patient organizations. Since its inception, the Dialogue Model has been used on fourteen different occasions (Teerling et al. 2004; Abma 2005a; Caron-Flinterman et al. 2005; Broerse et al. 2006; Caron-Flinterman et al. 2006; Nierse et al. 2006; RGO 2006; Broerse et al. 2010; Elberse et al. 2011; Konijn et al. 2011; Nierse et al. 2011; Elberse et al. 2012a; Elberse et al. 2012b; Nierse et al. 2012; Abma et al. submitted-b) (see Table 9.1).

It is generally acknowledged that patients should be involved in the actual agenda setting, and that their involvement should be sustained in the programming and implementation phases. However, the systematic evaluation of patient involvement in the latter phases is still lacking. Patients may have been engaged in agenda setting (Abma and Broerse 2010), but this does not guarantee that they will be involved in later phases, nor that their perspectives are included in those phases (Elberse and Broerse, 2013). When it comes to programming and implementation, funding agencies and researchers have their own procedures, culture and way of doing things, and they may not be (ready to be) open for patient input (Broerse et al. 2010). We also have to bear in mind that not everyone sees the benefits of engaging patients, and not all may feel interested in becoming involved in new topics listed by patients. Some are willing, but lack the knowledge to involve patients more structurally (de Wit et al. 2013). Even where there is goodwill, patient topics may be excluded (Elberse et al. 2011). Patients and their associations may also feel reluctant to enter the process, being concerned about overburdening, tokenism, and the overshadowing traditional tasks, such as fellow support (Boote et al. 2002).

This aim of this article is to contribute towards the knowledge gap concerning patient involvement in the phases of programming and implementation of research agenda setting. The article focuses on optimizing the Dialogue Model in order to sustain patient involvement in programming and implementation, as well as to provide tools to improve the implementation of topics that patients consider important. To this end, a responsive evaluation of nine agenda setting projects, which involved patients and used the Dialogue Model, has been conducted.

Table 9.1. Overview of research agenda setting projects which used the Dialogue Model
The aim of the Dialogue Model is for equal partnership among patients and other actors (e.g. health care professionals, researchers) in which control over the process is shared. Dialogue is seen as an ethical and fruitful
way for agenda setting as it helps professionals understand the societal impact of their research interests, and it makes room for including patients’ experiential knowledge and voice. Participants in dialogue listen, try to understand each other, and find common ground (Baart and Abma 2011). In the model, participants engage in a mutual learning process which leads to the fusion of perspectives into a new shared perspective that is acceptable and recognizable for all involved (Widdershoven and Abma 2007; Broerse et al. 2010). Hence, dialogue potentially stimulates the innovation of ideas and a sense of co-ownership (Elberse et al. 2011; Nierse and Abma 2011; Nierse et al. 2011).

The Dialogue Model assumes that patients first need the safe environment of their own group to develop their own voice (enclave deliberation); patients’ needs are not ready made, and they require deliberation if they are to become aware of their needs and priorities. Without this deliberation, patients tend to replicate the topics and high expectations of medicine communicated through the media (Baart and Abma 2011). Enclave deliberation equips patients for dialogue with professionals in the integration phase (Nierse and Abma 2011).

There are four phases to the Dialogue Model: exploration, consultation, prioritization, and integration. They lead to an integrated and shared research agenda, followed by two phases of programming and implementation:

- **Exploration**: The project team is established, key actors are identified, an initial list of issues, perspectives and ideas of patients and other actors is drawn up, and the social conditions for collaboration are created.
- **Consultation**: The different actor groups are consulted separately to develop a list of research topics from the perspective of each actor group.
- **Prioritization**: The actors prioritize the research topics identified in the previous phase.
- **Integration**: The prioritized research topics of each actor group are integrated into one integral research agenda.
- **Programming**: The integral research agenda is translated into a funding programme or plan.
- **Implementation**: The research agenda is actively used, action is taken and results are evaluated.

The Dialogue Model uses a mix of methods, including interviews and focus group discussions in the consultation phase, and questionnaires or the Delphi Method in the prioritization phase. In the integration phase, dialogue is used to integrate the different perspectives and encourage mutual learning. An external facilitator creates the conditions for dialogue, stimulates mutual learning and, if necessary, acts as a mediator.

### 9.3 Method

This article is based on the responsive evaluation of nine agenda-setting processes carried out along Dialogue Model lines in the Netherlands since 2003 (Table 1). We followed a purposeful sampling strategy, and selected processes that varied in terms of: a) type of funding agency (governmental; charity); b) number of actor groups involved (at least patients); and c) disease-specific research agendas. The agenda-setting processes should also have been completed at least one year ago, otherwise there would have been insufficient time for programming and implementation. The following agenda-setting processes were included: spinal cord injury; asthma & COPD (and revision); diabetes; neuromuscular diseases; renal failure; congenital heart disease; burns, and people with intellectual disabilities. The evaluated projects used external facilitators from academic institutes for the agenda setting. No external facilitator was present for programming and implementation. The evaluation took place between May 2010 and April 2012 and was carried out by five academic researchers (author team).
Design

Responsive evaluation is based on a constructivist theory, and assumes that all human beings endow meaning to their experiences (Stake 1975; Guba and Lincoln 1989; Abma 2005b; Abma and Widdershoven 2011). Construction is influenced by personal background, but outcomes of a socio-cultural process are also influenced by socio-structural and actor positions. Together, the various complementary actor perspectives will lead to a more informed understanding of what is evaluated.

Actors’ issues are not known in advance and emerge during conversation with them. The design therefore has an emergent character. The evaluation consisted of four, iterative phases, and the results from previous phases were input for the later phases. In the first, exploratory phase the nine agenda-setting projects (phases 1 - 4 of Dialogue Model) were described using desk study and eight interviews. In the second phase semi-structured interviews were held with actors involved in the agenda-setting projects and/or subsequent programming and implementation phases (patients, policymakers, researchers, project leaders) to gain a detailed understanding of their experiences, the consequences and pitfalls of the programming and implementation phases and the role patients had. Results were validated and integrated in the third phase through three feedback meetings (patients, funding agencies, researchers) and lessons learned and improvements for the Dialogue Model (by means of decision-aid models) were identified. Results were disseminated in the final phase at an invitational conference for participants and external audiences. A steering group of six people from science, research councils and patient organizations followed the study with a critical eye.

Sample, recruitment and participants

The sample is based on maximum variation. We wanted to involve input from as many actors as possible in the research agenda-setting processes. Inclusion criteria for the interviews were: a) being involved in one of the nine agenda-setting projects, and/or b) having knowledge of the phases after the agenda setting. The main inclusion criteria for the focus group discussions were: a) not having taken part in an interview; b) affiliation with a patient organization, health funding agencies or research; c) having experience with, knowledge of and interest in agenda-setting processes. An overview of the 54 respondents per agenda-setting process is given in Table 9.2.

Table 9.2. Consultation overview

<table>
<thead>
<tr>
<th>Research agenda</th>
<th># explorative interviews</th>
<th># in-depth interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spinal cord injuries</td>
<td>Patient organization (p): 1</td>
<td>Patient organization (np): 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Governmental funding agency: 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Facilitator research agenda: 1</td>
</tr>
<tr>
<td>Asthma/COPD (including update and extension)</td>
<td>Health specific funding agency: 1</td>
<td>Health specific funding agency: 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Researcher (members scientific committee): 2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Patient organization (p): 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Patient organization (np): 1</td>
</tr>
<tr>
<td>Renal failure</td>
<td>Health specific funding agency: 1</td>
<td>Patient organization (np): 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Patient organization (p): 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Facilitator research agenda: 2</td>
</tr>
<tr>
<td>Intellectual disabilities</td>
<td>Governmental funding agency: 1</td>
<td>Governmental funding agency: 2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Facilitator research agenda: 1</td>
</tr>
<tr>
<td>Health topics</td>
<td>Health specific funding agency:</td>
<td>Health specific funding agency:</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>--------------------------------</td>
<td>--------------------------------</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Burns</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Neuromuscular diseases</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Congenital heart diseases</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>General</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>8</td>
<td>18</td>
</tr>
</tbody>
</table>

*Patient organization (p)* refers to respondents who are patients themselves and are aligned to a patient organization; *patient organization (np)* refers to respondents who are no patients themselves, but who work as a policy maker for a patient organization.

The research team recruited the participants for the interviews and the focus group discussions, who were identified during the desk study and exploratory interviews. All the participants who were approached, except one, agreed to participate. She felt she would not be able to provide any relevant information.

**Data collection**

An interview guide comprising a topic list was developed for the semi-structured interviews. The topic list was derived from the desk study and covered the following topics: a) general introduction (e.g. permission to record the interview, anonymous nature of the interview, member check procedure); b) experiences with initiating and formulating the research agenda (first four Dialogue Model phases); c) verification of the data obtained by the desk study; d) experiences with programming and implementation; and e) barriers and facilitators for patient involvement in programming and implementation. The interviews were conducted by the second and third authors. They were familiar with the Dialogue Model, but were not involved in the evaluated agenda setting processes. The interviews were held in a location indicated by the respondent, usually at work or home. The interviews lasted approximately 1.5 to 2 hours. The interviews were audio-recorded after consent, and transcribed verbatim. A summary of the interview was sent to the participants for member check.

A script derived from the interview data was developed for the focus group discussions. There were three parts to the focus group discussions: a) introduction, including a presentation of preliminary results; b) inventory of current programming and implementation activities, and c) discussion and reflection on practical guidelines, based on the preliminary results. The focus group discussions were moderated by the third and fourth authors, and assisted by the second author. Care was taken to avoid certain pitfalls, such as some people dominating the proceedings, or group pressure. The focus group discussions were held at a central location and lasted 2.5 hours. The groups were audio-recorded after consent, and transcribed in full. A summary of the focus group discussions was sent to the participants for a member check.
**Data analysis**

The data analysis was iterative, i.e. the data were analysed during the process and the outcomes steered the rest of the process. The content analysis was open and oriented towards the inductive analysis of themes per phase in the agenda-setting process. The transcripts were read line by line and labels were attached to text fragments. The codes with labels were related to each other to form clusters. One cluster involved the factors that foster or impede agenda programming and implementation. Another cluster contained issues and questions regarding the Dialogue Model and how to improve it.

**Quality procedures and ethical considerations**

Participants received a summary of the transcript to check the validity of our interpretation and analysis (individual member checks). Group member checks were run with the focus group participants who received the report of the focus group discussion. The (intermediate) results were regularly presented to and discussed with the steering committee, comprising three representatives of patient organizations and three policymakers from funding agencies. The combination of interviews, desk study and focus group discussions enabled us to enrich our dataset and to follow up on any discrepancies in the data (triangulation). Theoretical saturation was reached, meaning that repetition of hypotheses formed in the process were robust and firmly established by the data. The team checked the codes and labels in the data analysis through discussion until consensus was reached (co-checking; inter-rater reliability).

**9.4 Results**

The nine agenda-setting processes differed in the way the agenda setting (Dialogue Model 1-4) had taken shape. Some projects only identified patients’ priorities for research (spinal cord injuries; renal failure; intellectual disabilities). The outcome in the other projects was a shared research agenda for patients, researchers and health professionals. In three projects patient research partners were engaged in the research team to collect and analyse data (spinal cord injuries; renal failure; intellectual disabilities) (Abma et al. 2009). In three other projects, one or two patients were involved in the project team. They advised on the design and implementation of the agenda-setting project (diabetes; asthma/COPD and revision).

**Follow-up after agenda setting: two patterns**

When the nine processes were compared, two follow-up patterns emerged:

- **No formal programming, some patient involvement:** This pattern is found in three of the nine agenda-setting processes, all financed by the government funding agency ZonMw, the Dutch Council for Medical Research. For example, there was no formal programming of the patient topics for spinal cord injury. However, together these projects did encourage patient involvement in ZonMw, for example the inclusion of patient representatives in programme committees. An annual meeting for patients at ZonMw was also initiated and is still continuing.

- **Formal programming and implementation, including patient involvement:** This pattern can be found in six agenda-setting processes, with many differences in the extent of programming and implementation, and patient involvement. These concerned the projects financed by charity foundations. The agenda was
sometimes translated into one specific programme (e.g. Burns Foundation, Diabetes Fund). In other
instances, the agenda was found to be relevant for all programmes, and diffused throughout a whole set
of programmes (e.g. Kidney Foundation). Patient involvement activities for most funding agencies are
restricted to the appointment of patient reviewers or the inclusion of a patient representative in an
advisory committee (Pittens et al. submitted-b). In the case of asthma/COPD we see that they have
invented new ways of implementing patient involvement. In 2004, they identified and prioritized a long
list of research topics put forward by patients, researchers and health professionals. The top ten themes
were adopted by the Lung Foundation. Two years later the Netherlands Respiratory Society (NRS) for
researchers was set up. Patient involvement was encouraged in the NRS task forces that identify
knowledge gaps in research. The review of research applications for grants presented to the Lung
Foundation was completed by the Scientific Advisory Board and a patient pool. Patient pool criteria
include clarity and relevance for the health condition of patients. The patient review was given full
consideration in the overall review process (Teunissen et al., 2013).

Factors influencing programming and implementation

A wide range of factors that influence programming and implementation was identified (see Table 9.3). A detailed
description of these factors can be found elsewhere (Pittens Submitted). For the purpose of this article we give an
overview, and focus particularly on the factors considered relevant for optimizing the Dialogue Model.

Table 9.3. Factors influencing programming and implementation of research agendas including the perspectives
of patients.

<table>
<thead>
<tr>
<th>Context</th>
<th>Prior attitude</th>
<th>Actor participation</th>
<th>Time &amp; timing</th>
<th>Organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>Process of programming and implementation</td>
<td>Nature of research agenda</td>
<td>Research proposal assessment</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Four contextual factors have been identified:
- **Prior attitude**: The broader the degree of commitment for a shared research agenda among relevant actors,
  the more supple the translation of the agenda into a programme. Existing partnerships between funding
  agencies, patient organizations and the research community are helpful for programming and implementation.
- **Actor participation**: Crucial for programming and implementation is the involvement of researchers and their
  willingness to collaborate in multidisciplinary research projects and to focus on topics not directly related to
  their research profile. Furthermore, when they either are or feel to be co-owners of the agenda, the greater
  the chance of implementation.
- **Time and timing**: A misfit between the timelines of agenda setting and programming hampers the uptake of
  agenda topics.
- **Organization**: Many funding agencies do not have sufficient resources to support researchers to develop
  proposals in line with ideas prioritized by patients and patient involvement. Moreover, adaptations of internal
  structures and procedures were often necessary for the research agenda to be implemented. This involved
  more effort for some organizations than for others.
In addition, we identified factors relating to the nature of the agenda. We found that a broader definition of the agenda creates more opportunities for multidisciplinary collaboration. However, when research topics become more specific, research will be more needs-oriented. A balance should be found between the broad formulation of research topics, and research topics that specifically address the needs of patients, in order to preserve the perspective of patients and to leave room for researchers to manoeuvre. Furthermore, factors relating to research proposal assessment were identified. When patients review research proposals it fosters implementation of the patient agenda. Ideally, patients are supported in reviewing by assessment criteria specifically drawn up for the purpose.

Implications for the Dialogue Model

The above factors indicate that both contextual factors and factors relating to the nature of the agenda and review procedures could be steered in the direction of more patient involvement in programming and implementation. In this section we discuss what the implications of this are for the Dialogue Model.

It was worthy of note that participants and commissioners had, beforehand, thought little about how to programme and implement the research agenda. One important lesson for the Dialogue Model is therefore to pay attention to programming and implementation at the beginning of and during the agenda-setting process. Actors in phase 1 (Exploration) should explore and determine how the research agenda will be used in phase 5 (Programming). Topics could be listed one-by-one in a call, and/or agenda topics could be used in a more general sense to steer the programme. If the options are more explicit and discussed at the beginning, it might be expected that fewer agendas remain unutilized. In addition, it is crucial that timelines and decision-making procedures are matched to connect the agenda to the programming phase.

Again attention should be given in phase 4 (Integration) to the pros and cons of a detailed agenda for both patients and researchers. Parties in this phase should be identified to pick up research topics. A particular group of researchers sometimes needs to be addressed to generate an interest in agenda issues. To reach intended users not everything need be carried out by the commissioner. Patient organizations and researchers may also act as ambassadors and lobby for certain topics. This also emphasizes the importance of good relationships among actors.

The first four phases are currently extensively facilitated by an academic institute, while programming and implementation activities are mainly the responsibility of the funding agencies. For successful programming and implementation more support should be provided to funding agencies in these phases by the facilitating academic institutes. In the current Dialogue Model more attention should be given to this by engaging actors in discussion forums on the composition of their scientific advisory board, the review procedure, review criteria, and patient reviewers. Respondents made clear that researchers often lack the expertise to implement patient involvement in their research. The Dialogue Model could include communities of practice and training courses to increase researchers’ knowledge of patient involvement (de Wit et al. 2013).

In all phases the attitude towards patient involvement in research deserves attention as there is still a considerable amount of resistance and ignorance. It therefore seems fruitful to engage funding agencies and the research community earlier in discussions on patient involvement in research to raise their awareness and increase understanding of researchers’ motives for and against patient involvement, their ideals of (good) involvement, their current practice of patient involvement and the challenges experienced. It is clear enough that most professionals are willing to embrace patient involvement as long as it is an ideal. However, the real challenge
comes when they need to put it into practice. Starting in phase 2 (Consultation) with a discussion based on their own experiences seems to be a good way to involve researchers in thinking about patient involvement.

Attention should also be given in all phases to issues related to actor participation to foster broad commitment and co-ownership. In phases 1-4 of the Dialogue Model one should already more deliberately search for participant involvement in scientific advisory boards as this will increase their sense of ownership. It is also crucial that connections between patients engaged in agenda setting and their decision-makers in the advocacy organizations are cherished. The model includes an inventory of researchers’ agenda in phase 2 (Consultation). In addition, researchers and their organizations can be included in the agenda-setting process and its outcomes, e.g. by attending research conferences and presenting findings.

Finally, in all phases the informal and formal relationships among the organizations involved require focused attention, as described in the following section. A strong and enduring relationship with shared goals should be built. This fosters and sustains collaboration among parties beyond the agenda-setting process. While these relationships tend to be vertical, with the funding agencies and researchers directing the agenda, the relationship with the patient organizations may, with time, become more horizontal.

**Guidelines for funding agencies and patient organizations**

Practical guidelines were developed (see Table 9.4) to help patient organizations and funding agencies include the patient perspective and patient involvement in the programming and implementation phases. These guidelines start from the social constructivist assumption that patient involvement requires a dynamic process of organizational change, pioneering and experimentation.

**Table 9.4. Guidelines for funds and patient organizations.**

<table>
<thead>
<tr>
<th>Starting position</th>
<th>Patient organizations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Open attitude towards</td>
<td>Appointment patient representative to work with fund, and to provide patient perspective</td>
</tr>
<tr>
<td>Willingness towards</td>
<td></td>
</tr>
<tr>
<td>Adequate resources</td>
<td></td>
</tr>
<tr>
<td>Expertise</td>
<td></td>
</tr>
<tr>
<td>Collaboration between fund &amp; patient organization with middle and long-term goals</td>
<td></td>
</tr>
<tr>
<td>Funds</td>
<td>Patient organizations</td>
</tr>
<tr>
<td>Appointment policy maker for inclusion patient perspective</td>
<td></td>
</tr>
<tr>
<td>Programming</td>
<td></td>
</tr>
<tr>
<td>Inclusion of patient representatives in program committee</td>
<td>Participation in program committee</td>
</tr>
<tr>
<td>Identification themes based on research agenda</td>
<td>Participation in identification themes based on research agenda</td>
</tr>
<tr>
<td>Writing scientific article on outcomes research agenda</td>
<td>Co-authoring in scientific article on outcomes research agenda</td>
</tr>
<tr>
<td>Active communication of funding program &amp; inclusion of patient perspective</td>
<td>Reviewing and adjusting program text</td>
</tr>
</tbody>
</table>
Organizations differ in terms of their development concerning patient involvement. An organization should therefore first conduct a quick scan of their starting position. Organizations with an open attitude and a willingness to adopt patient involvement and with adequate resources and expertise are in a good starting position for complex, dynamic activities. Furthermore, patient organizations and funding agencies should also consider building a relationship with each other, and set middle and long-term goals together. Organizations lacking abovementioned conditions may first invest in optimizing them, and/or should start with small initiatives regarding patient involvement, and build on these initiatives as their position continues to strengthen.

Funding agencies: Before programming and implementation, a more positive attitude to patient involvement internally should be fostered via active information and by appointing a policymaker responsible for including the patient perspective in all stages of programming and implementation. Ideally, a scientific article is written on the outcomes of the research agenda. During programming, the programme committee should include a minimum of two patient representatives. In collaboration with all actors, particularly patients, the committee should identify themes based on the research agenda. Furthermore, funding agencies should actively communicate about the programme and the inclusion of patient perspectives. During implementation, they could adjust their review procedure by including patient reviewers who use specific assessment criteria to conduct a review from a patient perspective (Teunissen et al. 2013). They should also provide adequate support and training for patient reviewers. Funding agencies with a better starting position could also involve patients with writing and disseminating the call for proposals, paying particular attention to patient issues and incorporating a lay summary in the proposals. Finally, funding agencies should evaluate the programming and implementation processes and disseminate the results to a wide audience, including patients and patient organizations.

Patient organizations: At the start of programming and implementation, a patient representative should be appointed to communicate with the funding agency. Ideally, this person would become a member of the programme committee of the funding agency and work closely with the policymakers responsible for patient involvement. In this role, the patient representative is mainly responsible for the patient perspective. During
programming, the patient organization should participate in the identification of themes, and co-authoring in the scientific article might be an option. Programme texts could be reviewed and amended from the perspective of patients, and patient topics should be explicitly brought to the fore. During implementation, a plea could be made in favour of appointing well-trained and supported patient reviewers. The patient organization could also inform researchers about working with patient research partners, and set up a pool of research partners. From the perspective of patients, the whole process should be evaluated, and the findings shared with the funding agency, and disseminated to the patient community.

9.5 Discussion

Research agenda-setting processes with and for patients are gaining in popularity. Several formal methodologies have been adopted (Gallagher et al. 1993; Jones and Hunter 1995; Dewar et al. 2003; Malcolm et al. 2009; James Lind Alliance 2010; Elwyn et al. 2010b; Lloyd and White 2011; Nasser et al. 2012), including the Dialogue Model (Abma and Broerse 2010). Scientific literature on the implementation of agendas is still rare. This evaluation study is among the first to assess the influence of agenda setting through the Dialogue Model on the programming and implementation phases.

We conclude that patient involvement in programming and implementation and the uptake of the research agenda is something that does not happen automatically, and it is influenced by a wide range of factors. Five out of the nine agenda-setting processes led to formal programming and implementation. This was not the case in the other instances, and indicates that there is not yet a shared idea as to how to translate a research agenda into a research funding programme and/or what the best way to involve patients is. This lack of consensus on effective patient involvement in research is in line with the findings presented by O’Donnell (2004) about the involvement of patients in charity funds in the UK (O’Donnell and Entwistle 2004). They report that many funding agencies (two-thirds) somehow involved patients in research aspects with a wide variety of involvement activities, such as proposal development and review, patients as members in committees and dissemination of results, but that there are many differences in involvement activities and that there are no guidelines on how to shape these activities effectively.

Although patient involvement activities in the agenda setting projects evaluated were mainly restricted to a few activities, we did observe attempts to improve the degree of patient involvement. Although this is far from ideal, there is a heightened awareness among participants that standard procedures and organizational routines need to be adjusted in order to guarantee patient involvement. This finding is in line with transition theory that assumes that innovations first need to start up in the relatively safe environment of a ‘niche’ (Broerse et al. 2010). However, scaling up requires a transition that touches on the rules and regimes of the larger medical and health research systems.

Based on the above findings, suggestions have been put forward to optimize the Dialogue Model. Attention should first be given to the intended use of the agenda in phase 1 (Exploration). In phase 4 (Integration) more attention should be paid to potential users of the agenda. The relevance of advance assessment, the intended use and potential users of findings in decision-making procedures is well-known in the utilization evaluation literature (Patton 1978; Weiss 1998). Tailoring the agenda-setting process to intended use and the needs of potential users fosters the uptake of the outcomes. Adjusting the timelines and procedures of the agenda setting to the decision-making processes of policymakers is also well-known in the utilization literature (Stufflebeam et al. 1971). Furthermore, the research agenda should be formulated comprehensively enough to leave some room for
reinterpretation by researchers (Lipsky 1980; Mackey 2008), and simultaneously be specific enough to preserve the patient perspective.

Deliberate attention needs to be paid in all phases of the Dialogue Model to the attitude towards patient involvement, actor participation and formal and informal relationships. The Dialogue Model was originally grounded in the notion of partnership and dialogue. In order to balance power asymmetries between researchers and patients the model pays a lot of attention to generating a genuine patient agenda and empowerment in a safe environment (Elberse et al. 2011; Abma submitted). Until now a lot of attention and time in those trajectories has been given to the least heard group. We should, however, bear in mind that researchers and funding agencies also need to be involved in those processes in order to change through it. Engaging these actors actively in discussions on patient involvement early in the agenda-setting process and keeping them informed about the outcomes help build enduring partnerships. During the programming and implementation phases support is needed to involve patients in writing the programme, in the programme committee and in adjusting the review procedure. Guidelines have been developed to assist funding agencies and patient organizations in the process, and the Lung Foundation and patient criteria are sources of inspiration (Teunissen et al. 2013).

Although the data in this article pertain to the Dutch context, and the experiences only involve agenda setting in line with the Dialogue Model, we believe readers might benefit from what is presented here, and transfer some ideas to their own context, based on patterns they recognize or consider relevant. Moreover, international literature describes corresponding challenges in research agenda setting and follow-up; in most approaches for agenda setting, patient involvement is limited to the actual agenda setting and there is little understanding of what happens next (Mitton et al. 2009; Stewart et al. 2011) and/or how to shape patient involvement activities in follow-up phases (O’Donnell and Entwistle 2004). The objective of this present study is to add to that emerging knowledge base, and open new horizons for patient involvement in programming and implementation of patient-driven research agendas.