

TOWARDS STRUCTURAL PATIENT  
PARTICIPATION IN HEALTH RESEARCH  
THE DUTCH NETWORK OF PATIENT RESEARCH  
PARTNERS IN RHEUMATIC RESEARCH

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## ABSTRACT

The role of patients within health research is changing from passive subject towards active partner. This article focuses on a two-years evaluation of a Dutch pilot; ‘Network patient research partner’, which aims for structural patient involvement in health research projects in the area of rheumatology. Eighteen partnerships between patients and researchers were established. A monitoring and evaluation method was used which was mainly qualitative. The pilot was analysed using a system innovation perspective.

The partnerships experimented with a new culture, structure and practice to learn what are effective ways to collaborate in the conduct of health research. Facilitators included the presence of resources and proactive people willing to experiment and learn. At the same time, the incumbent culture, structure and practice put pressure on the partnerships, which manifested as barriers. Barriers were the low priority given to the partnership by researchers, lack of initiative and know-how, and little interaction within the partnerships. Furthermore, the network structure operated in a rather isolated manner and offered limited support. To enhance structural involvement, strategies need to be developed that focus on strengthening competences (knowledge, attitude and skills) and building organizational elements in the structure of the health research system.

## Introduction

Traditionally, patients have had little influence on health research, but their position is changing from passive subjects and end-users of knowledge to active collaborators<sup>1-4</sup>. It is increasingly acknowledged that patient involvement could positively contribute to health research: it could increase the quality and relevance of health research because patients can complement the scientific knowledge of professionals with their experiential knowledge and can articulate their needs<sup>5-8</sup>. The legitimacy of health research can be increased because it becomes more democratic when patients have a voice in decision-making processes and become involved in determining the outcomes that are relevant to them. Also, involvement can lead to empowerment of the patients<sup>9-10</sup>.

During the past decade, patients and patient organisations have become engaged in a variety of activities related to health research, e.g. setting health research priorities<sup>11-13</sup>, being members in (scientific) advisory bodies<sup>14</sup>, reviewing research proposals<sup>15</sup> and providing advice on clinical study designs<sup>16</sup>. This development is increasingly supported by international health authorities (FDA, EMA), national governments and funding agencies. Although consultation is increasingly taking place, structural collaboration between patients and health researchers seems to be rather limited. Structural patient involvement can be defined as patients having a place in decision-making structures and an influence on the decisions taken, whereby both patients and researchers have a long-term commitment to collaboration throughout the research process. In dialogue with researchers patients provide experiential knowledge which is integrated in research.

Most described initiatives of patient involvement are ad hoc or one-off events<sup>17-19</sup> and are rarely incorporated in the conduct of research. As a consequence, patients' contributions are often limited<sup>17-19</sup>, knowledge and skills developed by participating patients are not optimally used, and established relationships between different stakeholders are not sustained. The current health research system provides little room for structural patient involvement since the current routines, structures, beliefs and values are hardly suitable to integrate the patient perspective structurally, and they are difficult to change due to the rigidity of the system<sup>17-20</sup>. The development towards structural involvement of patients in the health research system is therefore likely to evolve slowly. However, little is currently known on how to realize structural involvement, particularly with respect to the actual conduct of research. Therefore,

it is adamant to draw lessons from case studies to increase our knowledge on this highly relevant topic.

The aim of this article is to provide insight into facilitators and barriers to structural patient involvement in health research by means of partnerships between patients and researchers from a system innovation perspective. To this end we analyse an innovative pilot whereby the Dutch league of arthritis patient associations (Reumapatiëntenbond, RPB) takes up this challenge by establishing a network of trained and supported patients. Trained patients form a partnership with researchers with the intention to become structurally involved in medical and clinical research projects in the area of rheumatology.

### **A system innovation perspective**

To gain insight into facilitators and barriers, a ‘system innovation’ perspective is applied. System innovations are profound changes in dominant cultures, structures and practices which tend to encounter resistance from dominant stakeholders<sup>21-23</sup>. As change is difficult, system innovations are often slow processes, taking 20-30 years. The concepts ‘culture-structure-practice’ are described as relevant notions for system innovations<sup>24-27</sup>. Van Raak (2010) defines *culture* as ‘a set of values, perceptions and interpretative frames that are shared by most of the involved actors’; *structure* as ‘the physical, economic, legal, financial, organisational and power structures that facilitate and/or constrain the behaviour of the actors involved’ and *practice* as the actual actions undertaken by actors which are relevant for the functioning of the system. The culture and structures are shaped by the practices of the stakeholder groups involved, and at the same time, those practices are encouraged or limited by the structures and culture<sup>25,28</sup>. These three elements are strongly intertwined and reinforce one another. The current culture, structure and practice of the health research system will be indicated with ‘current C/S/P’.

Current C/S/P developed over time, resulting in a dynamic equilibrium, with stakeholders such as health researchers, funding agencies, research institutes and the government developing routines, rigid relationships and established ways of communication and interaction has been established<sup>17,20,29,30</sup>. Important characteristics of the culture are: Objective knowledge based on robust and validated research methodologies is key; autonomy and curiosity are important; reward is obtained by publication rates and citation scores. In terms of structure, leading researchers are often members of program committees and scientific

advisory boards of research funding organisations, and researchers/research departments have little interaction with patient organisations. Characteristics regarding practice are work being based on protocols and scientific training and the use of validated scientific methods to obtain ‘objective knowledge’. Lay knowledge is considered subjective and difficult to integrate<sup>31 32</sup>. Peer review and peer interaction are important ways to judge and discuss findings<sup>17 20 30 33</sup>. The role of patients has been restricted for a long time to ‘subject of study’ and beneficiaries of developed knowledge.

To induce a change in C/S/Pc, it is important to experiment with new cultures, structures, and practices (new C/S/P) in a protected space, on a small scale. It is unknown beforehand what this new C/S/P will look like. By trial and error, involved stakeholders jointly experiment to investigate new practices, values, beliefs and structures, adapt and improve them. Experienced-based learning is essential. Within the protected space, certain facilitators are considered key. Facilitators are factors in place or created in the protected space which stimulate the development of new C/S/P. Important facilitators are: available resources, open learning attitude and commitment, places to meet each other to exchange experiences and ideas, making expectations explicit, having a shared vision, and the presence of change agents<sup>34 35</sup>. Change agents are people or organisations who stimulate experimenting with and learning from the novelty at stake. They undertake actions and are willing and able to invest in terms of time, money and/or knowledge.

However, such a protected space experiences pressure from current C/S/P since the people involved normally function within current C/S/P. This pressure raises barriers to experimenting with new C/S/P, pushing things back to ‘business-as-usual’. If too many barriers are experienced by the people involved, the protected space will collapse, and no new C/S/P develops. On the other hand, if facilitators are sufficiently effective to overcome barriers, the protected space will become stronger and may expand. To expand, it should offer an attractive alternative (potential) to current C/S/P. As more people join and learn from new C/S/P, this increasingly consolidates it. The innovative ‘best practice’ may become normalized, challenging current C/S/P and adapt (part of) current C/S/P. This is often enhanced by coinciding societal trends<sup>36</sup> like in this situation increased patient empowerment<sup>10 37-40</sup>, democratization of science, public accountability of science<sup>41-46</sup> and decline in the authority of experts<sup>47</sup>.

The case described below can be considered a protected space in which patients and researchers experiment with the novel role of patients in the conduct of health research. In the case, stakeholders experiment with new C/S/P in a real-life setting offers a unique opportunity to identify facilitators and barriers and to test strategies that foster structural patient involvement.

### **Network Patient research partner**

The RPB is a Dutch patient association advocating for the rights and interests of people suffering from a rheumatic condition. They increasingly received requests from researchers and professional carers to provide input from a patient perspective for research proposals, information materials and questionnaires. Although the RPB considered it of great importance to provide this input and has become a valuable stakeholder in health research, the ad-hoc and last minute nature of many requests was not considered effective and entailed a danger of tokenism. Therefore, the RPB decided in 2008 to set up a pilot network comprising trained patients that would become structurally involved in health research in the area of rheumatology. The FIRST (Facilitation, Identification, Respect, Support and Training) model was used as framework to set up the network<sup>48,49</sup>. It describes components considered relevant for enhancing collaboration between patients and professionals. The network was managed by a RPB coordinator for 12 hours a week.

The principal investigators (PI) of five rheumatology centers were contacted since they have a good overview of ongoing and future research projects and executing researchers. The PIs, together with the coordinator, selected 18 research projects that seemed suitable for patient involvement. Projects varied from care research (e.g. developing e-health programs), social health research (e.g. relations between rheumatic conditions, work and sports), epidemiological research (e.g. often occurring co-morbidities), medical research (e.g. improvement of early diagnosis) and clinical research (e.g. drug compliance interventions or the influence of co-morbidity on physiotherapy).

Twenty-seven patients were selected based on a motivation letter, a checklist and a 'job' interview. They received a 2-day training in health research and patient involvement. After training, the patients became so-called 'patient research partners' and will be referred to as partners in this article.

Partners were matched with a research project, often based on their rheumatic condition and the travel distance to the centre. Partners and researchers formed partnerships, comprising preferably two partners and a small number of researchers engaged in a research project. In total 17 researchers were involved. Partners received a voluntary contract with the RPB and were reimbursed for expenses incurred.

## **Methodology**

### *Data collection*

Two researchers were appointed as ‘monitors’ to conduct a reflexive monitoring in action<sup>50</sup> study over a two-year period, starting in February 2009. Two external advisors were appointed to provide the monitors with solicited and unsolicited advice and to safeguard their objectivity towards the network. The pilot network was examined in a real-life setting with the aim to gain insight into the barriers and facilitators for structural patient involvement. As described by Barber et al.<sup>14</sup>, many evaluation studies in the area of patient involvement are retrospective, potentially losing valuable insights and data. The advantage of a formative evaluation is that direct insight can be obtained of the progress made. Moreover, timely adjustments can be made, and constraining factors may be resolved in an early phase<sup>50 51</sup>. Different methods, predominantly qualitative, were used<sup>52-54</sup> (see box 1), following an emerging research design in which data from earlier stages formed the input for later stages.

### **Box 1: Overview of data collection by the monitors**

- Literature study
- Document analysis including email correspondence
- Participant observations during meetings
  - Introduction meetings whereby partnership meets for a first time
  - Follow-up meetings of partnerships
- Regular updates of functioning of the partners via telephone or email
- Local meetings with partners to exchange experiences
- Local meetings with professionals to discuss patient participation, possibilities for involvement in research projects and progress
- Reflective discussion initiated by two monitors, attended by one partner from

each center, three researchers, the coordinator, a representative of RPB and two external experts

- Electronic survey for partners (response rate 24 out of 27) consisting of 17 topics related to expectations, experiences and benefits of the partnerships
- Electronic survey for professionals (response rate 15 out of 16) consisting of 17 topics related to expectations, experiences and benefits of the partnerships
- Four focus group discussions with partners at the four different locations (27 invited, 20 attended) to discuss the outcomes of the surveys, developments and potential strategies to enhance collaboration.
- Six interviews with professionals, purposive sample to discuss the outcomes of the surveys, developments and potential strategies to enhance collaboration.

All participants (partners and researchers) were informed by email and newsletter in advance about the monitoring and evaluation activities, the aim and what was expected from them. During meetings when the monitors visited the participating department or partnerships for the first time, they introduced themselves and explained their role in the network. All participants consented to participate in the monitoring and evaluation study.

After receiving approval from the participants, interviews and focus group discussions held by the monitors were recorded and transcribed. A summary was sent back for the members to check. Informal conversations, telephone calls and partnership meetings were often not recorded, but detailed notes were made by the monitor(s). Observations of meetings were done to investigate how partners and professionals interacted, collaborated and how the partnerships dealt with the partners' input. If requested by partnerships, monitors provided input for discussion and suggestions for collaboration. Both monitors documented their activities and findings in a log book, which was regularly discussed between the monitors, the network coordinator and two external advisors. The monitors had a facilitating role in stimulating dialogue between partners and researchers. To support the partnerships, strategies based on findings from earlier stages and in response to requests from partners and/or professionals were developed and applied if agreed upon by the network coordinator. For the pilot, successful partnerships are defined as ones which were sustained during the course of the project, with the partners involved in different phases of the research project and both partners and researchers experiencing the benefits of collaboration. In addition, in successful partnerships, a start was made with the development of new C/S/P.

### *Analysis*

The analysis explored the barriers and facilitators to structural collaboration in the partnerships. A first round of thematic content analysis was conducted to identify facilitators and barriers. In a second round of coding, themes related to barriers were coded in relation to 'culture', 'structure' and 'practice'. A round of open coding was applied to themes related to facilitators, followed by a comparison with facilitators described in the system innovation literature. The findings were discussed in the larger research team, and consensus was reached on the analysis.

### **Results**

Since forming partnerships was highly innovative and new for all participants, preconditions for successful partnerships were absent. There was a vast diversity in how the partnerships developed. Three of them never materialised or became silent shortly after the kick-off meeting. Three partnerships developed into well-functioning collaborations leading to expanded or prolonged involvement of the partners in new projects. The other twelve partnerships varied enormously in degree of success. Below, the various facilitators and barriers that were experienced in the partnerships are described. All partnerships encountered similar barriers, but in the more successful partnerships many facilitators were present that made it possible to overcome the barriers.

### *Facilitators*

The presence of *'financial resources'* to set up the network, appoint a part-time coordinator, train partners and arrange reimbursement for the partners' expenses facilitated the partnerships. For participating departments, there were in principle no costs involved.

When the partnership was perceived as a *'learning process'*, accepting that know-how was something that was not present beforehand but could be jointly explored and discussed, interaction within the partnership took place more regularly. Members were willing to experiment to gain new knowledge, to learn which tasks were suitable for partners, and to understand how collaboration could be optimized. This included the willingness to invest time and attention; time to get to know each other, meet each other and discuss the research process. Being open-minded towards the partners' input, making an effort to understand and discuss it, and looking for ways to integrate it in research facilitated collaboration.

The presence of *'change agents'* was an important facilitator, which was only seen in a few partnerships. Change agents were proactive, arranged meetings, actively requested information and updates, or suggested possible tasks or improvement for collaboration. In one centre, a partner took up the role of 'location coordinator'. She checked with researchers about which projects were being executed and which would start in the near future and discussed opportunities for new partnerships. She arranged local meetings for partners to brainstorm and exchange experiences and discussed possibilities for involvement with the principal investigator. This was very effective in fostering partnerships. In another centre, one of the principal investigators made fixed appointments with the partners, inviting them for 'social happenings' at the research department and stimulated the partners to make a poster to present at a congress.

The network coordinator regularly sent around a newsletter to inform partnerships about developments, examples of tasks, new partners or new research projects. However, no face-to-face meetings were organized or initiated by partners or partnerships. When partners expressed the need for this, the monitors decided to organize *'local meetings with partners'* to exchange experiences and create solidarity within and with the network. Partners considered the organized meetings as fruitful to exchange knowledge and ideas, and to get to know each other and have the feeling of being part of a network. Since these meetings were organized quite late in the pilot, the effect was not optimal.

In some partnerships, *'clear agreements'* were made about contact, responsibilities and potential tasks. This led to stabilized moments of interaction and less frustration. Partners knew that they needed to be patient if the research entered a slow phase, or whom to contact if they wanted an update. Potential tasks were explored by brainstorms and discussion sessions and experimenting. To stimulate making clear appointments in all partnerships as well as discussing the expectations, two forms were developed by the monitors. One could be used during the first meeting to agree on appointments, discuss the research project and make expectations explicit. The other could be used during follow-up meetings to guide discussions on the progress of the research, potential tasks and trying to make the added value of the partners' input to the research explicit. This last element was added since *'making the benefits of collaboration more explicit'* helped members to become or stay motivated about the partnership. By gaining insight into the added value, some researchers developed a more positive attitude and became more open-minded. Partners were also motivated by receiving

feedback on how their input was used or why it could not be integrated. This helped them to gain more insight into research procedures and the possibilities and constraints of their perspective.

When there was a '*personal click*' between partners and researchers, the collaboration was more natural, which made it easier to take the initiative, and both parties reported enjoying the collaboration. Recruitment by the participating departments brought substantial benefits over recruitment by RPB since it increased the chance of a good match and created stronger intrinsic motivation and responsibility on the part of the professionals.

The presence of '*neutral monitors*' who provided tailor-made advice and support, addressing specific needs or ideas, was another facilitator. With some partnerships, brainstorm sessions were organised to identify suitable tasks, while other researchers were advised to set fixed appointments in the agenda to update the partners. Some researchers were provided with materials like publications, handbooks or research reports describing patient involvement in health research to increase their understanding.

'*Creating more visibility and awareness*' of patient involvement and the network among researchers was a significant facilitator as well. A short training module for researchers was developed to address the concepts of patient involvement, potential tasks for partners and directions for successful collaboration. The intention was to increase awareness about patient involvement and knowhow (skills) on how to involve partners. This training made some researchers less insecure about their collaboration and provided them with tools to enhance the partnership. In addition, two articles were published in the *Dutch Journal for Rheumatology*. Also, the four 'best practices' of the network were showcased at the national rheumatology congress.

If we compare the facilitators identified in the case study with those mentioned in the system innovation literature, we observe that four new facilitators were identified: making clear appointments, a personal click, neutral facilitator, and creating visibility and awareness. What was lacking though is a 'shared vision', to which these collaborations should lead, which is considered a very important facilitator in the system innovation literature.

### *Barriers in practice*

Difficulties were experienced in '*identifying suitable tasks for partners*' within the research and creating room for dialogue. The current practices of researchers are activities which are

performed in accordance with validated methods and established routines of interaction. Scientific training and scientific competences were perceived as essential for this, and many tasks were not considered suitable for the partners. Identifying new, complementary or additional tasks for partners proved challenging. Some researchers indicated that they had difficulty understanding the patient role and how to combine ‘scientific knowledge’ and the ‘experiential’ knowledge of patients. How can the stories told or the input provided by the partners be used in their research project? Since the partnerships had difficulties identifying tasks, not many meetings were arranged. So a general discussion on the project, talking about research activities, findings and new developments did not take place. This again led to little dialogue within the partnerships, and thus no potential moment for partners to provide their view and explore new tasks together.

Some partnerships stopped or were kept low key because the researchers felt that the project was no longer suitable. These projects were considered, for example, too fundamental, requiring scientific competences like statistical analysis. Or everything was already agreed upon, and no changes could be made in the research proposal and related documents. According to a principal investigator, it was more difficult than expected to predict which projects were suitable, since there was a lack of criteria and the focus of research projects is often adapted during a study.

For the partners, despite having received training, being involved in research was not as easy as expected by some, and sometimes a *‘lack of insight in research procedures’* was experienced. For example, partners became impatient when little progress was made, due to waiting for funding procedures or approval from the medical ethics committee, or because the phase of data collection took a long time. Partners had not been aware that ‘doing research’ took so much time. Another example is the lack of awareness of the value of validated questionnaires and methods used in research. Partners did not always understand that questionnaires cannot be changed easily. Thus, input provided by partners could therefore not always be incorporated, which led to frustration. It should be noted that in one partnership, the partners indicated that the selected questionnaire was old-fashioned, and they did not recognize themselves in the items asked. They stated that if these questionnaires were used, the questions posed in the research proposal would not be addressed properly. Based on this input, the research team decided to use another questionnaire.

In many partnerships, a *'lack of taking initiative'* and little interaction were observed. Both partners and researchers were waiting for the other to initiate contact, update each other or plan a new meeting or activity. They also expected the other to come up with potential tasks. Often, there was also a difficulty to maintain interactions. According to some researchers, it was not yet in their routine to regularly contact and update the partners about their project. Some partners with a full-time job preferred to meet in the evenings or weekends, which did not suit their working hours for many researchers. This resulted in long periods of no interaction and dialogue during which partners lost the feeling of being part of a partnership, and researchers returned to 'business-as-usual'.

Optimal interaction was hindered by the fact that decisions were often made ad hoc in the research department. There was much *'quick communication'* during working hours between researchers. Issues were quickly solved by email or face-to-face interactions between researchers (e.g. at the coffee counter). It is hardly possible to postpone the discussion or decision to the next appointment with partners in order to include their perspective.

#### *Barriers in culture*

Researchers did not immediately see the *'added value'* of the partners' knowledge for their research. Patient involvement is a relatively new development, and little attention has been paid to it in the literature. Furthermore, there are few peer researchers who collaborate with patients. So without knowing what it could bring to the project, the researchers were requested to invest time and effort to develop a successful partnership. Researchers indicated that they were busy with their research; they needed to recruit patients (as subjects), finish analyses, had important deadlines for a publication or their PhD thesis, which were considered priorities. The involvement of partners provides little (scientific) reward, according to several researchers, and could even slow down progress.

The involvement of patients in an active role could conflict with the idea that scientific knowledge is objective; experiential knowledge is subjective and therefore often considered less valuable. Researchers expected their partners to represent a broader patient perspective; partners should have insight into the stories, needs and ideas of a broader patient group to create a more 'objective' patient perspective. However, this was rarely the case; partners mainly provided input from their own experiential knowledge. Another question arose: will their research still be considered 'scientific' by other researchers if input from patients is

integrated into it? For example, researchers were concerned that journals would not accept their papers anymore, since several tasks were executed by ‘partners’ and not by ‘professionals’.

In communication with researchers, much jargon is used. Although researchers are often unaware of this aspect, partners experienced difficulties in understanding documents and protocols. Another obstacle for many partners was the amount of English used, instead of Dutch, sometimes even as the main language for the project team. This constrained partners in following discussions, understanding documents they needed to read or questionnaires they wanted to comment on.

#### *Barriers in structure*

Some partners as well as the professionals indicated that they felt ‘*insufficiently supported*’. Where to turn to with questions or requests for support was sometimes unclear. Normally, young researchers discussed their work and difficulties with their supervisor. However, the knowledge on how to collaborate effectively with partners and which tasks are suitable for partners had often not yet been developed. The network did not yet have a clear position within the structure of research in the area of rheumatology and functioned in a rather isolated way. In addition, professionals as well as partners rarely looked for help proactively. Often, they let the collaboration slide without notifying the coordinator or monitors. This indicates that in those cases the urgency to develop an optimal partnership was not high enough.

Not establishing and maintaining a partnership had ‘*no negative consequences*’. When the network coordinator discussed with principal investigators the possibility of including a partner’s expenses in the budget when applying for grants, they were very reticent to do so. Two reasons were often mentioned. First, when there is room in the budget, they would rather put in the cost for a research nurse instead of a partner. The competences, tasks and responsibilities of a research nurse are clearer. Second, researchers doubt if research funding agencies will accept costs for a partner in a budget, since it is not a standard procedure, and it is not a criterion for receiving funding.

An interesting issue that arose from the data was the question, ‘Who is *responsible for the supervision of the partners* in the partnership?’ Should this be the network coordinator, providing support and stimulating collaboration, or should this be the principal investigator? This issue was very unclear, despite the fact that partners signed a ‘volunteer contract’ with

the RPB. It became apparent that no agreements were made between the principal investigators and the coordinator since they did not foresee this issue. Partners expected the network coordinator to provide the support, training and stimulation of the collaboration and the researchers to provide information regarding research, research procedures, etc. However, several researchers indicated that they expected the training, insight into research processes, facilitation and instructions to be the responsibility of the network.

Although the network was financed by the Dutch Arthritis Foundation, the foundation did not communicate to the researchers that the patients could become actively involved, nor did it create incentives for researchers. The network was not involved in interactions between the established stakeholders. Establishing new relationships proved time consuming, and the network coordinator needed to invest much time in initiating and maintaining contact. The 'available hours for the network coordinator' proved to be insufficient to establish and maintain relationships with the different stakeholders involved. Subsequently, new, potentially suitable, research projects started in the participating departments without a partnership. Also, several researchers who were already involved in a partnership did not involve the partners in other or new research projects they were working on. The network coordinator noticed that researchers and principal investigators rarely contacted her to actively ask for the involvement of partners in an upcoming project.

## **Discussion**

This case study is about patients trying to get a place in a relatively closed and stable community – C/S/P of health research. It shows that there is no understanding of what new C/S/P should look like. It also shows the importance of starting with people who are highly motivated and committed to the partnerships. They must be able to tolerate a high level of uncertainty and be willing to invest time and resources to investigate what new C/S/P could look like, thereby creating a strong protected space. Realizing patient involvement in the heart of research proved very challenging since many researchers do feel that it is their domain.

In light of system innovation theory, the question is: How can structural patient involvement in the health research system be enhanced? A system innovation can be enhanced if a protected space becomes strong and expands, so new C/S/P can adapt the system (part of it) from the bottom up. An important prerequisite is that either new C/S/P offers a beneficial alternative to the 'normal' way of doing things or people should be sufficiently open-minded and willing to

experiment to see if it offers benefits. To stimulate more people to experiment with the structural involvement of patients, it is important that best practices be developed which can be adopted by others.

This study reveals that the role of change agents in the partnerships is essential to make the collaboration successful. Two questions arise. Firstly, can people be trained to become a change agent, or is it more their ‘personality’? People could be challenged to think and act like a change agent with training and support, but ultimately they must be motivated and feel capable of doing so. It is important for both researchers and partners to become change agents to induce change. They can set an example for their peers and inspire others to follow.

Secondly, how can change agents (potential) and other interested people be optimally facilitated to operate in a partnership? To induce new behavior or new practices, it is important that stakeholders ‘know’, ‘can’ and ‘will’<sup>55</sup>, people should become aware of ‘patient involvement in health research’, attitudes towards involvement must be positive, and people need skills, knowledge and a structure to put it into practice. Therefore, we suggest that two types of strategies are needed: strategies to develop the necessary competences directed at a new culture and practice, and strategies to create strong organizational elements in the health research structure to support the embedding of new competences. Each will be discussed below.

Strategies to develop *competences* are directed at creating awareness of the issue, stimulating a positive attitude, developing skills and providing knowledge. Training in being proactive, knowledge of effective collaboration techniques, insights into what patient involvement entails, insight into how to provide input (partners) and how to integrate experiential knowledge into research projects (researchers) can improve skills and knowledge. However, one of the main priorities in this regard is gaining more and systematic insight into the impact patient involvement has on health research. Insight and visibility of the added value of partnerships in health research may increase the priority for patient involvement in research, stimulate a more positive attitude, address a lack of knowhow and encourage researchers. It can stimulate the development of a shared vision on what new C/S/P could look like and what the benefits of experiential knowledge are for health research. Ideally, added value and lessons learned are published in scientific journals. However, measuring the impact of structural patient involvement in health research will be challenging, mainly for two reasons. Firstly, there is no consensus on what impact exactly implies: empowerment of patients, change of

research procedures, more needs-oriented health research, better health outcomes or changing values and attitudes of the involved stakeholders<sup>56</sup>? Secondly, it is unclear how to measure impact since it is challenging to (re)assess the influence of involvement. For explicit changes made, like change of questionnaires used, improved intervention or priorities set, the impact can be quite clear<sup>14</sup>, but if patients provided input during decision-making processes, where decisions are made jointly, it is less clear how and how much this decision is influenced by the input of patients. Or what eventually the impact on health improvement is.

To organize structural patient involvement in the conduct of health research, we consider it is important to have central and evident *organizational elements* embedded in the health research system with the aim to organize patient involvement and provide incentives. Such elements should establish enduring relationships with important stakeholders. Ideally, a strong relationship is established with relevant funding agencies, so when grant proposals are submitted, researchers can be directed to this organizational element for the possibilities for patient involvement in the research project. Also, funding agencies can create incentives for researchers to establish a partnership, for example by providing funding for the partners' expenses, or setting patient involvement as a criterion for funding.

In the pilot, a network of trained patients was established as an organizational element and coordinated by a network coordinator. A network seems to have different advantages. With it, partnerships can be coordinated, partners and researchers can be brought together (looking for the right match), or research departments can be instructed on how to select an eligible partner. It can offer support by providing training, tools, information or advice for partnerships on suitable tasks or how to optimize collaboration<sup>49</sup>. Moreover, it can function as a 'knowledge junction' where expertise, experiences, information, knowledge, tools, etc. are collected and made available. Additionally, it can serve as a 'safety net'. When partners fall ill, the network can look for ways to continue the partnership. Furthermore, it can give more meaning to the people involved; they feel part of a group<sup>57</sup>.

Using a reflexive monitoring in action approach was very constructive in this study. It gave in-depth insights into barriers and facilitators in this real-life setting which would otherwise have been inaccessible. Meanwhile, reflexive monitoring in action provided a flexible and context-sensitive approach to study the pilot. As a result, some facilitators could be consolidated while some experienced barriers could be addressed (partly) due to developed and applied strategies by the monitors.

The conceptual framework applied in the analyses of the case study has been predominantly used descriptively in the areas of transitions in energy, agriculture and mobility. However, it also appears to be very useful in the domain of health and can be used in a more prescriptive way. It offers tools to unravel barriers and clarify facilitators. We would recommend considering current ‘culture, practices and structures’ in an early phase to develop strategies to forestall potential barriers, create facilitators and support those already in place.

#### *Limitations of the study*

An important limitation of the case study is that it is very context bound. The network was set up for research in the area of rheumatology, and we do not know to what extent the lessons learned can be generalized to other disease domains or other countries. Also, the data provided too little insight into the suitability of different types of research projects for partnerships new C/S/P. Moreover, since the monitors were closely involved with the network and the participants due to participatory observations, there is a risk of observation bias. Especially since the network coordinator’s organisational tasks were sometimes taken up by the monitors. Researchers’ bias was reduced by appointing two external senior advisors, keeping a detailed logbook, reflect regularly on findings and developments within the network, and incorporating members checks.

#### **Conclusion**

In the most successful partnerships, a change agent was present, somebody making an effort and being proactive. Making clear agreements about contact, tasks and responsibilities within the partnership, as well as making expectations and its added value explicit stimulated collaboration, as did a ‘personal click’ between the partners and researchers. Since new C/S/P was highly unclear, being open-minded and perceiving the partnership as a learning process were essential.

The aim of the network, to structurally engage partners in the conduct of research, has not yet been realised, but the first important steps have been taken. The partnership often has a low priority for many researchers since it has no evident scientific reward. In addition, partnerships interfere in daily practice. Moreover, involving patients is new, and researchers are inexperienced about how to do this. The parties did not always feel responsible for the partnership and collaboration was suboptimal. Furthermore, the network operated in a rather

isolated manner and offered little support. Due to a combination of the above-mentioned barriers, most partnerships did not start to develop new C/S/P.

Nevertheless, a growing number of partnerships are starting to function well, are becoming successful and are valued by the partners and researchers. Currently, there are only a few change agents involved in the network, which makes it fragile. Partners are patients, and they can become ill or have to stop being a partner due to disease-related issues. If only a few people take up the role of change agents, and they disappear for any reason, skills and motivation are lost. Therefore, it is important to increase the number of change agents involved (through better recruitment and training), exchange experiences and lessons learned, and build a strong supporting network.

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