



Enthusiastic connectors

Existing and desired professional profiles of practitioners of patient organizations as knowledge brokers within research projects with patient participation

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Abstract

Patients are becoming more involved in scientific projects, as evaluators, advisors or partners of academic researchers. From a science communication perspective, these experiences are a fascinating laboratory about the challenges of knowledge sharing and exchange between stakeholders with very different perspectives. Little is known about those who facilitate the blending of the experiential knowledge of patients and the scientific knowledge of researchers within these initiatives.

This thesis explores the professional profile of practitioners within patient organizations that are responsible for patient participation in research projects. Their position is analyzed from the perspective of the theory of knowledge brokering, which puts them at the center of the flow of science communication between the stakeholders. While existing literature has studied the emerging role of knowledge brokers in the transfer of scientific knowledge to decision-makers in healthcare, this thesis offers an original perspective on the context of patient participation, and compares the activities, professional knowledge, skills and personal attributes of the practitioners with that of knowledge brokers in healthcare. The needs that the practitioners express in terms of improvement of both their own profession as well as the process of patient participation have been analyzed using the concept of professionalization, which puts the focus on the development of new professional profiles.

A predominantly qualitative approach was chosen to gather reflections of nine practitioners on their current and desired professional profiles. They were selected after identifying Dutch patient organizations involved in participatory research projects. The methodology included semi-structured interviews and a card-sorting exercise inspired by Q methodology in which they were invited to rank skills and personal attributes related to knowledge brokering. The practitioners emerge as “enthusiastic connectors,” who put an emphasis on knowledge brokering activities and skills that foster the interaction between stakeholders, rather than on knowledge management. Many of the aspects they report as being part of their professional profile are consistent with those reported about knowledge brokers in the healthcare sector. However, the particular context of patient participation shapes their specific characteristics mainly related to their closest stakeholder, the patient. The practitioners confirm that academia, policy makers and funding organizations are increasingly interested in patient participation, and call for organizational changes in order to face this demand: increased recognition as a partner by external stakeholders, further internal recognition within their organization, as well as adequate human and financial resources.

The thesis serves to gain both academic insight, useful for developing measures of effectivity of knowledge brokering and further study, as well as practical insight, useful for recruitment of knowledge brokers and further professionalization of knowledge brokering and patient participation processes.

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1. Introduction

The participation of citizens in science is on the rise, pushed by public policies and research funding bodies in what has been labelled as Responsible Research and Innovation (RRI). This has sparked interest in how to make this involvement beneficial and efficient. This is also true for patient engagement in the field of healthcare. The role of patients in research is starting to diversify from simply being a study subject to much more inclusive roles, including being an equal partner within a project. However, the aims and priorities of patients may not be identical as those of researchers and medical professionals, and patient organizations are making an effort to align these different perspectives. In the Netherlands, patient organizations -often with aid from the network organization PGOsupport- are pioneering this process and have produced a set of nine recommendations for successful involvement of patients in medical scientific research, including advice on the phase of involvement, recruitment, training, support, evaluation and acknowledgement (De Wit et al., 2016).

This thesis analyzes the phenomenon of patient participation from the perspective of science communication. The patient organization is, a priori, placed in a central position to facilitate knowledge exchange between the patients it represents, and researchers or other partners within the project. This crucial communicative role has not been recognized as such and has been understudied in the academic literature. A preliminary review of empirical studies on models that foster including patients in research (Abma, Nierse and Widdershoven, 2009; Abma & Broerse, 2010; De Wit et al., 2015) suggests the importance of communication for effective collaboration, but so far little attention has been paid to the role and the profile of the human workforce within patient organizations that fosters the sharing of knowledge. The relevance of their contribution to patient participation justifies this study, which adds to the scant amount of academic literature and helps addressing the challenge of the consolidation of this emerging practice.

As this concerns a professional activity in early development, the study of these practitioners¹ can be addressed with a conceptual framework oriented towards the analysis of their professional profile and its process of *professionalization*. This

¹ In this thesis, for reasons of simplicity, the term practitioner is used to describe both paid employees as well as volunteers who belong to an organization and are responsible for its activities related to patient participation.

professional profile includes their job title and responsibilities, and is constructed from roles (comprising of general activities and specific tasks) and competencies (which include skills and knowledge, combined with personal attributes). Professionalization is the process of standardization and recognition of all these aspects of the profile of those who facilitate patient participation. This emerging professional group engages, in much of what they do, in what researchers describe as *knowledge brokering*, defined by Wenger (1998: 109) as “processes of translation, coordination and alignment between perspectives.” The aim of this thesis is to explore this professional profile and how practitioners would like it to evolve, in order to gain both academic insight, useful for developing measures of effectivity of knowledge brokering and further study, as well as practical insight, useful for recruitment of knowledge brokers and further professionalization of knowledge brokering and patient participation processes. The thesis will analyze to what extent the self-descriptions of practitioners are similar to the professional profile of knowledge broker in the healthcare sector as reported in the literature presented in the conceptual framework. The main question addressed is:

Which aspects of the professional profile of knowledge brokers within the healthcare sector do these practitioners consider relevant for their current and future role?

This question is answered using predominantly qualitative methods: in order to analyze the role and the activities of those who make patient participation happen, nine semi-structured interviews were carried out with practitioners, as well as a card-sorting exercise to rank skills and personal attributes associated to knowledge brokering. The categories of tasks, skills and personal attributes tested with these methods were drawn from existing literature on knowledge brokering in the healthcare sector.

The structure of the thesis is as follows: Chapter 2 presents the context of patient participation in scientific research and the role of patient organizations. Chapter 3 describes the conceptual framework that supports this research, focusing on knowledge brokering and professionalization. Chapter 4 develops the research questions and details the methodology. The results are presented in chapter 5 and include, among other aspects, the professional background of the respondents, their current activities and tasks, and the organizational changes they deem necessary to consolidate and improve their mission. Chapter 6 addresses the conclusions of the study, and chapter 7 discusses the challenges and limitations of the study, implications for the discipline of science communication, and recommendations for the field knowledge brokering and patient participation.

2. Context

This chapter puts patient participation in scientific research in historical context and summarizes its benefits and challenges. Section 2.1. starts with the evolution of science in the twentieth century, describing a paradigm shift towards public engagement and increased social responsibility of scientists. It explains the concept of Responsible Research and Innovation (RRI), and how it connects scientific and experiential knowledge through research projects in which scientists and citizens collaborate. This thesis focuses on one form of RRI, the collaboration of patients and researchers, and section 2.2. defines this phenomenon as patient participation. What follows is a compilation of the reasons that justify involving patients in research, but also describes the objections and challenges that exist. Emphasis is put on the role of science communication in the process of knowledge sharing and exchange as part of patient participation. Authors point out the need for a facilitator to address the challenges, and how practitioners within patient organizations may play that role. The chapter ends identifying key actors promoting patient participation in the Netherlands.

2.1. Bringing science and society closer together

The gap between science and society has become smaller over the last century. This section is a short summary of Rip and Boeker's report on how scientists became increasingly aware of their social responsibility since the beginning of the last century (Rip & Boeker, 1975). In the Netherlands, before the First World War, nearly all science was considered to be an art, and industrial applications were seen as "an added bonus." Social responsibility in science was not considered to be important. After the First World War, the importance of the benefits of science was stressed by many scientists, however, the dangers of atomic energy and the atomic bombs dropped on Japan in 1945 had an impact on the discussion about science. There was an increased emphasis on the organization of scientific research and higher education, but also on which role the scientists themselves should play in the future.

During the fifties, Dutch researchers found themselves reflecting on ethical issues, and from the beginning of the sixties there was a transition in the Netherlands to a more dynamic society: different opinions on not only the social responsibility but also political aspects of science could be discussed publicly. From the seventies, government-financed science had to be planned, budgeted, and adapted to government goals. There was a broad consensus amongst Dutch citizens that "[...] scientists should do more

‘relevant’ research, particularly of a kind relevant to the global problems of hunger, pollution and depletion of resources” (Rip & Boeker, 1975: 475).

The acceptance of society of the notion that scientists provide them with knowledge that is reliable and valuable decreased with the development of genetically modified foods, nuclear power, cloned mammals, and genetic screening (Guston & Sarewitz, 2002). This ultimately led to the development of ELSA (Ethical, Legal and Social Aspects) studies applied to a range of scientific disciplines (Rip, 2014). “The purpose has been to provide a knowledge base for developing emerging science and technologies in a responsible way.” (Forsberg, 2015: 1).

This approach evolved into the concept of Responsible Research and Innovation (RRI) in the early 2000s, triggered by the rise of a new discipline that also raised ethical questions, this time nanotechnology (Guston & Sarewitz, 2002). These authors called for “real-time technology assessment” of the social values embedded in innovations. A similar call had been made by Gibbons (1999: C81): “A fresh approach — virtually a complete ‘rethinking’ of science’s relationship with the rest of society — is needed.” He claimed that the separation between university science and industrial innovation is blurring, and even non-governmental organizations (such as patient organizations) are engaging in acquiring scientific knowledge. In this new context, science should not only be reliable in its methods, but also “socially robust,” relevant to the social environment in which findings will be applied (Regeer & Bunders, 2009). RRI has been explicitly fostered by research funding bodies, notably the European Commission hoping to develop a more competitive economy (Owen, Macnaghten, & Stilgoe, 2012). This means that the term has been introduced in a top-down manner rather than developed as a bottom-up initiative by the research and technology field (Zwart, Landeweerd, & van Rooij, 2014). In the Netherlands, an RRI approach named “Maatschappelijk Verantwoord Innoveren” (MVI) was introduced in 2013 by the national research council, the Netherlands Organisation for Scientific Research (Nederlandse Organisatie voor Wetenschappelijk Onderzoek, NWO), which funds and steers the course of Dutch science (NWO, 2017).

While ELSA mainly focused on anticipating the consequences of scientific innovations, RRI insists on the systematic involvement and reflexivity during the whole research process (Ofstedal, 2014). Von Schomberg (2011: 9) defines RRI as: “A transparent, interactive process by which societal actors and innovators become mutually responsive to each other with a view to the (ethical) acceptability, sustainability and societal desirability of the innovation process and its marketable products (in order to allow a proper embedding of scientific and technological advances in our society).” It is in this context that patient participation in research started to be discussed.

In the context of RRI, the production of knowledge is a process of sharing and exchanging two different types of knowledge that are produced by the stakeholders involved in participatory research projects:

- *Scientific knowledge*, created by the researchers using scientific methods.
- *Experiential knowledge*, accumulated by the citizens (more concretely patients in the case of this thesis) based on their experiences.

In the context of patient participation, and in order to avoid any suggestion of inferiority (a challenge discussed in the following section), Caron-Flinterman, Broerse & Bunders (2005) prefer the term “experiential knowledge” to alternatives such as “lay” or “non-expert” knowledge, as it “directly refers to the ultimate source of patient-specific knowledge—the often implicit, lived experiences of individual patients with their bodies and their illnesses as well as with care and cure. Experiential knowledge arises when these experiences are converted, consciously or unconsciously, into a personal insight that enables a patient to cope with individual illness and disability” (Caron-Flinterman, Broerse & Bunders, 2005: 2576).

2.2. Patient participation in scientific research projects

After World War II, with the development of the public healthcare sector, governments started to foster patient participation in health care (Abma, 2005). Castro et al. (2016), after a thorough literature review, proposed the following definition for the concept of patient participation in hospital care:

"Individual patient participation revolves around a patient's rights and opportunities to influence and engage in the decision making about his care through a dialogue attuned to his preferences, potential and a combination of his experiential and the professional's expert knowledge. Collective patient participation is the contribution of patients or their representing organizations in shaping health and social care services by means of active involvement in a range of activities at the individual, organizational and policy level that combine experiential and professional knowledge." (Castro et al., 2016: 1929)

Patient participation in scientific research on healthcare is driven by a similar process of democratization (Domecq et al., 2014), where patients and the organizations that represent them have developed an awareness on the value of their experiential knowledge as complementary to scientific knowledge: “They are no longer satisfied with their passive role, perceive themselves as experts, and complain about the fact that their expertise does not count” (Abma, 2005: 1311).

When patient participation is described in research projects, different levels of involvement can be distinguished. This is done in different ways, but it is usually based on a model of citizen participation originally proposed by Sherry Arnstein (1969): the

“participation ladder” (Abma et al., 2009; De Wit, Kvien & Gossec, 2015; De Wit et al., 2016). A normative interpretation of the model considered that the higher steps of the ladder were to be desired in patient participation as they imply “real shifts in shifts in decision-making power” from the researchers to the patients (Abma et al., 2009). However, Van de Bovenkamp & Zuiderent-Jerak (2015) nuance that “the difficulties in practice and critical views on participation” demand to take into account the context of any given initiative in order to decide which form of participation is the most suitable and desirable. Abma et al. (2009) also underline that the model has the limitation of solely focusing on control, when the interactions between stakeholders are what determine the effectiveness of an initiative.

In the aforementioned PGOsupport report, detailing recommendations for patient participation in research (De Wit et al., 2016), one interpretation of the participation ladder was made aimed at practical use by patient organizations, research institutes and health funds in the Netherlands (see figure 1). While the ladder has usually been depicted as a vertical scale, with “principal investigator” at the top, this version prefers a dotted horizontal layout in order to suggest that “integration of the patient perspective in scientific research demands a combination of different forms of participation, at multiple levels of the participation ladder” (De Wit et al., 2016: 3).

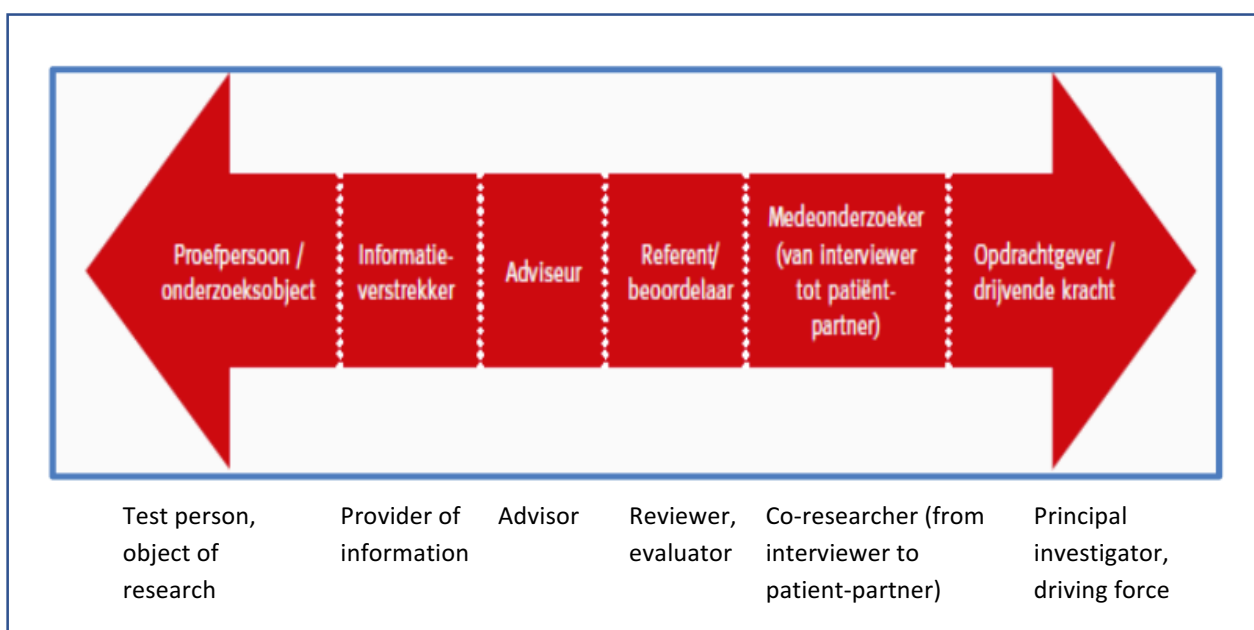


Figure 1. Diversity of roles for the patient in the context of scientific research. Source: De Wit et al., 2016. Translated from Dutch by Ingrid van Marion.

Many different reasons have been articulated for the beneficial impact of patient participation in scientific research. The most comprehensive reviews of existing empirical studies on participatory initiatives (Brett et al., 2012; Domecq et al., 2014) underline that the contribution of patients can have positive effects at different

moments of research projects: “Patient and public involvement is thought to improve the way the research is prioritized, commissioned, undertaken, communicated and used” (Brett et al., 2012: 638). The reasons summarized by the reviewers can be grouped into three overarching areas: 1) the relevance for the patients of the topics covered by the research project; 2) the adaptation of the methodologies to the needs and constraints of the patients; and 3) the applicability of the results of the studies.

1) Increased relevance for patients of topics covered by research projects

In general, authors agree that involving patients in research can foster the inclusion of research themes and questions that may have previously been overlooked by researchers (De Wit et al., 2016, Entwistle et al., 1998). The perspective of patients about their own illness can complement that of the scientific community, offering “pragmatic criticism” (Brett et al, 2012). Moreover, participative projects help to assure that the research agenda addresses patients' needs and priorities (Domecq et al, 2014). In fact, patients may prioritize topics for the research agenda as they participate in the research design phase of a project (Brett et al., 2012) and they can also help funding bodies to evaluate research proposals by adding additional criteria to the process, such as social relevance and patient-friendliness of the procedures (Abma et al., 2009; Brett et al., 2012).

2) Methodologies adapted to the needs and constraints of patients

Collaboration with patient-partners can improve the quality of questionnaires and research protocols of studies that involve other patients as research subjects (Abma et al., 2009; Brett et al., 2012). In the studies reviewed by Brett and colleagues, this included very concrete aspects, such as the “wording of questions, assisting with the timing of interventions and ensuring questions asked were acceptable” (Brett et al., 2012: 641). But the patients can also make a positive contribution by participating in the “collection, analysis and interpretation of data” (De Wit et al., 2016: 3). Abma et al. (2009) considers that patients are in a better position to interview other patients or organizing focus groups, as they are “better able to assess the acceptable workload, the appropriateness of methods, and use of resources” (Abma et al., 2009: 403). Patients may also support the recruitment of participants for studies involving patients, as they may know better than the researchers the circumstances, motivations and constraints of their peers (Abma et al., 2009; Brett et al., 2012; Domecq et al, 2014).

3) Applicability of the results of studies

During the phase of publication and diffusion of results, patient participation may reinforce the credibility of the results and the acceptance of the findings of

the study amongst stakeholders (Entwistle et al., 1998; Brett et al., 2012; Domecq et al, 2014). Reports of participatory studies benefit from “being grounded in user experiences” (Brett et al., 2012: 641). Patients can also help in adapting the academic language of reports for the general public (Brett et al., 2012) and “improve its translation into clinical practice” based on their own experiences (Domecq et al, 2014: 1) and their involvement in the dissemination of the results (Entwistle et al., 1998).

The empirical research proving the benefits of patient participation in research, as summarized in the previous paragraphs, confirms the arguments anticipated earlier by Entwistle et al. (1998) to counter many of the objections about the pertinence of patient participation. One central criticism was that the perspective of individual patients may not be representative of the average population and that professionals may have a better overview of their needs. However, leaving patients aside poses the risk of ignoring the patients' views and experiences altogether, and letting the prejudices and interests of professionals shape their research (Entwistle et al., 1998). The criticism that patients may not have the appropriate skills to participate in research is also common, but authors researching participatory initiatives consider this a challenge that can be overcome with training and guidance, rather than a definitive obstacle (Brett et al., 2012).

Besides these criticisms, authors acknowledge that other practical challenges for patient participation exist:

- The asymmetrical relationships between patients and researchers due to the higher status of scientific knowledge in comparison to experiential knowledge (Abma et al., 2009). The risk in this context is that the input of patients may be “devalued” by the researchers (Brett et al., 2012: 642), and only structured training, coaching, guidance and clear procedures can create the conditions for successful knowledge exchange.
- The divergences in objectives and timings of researchers and patients, as well as the prejudices and stereotypes they may have about each other, can complicate their collaboration if no effort is made to make them understand each other's position, perspective, language and expectations (Abma et al., 2009).
- Lack of clarity about the role of the patients participating in the project can hamper an effective involvement and discourage them from engaging in the future. Feedback mechanisms to assess the experience of patient participation and to show the participants how their input is valorized are important in any project (Minogue et al., 2005).

All these challenges have in common that they call for solutions in which science communication is at the core of making a participatory project successful. Nonetheless,

even if the existing literature mentions communication more or less explicitly as a key aspect of patient participation, there seems to be little attention paid by the academic research community to how communication actually contributes to knowledge sharing between the different stakeholders within projects with patient participation. Most emphasis is put on the process of including patients into the research process, with the focus on the patient experience of being part of this process and its impact (Domecq et al., 2014). However, it does not address the role, the activities and the responsibilities of those who facilitate patient participation, and it does not analyze in depth the processes and dynamics of knowledge exchange within the projects. While “strong communication and shared goals” is one of the key points in the guidelines for integration of patient research partners in scientific studies (Kirwan et al., 2017: 484), the specific implementation of such recommendation has not been systematically developed so far and the potential contribution of science communication as a discipline to this discussion has been overlooked.

Abma et al. (2009) propose to conceptualize patient participation as a *dialogue* between different stakeholders, and they argue that communication is crucial for fruitful interactions:

"Genuine dialogues require openness, respect, trust and engagement of all stakeholders. These conditions are not always in place, and need to be actively created and maintained throughout the whole process. The key to the creation of good social conditions is frequent, informal communication with all stakeholders. Interactive communication— ranging from informal contacts by telephone and e-mail to participation at meetings and conversations via interviews and focus groups— is most appropriate. This form of communication enables participants to engage in the process, to give advice, and to deliberate with each other." (Abma et al., 2009: 405).

But informal communication may not be sufficient to address all the communicative challenges: researchers may have difficulties to communicate professional knowledge to patients, especially when they use complicated jargon, and a lack of communication of the objectives and the procedures of the study can also hinder the progress of the collaboration, for instance when the goals of a discussion are not clearly defined (Abma et al., 2015). Without going into the details of what are the communication strategies put in place in the empirical cases analyzed, the literature reviewed by Brett et al. (2012) mentions how good planning of communication between stakeholders benefits the exchange of knowledge. For example, professional knowledge can be enriched with experiential knowledge after feedback from patients. When aims and expectations about the outcome of the project are shared between different stakeholders, a combination of professional knowledge and experiential knowledge may lead to more satisfactory and realistic research (Abma & Broerse, 2010).

The common assumption in existing studies is that communication is important, but the authors do not often reflect on who should or could take responsibility for facilitation of communication. In the context of reflections about RRI, Rip acknowledged that researchers may not be prepared to assume the responsibility of “embedding” their research in society. Non-governmental and civil society organizations are expected to take this role because of their privileged position as an interface between citizens and science, but the author questions whether they are “equipped (or willing) to do so” (Rip, 2014: 9). Studies on patient participation identify the role of a “facilitator,” “monitor,” “mentor” or “project team” as a key element for the effective knowledge sharing between the different stakeholders involved in the project. Facilitators may influence the process and increase knowledge sharing when there are different levels of professional and experiential knowledge present amongst participants in the project, through careful preparation of dialogical meetings (Abma & Broerse, 2010). De Wit et al. (2013) report on how researchers may lack competencies to be able to involve the patient partners, and how “monitors” can improve the process by providing them with training. In addition, projects can benefit from the activity of mediation by a facilitator, as it can help stakeholders to achieve consensus by making them aware of each other’s circumstances (Abma & Broerse, 2010).

In order to fill the void in academic research regarding who takes responsibility for facilitating knowledge sharing and exchange in research projects with patient participation, this thesis focuses specifically on the role played by practitioners within patient organizations. Previous research has shown that patient organizations may contribute positively to the process of patient participation for very practical reasons, as they structure networks of patients and can plan and manage their involvement more easily than researchers (Brett et al., 2012). Patient organizations may also take the initiative of organizing the training and coaching of participating patients (Abma et al., 2009), and enhance the dissemination and implementation of research results (Shea et al., 2005). All these activities require communication, knowledge sharing and knowledge exchange between different stakeholders involved in the research projects, and the next chapter constructs the conceptual framework for the analysis of the professional profile of the practitioners that perform these activities.

In the Netherlands, ZonMW (the Dutch Organisation for Health Research and Development) funds health research and promotes the actual use of the knowledge this research produces. Their principal commissioners are the Dutch Ministry of Public Health, Welfare and Sport (VWS) and the Dutch Organisation for Scientific Research (NWO). In 2006, ZonMW, together with the Reuma patiëntenbond and the VSOP (Alliantie voor erfelijkheidsvraagstukken), published a manual for patient participation

in scientific research (Vossen et al., 2006). ZonMW has also created its own panel of patient experts to advise them in the decisions about funding of research projects.

In 2009, an independent foundation was created to foster the sharing of knowledge and experiences between patient (and client) organizations:² PGOsupport. Promoting patient participation in scientific research is one of their core objectives, and they regularly organize seminars, workshops and training sessions for patient organizations, and their members, to improve their involvement in patient participation initiatives. In the report with recommendations they published in 2016, they confirm that within several Dutch patient organizations, “coordinators have been appointed that are responsible for recruitment, training and support of patient experts and contacts with (external) researchers” (De Wit et al., 2016: 5).

In 2014, ZonMW and the VSB Fonds (A Dutch Foundation that financially supports social and cultural initiatives), in collaboration with PGOsupport, set up Participatiekompas, an online platform where knowledge and practical experiences about patient participation can be shared and is aimed at patients and clients, their organizations, researchers and policy makers, who want to improve the quality of care. The website reports on dozens of patient participation initiatives in which patient organizations play a role, some of them connected to research projects with universities.

2.3. Summary

From the literature review on patient participation in research projects it is clear that science communication and knowledge exchange between the different stakeholders is necessary. However, it is not obvious who takes responsibility for knowledge exchange and knowledge sharing within this context. There can be many parties involved in these projects but, for time restrictions, the empirical work in this thesis focuses on those persons who belong to a patient organization and who have self-reported responsibility for knowledge exchange and knowledge sharing within research projects with patient participation. This study explores how their professional profiles have taken shape and which professional profile they would desire, in the context of improving patient participation.

² The term “client” is used to include those healthcare users that may not define themselves as a “patient.” For the sake of clarity and simplicity, in this thesis the term “patient organization” is used as this is how most of the cases analyzed describe themselves.

3. Conceptual Framework

This chapter describes the conceptual framework leading to the research questions and the methodological approach for this study, as explained in chapter 4. The contextual chapter has pointed out why this study focuses on practitioners within patient organizations who have self-reported to be responsible for activities related to patient participation in research initiatives, as they may be the ones responsible for facilitating the sharing and exchange of scientific and experiential knowledge between the variety of stakeholders involved. This process has been conceptualized as “knowledge brokering,” which is further explained in the first section of this chapter. Three domains of activity related to knowledge brokering have been identified by the academic literature (knowledge management, linkage and exchange, and capacity building), and they are central to the analysis of how practitioners facilitate the transfer of knowledge. These activities are applied to the networks of interactions that are typical of mode-2 of knowledge production, in this case, initiatives in which researchers and patients are the principal actors collaborating.

Once the theoretical concepts describing knowledge brokering are presented, the attention shifts to the individuals that take the responsibility of making it happen within the healthcare sector, and the multiple definitions of knowledge broker are explored. To be able to fulfil the aim of the thesis of getting insight into their professional profile, the second part of the chapter outlines some relevant aspects that construct a professional profile, including activities and tasks, professional knowledge, skills, and personal attributes. The academic literature on knowledge brokers in the healthcare sector is used to gather the most prominent features of these aspects. In order to address the aim of understanding the desired professional profile of the practitioners, the theoretical concept of professionalization is mobilized in the last section of the chapter in order to identify key facets that influence the evolution of knowledge brokering from an occupation into a profession: organizational change, training and communities of practice. With this collection of theoretical concepts (see figure 2), the subsequent empirical analysis, presented in chapter 5 and discussed in chapters 6 and 7, aims at contributing to academic debates in science communication and offers practical advice to patient organizations and other stakeholders who may take on a knowledge brokering role in relation to research projects with patient participation.

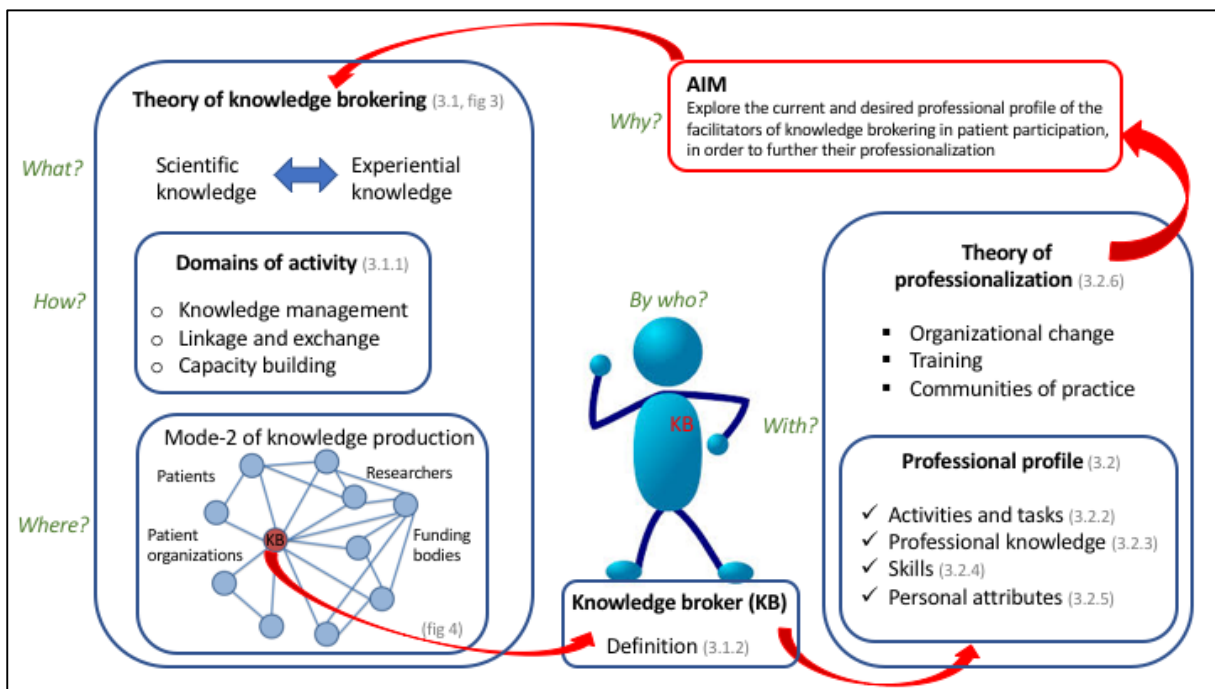


Figure 2. Overview of the conceptual framework

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3.1. Knowledge brokering

What is knowledge brokering? Meyer (2010), when discussing the rise of this professional activity, reaches back to a definition by Wenger: “Brokering... involves processes of translation, coordination and alignment between perspectives... It also requires the ability to link practices by facilitating transactions between them” (Wenger, 1998: 109). Meyer concludes that “[b]rokered knowledge is knowledge made more robust, more accountable, more usable; knowledge that “serves locally” at a given time; knowledge that has been de- and reassembled” (Meyer, 2010: 123). Much of what is known about knowledge brokering stems from the private sector, in which knowledge is shared within and between organizations (Ward, House, & Hamer, 2009). Johri (2008) describes an example of how globalization has fostered knowledge brokering as way to overcome geographical and cultural challenges within a multinational engineering company: workers find it hard to share knowledge and expertise due to a lack of mutual common ground, which often leads to breakdowns in communication and collaboration, interpersonal conflict and lack of trust.

Even though the public health sector may seem a very different context, its own challenges for knowledge exchange between different actors have risen attention to the process of knowledge brokering as a potential solution (CHSRF, 2003). Since the beginning of this century, the Canadian Health Services Research Foundation (CHSRF, nowadays renamed Canadian Foundation for Healthcare Improvement) has been a

pioneer in developing the field (Seidl, 2007), proposing a wider definition based on its experiences:

"[Knowledge brokering is] a process that stimulates the creation of effective new research by linking researchers and users of information early, helping to identify issues, and encouraging all parties to work together on solving problems. Brokering encourages a continuous exchange on many levels — from sharing experiences and searching out existing knowledge to turning management problems into workable questions for researchers to study." (CHSRF, 2003: 2)

Most recently, Hering defined knowledge brokering as follows:

"... an iterative and bidirectional process of translation, tailoring of information for specific contexts, feedback, and integration. In addition to facilitating the uptake of research into policy and practice, knowledge brokering should help to identify the information that could be useful to support policy decisions so that research can be directed toward filling critical knowledge gaps." (2016: 364)

Figure 3 presents a schematic representation of this definition. The schema illustrates how the process of knowledge brokering acts between topical knowledge and knowledge relevant to (social) contexts. Through integration of natural, social and engineering sciences, knowledge relevant to a specific topic can be exchanged, and it may be brokered and made contextual. The target audience receives direct output from the knowledge brokering process, through publications and databases (knowledge portals), or by participating in tests or demo cases. This process is not unidirectional but a two-way process, as the knowledge brokering mechanism allows for translation and tailoring to any actor while integrating additional relevant knowledge and feedback.

Even though the schema by Hering is applied to the context of policy- and decision-making, it may also be applicable to the context of patient participation in research. Researchers receive experiential knowledge from the patients via the knowledge brokering process during which it may be translated and tailored to their needs, integrated to their own knowledge, while feedback makes it an iterative process as researchers are able to request or supply additional knowledge from or to the patients. As knowledge brokering facilitates the inclusion of experiential knowledge of patients into scientific research, both the quality of research as well as the relevance of research to patient's daily lives may increase (Brett et al., 2012; Caron-Flinterman et al., 2005; Elberse et al., 2012) as well as the legitimacy of research policies (Tineke A. Abma & Broerse, 2010; Pittens, Elberse, Visse, Abma, & Broerse, 2014; Telford, Beverley, Cooper, & Boote, 2002). However, the evaluation of the effectiveness of knowledge brokering has not been thoroughly studied in previous studies (Jackson-Bowers, Kalucy,

& McIntyre, 2006; Bornbaum et al., 2015) and is out of the scope of this thesis (see the section on further research in discussion, chapter 7).

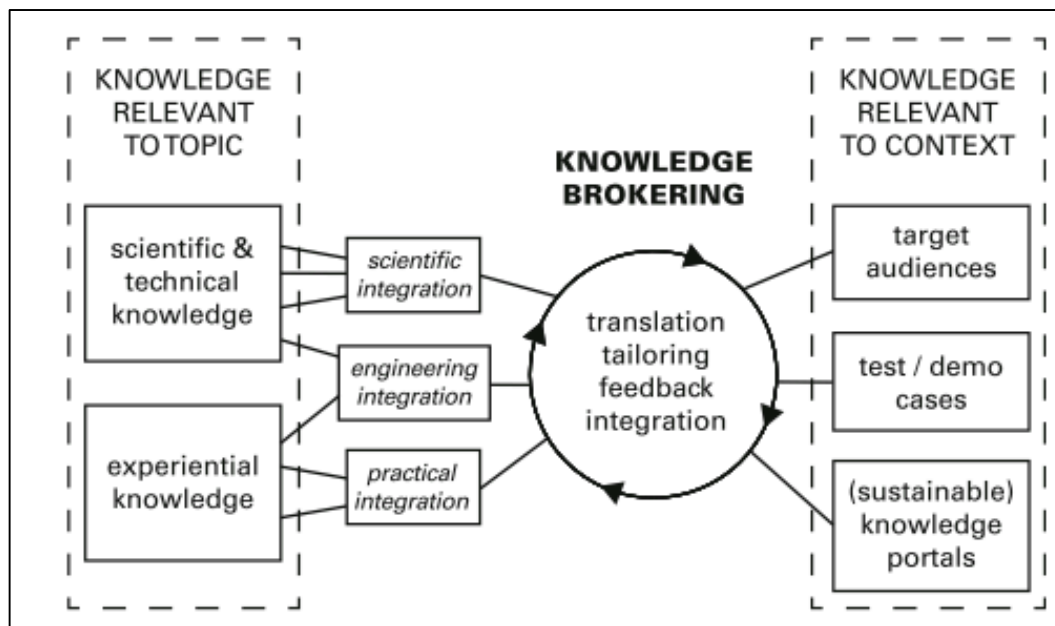


Figure 3. Schematic representation of knowledge brokering as an iterative process of translation, tailoring, feedback and integration that allows information to be exchanged (in both directions) between scientific and technical experts and policy and decision makers. Source: Hering (2016).

3.1.1. Three frameworks for the analysis of knowledge brokering

To look into knowledge brokering in more detail, Ward et al. (2009) identified three main frameworks on knowledge brokering processes, emerging from the literature on the topic: knowledge management, linkage and exchange, and capacity building (see textbox 1). The tasks relating to these three activity domains will be discussed in a later section of this conceptual framework. In practice, these three frameworks are not exclusive to each other but may overlap as knowledge brokering activities may belong to one or several of these domains. Moreover, the activities being performed are often dictated by the needs of stakeholders and therefore context and objectives play a role in defining how knowledge brokering actually takes place (Bornbaum et al., 2015).

The process of knowledge brokering may be carried out by individuals, as well as groups or organizations (Dobbins et al., 2009). The consequence of this is that several actors may simultaneously perform knowledge brokering activities within the same network of relationships. A report by the CHSRF states that “[m]uch of the brokering going on now is an unrecognized, largely unplanned activity; if we are to highlight and evaluate its role in knowledge transfer, there needs to be a concerted effort to recognize and formalize the work” (CHSRF, 2003). According to CHSRF, this would allow to promote and consolidate this professional profile.

Textbox 1. Analytical frameworks for knowledge brokering processes

1. Knowledge management

Knowledge management entails “the facilitation or management of the creation, translation, diffusion, and application of knowledge” (Bornbaum et al., 2015: 2).

2. Linkage and exchange

Linkage and exchange encompasses “the development of positive relationships between knowledge creators (e.g. researchers) and knowledge users (e.g. decision-makers, clinicians) as a means to stimulate new information, collaborative knowledge exchange, and the use of evidence-informed approaches” (Bornbaum et al., 2015: 2).

3. Capacity building

Bornbaum et al (2015) explain capacity building as the process of developing knowledge users’ understanding and skills, enabling evidence-informed decision-making, and enhancing capacity to access and apply knowledge.

The challenge of fostering effective knowledge exchange has therefore called for the creation of a specialized professional profile, an intermediary known as the knowledge broker (Lomas, 2007; Meyer, 2010; Ward et al., 2009). This scenario connects to the concept of “mode-2” of knowledge production, in which authors envisioned an important role for intermediaries, sometimes belonging to an institution and at other times independent, who foster the relationship between science and society (figure 4).

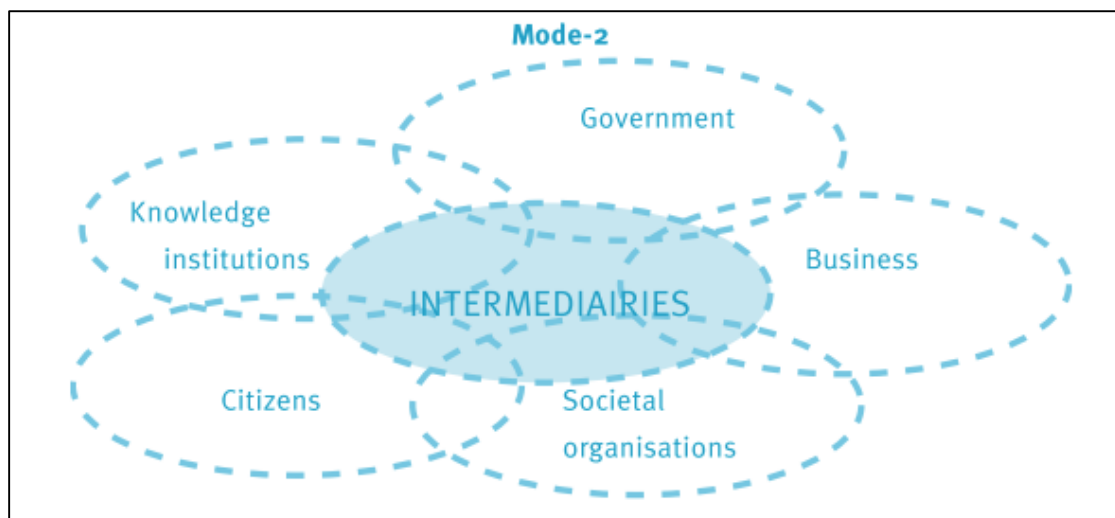


Figure 4. Relationships in mode-2 of knowledge production. Source: Regeer & Bunders (2009).

In the context of patient participation, patients and clients can be considered as “citizens” in the figure, while patient organizations are “societal organizations,” both of them in relationships with other actors including “knowledge institutions” such as universities, the “government” and, for instance, pharmaceutical companies (“business”). Knowledge brokers could thus promote integration, participation,

innovation and sustainability in the collaboration between this diversity of actors (Regeer & Bunders, 2009).

3.1.2. Definitions of the knowledge broker

In the literature, descriptions of knowledge brokers mostly vary around a combination of two of the frameworks of knowledge brokering: knowledge management, and linkage and exchange (see textbox 2). Capacity building is less present in literature (Bornbaum et al., 2015) and is only developed where authors detail the activities of knowledge brokers.

Textbox 2. Definitions of knowledge broker, in chronological order of publication

"[A] catalyst whose responsibility would be to connect those with knowledge and experience with those who needed it for particular purposes" (Hellström, Malmquist, & Mikaelsson, 2001: 33).

"[Knowledge brokers are] the human force that makes knowledge transfer (the movement of knowledge from one place or group of people to another) more effective" (CHSRF, 2003: i).

"Knowledge brokers are the links between different entities or individuals that otherwise would not have a relationship such as policy makers and researchers. Their core function is connecting people to share and exchange knowledge" (Jackson-Bowers, Kalucy, & McIntyre, 2006: 1).

"Knowledge brokers are individuals that bridge a gap in social structure and help knowledge flow across that gap by enabling translation, coordination and alignment between different perspectives and facilitating transaction between previously separated practices" (Seidl, 2007: 107).

"[Knowledge brokers] are often metaphorically referred to as bridges that link producers and users of evidence to facilitate two-way interaction and collaboration to identify issues, solve problems, and promote evidence-informed decision making" (Robeson, Dobbins, & DeCorby, 2008: 79).

"Knowledge brokers are people or organizations that move knowledge around and create connections between researchers and their various audiences" (Meyer, 2010: 118).

"Knowledge brokers are therefore agents who support interaction and engagement with the goal of encouraging knowledge exchange, supporting research use and strengthening research impact" (Lightowler & Knight, 2013: 319).

"Bridges, brokers and boundary spanners facilitate transactions and the flow of information between people or groups who either have no physical or cognitive access to one another, or alternatively, who have no basis on which to trust each other" (Long et al., 2013: 158).

"A knowledge broker is defined as an actor who uses his/her in-between vantage position to support innovation through connecting, recombining and transferring to new contexts otherwise disconnected pools of ideas; i.e. they get the right knowledge into the right hands at the right time" (Burgess & Currie, 2013: S132).

“[Knowledge brokers are] bridging organizations or gatekeepers that mediate the flow of knowledge and information between two unconnected actors” (Boari & Riboldazzi, 2014: 683).

“Knowledge brokers work collaboratively with key stakeholders to facilitate the transfer and exchange of information in a given context” (Bornbaum et al., 2015: 162).

In the literature describing the situation within the healthcare sector, there is an emphasis on knowledge brokers as those who connect researchers, practitioners and decision makers with the aim of a timely and optimal use of research evidence (Bornbaum et al., 2015; Traynor et al., 2014), but how about using those intermediaries for knowledge brokering of experiential knowledge of patients to researchers, policy makers and practitioners? This thesis takes into account that knowledge brokering may happen in many directions, with an emphasis on the knowledge brokering done by patient organizations in the context of patient participation in research. In order to explore to what extent do practitioners involved in patient participation embody the role of a knowledge broker, it is necessary to describe first some key elements constituting the professional profile of the knowledge broker in the healthcare sector.

3.2. Analyzing the professional profile of the knowledge broker

The literature analyzing professional profiles across different fields proposes several concepts that describe what is necessary to accomplish the objectives of a professional: roles (comprising of general activities and specific tasks) (Bornbaum et al., 2015) and competencies (which include skills and knowledge, combined with personal attributes) (Tench, Verhoeven, & Juma, 2015). The relationship between these concepts is laid out by Jeffrey and Brunton: “[C]ompetencies are the underlying foundational abilities that are integral to successfully carrying out the tasks and responsibilities” (Jeffrey & Brunton, 2011:60).

As discussed earlier, knowledge brokers may take on, fully or to some extent, one or more of three different roles within the domains of knowledge management, linkage and exchange, and capacity building. Within each domain the professionals perform tasks that together allow them to accomplish knowledge brokering activities. For example, a knowledge broker in the health sector may perform the task of appraising quality of evidence as part of the activity “identifying and obtaining relevant information,” which takes place in either of the knowledge management or capacity building domains. Which role a knowledge broker takes on and which activities are carried out may be influenced by the organizational context the knowledge broker is in as well as the needs of stakeholders (Bornbaum et al., 2015).

After review of literature on competencies (Tench et al., 2015), there is one statement that captures a general thought: “There is such confusion and debate concerning the concept of ‘competence’ that it is impossible to identify or impute a coherent theory or to arrive at a definition capable of accommodating and reconciling all the different ways that the term is used.” (Le Deist & Winterton, 2005). Other authors have argued for more pragmatism: “as tacit understandings of the word [competence] have been overtaken by the need to define precisely and [to] operationalize concepts, the practical has become shrouded in theoretical confusion and the apparently simple has become profoundly complicated” (Norris, 1991:332). Therefore, in an attempt to combine literature review with a pragmatic approach, for this thesis the following definition is used: competencies are “the mix of skills and knowledge held by a practitioner, which combine with personal attributes to produce effective professional behaviours” (Tench & Moreno, 2015:44). This definition breaks down competencies into concepts that allow for a systematic analysis.

Skills have been defined by Proctor and Dutta (1995:18) as: “goal-directed, well-organized behaviour that is acquired through practice and performed with economy of effort.” They are “the things practitioners are able to do to perform their job/role effectively” (Tench et al., 2013:19). Knowledge can be defined as “what practitioners are required to know in order to do their job/role effectively (Tench et al., 2013:19). It “includes underpinning theory and concepts, as well as tacit knowledge gained as a result of the experience of performing certain tasks” (Winterton, Delamare-Le Deist, & Stringfellow, 2005:9). Personal attributes, also described as qualities (Phipps & Morton, 2013), or as positive characteristics from a humanistic perspective (Korthagen, 2004), are “the psychological ingredients -processes or mechanisms- that define the virtues” of a professional (Seligman and Csikszentmihalyi in Korthagen, 2004). The difference between skills and knowledge on one hand and personal attributes on the other, is that the first can be taught while the latter can only be modelled or fostered (Jeffrey & Brunton, 2011). The literature suggests that personal attributes have “as much importance as most of the skills and knowledge attributes” (Tench et al., 2015: 9; see also Jeffrey & Brunton, 2011).

3.2.1. The professional profile of the knowledge broker in the healthcare sector

There is no specific professional profile known of knowledge brokers as part of patient organizations involved in patient participation. For this study, the health sector is considered to be the most relevant context. Consequently, even though the amount of it is sparse, the literature on knowledge brokers in the health sector has been taken as the inspiration to construct the analytical categories for this thesis. A summary of scientific and gray literature about knowledge brokering in the healthcare sector has

been made and was used to determine the elements of a possible professional profile of knowledge brokers involved in patient participation. This section gives insight into which methodology and samples other authors have considered to construct their views on knowledge brokers in the healthcare sector.

In 2002 the CHSRF (2003) held several meetings with knowledge brokers active in the Canadian health services and commissioned a review of literature on knowledge brokering in general. As this literature review focused on knowledge management and on private, for-profit enterprises, there “was a considerable rift between the ideas of brokering that arose in the consultations and the review.” This shows how context-specific knowledge brokering can be and demonstrates the importance to include grey literature³ in this thesis, as compensation for the scarcity of academic literature on knowledge brokering in the health sector. Bornbaum et al. (2015) also combined academic and grey literature, a total of 29 articles, when reviewing the nature of knowledge brokering in health-related settings. The results support “the knowledge broker role as a knowledge manager, linkage agent and capacity builder” (Bornbaum et al., 2015: 165).

Lyons et al. (2006) analyzed the effect of the implementation of knowledge brokers on the uptake of best practices in integrated stroke care. Their report describes a pilot study on the use of knowledge brokers aiming to increase the exchange of knowledge between stroke researchers and the users of stroke research. The authors used interviews and focus groups to discover factors influencing the implementation of knowledge brokers.

Based on her professional experience as consultant for the National Health Service, Pyper (2002) proposes key skills for different types of knowledge brokers, to promote more informed and independent patients, within the healthcare sector in the United Kingdom. One of the scarce academic publications on qualities of knowledge brokers is authored by Phipps and Morton (2013). Like Pyper, they describe their own experiences of being, developing and employing brokers in a range of roles connecting academic researchers with practitioners and policy makers, across several sectors including the health sector.

From this literature, it was possible to obtain an overview of the tasks, knowledge, skills and personal attributes of knowledge brokers within the health sector. These form the basis for the categories used in the research design of the thesis for data collection and analysis.

³ This mainly includes reports by non-profit organisations not subjected to formal academic peer-review.

3.2.2. Activities and tasks

Knowledge brokers in the healthcare sector are involved in a range of activities. The CHSRF lists the tasks of knowledge brokers as including:

- "bringing people together to exchange information and work together;
- helping groups communicate and understand each other's needs and abilities;
- pushing for the use of research in planning and delivering healthcare;
- monitoring and evaluating practices, to identify successes or needed changes;
- transforming management issues into research questions;
- synthesizing and summarizing research and decision-maker priorities; and
- 'navigating' or guiding through sources of research." (CHSF, 2003: i)

Summarizing this and other subsequent studies about activities and tasks of knowledge brokers, Bornbaum et al (2015) performed a systematic literature review, which resulted in a comprehensive classification (see table 1). Textbox 3 lists a short description of the ten main activities as identified by Bornbaum and colleagues.

Table 1. Classification of knowledge brokering tasks according to activity domains

Knowledge brokering activities and tasks ¹	Activity domain		
	knowledge management	Linkage and exchange	Capacity building
Identify, engage and connect with stakeholders		x	
Identify and engage relevant stakeholders		x	
Identify common goals among stakeholders		x	
Engage with stakeholders in-person		x	
Facilitate collaboration		x	
Organize workshops or forums for collaboration		x	
Facilitate dialogue between stakeholders		x	
Facilitate consensus between stakeholders		x	
Facilitate relationship building among stakeholders		x	
Identify and obtain relevant information	x	x	x
Conduct environmental scan or needs assessment	x		
Define problem or research question	x		x
Conduct evidence search and retrieval	x		
Appraise quality of evidence	x		x
Connect stakeholders to relevant information sources	x	x	
Identify opportunities for integrating evidence into practice	x		
Identify implications for local programs, policies or practices	x		
Stay current with emerging evidence	x		
Facilitate development of analytic and interpretive skills	x	x	x
Design tailored training or educational sessions			x
Deliver educational courses, seminars or workshops to enhance stakeholder skills		x	x
Provide assistance with interpretation of research	x		x
Support peer-to-peer learning		x	x
Create tailored knowledge products	x	x	
Prepare knowledge products and syntheses	x		
Tailor resources to stakeholder needs or local context	x	x	
Project coordination	x	x	
Provide administrative or research coordination support	x	x	
Support project funding proposals	x		
Support communication and information sharing	x	x	x
Develop and maintain communication tools or strategies		x	
Communicate with stakeholders	x	x	
Facilitate knowledge dissemination	x	x	x
Support knowledge sharing among stakeholders	x	x	
Network development, maintenance and facilitation		x	
Identify networking opportunities for stakeholders		x	
Develop a network or community of practice		x	
Maintain and facilitate a network or community of practice		x	
Networks with other KBs		x	
Facilitate and evaluate change	x	x	x
Assess readiness or capacity for change	x		x
Generate buy-in among stakeholders		x	x
Facilitate organizational change	x	x	x
Monitor the process of implementation or uptake	x		
Evaluate knowledge transfer process	x		x
Support sustainability			x
promote reflective practice			x
Support the development of knowledge products and policies			x
Encourage organizational leadership			x
Sustain engagement			x

¹Higher level items (blue) represent knowledge brokering activities, while sub items (white) represent the tasks performed in support of the overarching activity. Source: Bornbaum et al. (2015).

Textbox 3. Activities of knowledge brokers in the healthcare sector

1. Identify, engage and connect with stakeholders

Knowledge brokers aim to “find the right people” among stakeholders, which they often do through in-person contact, so they can clarify the diversity of needs and identify the common goals.

2. Facilitate collaboration

Knowledge brokers facilitate dialogue and collaboration between stakeholders through different channels. They support problem solving and facilitate relationship building.

3. Identify and obtain relevant information

Knowledge brokers help to define research questions, explore relevant knowledge within the field, evaluate information, and identify opportunities and implications to be presented to stakeholders.

4. Facilitate development of analytic and interpretive skills

Knowledge brokers design and deliver training and educational sessions. They also provide assistance with interpretation of research and foster peer-to-peer learning.

5. Create tailored knowledge products

Knowledge brokers produce content adapted to the knowledge and needs of stakeholders, mainly through summarizing and translating evidence into accessible formats.

6. Project coordination

Knowledge brokers often take responsibility for management tasks within a project, both administrative as well as organizational. They also support the preparation of grant applications.

7. Support communication and information sharing

Knowledge brokers develop and maintain communication tools and strategies, in order to facilitate knowledge sharing between stakeholders as well as knowledge dissemination to a larger public.

8. Network development, maintenance and facilitation

Knowledge brokers create, support and promote networks and communities of practice for stakeholder groups. They also network amongst each other to share expertise.

9. Facilitate and evaluate change

Knowledge brokers assess readiness for organizational change, they encourage it, and provide the knowledge that enables it. They monitor the change processes to evaluate the effect of their input.

10. Support sustainability

Knowledge brokers promote the sustainability of knowledge brokering activities in two ways: they foster a reflective attitude among all the actors, and they make sure that the leaders of the involved organizations recognize the value of knowledge brokering and create a supportive environment to consolidate it.

3.2.3. Professional knowledge

The literature on knowledge brokering in the healthcare sector discusses very scarcely on the knowledge that these professionals need to perform their role. Lyons et al. (2006: 59) state that knowledge brokers require “high level of proficiency in the subject matter to meet the diverse demands of the partners.” The CHSRF specifies that brokers are expected to accumulate professional knowledge in the fields of “marketing, communication and [Canadian] healthcare.” Moreover, Phipps and Morton (2013) find it important to combine experience in academic as well as non-academic environments:

“[Each of the knowledge brokers they employ] has academic (graduate student) credentials to ensure that they are able to understand and interpret research, along with non-academic experience working in community, policy or practice settings ... This extra-academic experience contributes to their credibility when working with non-academic agencies and also enables them to have empathy with and an appreciation of both the academic and community/policy/practice experience.” (Phipps & Morton, 2013: 258)

3.2.4. Skills

The literature focusing specifically on knowledge brokers in the healthcare sector suggests a variety of skills and personal attributes that are common for their role (Pyper, 2002; CHSRF, 2003; Lyons et al., 2006; Phipps & Morton, 2013). The articles focus on the role of the knowledge broker as an intermediary between researchers and other stakeholders in the healthcare sector, mainly policy makers.

However, the reflection of Tench et al. about communication professionals is also valid in the case of knowledge brokers: “[A]ttempting to specify particular skills that are required to fulfil the requirements of the profession is a complex process. The difficulty comes from a tendency to use different terms to define the same or similar skills. ... Adding to the complexity, skills are often broken down into sub-skills” (2012: 97). Knowledge brokers themselves are expected to have good communication skills, however, none of the publications on skills of knowledge brokers in the healthcare sector define or describe these explicitly (Pyper, 2002; CHSRF, 2003; Lyons et al., 2006; Phipps & Morton, 2013). A closer look at all the skills needed by a knowledge broker, mentioned in these articles, shows that in fact many of the skills are related to communication.

Among the skills more clearly connected to communication activities are translation of information into a form that the stakeholders find pertinent and accessible (CHSRF, 2003; Pyper, 2002), as well as “selling people on new ideas and presenting information

in useful and appealing formats” (CHSRF, 2003: 8). Pyper adds skills that include starting and moderating a dialogue, discussing sensitive topics and, more generally, listening to others: “they need to know how to put people at ease, how to listen and know how to ask open questions and feel comfortable to discuss sensitive subjects” (2002: 67). The Canadians confirm the importance of the first two of these abilities intrinsic to communication.

As the activities of “identifying, engaging and connecting with stakeholders,” and, in a similar manner, “facilitating collaboration between stakeholders,” are prominent in knowledge brokering, skills related to these are also often mentioned in the literature. Knowing how to network, build relationships (Lyons et al., 2006) and find out what other partners need are three of the skills on which Pyper (2002) and the CHSRF (2003) agree. Moreover, Pyper supports the introduction of what she calls a “community knowledge broker,” an intermediary between patients and professionals providing support to those who need help in expressing their health or social care needs. The skills of these knowledge brokers include “enabling those individuals or groups who are more isolated and less vocal or confident to articulate their needs and concerns and to work with them to seek solutions that are relevant to them” (2002: 64). Other key skills that have been identified are the ability to build trust (Pyper, 2002), to build a team (CHSRF, 2003) and “engaging individuals to participate” (Lyons et al., 2006: 59; see also Pyper, 2002). One more related skill is the ability to negotiate (CHSRF, 2003; Phipps & Morton, 2013).

For the activity of “identifying and obtaining relevant information,” the CHSRF stated that “Certainly, in all cases, an ability to find relevant evidence is key. Expertise in searching the web is crucial, both to search out academic research and to find other, less formal, contextual evidence” (2003: 7). They also pointed out that being able to assess evidence and interpret it is a basic skill for knowledge brokers. Pyper had also suggested this (2002).

For each activity identified by Bornbaum (2015), at least one associated skill could be found in the literature about knowledge brokers in the healthcare sector. In the case of “project coordination” the related skill is precisely to know how to coordinate tasks and people, as they provide “ongoing support or supervision” to the processes of information management (Pyper, 2002: 62). Similarly, “facilitating the development of analytic and interpretive skills” of the stakeholders requires the skill of being able to teach and coach others, “to build skills within their clients groups” so that they are relatively empowered to search and interpret information by themselves (Pyper, 2002: 62).

Some of the skills mentioned earlier are applicable to multiple activities. An example of this is selling ideas, which reappears in the literature in connection to activities such as

supporting communication, network development, facilitating and evaluating of change, and supporting sustainability. In the same way, the ability to find what other partners need may be recognized during the following activities: engaging and connecting with stakeholders, facilitating collaboration, identifying relevant information, creating tailored knowledge products, and facilitating change.

3.2.5. Personal attributes

Bornbaum et al. (2015: 9) note that, besides the tasks that KB in healthcare perform, personal attributes “may also play an important role in how they operate in practice.” However, it seems that the influence of personal attributes has received little attention in the literature on knowledge brokers. Nevertheless, the work of the CHSRF (2003) and Phipps and Morton (2013) gives an insight into the wide array of qualities that may shape this professional profile.

The literature review carried out for the CHSRF very briefly concluded that “knowledge brokers are imaginative, intuitive, inquisitive, and inspirational leaders” (2003:8), while participants in consultations about knowledge brokering “felt that the people who would work well as brokers have a certain type of mind: flexible, curious, and able to see the big picture, [in order] to make links among a range of ideas and bits of information” (2003:8). In addition, they think that having self-confidence is necessary, but they should not be arrogant.

Phipps & Morton (2013) use their own experience in being, hiring and training knowledge brokers to construct an image of the qualities of this professional profile. They have outlined seven key characteristics (see textbox 4).

Textbox 4. Key personal attributes of knowledge brokers in the healthcare sector

Nimble, fleet footed

Knowledge brokers need to be able to make quick decisions, in order to adapt to a variety of stakeholders and changes in agendas while keeping the aims of the knowledge brokering initiative in mind.

Enthusiastic

To be able to sell ideas to different stakeholders and get them engaged in the process it is important for knowledge brokers to be enthusiastic. Knowledge brokers are often passionate about the purpose of the initiative that they facilitate.

Creativity

Knowledge brokers sometimes need to be creative as they need to improvise when solving problems and find “new approaches to communication” (Phipps & Morton, 2013: 259) when relating to stakeholders with diverse backgrounds.

Courage

Knowledge brokers should not be scared to show initiative in leading the stakeholders when they are reluctant to interact. They should be brave enough to try something new and “encourage others to follow” (Phipps & Morton, 2013: 260).

Tact and negotiation

A knowledge broker role “is about balancing competing agendas and creating shared directions” (Phipps & Morton, 2013: 260). Therefore, they need to have tact when negotiating hierarchic relationships, conflicting interests and time management issues with and between stakeholders.

Tireless commitment

As “collaboration is harder and more time consuming than individual research” (Phipps & Morton, 2013: 260), knowledge brokers need to be committed to their cause.

Communicator, listener and supporter

As knowledge brokers have the skills to help stakeholders to express their views, listen to them and train them how to share their knowledge, it is important for the brokers to be communicative and supportive.

In the same way as communication is central to the activities, knowledge and skills of knowledge brokers as discussed in the previous sections, it is also prominent among their personal attributes. This fosters some ambiguity with concepts such as listening that some authors (CHSRF, 2003; Pyper, 2002) consider a skill (this thesis adheres to this interpretation) while others like Phipps and Morton consider it a quality.

3.2.6. Professionalization

The profession “knowledge broker” is still quite new and evolving (Phipps & Morton, 2013). The early diagnosis of the CHSRF was pessimistic in the healthcare sector: “A lack of identifiable brokers and broker groups undermines the function by fragmenting the actions and responsibility among different people” (2003: 5). Some years later, Meyer, contemplating a wider context, observed that despite the emergence of knowledge brokering as an activity, it “still tends to be unrecognized and unplanned” (2010: 122), and Traynor et al. complained that “a standard job description or widely-accepted [knowledge broker] qualifications do not currently exist” (2014: 541). Most recently, Glegg & Hoens warned of the implications of this uncertainty: “Recruitment, accountability, recognition, training, and professional development are each compromised without the clear delineation of the role and its expectations” (2016: 115).

Phipps and Morton (2013) advocate that knowledge brokering should be recognised as “a legitimate activity that needs to be funded and supported by skilled professionals with training and the right personal qualities” (2013: 263). This process can be

understood through the concept of professionalization, which entails “(1) education, training, and other activities that transform a worker into a professional and (2) social processes by which an occupation becomes a profession” (National Research Council, 2013: 15). The difference between the two is relevant: an occupation is a collection of tasks in order to perform a social activity, “while professions are the exclusively organized occupational groups whose members share a common occupational identity and commitment, and also have control over what their work is and how it is done” (Tran & King, 2007: 135). The concept of professionalization has been applied to analyze emerging specialized activities in diverse fields such as cybersecurity, museum education and science communication and has led to recommendations (Jeffrey & Brunton, 2011; National Research Council, 2013; Wehrmann & Waarlo, 2014). This approach is not only important to understand and foster the development of a profession, but also to make sense of how the individual professional profiles evolve over time.

The literature about the knowledge brokers in the healthcare sector has proposed several initiatives that could be interpreted as leading to professionalization. They include organizational change, with an emphasis on training and creating communities of practice.

Organizational change

Several authors insist on organizational change as the essential factor for the professionalization of knowledge brokers: changes in their organizational environment would provide support, resources, and recognition for their work not only from the stakeholders, but also from their direct managers (CHSRF, 2003). Organizations need to be committed to implementation of knowledge brokering, and for that they need to perceive its benefits: “valuable human and knowledge resources will be wasted unless management openly accepts and supports efforts to gather, sort, transform, record and share knowledge” (Smith, 2001: 311).

The activity of knowledge brokering is also developing itself within the field of patient participation in research. For this occupation of knowledge broker to become a profession established in this context, there needs to be a process of growth, recognition and consolidation, both for the profession as well as patient participation. However, the process is never easy: “The path toward professionalization of a field can be slow and difficult, and not all portions of a field can or should be professionalized at the same time” (National Research Council, 2013: 27).

Training

Knowledge brokers need to continuously develop their knowledge and skills in order to keep up with the expectations of stakeholders that start to appreciate the value of their work (Glegg & Hoens, 2016). However, according to Meyer (2010) there is lack of support and training for knowledge brokers, and literature about the healthcare sector confirms this (CHSRF, 2003; Phipps & Morton, 2013). The first initiatives are again to be found in Canada, where a strategy has been developed to “build capacity in the science and practice of [knowledge translation]” (Straus et al., 2011), and Scotland (Phipps & Morton, 2013). Training should include knowledge transfer (Straus et al., 2011), communication and networking (Phipps & Morton, 2013), marketing and management, as well as a focus on specialized knowledge related to their specific context (CHSRF, 2003). In addition, there are some tacit aspects than can only be learned through experiencing this role, for example the understanding of different environmental contexts that stakeholders may have (Johri, 2008).

Communities of practice

Communities of practice are groups of people, formal or informal, where members are sharing knowledge and develop work practices together, often across several organizations (Wenger, 1998). They “share a concern or a passion for something they do and learn how to do it better as they interact regularly” (Wenger & Trayner-Wenger, 2015: 1). The benefits of communities of practice include helping to deal with change, fostering access to expertise and increasing the confidence of practitioners on the meaningfulness of their work. Long term, these networks consolidate their professional identity (Wenger & Trayner-Wenger, 2015).

The CHSRF created a national community of practice answering to the needs of the participants in their consultation meetings. The aim of such a network is to exchange experiences and identify best practices (CHSRF, 2003). Phipps and Morton encouraged knowledge brokers to set up similar networks connecting professionals working for universities of Canada and Scotland:

"As an emerging profession it is important to be able to develop and share practice and these provide an opportunity to do this, which we have found invaluable and difficult to access elsewhere ... Until the profession is more developed, the opportunity to share emerging successes and challenges will be important in developing and understanding what it means to be a [knowledge broker] and what training might support the development of suitable skills and qualities." (Phipps & Morton, 2013: 263)

3.3. Summary

For the first time, this conceptual framework puts together theoretical concepts related to knowledge brokering and professionalization in order to analyze patient participation in scientific research facilitated through patient organizations. Previous studies on knowledge brokers in healthcare have not focused on participatory settings, but rather described the transfer of knowledge from researchers to policy makers fostering evidence-based decision-making. In patient participation, the knowledge exchange may be bidirectional and experiential knowledge of the patients plays a prominent role in the process. The role of the knowledge broker in patient participation has not been described yet, and the conceptual framework gathers the characteristics of this professional profile in healthcare as a benchmark for the exploration of this developing profession. It allows to study a wide range of facets such as their job title, educational background, professional experience, activities related to patient participation, professional knowledge, skills, and personal attributes. The perspective of professionalization, including aspects such as organizational change, training and communities of practice, serves to address both the current professional profile and the desired evolution deemed necessary to enhance the process of patient participation.

4. Research questions and methodology

After careful consideration of the relevant literature and the shaping of a conceptual framework, a main research question and several subquestions are discussed below. Regarding the methodology, this study utilizes an exploratory qualitative approach to gain insight into the profiles of employees of patient organizations who are responsible for patient participation, mainly in scientific research initiatives. After selecting appropriate respondents, semi-structured interviews were held, during which a card sorting method was carried out. For context, this was complemented with the analysis of print and online documentation related to patient participation, produced by patient organizations and other relevant stakeholders. The remainder of this chapter describes the research questions and the methodological choices in more detail.

4.1. Research questions

This thesis explores how patient organization practitioners, more specifically those who take responsibility for patient participation, reflect on their existing and desired professional profiles from the perspective of knowledge brokering. They have an intermediary role, connecting a diversity of stakeholders, including researchers, health professionals and patients who all have a shared aim of incorporation of experiential knowledge of patients into scientific research and medical practice. Because of this, the thesis puts forward the following working hypothesis: patient organization practitioners responsible for patient participation may have a similar professional profile to that of a knowledge broker in the healthcare sector. This includes their tasks, skills, professional knowledge and personal attributes. The main research question therefore is:

Which aspects of the professional profile of knowledge brokers within the healthcare sector do practitioners within patient organizations, involved in initiatives with patient participation, consider relevant for their current and future role?

To be able to address this main question, some subquestions need to be answered:

1. Who takes the role of knowledge broker within patient organizations to facilitate participation of patients in projects?
2. Which tasks, skills and personal attributes of knowledge brokers are relevant to them when facilitating patient participation?

3. Which tasks, skills and personal attributes of knowledge brokers would they like to take on, acquire or improve?
4. What, according to the practitioners involved in patient participation, needs to happen to further develop the professionalization of their role and patient participation?

These subquestions can be justified as follows:

1. Who takes the role of knowledge broker within patient organizations to facilitate participation of patients in projects?

To explore which aspects of the professional profiles of practitioners of a patient organization are similar to those of knowledge brokers in the healthcare sector, it is important to know who takes on the role of knowledge broker. Answering this subquestion should give an impression of the educational background, professional knowledge and experience, as well as the position of those involved in initiatives with patient participation, as well as their level of responsibility and their working conditions. This is the first question that needs to be answered to provide the context to address the other subquestions and subsequently, the main research question.

In addition, subquestion two explores the extent to which these practitioners take on the role of knowledge broker, as currently it is not known whether these intermediaries are indeed, knowingly or unknowingly, knowledge brokers. A possible answer to subquestion one could be that nobody takes the role of knowledge broker within patient organizations, subquestion two will help to determine this.

2. Which tasks, skills and personal attributes of knowledge brokers are relevant to them when facilitating patient participation?

To be able to explore if and how the practitioners perform knowledge brokering activities, it is important to make them reflect on the relevance of key aspects of the professional profiles of knowledge brokers: their tasks and the associated skills and personal attributes that allow them to carry out their work. An exploration of the current professional profiles is essential to compare them to their desired situation through the subsequent questions.

3. Which tasks, skills and personal attributes of knowledge brokers would they like to take on, acquire or improve?

Once details about the current tasks, skills and personal attributes related to knowledge brokers have been obtained from the practitioners, an inventory of desired tasks and skills, as well as reflections about personal attributes, can be investigated. This will help to determine which tasks, skills and personal attributes, related to knowledge brokering, may be important according to the practitioners for the improvement of patient participation.

4. What, according to the practitioners involved in patient participation, needs to happen to further develop the professionalization of their role and patient participation?

Once there is insight into the current and desired profiles to facilitate knowledge brokering by patient organizations, the study will provide a reflection on which changes may be useful to improve knowledge brokering initiatives concerning patient participation. These changes may affect the internal organization of their working environment, and their professional development through training, communities of practice, etc. This will also allow for a reflection on the professionalization of this role.

The answers to these questions may highlight common features as well as striking differences between the professional profiles of the practitioners included in the study, depending on their professional background and the specific context of their organization. Rather than producing a collection of ideal-typical profiles, the thesis will put forward a combination of characteristics of knowledge brokers that are present and wished for in patient participation from the perspective of the practitioners. Even if the data may not be widely generalizable, it provides a roadmap for the professionalization of those who take the responsibility for knowledge brokering in the development of patient participation in research and healthcare policy.

4.2. Methodological choices

Considering the aim of the thesis of exploring the professional profile of practitioners within patient organizations responsible for patient participation in research initiatives, an ethnographic study (Bryman, 2012b) was taken into consideration as a potentially fruitful method; an in-depth on-site observation of the knowledge brokering activities related to patient participation of a single patient organization, complemented with formal and informal questioning of behaviors and decisions. However, there were several consequences that would have to be taken into account: these patient participation initiatives can be long term processes which I would only be able to follow during a relatively short time-span. Additionally, through initial contacts with several patient organizations I was made aware of the constraints of time of the organizations and their employees or volunteers, in many cases having just one person engaged in patient participation initiatives and often does not happen as a regularly planned and systematic activity. Finally, confidentiality and ethical considerations play a significant role too as sometimes sensitive information is discussed with patients, researchers, and other parties involved. It would be difficult and disruptive to the work of the practitioner to obtain consent from all those she would be involved with (Bryman, 2012: 139). Therefore, it seemed more feasible to perform semi-structured interviews with those responsible for patient participation within several different patient organizations. The

interviewees were not observed while performing their activities, but rather asked about their experiences and points of view, which is coherent with the approach adopted in the research questions. A first challenge was the recruitment of relevant respondents for the study, which will be discussed next.

4.2.1. Sampling and preliminary questionnaire

There is a very limited amount of literature that describes the participation of patients in research projects and the role that patient organizations play in this process. This makes it difficult to have a systematic census of this kind of projects and therefore one of the initial challenges of this study was identifying potential respondents.

PGOsupport provided the most concrete leads to relevant respondents. As mentioned before, it has recently published recommendations for successful involvement of patients/clients in medical scientific research (M. De Wit et al., 2016), and even if they do not contain specific recommendations for knowledge sharing or communication between research partners within these projects, the document contains a list of Dutch (patient) organizations who support these guidelines. During a conversation with Annemiek van Rensen of PGOsupport it was confirmed that all the organizations in the list have to some extent experience with patient participation in research projects, and therefore it was pertinent to contact them. An agreement was also made to use the closed LinkedIn group of PGOsupport to place a call for involvement in the study (the text of this call can be found in appendix I). This resulted in three reactions, two of interested employees of patient organizations and another reaction of an interested patient advocate. However, she was not an employee or volunteer representing a patient organization or similar and therefore was not a suitable candidate for this study.

Phone calls were made to all organizations listed in the document mentioned above, as well as two others who stated involvement in patient participation on their website, to request for contact details of appropriate members of the organization. In some cases, email was the only way to reach the organizations. Those contacted by phone often requested an additional email explaining the project, so that my request could be forwarded to the appropriate colleague(s). Emails were also sent to two patient organizations after reading about their initiatives concerning patient participation on the website of Participatiekompas, www.participatiekompas.nl.

In total, 19 organizations were directly contacted, by phone and/or email after collecting contact details through their respective websites. Six organizations did not respond at all to my request while another five organizations did respond to my request, and often expressed interest, but declined to take part in the study for several different reasons including limited resources and a lack of time to take part in research studies.

Eight organizations responded positively to my request and I made appointments for a short preliminary interview by telephone with those who indicated to be the appropriate person for this study.

During the preliminary interviews information was collected to determine if these persons were indeed involved in patient participation as an intermediary between their organization, patients and scientists. I asked them about the roles of the patients in these initiatives to determine the level of patient participation, a short description of their own role in patient participation, if someone else within their organization is involved in patient participation and, if so, what their role entails. Twice I made a request to contact other colleagues who also may have an intermediary role between researchers and patients, this resulted in one more candidate for an interview. Some of the information obtained through this preliminary interview was used to find answers to subquestion number one: *Who takes the role of knowledge broker within patient organizations to facilitate participation of patients in projects?* The form used to guide the questions and collect information can be found in appendix II.

All preliminary interviews indicated that the respondents were indeed involved in initiatives with patient participation and had an intermediary role between their own organization and, amongst others, researchers and patients. Therefore, after a brief explanation about the aim of the interview, appointments were made with nine respondents of eight different organizations, to hold semi-structured interviews about their role in patient participation. This activity was expected to last approximately one hour. The location for the interview was agreed to be within their own working environment, often an office or meeting room, unless a different location was considered more convenient. Twice an interview took place in the informants' living room while once the interview took place in a meeting room within the library of the TU Delft. I made a request to all interviewees to have a table available. All interviews took place between 24th April and 5th of May 2017. Before beginning the interview, consent was asked for audio recording and permission to take a photograph of the result of the card sorting activity, for the sole purpose of analysis for this study.

The nine respondents included in this study were connected to eight organizations (see appendix III). In this thesis, for the sake of anonymity and simplicity, the organizations of the respondents will be referred to as patient organizations. The profile of the respondents will be discussed in more detail in the results chapter. Their names have not been included in this study, as this was agreed upon when arranging the interviews. In addition, an agreement was made to share the results of this study with the participants as they showed great interest and the insights can be very useful for them.

4.2.2. Semi-structured interviews

For this study, semi-structured interviews with open questions were used as one of the methods. As the scarce literature on the subject made it difficult to predict most likely answers, using open questions had the advantage of allowing a wider range of answers to emerge, some unexpected, allowing for a much richer discourse. Interviewees were able to discuss in their own words, which avoids imposing the theoretical framework on their points of view during the interviews (Bryman, 2012a; Qu & Dumay, 2011).

The interview protocol (see appendix IV) was designed to collect data which would enable answering all research questions. Textbox 5 presents an overview of how the different sections of the interview relate to each subquestion. The interview protocol also included introductory information about my background, the aims of the study, an overview of the course of the interview and the request for consent. To discuss the tasks of the practitioner, the ten key brokering activities as described by Bornbaum et al. (2015), and discussed in the conceptual framework, were used as a point of departure to construct the questions. The instructions for the card sorting exercise, focusing on skills and personal attributes, were also part of this protocol.

Textbox 5. Overview of the links between research questions and sections of the interview protocol

- RQ1.** Who takes the role of knowledge broker within patient organizations to facilitate participation of patients in projects?
- 2.1. Professional knowledge and experience
 - 2.2. Position within the organization
- RQ2.** Which tasks and competencies (professional knowledge and skills) and personal attributes of knowledge brokers are relevant to them when facilitating patient participation?
- 2.1. Professional knowledge and experience
 - 2.3. Tasks related to patient participation
 - 3.1. Skills and personal attributes important in the present (during and after the card sorting)
- RQ3.** Which tasks, competencies (professional knowledge and skills) and personal attributes of knowledge brokers would they like to take on, acquire or improve?
- 2.1. Professional knowledge and experience
 - 2.3. Tasks related to patient participation
 - 3.2. Desired changes in skills and personal attributes
- RQ4.** What, according to practitioners involved in patient participation, needs to happen to further develop the professionalization of their role in relation to patient participation?
- 4. Context and professionalization of knowledge brokering and patient participation
- Aspects related to this RQ were also discussed during sections 2.1, 2.3 and 3.2 of the interview.

For analysis of the interviews, transcripts were made and qualitative data analysis software (TAMS Analyzer, version 4.48b7ahEC) was employed. The data was analyzed using a coding manual and coding scheme (see appendix V), with variables based on the

conceptual framework. The analysis strived to preserve direct quotes from the interviews that illustrated the way respondents expressed their points of view.

4.2.3. Using a card-sorting method based on Q methodology

To determine which skills and personal attributes are important for the employees that are involved in patient participation, it was decided to use a card-sorting method to gain insight in the importance of a number of pre-determined skills and personal attributes. There is no scientific literature on the professional profiles of persons that are involved in patient participation. Therefore, a selection of skills and personal attributes was drawn from literature available about professional profiles of knowledge brokers in the health sector, as it is expected that the professional profile of the respondents shows similarity to that of a knowledge broker, albeit in the specific context of patient participation in research.

During a card-sorting exercise inspired by Q methodology⁴, the respondents expressed their opinions on the importance of these skills and personal attributes. Therefore, it is possible to explore this part of their professional profile and understand what is important for them and why. The ranking of each skill and personal attribute in relation to each other allows an analysis that appreciates the “bigger picture,” a more holistic viewpoint on the connections between the different competencies that are shaping the professional profiles of this group of respondents.

Q methodology was first developed by the psychologist William Stephenson in 1935 as he described it in the article titled “Correlating persons instead of tests” (Stephenson, 1935). It offers a scientific approach that enables researchers to carry out a systematic examination while obtaining an understanding of the subjectivity involved in a situation, whether that be perceptions of an organizational role, political attitude, or poetic interpretation (Brown, 1996). In healthcare, Q methodology can be used to identify the patients' viewpoints prompting adaption of change in practice of nurses in response to patients' needs (Simons, 2013). Recently, in the field of knowledge mobilization, Batac (2015) used Q methodology to conduct a preliminary study on how practitioners, intermediaries, brokers, and researchers prioritize competencies needed for knowledge mobilization in any discipline.

Q methodology “combines the strengths of both qualitative and quantitative research traditions” (Dennis & Goldberg, 1996, p104). The qualitative element of Q is granted as

⁴ The card sorting exercise follows Q methodology, as presented below. However, the statistical power of the method is not fully exploited due to the relatively small sample and that is why the thesis only claims to be inspired by the methodology. Instead, an emphasis has been put on the qualitative aspects of Q methodology.

the respondents provide rich data and attribute meaning to statements during a ranking process, so that the differences in respondents' points of view become the focus. The quantitative element is provided as the data is analyzed by correlation and factor analysis. Q methodology contains several steps in the process.

First, a collection of statements is made on the topic of study usually through preliminary interviews or focus groups, which will become a set of items that respondents of the Q study have to rank. For this research, because of time constraints and the small universe of potential respondents, the items to be ranked were drawn from relevant literature on skills and personal attributes of knowledge brokers in the health sector (see the corresponding section of the Conceptual Framework, and table 2). In this case, the items were 17 skills and 17 personal attributes, resulting in a total of 34 cards. This number allows for collection of rich data within a relative short amount of time, as the card sorting took place as part of a one hour interview with each respondent.

Second, the respondents are asked to rank each item. They were asked to sort the skills and personal attributes by responding to the following question: "When you think of how you currently carry out your work involving patient participation, which of these competencies are most important to you?" The respondents were provided with a pre-determined grid on carton, forcing them to place each of the 34 cards in a quasi-normal distribution, of which the shape was determined by the number of cards, ranking from "most important" on the right side of the grid to "least important" on the left side of the grid (see figure 5). It was explained to the respondents that there is no difference in importance between items that are placed in a vertical column. To facilitate the sorting, the respondents were advised to first rank each statement within one of three categories, by placing each card on one of three provided positions: most, neutral or least. After this initial sorting, the participant was requested to place each of the items on the grid, starting with the items initially placed in the "most important" pile, followed by those in the "neutral" pile and finishing with those in the "least important" pile. The respondents are prompted to think out loud and explain their reasoning during the sorting process. By asking for examples and situations in which certain skills and personal attributes are applied, the respondents provided insight into behavioral indicators (Campion & Odman, 2011). These allow to put the abstract concepts into the daily context of the practitioners, helping to add nuance to the analysis. Once all the cards are sorted a photo is made of the grid to facilitate analysis.

Table 2. List of competencies used for the card sorting activity

Skills
1) to know how to search for relevant information ¹
2) to know how to translate difficult text to easy to understand text ^{1,2}
3) to know how to network and build relationships ^{1,2,3}
4) to know how to help others to express their views ^{1,2}
5) to know how to coordinate tasks and people ²
6) to know how to motivate others to participate ^{2,3}
7) to know how to build a team ¹
8) to know how to listen ^{1,2}
9) to know how to sell ideas ¹
10) to know how discuss sensitive subjects ²
11) to know how to assess information for quality, relevance and usefulness ^{1,2}
12) to know how to negotiate ^{1,4}
13) to know how to present information in useful and appealing formats ^{1,2}
14) to know how to start and moderate a dialogue ^{1,2}
15) to know how to teach and coach others ²
16) to know how to find out what other partners need ^{1,2}
17) to know how to build trust ²

Personal attributes
18) to be creative ^{1,4}
19) to be innovative ¹
20) to have self-confidence ¹
21) to be willing to learn ¹
22) to be intuitive ¹
23) to be able to “see the bigger picture” ¹
24) to have tact ⁴
25) to be supportive ⁴
26) to be inquisitive ¹
27) to be flexible ¹
28) to be curious ¹
29) to have tireless commitment ⁴
30) to have courage ⁴
31) to be communicative ⁴
32) to be an inspirational leader ¹
33) to be enthusiastic ⁴ (Phipps & Morton, 2013)(Phipps & Morton, 2013)(Phipps & Morton, 2013)(Phipps & Morton, 2013)(Phipps & Morton, 2013)(Phipps & Morton, 2013)(Phipps & Morton, 2013)(Phipps & Morton, 2013)(Phipps & Morton, 2013)(Phipps & Morton, 2013)(Phipps & Morton, 2013)(Phipps & Morton, 2013)(Phipps & Morton, 2013)(Phipps & Morton, 2013)(Phipps & Morton, 2013)
34) to be decisive ⁴

Sources: ¹ CHSRF (2003), ² Pyper (2002), ³ Lyons, Warner, Langille, & Phillips (2006), ⁴ Phipps & Morton (2013).

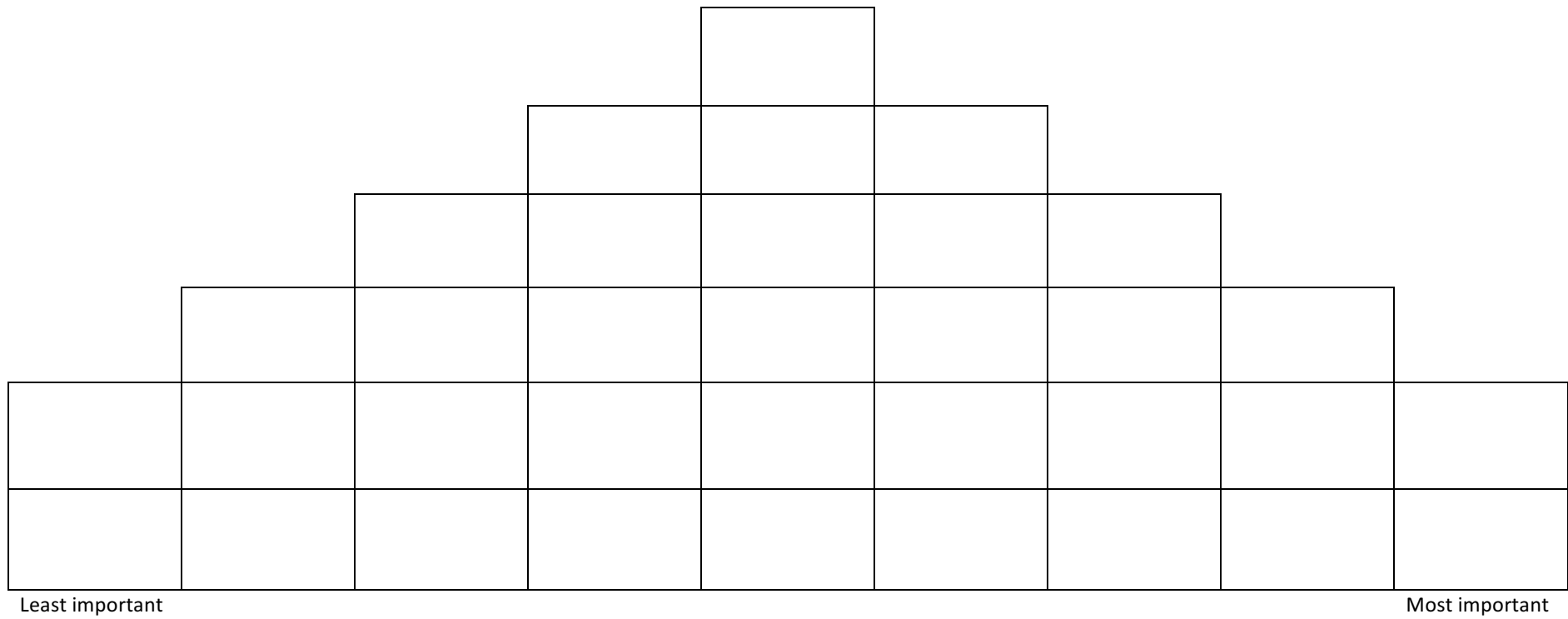
Third, the sorting process is followed by a qualitative interview about the ranking of items; this included questions about behavioral indicators. The respondents were also asked about any skills or personal attributes they perceived to be missing in the collection of items presented to them and which of the items they would like improve in regards to how they carry out their work related to patient participation.

A pilot session with a knowledge broker from a different field was conducted to test clarity of the protocol and the items as well as to obtain an indication of the amount of time needed for the card sorting and post-sort interview.

The fourth step is the factor analysis. A detailed explanation of these concepts and the statistical process for the factor analysis of this study is included in appendix VI (see also Watts and Stenner, 2012). To be able to interpret the different card sorts of the respondents, it is needed to make a transition from the card sorts, called Q sorts in Q methodology, to so-called factors via correlation and factor analysis. A factor reflects the key viewpoints that are held in common within the participant group, in this study a factor describes those respondents who have a similar point of view on which skills and personal attributes are important to carry out their work related to patient participation, and a factor load indicates how much an individual sort is exemplary for a factor pattern. For this study, PQMethod software, version 2.35 (Schmolck, 2014) was used for the analysis. In total, 9 sorts were inter-correlated and factor-analyzed. The correlation statistics determines the degree of agreement or disagreement between the set of item rankings produced by any two persons. Subsequently, the by-person factor analysis, which is typical for Q, identifies groups or persons who have rank ordered the items in a very similar manner. One of the methodological choices made was to perform a Centroid Factor Analysis, a commonly used and highly regarded factor extraction technique (Watts & Stenner, 2012).

4.5. Summary

The combination of semi-structured interviews with the card sorting activity adapted from Q methodology provides a balance between quantitative and qualitative data, allowing for an exploration of an almost uncharted professional field. The card sorting provides an opportunity to observe the commonalities between the different respondents in a systematic manner, while the interviews provided nuance and the chance for individualities to be expressed, enriching the overall analysis within a limited amount of time.



Least	Neutral	Most
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Figure 5. Q grid offered to the respondents to rank the statement cards.

5. Results

This chapter explores the professional profile of those who, within patient organizations, take responsibility for patient participation initiatives. It contains a detailed account, due to the nature of qualitative interviews, from the perspectives of nine respondents associated to eight different organizations. The identification code of each respondent is noted as (r+number), for example respondent 1 is (r1).

First, their views on the added value of involvement of patient organizations in initiatives with patient participation are described. This is followed by an explanation of their educational and professional background, their specific training related to patient participation and their own motivations to be involved in the process. The third section describes the position of the respondents within their respective organizations; amongst other aspects, it highlights the diversity of job titles and touches on their level of autonomy in their daily work. Section 5.4 details the views of the respondents about the ten knowledge brokering activities presented in the conceptual framework. The respondents report on a large variety of tasks related to these activities, while also reflecting on their, sometimes challenging, relationships with the different stakeholders they interact with. The results of the card-sorting exercise performed during the interview are presented in section 5.5, which focuses on their evaluation of the importance of a selection of skills and personal attributes related to knowledge brokering. A profile of “enthusiastic connectors” emerges from the analysis. The final section looks into the future: it presents not only the changes and improvements to their personal professional profile they feel are necessary, but also to the context within their organization and beyond. When talking about what it takes to improve the process of patient participation, the practitioners call for recognition and support, including resources, training, and the usefulness of communities of practice.

5.1. Added value of a patient organization for patient participation

As described in the introduction, patient participation in scientific studies is a relatively recent development, which is also expressed by one of the respondents: “It is something they started some years ago, and it has increased enormously in the past few years, also because there is pressure from funding organizations” (r6). Respondent 4 explains why she thinks it is important for her organization to be involved in patient

participation: “The organization does three things: inform, facilitate contact with peers, and advocacy. [Putting emphasis on patient participation] is a very nice and distinguishing opportunity when it comes to advocacy, but you have to actually do it. Asking the minister to give an extra 100 euro to patients with a condition is not effective. Patient participation provides a chance to have direct influence, but also to collect information.” Respondent 5 also reflects on added value for the patients to take part in initiatives with patient participation: “The patient has the idea that he or she is more human, takes part in society, has value and is useful. Some patients don't hold a job or have been disqualified and for them it is pleasant to join in and fulfil a role in society by making research more relevant.” In this context, the respondents put forward that the involvement of patient organizations adds value to this process; fostering improvement of quality and effectiveness, mainly through coordination and training of patient experts and through their networking activities.

Before discussing the added value of a patient organization, respondent 1 also insists on the benefits of patient participation: “Amongst other things, medication reaches the right patients faster, and I think it is nothing more than logical that a user of healthcare has a say in healthcare and research.” When asked whether it is necessary for a patient organization to play a role in this as researchers can also directly contact patients she states: “but they don't find each other, we bring them together.” Some other respondents also mention that not only recruitment, but also coordination and facilitation of networking opportunities is beneficial for patient participation (r2, r4, r8). Respondent 7 has similar thoughts on this: she argues that the added value of patient organizations is that they facilitate recruitment and training of the patients, activities that otherwise would have to be taken care of by the researchers. Providing training and courses by their organizations to patient experts also improves patient participation, according to respondents 5, 6 and 8. For respondents 3, 4 and 6, the responsibilities that the organizations take on are crucial as that centralizes the involvement of patients and increases the efficiency. Respondent 4 explains: “Patient organizations are closely connected to patients. It is the easiest way to make sure that it is not just one patient that tells you his opinion, but through a patient organization you can make sure you actually consult the patient community.”

Respondents 2, 5, 6 and 8 argue that the involvement of patient organizations improves the quality of patient participation. Respondent 5 explains: “We can help to make patient participation more professional through offering courses and training, facilitation of meetings for experience experts, and through learning from each other.” Respondent 2 elaborates about the recruitment: “We select participants very consciously, not just for their personal experience with the condition, but also on their acceptance of the condition and their willingness and capabilities to speak about it, because some people are incredibly driven, but this doesn't always help with the

bringing across of the message.” She also feels that the amount of work involved cannot be asked of a volunteer, and she suggests that it is important for researchers to have a trustworthy partner: “you become a more trustworthy partner for the researchers because I can warranty some continuity [...] and I have links with many people within the organization and that is very valuable, as my network is extensive and I can bring them in contact with others if my expertise is not sufficient.” Experience and continuity are also important added values for respondent 8: “[The organization] has a lot of experience in all sort of projects, research, medicine development, and as we have practical experience in this we know the difficulties in the processes but we also know how to communicate with our community and this makes a big difference.” She also mentions that her paid position is an advantage as it provides continuity and resources, and some activities can be carried out by volunteers under supervision.

Respondent 9 explains that a key aspect for her and her organization to be involved in initiatives with patient participation is increasing awareness of the need for patient participation: “An important added value is raising questions: Why do you do the research? What is the result? Is it worth doing? Is it actually relevant and beneficial to people? Those criteria, it is almost a philosophical added value, making people aware of and critical towards why we all do this.”

5.2. Background and knowledge

To preserve the anonymity of the respondents, in this section identification codes attached to individual results and responses may be omitted.

5.2.1. Educational background

All nine respondents have an education in one or more of three categories: health sciences, management, and pedagogy. Almost all respondents have a background in health sciences, often specializing in human movement sciences, with university degrees. Five respondents complement this with education in management and business administration. Three of the respondents have research experience through PhD studies or a previous career as scientist. A few have a background in pedagogy, again with an emphasis on healthcare-related topics.

5.2.2. Professional background and relevant experience

The respondents often mention that experience from previous employments is helpful in their work related to patient participation. One respondent mentions that her previous experience with patients is beneficial to her in relation to her current

professional activities. Another three of the respondents report that their familiarity with participation initiatives through their previous employments, or their personal experience, is beneficial to their work relating to patient participation. Respondents also report that they benefit from their experience related to education, training, management, quality control and organizational knowledge. One of the respondents explains: “Knowing how to build up an organization means -even though the tasks and responsibilities are different within a hospital- that I understand how an organization works.” For another one, experience in marketing communication helps her to carry out her tasks in her current position, as she needs to make sure that communication products, for example brochures, connect with the target audience. Another respondent reflects about similarities with earlier employment at a university: “training of researchers instead of students, [...] the communication with those students is not very different than with the researchers now, they also have to learn to be open to the perspective of patients and how it works, I hear myself say the same things now as I used to say to the students” and “organization and communication is a big part of my task package, it was like that at the university and it is not different now.”

For three of the respondents, having a scientific background is very useful to do their job. One of them explains: “I have been hired because of my background in education and my extensive knowledge, that is why they preferred me, and I also experience it like that. Having written research proposals myself and having experienced the bureaucracy at a university helps to have perspective.” Another discusses the usefulness of scientific knowledge in situations when patient experts request additional information about a research proposal, because that allows her to reformulate or translate the request to the patients. Two other respondents actually rely on other colleagues in the patient organization for their scientific knowledge.

5.2.3. Motivation

Several of the respondents mention that they prefer the level of practical involvement in their current employment compared to their previous ones. One respondent explains: “I wanted to do something a bit more in real practice, at the university the emphasis is on publishing and writing, this [position] is a lot more practical work.” Another respondent changed jobs to make sure it better suited her skills and interests: “I wanted to do more substantial work than just management, so I switched to more project leadership and patient-involvement, in that I could express both my leadership capacities as well as my meaningful interests.” This suggests that personal motivation is another factor for some of the respondents to be involved in patient participation. And indeed, a respondent explains she has always been motivated to help patients, to explore their drive and make it her “core business.” Her experience with business management helps her in her strategy for patient participation. Another respondent,

despite having a background as a human movement scientist, suggests it is not her professional background that helps her to do her tasks related to patient participation, but mainly her personal drive: “I think it's very personal, what you want yourself, because my motivation in research was always to help other people.”

5.2.4. Specific training related to patient participation

Some of the respondents have been engaged with patient participation in scientific projects since its very early development, others have become involved at later stages. This reflects in the different responses when the interviewees are asked about whether they received specific training related to patient participation: two of the respondents mention that they taught themselves about patient participation as no courses existed yet, another mentions she did not know if any courses existed at the time she got involved in patient participation.

Six of the respondents report that they followed training or courses related to patient participation. The majority are organized by PGOsupport, and one respondent even states: “It is really our only support when it comes to training.” The topics of the training and courses include advocacy, interviewing, leading conversations, story telling and story listening, participation in scientific research, development of guidelines, project management, and coordination of volunteers.

Even when sometimes the content of a course is already familiar to a respondent, it may be beneficial to follow a course as respondent 4 explains: “[During those courses] you meet people from other organizations and you learn from each other.” Similarly, another respondent describes how attending meetings is useful to her: “In the beginning I had a booklet from ZonMW, that is useful, but now I learn from practices from others and how we may be able to apply them within our organization.” Respondent 5 values both courses and attending events with peers: “It is not that I have built up all my knowledge just from those courses, but also through talking about it with other patient organizations. It is very nice that that is being facilitated.” Respondent 9 stresses the importance for her to meet with peers instead of attending courses: “I actually learn from experiences, stories of others, once or twice per year there is a meeting organized that I like to attend, and if I'm honest I learned a lot from that, but I can't say that I would want a very formal course, I think that symposia, and sharing of experiences, are very useful.”

5.3. Position within the organization

During the interviews the respondents shared basic information about their position within the organization. This section describes their job titles and role descriptions,

some aspects of their working conditions, for how long they have held this position, and their connection with colleagues within their organization related to patient participation. Each of the respondents were asked for their job title, as well as their role description in the following format: "As ... I am responsible for ..." Their responses are listed in textbox 6. From this, it is obvious that for some their titles and roles are very specifically connected to patient participation, while for others their responsibilities related to patient participation are part of a broader role within the organization.

Of the nine respondents, three report between five and ten years of involvement in patient participation, another three respondents between two and three years, and yet another three respondents for less than one year. Eight respondents hold a paid position within their organization while one is involved on a voluntary basis. Two of the respondents report having a full-time employment. Those who have "senior project leader participation" or "coordinator patient participation" as their job title, report spending 100 % of their tasks on participation. The other respondents, when asked how much time, on average, is spent on patient participation per week, often find this question difficult to answer. Some mention 10-20, 30 or 50% of their time can be spent on tasks related to patient participation; this may depend on the demands of the different initiatives and projects that the organization is involved in but the respondents also have many other tasks within their organization that are not directly related to patient participation. Nevertheless, four of the respondents explain that patient participation is a leading motive within their organization and influences many activities of the organization. One of the respondents illustrates: "I have many different roles and tasks within the organization, but I am someone who [...] asks the question: what does the patient think of this? I always take that role, or I always ask that question, so it is 100% at the back of my mind, but I'm not 100% working on it every day."

When asked about their level of autonomy in decision making, all respondents but one report that they feel they have sufficient autonomy. Five of the respondents specifically mention they report back to superiors or make "big decisions" in agreement with superiors. For two respondents, their superiors are the only other colleagues involved in matters related to patient participation within their organizations. Some other respondents explain that they are the ones with a specific focus on patient participation, even though other colleagues within the organization may be involved in projects with patient participation. Five of the respondents report that they have two, three, or four other colleagues that are involved with patient participation within their organization. These colleagues may be mainly responsible for coordination of scientific research, quality of care, advocacy, volunteers, or communication, and the respondents collaborate with them. One of the respondents says about the involvement of her colleagues in patient participation: "I think that three people are really active, three or four. I think that some other people do it, but they are not even aware of it."

Textbox 6. Job title and role description of the respondents

Senior Project Leader Participation

"As the recruiter of the suitable volunteer, patient, the one who fits a certain project, that is my role, **I am responsible for** finding the suitable person, but in a broader context of my responsibilities, I am responsible for a group of experiential experts."

Coordinator patient participation

"As coordinator within the patient association **I am responsible for** the first contacts, finding the right research partner, and I'm the helpdesk for all questions from both researchers as well as patients."

Coordinator patient participation

"As coordinator **I am responsible for** the matching of the right patient profile with what the researchers wants, actually like a sort of intermediary in this field."

Policy Advisor, focus area patient participation in scientific research

"As coordinator and facilitator of patient participation, I call myself often broker or bridge builder, **I am responsible for** that the researchers can formulate their question in a clear manner, creating the conditions so patients can participate, making agreements with researchers, but also recruiting, selecting and training of the patients, experiential experts -I use both terms-, and subsequently I coordinate and facilitate mostly that they can do what is requested from them. So they can be mostly occupied with the study, and not with all secondary matters that I will take care of, when there is a meeting nobody will have to organize that, or to write reports, I facilitate that."

Coordinator research

"As coordinator **I am responsible for** making sure that participation in policy and practice runs smoothly."

Policy officer quality and research

"As ... in one word? I think that is not possible to explain, and can be very different between projects [...], I can be a mediator, but also a project manager, **I am responsible for** mediating between patients and researchers, but sometimes I represent the association to think along in a focus group [...], but I can also be the project manager who connects patients to projects and then I am responsible for the practical matters, it is really something different so I'm not sure I can in one... "

Project officer quality of care

"As project officer **I am responsible for** resolving all inquiries related to research."

Employee quality of care

"As project leader of projects with patient participation **I am responsible for** the end result."

Director

"As on one hand someone who paves the road so others can do their job, and on the other hand someone who can explain, from literature and my own experience, to our own organization how [patient participation] benefits us, that is the connection, **I am responsible for** making sure the projects are valuable, that it matters, and that, in the end, you can say 'we have developed projects or initiatives in which we can really contribute to the patient perspective early in the research process, instead of finding out in hindsight what to do with the results.' "

5.4. Current tasks related to patient participation

Through analysis of the interviews, it is possible to make an inventory of the activities and tasks that are being carried out as self-reported by the practitioners involved in patient participation. The inventory has been constructed based on ten main knowledge brokering activities of knowledge brokers in health-related settings (Bornbaum et al., 2015).

5.4.1. *Identify, engage and connect with stakeholders*

The respondents are involved in personally engaging with other stakeholders in varying degrees. These stakeholders mainly consist of patients, researchers and funding organizations.

Most respondents specifically mention their involvement in recruiting patients for initiatives with patient participation (r2, r3, r4, r6, r7, r9). Motivating them to become involved in these initiatives is reported as central to their tasks in some of their self-reported role descriptions (r2, r3, r7). Respondent 9 admits that this can be trying, as “[the patients] often don't understand the process and think it is too difficult.” Many explain that they engage patients to evaluate a research proposal or take part in other research related activities (r3, r4, r5, r6, r7, r9). Respondent 4 stresses to the patients that they have an important role to play in research: “It is one of the most important reasons why you are involved in the research, so give that feedback because that is what you add as a patient.” Once patients have become part of a panel that evaluate research proposals, they usually repeat involvement according to one of the respondents (r7).

The most often mentioned stakeholder is researchers, towards whom interviewees have different approaches in how to engage and connect with them. While respondent 1 claims “we are often the initiator,” others tend to not take initiative in contacting research institutes or researchers (r2, r6). Respondent 2 explains: “We actually offer a sort of service to researchers, it almost always starts with a request from the researchers, sometimes through a funding organization, sometimes through the website, sometimes through other contacts.” Respondent 6 describes that her organization does have brochures explaining how the patient organization can play a role in patient participation, but often it is the researcher who calls and ask her to explain what the organization can do. When that happens, she advises the researcher on methods, for instance a meeting with patients, and then the invitation of patients is carried out by her.

The interviewees may identify common goals when getting involved in research initiatives: “When I have contact with a project leader or researcher we discuss about what they would want and subsequently what we could offer and if we agree with what they want” (r3). One of the respondents mentioned that she aligns the researchers and patients so that for both groups there is a research topic that is important and that they feel enthusiastic about (r9). Identification of common goals of stakeholders also happens by mediating between researchers: one of the participants received two comparable research proposals and discretely signaled to both research groups that they were active on similar topics and subsequently facilitated collaboration between the two research groups (r2). Another respondent acknowledges that she does not mediate between researchers but “sometimes we suggest that they need to increase collaboration with other researchers” (r7).

Interviewees actively identify and suggest additional stakeholders to be included in initiatives (r2, r6), but one of the respondents (r6) suggests that engagement of other stakeholders should be the responsibility of researchers. Respondent 6 also emphasizes the importance of engaging with funding organizations that support patient participation and fund research projects.

Engaging in person with stakeholders seems important for at least some of the interviewees (r3, r4, r6). One of them explains: “I think it is very important to go to information evenings for patients because there you hear what questions people have, and you can ask them questions too.” (r4). She feels her relationship with the patients is important as she continues to explain: “The moment that people perform a study together I propose to meet in person the first time, often there is a meeting with a researcher planned, and then we meet each other half an hour in advance so we know each other already. The minimal thing I do is to call in advance, so we have made contact already.” (r4).

5.4.2. Facilitate collaboration

When asked whether facilitation of collaboration is one of their tasks, one of the respondents answers: “yes, I'm the spider in the web really” (r8) and also respondent 9 reflects “I connect people, a bit like the spider in the web.” Respondent 5 sees herself more as a facilitator than a coordinator and respondent 1 agrees that facilitation of collaboration of different partners within projects is “an important task for us.” Another of the self-reported tasks of the practitioners is the facilitation of dialogue between stakeholders (r1, r6). Respondent 1 also points out about this that her organization is often the “leading party,” inviting stakeholders to come together to discuss new developments in healthcare. All respondents report that they are, in varying degrees, involved in the facilitation of relationship building among stakeholders.

Almost all respondents mention they are involved in facilitating dialogue and relationship building among stakeholders (r1, r2, r3, r4, r5, r6, r7, r8). One respondent explains that she brings patients and researchers together during informal meetings and encourages them to explain their respective motivations for engaging in patient participation, their reasons for research and their challenges. She reflects: “These meetings are often very inspiring, during which both groups learn a lot, and I always join them to think along and make them aware of possibilities for collaboration” (r2). Others are less involved in facilitating relationship building, for example only at the start of a project (r2, r5), or they just connect patients and researcher through providing of contact details (r6, r7). Respondent 5 describes her involvement as follows: “I make sure that at the beginning of a project, I introduce the right person to a research team, together we make clear agreements about what the researcher expects from the patient and the patient of the researcher, we have developed a brochure for that. We hold an introduction meeting so both parties know from each other how the collaboration will be, what the expectations are, and which role the patient will have and during which phases of the study.”

When asked about facilitating collaboration of patients in initiatives with patient participation, several of the respondents mention that they take the needs and personal situations of the patients that participate into consideration (r2, r9). Respondent 9 explains: “They may have to travel, have a job, and often have symptoms related to their disease, for example fatigue, and therefore they may prefer meetings during either the morning or the evening.” For those respondents who are involved at the initial stage of collaboration, one of their tasks is to make sure that the conditions for collaboration are clear and agreed on (r2, r5, r8). Respondent 2 says about this: “In the beginning I'm always in between, and if it is a one-off occasion it always is through me, but if the collaboration is over a longer period of time I will create the conditions for the collaboration so it is clear for everybody what the agreements are, and then I wish them good luck together and tell them I would like receive updates or to contact me when the collaboration is troublesome.”

Apart from facilitating contact between patient experts and researchers, facilitating contact between patient experts that take part in patient participation initiatives is also mentioned (r4). She adds that the contact should preferably happen in person but may also take place through phone contact.

5.4.3. Identify and obtain relevant information

When the respondents are asked about their involvement in identifying and obtaining relevant information, one of them replies that she is not involved in this activity for

research projects as they are “just provided” to her in a later stage of collaboration (r7). All other respondents report that they are at least to some extent involved in different activities related to knowledge gathering. Several confirm that they are involved in carrying out assessments of the needs patients have, including which topics they would like to see in a research agenda (r1, r4, r9). They also assess whether information provided to patients is relevant (r1, r6), and how that information is perceived (r1).

Respondents gather information from the researchers in order to decide whether their organization may get involved in an initiative with patient participation (r2, r5). One of the respondents is very outspoken about how demanding she is in this process of assessing the information about proposals of collaboration from researchers: “When a proposal comes in, then I need to have certain information, researchers need to give me at least two weeks before the deadline, if it is less we won't do it, and a letter of support we also only write when there is patient participation included” (r2).

When respondents receive requests from researchers to have research proposals evaluated by patients, they may become involved in defining the problem or research question and giving feedback (r2, r3, r4, r9). Some interviewees point out that their feedback may help to redefine the research proposals or clarify them to facilitate patient participation (r4, r5). Their motivation to do so seems similar for all these respondents: ensuring the quality and relevance of shared information, and the feasibility of patient involvement. An example is given by respondent 3: “When I get a request to [connect a patient] my first reaction is always to find out what the project is about, and what is being asked for, because very often the questions are not very clearly described,” and respondent 9: “I of course ask the researchers who write a research proposal for a summary that needs to be evaluated by the patients ... so I explicitly ask the researcher for information and to write it in a certain manner.” Respondent 2 explains: “Sometimes they ask the world, and I really have to make clear what the researchers want because I don't want to just bother the patients.” Once patients are involved, one of the respondents insists on the importance of being present during the evaluation meetings of research proposals, moderating the discussion and ensuring that the feedback of patients to researchers is relevant and adheres to their requirements (r9). In doing so, she can assess the quality of the feedback from patients to researchers.

Some of the respondents mention that they see it as their task to stay current with emerging developments in relevant research (r1, r5, r8, r9), however a lack of time may hinder this (r4, r5). For respondent 4 this means that the researchers she interacts with are the main source for her information about current scientific progress.

5.4.4. Facilitate development of analytic and interpretive skills

All respondents report that it is their task to ensure that patient experts receive sufficient information and training to be able to take part in initiatives with patient participation, including evaluation of research proposals provided by scientists and development of guidelines for professionals. In addition, experiential experts are also trained to give seminars at conferences and take part in educational sessions for students. Respondent 9 is present during evaluation sessions with experiential experts to assist with the interpretation of research proposals. Respondent 1 mentions that “it is very important that patients are well informed about all developments in the scientific field related to their condition.” Respondent 3 explains: “The aim is to make the persons I'm responsible for more knowledgeable, we expect participants to not just represent themselves but also to relay experiences of the so-called average patient, someone with a condition.”

Often the respondents educate patient experts themselves (r1, r2, r3, r4, r5, r6, r8, r9), on other occasions the organizations invite experts (r3) or encourage patients to follow courses or workshops related to patient participation externally (r1, r3, r4, r6, r7, r9). PGOsupport is an important partner for the respondents, as they facilitate training for patients (r1, r3, r4, r6, r7, r9) but they also assist in developing tailored courses (r1).

Even though the respondents think it is very important that patients receive adequate training, some of them mention they are aware that the experiential experts usually participate on a voluntary basis. Because of the time demands their organizations have chosen to make training not obligatory (r7, r9). Respondent 7 elaborates: “We want all of them to produce good work, but on the other side: can we oblige them to follow training and courses every year?” Related to this issue, an additional task for at least one of the respondents is the identification and evaluation of external courses regarding usefulness as training for patients who want to become involved in evaluating research proposals (r6).

Respondents also support peer-to-peer learning as they organize meetings for patient experts to talk about research (r4, r5) or are involved in organizing workshops related to patient participation (r5). Respondent 4 also encourages her organization to include patient participation as a discussion topic during other events for patients.

Several of the respondents report that it is necessary to educate researchers about patient participation and they actively contribute to this (r2, r3, r5). One of the respondents mentions that she is in contact with peers (those with similar responsibilities related to patient participation from other organizations) to set up master classes for researchers on how to integrate patient participation in their

scientific studies. She explains: “We are exploring options to create a masterclass for researchers, we gave one ourselves because it was needed but it is very costly, and whether the researcher studies one condition or another does not matter, patient participation is a way of working and you can share that together, so this is a theme in which I, we, are looking for collaboration to see if there is a need for this” (r5). Respondent 2 has previously organized a workshop for researchers about patient participation, however she reflects that for small organizations it is difficult because of time constraints as well as doubts about the amount of relevant expertise present within the organization. She thinks that PGOsupport could also play a role in organizing educative sessions for researchers.

5.4.5. Create tailored knowledge products

Most respondents are involved in the creation of tailored knowledge products, mostly for patients (r4, r5, r7, r9). Some may do so with assistance from or in collaboration with the communication department of their organization (r1, r7, r8, r9). The content they produce includes, but is not limited to, information about how the organization that can be helpful to researchers (r2), synthesis of scientific research articles (r1), information for patients about taking part in initiatives with patient participation (r4, r9), informative articles about patient participation (r5, r7), updates on initiatives with patient participation (r5), or information to be able to train people (r1). As many patient participation initiatives that the respondents are involved in entail evaluation of research proposals, the respondents may also be responsible for communicating the evaluations to the researchers (r7). For patients, respondent 1 explains what her organization offers on their website: “You can go to our website and you will see exactly which studies are ongoing, which you can join, what it means for you to participate in research, what the burden is, and what can be asked of you.”

Many of the respondents mention the importance of communication being understandable (r4, r7, r8) or “patient friendly” (r5). Respondent 5 explains the need to tailor information to the specific context of patients: “I try to rephrase the request [of the researcher] to make it clear for the patients so they can decide whether they want to join. [...] Actually I can almost never forward the original invite, I always have to translate it.” She insists that for this task some scientific knowledge is needed. Another respondent has created an online dictionary of relevant common terms, some of which related to patient participation (r4). Respondent 8 appreciates the help of the communication department, because she finds it challenging to write for two different target audiences, professionals and patients, as the communication should include an appropriate amount of jargon.

Some respondents express that writing progress reports and lay summaries of initiatives with patient participation is not their task, but the task of researchers, even though they may be willing to give input (r2, r9). Summaries are often in English or contain jargon, making them hard to understand for patients, and respondent 2 persuades researchers to translate them. The progress reports received from researchers may be adapted by the respondents, as translation is needed to make it understandable for patients (r6, r7). Respondent 6 reports that she reflects with colleagues from other organizations on how to improve information dissemination and translation, “because the outcomes of clinical trials are public, but the patients don't know where to find it, and if they find it they don't understand it.”

5.4.6. Project coordination

The level of involvement of respondents in project coordination varies, as it depends on whether the organization itself engages in funding of research or in initiating research projects. If this is the case, respondents do get involved in project coordination (r1, r8 and r9), however, project coordination may also be the responsibility of other colleagues within the organization (r3). When patient participation is a feature of a larger research initiative lead by scientists, the respondents are mainly involved in the coordination of recruitment and training of experiential experts and the evaluation of research proposals. Respondent 6 illustrates: “I can be a mediator, but also a project manager [...], the project manager who connects patients to projects and then I am responsible for the practical matters.” This seems to be usual, as most respondents report that they are not involved in the coordination of research projects but only take on coordination of tasks related to patient participation (r2, r3, r4, r5, r6). Respondent 2 explains the rationale for this position: “[The experiential experts] can be mostly occupied with the study, and not with all secondary matters that I will take care of, when there is a meeting nobody will have to organize that, or to write reports, I facilitate that.” Respondents 4 and 7 emphasize that for the core coordinating activities within research projects the responsibility lies with the scientists. Similarly, respondents do not usually coordinate the preparation of grant applications, but they contribute with some of the administrative tasks associated to the process, such as the writing of letters of support (r2, r7).

5.4.7. Support communication and information sharing

This activity combines tasks related to the creation and use of channels and strategies to share information, and to disseminate and exchange knowledge. The respondents use a variety of communication tools and strategies to inform about patient participation. Information and knowledge is shared through channels such as leaflets (r2, r4, r5), news articles on the website and social media (r1, r3, r4, r5, r6, r7), meeting

reports (r5), newsletters (r4, r5, r8), magazines (r4, r6, r9) and even a short explanatory movie about patient participation to use in calls to engage patients in initiatives (r9).

Beyond providing information, respondents also foster knowledge sharing among patients, researchers and other relevant stakeholders. When respondents are not the ones producing content, they may be engaged in encouraging others to do so; one of the tasks of respondent 8 is providing support to experiential experts who provide stories about patient participation for the newsletter. Furthermore, facilitating personal contact with and between stakeholders, usually through meetings, workshops and events, is important according to several respondents (r1, r2, r4, r5, r6). These events sometimes only involve patients, but respondent 6 especially values events where both patients and researchers are invited to discuss research topics. Respondent 8 points out that it is one of her tasks to make sure to include all relevant parties during this kind of occasions. Respondent 4 especially likes to meet patients in person to find out about their needs and preferred research topics. However, it is also pointed out how challenging in-person meetings can actually be in the context of a patient organization: “When you organize something there is always only a small group present, it is either too far away, or people are ill, or when they are not ill they may work during the day... but if we organize something in the evening, then people who work are able to attend but people who are ill are more often too fatigued, so in person meetings are not easy to organize for this group” (r3). Therefore, the use of email is an important tool for communication (r3, r7, r8). In this context, respondent 3 adds that the website of her organization is a central communication channel: “We have a digital platform where we announce requests [to take part in initiatives] but where we also place information, and I expect people to use this information” (r3).

Respondents shared some of the strategies that guide their communication efforts. For example, to make the role of patient participation in research visible, respondent 4 has an agreement with her colleagues of the communication department so that when they interview a researcher, he or she will be asked about the impact of patient participation and the role of the patient. She also actively fosters interviews with both the experiential expert and researcher at the same time to promote interaction. Respondent 9 explains how she adheres to a communication strategy that provides regular updates about funding of research and patient participation in the organization's magazine, as it provides transparency for both contributors as well as patients, which is important to the organization. There needs to be an increase in communication between stakeholders and she sees it as her task to foster this: “Everybody does their own thing, and unless you explicitly ask, you will not be automatically informed. I ask for an update of our scientific projects every three months.” (r9).

5.4.8. Network development, maintenance and facilitation

The respondents are very much involved in activities related to the development, facilitation and maintenance of networks, not only with a variety of stakeholders involved in patient participation (r1, r2, r4, r5, r6, r7, r8, r9), but also amongst those who have a very similar role to themselves (r2, r4, r5, r6, r7, r8, r9). Patient participation is still a recent and evolving process and the respondents indicate that there is a need to share knowledge and experiences; moreover, they foster the development of communities of practice.

Respondent 1 is often the initiator in establishing and maintaining networks with a variety of stakeholders to facilitate dialogue about patient participation, while respondents 8 and 9 network with others through professional organizations. Respondent 4 develops and maintains a network to update patients and researchers about the organization and patient participation. Respondent 5 actively networks with other patient organizations, to raise awareness for her organization, but also to exchange knowledge about patient participation, also internationally. She also networks with other patient organizations to discuss about how to organize masterclasses for researchers, with patient participation as the topic.

Respondents 2 and 4 explain that during meetings that happen between representatives from different organizations involved in patient participation (not exclusively patient organizations), different topics related to patient participation are being discussed. These include: communication (r4), letters of support (r2), Dutch summaries of research projects for a lay audience (r2), criteria for patient participation (r2), compensation for experiential experts (r4), how to involve researchers (r4), necessary information for researchers (r2), when is patient participation considered satisfactory (r2), etc. Respondent 2 suggests that having general guidelines for patient participation can help to improve patient participation as it improves the collaboration with researchers through standardizing the process. "When research is at the intersection of multiple conditions then one [organization] does it like this, another like that, it very much confuses researchers, and do we achieve something with that? No." Respondent 6 agrees on the need for joint establishment of criteria for patient participation: "Criteria [for patient participation] are being developed by umbrella organizations, and that is very important, it's good that everybody agrees with each other, and [the funding body] ZonMW has rules, which means that for researchers it is also important that patient organizations handle it in the same manner, so we have to work together." Respondent 7 defends that having these meetings 2-3 times per year would be useful and that also meeting in person is an important factor for exchange of this kind of knowledge.

Respondents acknowledge the important role of the Dutch Patient Federation and PGOsupport in networking related to patient participation as well as the establishment of a community of practice (r2, r4, r7). Meetings of peers from several organizations coordinated by PGOsupport resulted in a publication of guidelines for the involvement of patient and clients in medical scientific research (De Wit et al., 2016). During meetings with peers from patient organizations, they share knowledge about policies, guidelines and challenges, and try to learn from each other and find solutions together (r4, r8). Two of the respondents elaborate on the specific topics discussed during these meetings, including training for experiential experts (r7), the burden of patient participation on experiential experts (r7), and how the involvement of patients can be increased (r7). Some respondents mention that they attend these meetings regularly (r4, r5, r6, r8, r9). Respondent 6 explains: “It's a small world, so the lines are short, but not all organizations have this well organized, so not all organizations are in contact with each other. But some organizations do very well, then you can learn a lot from each other.” Both respondents 4 and 7 mention that this kind of meetings make them reflect on how practices of others may be useful for their own organization. Respondent 7 also reflects that her own organization “is not yet equipped” for a closer relationship with researchers even before a proposal is submitted. She says: “What I've learned is that the earlier you have contact with researchers the better, as it improves the influence on patient participation and that has a real effect.”

About the creation of a community of practice related to patient participation, respondent 2 says: “I'm always looking for ways to make sure we create a good basis in the Netherlands, to have one voice, we don't need to have the same thoughts about everything, but we shouldn't counteract each other.” Respondent 6 illustrates: “[Patient participation] is in development, so at the moment it is not so much about learning how to do things, but to think about what you would like to achieve and how you could do that, so we try this and that, and discuss with others about how to do it different, better. We recently had a discussion with a group of researchers on how we can do it better, connect to each other better, so it is not so much about training but about developing a vision and an aim, and discuss the possibilities.”

5.4.9. Facilitate and evaluate change

Most respondents see it as their task to actively encourage implementation of patient participation, within their organization, at national level (r1, r2, r3, r5) and even internationally (r1, r2). Respondent 1 comments about this: “I always feel like the *connector*, and I feel responsible to raise more awareness at a European level for the model that we have intuitively developed in the Netherlands.”

One of the main aims is to encourage researchers to engage in patient participation initiatives (r5), foster earlier involvement of patients in research (r1) or more intense involvement (r3). In the opinion of respondents 5 and 6, the researchers are not always easy to convince to take part in patient participation. They ask the respondents whether the value of patient participation has been proven, whether it may speed up research or what its relevance is. Respondent 5 considers that it is “hard to explain because it is not tangible, you know it will help, but you cannot translate it into money. That makes it difficult sometimes.” Therefore, respondent 6 argues it is the task of her and her colleagues to give researchers insight into the usefulness of patient participation: “Yes, we try it, we start conversations with people and in some research studies it may not be the case but in fundamental research it can play a role, it is different than in social scientific research but [it does play a role].” Respondent 3 comments: “Collaboration of patients with researchers is still in its infancy, it started with just giving feedback on research proposals, but now more often we ask researchers to give patients a role for the duration of the research project, to provide input. This is much more collaboration, and different than giving feedback or their opinion about a research proposal.” To facilitate that researchers implement patient participation in their studies, respondent 2 demonstrates to them how her organization can help with this process.

Respondent 3 also connects with other stakeholders such as health insurance companies to further develop patient participation in other areas than scientific research, and to increase the role of the patient in the process. By inviting a patient along with her to meetings, she promotes the added value of the input of a patient with experience.

Some of the respondents keep track of developments within other organizations, such as funding bodies, that may influence the process of patient participation (r5, r6). One of the respondents (r6) indicates that the relationship with funding bodies is “essential” in influencing the criteria for patient participation. She is aware that they communicate with researchers about these criteria amongst other aspects, and therefore it is important for patient organizations to stay in touch with them. Another respondent (r5) is aware that colleagues of her patient organization have contacts with those of the associated funding organization about patient participation, but she tries to foster a more structural collaboration between the two organizations, and she is monitoring the level of readiness for this to happen.

The respondents monitor and evaluate the process of patient participation through a variety of tasks. They are responsible for experiential experts involved in (evaluation of) research studies and regularly initiate contact with them to ask about their experiences and updates on the progress (r2, r3, r4, r5). Respondent 2 elaborates on this and explains that with new experiential experts she tries to evaluate their personal

experience after the first six months, to make sure the (working) conditions are reasonable and they enjoy their tasks. She tries to find solutions if this is not the case.

Some respondents mention that they evaluate patient participation when an initiative has ended, but not systematically and often informally (r1, r7, r8, r9), and it is not always possible due to lack of time and the number of participants (r2, r4). Respondent 4 asks the experiential experts how they would have done it differently and whether there has been a good match with the researchers or project. Respondent 6 explains that within her organization the evaluation process includes feedback from patients and from researchers (about how patients' contribution has been included in the participation initiative), and at the same time she also gives feedback to researchers. The training of patients is evaluated, and their scientific board also evaluates patient participation.

Respondent 6 acknowledges that the evaluation process is difficult, and others admit that their organizations do not have a formal procedure for the evaluation of patient participation, as illustrated by respondent 9: "I think it is a question that nobody has an answer to yet, because on what can you evaluate? What are the indicators? During meetings, the people I have spoken to about this, we came to the decision that [patient participation] is a process, and the fact that you are doing it makes indeed a difference, but it is very difficult to prove what the difference is." Respondent 7 suggests that systematic evaluation of patient participation would be an improvement, and one of her peers agreed that it is their responsibility to foster it (r3). Respondent 1 shares these reflections: "I think, in the end, [evaluation] is the least structured of everything. It is the last, or the next step we could make. (...) I think we evaluate it for ourselves more or less informally but, for example, we don't ask in a structured enough manner to the patients what they think about their own contribution in the whole process, and what their opinion is about our help to be able to carry out their contribution. I think we can still take steps to improve this." Respondent 3 makes a complementary suggestion: "For volunteers it is often frustrating that it stays unclear what is being done with their input." She argues that evaluation is important because it motivates people, and recommends that it should be part of guidelines for patient participation, involving researchers and other stakeholders in the evaluation process. When asked if she feels it is her task to promote this she answers: "I think so, absolutely" (r3).

5.4.10. Support sustainability

The respondents put little emphasis on current tasks related to supporting sustainability of scientific initiatives with patient participation. When discussing this activity, they tend to describe which improvements they would like to see developed (see section "Professionalization" below).

Currently, for the respondents, supporting sustainability is equal to promoting self-reliance amongst stakeholders. This is done through promotion and facilitation of education and training beyond the activities discussed in point 4. Respondent 3 argues education and training is important, she states: “I am a strong advocate for more schooling of researchers in patient participation during research.” In addition, training of experiential experts, which empowers them to discuss with researchers how they can be involved in research, also fosters self-reliance, as respondent 2 explains: “I try to educate both sides, and I'd like to do this more because [patient participation] is developing so fast, but I can't do this on my own. I'd like for some patient experts to be trained in this so they could do it themselves.”

They also support the development of knowledge products (r2) and policies (r2, r4, r8) in order to consolidate patient participation as part of scientific research, but they admit that current procedural guidelines are still underdeveloped (r1, r3, r6, r8). Several respondents mention the role of the Dutch Patient Federation and PGOsupport in creating guidelines that may help standardize patient participation (r2, r3, r4, r7). These respondents acknowledge that a community of practice (see activity 8) is crucial in this process.

When asked for any additional activities beyond the ten proposed by Bornbaum et al. (2015), some of the respondents could not think of any, others mentioned tasks that could be classified under the existing activities and were interpreted as such. Table 3 presents a summary listing the activities of knowledge brokers proposed by Bornbaum et al. (2015) and the activities reported by respondents during the interviews.

5.5. Current skills and personal attributes

This section describes the current skills and personal attributes of the respondents making use of the card-sorting method and the accompanying remarks by the respondents, as explained in chapter 4. The factor analysis with Q methodology resulted in the extraction of two factors, only one of them fulfilling the statistical requirements to merit further interpretation. The details of the process leading to this result are explained in appendix VI. The factor retained for interpretation is represented in figure 6 as a factor array, an estimated single Q sort presenting the aggregated viewpoint of the respondents about which skills and personal attributes related to knowledge brokering are most important to them when they carry out their work facilitating patient participation. What follows is the interpretation of this factor, which could be named “enthusiastic connectors.”

Table 3. Activities of knowledge brokers vs. those of the respondents

1. Identify, engage and connect with stakeholders
<i>From Bornbaum et al. (2015):</i> Knowledge brokers aim to “find the right people” among stakeholders, which they often do through in-person contact, so they can clarify the diversity of needs and identify the common goals.
<i>Findings of this thesis:</i> Researchers and patients are the key stakeholders for the respondents, but they may also identify and suggest additional stakeholders. They recruit and motivate patients to take part in the initiatives, and help all parties to identifying common goals. Not all respondents take initiative to connect with researchers, but engaging in person seems important for many of them.
2. Facilitate collaboration
<i>From Bornbaum et al. (2015):</i> Knowledge brokers facilitate dialogue and collaboration between stakeholders through different channels. They mediate to achieve consensus and facilitate relationship building.
<i>Findings of this thesis:</i> Respondents confirm that facilitating the collaboration of different partners is an important task for them. This includes fostering dialogue and relationship building. They take the personal situations of the patients that participate into consideration, therefore contributing to creating consensus among stakeholders.
3. Identify and obtain relevant information
<i>From Bornbaum et al. (2015):</i> Knowledge brokers help to define research questions, explore relevant knowledge within the field, evaluate information, and identify opportunities and implications to be presented to stakeholders.
<i>Findings of this thesis:</i> To some extent the respondents are involved in gathering knowledge, including assessing the needs of the patients and keeping up to date with developments in research. They give feedback to researchers and participate in defining the problem or research question. Their aim is to ensure the quality and relevance of shared information and the feasibility of patient involvement in research.
4. Facilitate development of analytic and interpretive skills
<i>From Bornbaum et al. (2015):</i> Knowledge brokers design and deliver training and educational sessions. They also provide assistance with interpretation of research and foster peer-to-peer learning.
<i>Findings of this thesis:</i> The respondents make sure that patient experts receive sufficient information and training. They also inform and educate researchers about patient participation.
5. Create tailored knowledge products
<i>From Bornbaum et al. (2015):</i> Knowledge brokers produce content adapted to the knowledge and needs of stakeholders, mainly through summarizing and translating evidence into accessible formats.
<i>Findings of this thesis:</i> The respondents create knowledge products, mainly for patients. They tailor information from researchers to the needs of patients and ensure it is understandable.
6. Project coordination
<i>From Bornbaum et al. (2015):</i> Knowledge brokers often take responsibility for management tasks within a project, both administrative as well as organizational. They also support the preparation of grant applications.

Findings of this thesis: The respondents are mainly involved in the coordination of recruitment and training of patient experts, and the evaluation of research proposals. They may write letters of support for grant applications.

7. Support communication and information sharing

From Bornbaum et al. (2015): Knowledge brokers develop and maintain communication tools and strategies, in order to facilitate knowledge sharing between stakeholders as well as knowledge dissemination to a larger public.

Findings of this thesis: The respondents use a variety of communication tools and strategies to inform about patient participation. They also foster knowledge sharing among patients, researchers and other relevant stakeholders through organization of meetings, workshops and other events.

8. Network development, maintenance and facilitation

From Bornbaum et al. (2015): Knowledge brokers create, support and promote networks and communities of practice for stakeholder groups. They also network amongst each other to share expertise.

Findings of this thesis: The respondents are very much involved in activities related to the development, facilitation and maintenance of networks with a variety of stakeholders involved in patient participation, including those who have a very similar role to themselves. They also create and take part in communities of practice.

9. Facilitate and evaluate change

From Bornbaum et al. (2015): Knowledge brokers assess readiness for organizational change, they encourage it, and provide the knowledge that enables it. They monitor the change processes to evaluate the effect of their input.

Findings of this thesis: The respondents encourage implementation of patient participation, within their organization, at national and international level. They monitor and evaluate the activities of the patient experts, although not systematically and often informally.

10. Support sustainability

From Bornbaum et al. (2015): Knowledge brokers promote the sustainability of knowledge brokering activities in two ways: they foster a reflective attitude among all the actors, and they make sure that the leaders of the involved organizations recognize the value of knowledge brokering and create a supportive environment to consolidate it.

Findings of this thesis: The respondents put little emphasis on current tasks related to sustainability of knowledge brokering activities but are active in communities of practice with peers. They mostly describe which improvements they would like to see developed (see section on professionalization). They support sustainability of patient participation mainly through promotion of self-reliance amongst stakeholders. They also support the development of knowledge products and policies.

				help others to express their views				
			willing to learn	be decisive	be able to "see the bigger picture"			
		negotiate	be inquisitive	have self-confidence	build a team	build trust		
	search for relevant information	be intuitive	be curious	translate difficult text to easy to understand text	present information in useful and appealing formats	teach and coach others	listen	
have courage	sell ideas	be innovative	be flexible	discuss sensitive subjects	start and moderate a dialogue	be communicative	be enthusiastic	network and build relationships
have tireless commitment	be creative	be an inspirational leader	have tact	be supportive	motivate others to participate	find out what other partners need	assess information for quality, relevance and usefulness	coordinate tasks and people
-4	-3	-2	-1	0	+1	+2	+3	+4
Least important								Most important

Figure 6. Factor array illustrating an estimation of the key viewpoints expressed by respondents about the importance of skills (listed as actions) and personal attributes (in blue, listed as qualities: be ... or have ...) related to knowledge brokering.

5.5.1. Enthusiastic connectors

These *enthusiastic connectors* put emphasis on skills over personal attributes, the viewpoint is that skills are most important when carrying out tasks related to patient participation. It is clear that networking and building relationships (+4) and coordination of tasks and people (+4) are the most important skills. Connections are made between patients and researchers, and for this it is important to be enthusiastic (+3), as one of the respondents points out: “If you are not enthusiastic, how is somebody else going to become enthusiastic?” (r9). In addition to being enthusiastic, some other personal attributes are still relevant to the respondents in the process of relation building, even if they are ranked in lower positions: having self-confidence (0), to be decisive (0) and to have courage (-4). Even if these competencies are not the highest ranked, and having courage is even the lowest ranked, respondents still see them as necessary: “You need to have self-confidence to be able to deal with all the parties with different interests at stake” (r9). Respondent 4 reflects: “If I don't have courage, I will never have my network constructed, because I have to dare to approach people.”

Being able to listen (+3) is also considered to be one of the more important competencies. One of the respondents explains why as follows:

“To be able to listen is very important, you have wishes of the patients, of researchers, in that way you have to be able to listen, you even have to be able to realize when someone doesn't feel at ease, for example, you have to be able to listen non-verbally, to what someone doesn't actually say, that is really the most important because actually the patients don't say so much because they are in a position in which they have to be professional too; yes, you have to be able to see a lot more in a human than only that what he says or writes” (r5).

Another respondent insists: “I think that it is very important, being able to listen, especially to patients, it is really being appreciated that moment you listen to them and involve them” (r8). Being able to build a team (+1) is considered as one of the elements of building a network and it also helps to be able to see “the big picture” (+1), while related skills, including being able to negotiate (-2) or to sell ideas (-3), are given much less importance within this factor.

Being supportive (0) is one of the higher ranked personal attributes in this profile, and respondents linked it explicitly to skills such as listening and building networks, but it was explained by them in many different ways, and not everyone was comfortable with it: “Should I be supportive? I am not a secretary... Should I be facilitating? Yes, because in the end we want to coordinate tasks and people.” Being supportive (0) is also associated with other skills by the respondents, such as “being able to teach and coach

others" (+2) or "being able to find out what other partners need" (+2). These competencies are important when working with researchers as well as patients: "If you want to ensure good participation then it is useful, because if you don't give them the information they need or the support they need, then it's not going to work" (r9).

But being able to teach and coach others (+2) is also important when recruiting others to take part in patient participation. A respondent insists: "[The fact] that you have to teach researchers what patient participation is, is actually very important" (r7). It helps to be able to "see the big picture" (+1) to promote patient participation and increase the involvement others: "Sometimes you have to motivate people for patient participation, and you can only do that if you yourself are able to see the big picture and you know how important it is and you can make others see what the added value of it is" (r5).

Building working relations (+4) with researchers seems to be an especially important factor in patient participation: "Absolutely, in the end a researcher needs to be willing to give that study to you, now they need you, but that is the first time, the second time they have to come back because it was a pleasure to work with you, or because they know how to find you, so we try to let people know [...] that they can contact me, that is important." (r4). In fact, the relationship with researchers is mentioned in relation to other higher ranked skills, like building trust (+2). For example, respondent 4 indicates that discretion is needed when communicating about researchers especially when two researchers work on similar studies independent of each other. Respondent 7 also mentions that building trust also happens when she helps the researchers with advice for their research proposals. The relationship with the researchers also shapes respondents' lower priority regarding some competencies: they expect researchers to take care of some of the tasks associated to specific skills, such as being able to present information in a useful and appealing format (+1), being able to translate difficult text to easy to understand text (0) and being able to search for relevant information (-3). Respondent 4 comments: "I have to be able to read a text and explain it to the patient, but I think it is the task of the researcher to do this."

On the contrary, assessing information for quality, relevance and usefulness is a highly ranked skill in this profile (+3). It is needed to assess proposals received from researchers, an activity within patient participation that involved patients are trained to do. Very often the patients are trained and coached (+2) in this by the person responsible for patient participation within the patient organization, but training may also be provided through an external organization. This is one of the examples illustrating why respondents highly value the ability to coordinate tasks and people (+4). They indicate that this skill is used in many different circumstances within the

organization (with the communication department or the secretariat) as well as for the coordination of the recruitment, training, coaching and participation of patients.

Apart from being enthusiastic (+3), another notable exception to the impression that mostly skills are important when carrying out work related to patient participation is the personal attribute “being communicative” (+2), although in the scientific literature it is sometimes classified as a skill (CHSRF, 2003; Lyons et al., 2006; Pyper, 2002). Being communicative (+2) is not seen as the most important factor, but is often mentioned to be a prerequisite for this work, as one of the respondents stated: “You can't do all this if you are not communicative.” (r4), and another concluded: “It's an open door, of course it is important.” (r8).

What seems to be a contradiction in the ranking of the respondents is their point of view about having to have tireless commitment (-4) in relation to their comments about it. In interpreting this, it is important to bear in mind that several respondents commented on the difficulty of having to rank all the skills and personal attributes. This is illustrated by the first impression of respondent 7 when confronted with all the cards: “When flicking through the cards, you think they are all quite important.” Respondent 9 comments after the sorting process: “Actually, nothing is unimportant.” The low ranking of having tireless commitment may be connected to how they see this personal attribute as something that is not part of their daily job: “It's important but we don't need it a lot” (r8). Nonetheless, another respondent sees its general relevance in relation to an increased involvement of patients in research: “Tireless commitment is more than important because we still have a lot to achieve in the field of patient participation” (r4).

5.5.2. Additional skills and personal attributes

When asked which skills and personal attributes are not represented in the card sorting task but are important for the respondents to carry out their activities and tasks, respondent 5 answers that it is important for her to be more pro-active, search for information herself, even though currently she mostly facilitates. She explains: “It is important to be more proactive, but I notice that I'm torn between who I am as a person and what I think a good coordinator should be like.” Respondent 9, however, thinks it is important to have a serving or facilitating attitude which helps to *empower* others: “you have to let others discover [what they can do].”

Respondent 2 responds that for her it is very important to pay attention to every individual. She explains: “I think I always have a very personal approach, I try to pay attention to every individual, whether that is a young researcher, an experienced researcher, a professor, a patient, a young patient, I don't make a distinction between

them. It's 'acknowledging each person' so to speak, that's what I've learned here, and I think I've also got it in me." She continues: "The human contact, personal contact, the phone calls with researchers cost a lot of time, but I have the feeling they understand better, that it is why they are prepared to take part [in initiatives with patient participation]." However, she also explains that it is important to be able to "say no": "saying no to researchers [when they ignore deadlines], [...] when patient participation was still in its infancy I was more inclined to be flexible, because I wanted it to happen, but now it is running, so I can afford myself to say no more often, there has been a shift in that."

Respondent 3 misses written communication skills amongst the options, she explains: "I have noticed it is very important to be able to write well, to be able to convince people, especially with activities related to policy, but also for all the email exchanges with the volunteers, that you know how to formulate well, meticulously, and clear." In addition, respondent 1 points out that storytelling is communication skill she has that is very useful for her, but that it was not among those she could choose from. She explains that it is a novel way to report about scientific studies, and "a bridge between old fashioned science and the kind of science patients will benefit from." She thinks it is important that research and evidence related to care conditions, often with single cases, is more often translated and communicated to, for instance, healthcare institutes to contribute to better care.

5.6. Professionalization: envisioned changes and improvements

The respondents think about the future of their professional role and of the process of patient participation in very intertwined ways: when they discuss tasks they would like to change (5.6.1), personal attributes and skills they aspire to have, or training they would like to follow (5.6.2) they tend to do so thinking of how that can improve patient participation. Similarly, when asked which changes they would need for them to be able to better carry out their tasks, they often discuss organizational changes (5.6.3) related to the recognition and support of their role as well as the development of best practices in patient participation. This suggests that, for the respondents, the professionalization of knowledge brokering and of patient participation processes mutually enhance each other, and make their role more meaningful.

5.6.1. *Desired changes in tasks*

When asked which changes are needed in their tasks to improve patient participation, some of the respondents would like to develop more activities that foster earlier and more systematic involvement of patients in scientific projects. This includes changes in tasks and activities related to engaging and connecting stakeholders (r7, r9), increased

coordination and collaboration (r4, r5, r9) and evaluation of the involvement of patient experts (r5, r7). Respondent 7 argues that such tasks are needed to develop better relationships with researchers: “The earlier the contact with the researchers, the better, as it influences how patient participation is included and how effective it is.” Respondent 9 explains how she thinks it is important for patients to be closer connected to scientific projects: “Maybe it is good to, once a year, have a meeting where also patient experts are present, so they can be informed about the progress and ask questions. I would like to organize this more often, there have been some meetings but there are few. I think in the future these meeting should include more stakeholders than just patients because I would also like to involve doctors and nurses.” She continues she would like to be the facilitator of the inclusion of “as many perspectives as possible when it comes to a problem or a solution.” She would also like to assume more coordination tasks, to be able to have an influence on the diversity of the roles that patient experts can have within research projects.

Some of the activities that respondents would like to take on or increase are related to communication and knowledge transfer. Respondent 9 would like to be a broker more often, to increase the communication between the different partners in initiatives with patient participation, for example concerning results and updates of projects. “There is space for improvement, and it is really what I would like to do, but I haven't found the right formula yet, how it should be done.” Respondent 6 thinks her activities related to translation of scientific information for patients should be more focused on improvement of this process and she feels it is her task to involve the appropriate partners to make this happen. Additionally, respondent 5 reports she would also like to improve the content of information leaflets for patient experts, to better suit the needs of this group. Some respondents envision increasing the amount of training for patient experts (r6, r8). Respondent 8 thinks that this would give the opportunity to provide them with more information, as, currently, it is often too rushed. Respondent 6 would like to give training to patient experts about how to write in a critical manner, this is related to the feedback patient experts give to researchers.

Carrying out these additional activities is perceived as necessary but troublesome, and some of the respondents mention “lack of time” as one of the factors that impedes from further improving the process of patient participation (r2, r3, r4, r5). The activities that they would like to have more time for to develop include more extensive training for patient experts (r3), more supervision of the patient experts (r2), setting up a communication channel to facilitate input from patient experts on their desired research questions (r4), and keeping up to date with relevant scientific findings (r5). Respondent 2 would like to provide more guidance to experience experts, instead of superficially check the procedures and the feedback provided to researchers, she feels more supervision and involvement from her side would improve the quality of the

involvement of the experience experts. When asked if she needs more time or additional involvement from colleagues, respondent 3 replies: “Absolutely, if you really want to do this right, because I constantly have the feeling I can only do half of what is needed.” Two other respondents also mention that they would like others to take over some of their current tasks to free up time for other tasks or increase efficiency. Respondent 2 would like patient experts to be trained in explaining to researchers what their involvement could entail within studies, so she could be less involved in this part of the process, while respondent 4 would like to be less involved in administrative tasks. Respondent 5 imagines that a solution could be for her activities and tasks to solely focus on patient participation, as she is currently responsible for many additional tasks.

Reflecting about the future of their role, respondents 6 and 9 argue that improving patient participation may not be a matter of additional activities and tasks, but rather the professionalization of those they already do. Respondent 6 expects that there will be an increase in the amount of initiatives with patient participation and this will subsequently increase her workload. She thinks that professionalization of the process of patient participation will have influence on her tasks, as she expects the relationships with stakeholders will change, but she could not elaborate on these changes. Respondent 9 replies, when asked which changes in tasks would be needed to improve the process of patient participation: “It's not that I think my tasks should change, but I just need to start doing things that I haven't done so far. I think patient participation needs to be further developed, and I'm partially responsible for that, but that means certain things need to be done. I'm not sure it is an expansion of my tasks, it is just improvement of what already is being done.”

5.6.2. Desired training, skills and personal attributes

The respondents give some suggestions about the skills they would like to have or improve, additional training they would like to follow to achieve them, and personal attributes that they think are needed. Respondents 1 and 3 would like to improve their listening skills, as that would help them in their collaboration and coaching activities. Respondent 6 would like to improve her networking skills: “From experience I have learned that networking is very important in the field of patient participation,” and she expects that she will gain self-confidence through experience and that will make her enjoy it more. Similarly, respondent 5 aspires to learn how to make herself known with potential stakeholders in patient participation, and how to build networks, topics that are, she says, related to “the more commercial side of patient participation.”

One important aspect of their daily work is the contact with experiential experts, who are mostly volunteers, and three respondents mention they would receive training related to recruitment (r5), management (r3, r8), and motivation of this group (r6).

Respondent 6 specifies that she would like to be more communicative, and gain more insight into what can be asked from volunteers, especially regarding the possible burden on this group. Respondent 8 explains how it would be useful for her to further develop her leadership and coaching skills: “You can always improve yourself in many ways, I think that 'being an inspiring leader' will evolve over years. [...] You should not be authoritarian, as you have to collaborate with the patients, but there has to be someone who takes the lead, motivates everybody, and pushes them when they do not carry out their tasks, at that moment you need to be the leader of your project.” She thinks that to be able to achieve this she will need experience, knowledge of the conditions, knowledge of procedures, but also “a good manager who guides you in that.”

Some participants feel that there is no relevant training available for them as patient participation is currently very much in development and they are involved in this development themselves (r1, r2, r6). Respondent 9 considers that most of her learning happens not during formal courses but through attending symposia and meetings and sharing experiences with others involved in patient participation.

5.6.3. Organizational change

The reflections about organizational change mainly revolved around their aspiration of being recognized in their role by other stakeholders and within their own organization, as well as around the idea of getting more support to their activities in the form of resources, a more structured work environment, and opportunities for training and networking.

Recognition

Two respondents call for more recognition of their involvement within initiatives from external collaborators when asked what they feel would help to make patient participation more successful: more communication (r6, r7), and acknowledgement as financial partners (r6). Respondent 7 comments on necessity for feedback on progress of the project from researchers, as she feels that the organization, with her as the representative, often does not receive sufficient recognition as a partner during later stages of the patient participation initiative. She worries about how it is unclear which responsibilities lie with each stakeholder regarding these kind of communication aspects. “Those studies often take a long time, so it could be that you have to chase it up a year later, because otherwise I'm scared that the researcher will forget us, but who is responsible for this?” Respondent 4 puts forward that the responsibilities for improvement of patient participation as a process do not rest solely with the patient organization, but with several parties involved: “If you really want to make changes then

[the researchers] should also find patient participation much more important. Patient participation should be anchored within studies, within a hospital, there should be a department for patient participation, so I'd try to promote it from the research point of view."

Respondent 6 is involved in changing policies regarding patient participation in collaboration with a variety of stakeholders including other patient organizations, funding bodies and policy makers. For future professionalization, she feels it is necessary to develop policy regarding efficiency of processes, the burden on volunteers, but also financing of patient participation. She explains that patient organizations need to be recognized as a receiving financial partner in initiatives, as she insists: "It has to happen, because with this growing number of requests we can't much longer finance involvement."

A number of respondents would like to receive more recognition for their contribution to patient participation from their own organization (r3, r4, r5, r7, r9). They may take initiative to foster organizational change: respondent 7 reflects on how she makes the management of her organization aware of current procedures and possible improvements in patient participation. She feels that more awareness about patient participation within the organization would help to achieve organizational change and improvement; she was surprised to discover that, contrary to what she had assumed, her colleagues were not aware of the protocols and criteria she uses in her work related to patient participation. Similarly, respondent 4 feels there is not enough recognition for her role related to patient participation within the organization, even if she makes the effort to regularly update her management about her activities. She comments: "I think the organization should be more professional, and I try to contribute to that, but it's difficult." When respondent 3 was asked which changes in her tasks would be needed to improve patient participation she reflected about recognition for her activities: "Well, maybe not a lot of changes in my tasks, but what I think is very much underestimated, and not just for patient participation but for the whole patient world, is the time it takes to coordinate and coach volunteers, that is really being underestimated."

Some of the respondents mention they would like more recognition for and clarity about their responsibilities related to patient participation. Respondent 4 suggests that it would be helpful to have a dedicated number of hours per week that would be solely dedicated to activities related to patient participation, while respondent 5 admits she often struggles to carry out the necessary activities related to patient participation in the available time, as she explains: "You just do this next to all the other tasks you have, there is no dedicated person for every role, but you often have three roles." Respondent 7 would also like more clarity about who has certain responsibilities within the

organization, for example who should take responsibility for the introduction and training of new colleagues involved in research within the organization.

Three of the respondents feel it is necessary for an organization to emphasize the importance of patient participation as part of their internal policy (r4, r5, r9). Respondent 5 suggests that to improve patient participation, it is helpful if the organization determines a vision on this topic. Respondent 4 also thinks it is necessary for the organization to determine the importance of patient participation, and to facilitate sufficient support, in balance with the aims of the organization. Respondent 9 has a positive outlook: when she started working at her organization, there were some initiatives with participation but she has actively increased the amount of initiatives with patient participation. There has been an organizational change in that the types of projects the organization is involved in has changed to those in which patient participation takes a more prominent place. She thinks it is important that the organization creates opportunities to develop more initiatives with patient participation and involve more colleagues within the organization. She feels it is important to promote the principle of patient participation within the organization so it becomes a widespread initiative, and she has started to coach other colleagues on how to implement patient participation.

Support

Aside from recognition, some respondents also call for more support for their activities; this can take the form of increased funding (r4, r8) and human resources (r1, r3, r4, r6, r8, r9). They also find it important that the organization provides opportunities for learning, training (r2, r7, r8) and networking through communities of practice (r1, r2, r5, r6). When asked about professionalization and organizational changes to improve patient participation, respondent 4 mentions that increasing the number of working hours and financial resources is important for her to improve patient participation within the organization. She reflects: "I think that if you find patient participation important, it has to be embedded in the organization, this means there has to be a board member responsible for it, and there needs to be a supporting structure, administrative staff, dedicated space on the website, things like that." Currently she is mostly responsible for these roles and activities and she would like for some her tasks to be taken over by others so it would give her more time available and increase efficiency. Concerning human resources, respondent 8 explains that for her, another requisite within the organization is that they allow you to be flexible with working hours, as a lot of meetings happen outside of "normal" hours, during evenings and weekends. She also insists that there is a lack of financial means to develop more initiatives with patient participation and share knowledge about it, and she thinks her organization is not alone in this.

Respondent 7 and 8 point out that more possibilities for training and professional development help to improve patient participation, and respondent 7 takes initiative to make her organization aware of training options. Respondent 2 is satisfied with the opportunities provided by her organization: “When I would like to attend a course or training I can always discuss it, and I already have done additional training.”

Respondent 5 would like to have guidelines on best practices, based on experiences of others and research about effective patient participation. Respondent 2 insists that developing a community of practice for patient participation is crucial: “I think it is very important that the field develops nationally,” and she is convinced that there needs to be a collective development. However, she points out that the development of best practices “is never a priority; if it happens, it happens very slowly.” When asked what is needed to make it happen, she answers: “Human resources, during these last months sometimes I think I have been overwhelmed by my own success, because we are getting so many requests, more than I can actually reasonably deal with. It means that these kind of 'extras' are left aside.”

With an increased amount of initiatives with patient participation, some of the respondents call for attention to a more structured system, including organizational decisions on the management style, protocols and guidelines, and accountability. Respondent 6 expects that a different management style will be needed to be able to manage the increase in initiatives with patient participation and she thinks stricter rules, for instance about deadlines for requests, and protocols for acceptance of projects will be needed. Respondent 7 reflects: “Now it is all a bit *ad hoc* still, it has to be fast and it has to be done as it was done before, there are not a lot of opportunities to reflect, but maybe with updating of the protocol and a little bit more thought about what we want to achieve.” Respondent 5 suggests that to improve patient participation, it is helpful if the organization produces a research agenda, to help structure making decisions on which projects to get involved in. For respondent 5 and 6, professionalization is also standardization and being consequent in procedures. Respondent 5 suggests that funding organizations should use the same forms for grant applications, including standardized sections related to patient participation. She would be willing to help develop such forms, and discuss which criteria and conditions should be included; for example prerequisites about remuneration for volunteers. By doing so, she explains, these forms could serve as guidelines for her and her peers to assist researchers with embedding patient participation in their projects. Respondent 6 thinks that agreements need to be made between different stakeholders about which services can be offered by her organization in a certain situation, and which costs would be incurred for those services. She confirms that she could be involved in the initiation of those agreements.

Respondent 7 would like to determine a vision for the future, and introduce evaluation of the processes on an organizational level as a tool to improve patient participation. Similarly, respondent 1 also thinks that accountability is crucial, and insists that the process of professionalization is necessary to consolidate patient participation: “I have a motto: 'Standing still is going backwards', I would like try to take it all to a higher level, [...] what we do internally here, I would like to have a nice platform for it, I would actually like to publish about it, but I don't have enough time or human resources to do so.” The respondent would like to make a critical review of the practices within her own organization, and subsequently share it with other organizations to improve the quality and efficiency of patient participation.

The next chapter summarizes these results, and answers the research questions before discussing the implications in chapter 7.

6. Conclusions

In this chapter, answers to the research questions are formed based on the results described in Chapter 5. The reflections provided by the respondents suggest that practitioners responsible for patient participation activities within patient organizations share many of the characteristics of knowledge brokers in the healthcare sector. The chapter also provides an interpretation of the perspectives of the practitioners about different aspects of professionalization, in comparison to the relevant academic literature. The discourses of the respondents reveal that professionalization of both the process of patient participation as well as of their own professional profile is very much ongoing.

RQ1. Who takes the role of knowledge broker within patient organizations to facilitate participation of patients in projects?

For this study, nine persons from 8 different organizations were interviewed. Health sciences is the most common educational background among the respondents, some also have an education in management and pedagogy. Not all respondents have received training specific to patient participation, and those who have followed courses usually did so through PGOsupport. All of them found learning from peers important, especially those who have been involved in the more recent stages of development of patient participation. Those who were involved in the early days learned by doing.

Before starting their current position, the respondents had professional experience related to education, training and management, most of them in the context of healthcare. Three of the respondents have research experience through PhD studies or a previous career as scientist, and respondents find this very useful in their current work environment. In addition, the respondents report that previous professional experience with patients is beneficial, as well as familiarity with participation initiatives. What brought them to their current job is their drive to help people, to feel useful. Compared to their previous professions, several of the respondents value the increased level of practical involvement, the proximity to society.

The respondents have a large variety of job titles, and only few explicitly connect to participation: senior project leader participation, coordinator patient participation, policy advisor (focus area patient participation in scientific research). Quality of care

and research are the other focuses in their titles: coordinator research, policy officer quality and research, project officer quality of care, employee quality of care. However, the titles do not always match with how they define themselves when talking about their activities specifically related to patient participation: the respondents use terms as recruiter, coordinator, facilitator, someone who paves the road so others can do their job, intermediary, mediator, bridge builder, project manager, project officer, or someone who explains how patient participation can be beneficial. When asked about their responsibilities related to patient participation, some explicitly mention coordination responsibilities, which may be implicit in the responses of the others. Most of them report being in charge of recruiting and coaching patients, advising researchers and mediating between both groups. One of the respondents summarizes her role with a metaphor: “The patients call me the spider in the web, and that's how I feel because I have contact with so many people” (r2). Actually, two others use the same metaphor to describe their role in other moments of their interview.

The educational background, professional experience and training of the respondents, as well as their job titles and self-reported responsibilities suggest that they could be considered knowledge brokers. The literature underlines that knowledge brokers should have specific knowledge related to the environment in which knowledge brokering takes place, which is the case for the respondents, as most of them have education and a professional background in the healthcare sector, and some even academic experience. However, regarding their responsibilities, the respondents put more emphasis on what Bornbaum et al. (2015) call “linkage agent” (mediating) and “capacity builder” (coaching, advising) than on “knowledge manager” (even if they actually do carry out activities connected to this, they do not mention them explicitly when describing their responsibilities). The omission of knowledge management is in contrast with previous studies which focused more on knowledge brokering connecting scientific evidence to policy, which may require more processing (translation, synthesis, adaptation) than the knowledge of experiential experts. Moreover, Phipps and Morton (2013) already perceived an evolution from more knowledge-focused responsibilities towards linkage-focused roles within knowledge brokers in the health-care sector in Scotland. These results are coherent with the idea that “it is not possible to produce a one-size-fits-all job description for a knowledge broker. The job is very context-specific” (CHSRF, 2003): job titles and role descriptions adapt to the culture of the local environment. When comparing the responsibilities reported by the respondents with the definitions of knowledge broker in the literature (see Textbox 2 in Chapter 3), the idea that the respondents focus mainly on linkage is reinforced, as there are clear parallelisms between “bridge builder,” “intermediary,” “coordinator,” or “mediating” with the definitions referring to “bridging gaps,” “supporting interaction,” and “linking between entities or individuals that otherwise would not have a relationship.” This provides a first indication that the respondents are knowledge brokers, but the answer

to the following research questions will further demonstrate the extent to which they can be considered so, through the analysis of their activities and skills.

RQ2. Which tasks, skills and personal attributes of knowledge brokers are relevant to them when facilitating patient participation?

A short summary of activities and tasks of knowledge brokers and those of the respondents can be found in Chapter 5, table 3. When the respondents were asked if they had any other activities in addition to those already listed by Bornbaum et al. (2015), the respondents did not report any other activities or tasks that could not be categorized under the already mentioned ones. This suggests that the activities as put forward by Bornbaum and colleagues encompass all activities that the respondents carry out in relation to initiatives with patient participation, however this does not mean that all tasks listed in table 1 in Chapter 3 are performed by each of the respondents. The activities related to initiatives with patient participation that the respondents have discussed, can be roughly divided into three different areas of attention: relationships with researchers and patients, knowledge and communication oriented activities, and consolidation of the process of patient participation. Bracketed numbers in the coming paragraphs correspond to the list of activities in Textbox 3, Chapter 3.

Activities connected to relationships with researchers and patients include (1) identifying, engaging and connecting with stakeholders, (2) facilitating collaboration, (4) facilitating development of analytic and interpretive skills, and (8) network development, maintenance and facilitation. All these activities belong to the knowledge brokering domain of linkage and exchange, all tasks in activity 4 relate to capacity building and one task touches on knowledge management. In this group of activities, the tasks reported by respondents match all those identified in the literature by Bornbaum et al. (2015).

Activities related to knowledge and communication oriented activities include (3) identifying and obtaining relevant information, (5) creating tailored knowledge products, and (7) supporting communication and information sharing. All these activities are related to the domain of knowledge management, additionally, all tasks in activity 7 belong to linkage and exchange, while some tasks from activity 3 and 7 also connect to capacity building. The respondents report to do many of the tasks proposed by Bornbaum and colleagues, but not as extensive and systematically. For example, they are more reactive than pro-active in gathering information. The respondents are probably more pragmatic than the knowledge brokers as described by the literature: they focus on very concrete needs, rather than performing a systematic scan of research

trends in the field of a condition and in patient participation. Moreover, they would like the researchers to take more responsibilities, especially in tailoring information to the needs of patients. On the other hand, as opposed to knowledge brokers who mainly ensure knowledge transfer from scientists to decision makers, the respondents facilitate bi-directional knowledge exchange between scientist and patients.

Activities related to consolidation of the process of patient participation include (6) project coordination, (9) facilitating and evaluating change and (10) supporting sustainability. Activity 6 and 9 are both related to the domains of knowledge management and linkage and exchange. All tasks in activity 10 and all but one in activity 9 belong to the knowledge brokering domain of capacity building. When discussing project coordination, respondents admit that researchers usually lead the initiatives, even though the respondents are very much involved in coordination of the actual participation of patients, as part of a larger research study. The respondents are involved in communities of practice, where the emphasis is put on the process of patient participation, rather than on consolidating the process of knowledge brokering. The tasks related to monitoring and evaluation are often done informally and not systematically. While discussing evaluation and sustainability, the respondents did not reflect much about current tasks related to the process of knowledge brokering, rather, they put forward their ideas about how sustainability of the process of patient participation can be achieved.

To be able to perform their activities related to patient participation, respondents may need certain skills and personal attributes, as proposed in sections 3.2.4 and 3.2.5 of the conceptual framework and listed in table 2 of chapter 4. The respondents were asked to sort the importance of skills and personal attributes relative to each other, based on the Q methodology, and the results should therefore be considered as an estimation of the entire item configuration (Watts & Stenner, 2012). Subsequently, the respondents were asked whether they missed any skills and personal attributes during the card sorting, and there were only few, mainly related to *being communicative* and *network and relationship building*, some of the top ranked items.

The resulting image of these 'enthusiastic connectors', depicted in figure 6 in chapter 5, puts emphasis on skills over personal attributes: the viewpoint of the respondents is that skills are most important when carrying out tasks related to patient participation, which suggests that appropriate training is important for their professional profile. *Networking and building relationships* and *coordination of tasks and people* are considered the most important skills. The latter is used in many different circumstances within the organization (with the communication department or the secretariat) as well as for the coordination of the recruitment, training, coaching and participation of

patients. Connections are made between patients and researchers, and for this it is important to be *enthusiastic*.

Another notable exception to the impression that mostly skills are important when carrying out work related to patient participation is the personal attribute *being communicative*, although in the scientific literature it is sometimes classified as a skill. *Being communicative* is not seen as the most important factor, but is often mentioned as a prerequisite for this work.

Being supportive is another one of the higher ranked personal attributes in this profile, and respondents linked it explicitly to skills such as *listening* and *building networks*, but it was explained by them in many different ways as it was also associated with other skills such as *being able to teach and coach others* or *being able to find out what other partners need*. These competencies are important when working with researchers as well as patients.

The relationship with researchers is mentioned in relation to other higher ranked skills, like *building trust*, but it also shapes respondents' lower priority regarding some competencies: they expect researchers to take care of some of the tasks associated to specific skills, such as *being able to present information in a useful and appealing format*, *being able to translate difficult text to easy to understand text* and *being able to search for relevant information*. On the contrary, *assessing information for quality, relevance and usefulness* is a highly ranked skill in this profile. It is needed to assess proposals received from researchers, an activity within patient participation that engaged patient experts are trained for.

The two personal attributes *need for tireless commitment* and *courage* were ranked as those with the lowest importance by the respondents. However, their point of view about this seems to be in contradiction with their somewhat positive comments about these qualities. When interpreting this, it is important to bear in mind that several respondents commented how difficult it was to rank all the skills and personal attributes presented to them, as they were forced to fit the items into a grid with a prearranged distribution of importance, obliging the respondents to judge each item relative to the others. Thus, the very low ranking of *having tireless commitment* and *courage* may be connected to how they see these personal attributes as something that is not prominent in their daily job, but despite their low ranking, respondents still consider them as necessary and comment positively about them. This suggests that the overall collection of skills and personal attributes of knowledge brokers that was constructed from the literature, as described in the conceptual framework in chapter 3, is highly relevant for the respondents in the context of patient participation in scientific research. As this is the first study exploring the ranking of importance of these items, no comparison can be made with other studies.

RQ3. Which tasks, skills and personal attributes of knowledge brokers would they like to take on, acquire or improve?

The results suggest that the professionalization process for the respondents may be happening at three levels: personal, knowledge brokering as a profession, and patient participation as a process. The first level directly relates to their tasks, skills and personal attributes and will be discussed here. The other two have more to do with organizational change, as developed in the answer to RQ4.

Some of the activities and tasks that the respondents would like to change to improve patient participation are related to the knowledge brokering domain of linkage and exchange; their aim is to build up better relationships with researchers, and facilitate improved engagement of patients in scientific studies. They would do so by fostering earlier and more systematic involvement of patients in scientific projects through engaging and connecting stakeholders, and through increased coordination and collaboration.

Other activities that respondents would like to take on or increase are related to communication and knowledge transfer within the knowledge management domain. The respondents would like to facilitate an increase in the knowledge transfer between the different partners engaged in initiatives with patient participation, for example concerning results and updates of projects. There is also a need for better evaluation of the involvement of patient experts in scientific studies. Concerning communication activities, there should be more attention paid to the content aspect of information sharing and translation of scientific knowledge to better suit the needs of patients and an increase of communication channels.

A few of the activities that respondents think would improve patient participation are related to the domain of capacity building. They would like to increase the amount of supervision and training for patient experts, to provide them with more information, but also to equip them with writing skills to improve the feedback they give to researchers.

Regarding which training, skills and personal attributes respondents would like to take on, acquire or improve, the answers mainly connect to the knowledge brokering domain of linkage and exchange. Several respondents would like to improve their networking and their listening skills to improve collaboration. Improving their self-confidence was also mentioned in relation to networking. Some respondents would also like to improve their leadership and listening skills, to help them in their coaching activities, which

belongs to the knowledge brokering domain of capacity building. One of the respondents aspires to be more communicative and to gain better insight into the needs of volunteers, both connected to the domain of knowledge management. The wish for improvement of these skills and personal attributes is not surprising, as most of these items were already highly ranked by the respondents during the card sorting activity, as illustrated in figure 7.

One important aspect of the daily work of the respondents is the contact with experiential experts, who are mostly volunteers, and three respondents mention they would receive training related to recruitment, management, and motivation of this group. However, others feel that there is no relevant training available for them as patient participation is currently very much in development and they are involved in this development themselves. Several mention that experience (i.e. informal learning leading to tacit knowledge) will help them improve the skills and personal attributes they need.

The relatively small number of tasks, skills and attributes that the respondents would like to change or improve, confirm that they feel comfortable with their professional profile. Even if they are in an early process of professionalization, they already have assumed the activities and competencies of knowledge brokers in healthcare as described in the literature.

RQ4. What, according to practitioners involved in patient participation, needs to happen to further develop the professionalization of their role in relation to patient participation?

For the answer to this question two complementary aspects will be discussed: professionalization of knowledge brokering and professionalization the process of patient participation in scientific research. From the interviews with respondents it becomes clear that there are different degrees of professionalization for both aspects within the different organizations. As discussed earlier, the job titles of the respondents are diverse and only some indicate an explicit responsibility for patient participation, while none can be immediately recognized as knowledge brokers. However, the literature (see section 3.2.6) shows that this lack of visibility is very common among knowledge brokering professionals, as they often do their activities without explicit acknowledgement.

				help others to express their views				
			willing to learn	be decisive	be able to "see the bigger picture"			
		negotiate	be inquisitive	have self-confidence	build a team	build trust		
	search for relevant information	be intuitive	be curious	translate difficult text to easy to understand text	present information in useful and appealing formats	teach and coach others	listen	
have courage	sell ideas	be innovative	be flexible	discuss sensitive subjects	start and moderate a dialogue	be communicative	be enthusiastic	network and build relationships
have tireless commitment	be creative	be an inspirational leader	have tact	be supportive	motivate others to participate	find out what other partners need	assess information for quality, relevance and usefulness	coordinate tasks and people
-4	-3	-2	-1	0	+1	+2	+3	+4
Least important								Most important

Figure 7. Selection of skills and personal attributes that respondents would like to improve (bordered in green).

The literature about professionalization indicates that organizational change is an important factor to move beyond the personal level: this entails changes in recognition and support, including resources, training and communities of practice. To some extent, recognition is present in the form of paid positions, but respondents insisted that many other facets of recognition need further attention from their organization. From the perspective of knowledge brokering, respondents would like to have more appreciation of their contribution, as well as clarity about their responsibilities. From the perspective of patient participation, they would like to be more often included in the communication by other stakeholders, acknowledgement of the patient organization as a financial partner, awareness of their management about procedures and possible improvements in patient participation, and an increased importance of patient participation as part of the organization's internal policy.

Both processes of professionalization are very intertwined and, when discussing the support they need, respondents call for improvements that would reinforce knowledge brokering and patient participation at the same time. For example, when they mention training to develop their own skills they emphasize that it mainly serves to improve patient participation. Other improvements include funding and human resources. Lack of time was often mentioned as limiting, and very few of the respondents devote 100% of their time to patient participation, as they have many other tasks within their organization. The respondents appreciate the autonomy they have, but at the same time some would appreciate to have clear guidelines for patient participation. As the phenomenon of patient participation further develops, they see the need to consolidate all these aspects of professionalization, and some of them take initiative themselves to achieve this goal within their organization and engage the management in their objectives. Beyond organizational change within their own organization, most respondents value the opportunity that communities of practice offer to support professionalization of patient participation, even though implicitly they often suggest that their knowledge brokering activities also benefit from these meetings.

Main research question: Which aspects of the professional profile of knowledge brokers within the healthcare sector do practitioners within patient organizations, involved in initiatives with patient participation, consider relevant for their current and future role?

In describing their responsibilities, the respondents put emphasis on linkage and exchange as a central aspect of their role in facilitating patient participation in scientific studies: they are the bridge between scientist and patient communities. Of the other two domains, knowledge management and capacity building, it is the latter they connect to more explicitly due to their context of having to train experiential experts.

When they discuss their activities, all three domains are represented, however, linkage and exchange is again most prominent, as it is the only domain of which they perform all the tasks as proposed by the thorough literature review of knowledge brokering in the healthcare sector by Bornbaum et al. (2015). Similarly, the respondents recognize and value the skills and personal attributes that are important for knowledge brokering according to the literature, but the ones they grant most importance to, are again those connected to linkage and exchange: networking and building relationships, and coordinating tasks and people. The respondents rank skills higher in importance than personal attributes, with two notable exceptions: be enthusiastic and communicative. However, some literature considers being communicative as a skill.

Previous empirical research suggests that knowledge brokering shows a diversity in its activities, depending on the context as described in section 3.2 of the conceptual framework. Therefore, an individual may not perform all those tasks previously identified. The variety of tasks reported by the respondents strongly suggests that they can be considered knowledge brokers: collectively they perform almost all tasks associated to knowledge brokering and their self-reported descriptions of their responsibilities adhere to those considered to be knowledge brokers by the literature.

Moreover, the changes in competencies and personal attributes they wish for (in order to improve the process of patient participation in scientific initiatives) suggest they would like to reinforce aspects of their professional profiles related to all three domains of knowledge brokering. In order to achieve this, they expressed a need for increased recognition and support from both their organizations as well as other stakeholders related to patient participation. This study shows that the professionalization of this emerging profile of knowledge brokers in patient organizations is ongoing, and could be very supportive to the consolidation of patient participation.

7. Discussion

As discussed in the conceptual framework, this thesis explores to what extent there are knowledge brokering activities carried out by patient organizations in the context of patient participation in scientific research. This is a very different context to that often described by authors who analyze knowledge brokering in the healthcare sector, where knowledge brokering mainly promotes evidence based policy. An example for the role of knowledge brokers is found in the report of the Canadian Health Services Research Foundation (2004):

"[Knowledge] Brokers should be activists, identifying issues, spurring research, and working to get research used in policy-making. They need to bring policy makers/managers and researchers closer together." (2004: 1)

The results of this thesis suggest that in the context of patient participation in research this statement can be adjusted to the following: Knowledge brokers should be activists, identifying issues, spurring research, and working to get *experiential evidence* used in research. They need to bring *researchers and patients* closer together. In both contexts, transfer of knowledge takes place; however, in the latter context the transfer of knowledge mainly has research as the destination point, while in the more frequently described studies research is the starting point. The context in which researchers have tried to find knowledge brokering in the existing literature tended to focus on scientific knowledge; this study proposes that the definition of knowledge broker should acknowledge experiential knowledge as one of the forms of knowledge that can be brokered. Hering (2016) acknowledged the bidirectional nature of knowledge brokering in her theoretical model, and the context of this study is a good example of that possibility in action.

One of the most obvious aspects of the context of patient participation, as repeatedly put forward by the respondents, is the presence of volunteers as one of the most important stakeholders. Many of the patients participating in the initiatives do so without being paid, and the more informal nature of the relationships has implications for the involvement of these volunteers. The respondents are often concerned about the level of burden that volunteers are asked to assume. Being an experiential expert in the healthcare context is probably not the preferred activity a person would imagine engaging in, but rather is related to the circumstances a person finds him or herself in, and a way to face those circumstances in a more empowered manner. In a way, it is

personal motivation rather than professional duty that encourages them to get involved in research, and that seems to influence the conditions for knowledge transfer processes. For example, the respondents deem it difficult to find a balance between the necessary knowledge and skills of volunteers for participation, and the amount of training that is feasible for them to attend.

This discussion takes into account these differences in context, in order to explore the implications of the conclusions. The limitations of the study are considered first, followed by a reflection on the connections to the discipline of science communication, the implications for practitioners involved in patient participation, and, finally, suggestions for further research.

7.1. Limitations

As a relative small number of practitioners participated in this study, the results should not be generalized to the whole population of practitioners involved in patient participation within patient organizations in the Netherlands.⁵ It is not known how many of these practitioners exist and their general characteristics, and therefore it cannot be assured that the sample is representative. Despite this, the fact that all the respondents in this study are female is no surprise considering an earlier observation by Phipps & Morton: “We observe from our own work and by observing attendees at [knowledge exchange] workshops and conferences that knowledge broker roles are dominated by women in both Canada and the UK” (2013: 258).

Instead of statistical representativeness, the card sorting exercise based on Q methodology allows for the development of concepts, categories, theoretical propositions and models of practice, by “establishing the existence of a viewpoint” (Watts & Stenner, 2012: 73). A similar logic applies to other aspects of the professional profiles explored through the interviews (Qu & Dumay, 2011). This small study therefore establishes the profile of the practitioners as knowledge brokers and makes the contribution of a first set of characteristics that can be further explored, as described later in this discussion.

Moreover, a larger sample would have implications on the amount of time needed for the interviews and the analysis. In that case, more quantitative approaches would have been more feasible given the time restrictions for this master thesis; surveys instead of semi-structured interviews, and online or mail-based Q methodology instead of the in-

⁵ As an indicator of the size of the population, the Patiëntenfederatie Nederland represents 170 patient and consumer organizations. It is not known how many of these organizations engage in patient participation as part of scientific research.

person card-sorting activity including elaborations about behavioral indicators. Despite the limitations, the richness of the qualitative approach seems to have been suitable for this explorative study.

As mentioned in chapter 4, the study cannot provide an assessment of actual practices, but rather of how do practitioners report about those practices. Further research can address this limitation, as explained below.

7.2. Connection of the research to science communication

As scientific research is increasingly including citizens in the process, it is important that the discipline of science communication acknowledges this trend and addresses the complexities of the multidirectional interactions and knowledge exchanges in these participative contexts. This thesis demonstrates that the process of patient participation in scientific research offers a suitable terrain to explore these complexities. The presence of bidirectional knowledge exchange between patients and researchers, and the emphasis of the respondents on linkage and exchange rather than on knowledge management, are examples of how science communication may be evolving. By exploring the communication practices of the emerging professional profile of knowledge broker within patient organizations, the theorization of science communication could be enriched to apprehend such an increasingly complex scenario.

As much as empirical research contributes to the theoretical development of science communication, it also may also assist practitioners in the field in their process of professionalization, by giving them conceptual tools to reflect about science communication. In the case of this thesis, the mere discussion with the respondents during the interviews invoked reflections about their identity and their practices. The respondents mentioned communication in several ways in the context of their tasks, and even if much of what they reported doing is connected to science communication, they do not have a structured perspective on it, as they are not engaged in the debates of the discipline. Science communication experts could help these knowledge brokers reflect on their practices with a different perspective that would enrich their self-reflections, the process of professionalization, and ultimately empower them to make strategic decisions that may reinforce their position as facilitators of patient participation in scientific contexts. This would then be in itself a mutually beneficial two-way process between theoretical and practical approaches to science communication, in which the science communication researcher and the practitioners learn from each other.

The results of the thesis show that the respondents most commonly have a background in health sciences, some in management and pedagogy, but none of the respondents

explicitly mentioned communication as an educational or professional background. Some aspects of science communication are considered less important by the respondents, such as translation and adaptation of content to the needs of experiential experts. In fact, the respondents would like researchers to take increased responsibility for these knowledge brokering tasks. However, the respondents did not mention if the researchers have the skills to do so and are aware of the need of adaptation of their communications; on the contrary, the respondents expressed that sometimes they felt obliged to adapt content provided by researchers to make it comprehensible for patients. Offering training in science communication for these knowledge brokers would help them make better informed decisions on their practices and how to distribute responsibilities related to knowledge brokering and patient participation.

7.3. Significance of the results to practitioners: need for further professionalization

Part of the social value of this thesis resonates with a recent blogpost written by Arja Broenland (2018), director of the Dutch Federation of Cancer Patient Organizations (Nederlandse Federatie van Kankerpatiëntenorganisaties, NFK). She highlights how patient organizations have been given an important position within the healthcare system by the Dutch government, as cancer patient organizations receive hundreds of requests related to a range of different topics including care trajectories, transparency, guidelines, new medication and so forth. In this context, patient participation is defended by the author as giving value to the quality of care, a “patient perspective” that is becoming compulsory in many health-related initiatives (such as the research projects discussed in this thesis). Broenland describes the “enormous logistical and coordination” challenges of patient participation, and deplors the lack of financing: “Bringing together a focus group of palliative patients is not something that you do on the side. The recruiting, selecting, training and coaching of voluntary experiential experts costs a lot of time and money. Patient organizations do not receive subsidies for this and that is quite strange.” For her, the ongoing professionalization process, the new tasks and the exploding demand for patient participation, do not receive sufficient financial support and recognition.

It is not surprising that, even if none of the respondents of the study were related to a cancer patient organization, this thesis confirms the existence of an emerging knowledge broker role in additional patient organizations (described by Broenland in the quote through their activities), and a perceived need for recognition and resources. And indeed, the respondents emphasize the increasing demand on them, and insist on the lack of time, their willingness to improve their skills, and have more support to do

their activities. The professionalization of patient participation, including increased finances, are a shared aim for Broenland and the respondents.

This is the first study that explores self-reported tasks, competencies and personal attributes related to knowledge brokering in the context of patient participation. The literature review by the CHSRF (2003) already suggested that “it is possible to list some of the skills that are necessary for effective knowledge brokering; blended with details of a specific organization’s needs and role, they could be worked up into a job description.” Patient organizations could get inspiration from the results of this thesis to reflect on the profile for future job advertisings. However, there is no one solution that perfectly fits all, because of at least four reasons: 1) the effectivity of knowledge brokering in the context of patient participation in scientific research has not yet been thoroughly studied (see below), which would be necessary to assess the minimal pre-requisites for knowledge brokers. 2) Patient organizations are very diverse in size, budget and internal structure, and therefore their knowledge brokering needs and organizational context may vary to some extent. Some are mostly run by volunteers with sometimes little experience in knowledge brokering while others already have very professional teams dealing with patient participation. 3) The difference between chronic diseases and acute or temporary conditions, and their respective severity. This may determine the length of the involvement of patients and the burden they can assume, and also require different knowledge brokering strategies in terms of capacity building. And 3), the nature of the research projects, the number of patients participating, and the moment and intensity of the involvement. Each organization may adapt the map of activities, knowledge, skills and personal attributes provided in this thesis to the circumstances of each participation project in order to find the knowledge broker they need.

For those knowledge brokers already involved in patient organizations, the process of professionalization also requires self-reflection on their activities and competencies. Not being familiar with the concept of knowledge brokering, they may not be aware of the scope of their role. In combination with the reflection on knowledge brokering and patient participation by scholars, they will obtain more systematic professional knowledge about their profile, and be able to make informed decisions on the path of professionalization of these processes.

As patient participation evolves over time, the involvement of experiential experts in research projects may increase on the different levels of the “participation ladder” (see section 2.2). The need for a knowledge broker in the future may be different than in the current scenario due to increased and more varied participation initiatives, and the balance between the three different domains of knowledge brokering activities (linkage and exchange, knowledge management and capacity building) may change. Will there

always be the need for a knowledge broker? Most likely yes, as regardless of the circumstances there will always be differences in the level and the kind of knowledge of the stakeholders participating in the projects. As the complexity of patient participation will increase and more actors will be recruited, it is a soothing thought that at least a professional profile is in place that is capable of mediating in this network. Patient organizations seem to be accepting the challenge of taking on these responsibilities.

7.4. Further research

As there was a predetermined list of tasks based on the literature, even if they were given the chance to add more, they may perform activities that may not have been captured in this study. An ethnographic study or activity diaries could give more insight and complement the existing literature. Even if no single practitioner performs all the activities, such a systematic observation would give a detailed overview of the universe of options that individuals can cover within the definition of knowledge broker in the context of patient participation. In any case, this study provides a base for the analysis of the development of this professional profile, and further research can monitor future evolution.

This study has identified several other stakeholders that are involved in patient participation within the context of academic research, and they may also have the knowledge broker role. These include scientists or their support staff in universities and academic hospitals, and employees of funding organizations. Abma et al. (2009) proposed a role for social researchers a facilitators of patient participation, in a position equivalent to that of a knowledge broker as described in this thesis. Including these different profiles in future studies would allow to identify similarities and differences between their respective roles in patient participation and their impact on efficiency.

One of the next steps is thus the creation of indicators for the effectiveness of knowledge brokering. Jackson-Bowers, Kalucy, & McIntyre (2006) noted: "Finding effective measures to evaluate the success or otherwise of knowledge brokering is proving a challenge." More recently, in their literature review, Bornbaum et al. (2015) "found insufficient evidence to draw conclusions regarding the effectiveness of [knowledge brokers] in health-related settings." Nevertheless, Jackson-Bowers et al. (2006) note that the continued use of knowledge brokers suggests that they must provide some added value to the healthcare sector.

8. References

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APPENDICES

Appendix I

Call for involvement in the study placed within the LinkedIn group of PGOsupport

Binnen projecten met patiëntenparticipatie kunnen onderzoekspartners met verschillende achtergronden en ervaringen veel van elkaar leren. Tegelijkertijd zijn er uitdagingen als het gaat om de uitwisseling van informatie binnen het project. **Wie zorgen er voor dat onderzoekers en patiënten/cliënten alle kennis met elkaar delen zodat een project met patiëntenparticipatie succesvol verloopt?**

Heb je, als patiëntonderzoeker/ -onderzoekspartner meegedaan aan een wetenschappelijk onderzoeksproject en herken jij jezelf in het bovenstaande en/of in 1 van de volgende rollen?

- kennismakelaar
- projectleider
- mentor
- coördinator
- contactpersoon

Dan ben ik op zoek naar jou! Ik zou je graag een keer willen interviewen over jouw ervaringen binnen zo'n project, wat ging er goed en wat kan er nog verbeterd worden? We gaan samen op zoek naar wat er nodig is om communicatie binnen dergelijke projecten optimaal te laten verlopen.

Voor mijn afstudeerproject wetenschapscommunicatie aan de TU Delft ben ik op zoek naar diegenen die ervoor hebben gezorgd dat kennis en informatie werd uitgewisseld tussen de verschillende partners, binnen een onderzoeksproject met participatie door patiënten(organisaties). Na afloop van deze studie (zomer 2017) zal het rapport met aanbevelingen voor iedereen beschikbaar zijn.

Als jij bereid bent om door mij geïnterviewd te worden, of je wilt meer informatie over dit project, neem dan het liefst vóór **24 maart 2017** contact met mij op via:

kennisdelen2017@gmail.com

Alle informatie zal vertrouwelijk worden behandeld en je kunt je op elk moment en zonder opgave van redenen terugtrekken uit dit project.

Alvast bedankt!

Ingrid van Marion

Appendix II

Preliminary questionnaire to determine eligibility for study

Informatieformulier zoektocht naar kennismakelaar

Datum: _____

Patiënt/Cliënt organisatie: _____

Naam: _____ Functie: _____

Tel nummer: _____

Email: _____

Contactgegevens verantwoordelijke patiëntparticipatie binnen organisatie

Naam: _____ Functie: _____

Tel nummer: _____

Email: _____

Onderzoeksproject met patiëntenparticipatie

Thema/doel project: _____

Naam project: _____

afgerond / gaande / gepland

Mate van betrokkenheid van patiënten in het project: _____

Rol(len) van patiënten/cliënten volgens de patiëntenparticipatie ladder:

0 proefpersoon/onderzoeksobject (clinical trial, delen van info via interview of survey)

0 informatieverstrekker (delen van info via interview of survey)

0 adviseur (klankbord/panels)

0 referent/beoordelaar (van onderzoeksvorstellen)

0 medeonderzoeker (van interviewer tot patiëntpartner, co-auteur, congresbezoek)

0 opdrachtgever/drijvende kracht (initiatiefnemer)

Universiteit en andere partners betrokken bij het project:

Contactpersonen (kennismakelaars, projectleiders, coördinatoren, etc)

Contactpersoon: _____ **Organisatie:** _____

Rol in project: _____

Tel. nummer: _____ Email: _____

Beste contact moment: _____

Contactpersoon: _____ **Organisatie:** _____

Rol in project: _____

Tel. nummer: _____ Email: _____

Beste contact moment: _____

Opmerkingen

Appendix III

Short description of the organizations participating in the study

De Hart & Vaatgroep (since 1-1-2018 Harteraad)

<https://www.harteraad.nl/over-harteraad/>

This patient support association advocates for those with cardiovascular disorders and their relatives, based on their experiences. Their mission is to improve quality of life and care. The organization has 26 employees and involves members and volunteers in their activities.

Longfonds

<https://www.longfonds.nl/wat-wij-doen/over-ons/organisatie>

During the course of this study, a fusion occurred between the patient organization and the health fund foundation to what is now the foundation Longfonds. The practitioner interviewed for this study was associated with the patient organization. The Longfonds promotes contact between patients, advocacy, education and information, quality of care, scientific research and prevention. In 2016, the patient organization had 85 employees, more than 35.000 members and over 650 active volunteers.

Nationale Vereniging ReumaZorg Nederland

<https://reumazorgnederland.nl/over-rzn/>

This independent patient organization is an association that was founded by patients with rheumatism in 2014. It connects local associations in the Netherlands. Their aims include advocacy to accomplish an early diagnosis, an active life, and good quality of care for all patients. The association depends largely on members and volunteers.

Nederlandse Brandwonden Stichting

<https://brandwondenstichting.nl/wie-zijn-wij/medewerkers/>

This foundation was initiated by two medical doctors in 1971. The organization still has three ambitions: prevention of fire and burns, increased of quality of care, and increased quality of life for persons with burns. The Nederlandse Brandwonden Stichting funds and coordinates initiatives with patient participation related to their ambitions. Employees of the foundation support the patient association, Vereniging Mensen met Brandwonden, and its volunteers, to achieve their shared goals.

Nederlandse Cystic Fibrosis Stichting

<https://www.ncfs.nl/ncfs-voor-u>

The mission of this foundation is a longer and better life for those with cystic fibrosis. The organization has ten employees, and is involved in advocacy, organizes meetings for fellow-sufferers, provide education and information, finances and coordinates scientific research, and raises funds to achieve all this. Since 2012, the foundation has a group of people with cystic fibrosis, and parents of cystic fibrosis, who evaluate national and international research proposals.

Nierpatiënten Vereniging Nederland

<https://www.nvn.nl/over-de-nvn/>

This association has the aim to help consolidate or improve the quality of life and care of kidney patients. Key focus points for the association are informing of patient and relatives, support for self-management, facilitation of sharing of experiential knowledge, advocate for an active involvement in society, promote organ donation, stimulate engagement of patients in improvements of quality of care and research. The association has 19 employees and around 170 volunteers for whom the patient perspective and their experiential knowledge will be leading during their activities.

Psoriasis Vereniging Nederland

(since January 2018 the PVN became part of Psoriasispatiënten Nederland)

<https://www.psoriasisvereniging.nl/de-pvn/>

At the time of interviews, the respondent was associated with the Psoriasis Vereniging Nederland. The association defends the interest of those with psoriasis, providing information about the condition and promoting scientific research with the aim of achieving an effective treatment for all. They also raise awareness among the general public and government policy makers about psoriasis. The association depends largely on members and volunteers.

Spierziekten Nederland

<https://www.spierziekten.nl/over-ons/>

Spierziekten Nederland is an association who advocates for those with a muscular disease. Their mission is to improve quality of care, promote effective scientific research and provide good education and information, also for medical professionals and other professional aid workers. The organization had 28 employees according to their annual report of 2016, and many of their members have an active role as volunteer within the association.

Appendix IV

Interview protocol

Fase 1. Introductie

Allereerst wil ik u bedanken voor deelname aan dit onderzoek, ik waardeer het dat u mij hier wilt ontvangen en tijd hiervoor heeft vrijgemaakt. Dit onderzoek is een onderdeel van mijn masterstudie wetenschapscommunicatie aan de TU Delft, maar ik heb ook ervaring als onderzoeker op het gebied van ziekten als ALS, Parkinson en Huntington.

Het doel van dit interview is om inzicht te verkrijgen in de rol van medewerkers van patiëntenorganisaties die betrokken zijn bij projecten met patiëntenparticipatie.

Het interview zal ongeveer 60 minuten duren en we zullen veel bespreken. Eerst zal ik een paar vragen stellen over uw professionele en opleidingsachtergrond, daarna gaan we het hebben over uw positie en taken binnen deze projecten. Vervolgens ga ik u vragen om een aantal kaartjes te sorteren die betrekking hebben op uw vaardigheden en eigenschappen. En tot slot zal ik graag luisteren naar uw gedachten over hoe patiëntenparticipatie in het algemeen verbeterd zou kunnen worden.

Dan zou ik u nu willen vragen om toestemming voor audio opname van dit interview om analyse mogelijk te maken.

Fase 2. Onderwerpen en vragen

2.1. Over de professionele en opleidingsachtergrond

- Kunt u mij kort iets over uw opleidingsachtergrond vertellen?
- Kunt u mij kort iets over uw professionele achtergrond vertellen?
- Welke andere ervaring heeft u die gerelateerd is aan patiëntenparticipatie?
- Heeft u specifieke training gehad die gerelateerd is aan uw werk met patiëntenparticipatie?
- Zou u aanvullende training willen volgen? Zo ja, welk soort training en waarom?

2.2. Over de positie binnen de organisatie

- Wat is de titel of omschrijving van uw functie binnen de organisatie?
- Zou u de volgende zin in kunnen vullen en af kunnen maken?

In projecten met patiëntenparticipatie, heb ik de rol van ... en ben ik verantwoordelijk voor [aansporen d.m.v kaartje]

- Is uw positie betaald of vrijwillig en is dit een full-time positie?

- Hoeveel tijd besteed u ongeveer per week binnen deze functie aan patiëntenparticipatie?
- Sinds wanneer bent u betrokken bij patiëntenparticipatie?
- Zijn er nog anderen binnen de organisatie betrokken bij patiëntenparticipatie en kunt u mij in het kort vertellen wat hun rollen of functies zijn?
- Hoeveel vrijheid heeft u binnen deze functie om beslissingen te maken over hoe u uw werk uitvoert?

2.3. Over de taken die gerelateerd zijn aan projecten met patiëntenparticipatie

Zou u mij kunnen vertellen over uw taken die gerelateerd zijn aan de volgende activiteiten, en kunt u mij voorbeelden geven?

Bent u betrokken bij:

- a. identificatie en verkrijgen van relevante **informatie** voor de projecten?
- b. identificatie, **betrekken van**, in contact brengen met partners voor projecten?
- c. het ervoor zorgen dat partners met elkaar **communiceren** en informatie uitwisselen?
- d. faciliteren van **samenwerken van de partners** binnen de projecten?
- e. **coördinatie** van projecten?
- f. het **trainen** van anderen binnen projecten?
- g. het **produceren van informatie** over projecten? Voor wie?
- h. het maken van **richtlijnen** voor projecten met patiëntenparticipatie?
- i. **evaluatie** van patiëntenparticipatie in projecten?
- welke **andere taken** heeft u binnen projecten met patiëntenparticipatie, die we nog niet besproken hebben?

Ik zal de deelnemer aansporen om meer details te geven als het gaat om het delen van

- **wetenschappelijke kennis,**
- **patiëntervaringen**
- **en informatie over procedures binnen projecten.**

-Welke **veranderingen in uw taken** denkt u dat er nodig zijn om patiëntenparticipatie te verbeteren?

- Heeft u contact met anderen die een **vergelijkbare rol** als u hebben binnen patiëntenparticipatie, en welke informatie deelt u met elkaar? Hoe gebeurt dit en hoe vaak?

Fase 3. Het sorteren van kaartjes, om vaardigheden en eigenschappen te rangschikken

3.1. Waardering van vaardigheden en eigenschappen

Het is belangrijk dat u tijdens de volgende opdracht hardop denkt en uitlegt waarom u iets doet. Bekijk de 34 kaartjes met vaardigheden (je moet kunnen...) en eigenschappen (je moet ... zijn).

Denk aan de manier waarop u uw werk wat betreft projecten met patiëntenparticipatie tot nu toe heeft uitgevoerd:

Rangschik nu de kaartjes in 3 stapels: minst belangrijk, neutraal, meest belangrijk.

Blijf vooral hardop denken.

Neem de stapel met kaartjes met vaardigheden en eigenschappen die voor u het meest belangrijk zijn. Spreid eerst de stapel kaartjes zodat u een overzicht heeft van de kaartjes. Plaats deze kaartjes nu op het veld, en begin daarmee aan de rechterkant (meest belangrijk) en werk toe naar de linkerkant. Als de eerste stapel op is neemt u de tweede stapel, neutraal, en plaatst u deze van rechts naar links op het veld. Als laatste neemt u de stapel die “minst belangrijk” weergeeft, en plaatst u deze ook op het veld. De verticale volgorde is daarbij niet belangrijk. Het gaat hierbij om uw mening, er is geen “goed” of “fout”.

Blijf vooral hardop denken en leg uit waarom u de kaartjes een bepaalde plaats in het veld geeft.

Kunt u mij een praktisch voorbeeld geven voor elk van de 5 kaartjes aan beide uitersten, waaruit blijkt dat u de competentie meer of minder belangrijk vindt?

[ik zal een foto maken van het veld waarop alle kaartjes een plaats hebben gekregen]

Zijn er vaardigheden of eigenschappen die u heeft en die u gebruikt tijdens uw werkzaamheden voor projecten met patiëntenparticipatie, maar die missen in dit veld?

3.2. Gewenste veranderingen in vaardigheden en eigenschappen

Selecteer de kaartjes met competenties die u zou willen aanleren of verbeteren, om daarmee om uw werk in patiëntenparticipatie nog beter uit te kunnen voeren.

Denk hierbij ook weer hardop na.

Waarom heeft u juist deze kaartjes gekozen?

Wat, denkt u, is er voor nodig om deze veranderingen te bereiken?

Als het niet spontaan genoemd wordt zal ik vragen om reflecties over professionele ontwikkeling, de organisatorische structuur van de patiëntenorganisatie en over “best practices” (richtlijnen) binnen projecten met patiënten participatie.

Fase 4. Context en professionalisering van patiëntenparticipatie

- Wat zijn uw gedachten over de toegevoegde waarde en voordelen van betrokkenheid van patiëntenorganisaties als partner binnen onderzoeksprojecten met patiëntenparticipatie?
- Wat zijn uw gedachten over het succes van projecten met patiëntenparticipatie in het algemeen, en wat zou u kunnen bijdragen aan promoten van mogelijke veranderingen en verbeteringen?

Laatste vraag: Wat vindt u leuk aan het betrokken zijn bij patiëntenparticipatie?

Ik bedank voor de deelname en het vrijmaken van tijd voor dit interview. Ik zal om een korte reactie vragen over het interview en of ik eventueel nog een keer contact per telefoon of email mag opnemen voor aanvullende informatie of om onduidelijkheden te verklaren.

Ik zal aanbieden om tzt een kopie van het masterproefschrift en/of een korte samenvatting van de studie te sturen.

Appendix V

Coding scheme

A. Professional knowledge and experience	
a. Current	1. Education
b. Desired	2. Professional experience
	3. Training related to patient participation
	4. Experience related to patient participation
	5. Other relevant experience

B. Organisational context	
a. Job title and description	
b. Role of... responsible for...	
c. Knowledge broker	
d. Status	1. Paid
	2. Voluntary
e. Form of employment	1. Full time
	2. Part time
f. Since when started working on p.p.	
g. Time spent on patient participation	
h. Colleagues involved in p.p.	
i. Autonomy in decision making	
j. Desired organisational changes	
h. Job advert	

C. Tasks	
a. Current	1. Identify, engage and connect with stakeholders
b. Desired	2. Facilitate collaboration
	3. Identify and obtain relevant information
	4. Facilitate development of analytic and interpretive skills
	5. Create tailored knowledge products
	6. Project coordination
	7. Support communication and information sharing
	8. Network development, maintenance and facilitation
	9. Facilitate and evaluate change
	10. Support sustainability
	11. Other

D. Skills	
a. Current	1) Relevante informatie kunnen opzoeken (search for relevant information)
b. Desired	2) Moeilijke teksten naar makkelijk te begrijpen teksten kunnen vertalen (translate difficult text to easy to understand text)
	3) Kunnen netwerken en relaties opbouwen (network and build relationships)
	4) Anderen kunnen helpen om hun gedachten en meningen te uiten (help others express their views)
	5) Taken en mensen kunnen coördineren (coordinate tasks and people)
	6) Anderen kunnen motiveren om deel te nemen (motivate others to participate)
	7) Een team kunnen bouwen (build a team)
	8) Kunnen luisteren (listen)
	9) Ideeën kunnen verkopen (sell ideas)
	10) Gevoelige onderwerpen kunnen bespreken (discuss sensitive subjects)
	11) Informatie kunnen beoordelen op kwaliteit, relevantie en bruikbaarheid (assess information for quality, relevance and usefulness)
	12) Kunnen onderhandelen (negotiate)
	13) Informatie kunnen presenteren op een bruikbare en aantrekkelijke manier (present information in useful and appealing formats)
	14) Een dialoog kunnen starten en modereren (start and moderate a dialog)
	15) Anderen kunnen leren en coachen (teach and coach others)
	16) Erachter kunnen komen wat andere partners nodig hebben (find out what other partners need)
	17) Vertrouwen kunnen opbouwen (build trust)
	35) Other

E. Personal attributes	
a. Current	18) Creatief zijn (be creative)
b. Desired	19) Innovatief zijn (be innovative)
	20) Zelfvertrouwen hebben (have self-confidence)
	21) Willen leren (be willing to learn)
	22) Intuïtief zijn (be intuitive)
	23) “Het grote plaatje” kunnen zien (be able to see “the bigger picture”)
	24) Tactvol zijn (have tact)
	25) Ondersteunend zijn (be supportive)
	26) Leergierig zijn (be inquisitive)
	27) Flexibel zijn (be flexible)
	28) Nieuwsgierig zijn (be curious)
	29) Volhardend zijn (have tireless commitment)
	30) Lef hebben (have courage)
	31) Communicatief zijn (be communicative)
	32) Een inspirerende leider zijn (be an inspirational leader)
	33) Enthousiast zijn (be enthusiastic)
	34) Besluitvaardig zijn (be decisive)
	36) Other

F. Context and professionalization of patient participation	
a. Added value and benefits of involvement patient organization	
b. Success of patient participation	
c. Motivation personal involvement	
d. Personal role in further development	
e. Organizational change and improvement	1. Recognition
	2. Resources
	3. Training
	4. Communities of practice
	5. Other

Appendix VI

Factor analysis using Q methodology

The factor analysis with Q methodology resulted in the extraction of two factors, together explaining 34% of the total study variance (22% for factor 1 and 12% for factor 2) and reflecting everything that the 9 Q sorts in this study have in common. To find only two factors is not unexpected as Watts and Stenner (2012: 107) suggest to “try extracting one factor for approximately every 6-8 participants in your study.” An overview of the statistical data supplied by the PQMethod software can be found in table VI.1. A factor's eigenvalue (EV) is indicative of its statistical strength and explanatory power, and it is calculated from the loading of each sort on that particular factor. The eigenvalue of factor 1 and 2 were calculated to be 2.02 and 1.07 respectively. The Kaiser-Guttman criterion (Guttman, 1954; Kaiser, 1960, 1970) has led to the notion that factors with an eigenvalue higher than 1.00 should be accepted for further analysis and interpretation while an extracted factor with an eigenvalue lower than 1.00 accounts for less study variance than a single Q sort (Watts & Stenner, 2005: note 7).

Table VI.1. Factor Matrix of the Q sorts.

Q sort	Factor 1	Factor 2
1	-0.1380	0.5943
2	0.2707	0.2630
3	0.2049	0.2822
4	0.5313	-0.0987
5	0.6247	0.5160
6	0.3256	-0.1089
7	0.7099	-0.5039
8	0.5967	0.1507
9	0.4943	0.0189
Eigenvalue	2.0171	1.0668
Exp. Variance (%)	22	12

In bold, the sorts that load significantly to a factor.

Brown (1980) describes two further parameters that can be taken into account when deciding on which factors to retain for further study. The first is to accept those factors that have two or more significant sorts loading on the factor following extraction. The following equation can be used to calculate a significant factor loading at the 0.01 level (Brown, 1980: 222-223):

$$\text{Significant factor loading for study} = 2.58 \times (1 \div \sqrt{\text{no. items in a Q set}})$$

As there are 34 items to sort in this study, the significant factor loading is calculated to be ± 0.44 at the $p < 0.01$ level. Both factors contain two or more significant factor loadings and pass this criterion.

The second parameter described by Brown is Humphrey's rule, which "states that a factor is significant if the cross-product of its two highest loadings (ignoring the sign) exceeds twice the standard error" (Brown, 1980: 223). The standard error is calculated as follows (Brown, 1980: 222):

$$\text{Standard error} = 1 \div (\sqrt{\text{no. items in a Q set}})$$

As there are 34 items to sort in this study, the standard error is calculated to be 0.1715, rounded up to 0.17, and twice the standard error results in 0.34. The two highest loadings are 0.71 and 0.62, and 0.59 and 0.51 on factor 1 and factor 2 respectively. This means that the cross-product for factor 1 is 0.44 (0.71×0.62) and for factor 2 is 0.30 (0.59×0.51). From this it is clear that factor 1 should be extracted, however, factor 2 does not pass Humphrey's rule. When looking at both factors in more detail (see table VI.1), four out of the nine sorts (no. 2,6,7,8) loaded significantly on factor 1 and are exemplary for this factor, while only 1 sort (no. 3) loaded significantly on factor 2, and another sort (no. 4) loads significantly on both factors, but higher in factor 1. The other sorts (no. 1, 5 and 9) were not significantly associated with either of the extracted factors. For the remainder of this analysis the focus will mainly be on factor 1 as this factor leads to key viewpoints that are held in common within the respondent group.

To be able to better visualize and explore the factors, it is possible to use the factor loadings as coordinates and create a mapping of relative positions, or viewpoints, of all the Q sorts in a study. Each extracted factor defines one of the dimensions within the space, and each individual Q sort, representing a unique and meaningful viewpoint, claims its own position according to its coordinates defined by the factor loadings. Close proximity of these mapped Q sorts illustrates that those respondents have similar viewpoints, while those that are further separated from each other represent quite different viewpoints. As the distance between the Q sorts increases, their respective viewpoints diverge more. Figure VI.1 illustrates the mapping of the Q sorts in this study. The space is defined by factor 1, via the y axis, and factor 2 via the x axis, and the range of possible factor loadings, from +1.00, through zero, to -1.00.

Factor rotation may improve the focus in relation to the collected data. The aim of this process is to position each factor in such a way that it closely approximates the viewpoint of a certain group of Q sorts. The group of Q sorts can then be used to construct a representative estimation of the viewpoint of each factor, which in turn supports a meaningful interpretation of the factor. The software PQMethod allows for by-hand or manual factor rotation using the PQRROT option. However, this did not lead

to a more meaningful positioning of the axes representing the factors, and analysis continued without alterations to factor loadings.

A factor estimate, an approximation of a factor's viewpoint, is constructed from the weighted averaging of all the individual Q sorts that load significantly on that factor. Significantly loaded Q sorts, those with a factor loading greater than 0.44, are marked in bold in table VI.1. PQMethod was used to construct the factor estimate for factor 1, including the Q sorts 2, 4, 6, 7 and 8. To create the final factor estimate, each Q sort's factor weight is applied to its own item rankings. In this study a nine-point or +4 to -4 distribution was used to rank the 34 items. To calculate a weighted score for each item, its ranking position is taken into account and multiplied by the factor weight for the sort it belongs to. This is done for each item in each sort, and the sum of the weighted score of each item leads to a total final factor estimate. The higher the number, the more positively this item has been valued within the factor.

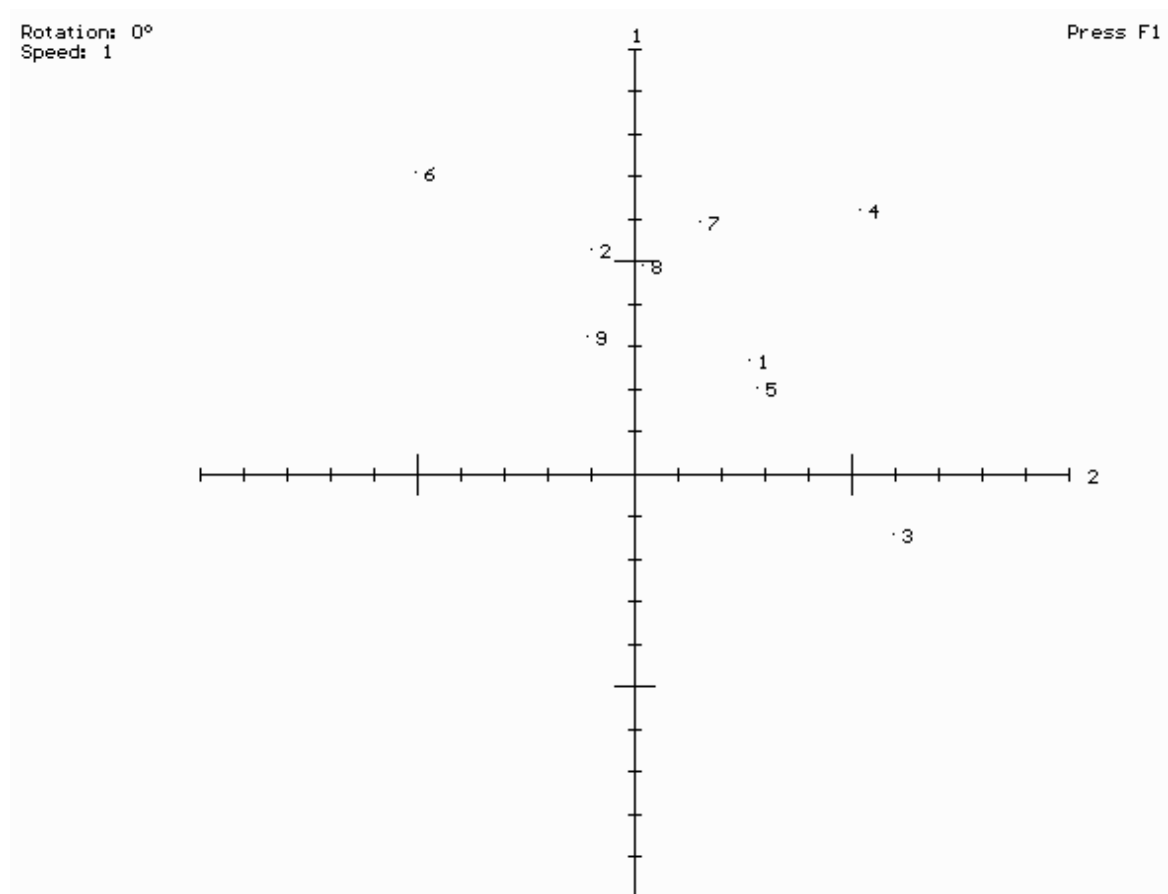


Figure VI.1. Visualization of the relative position of the Q sorts in relation to factor 1 (vertical y axis) and 2 (horizontal x axis), based on factor loading.

The total weighted score for each item within a factor offers insight into the viewpoint represented by a factor, however, it does not offer cross-factor interpretation. To be

able to do this, the number of Q sorts that contribute to each factor needs to be taken into account. The total scores must be converted into z (or standard) scores. Brown has described in more detail how to do this (Brown, 1980: 242-243) and the results of the calculations are also provided within PQMethod. The position in the grid (from -4 to +4) and z scores for each item in factor 1 are provided in table VI.2.

To be able to better visualize the order of item rankings of a factor estimate, the z scores can be used to construct a single factor array. A factor array is an estimated single Q sort representing the viewpoint of a particular factor. It has the same distribution as used in the original data collection and is constructed using the rank order of the z scores. The formation of this holistic configuration of items also reflects on the chosen methodology in that the respondents were asked to consider the items relative to each other and produce a single sort. The factor array for factor 1 in this study is shown in figure 6 in Chapter 5, and provides a best possible estimate, a starting point for the interpretation of the key viewpoints of the respondents about which skills and personal attributes are most important to them when they carry out their work related to patient participation.

The fifth and final step in Q methodology is the interpretation of the factors, discussed in Chapter 5.

Table VI.2. Factor Q sort values and z score for each statement in decreasing order.

Number	Statement	Factor array 1	Z score
3	network and build relationships	4	1.973
5	coordinate tasks and people	4	1.700
11	know how to assess information for quality, relevance and usefulness	3	1.424
8	listen	3	1.421
33	be enthusiastic	3	1.315
31	be communicative	2	1.196
17	build trust	2	1.168
16	find out what other partners need	2	0.956
15	teach and coach others	2	0.865
13	present information in useful and appealing formats	1	0.521
7	build a team	1	0.478
6	motivate others to participate	1	0.461
23	"see the bigger picture"	1	0.150
14	start and moderate a dialogue	1	0.116
2	translate difficult text to easy to understand text	0	-0.038
20	self-confidence	0	-0.084
25	be supportive	0	-0.152
4	help others to express their views	0	-0.194
34	be decisive	0	-0.284
10	discuss sensitive subjects	0	-0.301
27	be flexible	-1	-0.374
24	have tact	-2	-0.468
28	be curious	-1	-0.485
26	be inquisitive	-1	-0.495
21	willing to learn	-1	-0.546
19	innovative	-2	-0.563
32	be an inspirational leader	-2	-0.728
12	negotiate	-2	-0.801
22	intuitive	-2	-0.917
1	search for relevant information	-3	-1.082
18	creative	-3	-1.208
9	sell ideas	-3	-1.342
29	have tireless commitment	-4	-1.445
30	have courage	-4	-2.237

