Part 4: Towards structural involvement
Chapter 8 Don’t forget the professional

Abstract

The FIRST model describes five practical, experience-based components that enable equal collaboration between patients and professionals in clinical rheumatology research: facilitate, identify, respect, support and training. This study aims to assess the value of this model as a framework for setting up and guiding the structural involvement of people with arthritis in health research. The FIRST model was used as a framework during the guidance of a network of patient research partners and clinical rheumatology departments in the Netherlands. A ‘monitoring and evaluation’ approach was used to study the network over a period of 2 years. Data were collected using mixed methods and subjected to a directed content analysis. The FIRST components structured the collected data. During monitoring meetings alternatives and descriptors for each component were formulated. The FIRST model helps to guide and foster structural and equal partnerships between patients and professionals in health research projects. However, it should be broadened to enforce the pivotal role of the principal investigator regarding the facilitation and support of patient research partners, to recognize the requirements of professionals for training and coaching in order to develop new partnerships, and to capture the dynamics of collaboration, mutual learning processes, and continuous reflection. The FIRST model requires refinement and broadening to encompass the dynamics of collaboration by including time for reflection and relational empowerment during all phases of the project. Furthermore, the reciprocal character of the five components should be incorporated.

Introduction

Active patient participation in research is becoming more common in the field of chronic diseases (Abma, Nierse et al. 2009; Staley 2009). There are content, strategic and normative arguments for the active involvement of patients (Abma and Broerse 2007). Patients have experiential knowledge of their disease by living and coping with it every day. This complements the scientific knowledge of researchers (Schipper, Abma et al. 2010). Patient participation increases the relevance and practical use of research outcomes, and legitimates research that is often funded by public money. A review of the literature shows that the level of involvement of patients is often restricted to consultation, such as giving information through a questionnaire or interview. Their involvement is mostly restricted to a single event e.g. patients are given the role of advisor at the start of a research project or are invited to take part in a focus group (Stevens, Wilde et al. 2003). However, based on international experience, (Kirwan, Ahlmen et al. 2005; Kirwan, Hewlett et al. 2005) the structural involvement of patients may improve the knowledge production process and
the quality of knowledge considerably (Kirwan, Ahlmen et al. 2005; Caron-Flinterman, Broerse et al. 2007; De Wit, Engels et al. 2007).

Structural involvement requires the long-term commitment of patients and researchers, collaborating as partners, and the continued and consistent integration of experience-based knowledge in each phase of the research process (Jinks, Ong et al. 2009; Kjeken, Ziegler et al. 2010; INVOLVE 2012). Both parties deliberate and interact regularly and share decision-making power equally (Beresford 2007; Lindenmeyer, Hearshaw et al. 2007; Abma, Nierse et al. 2009; Ward, Thompson et al. 2010). A patient who collaborates on an equal and structural basis with researchers is called a patient research partner (de Wit, Berlo et al. 2011) or a co-researcher(PatientPartner 2011). Structural partnerships allow for relational empowerment and mutual learning. They provide time to adjust to each other’s working routines, language and personalities, and to reflect and learn how to cope with new collaborations, accompanying expectations and shifting power relations (Abma, Nierse et al. 2009; Schipper, Abma et al. 2010). We may speak of relational empowerment in this context if all who are involved gain more control over the research process. Secondly, in structural collaborations more room is created for patients to provide meaningful input (Nicklin, Cramp et al. 2010) and to enter a dialogue in which various sources of knowledge (experiential, practical, scientific) can be integrated (Abma and Broerse 2010).

There have been an increasing number of attempts to involve patient research partners, varying from the development of recommendations (van de Bovenkamp and Trappenburg 2009; Diaz Del Campo, Gracia et al. 2011), health technology assessment, (Bridges and Jones 2007; Facey, Boivin et al. 2010) systematic reviews, (Boote, Baird et al. 2011) clinical trials (Collyar 2000; PatientPartner 2011; PatientPartner 2011) and evaluation (Baur, van Elteren et al. 2010). However, working with patient research partners in a structural manner is innovative and poses various challenges. Although an awareness of patient involvement is growing among health researchers, they may not know how to act or what to expect (Thompson, Barber et al. 2009). In addition, they seem reluctant to collaborate with patients as equal partners (Schipper, Abma et al. 2010). Furthermore, the added value of experiential knowledge remains under discussion: Does experience-based knowledge have the same value as evidence-based knowledge, and if so, how can the two types of knowledge be integrated (Caron-Flinterman, Broerse et al. 2005)? The literature indicates that experiential knowledge is important for developing patient-reported outcomes (Nicklin, Cramp et al. 2010; Gossec, Paternotte et al. 2011) or setting a health research agenda from a patient perspective (Caron-Flinterman, Broerse et al. 2005; Welfare 2006; Wright, Corner et al. 2006; Tong, Sainsbury et al. 2008; Abma and Broerse 2010; Elwyn, Crowe et al. 2010; Petit-Zeman, Firkins et al. 2010; Elberse, Caron-Flinterman et al. 2011). But what is the added value of structural involvement? This question has been raised by patients as well as researchers. There are also several problematic issues regarding patient research partners. Issues concern the
willingness of patients, recruitment and selection, training and representation. Finally there are concerns regarding the risks of lack of influence, tokenism and overburdening (van Staa, Jedeloo et al. 2010) and the possible alienation or proto-professionalization of patient research partners (Van de Bovenkamp, Trappenburg et al. 2010).

In the field of rheumatology, the influence of patients on research has grown considerably over the past decade. Patient research partners are now included in scientific conferences, (Kirwan, Heiberg et al. 2003; Kirwan, Ahlmen et al. 2005; Kirwan, Newman et al. 2009) in systematic literature reviews (Shea, Santesso et al. 2005) and in developing recommendations (de Wit, Berlo et al. 2011). In Canada, (Shea, Santesso et al. 2005) the United Kingdom, (Hewlett, De Wit et al. 2006) Sweden and Norway, (Kjeken, Ziegler et al. 2010) and in EULAR (European League Against Rheumatism) (de Wit, Berlo et al. 2011), the structural involvement of people with arthritis in health research has been achieved by establishing networks of patient research partners. A network can create mutual support and guarantee continuation of involvement, leading to structural involvement. A practical tool, the so-called FIRST model, for organizing partnerships in clinical research was developed in 2006 (Hewlett, De Wit et al. 2006). It comprises five components that are considered relevant for collaboration between patients and professionals: Facilitation, Identification, Respect, Support and Training.

The primary objective of this chapter is to assess the value of the FIRST model as a practical framework for guiding structural patient involvement in health research. To this end we studied a network of 27 patient research partners established by the Dutch League of Arthritis Patient Associations (‘Reumabond’). The aim of the network is to encourage the structural involvement of patient research partners in arthritis research in the Netherlands. Below we describe the FIRST model and the Dutch network, followed by the methodology used to assess the model, the results, and the lessons learned. In this chapter patient research partners will be referred to as ‘partners’.

FIRST model

The FIRST model (Hewlett, De Wit et al. 2006) was developed within the context of research steering groups at the Academic Rheumatology Unit of the Bristol Royal Infirmary, and the workshop-based conferences of Outcome Measurement in Rheumatology Research (OMERACT). The first component of the FIRST model is ‘facilitate’. This refers to facilitating the involvement of partners in team meetings (e.g. by providing reimbursement and working in pairs). Inclusion at an early stage is preferable. The role of the principal investigator (PI) is key. The second component is to ‘identify partners, projects and roles’. It is recommended that suitable partners are identified through the clinic or through patient organizations. Partners require in-depth experience with
health issues, an ability to review and discuss information, and the confidence to step out of the ‘patient’ role. Projects addressing clinical interventions, outcomes or service delivery issues could benefit most from partner involvement. The term ‘roles’ refers to research tasks that partners fulfill, such as reviewing draft protocols and questionnaires, analyzing qualitative data, interpreting results and giving presentations. A job description is helpful. The third component is ‘respect’. For a successful partnership, mutual respect is a prerequisite. Respect is associated with confidentiality and acknowledgement of the contribution of the partner. The fourth component is ‘support,’ which is defined as all actions taken to help partners to work and communicate in a successful partnership, for example, by creating peer support or organizing a work place at the institute. The fifth component is ‘training’, which is considered essential for partners. During training, the focus should lie on basic understanding of the research process and of measuring outcomes.

**A pilot: Dutch network of patient research partners**

In 2008 Reumabond initiated a 3-year pilot with the aim of achieving the structural involvement of patients in rheumatology research by creating a network of partners (Elberse, de Wit et al. 2009). The pilot was financed by the Dutch Arthritis Foundation (Reumafonds) and managed by a network coordinator. The budget included the salary and travel expenses of the coordinator, reimbursement of the expenses of the partners and two training courses. The intention was to start with a small number of partnerships with the aim of covering all Dutch rheumatology centres at a later date. In the first tranche 12 partners were selected by Reumabond and trained by an external agency. They joined research teams at the academic rheumatology centres of Leiden and Maastricht. In the second tranche, in 2009, 15 partners were selected, trained and started working in projects at the VU Medical Centre and Reade (Amsterdam) and Radboud University Medical Centre and St Maartenskliniek (Nijmegen). The partners became members of a research team and contributed their experiential knowledge to a variety of research projects. In total, 16 professionals were involved.

About half of the partners were volunteers at Reumabond, working as self-management trainers or local board members. The other partners were not involved in regular activities in any patient organization, but were highly motivated to collaborate in health research, believing that this suited their competences and would enable them to “give something back” to society or to improve healthcare for future generations. The characteristics of the 27 partners are described in Table 8.1.
Table 8.1 Characteristics of members of the Dutch Network of Patient Research Partners (n=27)

<table>
<thead>
<tr>
<th>Gender</th>
<th>Female (22), Male (5)</th>
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<tbody>
<tr>
<td>Diagnosis*</td>
<td>Ankylosing Spondylitis (4), Osteoarthritis (3), Psoriatic Arthritis (3), Rheumatoid Arthritis (15), Scleroderma (2), SLE (3)</td>
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<tr>
<th>Mean age</th>
<th>51 years (SD: 1.9)</th>
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<tbody>
<tr>
<td>Mean disease duration</td>
<td>21 years (SD: 2.2)</td>
</tr>
<tr>
<td>Highest educational level</td>
<td>Secondary school (3), Higher education (9), Academic education (9), unknown (6)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Income status*</th>
<th>Disability pension (14), Elderly pension (4), Full-time paid job (7) Part-time paid job (3), other (1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Membership patient organization</td>
<td>Members (12), non-members (15)</td>
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</table>

More than one answer possible

Method

To assess the value of the FiRST model for establishing and guiding structural patient involvement, the model was used as a practical framework during a 2-year study in the pilot (2009–2010). An active monitoring and evaluation approach (Linnan and Steckler 2002; van Mierlo, Regeer et al. 2010) was chosen in which two evaluators adopted the role of interactive monitors: (Abma and Widdershoven 2011) one researcher with a rheumatic disease who was involved in the initiation of the pilot (first author) and an external researcher (second author). An emergent research design was followed: data from earlier phases formed the input for validation and discussion in later phases. This approach enabled the monitors to collect data using mixed methods, and to provide immediate advice and support to participants when needed. The time allocated to the coordinator was insufficient to support all participants (partners and professionals). She found that more support would be necessary because the recruitment, introduction, role, tasks, responsibilities and support of the partners were undefined and had to be developed and negotiated at each participating centre and with each research team. The insights of the monitors were used to directly improve the guidance of participants; the monitors were available to solve problems, identify flaws in the network, guide and support participants if partnerships were at stake, and assist in improving collaboration.

Activities were systematically documented in log books. The risk of observer bias was addressed by applying quality measures such as protocols, external transcribing and responder checks, and by including two external experts who had more distance from the pilot. The triangulation of methods and sources helped to increase the validity of the research (Barbour 2001; Hsieh and Shannon 2005). Besides participant observation data collection took place using a variety of
qualitative and quantitative research methods (Greene, Benjamin et al. 2001; Greene and Kreider 2005). A literature research was conducted. Initial and follow-up meetings with partners and professionals were organized to collect information about the expectations and experiences of collaboration. At the start of new research projects, partners attended face-to-face meetings. Participants were approached by telephone or e-mail, on request by the participant or initiated by a monitor or the coordinator. An interim discussion meeting was organized to inform stakeholders about the progress of the study and was attended by one partner from each participating centre, three researchers, two monitors, the coordinator, a representative of Reumabond and two external experts. An electronic survey was conducted among all participants to collect quantitative data. Two ‘mirrored’ surveys were developed, addressing similar topics, for partners and professionals. The survey contained 17 statements derived from the FIRST model, with responses being made using a 5-point Likert scale. All 27 partners received the survey (response: n=24) as well as all 16 professionals (response: n=15). Two partners filled in the survey twice because they were involved in two different projects. The survey outcomes were subsequently discussed in four focus groups with partners (27 invited, 20 participated) and six semi-structured interviews with senior researchers (n=4) and fellows (n=2), who were purposive sampled. All interviews and focus groups included the four participating centres and, after consent, were recorded and transcribed. The monitors constantly reflected on process, actions, findings and thoughts.

A directed content analysis was performed by the monitors, using the FIRST components and subcomponents as a set of codes, which were systematically applied to the data. The analyses and codes were discussed in the larger author team (co-checking; inter-rater reliability). Important information that could not be allocated to one of the FIRST components received an open code. The authors regularly compared, discussed and reflected on the data arising from different sources and developed alternative or additional descriptors for sub-components of the model.

The results are structured according to the five components of the FIRST model. To protect the anonymity of the participants all quotes are presented in the “she” form. Quotes from partners are indicated by “N”, those from professionals by “O”, and quotes from focus groups by “F”.

Results

Facilitate
In accordance with the FIRST model, partners received a voluntary contract with Reumabond, covering insurance and the reimbursement of expenses such as travel costs. The intention was to schedule meetings in accessible locations at suitable times to enable partners to attend. Professionals sometimes needed to be reminded of this.
Working in pairs - Both partners and professionals confirmed that allowing partners to work in pairs was important for successful collaboration, as it empowered the partners because they could reflect on their experiences and together form a stronger point of view. On a practical basis, partners reported that they could contribute more easily as the workload was divided and responsibilities were shared:

“At the beginning, when I started on my own, I thought: ‘That is a lot of work!’ Therefore I was really glad that you [second partner] joined me. I no longer felt that everything depended on me and we could share tasks”. (N21)

In addition, different partners bring different experiences and expertise. A partner with a medical background reported:

“We even allocated extra time so I could explain medical terminology and laboratory issues. This worked quite well.” (N20).

Instruction of professionals – Some professionals collaborated intensively with their partners without any instruction. However, the majority of professionals were hesitant about their role. They felt uninformed and did not know, despite their willingness, how to involve the partners. In response the monitors developed a training module on patient participation for professionals. They visited participating centres, explained the concept of patient involvement, and provided recommendations on how and when to include the partners in their projects. The monitors attended various meetings to help define potential tasks and to facilitate arrangements.

Principal investigator versus actual researcher – The inclusion of patients’ perspectives requires guidance by professionals to create enabling circumstances, supportive behavior and communication (Elberse, Caron-Flinterman et al. 2011). In practice it was apparent that partners were often not included because the responsibility for ‘facilitating’ and ‘supporting’ was not adequately addressed. The FIRST model describes both components, but professionals require more guidance. Clarification and refinement of these FIRST components are suggested (Table 8.2).

In many projects the principal investigator (PI), who agreed upon the involvement of partners, was not the professional who actually collaborated with these partners. This was often done by PhD fellows or junior researchers. Because the roles and responsibilities regarding facilitation and support were not always explicitly discussed in advance, misunderstanding between partners and professionals and among PIs and researchers arose. For this reason the role and responsibilities of the PI should be clearly distinguished from that of the actual researcher.
Table 8.2 Distinction between ‘facilitate’ and ‘support’

<table>
<thead>
<tr>
<th>Facilitate</th>
<th>Support</th>
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<tbody>
<tr>
<td>● Establishing optimal circumstances for structural involvement of partners is a key responsibility of the principal investigator</td>
<td>● Supporting partners is a key responsibility of the actual researcher</td>
</tr>
<tr>
<td>● Enabling contribution by removing external barriers (e.g. accessible rooms and timing) and enforcing extrinsic motivation (regulations or financial conditions)</td>
<td>● Enabling contribution in a genuine dialogue by removing internal barriers (e.g. encouraging partners to speak up; create open atmosphere; ask open questions; welcome partners; thank partners) and enforcing intrinsic motivation</td>
</tr>
<tr>
<td>● Creating conditions for collaboration in a team (e.g. instruction, training and motivation of the researcher as well as of the partners; rapid reimbursement of expenses; dedicated work place if applicable)</td>
<td>● Organizing regular contact, direct communication and individual learning processes.</td>
</tr>
<tr>
<td>● Planning regular communication and collective learning processes</td>
<td>● Providing information (share the research protocol, lay summaries and background information)</td>
</tr>
<tr>
<td>● Promoting partners working in pairs</td>
<td>● Promoting mutual empowerment between partners (peer support)</td>
</tr>
<tr>
<td>● Focusing on practical issues: ‘knowing how’</td>
<td>● Focusing on mental aspects: ‘willing to’</td>
</tr>
</tbody>
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Identify

Identifying partners – Potential partners were recruited through patient organization websites, monthly magazines, leaflets in the waiting rooms of the rheumatology centres and by personal invitation by professionals. Candidates had to apply for the voluntary position by sending a covering letter and CV, and filling in a checklist. Partners were selected by the coordinator and a professional from a participating centre, based on personal motivation, communication skills, mobility, willingness to commit time, and competences such as the capacity to think beyond the individual condition and having learned to cope with the disease. A total of 83 candidates expressed an interest. Following selection 50 were interviewed using a standardized protocol.

Selected partners differed from the average trial participant (Table 8.1), with a relatively long disease duration of 21 years, and a level of education that did not reflect that of the general Dutch population.

It became clear that recruitment through the clinics of participating departments had substantial benefits over recruitment by Reumabond. It created stronger intrinsic motivation and responsibility on the part of the professional, which generally led to a good match between
projects and projects. The monitors observed that partners recruited by professionals were more adequately facilitated than partners recruited by the coordinator. Recruitment and selection by the network coordinator kept the workload for professionals low, but showed disadvantages in terms of confusion about responsibility for guidance of the partners: Should support be provided by Reumabond or the professional?

Identifying eligible projects – Identifying projects that might benefit from partner involvement was challenging since clear criteria were lacking. In the first tranche, PIs suggested four research projects that could include partners. Once the partners had received their training, the network coordinator matched them with these projects. The partners assumed that they would start immediately, but the majority had to wait for a long period. The professionals gave different reasons for the delay in starting their collaboration. First, they were not adequately prepared. Some were told by their superior to include partners in their study without knowing what was expected from them. Secondly, for some projects the potential role of the partners was not considered thoroughly by the PIs and in practice appeared less appropriate, and thus it was difficult to set up partnerships. Finally, some projects were delayed because funding or ethical approval had not been secured. Partners who were actively involved in writing a project proposal were not aware of the long time period required for review; and those who were not appropriately informed about the delay lost motivation and expressed their frustration:

"Why don’t we hear anything? What is the status of the project? Are we forgotten?" (N10).

For the second tranche, only projects for which funding was in place were selected. According to the FIRST model it is important to identify eligible projects at an early stage when partners can fully contribute to the research questions and the desired methods and outcomes. However, in practice it seemed difficult to keep partners motivated during periods of inactivity. But the alternative, that is, entering a project for which funding had been secured, showed some clear disadvantages: it deprived partners of the opportunity to participate in the creative, initial phase when the project might have benefited most from their input.

Identifying roles or tasks – During the first tranche it became clear that partners and professionals struggled to identify suitable tasks, sometimes due to a mismatch in expectations. Professionals had a restricted view of the role of partners and their potential value. Both parties expressed a lack of knowledge regarding which tasks within the research project were suitable. In practice they did not exchange their views on this. In response the monitoring team developed a checklist via which the participants could identify tasks and phases in which collaboration was desired and feasible. The participants found this checklist helpful. Partners reported carrying out a wide variety of tasks (Box 8.1), although some envisioned more ways in which they could contribute:

"I don’t think our knowledge and experiences are being optimally used" (N18).
Box 8.1 Tasks of partners during the pilot

- Identification of research topics for medical products (agenda-setting)
- Design of an agenda setting project in the field of SLE (Systemic Lupus Erythematosus) research
- Reviewing research proposals and commenting on drafts for grant applications
- Reviewing and re-writing patient information letters
- Being a contact person for patients who want more information about the research project
- Searching for literature on participation of people with Ankylosing Spondylitis
- Reviewing web-texts regarding e-coaching project
- Reviewing existing questionnaires, e.g. for measuring physical activity
- Translation of an asthma-specific questionnaire into an RA (Rheumatoid Arthritis) questionnaire
- Helping to recruit participants for focus groups
- Back and forward translation of a questionnaire
- Observation of an educational intervention to increase treatment adherence and providing feedback using video recordings
- Participation in an international conference abroad, e.g. health economics, outcome research, development of recommendations
- Participation in an expert focus group meeting on improvement of outpatient health care services
- Playing a role in an instruction video for participants in a randomized trial
- Testing a new e-health intervention as a mock patient
- Giving an interview for publication on the homepage of the institute
- Giving a presentation at a symposium during the annual rheumatology congress
- Contributing to a poster on patient participation in research: the patient versus the professional perspective
- Coauthor of an article for the Dutch Journal of Rheumatology

During the pilot, partners and professionals reported an improvement in skills, self-confidence and trust over time. This showed that relationships are dynamic and that a longer period of collaboration stimulated trust and mutual learning processes. Therefore some partnerships experimented with extended tasks for partners. In one project such continuous collaboration resulted in a period of face-to-face meetings every fortnight. Both parties evaluated the development of their collaboration and presented a poster at a national research day with all participants as co-authors (van de Goor, Hoeve et al. 2009).

Underlying the divergence between the partners’ and professionals’ expectations was the wish of partners to have a more substantial role in the project. During their training, partners had been told that they could be involved in every phase of the project and although the pilot aimed to develop equal partnerships, the survey revealed that these were often not achieved. Only eight
partners and five professionals perceived the partners’ role as that of co-researcher. The assumption that equal relationships were only established after a period of at least one year of collaboration was confirmed by the partners during focus groups and interviews. The role that partners perform in a project is not static. One partner, working in two different projects, reported different roles: advisor in one project, and co-researcher in the other. Two partners working in the same research team perceived their role differently.

Researchers’ roles – Different professionals have different roles. The PI, mostly a senior researcher who coordinates research projects, needs to be distinguished from younger fellows who work under the supervision of the PI. Partners reported problems when there were different opinions among professionals. The following situations were experienced: a PI experienced in participative research versus a researcher without any experience in encouraging partners, and a distant and critical PI versus a motivated and competent young fellow. It is obvious that when both the PI and researcher are motivated to collaborate with partners and when their respective roles and responsibilities are clearly defined, the chances of success increase. The PI should mainly be responsible for creating the optimal conditions for collaboration, while the researcher should focus on supporting the partners (See Box 8.3).

Respect
Acknowledgement – The FIRST model stresses the importance of respect. The voluntary contract, training, support and reimbursement provided can be considered forms of respect. Some centres offered partners the opportunity to visit a seminar or congress. Other partners were, for instance, invited to a Christmas dinner. The pilot demonstrated that respect is partly expressed through practical and financial arrangements. However, partners not only provide personal, daily-based experience of a long-term condition, they also have extensive life experiences and professional expertise that could be beneficial for a project.

A professional relayed the following anecdote about one of her patients:

“The first time she entered my room, I had to apologize for the 20-minute delay and she answered: ‘That’s no problem, I have amused myself looking at the inefficiency of this clinic. I am eager to become involved to introduce greater efficiency here’.”

(O2)

The partner worked as a quality consultant in industry. The professional noted that the combination of professional expertise and experiential knowledge of the disease was unique and very useful. She acknowledged both competences by inviting the patient to become a member of the network.
If a partner is not recognized as an individual providing a valuable source of knowledge, then partners may experience a lack of respect. For example: If the research team did not contact them for meetings, or their input was not heard, partners complained:

“I have been asked to review patient information, which I did. But in the end they hired a professional text writer. That didn’t motivate me” (N15).

Like some partners, professionals sometimes did not feel rewarded for the time taken and effort made to involve partners. They indicated that they would also appreciate some recognition.

Partners learned about the importance of research ethics: the confidentiality of applications, data, publications and personal information. In some partnerships, a contract was signed to ensure secrecy. During the pilot no violations of confidentiality were reported.

Support
Contact – According to the partners not all professionals provided the support required to sustain their motivation. They expected regular contact, information about the progress of the study, explanation about particular phases or methods, and most of all: opportunities to provide input based on their own experiences of living with the disease. Some partners felt insufficiently informed by the professionals and were reluctant to contact the PI when they did not hear anything about the project:

“If I send an e-mail and they do not respond, I do not keep on trying; I am not begging them to be involved” (N10).

Some professionals felt unable to meet the expectations of their partners, and others thought that partners were expecting more than they could offer.

“Research partners are very enthusiastic, I think they are a little bit impatient. I can fully understand that!” (O8)

The time allocated to the network coordinator proved insufficient for supporting all partners and professionals. In addition, the responsibility for providing support was not always clearly divided between the local researchers and the coordinator. Therefore the monitors actively stimulated communication between partners and professionals and recommended that they contact each other on a regular basis, even when there was little progress on the project.

Peer support – During the interim discussion meeting partners reported that they would appreciate more face-to-face contact with fellow partners in other projects:

“Phone calls or e-mails cannot replace face-to-face contact between the partners. To see each other and to meet as a group is important. We want to exchange
experiences, support each other and learn from other projects. That is inspiring and motivates us to continue.” (N2)

For this reason the monitors organized local group meetings. The partners appreciated the opportunity to exchange experiences and create forms of mutual support. At one participating centre the group of partners appointed a local network coordinator from among themselves. By organizing meetings with all participants, this coordinator fostered relational empowerment among partners and researchers that guaranteed the sustained involvement of network members in new research projects.

Support for professionals – Professionals reported difficulties discussing the tasks of partners and did not know how to incorporate partners’ competences and experiential knowledge into their research, partly because they did not know what contributions partners were able to offer. The monitors tried to intervene by assuring professionals that the added value of partners may not be apparent at the first meeting, but will be revealed over time. When partners were encouraged to become involved and were given opportunities to provide input along the way, they gained trust and confidence. And when their experiences, expectations and concerns were openly discussed and addressed, the partners developed a sense of ownership of the research process and their contribution increased. In addition, the potential tasks for partners relevant to the professional were discussed. By referring to examples of colleagues who confirmed that positive experiences motivated continued involvement, some researchers became more enthusiastic and supportive.

During the pilot the monitors accepted responsibility for guiding and supporting researchers in their endeavour to establish constructive relationships with partners.

Training
All partners received two days of training at an accessible location. The training sessions prepared partners to engage in all research stages and to recognise the value of their experience-based knowledge. Basic information on the empirical cycle, evidence-based medicine and ethics were provided. Professionals reported that it sometimes took time to explain to partners that items on validated questionnaires could not be altered. They recommended incorporating more information on research methods into the training sessions. Partners felt insufficiently informed about the fact that conducting research and developing equal partnerships required time, energy and investment from both sides. As previously mentioned, this sometimes resulted in a mismatch between expectations that participants found difficult to deal with. Management of expectations became an important part of training.

A follow-up training day 9 months later took place to facilitate the exchange of experiences among partners. This was assessed as being very important for creating mutual support among
local partners and across centres. The regular exchange of experiences and mutual learning were felt to be important motivational factors and a crucial difference between a living network compared to “just a pool of partners” (F4). The group meetings increased self-confidence.

Training of professionals – From the survey it became clear that professionals also need additional guidance regarding how to conduct participative research and make optimal use of the experience-based knowledge of partners. Their professional background plays a role, as one rheumatologist admitted:

“I am aware of the importance of including patients in the development of a questionnaire, but for me it is difficult to work in an area that is not my expertise. I am not a social scientist.” (O23)

A young fellow suggested:

“Training about ‘what I can expect’, and how I can get the most out of my partners? That is currently a barrier for me because it is a pilot, we don’t know exactly ‘how to handle this’, ‘what I should ask’ and ‘what I should be aware of’” (O13).

During the pilot, the monitors developed training sessions for professionals focusing on the importance of discussing the potential roles and tasks of partners and the management of expectations, and the value of relational empowerment. It was stressed that the dialogue should not only take place at the start of the project, but should be a point on the agenda of every team meeting. This training included concrete examples of the surplus value of patient participation.

**Lessons learned**

The FIRST model is a practical framework that can be used by professionals to facilitate, support and acknowledge the contribution of partners. When applied in the context of the Dutch network the reciprocal character of partnerships seemed absent: what the professional should do to adjust the research process or how partners can support each other is not incorporated. The implicit underlying idea about empowerment is a one–way process: empowerment is a process of giving or taking control. It is a zero-sum game. This has been criticized as being problematic as giving control can also be turned around to mean taking away control (Abma, Nierse et al. 2009). And taking control does not acknowledge vulnerabilities and structural barriers. Our findings suggest that in many cases what is important to partners is similar to that of professionals. Relational empowerment(Abma, Nierse et al. 2009) means that everyone profits from the collaboration, that the learning curves of both parties are intertwined and that all invest equally, and all are trained, supported and facilitated. Hence the title: Don’t forget the professional.
In this pilot, the FIRST model appeared rather static. We learned that creating equal partnerships requires attention to the dynamics of the learning processes of all participants throughout the whole process: how initial prejudices and resistance resolve, how participants gain skills and get to know each other, change power relations and achieve mutual agreement. We also found that reflection on the collaboration should take place regularly. Because the dynamics of collaboration and the reciprocal character of the five components are currently not encompassed in the FIRST model, we propose broadening the model and clarifying or refining the (sub)components as suggested below.

**Facilitate**
We found it helpful to make a clear distinction between facilitate and support (Box 8.2): Facilitate refers to creating practical conditions and eliminating barriers for structural collaboration. It deals with procedural, environmental and physical factors. This distinction also enabled us to clarify the different responsibilities of the PI and the actual researcher: The PI is responsible for facilitating inclusive conditions for participative research, among which instruction and support of the researcher is key. The actual researcher is responsible for the support and encouragement of individual partners.

**Identify partners**
The FIRST model provides minimum criteria for recruitment and selection. Questions about selection criteria regularly arose in this pilot and thus clear guidance for researchers should be provided. Identifying partners through professionals in the clinic in which the partners will be working proved to be the preferred method of recruitment.

**Identify projects**
In practice a need appeared to develop criteria for identifying projects that will benefit from full or limited patient involvement.

**Identify tasks**
Separating ‘roles’ from ‘tasks’ proved useful for bringing clarity into the dialogue between partners and professionals. Partners can have different roles (level of involvement). Tasks refer to practical activities that partners can do to contribute in subsequent phases of the research process. Roles as well as tasks need to be regularly evaluated.

**Identify professionals**
In the context of implementing a network of partners, our results indicate that it may be useful to add the concept of ‘identifying professionals’ to the model. Relevant criteria include motivation and the ability to collaborate with partners as equal members of the research team.
Respect
We found that recurrent reflection on the quality of the collaboration in order to discuss questions about communication, sharing power, feeling part of the team and feeling rewarded for contributions is important. All participants need to be aware of the dynamics of establishing new partnerships by recognizing that individual learning curves and relational empowerment are valuable outcomes of the collaboration.

Support
As mentioned earlier, we learned that it is important to distinguish support from facilitation. Support refers to individual encouragement, communication and personal empowerment. Support should not be restricted to partners but should also be offered to professionals. Skills for and attitudes towards creating equal partnerships do not come automatically. In the pilot professionals required support tailored to their personal needs and competences. This kind of support might be organized under the supervision of the PI.

Training
Partners were not always aware of the limitations set by ethics committees, national law or scientific rigor, and it might therefore be beneficial to explain this in advance. For example, partners should understand that validated questionnaires cannot be adjusted easily. Professionals were often ignorant about how to include partners in their projects and what they could do. Providing information about the principles of participative research, examples of the complementary value of experiential knowledge, and practical do’s and don’ts related to communication proved to be helpful.

Discussion
This study describes the usefulness of the FIRST model for building a network of partners who can join research teams as equals. Although this model is a convenient tool for setting up new collaborations, it is not fully equipped to guide equal structural partnerships. However, by organizing continuous reflection in the pilot network, often initiated by the monitors, participants could take on their respective roles and start a process of relational empowerment. We believe that structural involvement will have benefits regarding continuity, peer support, the development of competences, trust and motivation, and result in the production of aggregated knowledge (Creech and Willard 2001). Establishing a network of partners might be one of the conditions required to achieve structural involvement of the patient perspective in health research. In such cases network-based support through a network coordinator, annual network days, training and e-coaching, local follow-up meetings and regular newsletters could be implemented. For the development of this kind of support, networks could use experiences of
other learning networks such as the communities of practice (Wenger 1999; Le May 2008). Other necessary conditions are, as we have described, an openness to mutual learning processes (Nierse, Schipper et al. 2011) and recognition of the fact that it takes joint efforts and regular dialogues to build sustainable relationships. Equal partnerships do not occur immediately, but are built by developing trust and self-confidence over a longer period of time.

Inclusion of patients is not just a matter of giving them a seat in the research team. Even when patients are equal partners the risk of being overshadowed by professionals remains (Elberse, de Wit et al. 2009; Abma and Broerse 2010; Baur, van Elteren et al. 2010). The literature shows that there is a substantial risk that partners will be marginalized or excluded (Elberse, Caron-Flinterman et al. 2011). Exclusion is often unintended and professionals are often not aware of the ways in which to avoid this. Our data indicate that despite the willingness of professionals, the structural involvement of patients is challenging. A number of barriers have been reported: Divergent expectations and opinions regarding the level of participation and the expected contribution; Lack of knowledge of participative research and tasks that can be shared or delegated to partners; Lack of skills on the part of professionals to create new kinds of partnerships, i.e. patients as full team members, sharing similar responsibilities with other team members and having an equal say in research decisions. Therefore professionals also need training, support, facilitation and encouragement (Israel, Schulz et al. 2001; Barber, Boote et al. 2007; de Wit, Berlo et al. 2011). In fact, most components of the FIRST model are also applicable to the professionals.

A limitation of this study is that it is context bound. However, we believe that a modified FIRST model, based on our research findings, might help guide comparable networks of partners in other countries or disease areas. New pilots could address the criteria for identifying projects that will benefit most from patient involvement and for identifying partners. We know that not all patients are able and willing to become partners in research (van de Bovenkamp, Trappenburg et al. 2010; Van de Bovenkamp, Trappenburg et al. 2010). We support the principle that patients should meet appropriate selection criteria to be able to fulfill the role of partner. This does not have to be a problem because representativeness is not the primary aim of the inclusion of partners – there are better methods of obtaining representative data. The added value of partners is that the patient perspective is provided from the informed and retrospective point of view of an individual.

We hope that the question of patient participation will be considered more often by health researchers. If both researchers and patients begin to realize that they are both the object and subject of power, and mutually dependent, this will ultimately enhance the relational empowerment of all collaborating members.