Chapter 1

General introduction

‘Experience is Something You Don’t Get Until Just After You Need it’

(quote, based on Murphy, of a patient with a chronic disease)
1. **Introduction**

Modern health care is increasingly directed at giving patients an active role in decision making rather than being simply the passive recipients of care as they were in the past.\(^1\) Patients are invited and willing to take a more leading role in managing their disease and life, not only in their treatment and individual contact with physicians, but also on other decision-making levels, such as guideline development, and the formulation of research agendas. Moreover, patients are also encouraged to be actively involved in local, regional or national policymaking.\(^1\) This may, to some extent, be seen as a form of coercion\(^1\) but patients themselves also actually want to be involved in research and policymaking. This thesis examines the various patient participation levels in research, and also the potential added value of the knowledge and experiences that patients can contribute as, for example, respondents in interviews or focus groups, or by being equal members in a research team (research partner).

1.1. **Attention for participation and experiential knowledge**

The increased attention for patient participation and patients’ perspectives and knowledge is part of several recent developments as described below.

**Societal developments**

First of all, the status of the knowledge and experiences of patients has changed as a result of developments in society. People today have less respect for authority figures: there is a lack of deference towards these figures.\(^2\) Furthermore, people no longer simply accept things from others, and tend to ask many more questions.\(^2\) They are more assertive and critical and show less respect for experts and their expertise. Doctors are no longer seen as heroic figures,\(^2\) and the traditional authority of the professional as an expert is currently challenged since society has shifted from being a command to a negotiation society.\(^3\) Relations are less hierarchical and scientific knowledge is no longer automatically accepted and adopted since people all too often encounter inconsistencies when experts from the same field contradict one another.\(^3\) The dethronement of professionals also stems from the rise and expansion of information technology. The internet means that many people are now in a position to turn to information and knowledge that,
in the past, was only available to professionals. Patients and consumers are increasingly empowered, and less willing to adopt a passive role. All these developments have led to more attention for patient participation, and for their knowledge and experiences to be heard.

**Shifts in views about knowledge**
In addition to changes in society, there are also changes in views about knowledge. Patients are nowadays increasingly seen as subjects who have valid knowledge about living with a disease, rather than as being objects that are known about by professionals. In this respect, patients’ knowledge is generally termed ‘experiential knowledge’. The nature of this kind of knowledge and its status has been the subject of discussion in recent years. Let us first define knowledge before exploring the status of knowledge among patients and professionals.

In this thesis we make a distinction between three kinds of knowledge: ‘knowing that’, ‘knowing how’ and ‘being familiar with’. ‘Knowing that’ is the explicit information and explanatory part of knowledge, also known as scientific or expert knowledge. ‘Knowing how’ is the competence part of knowledge and consists of skills and capacities, and is also known as practical knowledge. This kind of knowledge is partly implicit and must be acquired through training and practice. Finally, knowledge as ‘being familiar with’ is implicit knowledge that must be acquired through personal or even physical experience. This kind of knowledge is also referred to as experiential knowledge, which is the knowledge patients have as a result of their daily experience of living with a certain disease. It refers to the experiences individual patients have with their bodies, their illness and their treatment, as well as the day-to-day struggles and responses from their immediate surroundings and society at large. Experiential knowledge arises when these experiences are converted, either consciously or unconsciously, into personal insights that enable a patient to cope with the illness, the treatment and its consequences.

Professionals (researchers and clinicians) are often described as having expert or scientific knowledge on the one hand and practical knowledge on the other, whereas patients are often described as just having experiential knowledge (‘being familiar with’) alone. Traditionally, patients’ knowledge i.e. experiential know-
ledge has a lower status than the other two types of knowledge. It was believed for a long time that this kind of knowledge was limited because of its assumed lack of objectivity, verifiability, universality, and rationality. Expert or scientific knowledge on the other hand is traditionally seen as the ideal kind of knowledge, with more status than practitioners’ stories and experiential knowledge\(^\text{7-10}\) as it is founded on objective scientific methodologies and rational arguments, and strives for universality and absolute truth.\(^\text{7}\)

The thinking on knowledge changed around the mid 20th century. Philosophers have shown that scientific rationality is based on practice and presupposes experience.\(^{11,12}\) Experiential knowledge has been re-evaluated, resulting in a horizontal notion of knowledge in which scientific and experiential knowledge are both seen as relevant. All three types of knowledge can be considered to be potentially important and valid, and they do not differ from each other to the extent that has often been assumed.\(^\text{7}\) They are not opposed to one another, but can, in fact, complement one another. Moreover, they are not static and discrete, but can develop and converge. Caron Flinterman describes how patient knowledge develops from ‘being familiar with’, i.e. from experiential knowledge, into ‘knowing that’, in other words, into expert or scientific knowledge. Patients first acquire experiential knowledge by becoming familiar with their own body and illness, with care and cure and with their own social context. Patients subsequently develop practical knowledge (‘knowing how’), mainly consisting of physical and mental coping strategies. This type of knowledge is important in daily practice, both in patients’ own lives and in the support given by others. Only after they have made repeated observations, and have made experiences explicit and have reflected on them, can patients acquire a degree of expert knowledge (‘knowing that’) about the functioning of their bodies, the occurrence of symptoms, and the effectiveness of certain therapies, et cetera. This knowledge is confirmed and extended in the repetition of their experiences, and by similar experiences in other patients.\(^\text{7}\)

Professional knowledge also undergoes a development, and contrasts sharply with how patient knowledge develops. The first and most basic element in professional knowledge is expert knowledge (‘knowing that’) which is obtained through both written and oral knowledge transfer from external sources, starting during the first
years of academic study. Only later does professionals acquire practical knowledge ('knowing how') and experiential knowledge ('being familiar with'), both acquired during practical training and professional practice, and both essential to research practice.\(^7\)

Therefore, patients’ knowledge and professionals’ knowledge both comprise the three types of knowledge: ‘knowing that’, ‘knowing how’ and ‘being familiar with’. Yet, their distribution and the order in which they develop differ. Furthermore, expert knowledge is mainly acquired through detached and impersonal study and observation, whereas patients’ experiential knowledge involves their personal situation and is acquired through personal and physical experience. Ian Chalmers summarised the value of the patients’ perspective in the British Medical Journal as follows: ‘we need to recognise that patients have the experience and skills that complement the researchers. They know what it feels like to suffer a particular disease and to undergo the treatments with their various side effects’.\(^{13}\) Patients may therefore contribute to the clinicians’ understanding of both clinical issues and the needs of patients.\(^{14}\) The participation of patients in research may also, as a result of their experiential knowledge, lead to improvements in the quality and relevance of health research and knowledge.\(^{2,15}\)

**Normative and instrumental arguments for patient participation**

Changes in society and changes in the appreciation for experiential knowledge described above have paved the way for more active patient participation in research, and also for more attention to be given to their experiences. Various scholars have put forward normative and instrumental arguments that also support the participation of patients in research.

The normative argument states, first of all, that patients have the right to become involved because they will be affected by the outcomes of health research. Patients should have a ‘say’ and an influence on processes that affect their interests and lives.\(^{2,4,16-19}\) They should therefore be given the opportunity to be involved. Being involved and having a say may have a number of positive effects: it may lead to the empowerment of patients or patient groups which can be seen as a justification in favour of patient participation.

In addition to this normative argument, instrumental arguments are also put forward. Scholars argue that the legitimacy of research and the acceptance of its
outcomes are enhanced if patients are involved in deciding what will be researched and how.\textsuperscript{(4,20-22)}

Patients and patient organizations are today increasingly convinced that their experiences are a valid source of knowledge. They are no longer satisfied with a passive role, but perceive themselves as experts, and complain about the fact that their expertise does not seem to count.\textsuperscript{(2,23)} Patients are empowered and want, among other things, to have a say in research. They draw attention to the fact that they want to be involved and have their own particular perspectives incorporated in research. This requires research to be conducted in a particular way, as described in the following section.

1.2. \textit{Participation and incorporating experiential knowledge}

There are several ways to involve patients in health research, and also a number of methods to investigate their various perspectives. The first way is to see patients as a source of information. Patients can provide information in many different ways. The use of qualitative or quantitative methods or a combination of both is a customary way to gain information from patients in research projects. Quantitative methods have a prominent position in social science.\textsuperscript{(27)} Qualitative research was regarded with scepticism by the scientific community, who attacked its subjective nature and absence of facts.\textsuperscript{(27)} Since the 1970s, qualitative research has gained a political and an intellectual place in academe, with its own journals, academic associations, conferences and university positions.\textsuperscript{(28)} Journals that used to publish only quantitative articles now publish more qualitative studies and are in favour of the added value the qualitative approach contributes; qualitative and quantitative research can complement each other.\textsuperscript{(28)} It is acknowledged that both have advantages and disadvantages\textsuperscript{(29)} and that they can each be used to achieve certain research goals.

In this thesis we haven adopted a qualitative methodology since this data collection method is suitable for investigating patients’ perspectives and for improving the understanding of clinical issues, patients’ needs and wishes.\textsuperscript{(14,27)} Qualitative studies start from a patient-centred approach: interviews or focus groups leave room for patients to contribute their own themes and perspectives.\textsuperscript{(30,31)}
Consequently, these studies may result in new themes overlooked by earlier research. They give patients more control and thereby create room for their perspectives and experiences. Although open interviews or focus groups make it possible for patients to bring in their own perspectives, being a respondent is still a relatively low participation level in research, with minimal control. Patients may participate in different ways and on different levels in research. Higher levels of participation are linked with higher levels of control. The literature uses the ‘participation ladder’ to indicate degrees of participation in policymaking processes. Abma and colleagues translated this ladder to create a model for possible roles and tasks for patients in health research (see Table 1) in which the degree of participation and therefore control may differ.

As already mentioned, in both qualitative and quantitative studies, we find patients as object or respondent on the lowest rung of the ladder. The opportunity to bring in one’s own perspectives differs between qualitative and quantitative studies, but the level of participation and therefore of patient control in both methodologies continues to be low if they only act as objects or respondents.

Higher levels of participation and therefore control include patients as advisors. Patients can, for instance, be members of a research programming committee or be involved in reviewing research proposals. Finally, research funding agencies are increasingly involving patients in policymaking.

Patients as interviewers of fellow patients or as moderators of focus groups have even more control and participate on a higher rung of the ladder. There are advantages to patients as moderators of focus groups during preparation because patients are better able to assess what is an acceptable workload, the appropriateness of certain methods, and use of resources. It can also support the recruitment of participants, because patients know more about groups that get together on a regular basis. It also has advantages during the focus group itself. Patients are often more capable of asking the right questions and engaging participants which may lead to a better investigation of the experiences and perspectives of patients. These advantages also play an important role if patients interview fellow patients. Patient-interviewers are also less threatening to participants, which gives rise to more valid information and room for the
experiences of patients to be aired.\textsuperscript{(30)} This is something that has already been done in several research projects. For example, in the Netherlands and the United Kingdom, people with an intellectual disability are trained to interview other people with an intellectual disability, using semi-structured questionnaires on the quality of life.\textsuperscript{(30)}

**Table 1** Overview of the Roles and Tasks of Patients in Health Research\textsuperscript{30}

<table>
<thead>
<tr>
<th>Role</th>
<th>Task</th>
<th>Amount of control</th>
</tr>
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<tbody>
<tr>
<td>Research principal</td>
<td>Initiating research.</td>
<td>High</td>
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<tr>
<td></td>
<td>Developing and maintaining a knowledge base.</td>
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<td></td>
<td>Joining established research networks.</td>
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<tr>
<td>Research partner</td>
<td>Developing research design with academic researchers.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Gathering, analysing, and presenting data.</td>
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<tr>
<td></td>
<td>Writing publications.</td>
<td></td>
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<tr>
<td></td>
<td>Evaluating articles and research proposals.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Participating in scientific congresses.</td>
<td></td>
</tr>
<tr>
<td>Interviewer/</td>
<td>Compiling surveys and topic lists with academic researchers.</td>
<td></td>
</tr>
<tr>
<td>moderator</td>
<td>Conducting interviews with patients.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Preparing and/or leading a focus group.</td>
<td></td>
</tr>
<tr>
<td>Advisor</td>
<td>Bringing in experiences.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Discussing new developments.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Evaluating scientific articles and research proposals (as referent).</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Advising.</td>
<td></td>
</tr>
<tr>
<td>Object or</td>
<td>Cooperating in clinical trial.</td>
<td>Low</td>
</tr>
<tr>
<td>respondent</td>
<td>Sharing information in interview or survey.</td>
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</table>

Patients participate at an even higher degree when acting as research partners in a team of professionals.\textsuperscript{(30,35,39)} Research partners, also described as patient research partners, are patients or their relatives with experiential knowledge about the
disease under investigation, who join research teams on an equal footing with professional researchers. As members of a research team, patients conduct operational research tasks, such as doing interviews and moderating focus groups. This has the above-mentioned advantages. One of the main differences between patient-interviewers or moderators and research partners is that the scope of their tasks is broader and includes more than just data collection alone, but also data analysis and negotiation about methodological decisions. Research partners are therefore involved to a greater extent; they do not just carry out invisible work, but are engaged in intellectual work and strategic decision making. Action research, participatory research and the responsive methodology are examples of research stances in which participants are involved as co-researchers or research partners throughout the entire research process. Patients are in these examples, however not often involved as formal team members.

The final possible role of patients in research is that of research principal. As research principals, patients may instigate research projects that are grounded in their own illness experiences. This is one of the major characteristics of emancipatory research; patients should control the entire research process from formulation of the research question to dissemination of the findings. The aim of emancipatory research is to change the social relations of research production (i.e. the division of power between researchers and researched) by giving patients complete control of the research process. The two key elements of emancipatory research are therefore empowerment and reciprocity.

There are thus several ways to investigate the perspectives of patients and to make it possible for patients to participate in research. A higher level of participation is assumed to be related to a higher level of control which gives more room for the actual experiences, knowledge and perspectives of patients. The actual level of participation and roles of patients differ according to the context. It would be interesting to establish the prevalence of patient participation at the different levels. Since not all patient participation is mentioned in the literature, it is difficult to estimate exactly how widespread participation actually is. Another problem is the lack of unequivocality: the concept of participation, the division of roles and responsibilities between patients and professionals have not yet been defined sufficiently well, and it is still not unambiguous. As a result, it is almost 
impossible to compare patient involvement or participation in research and policy between projects and countries. We are already aware of the fact that patients are increasingly involved as advisors, for instance in guideline committees or commissions, but no hard figures are available. Involvement as an equal research partner with shared control is still rare and publications on this kind of collaboration are scant.

To conclude, patient involvement in research has gained more attention in recent years. Patients today are much more involved in research. Yet one may wonder whether patient participation and attention for patients’ knowledge and experiences truly has advantages or whether there are in fact potential risks or disadvantages. This is explored in the next section.

1.3. **Participation and attention for experiential knowledge in practice: benefits, concerns and doubts**

Section 1.1 presented a number of arguments advocating patient participation in research, and the investigation of their perspectives. The following arguments were given:

1) Patients bring in a unique perspective and improve the quality of knowledge and research: the substantial argument.
2) The moral and democratic principle of having a say: the normative argument.
3) The enhancement of the legitimacy of research projects and therefore acceptance of research projects and their outcomes: the instrumental argument.

One may wonder whether these theoretical arguments for patient participation and attention for experiential knowledge are also valid in practice. Are the results always positive? What negative effects can be expected? The literature mentions various positive outcomes, but negative effects are also reported. This section presents both the positive and negative aspects of patient participation as described in the literature. We summarise the empirical findings and critical discussions surrounding each of the three arguments.
The substantial argument

Studies have shown that patient participation and attention for the perspectives of patients in social scientific and fundamental research\(^{(43-45)}\) may indeed have certain benefits: patients actually do provide new and supplementary knowledge. Incorporating patients’ perspectives has, for instance, led to new themes on the research agenda. Patients stressed the relevance of research themes that had not previously been suggested or investigated by researchers.\(^{(2,20)}\) They did submit new themes that little attention has been given to, themes that would otherwise not even have been considered.\(^{(46,47)}\) Patient contribution to research processes has also led to the development and implementation of health care interventions and therapies that are more representative of patients’ ‘real’ needs.\(^{(47)}\)

Other studies have shown that if patients are actively involved in research, the quality of research processes and how research is conducted may actually improve.\(^{(48,49)}\) Examples include changes in the information material given to patients, increased recruitment levels and improved recruitment strategy, higher response rates, and changes to the study design and other research aspects such as data collection methods, the analysis of qualitative data, research questions, tools, priorities, and outcomes.\(^{(35,47)}\)

However, the effects of patient participation in research are not only positive: some negative or side effects have been mentioned. Hewlett and colleagues\(^{35}\) have, for instance, revealed challenges that may arise if patients are involved as research partners. They mention difficulties with access (e.g. to buildings due to physical impairment, or access to scientific journals) and communication. A second challenge is the relationship between patients and professionals. Creating an equal relationship can be hard for both parties since they are more accustomed to the somewhat unequal patient-professional relationship. Related to this is the fear patients may have about their new role. For example, patients talk of their concerns about their ability to make a contribution, and about whether what they have to say is actually worthwhile. A final challenge is tokenism: some professionals may collaborate with patients for the sake of political correctness and not because they really want to.\(^{(35)}\)
A study by Hanley and colleagues further described how patient participation in research does not necessarily really influence the study. For example, researchers who actively involved patients, made the following comments: ‘at the moment there is no obvious impact’ or ‘the role of consumers in this particular project was not great.’ Furthermore, some researchers stressed the undesirable time consuming and expensive nature of having patients involved in research: ‘Time consuming. Although wanting to be involved, they were extremely naive about the research process and funding problems’ or ‘the whole process took much longer’. Researchers’ fears about possible delays and the lack of knowledge among participants about doing research were also mentioned in a study by Caron Flinterman. Other researchers in the Hanley study expressed doubts about the representativeness of the participating patients. They believed that patients are not representative of other patients since they simply present their own particular perspective and not that of the group as a whole. Other stakeholders express doubts as to whether patients bring in ‘the’ perspective of all patients. All patients are different, and this gives rise to critical comments on the suggestion that patients present a general patient perspective. Patients are diverse and their perspectives are therefore also diverse. Stakeholders also speculate as to whether patients who participate in these processes can be seen as the ‘average patient’. Patients who participate have more knowledge and different knowledge from the ‘average patient’, and consequently they may not contribute the perspectives of the ‘average patient’. Related to this, doubts have been expressed about the identity of patients and the integrity of their experiential knowledge. Some stakeholders emphasise the influence the environment plays on people’s perspectives and experiences. Some scholars believe that patients’ knowledge is shaped by medical knowledge and practice since patients are part of this environment. This will inevitably change patients’ views and ideas. Some stakeholders also wonder whether patients are able to remain faithful to their own perspectives and agenda, or whether they will adapt, perhaps too much, to the perspectives of other stakeholders. Adapting too much may mean patients can be seen or used as pawns to justify the actions of professionals. It is also stressed that patients and patient organizations will always remain independent, which means it is unlikely that they can ever be a truly equal party with a perspective that is genuinely their own.
A final comment or doubt regarding the substantial argument surrounds the attitude and assumptions of researchers themselves. Researchers traditionally do not want external influence on the process of science. Patient participation may improve the quality of research projects but it also brings in external influence and the need to share control and influence. Researchers may have problems with these changes. They may also believe that they know better than patients themselves what they need. By doing this they may be ignoring the possible unique perspectives patients may contribute. A recent study by Caron Flinterman shows that many stakeholders feel that scientists know best what needs to be researched; they can identify the blanks in the scientific landscape and assess the feasibility of research.

We may therefore conclude that as far as the substantial argument is concerned, the literature mentions both positive experiences and advantages as well as disadvantages, doubts and concerns. Many stakeholders believe that the benefits of patient participation do not outweigh the disadvantages. Other stakeholders are, as noticed by us, willing to involve patients, but do not know how to involve patients in research since they have no experience with this way of working or they do not have the right knowledge in order to do so.

**The normative argument**

The normative argument is also under discussion. Many stakeholders agree with the assumption that patients should have the right to become involved in health research because they will be affected by the outcomes. Being involved in research may have a number of positive side effects. Benefits for participating patients themselves include, for example, acquiring knowledge and research skills, getting more self-esteem and confidence, empowerment, a creation of a sense of ownership of the research, and a better understanding of the nature and purpose of a clinical trial/research.

However, some stakeholders stress the possible risks of the right to be involved. They express concerns about possibly overburdening patient participants, and risks as a result of the coercive nature of participation. People are expected to play an active role in health care. They have the right to participate but policy should not force them to feel they must do so, i.e. an element of coercion. Patients should
be free to decide whether they want to participate or not, and critics question the individual’s willingness to participate and have their voice heard.\(^{(1,46)}\) Participation may result in hard work for patients and it has been expressed that patients should have enough time to simply focus on being sick, on getting better, and on trying to cope with their illness.\(^{(1)}\) Related to this is the argument that patients should not be overburdened by their wish to participate, and neither should they feel pressured into doing so.\(^{(1)}\) Participating in research can be tough. The general feeling is that patients need the relevant skills and knowledge in order to participate which the ‘average patient’ does not necessarily have at his disposal.\(^{(1)}\) It may, as a result, be hard to find patients who are able and willing to participate. Those patients who do participate may feel overburdened because of the demands made on them. The required skills may also give patients or patient organizations the feeling that they must become more professional and this may lead to a loss of experiential knowledge.\(^{(46)}\)

Patient involvement and the right to participate may also give rise to negative side effects if some patient groups are not able to participate, even if they are entitled to do so. The danger is that it will lead to differences in the quality of care provided to the people who can participate and those who cannot. Those who cannot are already more vulnerable: they tend to be lower educated, or elderly, or people with, for instance, a mental or psychiatric disability. There is a danger that people who are able to express themselves well and demand attention receive the best and this may lead to inequality among groups who can and those who cannot participate. This may undermine one of the central values in democratic participation/decision making.\(^{(1)}\)

\textit{The instrumental argument}

Finally, there is some evidence pertaining to the instrumental argument. Patient involvement may indeed lead to better implementation. The results of a research project are, as a result of patient involvement, easier to use and fit better with the actual needs and perspectives of patients.\(^{(3,20)}\) However, patient participation may also be used instrumentally as a way to achieve the goals of policymakers or researchers.\(^{(46)}\) Participation in this way does not lead to empowerment and ownership, and may even lead to feelings of being used or being disempowered.
1.4. **Aim and research questions**

As we have seen, several arguments and studies support patient participation in research and the incorporation of their knowledge and experiences in research. Patients may participate at different levels and they may be involved in research by, for instance, being respondents or advisors or research partners or research principals. However, there is also criticism and some reluctance: can the subjective individual stories of patients be transformed into shared, valid and collective knowledge? Or do patient involvement and knowledge only lead to subjective stories of individual patients and particularly the stories of the most assertive patients? And how can patients be involved so that knowledge is enhanced without the patients being overburdened? Our research was based on a positive attitude towards patients' knowledge and their participation in research. However, we also wanted to take the reluctance aspect seriously. We developed a number of research projects to elucidate the added value of involving patients and investigating and developing their knowledge. We were also interested in how to organize patient participation in research and how to foster a process of knowledge development.

This thesis therefore attempts to answer the question as to whether incorporating patient perspectives in research can be deemed to be valuable and, if so, how can it actually be achieved in practice e.g. by working together with research partners and combining several kinds of knowledge. Departing from this general research aim we formulated three specific 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
1.5. Method and participants

In order to answer these questions, we set up four research projects with patients with Acquired Brain Injury (ABI) or chronic kidney disease (CKD). We opted for these particular patient groups because of the differences in treatment options, characteristics/symptoms and perspective. The cognitive impairment that comes with ABI may influence the feasibility of participating in research and of developing one’s own voice. This section describes the patients groups and the general research approach of the studies.

1.5.1. Patient groups

Chronic kidney disease

CKD, also known as chronic renal disease, is the progressive loss of renal function over a period of months or years. The two main causes of CKD are diabetes and high blood pressure, which are responsible for up to two-thirds of cases.\(^{(51)}\) Other conditions that affect the kidneys and may result in CKD are:

- Glomerulonephritis, a group of diseases that cause inflammation and damage to the kidney's filtering units. These disorders are the third most common type of kidney disease.
- Inherited diseases, such as polycystic kidney disease, which causes large cysts to form in the kidneys and damage the surrounding tissue.
- Malformations that occur as a baby develops in its mother's womb.
- Lupus and other diseases that affect the body's immune system.
- Obstructions caused by problems like kidney stones, tumours or an enlarged prostate gland in men.
- Repeated urinary infections.\(^{(51)}\)

Most people may not have any severe symptoms until CKD is advanced. Patients may however experience some of the following symptoms:

- Fatigue and less energy.
- Difficulty concentrating.
- A poor appetite.
- Trouble sleeping.
- Muscle cramping at night.
- Swollen feet and ankles.
- Puffiness around the eyes, especially in the morning.
- Dry, itchy skin.
- Need to urinate more often, especially at night.\(^{(51)}\)

CKD can be identified by a blood test for creatinine. Higher levels of creatinine indicate a falling glomerular filtration rate and as a result the diminished ability of the kidneys to excrete waste products. To fully investigate the underlying cause of kidney damage, various forms of medical imaging, blood tests or renal biopsy (removing a small sample of kidney tissue) may be employed to establish whether there is a reversible cause for the kidney malfunction.\(^{(51)}\)

CKD has five stages, with stage 1 being the mildest and usually causing few symptoms and stage 5 being severe illness with poor life expectancy if left untreated. Stage 5 is also called end-stage renal disease (ESRD), chronic kidney failure (CKF) or chronic renal failure (CRF).\(^{(51)}\)

Across Europe, approximately 50-80 people per million develop ESRD.\(^{(52)}\) The number of patients with ESRD has steadily increased worldwide in recent decades,\(^{(31,51)}\) with much higher incidence rates of ESRD in the USA than in Europe.\(^{(52)}\) The kidney function of patients with ESRD is reduced to 10 percent or less of normal function, requiring the patient to have renal replacement therapy such as dialysis or transplantation in order to stay alive. Just like healthy kidneys, dialysis removes waste, salt and extra water to prevent them accumulating in the body, maintains a safe level of certain chemicals in the patient’s blood, such as potassium, sodium and bicarbonate and helps to control blood pressure. There are two types of dialysis: haemodialysis and peritoneal dialysis. In haemodialysis, an artificial kidney is used to remove waste and extraneous chemicals and fluid from the patient’s blood. The blood of patients with peritoneal dialysis is cleaned inside their body. Patients have a catheter inserted into their abdomen for access. During treatment, their abdominal area is slowly filled with dialysate through the catheter. Extra fluid and waste products are drawn out of the patient’s blood and into the dialysate.\(^{(51)}\) Although dialysis is more common, kidney transplants have
also become widely available and are medically considered as the treatment of choice for many people with ESRD as transplant has been associated with higher survival rates and fewer risks compared with people who undergo dialysis.\(^{31,51}\) A kidney transplant may be done using the kidney of a deceased donor or with the kidney of a living (often related) donor.\(^{51}\)

**Acquired Brain Injury**

ABI is damage to the brain that is acquired after birth and may result from traumatic brain injury or non-traumatic injury. Traumatic injury is caused for example by a car crash, a fall, violence or a shooting incident. Non-traumatic brain injury can be caused by cerebrovascular events, brain tumours, intoxication, infection such as meningitis or encephalitis, hydrocephalus or anoxia (not enough oxygen) due to cardiopulmonary resuscitation, drowning or a suicide attempt. Traumatic brain injury may also be caused by diseases such as Multiple Sclerosis, Parkinson’s disease, Creutzfeldt-Jakob disease, Alzheimer’s, or Huntington disease. Cerebellar ataxia and various metabolic disorders may also cause ABI.\(^{53}\)

ABI is not to be confused with intellectual disability. The damage can be focal or diffuse, and the brain injury can range from mild to severe, leading to mild or more severe symptoms. It has an extremely wide range of effects, and no two people can expect the same outcome. Cognitive deficits such as memory or concentration problems, and problem-solving deficits or perceptual problems can occur, as can motor deficits such as paralysis or spasticity, and communication problems such as aphasia. Patients may also develop problems with understanding and responding in social interaction, and they can become self centred. Most patients report extreme tiredness. Personality changes or neuropsychiatric symptoms such as apathy, emotional instability, irritability, anxiety, or depression may also occur.\(^{53}\)

Even a mild injury can sometimes result in serious disabilities that interfere with a person’s daily functioning for the rest of his or her life. Although the outcome of the injury depends largely on the nature and severity of the injury itself, the appropriate treatment plays a vital role in determining the level of recovery. Treatment starts with a period of clinical observation, mostly in a rehabilitation centre. The approach is multidisciplinary. Information about the pre morbid physical condition (of the head) and about the patient’s personality is important
for a better understanding of the patient and his or her behaviour. The treatment focuses on improving the physical condition and mobility, teaching the use of aids for daily living (such as an adapted spoon for eating, or a walking frame), training in practical skills, cognitive training, reintegration into work or school, and helping the patient to adapt to and ‘accept’ their losses. Understanding the pre morbid factors, neuropsychological profile, and cognitive impairments is necessary for the treatment of neuropsychiatric problems such as apathy, depression, aggression, or anxiety. Many problems can be minimised by early intervention based on the neuropsychological profile. Additionally, as patients find it difficult to accept the changes in their life, a system of care involving support, information, and instruction plays a crucial role in patients’ rehabilitation and reintegration. A gradual return into society follows the clinical phase. However, personal factors (such as cognitive impairment and feelings of insecurity) and external factors (such as a lack of facilities and unforgiving environments unsuited to people with ABI) can substantially frustrate reintegration. Some patients need professional support for the rest of their lives in the form of specialised nursing homes or day-care centres.\(^{53}\)

1.5.2. **General research approach**

The projects are diverse but do have some features in common: as will be explored in more detail later, they are all based on the assumptions and tools of the Dialogue Model.\(^{54}\) This model is specifically designed for the development of health research agendas. The Dialogue Model for agenda setting is grounded in participatory and interactive approaches and has a number of key principles i.e. active engagement of stakeholders, the creation of good social conditions, having respect for experiential knowledge, facilitating dialogue between stakeholders, using an emergent and flexible design and facilitation of the process.\(^{54}\) The use of a large variety of tools and methods\(^{54}\) is another core principle of the Dialogue Model.

The Dialogue Model is related to participatory research approaches, but places more emphasis on dialogue and relational empowerment. In participatory research, collaboration in the research process with patients, consumers or users can be characterized in terms of control over that process.\(^{55-57}\) In contrast, the Dialogue
Model emphasizes the use of dialogue to facilitate collaboration between patients and professionals. It creates space for the exchange of perspectives, opinions and experiences, and for possible controversy, contradictions and ambiguities.\(^{(30,54)}\) It values this diversity, rather than expecting a priori agreement between parties. Participatory research aims at empowering vulnerable and marginalized groups.\(^{(41,48)}\) The Dialogue Model shares this goal, but regards empowerment as a reciprocal process. Relational empowerment\(^{(59)}\) should not be understood as a transfer of control from the ‘empowerer’ to those in need of empowerment. On the contrary, it demands mutual acknowledgement that everyone is involved in constructing knowledge in research and that everyone enters with an open mind and can change during the process.\(^{(59)}\) All are both object and subject in the empowerment process. Finally, the professional researcher in participatory research acts as a coach or facilitator who delegates power and supports research partners in carrying out the research activities themselves.\(^{(55)}\) Patients are ultimately in control. The Dialogue Model places more emphasis on the exchange of perspectives between patients and professionals to generate a mutual learning process. The professional researcher, far from being a distant party, is also involved in this dialogical process, not solely as the coach of a vulnerable party, but rather as a facilitator of the dialogue between all involved in the process.\(^{(56,60)}\) Patients and professionals thus share control and collaborate.

The Dialogue Model consists of six phases and is characterized by a cyclical and emergent design.\(^{(54,61)}\) The research activities are not determined beforehand, but are developed during the process in consultation with the stakeholders. This allows researchers to adapt to the issues that emerge from the experiences and stories of stakeholders\(^{(61)}\) and to use the outcomes of former steps for the subsequent steps in order to validate, refine and integrate the various stakeholder issues.\(^{(54)}\) We will describe all these phases in more detail, starting with the exploration phase.

**Exploration phase**

In a dialogue approach different stakeholder groups such as patients and professionals deliberate and negotiate about their perspectives and experiences in order to develop a shared agenda. The aim of the first exploration phase is to create good social conditions for the dialogical process and to gain an initial understanding of the stakeholders’ issues. To this end the project team identifies and contacts
patient and professional organizations, and informs potential participants about the project, in an attempt to encourage them to take part. In this phase the team also considers or sets up research partner involvement. A literature search, document analysis, reading of internet forums, and informal conversations with representatives of the stakeholder groups are all helpful in order to become familiar with the stakeholder groups and to get initial information about the stakeholder issues.\(^{(54)}\)

**Consultation phase**

The aim of the consultation phase is to identify the research agendas of the relevant groups. The different stakeholder groups are consulted separately by using several methods: interviews, focus groups and observation. The project team must consider which methods are most appropriate for consulting the stakeholders. It is important to adjust the data collection methods to the group under investigation. The methods chosen have to give meaningful input from the various groups, and methods sometimes have to be adjusted to the possibilities and limitations of certain groups of stakeholders. It is also important to pay attention to diversity within the patient population and differences that matter to the specific patient group.\(^{(54)}\)

**Prioritization phase**

The aim of the third phase is to prioritize the research themes per group. This can be done by using a questionnaire or by organizing focus groups.\(^{(54)}\)

**Integration phase**

The aim of this phase is to integrate the agendas of different stakeholders through dialogue. A dialogue meeting with representatives of all relevant parties is organized to foster negotiation about the research agendas.\(^{(54)}\) The consultation and prioritization phases are aimed at developing the voice and opinions of each group. Patients are, as a result, empowered and prepared for equal interaction with professionals in this integration phase. Some preparation, such as the number and selection of participants, the use of non-technical language, the characteristics of the location, et cetera, are needed in order to create equal dialogue in which asymmetries between patients and professionals are resolved to the extent that this is possible.\(^{(54)}\)
**Programming phase**
The aim of this phase is to develop a programme based on the integral research agenda and to keep all groups engaged in it. (54)

**Implementation phase**
The final phase in the process is aimed at implementing the integrated research programme of all stakeholders. This can be achieved through ‘calls for proposals’ by the research sponsors, by matching research themes with research groups or by stipulating a number of key topics. Encouraging research networks may also be part of this phase. Furthermore, sponsors may choose to include patients and their representatives more structurally in their research programmes and commissions, to adjust the formats for grant proposals, to adjust criteria for proposal selection and to start working with patient reviewers. Patient organizations may also implement new procedures. They can, for example, add patients to their scientific advisory boards. Finally, research institutes can create conditions to encourage patient participation, for example, by adding societal impact as an indicator to assess research output. (54)

The Dialogue Model has proven to be a good methodology for developing research agendas, based on the perspectives of multiple stakeholders such as patient groups and professionals. (54) The assumptions and first phases of the Dialogue Model can also be used in other research contexts. (54)

This thesis consists of four distinct studies with two patient groups: renal patients, and patients with ABI. All four studies focused mainly on describing the perspectives of one or more stakeholder group(s) to gain new or more detailed insights and in order to develop recommendations for practice or research or to improve practice and research. The projects were not primarily aimed at integrating the perspectives of several stakeholder groups or the implementation of results. Therefore, the four studies in this thesis consisted mainly of the exploration phase and the consultation phase of the Dialogue Model. (54)

The exploration phase in the four studies was aimed at, among other things, creating good social conditions for the dialogical process and to gain an initial idea of the stakeholders’ issues. The second consultation phase in these four studies was, just as in the Dialogue Model, aimed at establishing the perspectives of the
different stakeholders. We divided the consultation phase into three sub stages in order to give vulnerable and marginalized patient groups the opportunity to develop their own voice and knowledge. By using several methods and steps in this second phase, we helped patients to empower themselves and to develop a shared voice. Only after patients have developed their own voice and power, will they be able to deliberate with other stakeholder groups such as professionals. By doing this, we also avoided pseudo-participation and overburdening the patients, as will be explained later. The consultation phase for these four studies was therefore divided into three sub stages: consultation, collaboration, and integration. The following section explains these sub stages and how the participation of patients and the use of their knowledge took place in each stage.

1.5.3. *Participation and knowledge development*

This thesis aims, among other things, to answer the question as to whether patient participation in research leads to knowledge development among patients and how this process of knowledge development can be fostered. We assumed that by applying several types of knowledge at several moments in time, we could promote such a process. We also assumed that involving patients at several participation levels would encourage this knowledge development process. We therefore incorporated, as presented in Table 2, patients with specific kinds of knowledge (experiential, practical, and expert) in each phase of our research projects.

Our choices were not only guided by the goal of knowledge development in order to get authentic experiences on the one hand and valid collective knowledge on the other, but also by our wish to contribute to a process of empowerment and ownership among patients. We also wanted to avoid pseudo participation and/or overburdening patients and to make it possible to involve more vulnerable patient groups. We will now explain how this worked out in practice for each stage in our projects.
Table 2 Phases of research process in relation with certain kinds of knowledge

<table>
<thead>
<tr>
<th>Stage</th>
<th>Kind of knowledge of participating patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exploration stage</td>
<td>‘being familiar with’ (experiential knowledge)</td>
</tr>
<tr>
<td></td>
<td>‘knowing how’ (practical knowledge)</td>
</tr>
<tr>
<td></td>
<td>‘knowing that’ (expert knowledge)</td>
</tr>
<tr>
<td>Consultation stage</td>
<td>‘being familiar with’ (experiential knowledge)</td>
</tr>
<tr>
<td></td>
<td>‘knowing how’ (practical knowledge)</td>
</tr>
<tr>
<td>Collaboration stage</td>
<td>‘knowing how’ (practical knowledge)</td>
</tr>
<tr>
<td></td>
<td>‘knowing that’ (expert knowledge)</td>
</tr>
<tr>
<td>Integration stage</td>
<td>‘knowing that’ (expert knowledge)</td>
</tr>
</tbody>
</table>

**Exploration stage**

The exploration stage of our projects was aimed at creating good social conditions for a dialogical process among stakeholders and at gaining an initial understanding of the stakeholders’ issues. Exploratory interviews with patients were part of this stage. The interviews included patients with all three kinds of knowledge in order to gain an initial, general understanding of the stories and experiences of patients. It can, for example, be assumed that the experiences and knowledge a renal patient who has just started dialysis has about his disease and treatment are different from patients who have been on dialysis for several years. The former will mainly bring in experiential knowledge (‘being familiar with’), while the second patient will have acquired practical knowledge (‘knowing how’). We also conducted interviews with patients who had reflected on their experiences and who had compared their experiences with those of other patients. By doing so these patients had developed expert knowledge (‘knowing that’) and they were often working as volunteers for patient organizations.

Although it is not easy to select patients according to their particular kind of knowledge, there are some general rules of thumb:
Patients who have just been diagnosed or have just started treatment or entered a new phase in their illness or treatment will mainly have experiential knowledge: ‘being familiar with’.

Patients who have been diagnosed for some years or who have undergone treatment for a number of years, will have developed some practical knowledge: ‘knowing how’.

Patients who work as volunteers or paid employees with other patients or for a patient organization, or patients who have participated in research or policymaking processes, are likely to have developed expert knowledge: ‘knowing that’.

**Consultation stage**

The consultation stage in our projects was aimed at generating the stories of all stakeholders, mainly by conducting interviews and through participant observation. The interviews in this stage deliberately included patients with only implicit experiences with their own illness and treatment. They were not aware of the stories of other patients and did not reflect much on their own experiences: they were selected for their experiential knowledge: ‘being familiar with’ or for having some practical knowledge: ‘knowing how’. This was done in order to reach the ‘average’ patient with his or her own authentic experiences. These patients, we assumed, would not be proto-professionalized and should still be able to express themselves in their own words and to relate their own experiences. Therefore patient recruitment also focused on including patients who were not active in one of the patient organizations and who had not participated in other studies. This was done in order to collect an ‘authentic’ contribution from each participant instead of hearing the more abstract voice of the patient organization or researchers/professionals.

The interviews were about the individuals’ own stories and the stories of the respondents were leading. A topic list was used in order to check whether all the relevant topics had been discussed during the interviews. The interviews were, after approval, audio recorded and transcribed line by line. The transcripts were separately analysed by two academic researchers and/or research partners and later discussed in research team meetings. The data analysis procedure included an inductive line-by-line reading of the transcripts to find recurring themes (open
coding). The themes identified were then placed in categories and labelled (axial coding) until no other information was added to the framework (theoretical saturation). To check the validity of the analysis each respondent received an account and asked whether they recognized the analysis (member check). Any comments were added but patients in general agreed with their account. The analyses led to descriptions of recurring themes and atypical or diverse issues that did not recur. These atypical issues were also included in the description: the description not only mentioned the recurring themes but the whole range of issues.

Collaboration stage

The collaboration stage of our projects was aimed at validating and at gaining more in-depth knowledge about the broad range of perspectives of patients found in the consultation stage. In order to achieve this, several focus groups with patients were organized. Patients were selected on the basis of their practical ('knowing how') or expert knowledge ('knowing that'). In this way, we hoped to hear less subjective experiences which would make data validation more reliable. Focus groups share several characteristics with other qualitative methods such as interviews; the social interaction and deliberation that occurs between participants is, however, unique. Several techniques, including 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 the process of knowledge development.

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 improving daily practice. Patients involved in this stage were selected for their expert knowledge ('knowing that'). These patients often had an active role in some of the patient associations, and had considerable knowledge about the experiences of patients and about actual situations that required improvement.

We therefore respected the experiential knowledge of patients and set about fostering a process of knowledge development by actively involving patients who had several kinds of knowledge. This was also done by collaborating with research partners. The other assumptions of the Dialogue Model, such as creating good
social conditions, facilitating a dialogue between stakeholders, using a wide variety of tools and methods and using emergent and flexible design, were also incorporated in each study, as described in the next section.  

1.5.4. Description of studies

This thesis consists of four studies with two different patient groups. This part describes each study in a nutshell. More details of the studies can be found in the following chapters.

Social scientific research agenda of renal patients

The first study was funded by the Dutch Renal Fund and was aimed at developing a social-scientific research agenda from the perspective of patients with chronic kidney disease. The Dutch Renal Fund wanted to develop an agenda like this because research priorities and themes were largely driven by professional agendas instead of patients’ agendas which is likely to lead to mismatches between research topics and patients’ actual needs. The Renal Fund was therefore interested in developing a research agenda in line with patient needs. The focus was on social scientific research to address the needs of patients irrespective of ongoing biomedical research. The research was conducted by a team of researchers, and two research partners. One of them was the author of this thesis, the other was the mother of a son with renal disease. As described above, the study started with the project team getting to know the participants of this study (by reading stories by renal patients, by having informal talks, by visiting hospitals and dialysis units et cetera) and by creating a good collaborative atmosphere with all stakeholders such as patient organizations and the Renal Fund. The second phase consisted of interviews with patients and observations (consultation phase). All patients were on dialysis or had had a kidney transplant. Participants were recruited by the patient organization and by a snowball effect i.e. patients recruiting other patients. The semi-structured interviews were completed in pairs comprising a researcher and a research partner. The interviews were aimed at getting information about what it is like to live with renal disease and what patients needed or what would have helped them handle their illness and treatment. The participants’ stories were leading and a list of topics was used to check whether all the relevant topics were discussed. The topic list was based on a
literature review and amended after three pilot interviews. The interviews lasted about one and a half hours and were audio recorded and transcribed line by line. The transcripts were analysed by the team members, using open and axial coding techniques. To check validity, participants received interpretation of the interview and asked whether they recognized the analysis (member check). All interview themes were then grouped into two emerging clusters: themes on daily life, and themes on the history of the illness. Based on the themes in daily life and illness history, we developed a preliminary overview of research themes as formulated by patients. The research themes were further explored and prioritized in the next collaboration phase by holding seven focus groups (n=54). The focus groups were led by a researcher and a patient research partner. In order to determine the most important research themes, participants were asked to put the research themes in order of importance. The individual preferences were then discussed in the group which finally led to validation of the research themes and a priority list. The final integration phase consisted of a literature search to check whether the research priorities of patients had already been investigated or not. It was also aimed at writing the research report.

This study resulted in 4 articles (chapters 2 to 5) and is helpful for answering all three research questions in this thesis.

*Development of intervention for patients after renal transplant*

The second study was also funded by the Dutch Renal Fund and concerned a descriptive, qualitative study. The study was aimed at the systematic investigation of issues that patients may experience after transplantation in order to develop a psychological intervention. An understanding of these issues helped us develop an intervention that fitted well with patients’ needs and wishes. The study was conducted by a team of academic researchers. The team was not completed by research partners but one of the team members, the author of this thesis, participated because of her professional and personal background. She combined her academic knowledge with experiential knowledge. The study started with an exploration phase, followed by the consultation phase in which 18 semi-structured interviews with transplant recipients were held. Participants were recruited by internet, patient organizations, and university teaching hospitals. The aim of the interviews was to get information about how patients experience their lives after
the transplantation. The stories of the participants were leading and a list with topics was used to check whether all the relevant topics were discussed. The interviews lasted about one and a half hours and were, with patients’ consent, audio recorded and transcribed. All transcripts were analysed using an inductive content analysis in line with the Grounded Theory approach. To check validity, participants received an interpretation of the interview and asked whether they recognized the analysis. The analyses of the interviews were compared and discussed in the different project-team meetings in order to increase reliability. In a subsequent step, the data from the different interviews were grouped into clusters based on the main (sub) themes that emerged in the interviews. The analyses resulted in some repeated, interrelated issues. These issues from the individual patient interviews were discussed in a focus group of kidney patients (collaboration phase). The focus group met twice. The meetings were aimed at the discussion and validation of the data that emerged from the interviews. The final integration phase aimed at writing the research report and was the starting point for developing the intervention.

This study has, to date, resulted in one article, reproduced as Chapter 6. This article will be used to answer the research question about any insights that can be gained by investigating patient perspectives and how these insights can be related to professionals’ perspectives.

**Acquired Brain Injury and the development of an integrative treatment programme**

The third study was aimed at the development of an integrative treatment programme for professionals working with clients with ABI. There is no programme like this, but it is needed in order to support patients with ABI as well as possible. Patients, their relatives and professionals were actively engaged in developing the programme, since their stories and experiences formed the input for the treatment programme. Patients with ABI did not participate as research partners but a small group of patients was involved as a ‘sparring partner’ throughout the research. Data collection started after the exploration phase and consisted of observations and interviews with patients, relatives, and professionals. We used a conversational interview style in order to collect the personal stories from each participant. The conversations started with an open question and were further guided by the
issues that came up in the dialogue. If respondents did not address certain issues, we introduced them, based on a topic list of relevant issues. All interviews were audio recorded, transcribed, analysed and discussed in project-team meetings. The analysis focused on the particularities of each story, but also paid attention to recurring themes. This holistic content analysis aimed to identify recurring themes in a story and their interrelatedness. The recurring themes were then linked to relevant issues in the literature. To check the validity of the interpretations of the interviews, the interviewee received a brief summary of the interview and our analysis of the transcript (member check). The interview findings were validated and developed in the next phase: the collaboration phase, by organizing focus groups with all stakeholders. The aim of the focus groups was also to create mutual understanding between clients and professionals. The last integration phase aimed to develop a treatment programme, based on the narratives of all stakeholders.

Chapters 7 and 8 present two articles based on this study. These articles can be used to answer the last research question since they give an insight into the added value of the experiences and knowledge of patients.

Societal participation of patients with Acquired Brain Injury

The last study was commissioned and funded by the Netherlands Brain Foundation. The study was conducted since earlier studies had shown that the participation of patients with ABI can be described as problematic. However, how these patients experience participation and exactly what influences their possibilities to participate is not known. The study aimed to answer the question as to how people with ABI experience societal participation and which environmental and personal factors may influence participation. A qualitative methodology was employed by a team consisting of researchers, people with ABI and a mother whose daughter had ABI. The data collection process and analysis was iterative so that emerging themes could be further explored and validated over the course of the research. To this end, the study was divided into four linked stages: exploration; consultation; collaboration, and integration; each stage produced the input for the following stage. The exploration phase was followed by the consultation phase in which semi-structured interviews were held with patients with ABI. Participants for the interviews and later phases of the study were recruited by patient organizations, the Netherlands Brain Foundation and health care institutions. The purpose of the
interviews was to get information about the experienced restrictions or bottlenecks regarding participation, the perceived opportunities for participation and the needs of participants regarding participation. The conversations were also aimed at obtaining information about how participants perceived the concept of participation and how they evaluated their own participation in society. The stories of the participants were leading during the interviews. A topic list was used in order to check whether all the relevant topics were discussed. The conversations were, if the participants agreed, audio recorded and then analysed using thematic content analysis. Individual participants received an interpretation of their interview and asked whether they recognized the analysis. The results from the interviews were subsequently, in the collaboration phase, validated and examined in more depth in 6 focus groups. The focus groups resulted in a dynamic model in which the participation influencing factors and their interrelatedness are visualized. The focus groups in the collaboration phase were followed by the formation of a working group, consisting of patients with ABI. The working group members met twice and the meetings were aimed at formulating methods and actions that may lead to improved participation among people with brain injury. The barriers that had been discovered earlier, and opportunities to participate and the dynamic model with participation influencing factors, formed the basis for formulating possible methods and action.

The article (reproduced as Chapter 9) is the result of this study and can be used to answer all the research questions.

1.6. Outline of the thesis

The main body of this thesis is divided into 2 parts: part 1 (chapters 2 through 6) deals with CKD, and part 2 (chapters 7 through 9) deals with ABI. Chapters 2 through 5 present the results and explain the above-mentioned agenda setting project, funded by the Dutch Renal Fund. The experiences of patients served as input for the joint formulation of research themes and priorities. Patients identified several social-scientific research themes regarding their daily life and the history of their illness. These themes are described in Chapter 4. This chapter is preceded by a case study which examines what it means to live with hereditary
renal disease (Chapter 2). Chapters 4 and 5 emanate from the same research project but focus on the research process instead of the results.

Chapter 6 is based on the second study with renal patients which aimed to develop an intervention for patients following renal transplantation. This article describes the positive and negative issues that patients may experience after transplantation. The intervention was developed based on these issues.

The second part of this thesis, chapters 7 through 9, deals with people with ABI. It is the result of 2 separate studies. The first study (chapters 7 and 8) aimed to develop an integrative treatment programme for professionals working with clients with ABI. Chapters 7 and 8 describe this study and explain how clients and professionals may have conflicting ideas about the concept of autonomy.

The other study with people with ABI (Chapter 9) aimed at answering the question as to how people with ABI experience societal participation and which environmental and personal factors may influence participation. This study resulted in ‘the participation model’ which is also described in this chapter.

The last chapter presents the main findings and discusses the results. Methodological issues are also addressed. Furthermore, implications for further research and recommendations for practice are also given. The thesis concludes with a summary, acknowledgments and the author’s curriculum vitae.


