Chapter 10

Conclusion and discussion

‘De wijsheid van een enkeling is nog niet meteen de kennis van iedereen met diezelfde ziekte of aandoening.’

10.1 Introduction

Nowadays patients are increasingly involved in scientific research. They may participate at different levels, ranging, for example, from being respondent with less control to being research partner with more control (the latter referring to patients with the illness under investigation or relatives who participate in a research team). This increased involvement is partly related to societal developments like a better educated population, loss of respect for the status of experts, a more critical and assertive attitude on the part of patients and citizens who no longer automatically accept the traditional authority of professionals or experts and desire less hierarchical relations.\(^1,2,3\) Changes in theories about knowledge production and the status of experiential knowledge of patients have also paved the way for patient involvement\(^4\). Traditionally, the experiential knowledge of patients, also known as ‘being familiar with’ has a lower status than the knowledge of professionals. Knowing as ‘being familiar with’ is implicit knowledge that must be acquired by personal or even bodily experience.\(^4\) Patients have experiential knowledge owing to the daily experience of living with a certain disease or disability. It refers to the experiences of individual patients with their bodies, their illnesses and their treatment as well as their day-to-day struggles and the responses from their environment and broader society. Professionals are often described as having expert knowledge and practical knowledge. Expert knowledge, also known as ‘knowing that’, is the explicit information and explanation part of knowledge. Practical knowledge or ‘knowing how’ is the competence part of knowledge and consists of skills and capacities. This kind of knowledge is partly implicit and must be acquired by training and practice. The experiential knowledge of patients has been re-evaluated resulting in a horizontal notion of knowledge in which all three types of knowledge are seen as relevant and complementary to each other. The experiential knowledge of patients is increasingly respected as a relevant and valid source of knowledge; patients are increasingly seen as subjects who possess valid knowledge about living with a disease\(^5\) resulting in more participation or involvement of patients in research.

In the introduction several advantages as well as risks and doubts about patient involvement and the incorporation of their knowledge and experiences in research have been discussed. Although there are many good examples in practice,
convincing scientific evidence about the methodology, feasibility and effectiveness of patient involvement and the process of knowledge development is still lacking. Some scholars have doubts about the objectivity of the knowledge brought in by patients. They are not convinced about the possibility of transforming the subjective stories of individual patients into shared objective knowledge: the patients’ perspective. They furthermore express doubts about the usefulness of the patients’ perspective. Does it really give new insights or is the perspective of patients similar to that of professionals? And how can patients be involved so that knowledge is enhanced without the patients being overburdened?
The studies presented here aimed to explore whether the use of patients’ knowledge and their involvement in research has an added value and how this value can be realized in practice. Departing from this general aim, we formulated three research questions:

1) Does patient participation in research lead to knowledge development among patients and how to involve patients in research in order to foster a process of knowledge development (from individual subjective knowledge to shared objective knowledge)?

2) To what extent is collaboration with research partners useful in investigating the perspectives of patients? How can research partners and researchers work together?

3) What insights can be gained by exploring the knowledge of patients? How are these insights related to the perspectives of professionals? Do they overlap with or confirm the latter?

This chapter aims to answer these questions. We summarize and discuss the main findings and reflect on methodological issues. We conclude with implications and recommendations for further research and practice.

10.2. Main findings and discussion

In this paragraph, we will discuss the research questions, referring to the main findings of the studies presented previously.
10.2.1. Participation and knowledge development

The first question to be answered is:

*Does patient participation in research lead to knowledge development among patients and how to involve patients in research in order to foster a process of knowledge development (from individual subjective knowledge to shared objective knowledge)?*

As described in the introduction of this thesis, we have applied several steps of the Dialogue Model for research agenda setting in our studies. The Dialogue Model was chosen because it seems particularly suitable for the investigation of the patients’ perspective, and the integration of patients’ and professionals' perspectives. We assumed that gathering and using several types of knowledge of patients at several points in time would foster a process of knowledge development. Consequently the subjective individual stories of patients would, we assumed, be transformed into a shared patients’ perspective which would be complementary to the knowledge and insights of professionals.

This part describes whether our assumptions were right and whether our methodology and use of specific types of knowledge of patients at specific stages actually led to knowledge development. Are we really able to develop individual subjective stories into shared objective knowledge of a patient group? We will answer this question by describing the processes that took place in our studies (see chapters 3, 6, 8, 9), in each research phase, starting with the exploration stage.

*Exploration stage*

The exploration stage is aimed at gaining a first insight into the study population and creating enthusiasm in and collaboration with all stakeholders. This stage is not aimed at knowledge development: it merely forms the basis for the next steps, since initial insight into the study population and a basis for collaboration form the preconditions for the next stages.
Consultation stage

As mentioned in the introduction, the consultation stage is aimed at generating information from patients and professionals. We organized, among others, interviews with patients with only implicit experiences of their own illness and treatment (‘being familiar with’ and ‘knowing how’). These patients were not familiar with the stories of other patients and were able to express their own authentic individual experiences. Patients were extremely willing to participate since they embraced the importance of the research aims of attuning research to their life context and appreciated the opportunity to talk freely about their experiences without being restricted by questionnaires or certain questions. Patients developed their knowledge through these interviews. They gained more practical knowledge (‘knowing how’) by talking about their experiences. Telling their story helped them to understand their life and illness better. It is noted in the literature that telling your story may enhance feelings of personal recognition. Meanwhile, the interviews resulted in topics and issues which are not just individual to but relevant for many patients. These issues served as material for discussions amongst patients in the next phase.

Collaboration stage

The collaboration stage of our projects was aimed at validating and deepening the broad range of patients’ issues found in the consultation stage. In order to achieve this, several focus groups were organized. Patients were selected on the basis of having practical knowledge (‘knowing how’). Focus groups share several characteristics with other qualitative methods like interviews; the social interaction and deliberation that occurs between participants, however, is unique. Several techniques like using creative methods, interactive methods or a round table approach were used in order to handle the group dynamics, to give each member a voice and to foster a process of knowledge development. Participants in the agenda setting project (chapter 3) were, for example, asked to write down their own ideas on post-its. Their input formed the basis for an interactive dialogue in which participants were asked to explain their ideas and to react on each other’s ideas. The participants in the study as described in chapter 8 (autonomy of people with Acquired Brain Injury, also known as ABI) talked together about the themes by using own pictures of their lives. By referring to the pictures, made for private purposes, they were able to discuss meaningful themes.
Participants in the study described in chapter 9 (participation of people with ABI) were asked to draw a model in which the mutual interrelatedness of the factors, according to them was displayed. By using these techniques patients were able to order, classify and relate the data. By having a dialogue and clustering themes together, patients were able to mention connections and relationships.

The focus groups turned out to be social spaces in which participants co-constructed the patients’ view by sharing, acquiring and contesting knowledge. Patients deliberated about the issues, themes and experiences found in the consultation stage. As a result of the conversations and reflections in the focus groups the implicit experiential knowledge gained in the former stage turned into explicit, shared and inter-subjective expert knowledge (‘knowing that’). Patients, for instance, developed the participation model described in chapter 9 and a research agenda for social scientific research as described in chapter 3.

Some other positive side-effects could be seen. Patients first of all developed a sense of ownership. They experienced the models or results actually as their own results, which fitted well with their actual experiences. Creating a sense of ownership is important since it results in better implementation: if they experience ownership, patients are more willing to accept the results. The focus groups furthermore facilitated the further empowerment of patients. Individual patients were empowered by the recognition of their stories in the consultation stage; the focus groups led to a mutual relational empowerment of the participants. Empowerment is, in this case, not a process of giving or taking power. Some understand empowerment as a process whereby power is given, granted, or delegated by one with power to one without power. Other scholars describe empowerment as something which must be taken. Empowerment thus is seen as a process one undertakes for oneself. It is done ‘to’ or ‘for’ someone. In contrast to these two views, the empowerment process in the focus groups can be described as a mutual learning and empowerment process: power is neither given nor taken. It emerges through interaction with others. The relational approach of empowerment states that one is never just empowering or being empowered: everyone involved, regardless of position of power and privileges, is both an agent and a subject in the empowerment process. Patients empowered each other by the recognition of each other’s experiences.
**Integration stage**

The integration stage of our projects consisted of focus groups or working groups aimed at integrating and translating the data into recommendations for the improvement of daily practice. Patients involved in this stage were selected because they had expert knowledge (‘knowing that’). These patients often had an active role in some of the patient associations, and had a lot of knowledge about the experiences of patients and the actual situation that needed to be improved.

The earlier collaboration phase had already resulted in the creation of a shared perspective (expert knowledge or ‘knowing that’) and the empowerment of the participants. Patients felt empowered by the discovery that other patients shared their experiences and they reinforced each other by accepting each other’s experiences. This phase led to the stronger formulation of a shared perspective and the development of the conviction that patients are allowed to express this perspective. The integration stage aimed at the development of capacities to express this shared perspective towards other parties like professionals. Consequently, the empowered patients were able to express their shared voice, to stay faithful to their own perspectives, to negotiate with other parties and to be equal discussion partners.

The shared objective perspective that emerged through the abovementioned process of knowledge development was the result of using interactive methods. Patients were engaged in a deliberative dialogue. Deliberation requires interaction and dialogue between participants. In dialogue, the participants will not just accept each other’s beliefs and convictions, but will explore them. This process is characterized by listening, probing and dialogue, rather than confronting, attacking and defending. Central features of dialogue are openness, respect, inclusion and engagement. Conditions for a deliberative dialogue are the willingness of stakeholders to participate, to share power and to change in the process.\(^{11}\)

A deliberative dialogue differs from other forms of public discourse, such as debate, negotiation, brainstorming, and consensus-building, because the objective is not to discuss and reach a conclusion but to think together and identify where a conclusion might lie. Thinking together involves listening to other points of view, exploring new ideas and perspectives, searching for points of agreement, and bringing unexamined assumptions into the open. It focuses on a question that needs
to be addressed, rather than on a problem that can be efficiently solved. A problem needs to be solved; a question cannot be solved, but it can be experienced and, out of that experience, a common understanding can emerge that reveals an acceptable path for action. A dialogue is not the sum of individual voices or votes as in a panel or voting procedure, but an interactive exchange of ideas and perspectives.\(^{(12)}\)

The social theorist Habermas\(^{(12)}\) formulated several conditions for a deliberative dialogue. Anyone who is competent to speak and act should be allowed to take part in the process of deliberation, and all those taking part in the process of deliberation should be allowed to introduce any assertion they wish to make and to question any assertion made by others. All participants should be allowed to express their views and no speaker should be prevented by internal or external pressure from exercising those rights. This has led to a series of normative criteria for assessing deliberative practices based on the notion of communicative competence.\(^{(12)}\) By focusing on communicative skills, reason and rational arguments, one may however exclude vulnerable groups of patients with fewer communicative skills who tend to express their views more emotionally and less rationally. Those who express their views and opinions in an emotional manner are often disregarded. Expressing views in disruptive or demonstrative ways risks not only condemnation of the person expressing such views but also the views themselves being labelled as ‘extreme’. A deliberative dialogue should therefore leave space for rational as well as emotional ways of expressing ideas and stories.\(^{(12)}\) We have experienced this especially in our projects with patients with ABI. Expressions were, as a result of the restrictions, not always rational or adjusted to implicit interaction rules. These expressions were not ignored or put down. All expressions were taken seriously and the researchers or research partners used communication techniques in order to give all participants the opportunity to talk.

**Concluding remarks**

We can conclude that patient participation in research may lead to knowledge development among patients if the right methods and strategies are used. Using such strategies can transform the individual subjective stories of patients into a shared objective patient perspective. Individual subjective experiential knowledge
(‘being familiar with’) or the individual subjective stories of patients can be
developed into shared valid expert knowledge (‘knowing that’). This development
of expert knowledge needs time and a certain way of working. Randomly asking
patients about their experiences, or organizing a panel discussion or voting, does
not lead to a shared intersubjective perspective/expert knowledge. We therefore
deliberatively divided the consultation phase of the Dialogue Model into several sub
phases, focusing on various kinds of knowledge. This helped us to overcome
potential problems expressed in the literature like overburdening or alienation of
patients. It also helped us to reach individual patients with authentic experiences
as well as those with more developed insights resulting from introspection and
interaction with fellow patients. Such a process also leaves room for individual
patients to choose whether they want to participate, and in what role. Not all may
be willing to join a focus group or be a research partner; some just want to tell
their story. Through an iterative process of data collection, joint analysis and
deliberative dialogue we were able to enter a process of development from
subjective individual experiential knowledge towards shared expert knowledge.

We partly agree with those who state that patients cannot be a representative of
other patients since they bring in their own perspective and not that of the whole
group.\textsuperscript{(13,14)} This is indeed true for patients with experiential knowledge (‘being
familiar with’). Patients with practical knowledge (‘knowing how’) and expert
knowledge (‘knowing that’) are, however, able to present a richer perspective.

Some authors question whether patients are able to stay faithful to their own
perspectives and agenda or whether they will adapt themselves (too much) to the
perspectives of other stakeholders.\textsuperscript{(13)} Patients in our projects did not unthinkingly
take on the ideas of professionals. The dialogue with patients about their own
perspectives resulted in the development of their own voice and the capacity to
negotiate about their perspectives with professionals. This process of helping
patients to gain a voice as individuals and subsequently developing a shared voice
based on collective experiences is also known as ‘enclave deliberation’.\textsuperscript{(15)} Enclave
deliberation helps to deal with power differences between groups and forestalls
domination by established groups.\textsuperscript{(15)} Certain other preconditions, also mentioned
by Abma and Broerse,\textsuperscript{(16)} were used in order to prevent the loss of their own
perspectives in a meeting between patients and professionals. Examples of these
preconditions are: thinking about the composition of the group, the use of non-technical language, the reservation of conversation time for patients, the assistance of patients in advance of the meeting, and collaboration about an appropriate time and location.\(^{(16)}\)

The deliberate use of the several kinds of knowledge in (the subphases of) the consultation phase of the Dialogue Model can, in conclusion, be seen as an optimalization of this model.

### 10.2.2. Collaboration with research partners

The second research question of this thesis concerns the collaboration between researchers and research partners in a research team:

*To what extent is collaboration with research partners useful in investigating the perspectives of patients? How can research partners and researchers work together?*

Working together with research partners presumes a certain level of participation. The participation ladder as described in the introduction\(^{(17)}\) can be used to assess the level of participation of patients and patients’ decision-making power in research. Patients may participate on several levels and have several roles in research. These roles range from being respondents with less control and a low level of participation to being research partners to being principal researchers with considerable control and a high level of participation. The extremes are ad hoc patient consultations on the one hand, and patient control on the other hand. Although consultation and control differ in terms of the degree of participation, in both instances there is one party which takes the lead in the interaction. Either the researchers are in charge and formulate questions to which patients can respond (patient consultation), or the patients are in charge and determine the research (patient control). The ownership lies in the hands of one of the actors and dialogue and interaction are kept to a minimum. This one-sidedness is absent if patients are involved as research partners. Patients participating as research partners are patients who join research teams on an equal basis with professional researchers. As members of a research team, research partners conduct operational research.
tasks, such as doing interviews and moderating focus groups. They are not only involved in the data collection, but also in the data analysis and negotiations about methodological decisions. The degree of involvement of the research partners is high: they do not just carry out invisible work, but are engaged in intellectual work and strategic decision-making. Working with research partners is characterized by collaboration: the research partners are, just like academic researchers, involved in all stages of the research process, share control and co-labour on an equal basis with academic researchers in an ongoing process of dialogue and interaction. The differences in responsibility or background between research partners and researchers cannot be ignored but it is important to strive for equality and to be alert to inequalities and subtle ways of involving or excluding research partners and their input.

Opponents argue that a higher level of participation of patients in research is not always desirable, possible or better. The method and level of participation should depend on the goals being pursued. It is furthermore unclear whether collaboration with research partners helps to investigate the perspectives of patients and how research partners and researchers should work together in order to get the best results. Studies about the effects of a collaboration with patients show conflicting results: positive as well as negative effects have been mentioned. In the following we will discuss the usefulness of collaboration with patients in the light of our experiences, and elaborate on productive ways of working together.

**Collaboration with research partners**

The projects in which we worked together with research partners were based on the assumptions of the Dialogue Model. This section describes how the collaboration between researchers and patients as research partners took place in practice and which circumstances were helpful in terms of reaching an equal collaboration. These reflections are based on chapters 4, 5, and 9 of this thesis.

**Background and recruitment of patients as research partners**

Collaboration between researchers and research partners starts with the recruitment of research partners. Research partners should, as described in chapters 4 and 5, have practical knowledge (‘knowing how’) or expert knowledge
knowing that) so they can talk on behalf of other patients. They should have contact with other patients but they should, ideally, not hold an active role in a patient organization, so they are able to share their own knowledge equally and freely rather than pursue an advocacy role for the patient organization.

Some of our research partners had an academic background and some of them did not. None of them had experience of conducting scientific research. This worked out well, since the research partners were explicitly asked to bring in their knowledge of their disease and since they learned by doing, as described in chapters 4 and 5. Yet research partners need to develop some understanding of the research process in order to be able to contribute in a meaningful matter. A short training course can provide research partners with basic skills and information but we opted for the ‘learning by doing strategy’. Chapters 4 and 5 show the experiences of a team of academic researchers and research partners who were not trained to work together in advance. In practice, they searched for a fruitful way of working. Ideas of working together, for instance by conducting the interviews in pairs consisting of a researcher and research partner, were discussed and tested in practice. The mutual collaboration was discussed before the interviews and seemed to be fruitful for the first interviews but was adapted gradually as the interviewers gained more experience. The team members researched together, for example, how to support each other and what questions could and could not be asked by the research partners. We have found that a joint search and learning process is extremely fruitful in terms of attuning expectations. We believe that this learning process by doing gives better results than may be obtained just by following a course or reading an article. Prior training may be helpful as a basis but should not be seen as a licence to ignore other attempts. The facilitation and support of a mutual learning process are crucial for finding proper ways of cooperation. Learning by doing and learning together in a team however presuppose a climate of support, trust, reciprocity, and encouragement. Both researchers and research partners have to be open to suggestions and learning and have to feel safe enough to share doubts, dilemmas and emotions. We have found that such a climate is engendered by people being interested in each other and supporting each other to share experiences. This relational way of working and learning in our projects created a sense of equality and reciprocity.
An important aspect of collaboration is the continuous expression of each other’s expectations, needs, wishes, possibilities, and restrictions. Tensions may arise, and did arise in our projects, if these issues are not kept in mind continuously. Later projects have taught us that initial training with researchers and research partners in a project provides opportunities for teambuilding and may help to prevent tensions as a result of unexpressed expectations, needs, possibilities, and restrictions. This training for all team members creates equality, which is not created if the training is only followed by research partners. It may be the starting-point for team development but the actual development takes place in practice.

Concerning recruitment, it is important that patients are able to be honest about their own ideas and personal agendas and can avoid letting their own persuasions dominate the research. This also applies to researchers. Both parties need to be aware of their prejudices and experiences and be prepared to enter into a dialogical relationship to which they can bring prejudices and experiences and in which they are open to other ideas and viewpoints. An open, equal and honest relationship in which every voice is emphasized as important is needed so that each member feels safe to share information and experiences. Each member should have a sense of being taken seriously and research partners should, gradually, be made aware of their unique complementary role.

Activities and tasks of research partners

The activities and tasks of the research partners in our projects were jointly discussed and (re)negotiated over time. The research partners in the agenda setting project with renal diseases participated in all activities and stages of the study (chapters 3, 4 and 5). They were, for example, involved in composing the topic list, recruiting patients, informing patient organizations in talks and meetings, doing the interviews, focus groups and analysis and writing the research report and articles. The research partners in the project with ABI had several restrictions as a result of their brain injury (chapters 8 and 9). The actual tasks were adjusted to their abilities and limitations. The combination of travelling and doing an interview was, for instance, problematic for one of the research partners since this required a lot of attention and energy. As a result, she did not participate in all interviews. Her self-confidence and abilities, however, grew during the project, so that she was able to combine both at the end of the study.
Her development was partly the result of the collaboration with two of the other team members. By working together, travelling together, talking together, sharing emotions, having belief in each other’s capacities, using and focusing on each other’s capacities and experiencing successes, the team saw her self-confidence grow gradually. Reading the transcripts remained hard so she was not involved in the content analysis. She brought in her experiences later on by relating the findings to her own experiences. The reading of the end report was also a hard task for her, but she and the research team came up with a solution giving her significant influence on the report: she completed the report by adding digital pictures, in line with her background as a professional artist. Her artistic gifts were not seen as a beautification of the report but as a distinct and more persuasive way of showing the perspectives of patients regarding participation. Her expressions were furthermore part of the process of analysing the data towards an integrated ‘picture’.

In sum, we learned that the actual activities and tasks of the research partners have to be determined together. They have to fit with the wishes, possibilities and restrictions, and the developmental process, of each individual research partner. Working together with research partners is not a ‘one size fits all’ situation. It asks for individual adaptations that may change during the research process. Practical preconditions like access, place and time of team meetings, possibilities of travel, reimbursement, et cetera have to be taken into account, as mentioned by Hewlett and colleagues.\(^{(21)}\) We would not have achieved the above-mentioned results if we had not paid sufficient attention to these preconditions. Our meetings were, for example, regular, at a time and place that were most optimal for the research partners. The content of the meetings and the way of working during the meetings was adapted to their needs. We also paid the research partners for their work. Working together on an equal basis and emphasizing the input of research partners requires a realistic compensation/payment. We calculated these costs in our budget and the funding agencies were willing to provide this budget since they support collaboration with research partners.

**Reflection and dialogue**

The projects have shown that reflection and dialogue are important preconditions for creating fruitful collaboration between researchers and research partners.
Chapters 4 and 5 particularly describe the reflection processes that took place during the project. We have, for instance, reflected on themes and feelings such as the experience of someone being left out or being disturbed during an interview. We also had several talks about the value of the knowledge of research partners and their doubts about this value. Other dilemmas included dealing with personal questions of patients, personal interests and agendas; overwhelming emotions or certain fears and insecurities were also often discussed in the team meetings. The risk of being overprotective towards one another was also a recurring theme in our talks. By fostering an open, inclusive and deliberative dialogue we were all able to learn from each other’s experiences and perspectives. This led to the personal and professional development of all team members. The ongoing dialogue was a force and forum for democratization and has led to a better insight into what patients want or mean. The collaboration also led to other advantages which will be described below.

**Benefits of working with research partners**

Our collaboration with research partners had benefits for the research process itself, the researchers, the research partners and the respondents of the projects. We will explore these benefits separately; in reality they are intertwined.

**Benefits for the research process**

Our collaboration between academic researchers and research partners, as described in chapters 4 and 5, had benefits for the research process itself. The research partners were, first of all, on the basis of their experiences, able to nominate interview and focus group topics that were not mentioned or contemplated by the researchers. The topic lists were therefore more suitable for the interviews and focus groups with patients, and resulted in interviews and focus groups which better covered the lives of the respondents. The complementary contribution of the research partners also raised the researchers’ awareness of the diversity of the patient population. The ability of research partners to relate the problems of the respondents to their own situation led to trust and an open atmosphere in which respondents felt their experiences were recognized. This in turn led to more profound interviews and focus groups and better results.
Research partners also stressed the importance of taking into account diversity in a certain patient group. The research partners in the agenda setting project with renal patients (chapters 3, 4, 5) mentioned, for example, the importance of investigating the perspectives of young teenagers and elderly patients instead of just focusing on the perspectives of adult patients. They stressed the potential differences in the perspectives of each group.

Furthermore, the participation of the research partners fostered the credibility and legitimacy of the projects. Patients were therefore more willing to participate and the overall recruitment was easier since research partners had easy access to fellow sufferers and they knew how, when and where to approach them.

The participation of the research partners also led to a better analysis. Analysing without research partners carries risks since the researcher predefines the questions, directs the analysis and draws conclusions, safeguarding the scientific quality of the research. Describing the perspectives in that way does not guarantee that the right questions were asked, that the right methods were used and that the results still represent the patients’ voices or that the results are relevant for patients. The unique perspectives and voices can easily get lost in the researcher’s interpretation of the outcomes, resulting in conclusions that are no longer recognizable by patients. The research partners in the participation project (chapter 9), for instance, stressed the importance of the enabling and disenabling environment whereas the researchers, in the first instance, were inclined to stress the role of individual factors and to lose sight of the environment. The research partners emphasized these factors time after time, by giving examples from their own lives and by relating these to the findings. The same occurred in the agenda setting process with renal patients (chapters 3, 4 and 5). The research partners stressed the importance of coping and family in order to prevent these themes getting lost. We have found that researchers can easily overlook the complexity and capriciousness of living with a chronic disease, reducing the meaning of life experiences to abstract themes and models. The research partners were able to prevent this, which was necessary since the researchers in our projects tended to simplify the complex world of living with a renal disease or ABI in order to arrive at models and recurrent themes. The research partners were able to relate the results to the patients’ personal circumstances and often provided a richer, more
metaphorical interpretation of the patients’ stories. They stressed and explained, day after day, the context in which respondents had mentioned various things which made it easier to analyse and understand these expressions. They stressed the importance of the interrelatedness of several themes. This led to the description of more integrated perspectives that were recognizable by the patient group under investigation.

The research partners had an important role in the writing of the research reports and scientific articles. As a result of their suggestions the reports were completed with pictures/art (chapter 9) or patient stories (chapters 3, 4 and 5), in order to provide a richer and multimodal description of the patient perspective. The shared authorship led, as a side-effect, to a further increase of the ownership and empowerment of patients. This was further increased by the development of brochures aimed particularly at patients and their relatives (chapters 3, 4, 5 and 9). Patient participation and the investigation of the perspectives of patients should, in our opinion, result in brochures like these. Research reports and articles are, however, often not converted into patient-friendly versions.

**Benefits for researchers**

The participation of research partners, as described in chapters 4 and 5, may have several benefits for the professional researchers in the research team. Their participation may first of all influence the understanding of researchers about what it means to live with a certain disease. The informal talks and personal stories proved very instructive and helped the researchers gain a better understanding of what it means to live with the disease under investigation. The professional researchers, thanks to these talks and experiences, were better able to relate to the problems of patients and were better prepared for the interviews. As a result of the talks and collaboration they were also confronted with their own judgements and behaviour towards the patient population and research partners. One of the research partners with ABI confronted us, for example, with our chaotic and unstructured behaviour and strong focus on argumentation and intellectual discussions instead of on emotions, relations and interactions within the team.
**Benefits for research partners**

The participation of the research partners also had benefits for the research partners themselves. Earlier studies have described how active involvement of patients may lead to empowerment of patients (introduction). This thesis confirms that patients are empowered by participating as research partners. Chapters 5, 6 and 9 describe how this empowerment took place. The empowerment was the result of working together, learning new skills, talking with other patients and team members, but it was mainly the result of the discovery that the empowerment of patients cannot be seen as a one-way process. The empowerment that took place was a relational process: both research partners and researchers were empowered by the collaboration. Both learned and grew by working together. They discovered that each one was an actor as well as subject to the processes of power. By acknowledging vulnerability and being open about it towards each other, both can become stronger and more powerful.

Participation as research partners also has other benefits. Chapters 4 and 5 describe how they gained more (research) skills through participation (also known as objective empowerment) and how the self-confidence (also known as subjective empowerment) of research partners grew during the research process. The research partners also gained a better understanding of their own situation from talks with fellow patients or parents of young patients. The talks sometimes created mutual recognition between the research partners and the respondents which helped both of them to better understand and accept their own situation.

**Benefits for the study participants**

The paired interviews of a research partner and researcher led, as mentioned in chapters 4 and 5, to a more familiar and less formal way of interviewing. Patients felt more comfortable in the presence of the research partners. They felt it easier to talk about their experiences since there was a mutual recognition between the patients and research partners. The research partners were able to relate the problems of the respondents to their own situation which led to trust and created an open atmosphere in which respondents felt their experiences were recognized. The interviews were consequently more profound, less superficial and gave more space to the actual experiences of patients. Respondents even directed questions to the research partners, which also contributed to the atmosphere and
participants’ willingness to talk about their own experiences. The same dynamics occurred in the focus groups. These focus groups not only were less superficial experiences but, owing to the contribution of the research partners, were also better adapted to the possibilities and restrictions of each group. Organizing the focus groups started with improved preparation. People with ABI (chapter 9) received, for instance, an invitation letter with the pictures of the facilitators of the focus group. This was at the suggestion of one of the research partners with brain injury and was much appreciated by the participants of the focus groups: ‘It made me feel more comfortable’. The actual performance of the focus groups was also adjusted according to the advice and experiences of the research partners. The groups with people with ABI were, for instance, located in well-chosen accommodation, were shorter and had a longer break since the research partners stressed the influence of tiredness, travel problems and concentration problems.

**Concluding remarks**

In sum, collaboration with research partners has several benefits for the research process itself, the researchers, the research partners and the study participants. It results in more profound and patient-relevant findings and an emphasis on topics different from those emphasized by researchers. Research partners in our studies stressed the importance of an integrated way of thinking and working, leading to more practical and less reductionist results. The collaboration with research partners has resulted in quality improvement of the research processes and the projects. This is in line with earlier studies and refutes the idea that the participation of patients in research does not result in actual influence on the study.

These benefits can only be achieved if collaboration is characterized by equal relationships in which all team members are open to learning from each other and are willing to share their emotions and experiences in an ongoing dialogue. If research partners or researchers are not really willing to work together and to learn from each other, this results in tokenism. Collaboration, in line with Van de Bovenkamp,⁸ should not be motivated by political correctness. Collaboration is ideally characterized by equality, shared control, shared ownership, reflection, learning by doing and relational empowerment. Research partners and researchers may experience certain doubts and emotions; these should be taken seriously.
Participation of patients in investigating the perspectives of patients may be time-consuming\textsuperscript{13} but leads to new insights, better research, knowledge development and the empowerment of patients.

**Box 1 Reflection**

This thesis makes a clear distinction between research partners and academic researchers. Research partners were described as patients or patients’ relatives with experiential knowledge about the disease under investigation, who join research teams on an equal basis with professional researchers. Research partners should, as stated earlier, have practical knowledge (‘knowing how’) or expert knowledge (‘knowing that’) about the disease under investigation, so they can talk on behalf of other patients. They should have contact with other patients but they should, ideally, not hold an active role in a patient organization so they are able to share their own knowledge equally and freely rather than pursue an advocacy role for the patient organization. Research partners are assumed to bring their experiences and those of other patients, whereas academic researchers are assumed to bring academic knowledge, e.g. about the methodology and research activities.

Attentive readers may have noticed a role change by the author. I started my career at the university as a research partner since I was diagnosed with the same hereditary renal disease that my mother suffered from. My initial role as a research partner had a certain focus. I was not asked to participate because of my academic or professional background but because of my experiential knowledge. I was constantly invited to talk from my experiences as a daughter and patient and not from my professional background. After the project I decided to start a PhD trajectory and so my role formally changed from that of a research partner to that of an academic researcher/PhD student. This led to certain doubts and role confusion, which have also been described in the literature.\textsuperscript{(23)} The first issue one has to deal with is openness. Susan Squier describes doubts expressed by researchers with a mental disability. What happens when a researcher identifies him/herself as mentally disabled? Can he or she still work effectively as a scholar? Would the legitimacy of the work be called into question? She cites the example of Key Redfield Jamison, clinical psychologist and patient with a bipolar disorder.
Jamison’s career is in her eyes an example of how a dual identification, namely as a disabled person and as a professional practitioner/scholar, can be viable. Her fame shows the potential power of integrating both aspects in one’s identity. Integrating both aspects in your identity can anyhow be experienced as difficult. Squier, having a mental disorder herself, describes, for instance, how her identity oscillated during her research projects. Sometimes she certainly identified herself with her disease but at other times the label seemed to be incomplete and unhelpful to her.\(^\text{(23)}\)

I really understand her reasoning and recognize the doubts she describes. At certain times I felt my own resistance. At those moments I did not want to be a renal patient or the daughter of a renal patient. I just wanted to be a professional researcher or PhD student, just like my colleagues. At other times I wondered if I was ‘ill’ enough to understand other patients. I only have a renal disease on ‘paper’ and I do not experience any problems. At other times, for example during my first period as a renal patient in a clinical medicine trial, I was confronted with the disease day after day and it changed my identity and my image of myself. Talking and being open about my background and writing parts of this thesis evoked and still evokes doubts and fears: would people continue to take me seriously? would people still see my abilities? would people reject me? Gradually I learned to see the power of being open about my background and combining both aspects in my identity and work. Just like Karen Mogendorff,\(^\text{(24)}\) my identity has changed by doing this work: I have, just as she did, integrated my illness and background into my personal identity in the same way that other identifiers are part of my identity. I truly identify myself with Squier who, at certain times, preferred to describe herself as: ‘I am that I am’.\(^\text{(23)}\) I experience her statement as a lesson for me and probably for other researchers with a physical or mental disability or disease who wrestle with their role and identity. My body and experiences, as also described by Karen Mogendorff,\(^\text{(24)}\) have become a ‘tool’ for understanding life’s experiences and the world I live in.
10.2.3. New insights

For a long time the relevance and validity of the experiential knowledge of patients have been underestimated, because of its assumed lack of objectivity, verifiability, universality and rationality. Patients are increasingly seen as subjects who possess a relevant and valid source of knowledge about living with a disease.\(^6\) It is argued that patients are able to bring in new and additional insights\(^{5,13,19}\) based on their unique, daily experience of their disease\(^{20,25-30}\) and the stories they tell.\(^{31}\) It is now assumed that patients can provide an alternative and relevant view on matters of health and illness,\(^{27,32}\) in addition to the views of professionals.\(^4\) Doubts about the added value of the perspectives of patients are also expressed, however.\(^{5,14}\) We therefore formulated the last research question:

*What insights can be gained by exploring the knowledge of patients? How are these insights related to the perspectives of professionals? Do they overlap with or confirm the latter?*

We will answer this question by elaborating on themes that were brought in by patients in our studies. Each separate study of this thesis has provided practical insights drawn from the knowledge and experiences of patients. These insights are described in each separate chapter. This paragraph describes the insights that could be drawn from all these studies together.

*Continuous care and attention in the chronic stage*

Chapters 2, 3, 6, 7 and 9 stress the importance of the continuous availability of adequate psychological and psychosocial support in the acute, rehabilitation and chronic stages of an illness; current support is often intermittent and focused on the acute and rehabilitation stages.

The individual stories of the first author (chapter 2) and Linda (chapter 7), a female with ABI describe, first of all, how they tried to deal with their illness and what they needed to do this. The story of Linda shows her struggle with the recovery and acceptance process. She struggled, in the first instance, to become the same person as she was before, but she gradually realized that her life had changed dramatically and that she would never be the same again. The brain injury forced her to radically
change her views and dreams about the future. This was not an easy process; it gave rise to emotions like despair and not knowing how to face the future. Step by step, she recognized her restrictions and learned to focus on the things she can still do and enjoy. Linda emphasizes the importance of getting support in finding a new balance and fulfilment in one’s life.

Her story is in line with the findings in chapter 9. Patients with ABI emphasized the importance of psychological or psychosocial support in the chronic stage of their illness process. Support is, according to patients, particularly needed in this stage since they are then confronted with lasting restrictions. Such support is however often lacking in the chronic stage. Patients with ABI find, as described in chapter 7 and 9, that current care is too much focused on recovery in the acute and rehabilitation stages and too little on acceptance of lasting restrictions and dealing with restrictions in the chronic stage.

Patients with ABI also describe problems with the organization of care. They perceive current Dutch health care as intermittent, unclear and hard to access and they emphasize the importance of better structured, continuous care and collaboration among professionals in order to offer patients the support they need in each stage of their illness process. A regional chain of professionals who work together as a network to supply integrated and coherent treatment and care for people with ABI in all phases - i.e. acute, rehabilitation and chronic - of the ailment is considered necessary.

This need for continuous support in all stages of the illness process is not only expressed by patients with ABI but also by renal patients, as can be concluded from chapters 2, 3 and 6. The support should cover patients as well as their relatives (chapters 3, 6 and 9).

The above-mentioned points are partly a confirmation of earlier findings. The lack of psychological support in the chronic stage of ABI was, for example, mentioned in a recent study.\(^{(33)}\) This finding is however based on an evaluation of existing interventions and does not derive from a systematic investigation of the wishes of patients. Our findings can be seen as a complementary plea, deriving from the perspectives of patients, for developing and offering such support.
**Integrated perspective and multidisciplinary approach**

This thesis shows that the lives of patients with a chronic disease can be characterized as complex, interrelated and dynamic and researchers and healthcare professionals often tend to divide the diseases into certain stages, themes or problems, which does not do justice to the situation as experienced by patients.

Chapter 3 describes a social scientific research agenda based on the perspectives of renal patients. Renal patients formulated and prioritized 17 research themes concerning daily life and illness history. Examples of research themes in daily life are mastery, partnership, work, social contact, sexuality and appearance. Examples of research themes in illness history are coping, family, tiredness, knowing & trusting your body signals, healthcare organization and side-effects. Patients stressed how these themes are interrelated in daily life and how they influence each other. Together these research themes give us an understanding of the complexity of living with a renal disease. They also provide insight into the needs and wishes of patients regarding scientific research. The research priorities of renal patients reveal white spots not yet covered by professionals, including researchers and healthcare professionals. Patients mentioned research themes that, owing to their interrelatedness, often lie at the interface of social scientific research on the one hand and (bio)medical research on the other. Examples of these themes are tiredness and sexuality. Researchers should, according to patients, work together and they should recognize the interrelatedness of themes and the complex and dynamic character of a renal disease. This requires a more intense, transdisciplinary collaboration between biomedical and social scientific researchers and patients.

Our research with patients with ABI also shows the importance of an integrated perspective and transdisciplinary approach. In chapter 9 we described the societal participation of patients with ABI. A model was constructed that was based on their experiences, and includes four factors which, in interaction, influence societal participation. The model developed by patients with ABI shows, just like the ICF model of professionals, that the level of participation is determined by the interaction of personal and contextual factors. The patients’ model can be seen as a further specification of the ICF model since it draws attention to more specific
aspects affecting the participation of ABI patients. Since all these factors interact in specific ways in each individual with ABI, participation must be considered as a continuous, dynamic and complex process. The patients’ model suggests that participation of ABI patients can be enhanced via interventions in all the distinct but related factors. This asks for an integrated and transdisciplinary approach in the acute, rehabilitation and chronic stages which is often lacking.

In conclusion, patients stress the importance of integrated and transdisciplinary research and support. They stress the importance of collaboration between social scientific and (bio) medical researchers to this end.

**Moral aspects of living with a chronic disease**

From the chapters in this thesis, we can conclude that researchers and healthcare professionals should pay more attention to the moral aspects of living with a chronic disease. Attention to these aspects is often missing although patients stress their importance.

Chapter 6 shows that renal patients can experience a wide range of positive and negative emotions like gratitude, fear, and guilt. Our study suggests, in line with earlier studies, that gratitude and joy may be tempered by guilt and sadness.\(^{34-39}\) Our study is the first to explain the role of normative expectations. Feelings of gratitude may change into feelings of guilt as result of normative expectations or underlying values like ‘I have to be grateful’ or ‘I’m not allowed to complain’. Another novel finding is that such normative expectations and underlying values may lead to non-adaptive behaviour, like not expressing emotions or transcending one’s borders.

The importance of attention for underlying values is also mentioned by people with ABI. Chapter 8 shows that professionals and patients have different ideas about the concept of autonomy. Being independent and self-sufficient are seen as important by professionals whereas patients want recognition for being vulnerable, sometimes dependent and not always able to perform as agreed. Being dependent and asking for help may give them a greater sense of being autonomous than being independent and doing things without help. These conflicting views on autonomy lead to clashes and tensions between patients and professionals. The daily support
of professionals should, on the basis of these findings, not be focused solely on autonomy in terms of being independent and self-sufficient but also on the recognition of vulnerability and dependency. Professionals should listen to the stories of patients and should adjust their way of working to patients’ needs and wishes. They should furthermore engage in a dialogue about each other’s values in order to understand and respect each other and to increase patient autonomy.

Chapter 9 stresses the importance of having a dialogue about values. Patients with ABI, in contrast with professionals, did not perceive (returning to) work as the most important aspect of societal participation. Participation, according to patients, is to do with having a valuable role and taking part in communal activities, giving something to others and being someone in a specific context. Patients stressed that rehabilitation and support should not be focused solely on returning to work but on having a conversation and deliberation so as to come to an understanding of the personal values that matter in one’s life in order to adapt the support and rehabilitation goals to these values.

The investigation of the perspectives of renal patients and patients with ABI gives new insights into the role of normative expectations and values in dealing with a chronic disease. These aspects are often underexposed in research and daily support.

Concluding remarks
We can conclude that patients are able to bring in new and additional themes for research and care. This finding strengthens the results of earlier studies that showed that patients are able to formulate new themes that are underexposed and otherwise would not be taken into consideration.(13,19) The investigation of the perspectives and knowledge of patients has, among others, given new insights into the organization and focus of health care, moral aspects of living with a chronic disease and the importance of integrated and transdisciplinary research and care. The perspectives of patients, as found in this study, are largely new in comparison with the perspectives of professionals. Yet they also partly overlap and confirm the perspectives of professionals. In the case of confirming, the issues of patients form a legitimate stimulus for professional work in the direction as suggested by both patients as well as professionals.
Critics may say that the knowledge of patients is not truly their own perspective. They may state that patients’ knowledge is shaped by medical knowledge and practice\(^{(5)}\) and that this changes the views and ideas of patients.\(^{(13)}\) It is indeed true that patients, as well as other stakeholders like medical specialists and researchers, do not live in a vacuum. Each individual is influenced by the opinions of other people and the environment s/he lives or works in. The world of patients consists largely of medical specialists, professionals and medical knowledge and it is reasonable to assume that their views are influenced by their environment. Yet patients have their own, unique, complementary perspectives on what it means to live with a chronic disease, and what is required, in terms of research and care, to meet their needs and to answer their often complex questions and doubts.

10.3 **Methodological issues**

This paragraph consists of two parts. The first part focuses on methodological strategies to increase the quality of a study. We will start with a description of these strategies, followed by a reflection. The second part of this paragraph entails a broader reflection on the strengths and weaknesses of our studies.

**Methodological strategies**

The articles published in this thesis are all based on qualitative studies. Qualitative research used to be regarded with scepticism by the scientific community, and criticized for its subjective nature and absence of hard facts.\(^{(40)}\). Over the years, however, the methodology has acquired a more prominent position in the scientific world, and is being seen more and more as a valid and reliable method.\(^{(41)}\). Yet doubts about the value, validity, reliability and generalization of this kind of inquiry remain.

The quality of quantitative research is often related to its validity, reliability and objectivity. These criteria cannot be directly applied to qualitative research and need to be adapted so the quality of this kind of research can be assessed.\(^{(40,42)}\) Many criteria have been suggested for assessing qualitative research. The most important are credibility, confirmability, dependability and transferability.\(^{(42)}\) These criteria can be seen as an alternative to the quantitatively-oriented criteria.
of internal validity, external validity, reliability and objectivity. The proposed qualitative criteria and the ‘analogous’ quantitative criteria are listed in table 1.

Table 1 Comparison of criteria for qualitative and quantitative research

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<th>Traditional criteria for judging quantitative research</th>
<th>Alternative criteria for judging qualitative research</th>
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<tr>
<td>Internal validity</td>
<td>Credibility</td>
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<tr>
<td>Objectivity</td>
<td>Confirmability</td>
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<tr>
<td>Reliability</td>
<td>Dependability</td>
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<td>External validity</td>
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We will first describe the strategies to increase the credibility, confirmability, dependability and transferability of our data and end with a reflection on how this worked out in our projects.

Credibility
Credibility in qualitative studies is comparable to internal validity in quantitative studies. Credibility refers to confidence in the truth of the data and the interpretation of them. Various techniques have been described which may improve the credibility of data.\(^{42-44}\) We have used the most important of these techniques, namely: prolonged engagement, persistent observation, triangulation, member check, searching for disconfirming evidence, (theoretical) saturation and researcher credibility.

The first activities or steps which can be used are prolonged engagement and persistent observation: the investment of sufficient time in data collection activities to ensure an in-depth understanding of the group under study and to focus on the aspects of the situation that are relevant to the phenomenon being studied. Prolonged engagement is also essential for building trust and rapport with respondents.\(^{42}\) In most of the studies, we applied prolonged engagement and persistent observation by making a time schedule that left enough time for data collection. In the study described in chapter 6, however, the period of data collection was relatively short. The qualitative study was meant to provide a basis for the intervention and the quantitative effect study, making rapid data collection
necessary. Given the personal background and previous research experiences of the researcher (the author of this thesis), it was, however, relatively easy to build trust and rapport with the respondents. An in-depth understanding of the patient group had already been gained in the previous agenda setting study, so that the period for getting to know the patient group could be shortened.

Triangulation is a third strategy for enhancing credibility. This implies using multiple data sources and methods (e.g. interviews, observation, focus groups) and involving more than one person in collecting, analysing and interpreting data. Our studies used multiple data sources and methods.

The use of member checks, also known as respondent validation, can be seen as another way to establish the credibility of qualitative studies. Respondents should receive an interpretation or analysis of the data and be asked if they recognize the analysis. Reactions of the participants to the analyses have to be incorporated into the study findings. We have consequently made use of member checks in all our studies. All analyses were checked by respondents and discussed in the project team meetings to prevent distortions caused by the personal and professional background of the researcher. The member checks were quite difficult in the study described in chapters 8 and 9. Most of the respondents in this study had severe brain injury which often made reading the report of their interview impossible. The member checks were therefore done by reading the reports aloud. This was done by one of the researchers. We urged the respondents to be honest and emphasized the possibility of changing or adding things to the report. Some of them did change or add information, but most of them agreed with the analysis and report. One may wonder whether their agreement was influenced by the presence of the researcher. The respondents of the other studies, who received the member check at home, however, did not make many comments on the reports either. All reactions of the participants to the analyses were incorporated into the study findings.

Credibility can also be enhanced by selecting respondents purposively. Qualitative research aims to reflect the diversity within a given population. Patients need therefore to be deliberately selected, and relevant characteristics taken into
During the research process cases have to be selected that are most likely to produce the most relevant data that will discriminate or test emerging theories (theoretical saturation). Researchers should search for disconfirming evidence in order to enhance the credibility of the data. The data collection should end when new data do not shed further light on the issue under investigation (saturation).

The respondents in our studies were selected deliberatively, through systematic searching for individuals who could offer conflicting viewpoints. This strengthened the comprehensive descriptions of the situation under investigation and it ensured that the research design explicitly incorporated a wide range of different perspectives so that the viewpoint of one group did not represent the sole truth about a situation. The data collection was stopped if we did not obtain any new information (saturation). The number of interviews needed to reach saturation differed in the several studies.

Finally, researchers can enhance credibility by ensuring researcher credibility or reflexivity. Reflexivity means sensitivity to the ways in which the researcher and the research process have shaped the data, including the role of prior assumptions and experience, which can influence even the most avowedly inductive inquiries. Personal and intellectual biases have to be made plain to enhance the credibility of the findings. Researchers should be aware of the effects of personal characteristics such as age, sex, social class, and professional status (doctor, nurse, physiotherapist, sociologist, etc.) on the data collected and on the ‘distance’ between the researcher and those researched.

We used a reflexive journal in which we described all steps and decisions. The data collection, analyses and interpretation in the study described in chapters 8 and 9 were done by three people. Quality was ensured by regular team meetings in which we reflected on our role and behaviour during the interviews. Controlling and discussing the analyses and interviews also fostered quality. Finally, we enhanced credibility by reflecting on our own personal and professional background and its potential influence. We wrote down these reflections in our personal reflexive journals and shared these reflections within the project teams. We did however not report extensively about this in all our articles. Readers cynical about qualitative research may therefore have doubts about the credibility of the study.
Confirmability
A second important issue in qualitative research is confirmability. This refers to the objectivity or neutrality of the data. Maintaining a reflexive journal and reporting each step and decision can enhance confirmability. As described above, we used a reflexive journal in which we described each step and decision.

Dependability
The dependability of qualitative data refers to data stability over time and under certain conditions. It could be said that credibility (in qualitative studies) is to validity (in quantitative studies) what dependability (in qualitative studies) is to reliability (in quantitative studies). In line with the reliability-validity relationship in quantitative research, there can be no credibility in the absence of dependability. Inter-rater reliability is an important aspect of dependability. We checked the mutual agreement of each team member by discussing each separate analysis.

Transferability
The transferability of qualitative data refers to the extent to which the findings from those data can be transferred to other settings. This is comparable to the concept of generalization/external validity in quantitative research. Quantitative research aims to provide results that can be generalized to a broader population. It focuses on statistical generalizations, using probability theory to estimate the likelihood that the patterns observed in the smaller group, the sample, will hold for the larger group, the population. Probability theory enables researchers to say, with a certain degree of confidence, how likely the patterns in a sample are to reflect those in a wider population. These statistical generalizations rely on randomly drawn representative samples.

Qualitative research does not aim at statistical generalizations. Qualitative researchers talk about possible and legitimate relations between concepts or factors without saying anything about frequencies and statistical correlations. In qualitative research, transferability and generalization are not guaranteed by the researcher but by the reader. Readers can judge whether or not the findings apply in similar settings on the basis of the details and descriptions provided by the
By providing relevant details to the reader, the researcher can enable the reader to draw conclusions regarding transferability. Details enable readers to undergo a substitute experience. We tried to increase the transferability of the data by providing sufficient information to permit judgements about contextual similarity.

**Strengths and weaknesses**

The research on which this thesis is based has several strengths and weaknesses. The thesis consists of several studies. Using more studies offers the chance to compare results and reach strong conclusions. A drawback of using more studies is the risk of losing depth.

We used the Dialogue Model as a basis for our studies. Working with this model implies investigation and integration of the perspectives of all relevant stakeholders, for instance patients and professionals. Given their aims, our projects mainly focused on investigating the perspectives of patients. We have chosen to try and gain a detailed insight into the perspectives of patients and to focus on the empowerment of patients, the development of ownership and knowledge development. Starting from the normative ideal of ownership and empowerment, we decided to take time for and give attention to these processes. We succeeded in giving patients a voice and creating a basis for an exchange with professionals. Since we wanted to focus on the patient perspective, we did not systematically investigate the perspectives of professionals and were not able to compare and integrate the two perspectives. This can be seen as a missed opportunity since the exchange and sharing of and negation about perspectives might have led to better mutual understanding and joint learning. Patients and professionals together may, after all, develop new issues, insights, questions or recommendations which are shared by all stakeholders instead of just one party.

A strong point of our research is that we have been able to study the patient perspective and the process of knowledge development in depth; a weak point is that we did not integrate the perspectives of all relevant stakeholders.

Our research shows that working with research partners is crucial when investigating the patient perspective. A strong point of the research presented in this thesis is that we cooperated with research partners in most of the studies. A weak point is that we did not do this in all of the studies.
10.4 Implications of the study

The practical implications of the individual studies have been mentioned in the chapters above. In this chapter, we will focus on the implications of the studies.

Implications for investigation of the perspectives of patients
This thesis shows that it is possible to investigate the perspectives of patients and to work towards participation of patients in research. The use of qualitative methods has proven to be appropriate for exploring the actual experiences of patients. The Dialogue Model, which implies deliberative dialogue, has proven to be a good methodology for exploring the perspectives of patients. This thesis has shown that focusing on various kinds of knowledge depending on the stage of the research process fosters the translation of subjective individual knowledge into objective shared expert knowledge. This overcomes the risk mentioned by Epstein\(^{(22)}\) of romanticizing the knowledge of patients. It also prevents over-burdening, alienation and the loss of the actual voice of patients.

Implications for participation of patients in research
This thesis shows that patients actually bring new and complementary insights. It also shows that patients are willing to participate in research. Patient groups are, however, not always aware of the possibility of participating in research. This does not mean that they are not interested in research. We have seen that patients who have participated in research (by being respondents or research partners) have experienced benefits and advantages like recognition of their views and experiences, attention to important themes, and empowerment as an individual or patient group. These patients are enthusiastic and are willing to participate in other studies. Yet we agree with Van de Bovenkamp,\(^{(13)}\) however, that participation should not be a duty, and that patients may have legitimate reasons for opting out. We have however noticed that patients are extremely willing to participate in research if they acknowledge the aims of the research project. It is therefore desirable to search for opportunities to work together with patients and to prevent tokenism, dependability and pressure.\(^{(13,19)}\). Starting with the themes and research aims which are meaningful and important for patients themselves, instead of starting from those of professionals, fosters their motivation.
We have learned that even vulnerable patients, with support, are able to participate in research. Researchers should accommodate the process of data collection to make possible participation of these vulnerable or dependent patient groups and prevent the risk of inequality between groups who can and cannot participate, as mentioned by Van de Bovenkamp.\textsuperscript{(13)} The participation of relatives of patients (proxies) may be an alternative solution if patients cannot or do not want to participate. It is however important to consider the limitations of proxy participation.

Although participation of patients in research is increasing, it is still relatively rare in biomedical and fundamental research. Researchers may be afraid of sharing their control and influence.\textsuperscript{(14)} They may have the idea that the patient perspective is not of use here or lack knowledge how to involve patients in an appropriate manner. More research and insight into ‘best practices’ are needed to show the possibilities and benefits of the participation of patients in these research areas, and researchers should be stimulated to work together with research partners. Some examples have already been described, like the development of mouse models where patients’ input was helpful and complementary. Training or coaching of transdisciplinary research teams, followed by learning by doing, deliberation and reflection, may further help researchers to overcome restraints.

**Implications for collaboration with research partners**

Collaboration with research partners has several advantages for the research team, the respondents and the research process. It furthermore leads to results that are more recognizable for patients. Researchers should therefore work together more with research partners. It is desirable to search for research partners who have not participated in earlier studies and do not work for a patient organization. This may prevent overburdening of a small group of patients and loss of the actual patient experiences. The risk of the latter is in any case limited, as patients stress that they will never lose their illness experiences. They are confronted with these experiences day after day. The collaboration with research partners should be characterized by equal collaboration, sharing control, reflection, dialogue, learning by doing and relational empowerment. Even if this ideal is embraced by all, however, in practice struggles will be part of the process. Researchers and research partners can learn from each other if they reflect on their collaboration.
Eventual training activities should not solely focus on research partners but on researchers as well.

**Implications for further research**

Patients stress the importance of fundamental, clinical research: for example, to prevent illness or to find a treatment for certain diseases. They also ask, however, for studies that could be useful to them within a relatively short time frame whereas researchers tend to place more emphasis on the importance of fundamental research and the long-term effects of new insights.\(^{(49)}\). Besides following scientific pathways, researchers should adjust their research projects to issues that are prioritized by patients. They should focus more on research that is actually useful and practically oriented in order to help patients to live with the daily consequences of their disease and treatment. Research should be integrated and multidisciplinary since patients ask for attention to topics that cannot easily be studied as mono-disciplines or separated from other topics.

**Implications for care**

Patients emphasize the importance of attention to relational and moral aspects of health care. They see a need for more support in the chronic stage for themselves and their relatives. Professionals should pay more attention to these issues and develop methods for supporting patients and their relatives. Examples are psychological support for renal patients after transplantation regarding their normative persuasions, observing the autonomy of patients with ABI and supporting patients with ABI in finding new fulfilment in their lives (participation).

**11.5. Final conclusion**

Participation of patients in investigating the perspectives of patients leads to new insights, better research, knowledge development and the empowerment of patients.
To summarize, we propose to use the acronym ‘POWER OF VOICES’:

Participation
Orientation towards various kinds of knowledge
Working together: collaboration
Engaging in deliberative dialogue
Reciprocity

Open-hearted
Facilitating a process of mutual learning

Valuing respect for each other
Openness
Inclusiveness
Clarifying multiple perspectives
Empowerment of all stakeholders
Shared control
References


