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# Patient–expert partnerships in research: how to stimulate inclusion of patient perspectives

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## Abstract

**Objective** To gain more insight into exclusion mechanisms and inclusion strategies in patient–expert partnerships.

**Background** Patient participation in health research, on the level of 'partnerships with experts' is a growing phenomenon. However, little research is conducted whether exclusion mechanisms take place and to what extent patients' perspectives are included in the final outcomes of these partnerships.

**Case study** A dialogue meeting attended by experts, patients and patient representatives to develop a joint research agenda. Different inclusion strategies were applied during the dialogue meeting to avoid possible exclusion.

**Method** Data were collected by the means of audio and video recordings, observations, document analysis and evaluative interviews. The data are clustered using a framework that divides exclusion mechanisms in three categories: circumstances, behaviour and verbal communication. The data are analysed focusing on the experiences of participants, observation of occurrence of exclusion and difference between input and outcome of the dialogue meeting.

**Results** The circumstances of the dialogue and the behaviour of the participants were experienced as mainly inclusive. Some exclusion was observed particularly with respect to verbal communication. The input of the patients was less visible in the outcome of the dialogue meeting compared to the input of the experts.

**Conclusion** This case study reveals that exclusion of patients' perspective occurred during a dialogue meeting with experts, despite the fact that inclusion strategies were used and patients experienced the dialogue meeting as inclusive. To realize a more effective patient–expert partnership, more attention should be paid to the application of some additional inclusion strategies.

## Introduction

During the past two decades, patient participation in health research has slowly become more established. This trend is supported by a general increase in empowerment of patients[1–3] and by democratization of science.[4–7] Different scholars have argued that active involvement of patients may lead to an increase in the quality and relevance of health research, because experiential knowledge of patients can complement scientific knowledge of experts (substantive argument).[8–12] In addition, it has been argued that patients have the right to become involved because they will be affected by the outcomes of health research (normative argument).[13,14] A third argument is that patient participation can lead to a better acceptance of research and its outcomes by patients (instrumental argument).[15–17]

In this article, the term participation is defined as 'an involvement in and influence on decision-making processes.' Different levels of participation can be distinguished. A common model to indicate the level of participation (although criticized for its lack of operationalization[18,19]) is the ladder of citizen participation developed by Arnstein.[20] It comprises eight steps that stand for eight levels of citizen influence in political processes. By replacing 'citizens' for 'patients', the model is applicable in the context of patient participation. It ranges from manipulation of patients (a form of non-participation) via different forms of tokenism to patient control (a form of patient power). In this model, partnership is a more egalitarian form of patient power whereby patients and professionals jointly take decisions. Caron-Flinterman *et al.*[21] argue that granting patients actual influence in the decision-making process on health research requires at least a level of partnership between patients and experts. In such a partnership, decision-making power is shared; different perspectives are taken into account and genuine deliberation and negotiation can lead to final outcomes supported by both parties. Different examples of partnerships between experts and patients are described in the literature.[22–26]

It is one thing to strive for patient–expert partnerships, but another to operationalize genuine patient–expert partnerships. Experts generally are the dominant decision makers in health research, so there is no history of equal partnership between patients and experts to build upon. Instead, the relationship between experts and patients can be described as asymmetrical because of the traditional difference in social status,[27] as well as to the value assigned to the knowledge of both groups.[28,29] The higher social status of experts is derived from their high level of education, income and prestige of occupation; experts are considered intelligent and able to perform difficult and specialized tasks. While the relevant knowledge of patients is based on their experience in daily life, the knowledge of experts is science based and therefore often considered to be more objective and superior to the subjective experiential knowledge of patients.[30,31] It is expected that this asymmetrical relationship may form an obstacle to the realization of a genuine partnership between experts and patients.

Currently there is limited insight into, and attention for, inclusion and exclusion of patients and/or their perspectives in a partnership. It is often assumed that if patients are involved as active participants, inclusion of their perspectives and knowledge input in decision-making processes is somehow automatically guaranteed. Participation does not, however, necessarily imply *equal* participation, because the 'voices and views of some groups are easily given greater weight than the voices of other groups'.[32,33] Previous research on patient participation in research agenda indicates that exclusion of patient perspectives may occur in patient–expert partnership relations.[34]

The aim of this article is to gain insight into exclusion mechanisms and inclusion strategies in patient–expert partnerships. To this end, a dialogue meeting on research agenda setting is analysed, in which congenital heart disease (ConHD)-care users and child cardiologists participated as partners. Based on this analysis, a number of recommendations for a better inclusion of patient's perspectives in a more genuine expert–patient partnership relation are formulated. This is achieved by further investigating the issue of exclusion mechanisms to formulate an analytical framework. This is followed by a case description and presentation of research methodology. The results are then presented, followed by conclusions and discussion.

## Exclusion mechanisms

In this article, 'exclusion' is defined as the process whereby members of a certain stakeholder group – in this case patients and patient representatives – or their perspectives are not taken up in the decision-making process, because of actions taken by members of other stakeholder groups or the process facilitator. Exclusion can be intended or unintended[35] and can be induced by various mechanisms. A brief overview of different exclusion mechanisms is given below, which may be relevant for participatory and dialogical processes. The described exclusion mechanisms, although often not explicitly referred to as such, are based on literature and personal extensive observations within participatory processes. The exclusion mechanisms are divided into three different categories: 'The setting' (circumstances), 'What is done' (behaviour) and 'What is said' (verbal communication).

### The setting (circumstances)

In this category, possible exclusion mechanisms that are caused by the setting of the dialogue are described. The setting is defined as how the dialogue is organized (considering the location), the focus of the meeting and who is invited. Exclusion can occur as a result of the choice of place, time and duration of the dialogue.[36] For example, patients may feel uncomfortable in a hospital or a scientific surrounding[37] or because the location is not easily accessible to patients.

Exclusion can also result from the chosen working methods within the dialogue, and the focus of deliberation. A topic can be pre-framed in such a way that certain issues of relevance to a certain stakeholder group are left out. It is also possible that the focus of the discussion is closely related to the expertise of only one of the groups. This may be the case if the discussion on health research is specifically focused on scientific questions related to research methodology and scientific validity, which links up well with the knowledge of experts, but less so with that of patients. It may also be that the working methods used by the facilitator enhance exclusion of certain participants.[35,37]

According to Young,[36] exclusion can also take place by not inviting certain people or stakeholders. Young defines this as external exclusion. Often, certain patients or patient groups are not invited for a participatory process because they are forgotten or presumed not capable of adding something to the process; e.g., children or people suffering from mental diseases. Exclusion can also occur when there is an imbalance between the numbers of people from different stakeholder groups. When the patient group is not sufficiently represented – e.g., only one or two patients are invited compared to ten or more experts – it will be difficult to give enough weight to their perspectives in the process.

### What is done (behaviour)

In this category, possible exclusion mechanisms are described that result from the behaviour of participants or the facilitator. An obvious way to exclude participants of a certain stakeholder group is to grant them less speaking time, attention or respect. Facilitators may treat certain stakeholder groups with a high social status, such as professors or medical experts, with more respect than other participants.[38] Another mechanism is strategic behaviour, for example, the formation of a coalition. When participants behave in an unfriendly or hostile way, wanting to gain the maximum profit only for their 'own' stakeholder group, exclusion may occur.

### What is said (verbal communication)

In this category, possible exclusion mechanisms that are caused by the verbal interaction of participants or the facilitator are described. Verbal communication is an important mechanism for exclusion.[39] When experts use jargon, patients can be excluded because they are unable to follow the discussion.[40] Also, the sidelining of issues of a stakeholder group by labelling them as irrelevant, subjective or not feasible are mechanisms to exclude the perspectives and knowledge inputs of a certain stakeholder group from the process. Experiential knowledge is not always considered relevant or legitimate by experts, which may lead to ridicule of certain participants or their perspectives. Humour, by making fun of someone's input, or making jokes only understood by one stakeholder group, can lead to exclusion in communication. Nonetheless, humour can lead to inclusion because the atmosphere can become less formal and people feel more at ease by shared laughter. Rogerson-Revell[41] describes that in business meetings, humour can be used to create solidarity and a supporting, informal atmosphere, but can also be used as a means to compete.

The distinction between the three categories of exclusion mechanisms described earlier is not rigid. If a setting, a behaviour or phrasing (or a combination) is in some way uncomfortable or intimidating to members of a certain stakeholder group, then this may contribute to 'self-exclusion' and members of that group will not show up or speak up at meetings. In a partnership process, it is important that care is taken to prevent that the aforementioned exclusion mechanisms take place to strive for a genuine partnership. In this article, a dialogue meeting with experts and ConHD-care users is described, whereby procedures were designed to avoid exclusion. The effects of these procedures are then evaluated.

## The dialogue meeting during a research agenda setting project

In the year 2007, a project called 'Towards a shared vision on research for children with a congenital heart disease' took place which was financed by the Netherlands Heart Foundation (Nederlandse Hartstichting, NHS).[42] In this project, experts, patients and patient representatives participated in setting a research agenda. The project design was based on the interactive learning and action (ILA) approach, which has also been applied in two other health research agenda setting projects concerning asthma and COPD,[43] and burns.[44] This approach focuses on enhancing trust, fostering respect and facilitating knowledge exchange and mutual learning between relevant stakeholders. The ILA approach is more extensively described by e.g., Broerse and Bunders,[45] Roelofsen *et al.*,[46] and Swaans *et al.*[47]

The project consisted of three phases: (1) preparation; (2) consultation of the stakeholder groups separately; and (3) integration and prioritizing. In phase 3, a dialogue meeting took place whereby patients, patients' representatives and experts were involved. The dialogue meeting provides the main empirical setting for this study (in phases 1 and 2 experts and patients were consulted separately, therefore no direct expert–patient interactions took place).

Based on former experiences with participatory processes, procedures were developed to prevent exclusion mechanisms in a partnership during a dialogue. In this article, these procedures are referred to as 'inclusion strategies'. During the dialogue meeting, the various inclusion strategies, which were expected to reduce exclusion of the inputs of ConHD-care users, were systematically applied. Table 1 provides an overview of the applied inclusion strategies.

ConHD-care users and experts (child cardiologists) were invited to the dialogue meeting. In total, 29 ConHD-care users participated; nine people with a ConHD in the age range of 16–27, 16 parents/relatives of a child with ConHD and four representatives of the patient organization on Congenital Heart Diseases (Patiëntenorganisatie Aangeboren Hartafwijking, PAH). The Dutch child cardiology departments were asked to delegate one or two experts to participate in the meeting, resulting in 13 experts being present. The dialogue meeting, which took place in October 2007, lasted for 7 h and the main facilitator was a professor in 'Bioethics'. The facilitators had no personal interest in the outcome of the meeting. The set-up of the dialogue meeting is described in Box 1.

**Box 1** Description of the dialogue meeting (Phase 3)

*Step* 1. Presentation of the patients' perspectives: During the previous consultation phase 3 focus groups[37] (33 participants in total) and 28 interviews with ConHD-care users took place. Based on the identified problems and needs, a topic list comprising 38 topics was established. This ConHD-care user topic list was used as input for the dialogue meeting (together with the experts topic list, see step 4) and was presented in step 1 in a plenary session. The chairman of the PAH was invited to give a short reflection.

*Step* 2. Parallel work sessions: The participants were divided in five heterogeneous working groups (7–8 participants) to discuss the presented topics. The assignment was to discuss the possibilities of medical research to (partly) solve the presented topics (for future generations). A list of research topics was made, which could contribute to the solution of the topics of the ConHD-care users.

*Step* 3. Combining results: The research topics were presented plenary by the independent facilitators of the working groups. After this plenary session, there was a lunch break whereby participants had the opportunity to meet with each other. Meanwhile, the facilitators combined the different working group results into one list.

*Step* 4. Presentation of the experts' perspectives: During the consultation phase, 18 interviews with experts took place. This resulted in an expert topic list of 15 research topics. This list was considered as input for the dialogue meeting. A plenary presentation was given regarding the perspectives and the topic list of the experts. A brief reflection was given by a child cardiologist.

*Step* 5. Discussion and creating a final list of research topics: The research topics newly mentioned in step 4 were added to the list. This list was plenary presented and discussed to reduce the number of topics by combining similar or overlapping topics. This discussion was also used to clarify the different perspectives regarding the research topics. This deliberation continued until everybody agreed on the final list. All participants could indicate two priorities on a card; the research topic they considered most important and the one they considered second most important. The priority cards were gathered and processed by the facilitators.

*Step* 6. Reflection on prioritization: The results of the prioritization were shown on a screen, divided into priorities of ConHD-care users and experts and marked according to first and second priorities. In this way it was clear which research topics had the highest priority and by which stakeholder group. By making a distinction between the ConHD-care users' priorities and the experts' priorities, the differences and ⁄or similarities became clear. A discussion was held to create mutual understanding for each others perspectives. The prioritized topic list was the output of the dialogue meeting.

## Methodology

To evaluate the applied inclusion strategies during the dialogue meeting, different methods of data collection were used.

1. Audio and video recordings were used to register verbal communication, behaviour and speaking time of the participants.
2. *Ad libitium* observation sampling was used to detect possible behaviour reflecting explicit or implicit exclusion mechanisms.
3. Document analysis was used to compare input from ConHD-care users and experts (in the form of the two topic lists derived from phase 2 of the project) with the output (shared priority list) to see how much of the input of the separate stakeholder groups was represented in the shared output document.
4. Semi-structured evaluative interviews were held with 22 ConHD-care users and eight experts. These interviews focused on the general impression of the dialogue meeting, how the participants experienced the dialogue meeting and whether they considered the dialogue meeting useful.

The results were grouped according to the previously specified categories: i.e. the setting (circumstances), what is done (behaviour), and what is said (verbal) and analysed using the list of exclusion mechanisms and inclusion strategies presented in Table 1.

The following three questions were used to evaluate the effect of the inclusion strategies:

1. To what extent was exclusion identified by the observer ⁄ in the collected data?
2. How much of the input of the different stakeholder groups was represented in the output of the dialogue meeting?
3. To what extent did the participants feel excluded or included during the dialogue meeting and how did they perceive the inclusion strategies?

In the next section, the results will be presented. When appropriate, quotes are included; quotes from ConHD-care users are indicated by 'CCU' and quotes from experts by 'E'.

**Table 1** Overview of possible exclusion mechanisms during a dialogue meeting attended by experts and congenital heart disease (ConHD)-care users and the applied inclusion strategies to counteract on exclusion

| Category | Possible exclusion mechanisms | Applied inclusion strategies |
|---|---|---|
| Circumstances | Uncomfortable location for patients<br>Experts outnumber patients<br>Unfamiliar with working methods<br>Choice of focus and scope<br>Uncomfortable setting | Non-medical ⁄ scientific location owned by the Heart Foundation which was well accessible<br>More ConHD-care users than experts were invited. Power in the number. It was expected that outnumbering experts would contribute to reducing the asymmetrical relation because the ConHD-care users group will feel more supported by each other to speak up during the dialogue<br>Clear explanation and instruction were given to participants on what to expect<br>Programme was designed with a focus on the (perspective of) ConHD-care users, especially in the morning sessions. In the afternoon, there was a short focus on the experts' perspective followed by a general focus on the whole group and a shared research agenda<br>ConHD-care users were placed in different working groups as their treating medical specialist. The ConHD-care users might feel restricted to speak freely if 'their' expert is in the same working group |
| Behaviour | No opportunities for patients to speak<br>Forming a coalition<br>Stress position experts<br>Uncomfortable behaviour | Working methods provided equal opportunities to speak. Facilitators were instructed to stimulate input of ConHD-care users<br>In the working groups, experts from the same hospitals are separated in different groups<br>No titles or profession were indicated on batches, equal treatment<br>The facilitator systematically invited the ConHD-care users to start, neglecting the experts (temporally) |
| Verbal | Ridicule patient inputs<br>Use of jargon<br>Sidelining patient issues as not relevant, not feasible, etc. | Facilitators were instructed to correct ridiculization<br>Experts were requested to use plain language, if needed, difficult terms were explained<br>Facilitators were instructed to guard the input of the non-experts |

## Results

### Setting (circumstances)

Evaluative interviews with ConHD-care users indicated that the dialogue meeting in general was positively perceived. The information and instructions provided were considered clear. It was appreciated that the dialogue did not take place in a hospital; the hospital is mainly associated with negative feelings and perceived by ConHD-care users as the territory of experts. In addition, the fact that the number of ConHD-care users in the meeting outweighed the number of experts was well received. This made them feel supported by each other in terms of shared needs and encountered daily-life problems. Finally, many ConHD users appreciated being separated from their treating physician in step 2 of the meeting; it made them feel more at ease.

Some remarks can be made regarding who was present. From the observations during the meetings and the evaluative interviews from experts, it became apparent that some of the experts were not open minded to the idea of involving patients in health research. These experts indicated that setting priorities for research should be done by experts, because ConHD-care users are subjective and do not possess the required knowledge. Nonetheless, most experts were responsive to the inputs of the ConHD-care users and stated that patient participation is important. Regarding the ConHD-care users, it was observed that those who had already participated in the previous consultation phase found it easier to speak up during the plenary sessions. The consultation phase seemed to serve as an empowering step for them. A few ConHD-care users barely spoke during the dialogue meeting and it is questionable if they were empowered enough.

### What is done (behaviour)

When participants arrived at the location, they received instructions for the day and their badge. All participants were treated by the facilitators with the same respect, independent of their titles. Nonetheless, a clear difference in behaviour with respect to the way people dressed and interacted was observed. Experts were dressed more formally, behaved confidently and grouped together. In contrast, most ConHD-care users did not know each other and were more reserved, grouping less easily. For most of them, an event like this was a new experience. There was little interaction between the two stakeholder groups, even during lunch and coffee breaks. This meant that the groups could not exchange information or perspectives with ease during even the most informal moments of the meeting.

However, both stakeholder groups were interacting actively during the parallel work sessions (step 2). There was little need for the facilitators to create opportunities to speak for the different participants and it was observed that speaking time was well divided between the different participants. Both groups were respectful of each others' input and many personal stories and experiences were voiced. During this step, the main focus was on the experiential knowledge of the patients and their needs. With respect to steps 1 and 2, a ConHD-care user commented:

> This morning when we drove up here, I discussed with another parent which topics were important for us to talk about and all these topics came back in the presentation. It was really familiar to me.

During the discussion and reflection (steps 5 and 6), however, an imbalance in speaking time between experts and ConHD users emerged. The experts used considerably more speaking time and dominated the discussion. A reason for the more passive attitude of the ConHD-care users may have been a shift in focus initiated by an expert in step 4. In step 4, the 'research topic list' of the experts was presented by one of the facilitators, followed by a reflection from one of the experts. The expert gave a short presentation in which he introduced the topic 'heart failure' as a highly important overarching topic. Subsequently, the dialogue focused on the extent to which this overarching topic was considered relevant by the other participants. From that point onwards, the focus of the discussion became technical and was dominated by experts. Although the facilitator tried to involve the ConHD-care users by specifically asking for their point of view, their role remained quite passive. The evaluative interviews indicated that in steps 4 and 5, ConHD-care users had more difficulty in relating their own experiential knowledge to the topic of discussion; many indicated that they became insecure. In the evaluation, a ConHD-care user stated:

> The afternoon was less clear to me. I had the feeling I had too little knowledge to make a useful contribution and to know which topics were most important to prioritise.

In step 5, most experts seemed to support the importance of the topic 'heart failure'. It appeared that a coalition of experts formed in advocating one specific topic. This strong change of focus was not anticipated by the facilitators.

### What is said (verbal)

The inclusion strategy applied to avoid exclusion based on status, whereby all participants are indicated only with their first and family name on their badges, helped to create a friendly and informal atmosphere at the meeting. This was also expressed in a general use of informal language. The experts explained themselves clearly during the interaction with ConHD-care users and reacted surprised when ConHD-care users used medical jargon.

During step 2, the ConHD-care users actively included themselves in the conversation by telling their personal stories and experiences, and by adding new facts and details to other stories. Experts posed questions to ConHD-care users, and actively included them in the work session. Humour was used by both stakeholder groups during the day to keep the interaction light and informal. Humour proved to be an effective way to include people in the dialogue and was never used in a negative or humiliating way.

Despite the apparent informal atmosphere, various exclusion mechanisms were identified. In contrast to ConHD-care users, experts often spoke in terms of 'we' and 'us', suggesting power gained from a shared vision or knowledge, while ConHD-care users referred to themselves mostly as 'I' or 'my son/daughter'. In addition, perspectives of ConHD-care users were sometimes excluded after being labelled as subjective and/or irrelevant for research by experts.

> CCU: My son can not play football, because he is not able to run that much. I don't know which sport is suitable for him.
>
> E: We should move away from the interesting individual stories and go towards more collective problems.

Or

> E: In my opinion, these are subjective stories whereby parents indicate what they consider important, but you want to link it to something relevant to do research on.

Some issues raised regarding the ConHD-care users' perspectives were considered irrelevant: for instance, the problem of sports was stressed as very important by ConHD-users, because many children had encountered this problem as serious. In some of the working groups, however, this problem was excluded by experts based on its presumed 'subjectivity'.

Another exclusion mechanism was the sidelining of topics of ConHD-care users, because their inputs were not considered to be within the scope of child cardiology research. Some examples:

> E: I agree that the lower endurance of the kids is a major problem. But is that not something the school should deal with?
>
> E: This [endurance and concentration] is about individual guidance and communication.
>
> E: The effects of having scars is maybe a topic which can be taken up in a broader field, because it is about outer appearances, which more people with other diseases also have to deal with.

A further two topics that people with ConHD indicated as important were sidelined by some experts in the working groups, because according to them, these topics were already solved.

> E: Considerable research is done on this topic [pregnancy]. Already much is known, but apparently, this information does not reach the patients.
>
> E: This [scars] is something we need to learn how to deal with. It is needed for the operation. And already much is known about the psychosocial effects of scars.

ConHD-care users (and the facilitators) lacked insight into the scope of child cardiology research and into topics that have already been addressed in research. The ConHD-care users were therefore unable to judge whether the arguments the experts used were valid or whether they were used to strategically sideline certain issues.

Introduction of the topic 'heart failure' as an important overarching topic resulted in exclusion based on the use of jargon.

> E: I'm a little concerned because now it seems that heart failure [as a topic] comes from us as experts and that for the patients this topic does not really play a role, while many topics and needs brought in by patients can be perfectly covered by this topic.
>
> Facilitator: What do the ConHD-care users think of this? Do you consider it as an overarching topic?
>
> CCU: Yes…
>
> Facilitator: Do the adolescents also think this topic is combining different topics?
>
> CCU: Partly, I think it is very important to know where it comes from. Also when things are going well.

> CCU: When it is not going so well, you will be more confronted with this topic, while when I'm feeling good, I think more about the things that I can do. However, of course this is an important topic; I do not want to drop dead suddenly.
>
> [….]
>
> E6: You can make combinations between different topics, for example, stem cell research can be part of the topic heart failure. Also palpitation is part of it.
>
> CCU: I think that if you improve techniques and surgery, this will also improve.

The definition of 'heart failure' was not clear to most ConHD-care users. When a ConHD-care user mentioned that he thought it was important because he did not want to 'drop dead', nobody corrected his ideas of what this topic entailed (heart failure is the temporary or chronic inability of the heart to pump enough blood to sustain normal bodily functions. This can vary from a mild to severe inability). Some experts stated that this topic is of major importance; therefore, most ConHD-care users believed this to be the case without questioning its meaning and relevance. During this step, different topics were reframed in such a way that it became part of this topic. During the discussion, ConHD-care users hardly spoke up, and when they did, it was often in line with what the experts expressed. By aligning almost completely with the experts and emphasizing their own perspectives less, it could be argued that ConHD-care users to some extent excluded themselves.

### Input and output of the dialogue meeting

The two topic lists derived from the consultation phase were used as input for the dialogue meeting. The topic list of the ConHD-care users consisted of 38 items. Although no absolute priority list was derived from the interviews and focus groups in phase 2, some topics were indicated by ConHD-care users as most important (see Box 2). The item list of the experts consisted of 15 items; five important topics are described in Box 2. Between the two topic lists, there was a certain amount of overlap. During the dialogue meeting, a shared topic list was developed and subsequently prioritized. The highest prioritized topics are presented in Box 2.

**Box 2** The input and output of the dialogue meeting

Input ConHD-care users
  - Obscurity on what is/is not possible regarding physical activity
  - The causes and consequences of palpitation
  - Possibilities for less mutilating/more effective surgeries and treatments
  - Low endurance which is experienced during sports, school and social activities
  - Causes of ConHD

Input experts
  - Creating a database for biomaterials and patient information
  - Long-term research
  - Causes of ConHD
  - Adaptation and workload of the heart
  - (Further) development of (non-invasive) methods and techniques

Output dialogue meeting
  - Heart failure
  - Long-term research
  - Causes of ConHD
  - Adaption and workload of the heart
  - Medical surgery/treatments which are less damaging/more effective

From the output, three of five topics (heart failure, long-term research, adaptation and workload of the heart) were brought in by the experts and prioritized by both stakeholder groups. One topic (causes of ConHD) was brought in and prioritized by both stakeholder groups. The last topic (medical surgery/treatments which are less damaging/more effective) was brought in by the ConHD-care users. Notably, this last topic was only prioritized by ConHD-care users. Important topics for ConHD-care users (e.g. low endurance, obscurity on what is/is not possible regarding physical activity) disappeared in the outcome. The experts hardly prioritized topics brought in by ConHD-care users, while ConHD-care users mostly prioritized topics brought in by the experts.

### Evaluation

The ConHD-care users indicated during the interviews that they were highly satisfied with the interaction with the experts and the final outcomes. They felt taken seriously and felt that they could contribute useful knowledge. They also indicated that patient participation was very important, because they are the ones affected by the research. Most of them would like to participate again when given the opportunity.

Also, the experts were positive about the dialogue meeting. They mostly appreciated the fact that they had time to listen to the ConHD-care users more extensively. Many experts indicated that they had learned from the ConHD-care users during the dialogue. They obtained more insight into the problems ConHD-care users encounter in daily life and they gained a better understanding of the impact of a ConHD 'outside of the hospital'. Nevertheless, despite the general positive evaluation, some experts stressed that they could not see the benefit of involving patients in research agenda setting. Also, after the dialogue meeting they still had the opinion that patients do not possess the required knowledge to make those decisions. In addition, some experts indicated that they would have preferred a ConHD expert as facilitator, who would 'better understand the subject'.

## Conclusion

The aim of this study was to improve insight into possible exclusion mechanisms and the effectiveness of inclusion strategies in a dialogue meeting. The dialogue meeting was part of a project to create a shared research agenda for ConHD wherein a patient–expert partnership was formed. Many of the applied inclusion strategies appeared to be effective. The atmosphere was considered pleasant and respectful. The ConHD-care users appreciated the setting and the interaction with experts; they felt included in the process. The outcome, a research agenda, was widely supported by the different participants.

Most inclusion strategies implemented in the setting of the process were considered successful by the participating stakeholder groups and observers. It is important that in this category exclusion is avoided as much as possible because a functional setting is a basic requirement for a genuine dialogue. These precautions are in the sphere of preparation and organization. The balance between ConHD-care users and experts (2:1) and the choice of location (neutral) enhanced the inclusion of the ConHD-care users in the process. Both the ConHD-care users and the experts enjoyed interacting in a setting outwith the hospital. In addition, separating ConHD-care users from their treating physician turned out to be an important strategy to reduce exclusion by avoiding feelings of discomfort among ConHD-care users. In general, ConHD-care users were enthusiastic and felt that their contribution and input was useful and taken into account.

Nonetheless, exclusion was not totally prevented, as various exclusion mechanisms were observed. In the first instance, not all of the invited ConHD-care users were empowered enough to speak up, while some experts were not open minded towards the idea of patient participation in research. Furthermore, despite the instructions to facilitators to ensure that issues raised by ConHD-care users were given due attention during the discussions, inputs from ConHD-care users were sidelined on various occasions by being labelled as irrelevant or subjective by experts. Exclusion also took place by use of jargon. The term 'heart failure' was unclear to ConHD-care users and was not clarified. ConHD-care users became insecure and hardly contributed to the discussion in the afternoon. When the experts stated that most other topics could become part of this topic, ConHD-care users did not question this; they aligned with the experts. In addition, an exclusion mechanism that may be called 'verbal coalition' was observed; experts often spoke as 'we', while ConHD-care users spoke as 'I'.

This case study demonstrates the complexity of achieving a genuine dialogue between experts and care users, despite attempts to realize an equal position within a partnership. In this case, a partnership did not automatically mean *equal* participation in the deliberations, or in the inclusion of patients' perspectives in the outcomes. Interestingly, there was a high level of satisfaction experienced by ConHD-care users. In the next section, the reasons underlying the difficulties encountered in the case study are discussed and ways forward are suggested.

## Discussion

Returning to the ladder model of Arnstein,[20] our case is positioned around step 5 (placation) and step 6 (partnership). 'Placation' (of patients) is a participation level that acknowledges traditional differences in authority and culturally embedded role patterns between experts and patients.[48] In a genuine partnership, power is mutually negotiated and not subject to unilateral change. The movement towards partnership can be seen as an *emancipatory* process for the patients. The experts, in contrast, probably experience it as a *strategic* process. It is to be expected that many experts will not give up their current position in decision making on health research easily. The described dialogue meeting was designed and facilitated by anticipating on exclusion mechanisms, thus providing a good setting to pave the way towards genuine partnership, although it was realized that it may not be possible to accomplish this in one session.

It is important to recognize that exclusion is not merely a matter of one party actively dominating the position of power. Exclusion is partly an unconscious process, a practice based on culture. People are often unaware that they exclude or include others through their use of verbal and non-verbal communication. ConHD-care users felt highly included in the dialogue and did not question whether reasons for sidelining issues as subjective or irrelevant by experts were justified. It is proposed that exclusion in this case study was based on embedded assumptions concerning the lower value of experiential knowledge compared to scientific knowledge, and the idea that experts are best suited to define the research agenda. This view was not only observed among experts, but also among ConHD-care users, who seemed to have a large degree of trust in the experts.

In a dialogue approach, it is expected that participants change their opinions during the meeting because of a new input of other participants and reflection on their own perspectives. In particular, when stakeholder groups have an equal position, but complementary knowledge, one could expect that both stakeholder groups change their opinions during the interactive meeting. In this study, however, the ConHD-care users seemed to align their priorities more with those of the experts, while the experts stuck to their own perspectives and prioritized their topics. There is a thin line between changes in opinion due to carefully listening to others and subsequent contemplation and adaptation, and changes due to acts of persuasion and overruling. During the evaluation, the ConHD-care users indicated that they were satisfied with the final outcome. There was not a thorough reflection, however, on how participants felt about the exclusion of specific inputs. It would have been beneficial to understand if ConHD-care users felt that exclusionary sidelining took place, or that based on the used arguments, they agreed with this sidelining and that the final prioritized topics gained importance for the ConHD-care users during the dialogue.

A question remains as to how these underlying factors of power and culture can be addressed more effectively in the dialogue process? Some suggestions are given below with respect to preparation, design and facilitation of a dialogue meeting during a partnership.

One option would be to focus more on the selection of participants. Organizers could, for example, select only experts who are open minded towards the idea of actively involving patients; it can lead to a more constructive atmosphere where more room is provided for different perspectives. Such an approach may not be representative for a 'real-life' situation, however, in which many experts have different opinions regarding the desirability of patient participation. In that case, it could be more helpful to develop new inclusion strategies to increase familiarity with, and acceptance of, the phenomenon of patient participation among the wider group of experts. Such an approach might also help to contribute to the establishment of effective partnerships in the long-term, because long-term success will require that the phenomenon of patient participation and its benefits is brought to the attention of the wider field of experts and is made more visible in the research field.[44,49] Most experts are unaware of the opportunities of patient participation for research, because such studies are not published in 'their' journals. It is therefore unsurprising that experts are, at face value, hesitant or sceptical towards patient participation.

Another option would be to enhance the empowerment of patients prior to a dialogue meeting. A preparatory meeting could be organized with patients before the dialogue to discuss the outcomes of the consultation phase and reflect on shared values and needs.[44] This may increase inter-subjectivity between patients and help to make explicit why they find certain topics important.[50] Often, the problems and needs of patients are quite similar. Awareness of this fact creates empowerment among patients and refutes the accusation of subjectivity that is used to exclude them. It is important, however, to realize that assisting patients in articulating shared topics and values may elicit counterproductive effects associated with creating a feeling of ownership. By creating ownership, patients may become less open to inputs from other stakeholder groups. In that case, a dialogue may result in a debate in which each party wants to convince the other of their preferred position. Steps therefore need to be taken to prevent that an activity used to enhance empowerment results in a 'we' against 'them' attitude; a balance needs to be found between open-mindedness and creating inter-subjectivity and ownership.

Designing effective inclusion strategies in the area of verbal interaction appeared to be difficult. An experienced, well-trained facilitator is an important inclusion strategy, but not a panacea. A facilitator could for example recognize verbal exclusion mechanisms and react on it, but this is rather difficult in an on-going dialogue. Often, the damage has already been done. With respect to the introduction of jargon, however, such as the term 'heart failure', a facilitator could play a more mediating role than observed during this case study. During the afternoon session, the focus became more expert-oriented and technical, which was difficult to follow for the ConHD-care users. The facilitator could have asked for clarification and could have challenged the claim that most topics of ConHD-care users would fall under this term. The plea of the experts for a ConHD expert as facilitator, who would have more knowledge on the subject, would probably not be helpful, but instead would rather increase the asymmetry between the two stakeholder groups. A suitable facilitator is able to create trust among both sides, is neutral with respect to the outcome, has strong communication skills and is able to provide room for the interests of all involved stakeholders.[51,52]

A change to the set-up of the meeting could have possibly prevented some of the exclusion mechanisms that took place, particularly with respect to the shift in focus during the afternoon. An alternative design would be that both topic lists are plenary presented in the morning session, followed by small parallel working groups, discussing the input of both stakeholder groups. Attention can then be paid to similarities and differences in the two topic lists, and the creation of a shared topic list. In a smaller setting, it is also easier for a facilitator to steer the discussion.

Based on the present analysis, a further four inclusion strategies are recommended in addition to the ones used in this study, to realize a more equal expert–patient partnership. The first two are related to the pre-setting of dialogue meetings. First, the benefits and effects of patient participation in research could be made more visible to experts in the research field. This might reduce prejudice of experts towards patient involvement in research. Secondly, it is important to prepare and empower patients beforehand so that their experiential knowledge can be properly articulated and exerted at the level of equal partnership. Thirdly, strong facilitation of the process by a facilitator during dialogue meetings could help to reduce exclusion mechanisms. And finally, the dialogue meeting could be designed in such a way that the focus is understandable for all participants during the meeting and does not provide opportunity for one of the parties to dominate.

Despite the occurrence of exclusion mechanisms, the dialogue meeting was an important step in an improved interaction between experts and ConHD-care users and a growing involvement of the ConHD-care users in the field of research. Both groups were enthusiastic about the dialogue and its outcomes. The fact that the ConHD-care users felt taken seriously is a key measure for meaningful involvement.[53] Wallerstein[27] indicated that including marginal groups as partners on an equal basis is difficult. The results of this study act to confirm this assertion, as a perfectly 'equal' partnership relation was not realized. To establish a more equal partnership, power differences should be dealt with structurally. Experts and patients need time to establish a partnership relation; this needs a 'safe space', frequent recurring opportunities for contacts and time to define new norms.[40,54,55] It is concluded that this is not a matter of singular dialogue meetings, but is rather an on-going process requiring time, effort and due attention to fostering learning processes between all those involved.

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