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COLLABORATION BETWEEN RESEARCHERS AND PATIENTS IN SCIENTIFIC RESEARCH

A QUALITATIVE STUDY ON PRECONDITIONS FOR SUSTAINABLE
COLLABORATION BETWEEN RESEARCHERS AND PATIENTS

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A qualitative study on preconditions for sustainable collaboration between researchers and patients

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ZonMw

Summary

Context

Scientific research in healthcare is of great importance to gain insight into different aspects of diseases, healthcare and healthcare systems. These insights can contribute to improvements in healthcare. However, there is also criticism on healthcare research. This criticism is related to that research and research agenda setting is mainly driven by researchers and professionals. Patient participation in healthcare research is an approach to overcome this. Patient participation improves the relevance and quality of the research, because more accurate and relevant data can be gathered by involving patients. Patient participation is used to indicate patients, patient representatives, patient groups, or other actors that represent the views and perspectives of patients in decision making being actively involved and having an influence on decision-making processes in health research. The goal in patient participation is a sustainable collaboration between researchers and patients. A sustainable collaboration is characterised by factors as trust, communication, shared vision and cultural sensitivity. In addition, sustainable collaboration is based on the willingness of all actors to collaborate, since they acknowledge the added value of collaborating. The Netherlands organisation for health research and development (ZonMw) observed that patient participation is ad hoc collaboration and are one-off events in many research projects they financed. However, an in-depth insight into the preconditions for a sustainable collaboration is lacking. Therefore, ZonMw prefers to have in-depth insight into the preconditions for a sustainable collaboration between researchers and patients. This insight can contribute to improvements in practice and thereby increase the quality of care.

Methods

Both researchers and patients were selected to participate in this study in order to gain insight from both perspectives on collaboration in healthcare research. The research population consisted of twelve researchers and ten patients from a diverse range of research areas, derived from twelve different research projects from eight different ZonMw programmes. These projects were selected based on three selection criteria: 1) ongoing or recently finished project, 2) direct involvement of patients, 3) requirement for participation had to be clear. Ten interviews were conducted face-to-face and twelve interviews were conducted by telephone. All interviews lasted between 35 and 65 minutes and were conducted in spring 2017. The records of the interviews were transcribed verbatim, using Express Scribe Transcription. Subsequently, the transcripts were coded by using ATLAS.ti. Content analysis was used to analyse the data. During the first phase of coding, there was coded based on the concepts of the conceptual framework – culture, structure, practice. During the second phase, open coding was used. A narrative summary of the interview was sent to the participants and three interviews were coded and discussed with other researchers in order to increase the validity and reliability of this study.

Results

To establish a shift from ad hoc and one-off collaboration to sustainable collaboration, a transition is necessary in three domains: culture, structure, practice.

In the cultural domain the participants had a positive attitude towards patient participation. The patient's perspective increased the relevance of the project for patients, since the wishes and relevant topics for patients were discussed. However, some researchers were more critical by mentioning that researchers should not rely on the experiential knowledge of patients, since researchers had the knowledge and expertise of a certain research field. In fundamental research, collaborating was experienced as difficult, because the distance from the research to the patient was large. In many research projects, there was collaborated with patients due to the experiential knowledge of patients. Patients had their world with their experiential knowledge and researchers had their world with their

scientific knowledge and expertise. It was not necessary for patients to meet the researcher's world, because the patient's perspective was seen as the added value of collaborating with patients. Patients came up with surprising and interesting ideas, where researchers were used to address these aspects of research differently. A number of patients had specific roles, for instance in the communication to other patients, in recruiting patients for the research project. In other research projects, patients were involved during the entire research process. Furthermore, an equal relationship between researcher and patient was of great importance for collaborating. In this equal relationship it was important to be aware of the possibilities and impossibilities of all stakeholders involved in the collaboration. On one hand, a good communication structure between researchers and patients enhanced the relationship, and on the other hand a lack of communication structure impeded the relationship.

Several structural elements appeared to be important in the collaboration between researchers and patients. First, researchers and patients mentioned that was important to collaborate from an early phase of the research project. However, no funding was assigned to research projects at an early stage. This made it difficult to collaborate with patients, since there is no possibility for financial reimbursement for patients for instance. The financial reimbursement was also experienced as difficult by researchers during the research project. Patients were thinking about this differently. Some patients did not want to receive reimbursement, other patients mentioned that they were also willing to participate without reimbursement and other patients perceived the reimbursement as essential since they were spending a lot of time on the project. Furthermore, collaborating with patients took more time than without collaborating with patients in a research project. It took time to build up the relationship, for patients it took more time to prepare for meetings and reading papers, the decision-making process was slowed down since more people were involved and researchers had to find a new way of working.

In the practical domain, it was for all patients extremely important that researchers were taking their input seriously. However, in some situations it was for researchers not possible to meet the wishes of patients, due to limitations in time, money or external barriers, such as funding restrictions or disapproval of the Medical Ethics Review Committee. Patients became frustrated when they experienced that the researchers were not taken their input seriously. This damaged the relationship and a huge amount of mistrust was created. However, when researchers were taken the input seriously, patients felt heard and appreciated, consequently more meaningful and valuable input was provided by patients for the rest of the research project. Language was an important aspect of collaborating in scientific research. Scientific (English) literature and jargon were sometimes difficult for patients to understand. Additionally, researchers and patients noticed that they were sometimes not speaking the same language. This difference in language caused misunderstanding and tension between researchers and patients.

Conclusion

To establish the shift from ad hoc and one-off collaboration to sustainable collaboration a transition is necessary. This study investigated the preconditions for this sustainable collaboration. In the practical domain, it was an important precondition that researchers were taken the input of patients seriously. In addition, flexibility in terms of time and money was an important precondition in the structural domain. However, to make the shift to sustainable collaboration, it is also important to change the cultural domain. In order to change the cultural domain, it is of great importance that stakeholders acknowledge and experience the added value and benefits of the collaboration. Eventually, this will lead to more motivation to collaborate and stakeholders will see collaboration in health research as a logical process. However, transitions are complex, therefore the shift to a sustainable collaboration could take a long time.

Recommendations

Considering the results of this study, recommendations towards ZonMw can be made. First, ZonMw could use ambassadors of patients participation to facilitate that stakeholders acknowledge or see the

added value and benefits of the collaboration. Second, ZonMw could make patient participation a requirement for research calls. However, ZonMw should provide more information regarding different methods on how to collaborate and what ZonMw means by collaborating. Furthermore, these requirements have to be tailor made for every different ZonMw programme, since different possibilities appeared to be important within different programmes. Additionally, in the evaluation of the research project, ZonMw should focus on the execution of the collaboration. Third, ZonMw should be more flexible in terms of time and money. Flexibility provides researchers the opportunities to follow the wishes and input of patients. On beforehand it is impossible to know the entire progress of the research project. Therefore, ZonMw should be more flexible in this. Furthermore, ZonMw should provide a small amount of funding to research projects in order to elaborate on a research proposal in collaboration with patients. However, research is necessary in order to decide how to design this, how much funding should be provided and how is decided who will receive this funding.

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1. Introduction

Scientific research in healthcare is of great importance to gain insight into different aspects of diseases, healthcare and healthcare systems (Smit, de Wit, Vossen, Klop, van der Waa et al., 2008). Research can, for example, provide information about disease trends and risk factors, healthcare costs, patterns of care, functional abilities and outcomes of treatment or public health interventions (Institute of Medicine, 2009). These insights can contribute to improvements in healthcare. Improving the healthcare system is of great importance since the healthcare system in the Netherlands is currently confronted with certain challenges (van Rooijen, Goedvolk & Houwert, 2013). These challenges include an increased demand of care and supply of expensive new technologies and treatment methods, restricted budgets and increasing attention to quality of care. To deal with these challenges, arrangements are necessary to make healthcare more efficient and effective. Scientific research in healthcare can support these arrangements (van Rooijen et al., 2013).

Despite the fact that healthcare research provides a great amount of knowledge and insights, there is also criticism on healthcare research (Elberse, 2012). This critique is related to the fact that research and research agenda setting is driven by researchers and professionals. This supply-driven approach could cause that research is not focused on problems and needs of patients. Moreover, research is not always conducted in a patient-oriented approach (Elberse, 2012). An approach to overcome this would be patient participation in healthcare research. Patient participation can improve both the relevance and the quality of a research (Elberse 2012; Vahdat, Hamzehgardeshi, Hessam, Hamzehgardeshi, 2014; Groenewegen, Kroneman, van Erp, Broeren, van Birgelen, et al., 2016). Improvements in the quality of research can be made because more accurate, more applicable and relevant data can be gathered by involving patients (Sacristán, Aguarón, Avendaño-Solá, Garrido, Carrión et al., 2016). The trend of patient participation began in the 1980s when people with disabilities mobilised under the slogan “Nothing about us without us” (Charlton, 2000). Over the past decades, patient participation has become more established in research and it has become increasingly important (Elberse, 2012).

According to Elberse et al. (2011) patient participation *‘is used to indicate patients, patient representatives, patient groups, or other actors that represent the views and perspectives of patients in decision making being actively involved in and having an influence on decision-making processes in health research’* (p 7). Patient participation in research is applicable during all phases of research, which ranges from agenda setting till guideline development (van de Bovenkamp, Trappenburg & Grit, 2010). Patients can be involved in healthcare research in different ways, as object of respondent, as advisor or research partner (Abma, Nierse, & Widdershoven, 2009).

In the literature, there are three arguments described for using patient participation; the substantive, the normative and the instrumental argument (van de Bovenkamp et al., 2010; Teunissen, 2014). First, the substantive argument, which entails that when taking the perspectives and needs of patients into account in research the quality of care could be improved (Epstein, 2008). This is based on patients’ experiences with their condition in their daily lives and their experiences with healthcare. This perspective besides the healthcare professional perspective increases the chances for new, original ideas and solutions. The second argument is the normative argument and is based on legitimacy (Baker, 2007). As patients are directly involved in healthcare, they have the right to be involved and participate in research. Moreover, transparency in the accountability in the decision-making process creates support and social acceptance amongst patients (Caron-Flinterman, 2005). Third, involvement in the decision-making process can empower patients and decreases the power imbalance between

patients and professionals (Elberse et al., 2011). This might result in a more equal, cooperative and beneficial relationship between patients and professionals. In this way, patient participation could contribute to an increase in the quality of the network of social connections for patients and professionals (Boote, Telford, Cooper, 2002).

To date, many studies have been performed with respect to patient participation. Advantages and disadvantages of patient participation, difficulties of patient participation and facilitators and barriers for patient participation have been studied (e.g. Van de Bovenkamp, Grit, Bal, 2008; Smit et al., 2008; Dedding & Slager, 2013; Vossen, 2013; Teunissen, 2014; Groenewegen, et al., 2016). Furthermore, guidelines for patient participation are developed and advisory reports on patient participation have been written. However, to date patient participation is still not completely successful in many research projects and collaborations are ad hoc or one-off events (Caron-Flinterman, Broerse, Bunders, 2007; de Wit, 2014). However, for succesful patient participation in healthcare research, a sustainable collaboration between researchers and patients is necessary (Elberse & Broerse, 2013). A sustainable collaboration is characterised by factors such as trust, communication, shared vision and cultural sensitivity. In addition, sustainable collaboration is based on the willingness of all actors to collaborate, since they acknowledge the added value of collaborating (Abma & Broerse, 2010; Elberse, 2012; Dedding & Slager, 2013). Despite the fact that difficulties and barriers of patient participation are known, such as limited amount of time and difficult patient target groups (Dedding & Slager, 2013), an in-depth insight in the preconditions that could establish a sustainable collaboration is lacking.

The Netherlands organisation for health research and development (ZonMw) aims to stimulate the involvement of patients in research. Therefore, ZonMw prefers to have in-depth insight into the preconditions that contribute to a sustainable collaboration between patients and researcher from both a patient and researcher perspective.

Hence, the main objective of this study is to provide recommendations on how to improve patient participation in research projects funded by ZonMw, by gaining insight into preconditions for sustainable collaboration between patients¹ and researchers in research projects funded by ZonMw. This can contribute to improvements in patient participation in practice and thereby increase the quality of care.

In order to accomplish the aim of providing recommendations to ZonMw, the following research questions will be answered: *What are preconditions for sustainable collaboration between researchers and patients in research projects funded by ZonMw?*

¹ Where is referred to patients in this study, there can also be referred to patient representatives, informal care givers or people with a mild mental disability.

2. Contextual background

In this chapter, context about patient participation in health research and the actors involved in patient participation is provided. In the first section, general background information about patient participation is described, followed by the participation ladder of Arnstein. Subsequently, an important concept in patient participation, co-creation of knowledge is described and explained and the effects of patient participation are discussed. In the second section, the different actors in patient participation in health research are discussed.

2.1 Patient participation in healthcare research

An active role of patients is becoming more important in the current healthcare system. This active role of patients is associated with patient-centered care (Schipper, 2012). Patient-centered care focuses on the individual's healthcare needs (Reynolds, 2009). Over the last two decades, patient centered care has been a strong focus of the Dutch healthcare system (van de Bovenkamp et al., 2010). The goal of patient-centered care is to empower patients to become active participants in their care, which includes decisions about their treatment but also involvement in research agenda setting. In other words, patient-centered care is a broader term than only patient involvement in their treatment and individual contact with physicians, but can also include participation in decision-making, such as guideline development (Schipper, 2012).

In patient participation in scientific health research, patients are actively involved in directing and influencing the research from a patient's perspective. Patients are not participating in their usual role as respondents, who fill in a questionnaire or as participants in an interview or focus group, but they participate as partners in research or as co-researchers. In this role, patients can be involved in research agenda setting, guideline development and government policy-making. Patient can be involved in different types of health research, varying from biomedical research, applied and clinical research to health service research (Caron-Flinterman, 2005; Pittens, 2013).

2.1.1 Participation ladder

The intensity of patient participation in research can be determined according to the patient participation ladder by Arnstein (1969) (Figure 1). The ladder of Arnstein is explained here to illustrate the different levels of participation. This ladder consists of eight rungs that represent the eight levels of citizen participation in local policymaking. A distinction has been made in these eight levels, which resulted in three categories; non-participation, tokenism and citizen control (Arnstein, 1969). The first category is non-participation, which includes manipulation and therapy. In these situations, patients have no influence on decision-making (Arnstein, 1969). Tokenism is the second category and refers to a situation in which patients are involved in decision-making and are able to share their views and experiences. However, researchers are still responsible for definitive decisions (Hahn, Hoffmann, Felzien, LeMaster, Xu, et al., 2016). Tokenism includes informing, consultation and placation. During the level of informing, patients are

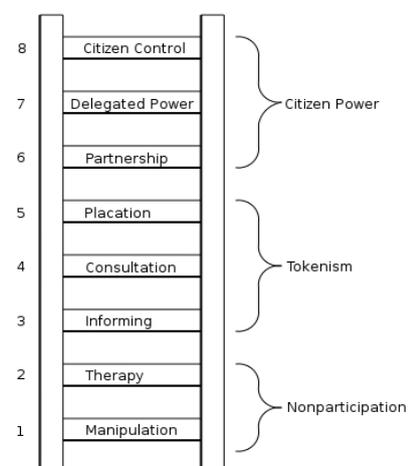


FIGURE 1: PARTICIPATION LADDER OF ARNSTEIN (1969)

informed about the research, however they are not involved in the process of decision-making (Caron-Flinterman, Broerse, & Bunders, 2007). During the level of consultation, patients are consulted for their research needs, judgements and priorities for instance in questionnaires, interviews or group meetings. This does not imply that these inputs are actually taken into consideration, this is decided by researchers. In placation, patients participate in decision-making or advisory structures in a formal way, without ensuring that their inputs are being honoured. Researchers are making the final decisions (Caron-Flinterman, 2005; Caron-Flinterman, Broerse, & Bunders, 2007). The third category is citizen power and includes partnership, delegated power and citizen control (Arnstein, 1969). In partnership, researchers and patients take decisions jointly. The different perspectives are taken into account, and genuine deliberation and negotiation can lead to final outcomes supported by both parties (Elberse, 2012). Partnership in patient participation is supposed to be the most desirable phase of patient participation (Caron-Flinterman, 2005; Elberse, 2012, Pittens, 2013). Delegated power refers to a situation in which patients have a dominant position in the decision-making process to ensure the accountability of research programs or projects to their needs. At the highest rung, citizen control, patients fully control all stages of decision-making on healthcare research (Caron-Flinterman, Broerse, & Bunders, 2007). According to Arnstein full citizen control is not realistic and may endanger the professional autonomy of researchers.

Despite the fact that the levels of the participation ladder are presented in an ascending order, this does not imply that a higher level of patient participation is more effective (Arnstein, 1969; Pittens, 2013). A higher level on the ladder implies more influence in the decision-making process by patients. The effectiveness of participation depends on the context and is mainly influenced by the attitude of researchers and patients towards patient participation, patients' competences and knowledge, and established relationships between researchers and patients (Pittens, 2013). This is also a point of criticism on the participation ladder. According to Collins & Ison (2006), Arnstein's meaning of participation is devoid of context and has no means of making sense of the context in which the ladder is used.

2.1.2 Co-creation of knowledge

An important aspect of patient participation is co-creation of knowledge. In general, co-creation of knowledge represents the development of knowledge within science and society (Pittens, 2013). During the process of co-creation of knowledge in healthcare research, knowledge is developed through sharing perspectives and experiences, in which collaboration between researchers and patients is of great importance (Gillard, Simons, Turner, Lucock, & Edwards, 2012). In research involving patient participation, this new knowledge is constructed by the use of the perspectives and experiences of patients. Patients are considered as stakeholders and repositories of experiential knowledge, which is consulted by health researchers in order to develop this new knowledge (Elberse, 2012). This experiential knowledge and views of patients can be taken into account from the start of a research project until the implementation of the research outcomes (Pittens, 2013).

The process of knowledge co-creation consists of three elements; 1) knowledge articulation, 2) knowledge integration, 3) knowledge embedding (Regeer & Bunders, 2009). The phase of knowledge articulation entails the interactive process of implicit knowledge which is made explicit. Knowledge integration is characterised by a dialogue between multiple actors in which different perspective are brought together in a learning process. This ultimately generates 'socially robust knowledge', which refers to knowledge which is not only scientifically reliable, but that is also accepted and used in society: knowledge embedding (Regeer & Bunders, 2009; Pittens, 2013).

Co-creation of knowledge is considered to be of high value in the contribution of patient participation in healthcare research, since patients can be involved during all phases and they are important stakeholders in healthcare research (Hardyman, Daunt, & Kitchener, 2015). Valued co-creation can only occur through direct interactions between researchers and patients, which makes valued co-creation a dialogical process (Hardyman *et al.*, 2015). Despite the fact that knowledge co-production is highly valued, the impact of the approaches involving patients have on the decision-making process is generally low (Pittens, 2013).

2.2.3 Effects of patient participation

It is widely argued that patient participation in healthcare research increases the quality of care, patient empowerment, accountability, legitimacy and the implementation of process of policies (Caron-Flinterman, 2005; van de Bovenkamp *et al.*, 2008; Elberse, 2012). Furthermore, patient participation contributes in making sustainable decisions, which means that resources will be used in a way that suits the needs of the society (Lemire, 2015). Additionally, patient participation can also be used to identify the gaps in healthcare (research). Patients have additional insights into these gaps and can therefore be of great value in identifying and solving them (Groenewegen *et al.*, 2016).

Despite the fact that the value and benefits of patient participation are widely acknowledged, the impact of patient participation is hard to determine (Groenewegen *et al.*, 2016). In general, a process evaluation in research is done about effects of participation instead of investigating the outcomes of participation (Dalton, Chambers, Harden, Street, Parker, *et al.*, 2016). Two sorts of effects of patient participation can be distinguished: effects on the organisation of care and effects on outcomes of care (Groenewegen *et al.*, 2016). The effects on the organisation of care are mostly discussed in research. Especially the organisational goals, which are easily defined, and the organisational goals whereby the interests of healthcare professionals and patients come together are mostly discussed. This concerns, for example, improvements in waiting areas, opening hours of healthcare facilities and accessibility of health care facilities (Paine, 1983; Groenewegen *et al.*, 2016). The actual organisational impact of patient participation is however difficult to determine. The impact appears to be context-specific in which the success of participation depends on local dynamics, historical context and the expectations of patients (Dalton, *et al.*, 2016).

There is hardly no evidence of effects of patient participation on outcomes of care. There is a lack of high quality research which investigated this effect of patient participation on outcomes of care (Sanders, van Weeghel, Vogelaar, Verheul, Pieters, *et al.*, 2013). Patient participation is a small step in improving health and a part of a long chain of elements, which can improve health. However, this makes isolating, and thereby investigating the effect difficult. Though, Bath & Wakerman (2015) found a positive effect of patient participation on health outcomes in projects that are focused on specific health interventions. Negative effects of patient participation are rarely reported (Dalton, *et al.*, 2016).

Despite the fact that there is no actual scientific evidence for an effect on health outcomes or organisational outcomes of patient participation, patients and researcher agreed that patient participation is of great value, in multiple ways (Groenewegen *et al.*, 2016). For example in the applicability and relevance of the research.

2.2 Actors

In patient participation in healthcare research a number of actors are involved, for instance researchers, patients/patient organisations, ZonMw and the ministry of Health, Welfare and Sports (VWS). A simplified graphical overview of the main relationships between the actors is presented in figure 2. Four types of relationships are illustrated, namely knowledge, power, communicative and financial relationships. First, the knowledge relationship demonstrates the division of knowledge between actors. Second, the power relationship indicates which actors have power over the other actor. Third, the communicative relationship describes which actors are negotiating partners. Fourth, the financial relationship demonstrates which actors receive money, for instance in the form of funding or subsidies, from another actor. The different actors are described below.

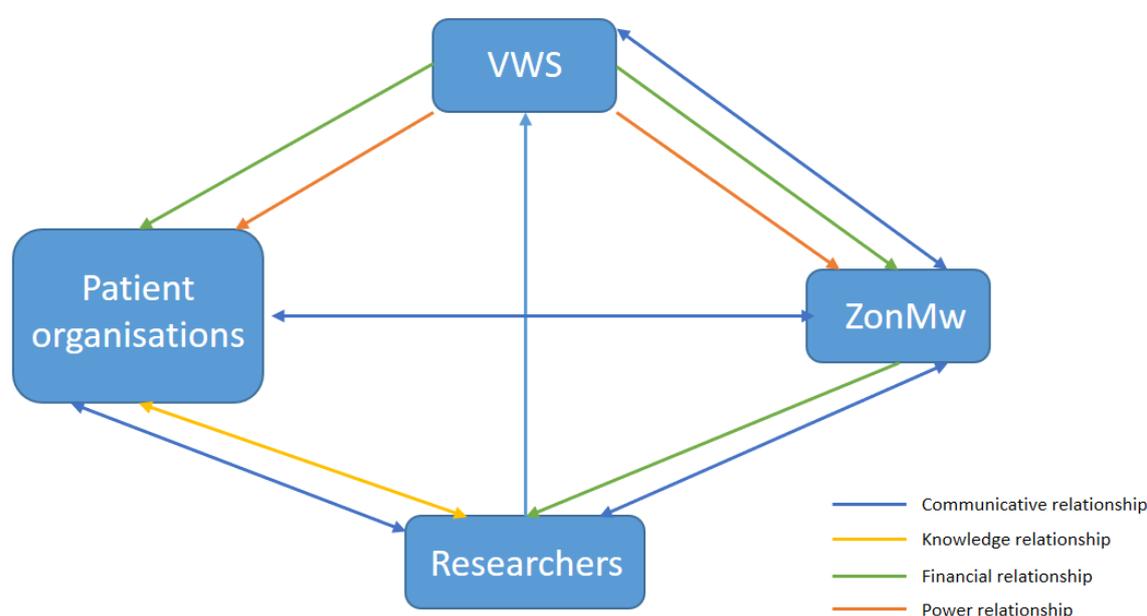


FIGURE 2: ACTOR CHART OF RELEVANT STAKEHOLDERS IN PATIENT PARTICIPATION IN RESEARCH

2.2.1 Ministry of Health Welfare and Sports

The ministry of Health, Welfare and Sports (VWS) stimulates people to behave healthy. In stimulating this, VWS has power, since they set the rules and regulations on health related topics and decide which research programs will be funded (VWS, 2017).

The National Institute for Public Health and the Environment (RIVM) conducts research on (public) health and environmental related topics commissioned by VWS (RIVM, 2017). However, VWS also stimulates other research institutions to conduct research on healthcare by financing their research. VWS provides funding to ZonMw, which divides the funding among health research projects. Subsequently, VWS has great power in the decision making process regarding healthcare related research. Additionally, The ministry of Education, Culture and Science provides funding to the Netherlands organisation for Scientific Research (NWO), which divides the funding among other research projects in the Netherlands next to health research projects.

2.2.2 ZonMw

ZonMw is the Netherlands organisation for Health Research and Development. In the Netherlands, ZonMw has a central role in research and innovation as national funding organisation. ZonMw aims to promote quality and innovation of health research in order to make healthcare better and to keep healthcare affordable. VWS and NWO are the principal commissioners of ZonMw.

ZonMw defined multiple research programmes, based on the problems and challenges in healthcare and health research. These programmes can address for instance the development of a certain scientific field, such as the correct use of medicines, or the development and research into innovations in healthcare (ZonMw, 2017). Within these programmes, academic institutions can do research or they can develop, test and implement innovations on a project basis. Researchers can participate in these programmes by requesting funding for projects that fit the programme. For most of the programmes, ZonMw publishes calls for the submission of project proposal through its funding calendar (ZonMw, 2017).

Grant applications of projects are assessed separately for their relevance and quality (ZonMw, 2012). Criteria for quality are generally applicable to any type of programme, and are related to the objectives, approach and deliverables, the project group, the feasibility and the budget justification (ZonMw, 2012). In contrast, criteria for relevance are specifically related to the aims of the programme. The criteria for relevance are related to the project's contribution to the aims of the programme, the innovative potential, a cost-benefit analysis, the potential to close societal and scientific gaps, the acknowledgement of diversity and the active contribution to knowledge transfer and implementation (ZonMw, 2012).

In most programmes, the applications have to be prioritised since the majority of the applications eligible for a grant exceed the available budget. The programme committee decides which applications should be given priority based on their final assessment of their quality and relevance. Applications are eligible if the relevance and quality are at least satisfactory (ZonMw, 2012).

ZonMw has defined six policy priorities in healthcare research, of which participation is one of these. ZonMw stimulates the involvement of patient experts in projects and programmes. According to ZonMw, patient participation entails the involvement of stakeholders during the process of developing knowledge and renewal of healthcare and healthcare research. ZonMw argues that patient experts should be involved at an early stage in research causing that new insights, ideas, interests and desirable outcomes can be taken into account during the process of initiating a project. In addition, ZonMw has influence on which projects tax money will be spend. This brings a moral duty to spend this money on relevant and valuable topics for society. In a number of programmes patient participation is a requirement for receiving funding.

2.2.3 Researchers

Researchers are important stakeholders in the process of patient participation. In this study, researchers refer to everybody that conduct health research in order to discover new information or understand a subject better. This new information or understanding can contribute to policy-making, guideline development or attention for a certain topic. In health research, many researchers are also medical doctors and combine scientific research with their clinical tasks. Researchers can work in many different fields of research, from fundamental research until translational and practice oriented research.

2.2.4 Patient organisations

Patient organisations support and represent patients with respect to prevention, treatment and accessibility to care and information. Furthermore, patient organisations enable contact with fellow sufferers by organising (information) meetings and excursions. Since there are many types of disorders, there is a wide variety of patient organisations. Each patient organisation is dependent on donations, contributions and grants of the government. Especially for the smaller patient organisations finance could be a barrier for the involvement in research (Adonis, 2016).

Patient organisations can have six roles in patient participation in research (NVN, 2014; van de Bovenkamp et al, 2008). First, patient organisations can be very helpful for researchers to come into contact with patients for their research. This can be done by writing an advertisement on the website or club magazine or the organisation will bring the patients into contact with the researchers (NVN, 2014; van de Bovenkamp et al, 2008). Second, patient organisations can provide information to researchers. Patient organisations have often a great amount of knowledge and experiences about a specific disease, which can provide new insights and ideas in research (NVN, 2014; van de Bovenkamp et al, 2008). Third, patient organisations can have an advising role. However, the advisers need to have sufficient knowledge and skills regarding scientific health research in order to become an adviser, this applies to member and also employees of the patient organisations. Fourth, patient organisations can be reviewers or referees of research (proposals). In this role sufficient knowledge and skills regarding scientific health research are also important and conflicts of interest with research proposal requested by the patient organisations should be prevented (NVN, 2014; van de Bovenkamp et al, 2008). Fifth, patient organisations can also participate as co-researcher. In this role, patient organisations are more involved in the research than only advising. A shared communication context is important and may result in mutual respect and empowerment of patients and in-depth insight at researchers (NVN, 2014; van de Bovenkamp et al, 2008). Lastly, patient organisations can be co-founders of scientific research. The research agenda derives from the aspects that are discussed within the patient organisation (NVN, 2014; van de Bovenkamp et al, 2008).

3. Theoretical Background

In this section, a conceptual framework will be discussed in order to investigate preconditions for sustainable collaboration between researchers and patients in research projects funded by ZonMw. First, an important concept, sustainable collaboration, is described. After that, three main domains which need to be changed in order to make a transition to a sustainable collaboration are discussed. From these domains, a conceptual framework is derived. Furthermore, based on the conceptual framework, sub-questions are established.

3.1 Collaboration in health research

A sustainable collaboration between researchers and patients is necessary for successful patient participation (Elberse, 2012; Dedding & Slager, 2013). In a sustainable collaboration, researchers and patients work jointly on a research project and patients are actively and regularly involved in the research process. Patients are established actors in the research system and are involved in more (or all) phases of research. Thereby, the input and influence of patients is ensured throughout the research process (Dedding & Slager, 2013). This involvement of patients is driven by the willingness of different actors to work together, as they see the added value of patient participation (Elberse, 2012). In this study, this is applicable to health research. Health research spans the entire range from (bio)medical research, clinical research, public health research, epidemiological research to care research (Elberse, 2012). Collaboration between researchers and patients in patient participation is applicable to all levels of participation, based on the levels of participation of the participation ladder of Arnstein. Even in the levels where patient participation is minimal, there has to be collaboration between researchers and patients in greater or lesser extent.

3.2 Culture, structure, practice

To establish a sustainable collaboration between researchers and patients, there is a need for a transition of the health research system. A transition is defined as a process of fundamental and irreversible change in a society's culture, structures and practices (Gaziulusoy & Brezet, 2015; Broerse & Grin, 2017). Transitions can be identified in societal systems like energy, water, mobility, agriculture and healthcare (research). Furthermore, transitions are the result of co-evolution of economic cultural, technological, ecological and institutional developments at different levels (Broerse & Grin, 2017). In transition there are multiple causes and effects, which are constantly interacting. Periods of transition entails phases of slow and fast change, whereby four different phases can be determined; predevelopment, take-off, acceleration and stabilisation (Rotmans, 2003; Loorbach, 2010). A transition is a gradual process on the long term. However, on the short term, abrupt changes could facilitate or impede the process of transition (Rotmans, 2003).

The concepts 'culture', 'structure' and 'practice' are considered as relevant notions for transitions (e.g. Loorbach & Rotmans, 2010; de Wit, 2014; van Raak, 2016). In order to establish a sustainable collaboration, a transition in the three domains of the healthcare research system are necessary. Transition management is of great importance to establish this. Transition management is an approach to deal with complex societal problems and governance in the context of these problems, for instance in the context of patient participation in health research (Loorbach & Rotmans, 2010).

Culture is defined as *“a set of values, perceptions and interpretative frames that are shared by most of the involved actors”* (p.68) (van Raak, 2010). In other words, culture is the sum of shared images, norms and values that together establish the perspective from which the actors act and think. Changes in culture entail shifts in perceptions, mental models and thinking (van den Bosch, 2010). For this study, the domain of culture defines the way in which researchers and patients perceive and interpret knowledge and values and how they frame this. A shared culture of researchers and patients may be a stimulating factor in the participation of patients in research. However, differences in culture between researchers and patients could also drift them apart and make collaboration more difficult (Elberse, 2012).

Van Raak (2010) defined structure as *“the physical, economic, legal, financial, organisational and power structures that facilitate and/or constrain the behaviour of the actors involved”* (p.68). Physical structures entail infrastructure, technologies, resources and materials. For organisational structures there could be thought of rules and regulations and financial structures including market, economics, consumption and production (van den Bosch, 2010). These different structures facilitate and/or constrain the behaviour of the actors involved (Elberse, 2012). Changes in structure entail changes in how actors organise the things they do, either economically, institutionally or physically (van den Bosch, 2010). In the case of patient participation in research, the domain of structure entails mainly the financial and organisational structure of the research. For researchers it is crucial to have a financial structure in their research to collaborate with patients. Furthermore, an organisational structure can impede or facilitate patient participation in research.

Practice can be seen as the sum of activities, such as routines, behaviour, ways of handling and implementation, that actors perform (van den Bosch, 2010). According to van Raak (2010), practice is defined as *“the actual actions undertaken by actors which are relevant for the functioning of the system”* (p.68). Changes in practices entail changes in what actors actually do, how they behave or how they work. For patient participation, the domain of practice is of great importance. Without the behaviour and ways of handling of researchers and patients no patient participation in research would take place (Elberse, 2012). However, different behaviours can lead to different levels of participation according to the participation ladder of Arnstein. These actions and behaviour by both researcher and patients are therefore important for successful or unsuccessful patient participation in research.

These three elements are strongly intertwined and reinforce each other. Culture and structure are shaped by practices of researchers and patients involved (van den Bosch, 2010). When actors work and behave in a certain way (i.e. practice), this will have an influence on the norms and values of actors (i.e. culture) and likewise on the structure. For instance, when actors work in the specific way (i.e. practice), the infrastructure and resources (i.e. structure) have to be available to work in that specific way. At the same time, those practices are encouraged or limited by the structures and culture (van den Bosch, 2010). When resources or financial structures are not available, actors cannot behave or work in a certain way (i.e. practice).

3.3 Conceptual framework

The conceptual framework of this study is based on the concepts culture, structure and practice. From previous research is known that the three concepts, are very useful in the domain of health and can be used in prescriptive way (de Wit, 2014). In order to establish a sustainable collaboration, a transition is necessary in in these three domains (Figure 3). Insight into collaboration in these domains will provide an overview of collaboration between researchers and patients in research projects. This insight can provide understanding of how patient participation can be improved as a whole, but also within a specific domain in order to create a transition to a sustainable collaboration. A visual representation of the conceptual framework is presented below:

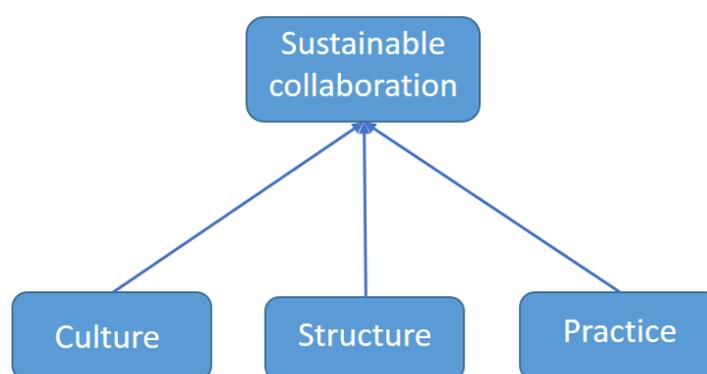


FIGURE 3: CONCEPTUAL FRAMEWORK

3.4 Sub-questions

Following the research questions of this study “*What are preconditions for sustainable collaboration between researchers and patients in research projects funded by ZonMw?*” and the conceptual framework, three sub-questions were formulated:

- What are preconditions for sustainable collaboration between researchers and patients in the cultural domain?
- What are preconditions for sustainable collaboration between researchers and patients in the structural domain?
- What are preconditions for sustainable collaboration between researchers and patients in the practical domain?

4. Methodology

The methods used in this study will be discussed in this chapter. The following subjects will be discussed: research approach, research population, data collection and data analysis.

At the start of this study, background information was gained. This background information provided more in-depth knowledge and insights in the context of this study (patient participation), collaboration between patients and the actors involved in patient participation in research. Based on these knowledge and insights, a conceptual framework was established, which provided a basis for semi-structured interviews with researchers and patients.

4.1 Research approach

In this qualitative study, semi-structured interviews were used to gain insight into preconditions for sustainable collaboration between researchers and patients. Both researchers and patients were interviewed to gain insight into both perspectives.

4.1.1 Justification of methods

There are several reasons why a qualitative approach with semi-structured interviews was applicable for this study. First, there is limited knowledge on in-depth insights into preconditions for sustainable collaboration between researchers and patients in health research. A qualitative method and exploratory approach allows to gain this in-depth insight, which made a qualitative approach applicable for this study (Gray, 2013). Second, semi-structured interviews follow a predetermined and standardised list of questions about patient participation, but allow at the same time flexibility in the way issues are addressed (Verschuren & Doorewaard, 2010). By preparing a topic list and an interview guide beforehand, the interviewer is prepared during the interview. This increases the reliability and makes it easier to compare the different data obtained from researchers and patients. Third, semi-structured interviews encourage two-way communication. This can confirm what is already known and provides the opportunity to gain new insights. These insights do not only provide answers on questions during semi-structured interviews, but also the underlying reasons. This was especially applicable for this study, since this underlying insight into preconditions for sustainable collaboration was lacking. Lastly, in this study there was a need for highly personalised data, since this study is based on personal experiences of researchers and patients. This can be obtained by semi-structured interviews since the researcher has the opportunity to ask personalised questions to the participant (Gray, 2013).

4.2 Research population

Both researchers and patients were selected to participate in this study. To gain insight into the collaboration between researchers and patients it is important to have perspectives of both actors, as they are both involved in the collaboration. Furthermore, potential discrepancies in collaboration between patients and researcher and the reason for these potential discrepancies can be investigated when involving both researchers and patients. The research population of this study consisted of twelve researchers and ten patients from a diverse range of research areas.

4.2.1 Sampling strategy

A purposive sampling strategy was used in this study, since the research projects had to be information-rich. This was necessary in order to study the topic of this study in-depth (Gray, 2013). In order to decide which research projects were suitable to investigate in this study, eight meetings were held with eight different programme secretaries of ZonMw. These programmes included, Handicap and Chronic diseases; Efficiency studies; Fundamental research; Visual disabilities (InSight); Innovation programme Rehabilitation; Palliative Care; Mental Health; Medicines. In selecting projects the following criteria were used: 1) projects were ongoing or finished in the last nine months, 2) it must be clear for the researchers what the requirements of patient participation were, 3) there had to be patients involved who can be interviewed. Based on these criteria and the meetings with the programme secretaries of ZonMw, fifteen different projects among all eight programmes were selected for this study. Multiple projects within one programme were selected, since this provided the opportunity to gain insight into collaboration in a certain research area. By combining multiple research areas, it became possible to gain insight into preconditions for collaboration between researchers and patients in health research in general.

4.2.2 Recruitment

After the process of selecting programmes and projects, researchers were approached by email whether they were willing to participate in this study. In this email, it was described what the purpose of the study was, what was expected from them, what they could expect from the interview and that there were no negative consequences when they refused to participate. Furthermore, it was made clear that this study is no evaluation of their research project and that this study has no influence on the funding they received from ZonMw. When researchers were willing to participate, an appointment for the interview was made at a time and location suitable for the participant. Subsequently, patients who were member of the research group were also contacted, since contact details were already available from the database of ZonMw. If patients were not a member of the research group, no contact details were available. Therefore, via snowball sampling researchers were asked to come up with a name and email address of a patient who participated in their research projects who could possibly participate in the current study. These patients were also contacted by email whether they were willing to participate in this study. In this email was also described what the purpose of the study was, what was expected of them and what they could expect of the interview. When patients were willing to participate, an appointment for the interview was made on a time and location suitable for them. Also for patients, it was made clear that this study was not an evaluation of their performance in research projects, but that it was intended to learn lessons from. Researchers and patients were recruited until data saturation was reached.

4.3 Data collection

4.3.1 Interview procedure

All 22 interviews were conducted by the same researcher. To ensure confidentiality, only the researcher and the participant were present in the room where the interview was conducted. Ten interviews were conducted at or near the office of the researcher and twelve interviews were conducted by telephone. At the start of the interview, the purpose of this study was explained. Furthermore, participants were put at ease by informing them about that anonymity was ensured and that there were no right or wrong answers. All participants gave permission for recording the interview. All interviews lasted between 35 and 65 minutes and took place in spring 2017.

4.3.2 Interview design

Two interview guides, one for researchers (Annex A) and one for patients (Annex B) were developed. The interview guides were based on the concepts of the conceptual framework (figure 3) and included questions to determine preconditions for sustainable collaboration between researchers and patients in the three domains of the conceptual framework (culture, structure, practice). In addition, six factors that could possibly influence collaboration between researchers and patients were also used in the interview guide as a direction. These six factors are communication related factors, task related factors, patient related factors, researcher related factors, illness related factors and research setting related factors. These factors are explained in annex C. In order to compare the results of the researchers and patients, the basis of the interview designs were similar and was adjusted to the situation of each participant. Furthermore, probing questions and follow-up questions were prepared in order to stimulate participants to reveal the underlying reason(s) for their opinions, statements and experiences. Additionally, in order to gain a general insight into the collaboration, it was asked to scale the collaboration with a mark between 1 and 10. Discrepancies in this mark between researchers and patients in the same project were extensively questioned in order to reveal the underlying reason for this.

4.3.3 Ethical considerations

According to Sanjari *et al.*, (2014) several ethical challenges should be considered in conducting research: anonymity, confidentiality, informed consent, voluntary participation and protection from harm. First, anonymity was guaranteed in this study by ensuring that specific data could not be deducted to the identity of participants. This also ensured that data was processed confidential (Gray, 2013). Second, all participants signed an informed consent to confirm participation in this study. Third, to ensure that participants participated voluntary, extensive information was provided on the purpose of this study to make a considered decision to participate or not. Furthermore, it was made clear to potential participants that there were no negative consequences when they would refuse to participate for instance in the funding they receive from ZonMw. Finally, while conducting the interviews no harm should be granted to the participants (Gray, 2013; Sanjari, Bahramnezhad, Fomani, Shoghi, Cheraghi, 2014). Several types of harm, such as physical, psychological and embarrassment should be avoid while conducting the interviews (Gray, 2013). In this study, the potential harm was minimised by extensively informing the participants about this study to make sure the participants are well informed and well prepared.

4.4 Data analysis

The data gathered in this study was analysed using content analysis. Content analysis involves conclusion making about data by systematically and objectively identifying special characteristics (Gray, 2013). Content analysis takes place in a number of steps, which include 1) transcribing the data, 2) collecting and coding as an iterative process, 3) familiarisation, 4) focused reading, 5) amended codes, 6) interpretation of the data and codes (Gray, 2013). In the first step, the interviews were transcribed verbatim, using Express Scribe Transcription Software. By transcribing the interviews and reading the transcripts thoroughly, the researcher became familiar with the data and the overview of thinking patterns became more structured. Subsequently, the transcripts were analysed by the process of coding by using qualitative analysis software ATLAS.ti. In the process of coding, information is labelled according to codes that classify the information from the transcripts. During the first phase of coding, a coding guide based on the conceptual framework of this study was used, which included the three domains; culture, structure, practice. During the second phase of coding, open coding was

used in order to determine concepts there were not included in the conceptual framework in order to complement the coding guide. These codes were added to the coding guide and adjusted till the last interview was analysed. The coding guide was used to assign labels to the transcripts to identify the key patterns in the data (Gray, 2013). During the last step of interpretation of data and codes, the data related to the labels was placed in the context of the conceptual framework. This was used a directive for writing the results of this study.

4.4.1 Validity and reliability

In order to ensure the objectivity and credibility of the obtained data, it is of great importance to reflect on the validity and reliability of the data (Gray, 2013). Validity refers to the extent to which the data can be generalised to other social or organisational settings and reliability refers to the degree to which the data can be replicated (Verschuren & Doorewaard, 2010). In this study, the reliability and validity were assured by sending a narrative summary of the interviews to the participants after the interviews for verification. This provided the opportunity for participants to check the interpretation of the research and to verify or adjust parts of the interview. Furthermore, expert checking increased the validity of this study (Gray, 2013). Three interviews were coded and discussed with other researchers and supervisors. Discrepancies between the researchers were discussed until consensus was reached. Furthermore, the coding guide was also discussed with different researchers and supervisors to determine the extent of agreement and consistency, which increased the reliability of this study (Verschuren & Doorewaard, 2010; Gray, 2013)

5. Results

In this section the results of this study will be presented. First, a description of the research population and the projects will be described. In order to answer the sub-questions of this study, the collaboration between researchers and patients is described according to the three domains of the conceptual framework; culture, structure and practice. For each domain, the important themes and the relations between these themes will be presented.

5.1 Research population

In total, in twelve projects the collaboration between the researcher and the patient was investigated. These twelve projects included eight different ZonMw programmes; Handicap and Chronic diseases; Efficiency studies; Fundamental research; Visual disabilities (InSight); Innovation programme Rehabilitation; Palliative Care; Mental Health and Medicines. These eight programmes represented a wide variety of research fields and entailed research from fundamental until practice oriented research. In eight projects, both a researcher and a patient participated in this study and were interviewed. In three projects only the researcher was interviewed. In two of these three projects, there were no patients available that could be interviewed. This was due to the involvement of different organisations (e.g. Veilig Verkeer Nederland and ANWB) than patients in the research and due to misunderstanding about patient participation by the researcher. In one of these three projects, the patient was not willing to participate in this study. In one project, only a patient was interviewed. In this case, the researcher did not react on the invitation to participate in this study.

5.2 Culture

In the cultural domain of the collaboration between researchers and patients, several things appeared to be important for researchers and patients. The general perspective towards patients participation from both the researcher and patient perspective will be discussed. The way in which researchers and patients saw patient participation in research influenced how they perceived the role patients in research and how they perceived the added value of the collaboration. This will be discussed subsequently. Additionally, the relationship between researchers and patients appeared to be an important aspect of the cultural domain.

5.2.1 Perspective towards patient participation

In general, researchers had a positive attitude towards patient participation. They agreed on the fact that when conducting a research project for a certain target group, researchers should involve this target group in their research. Researchers should think in 'we' and not in 'we, they'. The patients' perspective increased the relevance of the project, since this perspective showed the relevant aspects for patients in a certain (research) field. As a result, projects followed the wishes and relevant topics for patients. Collaboration between researchers and patients took place during different phases of research projects. For example, patients came with research questions, and researchers initiated a research to answer these questions. Furthermore, when collaborating with patients in research it was easier for researchers to translate the research results to practice.

However, the minority of researchers were critical by mentioning that researchers should not rely on the experiential knowledge of patients and that a compromise had to be found in the researcher's knowledge and the patient's experiential knowledge.

"We are doing research for patients, not for science" (Interview 9, researcher)²

The majority of the participants in this study had a positive attitude towards patient participation. However, it was also noticed that the general perspective of the scientific world towards patient participation is much more negative. The general idea of the scientific world is that researchers do not need to collaborate with patients in research. Currently, the scientific world is more focussed on evidence based research, while research, in which is collaborated with patients, is more focused on practice based research. The focus on evidence based research should be integrated with the input of practice based research. The combination of these would create a new sort of research world in which collaborating with patients becomes a normal phenomenon. According to a number of researchers and patients, this new way of thinking in the scientific world is necessary to create a mind shift.

In fundamental research patient participation was experienced by a number of researchers as more difficult and more challenging compared to practice related research. In more fundamental the 'distance' to practice and patients was much larger compared to practice oriented research. For specialised fundamental research projects specialised knowledge was required, which was not present in patients in most cases. This made it harder for researchers to collaborate with patients during all phases of research. A small number of patients mentioned the same difficulties in research projects that are further away from practice. However, also in fundamental researcher there was also a role for patients. Especially in addressing research topics and the communication to other patients about the research. For example, patients were involved in writing newsletters, patient information letters and the dissemination of the results among patients.

Role of patients in research

The perspective towards patient participation also included how the role of patients in research was perceived. In many projects, patients were involved due to their experiential knowledge with a certain disease or condition. Patients had their world with their experiential knowledge with a certain disease or condition and researchers had their world with their scientific knowledge and expertise. These two worlds collaborated in scientific research, while maintaining both worlds. According to many researchers, it was not necessary for patients to meet the researcher's world. In patient participation, the patient's perspective was the added value of collaborating with patients in scientific research. Therefore, patients did not become a researcher with the corresponding scientific knowledge and skills. The knowledge and skills patients had due to their experiences with a certain disease or condition were sufficient to collaborate in research. For instance, for patients it was not necessary to become trained in research methodology. This knowledge came from the researcher. However, insight in the research process by patients facilitated the collaboration.

The role of patients differed between various phases within a research. This also differed between research projects. In some projects, patients were involved during the entire research process, from involvement in the research proposal until the implementation of the results. However, in the majority of the projects, patients had a specific role, for instance in the communication to other patients, in recruiting patients for the research or in collecting additional funding. Not in all research phases patients had a large role. During the executive phase of collecting data, patients were less involved in a number of research projects. In consultation with researchers and patients was decided in which

²*"Wij doen onderzoek voor patiënten, niet voor de wetenschap"*

research phase it was desirable for the patients to have a bigger role or not. In projects where this was not discussed between the researcher and patients, this had led to frustrations and misunderstanding from both sides.

Added value of collaboration

The way in which researchers and patients perceived patient participation in research is partially based on the experience they had in their current project or previous experiences. This was influenced by how the added value of the collaboration was perceived. The most frequently mentioned added value of the collaboration with patients was the different perspective that was brought in by patients. This made researchers more aware whether they were using the correct methods to find the information they needed. Patients came up with interesting and surprising aspects and ideas, where researchers were used to address these aspects of research differently. The patients' perspective also increased the relevance of the research. When important topics for patients were taken into account in the study, the study was more in line with the needs and wishes of patients. Furthermore, the applicability of a research was increased. In almost any research it was necessary to involve the results of the study into practice. When involving patients in a research project, this translation to practice was almost made automatically, because patients were involved during the research process. Thereby, practice is taken into account during the process and the translation from research results to practice already took place. The following quote illustrates how a patient perceived the added value of the collaboration:

“I think patients can solve some blind spots of researchers. Researchers have quite a distance to practice, and we do not. I experience what is going well and what is going wrong. I think that the experiences in practice are a valuable contribution to a research project and also affects the results of the research.” (Interview 8, patient)³

Furthermore, the collaboration with patients was of added value in the acceptance of the research by other patients. In one research, there was an email address launched for patients, where they were able to ask questions about the research and ask questions to experts by experience. These questions were answered by the patients who collaborated with the researchers in that project. As a result, patients were more willing to participate as a subject in the study. When patients or experts by experience supported a research project, other patients were more willing to participate in that research project as a research object. Additionally, researchers were also forced to explain their research in conceivably language for patients, when collaborating with patients. This made them focus on the core aspects of their research. This was also supporting in the acceptance of the research by other patients.

Despite the fact that the vast majority of both researchers and patients experienced added value of their collaboration in the research project, they experienced that the majority of the academic world was unaware of the added value of collaborating with patients. Many people in the academic world did not see the possibilities in collaborating with patients or did not perceive the added value. Collaborating with patients in research projects should be a natural process in the academic world according to the majority of the researchers and patients in this study.

³ *“Ik denk dat patiënten blinde vlekken van onderzoekers kunnen wegwerken. Onderzoekers staan redelijk ver van de praktijk, en dat staan wij niet. Ik denk dat juist die praktijk ervaring in projecten ook voor de onderzoekers een waardevolle bijdrage levert en ook zijn effect heeft op het resultaat.”*

5.2.2 Relationship between researcher and patient

A relationship between researcher and patient was of great importance when collaborating (intensively) in a research project. In this relationship it was important to be aware of the possibilities and impossibilities of all stakeholders involved. One researcher mentioned that it took them almost a year before they were completely used to each other and were aware of each other's qualities and capabilities. Therefore, it saved time at the beginning of a research project when researcher and patients have built a network surrounding them with researcher and patients in their research field.

Despite the fact that it can take a lot of time to create a relationship in the first phase of a research, it was of great importance to discuss each other's expectations about the research. This prevented misunderstanding and mistrust. Patients and researchers in a few projects became frustrated when expectations were not communicated in a right manner at the beginning of a research and misunderstanding arose. Consequently, patients did not feel appreciated and acknowledged. Furthermore, a respectful relationship, which includes honesty and equality was of great importance for all patients. This made them feel at ease, and made them more open towards the researchers. A pleasurable ambiance also stimulated this. For instance multiple patients experienced that researchers who brought biscuits to their meetings and a warm welcome created this pleasurable ambiance.

Many researchers and patients experienced that their relationship was equal, which was experienced as very pleasant. Patients felt equal within the research group they were collaborating with. In an equal relationship the position of the patients was acknowledged and appreciated and researchers were taken the input of patients more seriously. Within the research group each individual had his or her one position and each individual contributed by his or her own expertise. The researcher contributed by bringing in scientific knowledge, the medical professional by bringing in medical knowledge and the patient by bringing in experiential knowledge. Within an equal relationship, the group members were dependent on each other. Patients needed researchers but researchers also needed patients for their research. The following quote illustrates how a patient perceived the relations within the research group:

"I feel connected to the research group, there is no distinction. Everyone has his or her own role and brings in his or her specialism and expertise." (Interview 5, patient)⁴

Another aspect of an equal relationship between researchers and patients is related to balanced meetings. For patients it felt intimidating that there was an unequal distribution in researchers and patients in a meeting. A meeting with eight researchers and one patient or patient representative felt unequal for patients. Also researchers acknowledged that this aspect is of great importance to create an equal relationship.

Communication between researchers and patients was of great importance to create a (equal) relationship and also for collaborating. A good communication structure between researchers and patients enhanced the relationship on one hand, and on the other hand a lack of communication structure impeded the relationship. All researchers and patients communicated through email, phone and also face-to-face meetings. Email contact was important for communication, since this can be done quickly and at any time when it fits people. However, for researchers it was easy to communicate through email, since they worked at their computer every day. However, receiving a reaction from patients through email was perceived by some researchers as more challenging sometimes, due to

⁴ *"Ik voel me één met de onderzoeksgroep, er is geen onderscheid. Ieder heeft zijn of haar eigen stem en brengt zijn of haar specialisme en expertise in."*

older patients or patients who did not check their email daily. This required creativity and time to discover a new communication style that fitted both researchers and patients. Patient organisations could, for instance, act as a communication bridge between researchers and patients in situations where a new communication style needs to be established. Patient organisations had experience in communicating with patients regarding research. This expertise and experience facilitated the communication process between researchers and patients

Next to email and phone contact, face-to-face meetings were important to create and maintain the relationship between researchers and patients. In addition, the majority of the patients mentioned that they appreciated updates about the research in research phases where they were not collaborating intensively.

5.3 Structure

In the structural domain of the collaboration between researchers and patients, several structural elements, such as time, money and workspace appeared to be important in the collaboration between researchers and patients. Additionally, these structural elements were also connected to each other. For instance, in the scientific world, money is related to time. When there is money to conduct a research, there is time to execute the research. These structural elements of the collaboration between researchers and patients will be discussed below.

5.3.1 Structural elements

In a collaboration between researchers and patients there were many structural factors that needed to be arranged and discussed, such as the (financial) reimbursement patients received. Especially in the first phase of the research these arrangements had to be made. Arranging reimbursement for patients, and arranging reimbursement of travel expenses took a lot of time for researchers at the beginning of a number research projects. For patients who received a benefit, this was sometimes problematic, since they could lose their benefit if they had another income next to their benefit. This caused some difficulties and delay at the beginning in a number of research projects.

The financial reimbursement and the reimbursement of travel expenses for patients were included in the budget in all research projects. At the beginning of all research projects, the researchers made an estimation of the budget, which included the costs of collaborating with patients. However, during the process, it appeared that in a number of the research projects the budget was not sufficient. For instance, costs of taxis were not taken into account in the budget or some aspects, such as costs of organising meetings, were higher than estimated in a small number of research projects. Many researchers addressed the point that they would have liked to have more flexibility in their budget. They preferred more flexibility in shifting money to different aspects of the research.

As mentioned before, researchers and patients experienced it as important to collaborate at an very early stage of a research project. However, many researchers addressed the point that this was not possible at that moment since there was no funding assigned to the research project yet. This made it impossible for researchers to reimburse patients for their input in the research project in that phase. One researcher mentioned that they invested as a department in the collaboration with patients at that moment. Furthermore, a researcher argued that they would preferred to have a structural patient panel, which can always be consulted when necessary, independent on whether the research project already has assigned funding to. However, for establishing a patient panel, money and time is needed.

Financial reimbursement

The vast majority of the patients agreed that reimbursement of travel expenses was important and indispensable. About half of the patients mentioned that they were also willing to collaborate with researchers if there was no financial reimbursement. For them it was more important to feel appreciated and to contribute with meaningful input, instead of receiving a financial reimbursement, as illustrated in the following quote:

“I receive a financial compensation, but that is not why I am doing it. It is about the feeling you can make a valuable contribution, that is why you are doing it. Appreciation, not in a financial way, but in seeing that your input is taken into account, that is important.” (Interview 8, patient)⁵

On top of that, there were also a few patients who did not want to receive reimbursement. For them it was important to be appreciated by the contribution to the research project and they did not want it to be a job for which they got paid. For researchers, it was experienced difficult when patients did not receive reimbursement, because it was hard to estimate to which extent they could oblige patients to honour existing commitments. However, the other half of the patients mentioned that a financial reimbursement is necessary due to the amount of time they had spent on the research project.

Time

In the scientific world, money is related to time. When a research project will take more time, also more money is needed. For collaborating with patients a sufficient amount of time was an important condition, as mentioned by the vast majority of the participants of this study. However, in the scientific world, there is a time pressure on every research project which made collaborating with patients more challenging. As mentioned before, in the first phase of the research project, it was important to build a relationship between the researcher and the patient. For some researchers and patients this took a lot of time. Especially when the researcher and the patient had to collaborate intensively, it took several months up to a year before the researcher and patient were used to each other. In other projects, where the researcher and patient already knew each other, this saved a lot of time.

Researchers and patients experienced several aspects in their collaboration that took a lot of time or that took more time than expected. When estimating the amount of time of different aspects of the research would take, the researchers took themselves as a reference. However, patients were spending much more time on reading papers, preparing meetings or preparing presentations. This was not taken into account, and slowed down the research process. Another aspect that slowed down the research process, was the process of taking decisions in the research project. Researchers and patients needed to have meetings and good conversations with each other in order to come to a decision, which took a lot of time. Some decisions were discussed back and forth with patients instead of just taking the decision by the researcher. Furthermore, most researchers were used to conduct research in a certain way without patients. Finding a new way of working, conducting a research and collaborating with patients took more time for researchers. Some researchers were used to this new way of working very quick and for them it felt as a natural way of working. On the other hand, for some researchers this was more challenging and was it a learning processes for themselves as well. The following quote illustrates how a researcher experienced the extra time collaborating with patients took:

⁵ *“Ik krijg een vergoeding, maar dat is niet waarom ik het doe. Het gaat om het gevoel dat je een waardevolle bijdrage kan leveren, dat is waarom ik het doe. Waardering, niet in financiële zin, maar in dat je terugziet dat er wat met je inbreng is gedaan, dat is belangrijk.”*

“The pace you expect in a project is a very different pace than what you can achieve when you really want to take the input of patients seriously.” (Interview 17, researcher)⁶

The majority of the researchers experienced that when collaborating with patients their research project took more time to conduct compared to research projects where they were not collaborating with patients. However, according to a small number of researchers, collaborating with patients did not take extra time. For them, patients were part of the research group, for which no extra time was needed to collaborate with patients. Collaborating with patients was for a number of researchers also experienced as time saving, since their research was done more efficiently and more relevantly for patients.

Workspace

A permanent workspace or the same location where meetings were held was experienced as pleasant by both researchers and patients. For patients it was important that they felt comfortable at the location. For a number of patients it was also important that the location was also easily accessible by public transport or by car. Furthermore, when researchers and patients were situated across the Netherlands, it was experienced more challenging to find a suitable time and place for everyone for face-to-face meetings. These meetings did have to be at the office of the researcher, also other locations were suitable, such as a conference centre or a museum.

5.4 Practice

In the practical domain of the collaboration between researchers and patients several themes appeared to be important. First, the practical elements of the collaboration, such as the contribution of the patients and in which phase they were involved, will be discussed. The input patients made to the research, was partially influenced by the skills and knowledge of patients, which will be discussed subsequently. Secondly will be discussed how was dealt with the patients and their input. In which language was an important aspect.

5.4.1 Collaboration

In most projects, there was collaborated with patients during most research phases. Depending on the phase to a greater or lesser extent. In a small number of projects, patients were involved during the phase of preparing the research and writing the research proposal but in the majority of the projects, patients were involved from the start of the project. Patients came up with relevant research topics for them and provided feedback on the research proposal. Furthermore, patients were involved in the process writing the patient information letter, how patients could be approached for participating in the research, how the inclusion of patients could be improved, checking and providing feedback on the questionnaires, interviewing, analysis and interpretation of data, implementation of results and writing newsletters for patients. The more intensive and more difficult tasks, such as interviewing and data analysis, were only performed by patients when the patient collaborated with the research in the role of a co-researcher. In this role, the patient also performed research tasks next to patient related tasks. In many projects, patients provided feedback on the questionnaire that was used. However, researchers experienced some difficulties in implementing this feedback on the questionnaire, as they used valid questionnaires. It was not possible to adapt these valid questionnaires completely taking the feedback of the patients into account, as the questionnaire would not be valid anymore. Researchers and patients solved this by adapting the questionnaire in

⁶ *“Het tempo wat je bedenkt in een project is een heel ander tempo dat je kan waarmaken op het moment dat je echt de inbreng van patiënten serieus neemt.”*

the range of the possibilities of a valid questionnaire. The following quote illustrates how a researcher experienced it to collaborate with a patient:

“It’s difficult, it isn’t easy, it asks creativity, it asks letting it go, you will encounter unexpected things, you will lose control, but then you know why you are doing it.” (Interview 4, researcher)⁷

The vast majority of the patients experienced it as essential that they were involved in the research from the very beginning of the research project. By involving patients from the beginning, patients were aware of the entire process that already took place, they felt more connected to the project and the researchers and they knew better what was expected from them. This was related to the fact that patients preferred that the study design and the goals of the research were clear to them and no surprises will come along during the research process. When patients were involved from the beginning of the research, they were involved in designing the research, which made it easier for them to be aware of the study design.

Skills and knowledge

In order to contribute to the research project it was experienced by the majority of the researchers and patients, that it was helpful for patients to have a relevant background or working experience in the field of research. This helped them to be prepared for collaborating with researchers. For a number of researchers it was more challenging to collaborate with patients when they were new in the research world, since it was difficult for patients to feel comfortable in the research world. Furthermore, it was taking a lot of time before patients were used to the research world. According to the vast majority of the researchers and patients it was for patients not necessary to have research skills. For patients it was important to have experiential knowledge. Furthermore, for patients it was considered of great importance to have an helicopter view, which means that not only his or her perspective had to be represented, but the perspective of all patients with that certain condition or disease. This was experienced as problematic by a small number of researchers. One researcher experienced that the patients from the patients organisation, who were involved in the research project failed in bringing in the perspective of all patients in general, but represented their own perspective.

When recruiting patients for a collaboration within a research project, it was essential to take a person’s qualities and skills into account according to a number of researchers and patients. In some research projects, this caused some difficulties in recruiting patients for the collaboration. There is not a large group of patients available who are willing to collaborate in research and these patients also needed to have certain knowledge and skills, which makes it difficult for researchers to find patients. However, patient organisations, General Practitioners (GPs) and the researchers’ own networks supported in recruiting patients for the collaboration.

Furthermore, patients’ qualities and preferences were taken into account when starting a new research phase. Multiple researchers and patients agreed on the fact that it was important to consider which activities fit a person’s preferences, qualities and skills. This had to be considered at the beginning of every new phase. In consultation with researchers and patients it was decided what the role of the patient would be in that phase. Other researchers and patients discussed this at the beginning of the research.

⁷ *“Het is lastig, het is niet makkelijk, het vraagt creativiteit, het vraagt loslaten, je komt onverwachte dingen tegen, je raakt de controle kwijt, maar dan weet je wel waarom je het doet.”*

5.4.2 Dealing with patients and their input

For all patients it was extremely important that the researchers were serious in dealing with the input the patients gave. However, in some situations it was for the researchers not possible to meet the wishes of the patients, due to limitations in time, money or external barriers, such as funding restrictions or disapproval of the Medical Ethics Review Committee (METC). This needed to be explained by the researcher to the patient why their input could not be taken into account in the research. Patients became frustrated when they experienced that researchers were not taken their input seriously. This also damaged the relationship between the patients and the researcher and created a huge amount of mistrust. Therefore, it was mentioned by the majority of the researchers, as important for researchers to explain appropriately to the patients why it was not possible to use their input in the research. The frustration and mistrust when researchers were not taken the input of the patient seriously is illustrated in the following quote:

“Eventually, it’s just taking someone by the hand for a long time and creating trust. And the moment you have to walk a ravine, they leave you. When it matters, we would have liked to see acknowledgement of that trust.” (Interview 2, patient)⁸

For some researchers it was also difficult to accept that patients were involved in their research and it was for them sometimes difficult to let go some aspects of decision making and influence on the project. However, in the process of the collaboration it was becoming more easy, since they saw the benefit of the collaboration. This was a learning processes for these researchers as well.

As mentioned before, for patients it was of great importance that researchers were taken their input seriously. The vast majority of the patients experienced it as pleasant when researchers did not had a tunnel vision and were open for their input during the research process. Furthermore, it was experienced as pleasant by all patients when they recognised their input in for instance a patient information letter, questionnaire or decisions that were made regarding the research design. Patients felt appreciated and heard at these moments. This created trust and stimulated the relationship between researchers and patients. When patients gave more meaningful and more valuable input, the researcher were also more inclined to use this input, which caused positive experiences by patients.

In collaborating with patients in research it was for researchers not only important to deal with the input the patients gave, but it was also important to take the disease or condition of the patients into account. This was done by planning meetings at an appropriate place and time for the patients. For instance, when collaborating with patients in wheelchairs the location needed to be wheelchair accessible. The vast majority of the patients experienced that their disease or condition or their preferences were taken into account when collaborating. However, one patient felt uncomfortable due to all the adjustments that had been made by the researchers when taking the condition into account.

Another aspect of dealing with patients, which is also related to taking the disease or condition of patients into account, is the workload capacity of patients. The majority of the researchers did not wanted to overload patients, who are dealing with a disease or condition. When several patients are involved in the research project, it was experienced easier to not overload patients. As mentioned before, in a number of research projects there was discussed at the beginning (of every phase) what

⁸ *“Uiteindelijk is het als je iemand bij de hand neemt en dan vertrouwen wekt. En op het moment dat die een ravijn over moet lopen, laat je hem los. Als het er echt om gaat hadden we heel graag dat vertrouwen erkend willen zien.”*

the role of the patient would be. When multiple patients are involved, a suitable role for each patient was found. This decreased the chance of overloading patients. Furthermore, patients mentioned that they felt stronger within a research group when there were more patients involved. However, a number of researchers also mentioned that the patients who are involved in the research, were easily asked for other research projects or other projects. This increased the workload for patients. Therefore, these researchers were careful with this.

Language

Language was an important factor that was encountered in practice by researchers and patients. Scientific literature and jargon was sometimes difficult to understand for patients. Especially the literature written in English was difficult and took a lot of time to understand and read. This was especially the case in projects in which patients were co-researchers and performed also researcher tasks next to patient related tasks. Furthermore, it was experienced by a number of researchers and patients that they were speaking a different language. Researchers were speaking their scientific language and patients were speaking their patient language. This could be illustrated by the following example. A number of researchers mentioned that there were differences in the perspective of a 'good' research from the researcher's and patient's perspective. For patients, a 'good' research was more related to a good outcome of the research. However, for researchers this was more related to the scientific and methodological quality of the research. This difference in definition caused misunderstanding and tension between researchers and patients. The language difference is illustrated by the following quote:

"Somebody says something and then you have to translate it into what it means for the research. It was not always easy to understand for us what the patients were saying." (Interview 12, researcher)⁹

In some projects, this was extensively discussed in order to create a common definition and a common language. In contrast, in one research project the researcher and patient did not come to a common language, which caused frustrations on both sides.

Despite the fact that not speaking the same language caused difficulties, it was also of great value for the research. Patients were bringing in their patient language, consequently researchers were forced to take this perspective into account in their research. Furthermore, the patient language was also of great importance for the communication to other patients. For instance, in the patient information letter.

⁹ *"Iemand zegt iets en dan moet je het vertalen naar wat het dan betekent voor het onderzoek. Het is voor ons niet altijd makkelijk om het te begrijpen wat de patiënten zeggen"*

6. Discussion

6.1 Main findings

The aim of this study was to gain insight into preconditions for sustainable collaboration between researchers and patients in order to provide recommendations to ZonMw to improve patient participation in research projects funded by ZonMw. For each domain - culture, structure, practice - in which the collaboration needs to take place for a sustainable collaboration, important preconditions were identified.

In the cultural domain, an important precondition was that researchers and patients needed to see the added value and the benefits of the collaboration. When researchers were really seeing or experiencing the added value of the collaboration, they had a more positive attitude towards collaborating with patients and were also more willing and motivated to collaborate. The relation between a positive attitude towards patient participation by seeing the added value and willingness to collaborate was previously described by Abma *et al.* (2013). They described that researchers became more motivated to collaborate and more open-minded when they had insight into the added value of the collaboration. Making the added value explicit on a larger scale could for instance serve as an incentive to new researchers to start to experiment with collaborating with patients (Elberse, de Boer, Broerse, 2017).

The positive attitude towards collaboration with patients that was found in this study is in contrast to what is written in literature. In literature, the perspective of researchers towards patient participation is much more negative. Researchers see many barriers for collaborating with patients, are a bit anxious and think that collaboration with patients is not applicable to their research (Abma, Broerse, Elberse, Wit, 2013; Dedding & Slager, 2013). Furthermore, they see patients as research objects and not as partners in their research. This contradiction could be explained by the 'Social Learning Theory' (Bandura & Walters, 1977). This theory states that new patterns of behaviours and attitudes can be acquired through direct experiences or by observing the behaviour of others. As a result of previous experiences, people will value certain outcomes more (Bandura & Walters, 1977). The participants of this study learned through experience and observations during their current or previous research projects the added value of collaborating with patients. This caused them to be motivated and willing to collaborate with patients for now and also in the future.

Furthermore, an equal relationship between researchers and patients was an important precondition. In an equal relationship the position of patients was acknowledged and appreciated and researchers were taken the input seriously. However, creating this equal relationship could take a lot of time. Therefore, it was for researchers important to investigate in a network of patients and patient organisations surrounding researchers in their research field. These findings are in line with previous literature. A review of D'amour *et al.* (2009) stated that an equal relationship between stakeholders is essential for collaboration. A non-hierarchical relationship and a relationship in which stakeholders are equal are frequently mentioned as attributes of sufficient collaboration.

Looking at the structural domain, an important precondition for researchers is to have flexibility in terms of time and money. When researchers and patients want to collaborate at an early stage, when no funding is received yet, it is important that researchers can shift funding to the stage where this is necessary in order to facilitate the collaboration. This could also make the collaboration more constructive, as researchers can adapt their research project more easily to the wishes and input of patients. This also applies to flexibility in time, where there should be more flexibility in the amount

of time that is spent on different research phases. As a results, researchers can take the input of patients more seriously, as they have the possibility to be more flexible in the division of time over different research phases. From previous experiences, it is known that flexibility is important in collaborating with patients to fit the situation and wishes of patients (Elberse & Broerse, 2013).

In the practical domain of the collaboration an important precondition for sustainable collaboration was that researchers were taking the input of patients seriously. Patients felt appreciated and heard when they saw their input was processed, which was related to providing more meaningful and more valuable input, This made researchers more inclined to use this input. A second important precondition in the practical domain was that researchers and patients should focus on speaking the same language, since English scientific literature and also jargon could result in difficulties for patients in collaborating with researchers. Differences in language, definitions and ideas caused misunderstanding and thereby constrained the collaboration. Focusing on speaking the same language could facilitate the collaboration as researchers and patients could speak more in agreement. A study by de Wit (2014) mentioned that difficulties in language could constrain collaborations in following discussions, understanding documents patients needed to read or questionnaires patients wanted to comment on. This illustrates that language is also an important part of taking the input of patients seriously. On one hand, when patients have difficulties in preparing input due to language differences, it will be more difficult for researchers to take the input more serious, as the input could be less valuable for instance. On the other hand, for researchers it could also be more difficult to take the input serious when they are not speaking the same language as patients, since they do not know what is meant exactly by patients.

6.2 Transition and transition management

Based on the preconditions mentioned above and the results of this study, implications to establish a sustainable collaboration can be made. A transition is necessary to establish this change to a sustainable collaboration. As discussed in chapter 3, for a sustainable collaboration, a transition needs to take place in which profound changes in the cultural, practical and structural domain need to take place. Transition management is necessary to induce this changes. ZonMw, could for instance play a role in this. Therefore, in the following section will be discussed which changes in these domains are necessary in order to establish a transition, and thereby sustainable collaboration.

6.2.1 Structural domain

In the structural domain is was important to consider and change the following aspects. First, it is important to consider and make a realistic estimation of the amount of time and money spent on the research project. Collaborating with patients will take more time than without collaborating. In making an estimation for the amount of time that should be spent on a research project, it is important to consider the skills and knowledge of patients in collaborating in research. By doing this, the amount of time patients will spent on reading papers or preparing meetings will fit their possibilities and thereby match the research process. Furthermore, the decision making process slowed down the research process, as decisions were discussed back and forth. Therefore, it is important to define a decision-making structure (Elberse, 2012). This will facilitate the decision-making process and thereby the research process. Additionally, it is for researchers also important to accept that collaborating with patients can take more time. However, also external organisations which are involved - such as the funding agencies and universities, which evaluate researchers on the amount of publications – should also consider this. They should accept that when collaborating with patients, a research project will take more time, but that this will provide a higher quality and relevance of research.

Second, there should be made some changes in the structural domain with respect to funding and reimbursement. There should be a small amount of funding at an early research phase in order to elaborate on a research proposal. This will enable researchers and patients to collaborate from an early stage. In addition, incentives should be created by funding agencies to establish a collaboration (Elberse & Broerse, 2013). Furthermore, researchers and patients should come to an agreement regarding reimbursement at the beginning of a collaboration, since patients can have different preferences for reimbursement. This reimbursement does not necessarily have to be related to money, but can for instance also be flowers or a gift voucher. However, travel expenses should always be reimbursed.

Despite the fact changes in the structures and practices of a health research system can be adapted, this does not automatically imply that the way of thinking, and the norms and values are changed (Elberse, 2012; Elberse & Broerse, 2013). To establish sustainable collaboration, a culture shift is necessary. This cultural shift involves changes in competences, knowledge, attitudes and skills (Elberse & Broerse, 2013).

6.2.2 Cultural domain

In sustainable collaboration there is a continuous collaboration between researchers and patients during the research process. This is supported by practice and organisational structures, but is mostly driven by willingness to collaborate because researchers and patients acknowledge the added value of the collaboration. In a sustainable collaboration, the workload capacity of patients is taken into account and there is efficiently worked in terms of resources, humans and time. In consultation with all stakeholders there is looked for the optimal way of collaboration and the role of patients in a certain context. It is considered as essential to make the added value and benefits of the collaboration explicit (Elberse, 2012; Elberse & Broerse, 2013; de Wit, 2014). This will keep researchers and patients motivated to continue the collaboration but also to initiate a collaboration. In the current study, all participants acknowledged the added value and the benefits of the collaboration, due to their experiences with collaboration in a research projects. Consequently, they had a positive attitude towards patient participation and were motivated to collaborate. This insight should be demonstrated and be made explicit to persuade other researchers and patients to see the benefits and the added value of a collaboration. For a change in the cultural domain, this would be of great importance in order to establish a sustainable collaboration between researchers and patients. Making the added value explicit on a large scale could serve as an incentive to new actors to start to experiment with patient participation (Elberse, de Boer, Broerse, 2017). Having a clear idea of the added valued increases the understanding of effective collaboration, and could therefore make researchers more motivated to collaborate with patients (Elberse, 2012).

Currently, in general researchers and patients do not acknowledge the added value and benefits of collaborating. This could possibly be explained by two different reason. First, participatory research is not embedded in the current curriculum of the vast majority of scientific and practical education (Dedding & Slager, 2014). This causes that future researchers are not aware of the possibilities of patient participation and that collaborating with patients is also not seen as a logic form of conducting research. However, for collaborating with patients is important to be aware of the background of participation, the preconditions of participation and the tools for the actual collaboration (Dedding & Slager, 2014). Therefore, in order to create a change in the cultural domain, it is essential that patient participation is included in the curricula of both scientific and practical education. Second, there is the general idea that collaborating with patients contributes to a more relevant and more effective care of better quality (Pollard, et al., 2014; Groenewegen et al., 2016). However, the impact of collaborating with patients is difficult to determine (Groenewegen et al., 2016). There is no consensus on what

impact exactly implies: empowerment of patients, change of research procedures, more needs-oriented health research, better health outcomes or changing values and attitudes of the involved stakeholders (Boote, Barber, Cooper, 2006)? This causes that researchers and patients need to invest time, money and resources in an approach, where there is limited scientific evidence of its effectiveness. As this study showed, making the added value and the benefits of patient participation more explicit to researchers could change the attitude of researchers. However, more scientific research is necessary in order to make the effectiveness of patient participation clear.

6.2.3 Sustainable collaboration

For a change from one-off and ad hoc participation to sustainable collaboration, it is important to change aspects of the structural domain of the collaboration. Realistic time estimations, a decision-making structure, funding at an early research phase, flexibility in time and money and agreements regarding reimbursement are important aspects to consider and adapt. However, in order to establish a sustainable collaboration, also a shift in the cultural domain is necessary. An important precondition for this would be making the added value and benefits of collaborating in health research explicit. Therefore, changes in the curricula of scientific and practical education should integrate participatory research and more scientific research is necessary in order to demonstrate the effectiveness of patient participation. Furthermore, the research projects where patient participation is successful, could occur as ambassadors of patient participation. This could cause that patient participation is embedded in the norms and values of researchers and patients. However, a transition is a long and laborious process, because the current system is refractory. Therefore, a transition is not expected on a short term. A sense of urgency needs to be created at researchers and patients, but also at external organisations (Broerse, Elberse, Caron-Flinterman, Zweekhorst, 2010). From the changes in the structural and cultural domain, the changes in the practical domain will follow. As the structure and culture is adapted, patient participation is executed differently, in a more sustainable way, which will also result in some practical changes.

6.3 Implications

To our knowledge this is the first qualitative study that investigated preconditions for sustainable collaboration within the cultural, practical and structural domain. Previous studies described facilitators and barriers for structural collaboration in health research (Abma et al., 2013) and how to realise patient participation in health research in a way that it is embedded in the research system (Elberse, 2012). The current study focused specifically on collaboration between researchers and patients, while other studies were focussing on patient participation. In patient participation, tokenism is a frequently occurring phenomenon in which researchers are giving a voice to patients in the decision-making process. However, the researchers are still responsible for definitive decisions. In contrast, in a collaboration, researchers and patients collaborate during the entire research process, decisions are made jointly and the different perspectives are taken into account. This can lead to outcomes supported by both researchers and patients. By focusing on the collaboration between researchers and patients more in-depth insight was gained in the concept and process of patient participation.

The current study provides useful findings for health policy, which aims to improve patient participation in health care research. The results show policy makers important preconditions for researchers and patients in order to establish a sustainable collaboration. Policy makers should take these preconditions into account when developing new policies regarding patient participation or when adjusting current policies regarding patient participation for health research institutions.

Furthermore, health research funding agencies, such as ZonMw, should consider whether they have a role in meeting these preconditions. Funding agencies will mostly be involved in the preconditions of the structural domain. For instance, funding agencies could make adaptations in their policies regarding funding at an early research phase. However, since the different domains are interrelated, funding agencies will also have a role in the cultural and practical domain. For instance, funding agencies can be involved in the cultural domain in demonstrating the added value and benefits of the collaboration or in providing information regarding the effects of patient participation on the quality of research and quality of care. In the practical domain, information could be provided on how to collaborate with patients. Recommendations towards ZonMw will be discussed in chapter 7.

Furthermore, researchers are also of great importance in order to establish a transition to a sustainable collaboration between researchers and patients. This study provides information for researchers about important aspects and preconditions which they should take in mind when initiating collaboration with patients. The results of this study also show researchers that it is possible to collaborate with patients in a structural and sometimes sustainable way and that is important to experience collaborating with patients. However, there are also several difficult elements in collaboration with patients. Demonstrating this, it could provide researchers insight into the process of collaborating with patients and could cause that researchers will be more prepared for collaborating with patients and eventually probably more willing to collaborate. This could contribute to higher quality research.

6.4 Strengths and Limitations

6.4.1 Strengths

Evaluating this study, there are a number of strengths. First, by including a wide variety of research projects of a diverse range of ZonMw programmes a representative sample of the entire health research field was used. This implies that the results of this study can be generalised to a broader field of health research. The wide variety of projects provided the opportunity to gain insight into preconditions for sustainable collaboration for certain research areas. However, by combining multiple research areas, it became possible to gain insight into preconditions for collaboration in health research in general, which increased the generalisability of this study.

Second, using the method of semi-structured interviews provided the in-depth insight into preconditions for sustainable collaboration. To date, many studies have been performed with respect to patient participation. Advantages and disadvantages of patient participation, difficulties in patient participation and facilitators and barriers for patient participation have been studied. However, especially this in-depth insight into collaboration between researchers and patients was lacking. This in-depth insight was gained by this study. Therefore, it can be said that using semi-structured interviews is a strength of this study, as the correct method for the purpose of this study was used.

Third, data saturation was achieved during the interviews. In the last four interviews with researchers and in the last three interviews with patients, no new elements of collaborating in health research were mentioned. Furthermore, the three domains were at that point also discussed extensively by all participants. This implies that data saturation was achieved. Achieving data saturation implies that the sampling strategy of this study was sufficient for this study.

Lastly, all participants of the interviews were very enthusiastic about the study and were willing to participate. This indicates that the topic of patient participation matters for researchers and patients and that they are thinking about it. For many researchers and patients it was also important to show

the benefits and added value of their collaboration to convince other researchers to collaborate with patients. This shows that the research topics of this study is not only of great importance for funding agencies, such as ZonMw which indicated the knowledge gap in the first place, but also for researchers and patients who are working on patient participation.

6.4.2 Limitations

There are also a number of limitations of this study. First, there could be selection bias in this study. A selection was made of projects where collaboration was taking place, because one of the selection criteria was that there had to be patients involved in the research project that could possibly be interviewed. By doing this, a relatively large part of the research world was excluded as there is no collaboration between researchers and patients in the majority of the research projects. This could have caused that the results of this study do not represent the entire research field. The attitude towards patient participation in this study could be more positive, compared to the entire research field, since it was found that when researchers experience collaboration with patients they see the added value and benefits and their attitude will become more positive. However, in order to conduct a research on collaboration, it is important to have insight from both the researcher and the patient perspective. Therefore, for this study it was necessary to only include research projects where was collaborated with patients. Otherwise, it would not have been possible to gain insight into collaboration from a researcher and patient sight.

Second, around half of the interviews was conducted by telephone and the other half was conducted face-to-face. By conducting the interviews by telephone, the researcher was not able to react on the non-verbal attitude of a participant. This could have caused differences in results for both methods. However, no different results were found in the face-to-face interviews compared to the telephonic interviews, which implies that this was not of a major influence on the results of this study. Furthermore, by conducting telephonic interviews it was possible to conduct a large number of interviews in a short amount of time. This large amount of interviews caused that data saturation was achieved for both researchers and patients.

Third, all interviews were conducted by the same researcher. This makes this study sensitive for researcher bias (Pannucci & Wilkins, 2010). This could have influenced the results, since only the interpretation of one interviewer was used when conducting and analysing the interviews. However, the coding book and the process of coding was discussed with a supervising researcher and three interviews were coded by a fellow-researcher and discussed until consensus was reached. This reduced the chance that interpretation of data was dependent on only one researcher.

Lastly, the patients that were included in this study were mainly high educated people in general. This could have influenced the results in that researchers and patients were experiencing the collaboration as more positive, because higher education patients have probably more insight in the research world and could therefore also provide more valuable input. As researchers get more valuable input of patients, they also experience the added value of the collaboration more, which causes a more positive attitude. From literature is know that patients with a higher educational level, developed skills to discuss with researchers and to argue their input (Broerse, Pittens, de Lange-Tichelaar, 2013). This could have caused a more positive experiences at both researchers and patients. However, the general experiences researchers and patients had and the structural and practical elements they encountered are mostly little influenced by the level of education of the patients. Furthermore, also people with a mild mental disability participated in this study. These people are not highly educated, and the collaboration was in these research projects also experienced as positive.

6.5 Further research

There is a number of implications for further research in the field of patient participation. First, more research should be conducted on the effects and effectiveness of patient participation. From this study it is known that is essential to make a shift in the cultural domain to establish sustainable collaboration, wherefore it is important that researcher experience or acknowledge and see the added value of patient participation. By conducting research on the effects and effectiveness of patient participation, it will be become more clear and explicit for researchers what the added value and the benefits of patient participation are. This will contribute to a shift in the cultural domain. Furthermore, more research should be conducted on how a shift in the cultural domain should be organised. From this study it is known that is important that researchers see or experience the added value of patient participation. However, more research is necessary in order to investigate whether there are more ways to establish a shift in the cultural domain and how this needs to be arranged. This reflects on an implication for further research, that more research is necessary on how the new domains of culture, structure and practice have to be shaped in the new system. The current study provided preconditions to make a shift in these domains, but further research is necessary to determine how health research should look like in the three domains. With these insights, it can be determined more specifically what is needed to come to a sustainable collaboration in the end.

6.6 Conclusion

To establish a shift from ad hoc and one-off collaboration to sustainable collaboration a transition is necessary. Several preconditions in the cultural, structural and practical domain are important to initiate this shift and are thereby preconditions for sustainable collaboration. An important precondition is that researchers and patients need to acknowledge the added value of collaborating. This can be accomplished by experiencing the added value during a collaboration, or by for instance using ambassadors who demonstrate the benefits and the added value of the collaboration to colleagues. Furthermore, an equal relationship between a researcher and a patient was an important precondition. In an equal relationship the position of patients was acknowledged and appreciated. In the practical domain, an important precondition for sustainable collaboration was that patients were taken seriously and also the input of patients was taken seriously. This made patients feel heard and appreciated, and caused them to provide more valuable input for the rest of the research project. Additionally, in the structural domain it was an important precondition for a sustainable collaboration to have flexibility in terms of time and money. Flexibility provides the chance to follow the wishes and needs of patients.

In order to make a shift from ad hoc and one-off collaboration till sustainable collaboration, adjustments in the cultural, structural and practical domain have to be made. To adjust the cultural domain, changes have to be made in the norms, values and shared images of stakeholders. For this it is important to make the added value and the benefits of the collaboration explicit, to exhibit successful examples or to experience collaborating with patients. This will eventually cause that stakeholders become more motivated to collaborate and will see collaboration in health research as a logical process. Funding agencies, such as ZonMw, could play a role in this. Furthermore, funding agencies should also make structural changes in order to create a shift in the structural. However, transitions are complex, and the shift to a sustainable collaboration could take a long time.

7. Recommendations

Considering the results of this study, recommendations towards ZonMw can be made. ZonMw could use these recommendations to critically reflect on their current policies and to reflect on possible future policies. Based on the recommendations and possible changes in policies of ZonMw, patient participation in research could be improved. In the following section the three main recommendations to ZonMw will be discussed. However, in the Netherlands healthcare funding agencies also finance healthcare research. These funding agencies are facing the same difficulties in stimulating patient participation. Therefore, other funding agencies next to ZonMw could consider this recommendations into account.

Ambassadors

As mentioned before, it is for researchers and patients of great importance to acknowledge or see the added value and the benefits of the collaboration. ZonMw could facilitate this by using ambassadors of patient participation. There are multiple research projects in which the collaboration between researchers and patients is occasionally sustainable. These research projects could function as ambassadors of their research field and illustrates thereby the added value and benefits of a collaboration. Not only the added value and the benefits of the collaboration should be illustrated, but also the effects on the quality of care should be demonstrated. ZonMw could demonstrate these ambassadors in multiple ways. First, on the website of ZonMw¹⁰, interviews with researchers and patients can be displayed. If desired, also contact details of the researchers and patients could be provided, which makes it easier for other researchers and patients to contact these ambassadors when they have questions. Second, ZonMw could invite ambassadors on information events regarding new research calls. This provides the opportunity for ambassadors to demonstrate their experiences. These experiences should not only be made explicit to researchers, but also to patients.

Requirement

In order to stimulate the patient participation in health research, ZonMw could make patient participation a requirement in new ZonMw research calls. However, as mentioned above, it is for researchers important that they see the benefit and the added value of patient participation. In a number of ZonMw programmes, patient participation is already a requirement for funding. In these programmes, they noticed that it is still difficult for researchers how to execute this. Therefore, ZonMw should provide more information regarding different methods on how to collaborate, what ZonMw means by collaborating with patients, how researchers and patients should shape the collaboration. However, more research is necessary what the specific requirements should be for each research programme. As collaborating with patients in health research is different for each research field and each research type, it is important to make tailor made requirements for each programmes.

Making participation a requirement for funding, also means that in reviewing the research proposals, the different aspects of patient participation should be taken into account. There should be focused on the financial budget, but also on the exact plan of the collaboration. Reviewers should also be trained in judging research proposals on patient participation. Furthermore, also during the research project, there should be evaluated on patient participation. From previous experiences is known when the collaboration is not executed as planned, and ZonMw currently does not evaluate this strictly. Therefore, also in the evaluation half-way and in the evaluation at the end of the research project, ZonMw should focus on the execution of the collaboration. Additionally, when difficulties are

¹⁰ <https://www.zonmw.nl/nl/over-zonmw/participatie/>

experienced in the collaboration, ZonMw could also fulfil the role of independent referee. For instance, when there is a conflict between a researcher and a patient ZonMw could mediate this conflict. This could cause that a collaboration can be continued.

Flexibility

As discussed above, flexibility in terms of money and time is of great importance for a (sustainable) collaboration. Many researchers addressed the point that when collaborating with patients it is difficult to make an estimation of the amount of time that will be spent on a certain research project. However, currently researchers have to provide a detailed time schedule for their research. When there is a need to adapt this time schedule, for instance due to the input of patients, it takes a lot of time and effort for researchers to get permission for this at ZonMw. Therefore, ZonMw should be more flexible in time schedules. This will facilitate the collaboration, as the research project could follow more easily the wishes and needs of patients when necessary and not after when permission is given. Also more flexibility in the division of money should facilitate the collaboration for the same reason. Multiple researchers acknowledged that when collaborating with patients, it is impossible to know the entire progress of the research project on beforehand. Therefore, ZonMw should be more flexible in this.

Another aspect that is related to flexibility is funding at an early research phase. ZonMw should provide a small amount of funding to research projects in order to elaborate on a research proposal in collaboration with patients. Currently, the lack of funding is experienced as a barrier for collaborating by many researchers. Furthermore, patients preferred to be involved from the early beginning of the research project, this helped them in collaborating with researchers in the rest of the project. Therefore, by providing a small amount of funding at an early research phase, collaboration between researchers and patients could be more solid from the beginning. However, more research is necessary on how to design this, how much funding should be provided and how is decided who will receive the funding.

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Annex A: Interview guide researchers

Erg fijn dat u wilt deelnemen aan dit onderzoek en tijd heeft vrijgemaakt voor dit interview. Ik zal eerst wat algemene informatie geven over het onderzoek en daarna zal ik beginnen met de vragen. Ik zal mezelf ook nog even voorstellen. Ik ben Jolijn en ik studeer Management, Policy-Analysis and Entrepreneurship in health and life science aan de VU. Hiervoor doe ik een onderzoekstage naar patiënten participatie bij ZonMw. De aanleiding voor dit onderzoek is dat ZonMw heeft gemerkt dat de participatie van patiënten in de projecten die zij financieren nog niet zo loopt als van tevoren verwacht, of zoals beschreven is in het voorstel. Daarom wil ZonMw graag weten hoe de samenwerking tussen patiënten(vertegenwoordigers) en onderzoekers verloopt en wat de samenwerking tussen beïnvloedt. U bent geselecteerd om deel te nemen omdat u samen met patiënten(vertegenwoordigers) samenwerkt of heeft samengewerkt in een project gefinancierd door ZonMw.

Er zullen geen gegevens van u worden genoemd en ook het project zal niet specifiek bij naam worden genoemd in het rapport. Uw gegevens worden vertrouwelijk en anoniem verwerkt.

Mocht u een vraag niet willen beantwoorden of willen stoppen met het interview dan kunt u dit aangeven, dit zal geen verdere gevolgen hebben.

Ik zou dit gesprek ook graag willen opnemen. Als ik de recorder zo aan zet, zou u dan expliciet toestemming willen geven voor het opnemen van dit interview.

Introductie vragen:

- Zou u wat kunnen vertellen waar uw onderzoek over gaat?
- Op welke manier zijn patiënten(vertegenwoordigers) betrokken in uw onderzoek samen?
- In welke fase van uw project heeft u patiënten/cliënten betrokken?
 - o Zijn dit nog steeds dezelfde mensen waar u mee samen werkt?
- Hoe ervaart u deze samenwerking?
 - o Zou u dit nog wat verder kunnen uitleggen?
 - o Kunt u een situatie noemen waarin dit naar voren kwam?
- Tegen welke belemmerende aspecten loopt u aan bij de samenwerking tussen u en de patiënt in uw onderzoek?
 - o Wat maakt dit lastig?
 - o Welke verwachtingen had u van te voren? Waren dat ook redenen waarom u van tevoren wel/niet wilde samenwerken met patiënten?
 - o Wat zou u kunnen doen om dit te verhelpen/verbeteren?
- Welke aspecten lopen volgens u al goed bij de samenwerking?
 - o Wie of wat zorgt ervoor dat dit goed loopt?

Culture:

- Wat is volgens u de meerwaarde van patiënten participatie in onderzoek?
- Denkt u dat patiënten genoeg kennis en vaardigheden hebben om te kunnen participeren in onderzoek?
 - o Waarom denkt u dat?
- Denk u dat u genoeg kennis/vaardigheden heeft over patiënten participatie om patiënten te laten participeren in uw onderzoek?
 - o Zou dit kunnen worden verbeterd?
 - o Hoe heeft u die kennis/vaardigheden opgedaan?
- Denkt u dat patiënten een rol kunnen spelen in alle fasen van onderzoek, van fundamenteel tot toegepast?
 - o Kunt u dit misschien verder uitleggen met een voorbeeld of een situatie die u heeft meegemaakt?
- Waarom heeft u er voor gekozen om patiënten ook te betrekken in dit onderzoek?/ Vanuit uit welk motief werkt u wel/niet samen met patiënten in uw onderzoek?

Practice:

- Kunt u omschrijven hoe de werkzaamheden eruit zien in de samenwerking met patiënten, wat doet u daarvoor of daaraan?
- Welke taken voert u anders uit in het onderzoek, wanneer er geen patiënten zouden participeren?
- Hoe gebruikt u de inbreng van patiënten in uw onderzoek?
 - o Zou u dit nog kunnen verbeteren? En hoe dan?
- Zou u het bij een volgend project ook weer zo doen?
 - o Wat zou u dan anders doen?

Structure:

- Denkt u dat uw onderzoeksdesign geschikt is voor participatie van patiënten?
 - o Waarom denkt u van wel/niet?
- Welke middelen, zoals organisatorische middelen of financiële middelen, zou u nodig hebben voor een goede samenwerking met patiënten in uw onderzoek?
 - o Hoe zou u aan deze middelen kunnen komen?
 - o Wat verwacht u hierbij van ZonMw?
 - o Heeft u er bij de budgettering van het project rekening gehouden met patiënten participatie?
 - Op welke manier dan?
- Welke middelen zijn al aanwezig voor een goede samenwerking met patiënten?
 - o Hoe bent u aan deze middelen gekomen?
- Wat denkt u dat patiënten zou kunnen stimuleren om mee te werken met een onderzoeksproject?
- Welke rol had ZonMw in het stimuleren van patiënten participatie? / Hoe zou ZonMw dit verder kunnen stimuleren?
- Welke voorwaarden, eigenschappen en vaardigheden zijn volgens u nodig voor een goede samenwerking met patiënten?
- Wat heeft de samenwerking met patiënten u opgeleverd in dit onderzoek?

Afsluitend

- Welke lessen heeft u zelf geleerd omtrent patiënten participatie en zou u graag willen meegeven aan andere onderzoekers?
- Zou u zelf nog kunnen iets verbeteren aan de samenwerking met patiënten?
 - o Hoe zou u dit kunnen doen en wat is minimaal nodig?
- Zouden patiënten nog kunnen verbeteren in de samenwerking?
 - o Waarom denkt u dat?
 - o Waarom denkt u dat dat zo belangrijk is?
- Welk cijfer tussen 1 en 10 zou u de samenwerking geven tussen u en de patiënt in uw onderzoek?
 - o Waar baseert u dit cijfer op?
 - o Bent u hier tevreden mee?
- Heeft u verder nog opmerkingen of vragen over dingen die nog niet besproken zijn?

Hartelijk dank voor uw tijd. Ik zal dit interview gaan uitwerken en een samenvatting maken en naar u opsturen zodat u kunt controleren of ik alles goed begrepen en geïnterpreteerd heb. Heeft u verder nog vragen voor mij? U kunt ook altijd contact met mij opnemen via de mail of mij bellen.

Annex B: Interview guide patients

Erg fijn dat u wilt deelnemen aan dit onderzoek en tijd heeft vrijgemaakt voor dit interview. Ik zal eerst wat algemene informatie geven over het onderzoek en daarna zal ik beginnen met de vragen. Ik zal mezelf ook nog even voorstellen. Ik ben Jolijn en ik studeer Management, Policy-Analysis and Entrepreneurship in health and life science aan de VU. Hiervoor doe ik een onderzoeksstage naar patiënten participatie bij ZonMw. Bent u bekend met ZonMw? Zo nee, uitleggen. De aanleiding voor dit onderzoek is dat ZonMw heeft gemerkt dat de participatie van patiënten in de projecten die zij financieren nog niet zo loopt als van tevoren verwacht, of zoals beschreven is in het voorstel. Daarom wil ZonMw graag weten wat de samenwerking tussen onderzoekers en patiënten/patiëntvertegenwoordigers beïnvloedt. U bent geselecteerd om deel te nemen omdat u samen met onderzoekers in een onderzoeksproject (en daarin patiënten vertegenwoordigd).

Er zullen geen gegevens van u worden genoemd en ook het project zal niet specifiek bij naam worden genoemd in het rapport. Uw gegevens worden vertrouwelijk en anoniem verwerkt.

Mocht u een vraag niet willen beantwoorden of willen stoppen met het interview dan kunt u dit aangeven, dit zal geen verdere gevolgen hebben.

Ik zou dit gesprek ook graag willen opnemen. Als ik de recorder zo aan zet, zou u dan expliciet toestemming willen geven voor het opnemen van dit interview.

Introductie vragen:

- Zou u in uw eigen woorden wat kunnen vertellen waar het onderzoek over gaat waarbij u betrokken bent?
 - o Weet u ook wie het onderzoek financiert?
- Wat is uw specifieke rol binnen het project?
- Op welke manier werkt u samen met onderzoekers in het onderzoek?
- Hoe ervaart u deze samenwerking?
 - o Zou u dit nog wat verder kunnen uitleggen?
 - o Kunt een situatie noemen waarin dit naar voren kwam?
- Tegen welke aspecten loopt u aan bij de samenwerking tussen u en de onderzoeker in het onderzoek?
 - o Wat maakt dit lastig? Waarom is dat lastig voor u?
 - o Sluit dit aan bij de verwachtingen die u had voor uw deelname aan het project?
 - o Had u dit van tevoren ook verwacht? En waren dat ook redenen waarom u van tevoren wel/niet betrokken wilden zijn bij het onderzoek?
 - o Wat zou u kunnen doen om dit te verhelpen/verbeteren?
- Welke aspecten lopen volgens u al goed bij de samenwerking met onderzoekers?
 - o Wie of wat zorgt ervoor dat dit goed loopt?
 - o Kunt u hier een voorbeeld van geven?
 - o Sluit dit aan bij de verwachtingen die u had voor uw deelname aan het project?

Culture:

- Hoe ziet uw de meerwaarde van patiënten participatie in onderzoek?
- Bent u al eerder betrokken geweest bij een project?
 - o Hoe heeft u dit ervaren?
 - o Hoe verschilt het huidige project met eerdere ervaringen?
- Waarom heeft u er voor gekozen om betrokken te zijn in dit onderzoek?/ Vanuit uit welk motief bent u betrokken bij dit onderzoek?
- Denk u dat u genoeg expertise en vaardigheden heeft om te participeren in wetenschappelijk onderzoek?
 - o Zou u vaardigheden en expertise willen verbeteren? Zo ja, welke vaardigheden en hoe zou u dit kunnen doen?
 - o Hoe heeft u die kennis opgedaan?
- Denkt u dat onderzoekers genoeg kennis en vaardigheden hebben om samen te kunnen werken met patiënten in onderzoek?
 - o Waarom denkt u dat?

Practice:

- Welke taken voert u uit binnen het onderzoek?
 - o Hoe ervaart u dit?
 - o Kunt u hier een voorbeeld van geven?
- Heeft u het idee dat u beperkt wordt in uw aandoening/ziekte om te participeren in het onderzoek?
 - o Hoe ervaart u dat dan?/ hoe gaat u hiermee om?
 - o Wordt er in het project voldoende rekening gehouden met uw beperkingen/worden er speciale maatregelen genomen?
- Wat wordt er met uw inbreng als patiënt (vertegenwoordiger) gedaan in het onderzoek?
 - o Bent u hier tevreden over?
 - Waarom wel/ niet?

Structure:

- Hoe verloopt de communicatie tussen u en de onderzoeker?
 - o Wat is hier een voorbeeld van?
- Welke middelen, zoals organisatorische middelen of financiële middelen, zou u nodig hebben voor een goede samenwerking met onderzoekers in het onderzoek?
 - o Wie of wat zou die middelen moeten/kunnen faciliteren/regelen?
- Welke middelen zijn al aanwezig voor een goede samenwerking met onderzoekers?
 - o Hoe bent u aan deze middelen gekomen? (onkosten/reisvergoeding?)
 - o Kunt u een situatie noemen waarin dit naar voren komt?
- Wat denkt u dat andere patiënten(vertegenwoordigers) zou kunnen stimuleren om mee te werken aan een onderzoeksproject?
- Welke voorwaarden zijn volgens u nodig voor een goede samenwerking met onderzoekers?
 - o Zijn dit voorwaarden waarin in uw situatie al aan wordt voldaan?
 - Wat mistte u dan nog?
- Wat heeft de samenwerking met onderzoekers u opgeleverd?
 - o Bent u hier tevreden over?
 - Waarom wel/niet?

Afsluitend

- Wat zou u zelf nog kunnen verbeteren aan de samenwerking met onderzoekers?
 - o Hoe zou u dit kunnen doen?
- Wat zouden onderzoekers nog kunnen verbeteren in de samenwerking?
 - o Waarom denkt u dat?
- Welk cijfer tussen 1 en 10 zou u de samenwerking geven tussen u en de onderzoeker in het onderzoek?
 - o Waar baseert u dit cijfer op?
 - o Bent u hier tevreden mee?
- Heeft u verder nog opmerkingen of vragen over dingen die nog niet besproken zijn?

Hartelijk dank voor uw tijd. Ik zal dit interview gaan uitwerken en een samenvatting maken en naar u opsturen zodat u kunt controleren of ik alles goed begrepen en geïnterpreteerd heb. Heeft u verder nog vragen voor mij?

Annex C: Explanation six factors

The six factors explained below are used in order to determine the questions of the interview guide.

Communication related factors

For a sustainable collaboration, communication between researchers and patients is of great importance. Direct communication is essential in commencing the involvement of patients in research, whereby shared goals are relevant for a sufficient communication structure (Vahdat, Hamzehgardeshi, Hessam, Hamzehgardeshi, 2014). Not only during the starting phase, but during the whole process a sufficient communication structure between researchers and patients is essential (Broerse et al., 2010). There are examples in research in which both researchers and patients had the idea that the other party would contact them. This resulted in that both parties did not contact each other and the patient involvement came to an end (Dedding & Slager, 2013).

Task related factors

Task related factors are the specific actions and/or behaviours that are required for patient involvement in health research (Davis et al., 2007). These task related factors could be from a patient and researcher perspective. Both researchers and patients have to perform certain task, depending on the level of participation and the phase of the research. For a number of patients, certain tasks could be too difficult or could be a burden due to a lack of knowledge or skills or their disease symptoms (Elberse, 2012; Abma, 2005). At the same time, researchers also have to perform certain tasks, which are related to the involvement of patients in health research. For instance, researchers need to combine the experiential knowledge of patients with scientific knowledge gathered by researchers.

Patient related factors

Patient related factors are patient's knowledge and beliefs about health research and about their contribution in health research. If patients perceive themselves as a valuable contribution to health research, they may be more willing to participate in health research (Elberse, 2012). Additionally, the sense of urgency among patients and their motivation to participate in health research refers to patient related factors (Broerse et al., 2010). Furthermore, patient related factors are also characterised by demographic characteristics of patients. In general, younger and more educated patients tend to have greater capacity, knowledge and skills for a sustainable collaboration between researchers and patients (Elberse, 2012).

Researcher related factors

Researcher related factors refer to the researcher's knowledge and beliefs about health research and specifically their knowledge and beliefs about patient involvement in research and the value of patient involvement in research (Davis, Jacklin, Sevdalis, & Vincent, 2007). Previous experiences with patient involvement in research could play a role in this. When researcher see and acknowledge the value of patient participation or experienced this before, they will be more willing and more motivated to involve patients in their research (Elberse, 2012). Researchers are of great importance in the involvement of patients, they can stimulate or impede patient participation in health research (Broerse et al., 2010).

Illness related factors

Illness related factors refer to stage and severity of the patients' illness(es). Patients with less severe conditions and less severe symptoms may take a more active role in participating in health research

than patients who suffer from more debilitating illnesses (Elberse, 2012). For instance, when patients have to come to a hospital once a week for taking blood, this could be a burden for patients who have a very serious condition and do not have much energy. Illness related factors are especially applicable for patients. However, also researchers can experience that a certain illness motivates them even more or the opposite. Illness related factors are related to patient related factors, as how patients experience their disease is related to patients.

Research setting related factors

The research setting includes the available resources for both researchers and patients to conduct a research in which patients are involved. Certain structures, such as a financial structure in which patients are compensated for their contribution in research, appeared to be stimulating for successful participation (Broerse et al., 2010). Furthermore, in this study the research setting entails that both researchers and patients have time, and a workspace where they can work.