Organizing Patient Involvement

An Ethnographic Study

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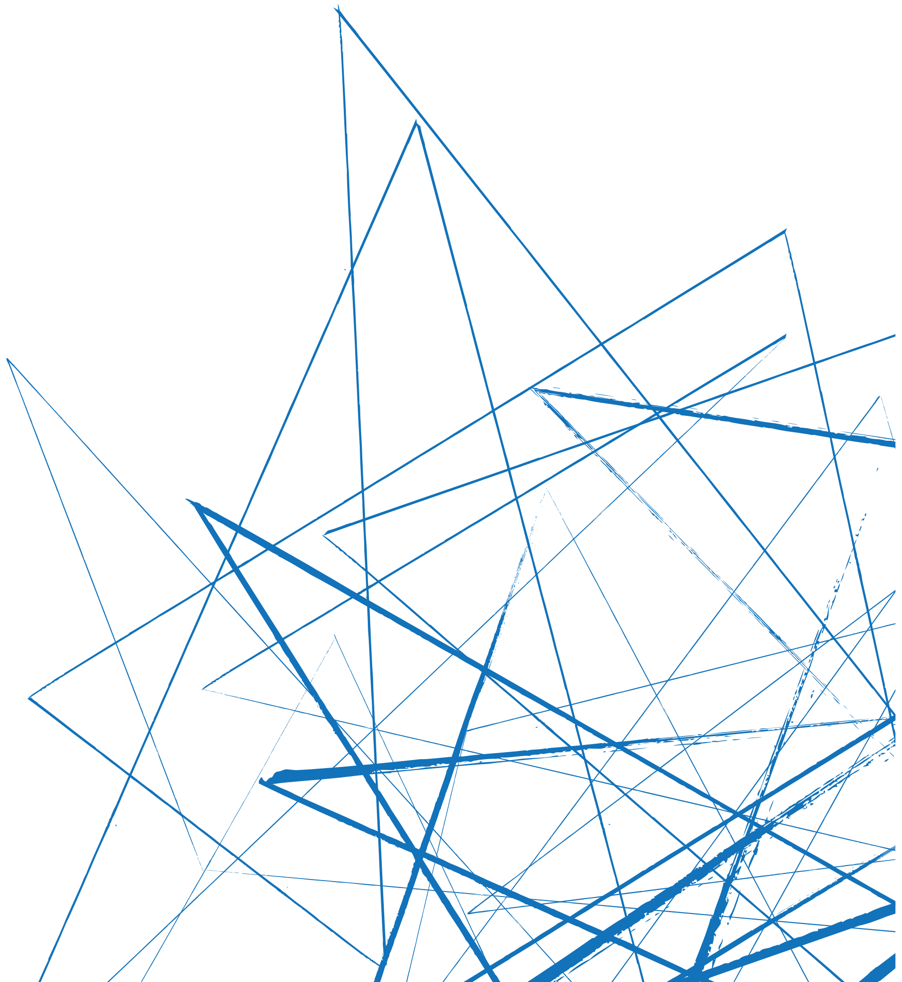

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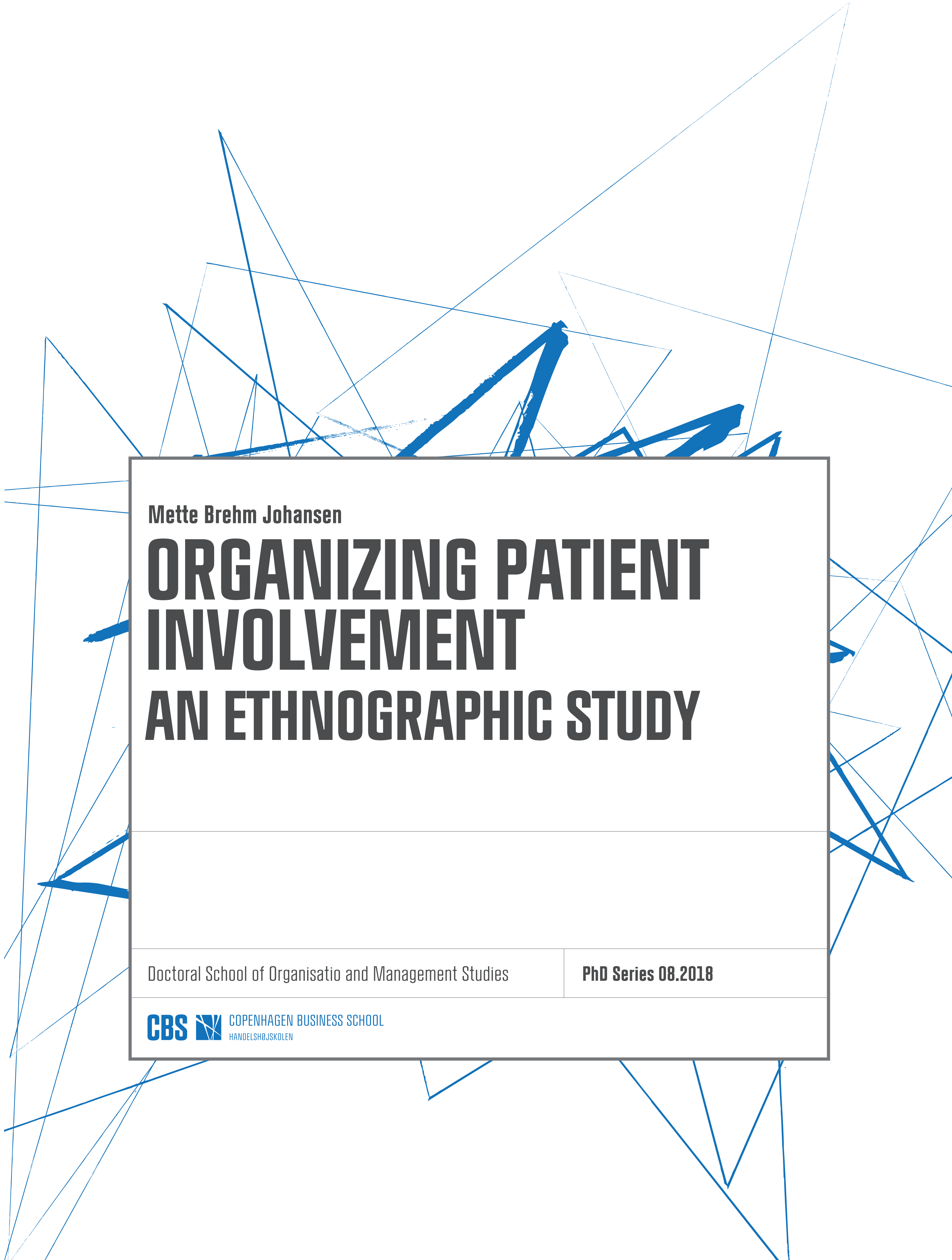

Mette Brehm Johansen

ORGANIZING PATIENT INVOLVEMENT

AN ETHNOGRAPHIC STUDY

Doctoral School of Organisatio and Management Studies

PhD Series 08.2018

CBS COPENHAGEN BUSINESS SCHOOL
HANDELSHØJSKOLEN

Organizing patient involvement

An ethnographic study

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CHAPTER 1. INTRODUCTION

Looking for “the patient”

My entry into the world of patient involvement in quality improvement was different than I had expected. Just two weeks after starting as a PhD student, I went on a two-day study trip with 14 clinical managers and their manager team to Rotterdam to visit hospitals working with a specific patient-centred care model considered to be implemented in the medical centre in the Danish university hospital from which the managers came. I did not understand much of what was talked about during the meetings, the informal conversations, and dinners during these two days, since I did not know much about the background for the trip or about the organization I had been invited into through my affiliation with what was then named the Unit of Patient-Perceived Quality, Capital Region of Denmark. Nevertheless, one moment in a meeting room in a Dutch hospital was very clearly an important one – the moment when the head of the centre asked the managers: “Are we in?” and the managers slowly nodded and expelled quite different tones of “yes”. One of them, a head nurse, quickly added: “But shouldn’t we get the patients involved soon?” This was left uncommented in the small talk of the moment. As it turned out, it would actually take almost a year before patients were involved through an extensive organizational analysis based on interviews and, furthermore, the question would be asked many more times before a patient was involved in a “more than data” manner suggested by the head nurse in the meeting room. However, it was certainly a crucial question for the patient-centred care model implementation process that I was about to follow for the next one and a half years. I followed the process as it was planned, negotiated, and pushed forward in managers’ workshops, seminars, and in numerous centre council meetings. The overall goals of systematically involving patients when relevant and of bettering patient and employee satisfaction were negotiated, and, after just under a year, an extensive organizational analysis based on interviews with patients, relatives, and employees was one of the first milestones on the way to initiating specific changes in the centre.

However, after a couple of months of fieldwork and of observing meetings in the centre council around the implementation of the patient-centred care model and meetings with the management teams of the hospital and the region,[1] I became very curious about how the managerial negotiations and discussions I observed related to what was already going on in terms of patient involvement in the departments of the medical centre. Moreover, a strange feeling of meeting too few patients (that is, none) in an ethnographic study of patient involvement sneaked in on me. Certainly, I had met one aspect of patient involvement in the managerial discussions on the implementation of the patient-centred care model, and it was an important and often undiscussed one, since patient involvement as a managerial issue is usually only articulated as a background. My curiosity regarding *how* the ideal of involving patients was put into activities involving actual *patients* as concrete persons, a different aspect, if you will, led me to look into some of the existing activities in the oncology department of the medical centre that was my field. This choice was based on my knowledge of the departments from meetings and seminars related to the model implementation process, from informal talks with the managers, and a round of interviews with each of the management teams of the four departments. These interviews focused on exploring what they did that they would call patient involvement in their respective departments and were necessary in order to locate the involvement activities relating to quality improvement, since they were hard to "find". This was due to patient involvement in quality improvement being not very formalised either in spaces or in the formal organization of the departments, they were largely project based, episodic, or informal. At one of the managers' seminars, I coincidentally made contact with a nurse who happened to be the manager of one of the disease-specific teams comprising the oncology department. I started following this nurse's local experimentation with using input from patients' sharing of experiences in an already running patient education forum to detect and act on quality-related problems voiced by the patients in their conversations. This brought me closer to the daily life of treatment and care and patient–professional interactions but not closer to patients in a formal role of being involved in quality improvement. The question of whether patients need to be aware of being involved in order for something to be called involvement surfaced. I saw a very short way from quality-related problems being indicated by patients to the problem being acted upon in the team. However, it did not make sense for me to ask the patients about their involvement since they did

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[1] I did not observe in person the meeting with the hospital management team – it was recorded for me to listen to due to me not being in the country on the day of the meeting.

not know about it. I continued to follow the nurse and the patient education sessions but still felt a need to “find” some explicitly involved *patients*. As a way of getting closer to this aspect of patient involvement, I got permission to participate in the ongoing patient panel in the oncology department. Here, again, I met a very different side of patient involvement in quality improvement – most notably one where *patients* together with professionals were working on quality improvement-related issues in a more permanent and formalised setup. Finally, I had arrived in a context that I could *easily* recognize as patient involvement in quality improvement. In the meetings, discussions, and the solving of specific tasks in the patient panel, questions of representation were evidently an issue concerning both the professionals and the patients in both explicit and subtle ways. The complexity and intricacies of this element of being a patient panel intrigued me – and it still does. Entering the patient panel widened my understanding of the two other kinds of patient involvement in quality improvement that I was still following and vice versa. The contrasting differences in scale, setup, methods, goals, roles possible for patients, and the specific work done gave me a more nuanced insight into the doings of patient involvement than if I had just stayed put in the patient-centred care model process that was my point of departure.

As in many other countries, patient involvement is on the political agenda in Danish healthcare – and thus is also on the table of the managers and healthcare professionals who are the ones to transpose this ideal into doings in the hospitals and other healthcare arenas. This thesis is about patients, healthcare professionals, and managers and the work they do to fulfil the policy call for involving patients in quality improvement in a medical centre comprised of four departments in a Danish university hospital, zooming in on the oncology department. In *Consuming Anthropology*, Suchman (2013) points to “a difference that matters between normative research enlisted in the service of agendas – public or private – in which the frame is not itself open to questions, and research that affiliates with efforts to question the frames within which politics, markets, or any other entities are disciplined” (p. 157). My interests and errand with this thesis is not how to get more or better patient involvement per se – what is to be explored in the coming pages is what the political imperative of patient involvement in quality improvement can become in its specific workings in a hospital department. In this thesis, I thus try to unravel some of the tensions of these endeavours by looking at the seemingly mundane work that professionals, patients, and managers do in the clinic when they involve patients in quality improvement work. By taking an ethnographic approach, it becomes possible to escape a narrow focus on patient involvement as the simple deployment of decontextualized and "innocent" methods used for "extracting" patient perspectives. The ethnographic approach taken makes other elements visible and discussable. Through my empirical anchoring in the three specific ways of involving patients in quality improvement – a patient panel, patient input "extracted" from patient education sessions, and a patient-centred care model implementation process – I came to observe the work and negotiations of patients (in many different guises), healthcare professional, and managers that go into organizing patient involvement in quality improvement work.

Delineations and a few words on terminology

Since patient involvement as a concept denotes a wide variety of practices going on in the clinic, a first delineation has been made between individual involvement and involvement on an organizational level. I delineate my study as one concerning involvement at the organizational level where patients are involved in different ways in the planning and development of healthcare. This thus excludes involvement activities focusing on individual patients and how they are involved in questions and decisions about treatment and care in their own course of treatment. Another dimension of delineation regards the grounding of the project in the somatic hospital – in this project, I thus do not treat patient involvement in areas such as mental health or in general practice. Having arrived at the hospital as the field and with activities aimed at involvement on an organizational level, a further delimitation is needed regarding the subject field. I ground my study empirically in activities related to involving patients in quality improvement and thus do not consider how patients are involved in research, in patient safety, or in policy development, to mention a few other possible areas of involvement on the organizational level.

The choice of wording has implications and here I will briefly mention some of the choices taken in this thesis. Regarding the wording in this thesis, I have chosen to use the term "patient" – even though user, consumer, customer, citizen, and public are words also used in the literature, since many conceptualizations of the phenomenon exist. With the exception of "user", these words all have connotations that are absent both in the empirical field and in discourses surrounding Danish healthcare, since neither the market-oriented consumer/customer aspect nor the democratic citizen/public aspect have been prominent in the field as arguments for involving patients in quality improvement. These discourses are somewhat part of the framing of the scene in policy and in the origin of some of the involvement methods; nevertheless, in this thesis, I use the term "patient" because, in the field, the persons who participated in the involvement activities were almost exclusively former or current patients in the departments studied. Moreover, the patient identity was an oft-used explicit criteria for selecting patients to participate in the involvement activities. The term "patient" places emphasis on what can be argued to be just one of many dimensions – and also the formally emphasized one - of the persons participating as patients in the involvement activities, and was not necessarily the only dimension drawn upon when involved in the specific activities, this is important to mention. Lastly, the term "involvement" has been chosen in order to denote the practices that have been central in the fieldwork due to the character of the involvement encountered – the involvement activities I have studied have been initiated, framed, and managed by the healthcare professionals and managers, however, occasionally leaving room for the patients to bring issues to the table. Terms such as participation, engagement, deliberation, and consultation could also have been chosen, but no strong democratic rationale for involvement (Martin, 2008b), that could have called for a wording using "public" and "deliberation", has been dominating in the activities and processes I have studied. In the medical centre and oncology department studied – and in Danish health policy – the technocratic rationale (Martin, 2008b) is most prominent. It builds the justification of involvement on patients having a special kind of input in the processes due to their experiences of having been through treatment and care processes in the hospital that make them able to contribute with a different kind of input that healthcare professionals cannot provide in the governance of healthcare. Moreover, involvement has the connotation of a patient being involved by someone and this resonates with the situation in the field, where the involvement of patients in quality related issues was initiated and managed by healthcare professionals and managers. It can duly be argued that the patients participating in the activities studied were not just passive objects of involvement but also involved the healthcare professionals in what it is like to be a person living a life heavily shaped by a cancer disease, but that is another discussion. Lastly, the term “patient involvement” resonates with the Danish term “patientinddragelse” that is widely used in the field. Thus, when I subsequently write “patient involvement”, the above-mentioned delineations are implicit in the wording.

The field, the problem, and the research question

In this section, I will introduce my research question and the analytical concepts and methodological approach I will take in order to answer it. Finally, I will present the structure of the thesis.

Why a thesis on patient involvement in quality improvement?

In society, involving users is on the agenda in many welfare sectors, not least healthcare. In healthcare policy, patient involvement has become an expectation for healthcare providers both with regard to patients’ involvement in their own treatment and care but also when it comes to quality improvement work. However, the strong policy ideal comes with very few specifications on how it is to be carried out locally. In hospitals, patient involvement in quality improvement has thus also become an expectation – quality work is no longer solely a local matter defined by healthcare professionals, quality is now also regulated (e.g., through performance indicators and standards (Zuiderent-Jerak & Berg, 2010; Timmermans & Berg, 2003). Moreover, patients are to be involved and their “perspective” taken into account in quality work. However, when considering Danish healthcare, how patients are to be involved in quality work – besides participating in and relating to the results from the annually occurring National Danish Survey of Patient Experiences – is largely left to the local managers to determine. Moreover, an implicit assumption is that the “patient perspective” can be found through the employment of methods. In the literature on patient involvement, the question of why this strong and seemingly straightforward ideal is not more readily accomplished is ascribed to, for example, problems with implementation (Coulter, 2011; Freil & Knudsen, 2009); problems of conceptual vagueness (Forbat, Hubbard, & Kearney, 2009; Fredriksson & Tritter, 2017; Tambuyzer, Pieters, & van Audenhove, 2011; Tritter 2009; Tritter & McCallum, 2006; Warsh, 2014); differences between patients’ and professionals’ values, commitments, perspectives, and understandings (Daykin et al., 2004; Fudge et al., 2008; Rise et al., 2013; Rutter et al., 2004). Moreover, the impact and evidence of patient and public involvement in the planning and development of healthcare are discussed as limited and hard to discern (Crawford et al., 2002; Groene & Sunol, 2015; Mockford et al., 2012; Nilsen et al., 2006).

I have a different interest namely that of enquiring into what the specific work involving patients in quality improvement entails, a largely undiscussed element in the literature. When entering the field, I entered the efforts and negotiations of healthcare professionals and managers trying to answer the taken-for-granted questions of what roles patients can take – and in what shape – and what relations they can be part of when being involved in quality improvement. However, at the same time, the "patient perspective" of patients as a general category was used as a self-evident term. This made me curious. Moreover, what I saw in the initial months of fieldwork was the work of healthcare professionals and managers establishing contexts and frames of the involvement activities, either through formalized models and methods or in more informal ways. This caught my attention and made me wonder why the work, efforts, and negotiations going into involving patients in quality improvement were not more explicitly addressed in the literature.

In order to explore the role of patient perspectives and the work of healthcare professionals and managers when patients are involved in quality improvement in the clinic, the following research question has guided the study:

> *How is patient involvement in quality improvement organized in the hospital? More specifically, how does it relate to the work of healthcare professionals, to patient perspectives, and how is it a part of managerial work in the clinic?*

These questions pertain to my curiosity about how the call for involving patients in quality improvement is accomplished through specific practices in the clinic and the work this entails. The first part of the research question concerns the work of healthcare professionals when involving patients in quality improvement. The second part of the research question concerns "the patient perspective" and how patient perspectives are accounted for and created when involving patients in quality improvement. The third part of the research question concerns the ways patient involvement in quality improvement is a part of managerial work. In order to answer the research question I have taken theoretical inspiration from sociology of work and ways of thinking prominent in science and technology studies (STS), where “work” has been a central object of study (e.g., Strauss et al., 1997/1985; Star, 1995a; Star & Strauss, 1999). The microsociological approach to work is inspired by Anselm Strauss and colleagues, who argue that work is an often neglected but highly relevant object of study in itself, not just a background: “its task sequences, its organization, its many variants and their conditions and consequences, its articulation, its evaluation processes” (Strauss et al., 1997/1985, p. 289). In this thesis, some of the different kinds of work going into the accomplishing patient involvement is explored and this approach allows for a deeper and more nuanced understanding of the phenomenon of patient involvement in quality improvement. The central analytical concepts in the articles comprising the analytical part of this thesis are: contexting (Asdal & Moser, 2012), the patient perspective (cf. Pols, 2005, Velpry, 2008), boundary work (Gieryn, 1999) and representation work (cf. Strauss et al, 1997/1985; Star, 1995b; Hacking, 1983). Contexting, the patient perspective, boundary work, and representation work are all analytical concepts that in different ways provide analytical sensitivity to discuss different but related elements of the work that goes into giving patient involvement in quality improvement its contours through specific practices in the clinic.

Empirically, this thesis is concerned with how patient involvement in quality improvement is done in a medical centre, zooming in on the oncology department of this medical centre in a Danish university hospital. An ethnographic approach was taken and the fieldwork carried out with varied intensity from 2012-2015 was anchored in three involvement activities in the medical centre and oncology department: a patient panel, a patient centred-care model implementation process and an informal patient feedback mechanism related to patient education sessions. Patient involvement has thus been studied as an organizational phenomenon which provides a broader perspective, where patient involvement is not only taken to be isolated activities taking place in the realm of formal patient involvement methods. By taking an ethnographic approach looking across more kinds, aspects and practices of patient involvement in quality improvement makes other elements than formal involvement methods come to the fore. In the analytical part of this thesis some of them will be explored. This thesis is written up in the article format. The first article provides a methodological discussion of how to study a phenomenon ethnographically that is neither an everyday activity in the clinic nor routinized. It also approaches the phenomenon of patient involvement with an emphasis on the healthcare professionals, and some of the work that establishing patient involvement as concrete activities entails. It is argued how involving patients in quality improvement work involves contexting (Asdal & Moser, 2012) work from the professionals, since the phenomenon is not routinized and does not have taken-for-granted or "naturalized" ways of doing it attached to it. The second article has the delicate interplay between issues of representation, authenticity, and situated tasks and concerns of involving patients in quality improvement work as its focal point. Through an analysis of interviews and observations from the specific setting of a patient panel, the article discusses a fundamental question surfacing when involving patients in quality improvement issues – how are some patients to speak on behalf of other patients and how is "the patient perspective" used in accounts and specific situations. The analysis points to how very different accounts on what the patients are to contribute surface both in the formal setup and in the doings of patient involvement in a patient panel and how this can be achieved. It adds to the existing literature by showing how form, tasks, interaction and situations also partake in shaping what a suitable patient perspective is, they are not pre-existing in especially well-selected patients, and broadens the question of patient perspectives and representation away from residing solely in patients. The third article discusses the managerial representation work entailed in involving patients in quality improvement. The article shows that producing patient representations found suitable for use in guiding interventions involves managerial representation work, boundary work, and articulation work in order to be accomplished – they are not given outcomes of involvement methods. My co-author and I explore two kinds of involvement methods: research-like methods where patients are represented as data and participatory methods where patients are represented by persons and show some of the dilemmas these methods entail. We point to how the process of going from patient representation to intervention can vary in length and complexity and that the aims of the impact of involvement can vary in concreteness. The article thus suggests two dimensions to be aware of when planning and performing patient involvement: the representational complexity and the goal of intervention.

The structure of the thesis

In order to answer the research questions, I have structured the thesis as follows. In Chapter 2, I explore the Danish healthcare policy landscape of patient involvement in quality improvement and how patient involvement and quality improvement became connected. This is followed by examining the literature on patient involvement, giving the literature on patients and representation, patient-professional relations, and involvement as a managerial concern specific attention. In Chapter 3, the theoretical positioning and analytical framework for the thesis is developed, and, in Chapter 4, methodological choices and reflections are presented and discussed. Chapter 5 comprises the analytical body of the thesis. It consists of a book chapter[2] and two articles that through different analytical means explore different but interrelated aspects of patient involvement in quality improvement and the specific kinds of work it entails. Finally, in Chapter 6, the findings and contributions of the thesis are discussed and concluded.

This is a book chapter published in ’Doing Organizational Ethnography’ Pedersen & Humle (Eds.)(2016) but for the sake of easy reading I term it “Article 1” when referring to it in the text.

CHAPTER 2. DANISH HEALTHCARE POLICY AND PATIENT INVOLVEMENT LITERATURE

Patient involvement in Danish healthcare policy

In order to relate the empirical phenomenon studied to the policy context in which it has at least one of its origins,[3] we now turn to the Danish policy landscape of patient involvement in quality improvement. The following examination of policy documents is included in the thesis because, when figuring in policy, patient involvement becomes a certain kind of expectation in healthcare – regardless of whether it is accepted and readily taken in, whether it is resisted and fought against, or whether it is something in the middle, as I will argue in the following. I have included central Danish healthcare policy documents from 1990 to 2016 on a national level with an eye to the regional level. I have read the documents with the intention of exploring how quality improvement and patient involvement became connected in policy. Before we turn to policy documents and the question of how patient involvement and quality improvement became connected, I will explore some of the characteristics of the *Danish* context of patient involvement in quality improvement.

The Danish context: A central distinction and the sparsity of formal structures

A common distinction used in the Danish healthcare field when speaking of user involvement in healthcare is the distinction between two dimensions: individual involvement and what can be translated as "organizational involvement". Individual patient involvement is conceptualized as ways of involving the patient in questions and decisions regarding her own treatment and care, while organizational involvement is described as involvement where patients or users are involved as representatives of "the user perspective" in quality improvement and in the organization, development and evaluation of healthcare (Freil & Knudsen, 2009; Danske Patienter, 2017a). Patient involvement in quality improvement is carried out through many different activities and methods with the goal of including patients in different ways and through different means in the development of healthcare. The fundamental idea is that through patient

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[3] It can duly be argued that patient involvement has had a long history in healthcare before it came to be a policy phenomenon; however, this discussion is beyond the scope of this chapter.

involvement, patients' inputs are represented, and when patients are included it will be possible to develop practices in the clinic so that they to a greater extent meet the patients' needs and wishes and thus improve quality for the patients.

Another characteristic of the Danish healthcare field is the very few formal structures, guidelines, or demands of how to involve patients in quality improvement locally in hospitals. An exception is the National Danish Survey of Patient Experiences, an annually recurring and obligatory survey for the hospitals/departments to be part of. The National Danish Survey of Patient Experiences is carried out by the regional Kompetencecenter for Patientoplevelser[4] (Centre for Patient Experience) and DEFACTUM on behalf of the Ministry of Health and the five Danish regions responsible for running the Danish hospitals. The questionnaire is sent out to 250,000 patients and consists of 40 questions addressing themes such as admission, course of treatment, staff, information, and overall impression of the stay in the department.[5] The aim of the survey is to identify and compare patients' experiences on different themes, provide input to use for quality improvement, and to track the development of patients' experiences and opinions in a systematic manner over time (Patientoplevelser, 2017). The National Danish Survey of Patient Experiences was included as an indicator in the Danish accreditation programme for healthcare providers, the Danish Healthcare Quality Programme (Den danske kvalitetsmodel [DDKM]),[6] and was expected to be used as a tool for quality improvement (IKAS, 2012, standard 1.2.11). Moreover, regional centres with specialised competences in patient involvement exist (e.g., Center for Kvalitet Region Syddanmark; DEFACTUM, Region Midtjylland; Kompetencecenter for Patientoplevelser, Region Hovedstaden) and ViBIS, a national knowledge centre for user involvement in healthcare was initiated in 2011 by Danske Patienter (Danish Patients), an umbrella organization of Danish patient and relatives' associations, and Trygfonden

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[4] At the time of initiating the PhD project, it was named Enheden for Brugerundersøgelser (Unit of Patient-Perceived Quality) but was renamed to Enhed for Evaluering og Brugerinddragelse (Center for Patient Experience and Evaluation) early in the process of fieldwork. In 2017, it was renamed to Kompetencecenter for Patientoplevelser (Center for Patient Experience). In this thesis, I use the name the unit had during the main part of fieldwork, Enhed for Evaluering og Brugerinddragelse (Center for Patient Experience and Evaluation) when writing about fieldwork and Kompetencecenter for Patientoplevelser (Center for Patient Experience) when writing about them in the present as in this chapter.

[5] The survey was changed in different ways during the duration of fieldwork; however, I will not go into the technical details of these changes. The categories mentioned here are from the 2012/2013 version of the survey in use at the time of fieldwork.

[6] The Danish Healthcare Quality Programme. This programme was abandoned in 2016 but was in place at the time of fieldwork.

(Danske Patienter, 2017b) whose objective is to build a knowledge base and carry out competency development with regards to user involvement. Furthermore, large national patient involvement conferences have been initiated by Danske Patienter, Sundhedsstyrelsen (Danish Health and Medicines Authority), ViBIS (National Knowledge Centre for User Involvement in Healthcare), Danske Regioner (Danish Regions), and KL (National Association of Municipalities) and have been held bi-annually since 2012.

Now, we will turn to Danish policy documents in order to explore how patient involvement and quality improvement became connected.

The policy context of patient involvement in quality improvement in Danish healthcare

The Danish law of health states that patients have a right to be involved in the minimal sense that no treatment can be initiated without the patient's acceptance. Moreover, the patient must be ensured information about their health status and possible treatments and about risks of complications and possible side effects of the treatment (Law of Health §15+16). In this sense, involvement seems to revolve around providing sufficient information for the patients to accept or reject the treatment offered. However, the patient involvement examined in Danish healthcare policy below concerns the involvement of patients not in questions and decisions concerning their own treatment and care but specifically patient involvement in more general questions concerning quality improvement in Danish hospitals. In Danish healthcare, quality improvement is no longer solely a local matter of concern for healthcare professionals. New actors (e.g., patients) are now expected to be involved, and, furthermore, new professional roles (e.g., quality coordinators) have been introduced in the process of making quality something externally regulated and largely standardized (e.g. through evidence-based clinical guidelines and quality standards and indicators; Albæk, 2009; Knudsen, Christiansen, & Hansen, 2008; Madsen, 2015). In the following, I will focus more narrowly on the development in policy regarding how the patient and quality improvement have become related.

In 1991, the Danish Society for Quality in Healthcare established as a forum concerned with issues of quality assurance and quality development by a cross-disciplinary group of healthcare professionals. In 1993, the Ministry of Health and the National Board of Health published "National strategi for kvalitetsudvikling i sundhedsvæsenet" (National Strategy for

Quality Development in Healthcare; Sundhedsstyrelsen & Sundhedsministeriet, 1993), a tool for working with quality improvement in healthcare. In this publication, it is recommended to involve patients and their families in quality improvement and in evaluating quality in health services:

> Involving the users' and patients' **needs, wishes and experiences** [emphasis added] in determining **goals and in evaluating the performance** [emphasis added] is an important part of quality improvement.... Since patient satisfaction surveys often are difficult to assess the development of suitable **methods** [emphasis added] is an important task (Sundhedsstyrelsen & Sundhedsministeriet, 1993, p. 14, translated from Danish by the author).

In this view, the patients are to be involved both in making the goals and in evaluating the practices. This strategy for quality improvement had an overall focus on it being driven locally and bottom up by committed healthcare professionals, which resulted in many local initiatives; however, these initiatives were not necessarily carried out in a goal-directed and systematic manner (Mainz et al., 2011, p. 27). Later, in 1999, Det Nationale Råd for Kvalitetsudvikling was established, resulting in national quality improvement initiatives, such as the national patient satisfaction survey (forerunner for the National Danish Survey of Patient Experiences) and the National Indicator Project (Mainz et al., 2011, p. 28), pointing towards a more formalized approach to quality improvement in Danish healthcare.

In 2002, a new strategy was published: "National strategi for kvalitetsudvikling i sundhedsvæsenet. Fælles mål og handleplan 2002-2006" (Det nationale råd for kvalitetsudvikling i sundhedsvæsenet, 2002). It is more specific about involvement related to quality improvement:

> Involvement should happen on all levels that is both in relation to the individual patient's treatment and care, in working with the **organizing of care and treatment pathways** [emphasis added] for groups of patients and in the more general planning of the health sector (2002, p. 18, translated from Danish by the author).

Here, both "organizing of care and treatment pathways" and "general planning" are added as areas where patients are to be involved, thus broadening the scope. This publication foreshadowed the establishment of the Danish Healthcare Quality Programme as a way of developing a systematic and coherent quality system based on documentation, quality improvement, and accreditation in Danish healthcare (Mainz et al., 2011, p. 28). In 2005, Institut for Kvalitet og Akkreditering i Sundhedsvæsenet was established to develop and implement the Danish Healthcare Quality Programme and manage the accreditations. In the first version of the Danish Healthcare Quality Programme (IKAS, 2009), patient involvement is mentioned as a distinct focus area – in the first version, patient involvement is primarily specified in relation to individual involvement, but in the second version it is part of the standards relating to organizational processes. This is a prominent change. The heading of one of the standards is: "Involvement of the citizens in quality development regarding the services of the hospital" (IKAS, 2012, p. 30, standard 1.1.7), and one of the indicators is that the hospital has a policy for involving citizens. Another standard's heading is: "Involving patients' and relatives' experiences" (IKAS, 2012, p. 44; standard 1.2.11), which has an indicator stating the need for a plan for how to ensure that patients' and relatives' experiences are used in quality development. The minimum requirement consists of two elements: 1) having a plan for how to involving patients and relatives in quality improvement and in the development of services and 2) participating in the National Danish Survey of Patient Experiences supplemented with not specified local initiatives – activities such as focus group interviews, dialogue forums are suggested as examples (IKAS, 2012, p. 44). This increased attention to patient involvement as more than a right to information can be seen as part of a movement from viewing quality work as something initiated and defined locally to something that needs to be worked with systematically on a national, regional, and local level (Mainz et al., 2011, pp. 27–28). This development can also be seen in regard to patient involvement, as it is increasingly incorporated as a separate theme in policies and strategies on a national, regional, and local centre level (e.g., Region H, 2008, 2010a, 2010b, 2012; Medical centre of the hospital studied, 2010). For instance, the Capital Region of Denmark has stated that patient empowerment (including patient involvement in their use) is about *culture and cultural change* (Region H, 2012, p. 6), also pointing to this change of focus.

Recently, professional competences and the role of management have been added as focus points in policy on patient involvement; for instance, managers are now highlighted as crucial in giving priority to involving patients and changing the culture (Ministeriet for Sundhed og Forebyggelse, 2014, p. 6) and citizens and patients are now described as playing central and natural roles in the planning and development of health services:

> The citizens must be taken into account as a natural part of decision-making processes on organizing, development and evaluation of health services. Their opinion and experiences must be actively part of the continuous improvement of health services (Ministeriet for Sundhed og Forebyggelse, 2014, p. 24).

User panels and reference groups are now explicitly mentioned together with patient-reported outcome data, user surveys, and satisfaction surveys as ways of making the citizens' voice heard, and the patients' perspective and feedback are referred to as a resource in the future work of improving quality (Ministeriet for Sundhed og Forebyggelse, 2014, p. 24). However, it comes with very few specific requirements or specifications.

In 2016, the government and the Danish Regions agreed to phase out the Danish Healthcare Quality Programme for public hospitals (Finansministeriet, 2015) and a new approach to quality work building on eight national quality targets has been proposed to replace it (Ministeriet for Sundhed og Forebyggelse, 2015; Sundheds- og ældreministeriet, KL, & Danske Regioner, 2016). In the National Quality Programme for Healthcare 2015–2018, the role of managers, competence development in patient involvement and the systematic use of data were highlighted as three central elements in realizing the new quality programme (Ministeriet for Sundhed og Forebyggelse, 2015, p. 2). This new programme is supposed to mark a shift in Danish healthcare from focusing on process demands and documentation in the old quality model to a focus on quality development through national targets that are to be translated into local targets and initiatives. The targets are to reflect the value, quality, and results created for the benefit of the patients (Sundheds- og ældreministeriet, KL, & Danske Regioner, 2016, pp. 3–4). In this shift, patient involvement has become a separate quality target – one of the eight – with two indicators attached to it: patient satisfaction and patient-experienced involvement that are to be measured via the National Danish Survey of Patient Experiences (Sundheds- og ældreministeriet, KL, & Danske Regioner, 2016, p.7). Moreover, shared decision-making is suggested as a central tool on the individual level (Ministeriet for Sundhed og Forebyggelse, 2015, p. 11). It can be argued that "satisfaction" is not necessarily very indicative of what level or kind of involvement has taken place but is instead indicative of the personal experience of satisfaction with whatever it covers for the individual. Moreover, experienced involvement is not necessarily indicative of involvement practices as such but again is more of the subjective experience of being involved or not. These are turning the focus of patient involvement in quality improvement towards the satisfaction and personal opinion of the patients and other kinds of patient-reported data to be used in quality improvement on an on-going basis with the point of departure in the patients' experiences (Ministeriet for Sundhed og Forebyggelse, 2015, p. 10). It can be argued that this suggests patients being involved as aggregated data to be handled by managers and healthcare professionals when it comes to quality improvement.

Summing up, the policy frame for involving patients in quality improvement has undergone quite some changes. Three periods can be fleshed out. First, the period 1991–2002, where the initial formalization of quality improvement as more than a local concern took place. However, quality improvement was still driven locally by engaged healthcare professionals experimenting with different initiatives in a non-standardized way. The second period, 2002–2015, is the period where the Danish Healthcare Quality Programme was planned and established. It added formalized requirements to processes and documentation. However, having a plan for how to involve patients in quality improvement and participating in the National Danish Survey of Patient Experiences were the only obligatory elements of involving patients in quality improvement. The departments were *encouraged* to supplement these obligatory elements with other ways of involving patients in quality improvement. Therefore, local experimentation with different ways of involving patients in quality improvement was highly dependent on local attitudes, the initiative of engaged professionals and managers. This resulted in a wide variation between departments and hospitals regarding the degree and character of the involvement activities initiated. Since 2015, there has been a shift with a move towards quality through targets, results, and data. Individual involvement is included in policy as an integrated element. Involvement in quality improvement is to happen through the use of patients' experiences as survey data and data on patient-reported outcome measures. This has widened the focus on data and measures and has lessened the formal focus on other ways of involving patients in quality improvement, which are still left to the be decided locally. However, it can be speculated that the shift towards measuring progress and benchmarking will influence what kinds of involvement tools and methods will be used locally.

The fieldwork grounding this thesis took place from 2012 to 2015 and was thus situated in a policy landscape where DDKM was in place and created certain expectations of involving patients in quality improvement - but quite a vague expectation of having a plan for involvement and of participating in the National Danish Survey of Patient Experiences (and the encouragement of supplementing it with unspecified local initiatives). Thus, a not very specific or action oriented expectation. Looking across the departments in the medical centre where the fieldwork for this study took place, it was apparent that what involving patients in quality improvement entailed in the different departments varied heavily: one department had quite a lot of experience with different methods and initiatives, another department had primarily worked with the National Danish Survey of Patient Experiences and an informal way of tuning in on the patients' experiences in the department through the head nurse's early morning rounds in the waiting room.

So, these policy documents are the broader policy framework and one of the many contexts for the patient involvement work going on locally in the hospital. I am of course fully aware that whether these policy documents are used and related to locally and in what ways clearly is an empirical question. Only on a very few occasions did I "meet" policy concerns during fieldwork, and so it appears that there are very few direct or explicit linkages between the policy landscape and the practices in the hospital studied. However, it is one of the larger frames for understanding the involvement activities going on in the clinic, and, moreover, these documents do place patient involvement in quality improvement as an explicit expectation to the hospitals, albeit an expectation with very few directions for action coupled to it. After having delved into how the phenomenon of involving patients in quality improvement is shaped in Danish policy, let us now turn to the literature.

Turning to the patient involvement literature

Patient involvement is part of a broader development where patients, users, consumers, and the public are increasingly expected to participate, be involved, co-create and be partners both in different arenas of the welfare state, in product development and in design and innovation processes, just to mention some areas. Thus, other related literature deals with a number of the same questions, such as the relation between users and technology and innovation (Hyysalo, Jensen, & Oudshoorn, 2016; Oudshoorn & Pinch, 2003) or between the "public" and public participation on a more general level (Barnes et al., 2003; Barnes et al., 2004; Felt & Fochler, 2010; Newman et al., 2004).

When turning to healthcare, we find elaborate discussions on patient and public involvement (PPI). Patient involvement usually refers to patients' involvement in their own treatment and care (e.g., in decision-making in the shape of shared decision-making; Charles et al., 1997; Coulter & Ellins, 2006). Public involvement usually refers to involvement in planning and the development of health services and policy (Crawford et al., 2002; Florin & Dixon, 2004). Theoretical discussions on the conceptual vagueness of the concepts and models of PPI and frameworks attempting to relieve this vagueness are suggested (e.g., Forbat, Hubbard, & Kearney, 2009; Fredriksson & Tritter, 2017; Tambuyzer, Pieters, & van Audenhove, 2011; Tritter, 2009; Tritter & McCallum, 2006; Warsh, 2014). Moreover, it is argued that the knowledge on the impact of involving patients in the planning and development of healthcare is vague partly due to the vague conceptualization and to the lack of reliable measurement tools (Crawford et al., 2002; Mockford et al., 2013; Nilsen et al., 2006).

Others discuss the rationales for participation found in the literature and in the policy base of PPI and point to the complex roles of publics found in policy that go beyond the technocratic and democratic rationales identified in the academic literature (Martin, 2008b, 2009). Furthermore, the different roles of patients and publics are explored based on wider analysis of the literature (McDermott & Pedersen, 2016; Degeling et al., 2015). Degeling et al. (2015) find three categories of publics related to deliberative methods: citizens, consumers, and advocates. Furthermore, they point to the inexplicitness of these roles and their constitution. In an editorial, McDermott and Pedersen (2016) develop five ideal types of patient positions based on the articles in the special issue. They couple what they call the individual's openness to engage and the opportunity afforded them from the organization to be engaged and develop the categories: invisible, inarticulate, induced, invited, and involved patients (McDermott & Pedersen, 2016, p. 4).

Another way of approaching patient involvement is to take an empirical point of departure. Existing empirical studies point to several specific themes and concerns of PPI. Of particular interest to this thesis are the following three themes, which reflect the analytical themes going through the thesis: 1) What is a patient and how do they come to represent others?, 2) The relation between patients and healthcare professionals, and, 3) involvement as a managerial concern.

What is a patient and how do they come to represent others?

The literature discussed in this section deals with the question of *who* to involve and on what grounds. In the existing literature on patient involvement, the theme of representation, representativeness, and the legitimacy and credibility of patient participants' knowledge, experience, and expertise are central concerns (van de Bovenkamp & Zuiderent-Jerak, 2015; El Enany et al., 2013; Maguire & Britten, 2017; Martin, 2008a, 2008b; Thompson et al., 2012).

Martin (2008a) explores how staff and users construct representativeness. He finds that professionals are concerned with the typicality of users with regard to interests of the wider public, while users point to their specific skills and experiences as the basis of their legitimacy. Martin (2008a, p. 1765) argues that the diverging constructions of and disputes over representativeness cannot simply be explained as struggles of power, as has been suggested, but also reflect ambiguous objectives at the policy level. Maguire and Britten (2017) explore the concept of representation and how it is used by patient/lay representatives. They find nine different conceptualizations provided by the patient participants themselves and point to this diversity as a reason for why representation can always be challenged, since all of these are never in place at the same time and can thus be used to question the legitimacy of an act of representation (Maguire & Britten, 2017, p. 68).

Others discuss the question of experience, expertise, and how they relate to credibility. Thompson et al. (2012) explore the question of experience and expertise of participants in health research settings. They find that participants highlight more forms of expertise – such as professional skills or training in relation to their involvement (e.g., on clinical trial methodologies) – than experiential expertise on which to build their credibility as participants in a cancer research setting. They also argue that these additional forms of expertise contribute to the professionalization of some of the participants. Professionalization is also discussed by El Enany et al. (2013), who couple professionalization and unrepresentative involvement. They argue that the professionalization of users is a relational phenomenon involving not only professionals but also the users themselves. They find self-selection/selection of articulate users with “expert” knowledge based on training, education, and previous managerial experiences to be part of the processes, leading to what they term unrepresentative involvement (El Enany et al., 2013, p. 29). Others point to professionalization as being not just about qualifying and adding credibility – it can paradoxically both be a way of gaining and losing credibility. Van de Bovenkamp and Zuiderent-Jerak (2015) explore patient participation in guideline development and why problems arise in these processes. They find that the professionalization of patients needed in order for them to gain credibility to participate in guideline development is also what comes to undermine their credibility to be representatives of “true” patients (Van de Bovenkamp & Zuiderent-Jerak, 2015, p. 9). These authors thus point to the complex and situational character of what patients are to contribute with in what involvement setting and that credibility is not static, it can be gained and lost as the processes develop.

Others go broader and add other dimensions to the question of who the patients/users/public are and what they draw on. Lehoux et al. (2012) explore the question of what a citizen is in the involvement of citizens in health policymaking. They show the complexity and richness of the individuals participating and how they drew on cultural, relational, and cognitive resources as well as their lived experience when participating. The authors therefore question the quest for the “ordinary” citizen and for representativeness altogether (Lehoux et al., 2012, p. 1849). Renedo and Marston (2015, p. 502) take into account how another contextual element, spatiality, is important in order to understand what participation means in practice and to escape the focus on individual skills or official structure for involvement. They point to the tactics of “plotting”, “transient combination”, and “interconnecting spaces” and argue that space is a central element in involvement practices because participatory spaces and citizenship are co-constituted (Renedo & Marston, 2015, pp. 500, 502). These studies share an interest in widening the room for understanding patient involvement in taking a bibliographical and ethnographic approach respectively. This makes them able to argue that citizens can never be “ordinary citizens” and to study processes and contextual elements, e.g., how spatiality is important and co-constitutes participatory citizenship.

In the discussions on representation, representativeness, credibility, and expertise, these studies retain a focus on representation and representativeness as something tightly coupled to persons in one way or the other. However, I will argue that the specificities of the tasks to be solved and the forms of patient input (e.g., the patient story, percentage figures from a survey or citations from interviews) also participate in shaping the representation taking place (see Article 2).

Let us now turn to studies dealing with the relation between patients and professionals and the relational aspect of patient involvement.

Patient-healthcare professional relations and professional work

Studies on different aspects of the relations between patients and professionals in patient involvement are many. Some studies explore the theme of the relation between the professionals and patients involved by focusing on elucidating *expectations*, *perspectives*, and *definitions* of the professionals and users (Daykin et al., 2004; Rise et al., 2013; Rutter et al., 2004). Rise et al. (2013) explore the service users' and service providers' own definitions of PPI. They find that users and providers share a common definition of PPI but ascribe different value to its components. Users valued respect through dialogue and providers found dialogue as a way to reach a good outcome. Others find conflicting perspectives and relate these to the question of power and control. Rutter et al. (2004) explore the expectations of staff and users in two mental health trusts. They find that the staff retained control over decision-making and wanted the uses to relate to their agendas. On the other hand, users wanted concrete changes to policies and services and to better conditions for users. Daykin et al. (2004) explore professionals' and users' perspectives on user involvement. They find professionals' responses to be partly connected to occupational standpoints and strategies and that these can be used to define and limit users' involvement. These studies thus share a focus on involvement as shaped by professionals' power to use their expectations, definitions, and perspectives to limit or control the influence of patients. Other studies point to professional control and power imbalances in the relation between professionals and patients in the involvement activities due to a hierarchy of knowledge (Fudge et al., 2008; Solbjør & Steinsbekk, 2011). Solbjør and Steinsbekk (2011) explore how healthcare professionals having voluntarily initiated user involvement negotiate user knowledge. They find that professionals valued access to user knowledge but ascribed it two main functions: as an alternative to professional knowledge, providing new viewpoints, or as support for professional knowledge. However, the professionals ultimately valued professional knowledge over user knowledge, thus maintaining a hierarchical relation. Fudge et al. (2008) explore how the policy of user involvement is interpreted in a programme of service improvement initiated to modernize stroke services. Among other things, they find that involvement was initiated and led by professionals and that the experiential knowledge of patients was seen as useful in some areas (e.g., of educating healthcare professionals) but was not sufficient to contribute to more technical areas (Fudge et al, 2008, p. 5).

Moreover, some studies take a different relational perspective that considers relations to be starting points in exploring the theme of patients as team members, being part of patient–professional partnerships, and involvement as a collaboration between patients and professionals (Martin & Finn, 2011; Pomey et al., 2015; Renedo et al., 2015). Martin and Finn (2011) explore five cases where users were included in teams responsible for managing and developing new services. They find that when creating teams consisting of both users and professional groups, users may lose the distinctiveness of the user role and their specific contribution in the processes (Martin & Finn, 2011, pp. 1063–1064). Renedo et al. (2015) explore how patients use specific elements of organizational culture as enabling resources for their involvement in quality improvement work. They place emphasis on non-hierarchical collaboration, mutual recognition and respect, commitment to rapid improvement and using improvement methods for constant data collection, and reflection processes to be enabling resources for participation that help patients collaborate with professionals (Renedo et al., 2015, p. 31).

Just as “the patient” as a category and the elements on which they build their involvement has been widened, as we saw in the previous section (e.g., by pointing to how patients use organizational resources in the involvement processes), I will argue that this category of the relations between patients and professionals also needs widening. What has not, to my knowledge, been considered is for example the *specific kinds of work* going into involvement processes, for example with regard to fleshing out the new kinds of relations between patients and professionals and in establishing contexts for the involvement work, which I will return to in Article 1. Moreover, how professionals are involved in shaping the patients’ contributions in specific situations and interactions e.g. through the selection of tasks and determining legitimate input forms, has also not been considered, this I will return to in Article 2. Let us now turn to studies concerned with the role of managers and management when involving patients in the planning and development of healthcare.

Involving patients: A managerial concern?

Studies concerned with the role of managers and management when involving patients in the planning and development of healthcare is scarce. When managers and management are considered in the broader literature on involving patients in planning, service development, quality improvement, and related areas, it is either as calls for the need for more research, e.g. El Enany et al. (2013) who point to the need for studying the processes of professionalization of patients both within and beyond managerially controlled spaces (2013, p. 30). Or it is by emphasize the importance of managers on a more general level and in a normative manner in pointing to their role in achieving a more strategic and/or successful implementation or adoption of the patient involvement agenda among staff (Armstrong et al., 2013; Coulter, 2012; Wiig et al., 2013). Armstrong et al. (2013) build on en ethnographic study of three cases of involving patients in quality improvement. They show the very different rationales for involving patients in three cases and the different roles for patients in the three cases. As an implication, the authors conclude that careful management is important in order for involvement in quality improvement work to reach its full potential (Armstrong et al., 2013, p. e46). Coulter (2012, p. 4) argues that a more strategic approach is needed in order to create a shift in beliefs, attitudes, and behaviours necessary in order for patient and public engagement to have an impact. On the basis of three NHS cases and two US-based studies, eight core elements of a successful change strategy are identified: strong, committed senior leadership; dedicated champions, active engagement of patients and families; clarity of goals; focus in the workforce; building staff capacity; adequate resourcing of care delivery redesign; performance measurement; and feedback (Coulter, 2012, p. 14). Lastly, Wiig et al. (2013) report from a case study on patient involvement covering macro, meso, and micro organizational levels in two Norwegian hospitals. They conclude that patient involvement has gained most prominence at the macro level, that tools for measuring it are lacking, and that available measures are not used (Wiig et al., 2013, p. 11). Furthermore, they stress the importance of managers in developing strategies to help the staff recognize the value and contribution of patient involvement and patient experiences for quality improvement (Wiig et al., 2013, p. 12). Thus, when managers and are mentioned it is mostly through a normative stance in pointing to the important role of managers for achieving more and better involvement, that seems to build on the assumption that managers themselves consider patient involvement a value and that it can be passed on to staff.

Only few studies take the relation between management and patient involvement as their central object of empirical study. Croft et al. (2016) are one exception, they foreground the role of managers in their study on managerial influence on public involvement in the area of healthcare commissioning. They argue that the variance in the implementation of the public involvement policy can be attributed to the role of managers more than professionals, as has previously been argued. Croft et al. (2016, pp. 131–132) argue that rational ideologies of managerial control have a negative impact on public involvement and that normative ideologies of control leave more room for enhancing public involvement. In addition, they argue that regardless of ideology of control, managerial domination is a reason why public involvement in service delivery is not more radically accomplished (Croft et al., 2016, p. 132).

These studies take managers and management to be either a kind of background element that can ensure better and more involvement or an element setting certain scenes for involvement through different kinds of control. However, they do not consider the more specific work of managers related to involving patients in quality improvement, for example of negotiating roles and relations, the work going into establishing frames for the involvement taking place or the work needed in order for involvement methods to provide patient representation found useful for guiding intervention, this I will return to in Article 3.

CHAPTER 3. THEORETICAL POSITIONING AND ANALYTICAL FRAMEWORK

In order to study the phenomenon of patient involvement in quality improvement, I have been inspired by two theoretical strands. Though they differ in their foci and conceptualizations, they unite around a set of principles regarding the understanding and exploration of social phenomena: 1) that a phenomenon is not essentially given but arises from the interaction of people, meaning, and materials in specific settings, 2) that a social phenomenon must thus be understood as contextually defined and varying across different contexts, and 3) that the role of the researcher is to study one (or more) of these contextual productions by describing and analysing the involved practices. These three principles are central to both microsociological approaches to the study of work and science and technology studies (STS) – the two strands of theory having been an inspiration for this thesis.

Sociology of work and the intertwinement with STS

The interest for this thesis has been to explore how patient involvement is carried out in the clinic – how this very normative yet very vague idea of patient involvement in quality improvement work is turned into concrete work practices and what the consequences are. Drawing theoretical inspiration from microsociological studies of work and STS is a fruitful approach to take in order to capture how this phenomenon becomes concretized through the relational work done by patients, professionals, managers, involvement methods and tools in specific situations in the clinic. In order to understand how work is not something self-evident and given or a static background for studying something else but is rather emerging and negotiated situated practices, I have taken inspiration from a microsociological interest in work practices going back to the Chicago School as a starting point for studying how patients are involved in quality improvement in the hospital. With its root in American pragmatism, the Chicago School was an inspiration for what came to be symbolic interactionism. It was coined as symbolic interactionism by Herbert Blumer (1969, p. 2), who puts forward three premises for symbolic interactionism: 1) humans relate to things (physical as well as psychological and social) on the basis of the meaning the thing has for them, 2) meaning is constantly created and recreated in human interaction, and 3) meaning on an individual level is filtered through processes of interpretation. Meaning is thus not something inherent in things or something that can be ascribed to individual motives, emotions, or attitudes or needs but something created in interaction in social definition processes. The relational, situational, and contextual nature of meaning making is thus brought to the fore and has a pragmatic approach to analysing the meaning of phenomena: meaning is a relational phenomenon that can only be determined situationally in relation to a specific context (Järvinen & Mik-Meyer, 2005, p. 10). More specifically, I take inspiration from the work of Howard Becker and Anselm Strauss who both build on symbolic interactionism and their attention to collective action and the events they produce (Becker, 1974, p. 775) and the detailed exploration of the specific kinds of work going into medical nursing care (Strauss et al., 1997/1985). Their interest in collective action and the detailed study of medical work has also come to inspire interactionist studies in STS. Anselm Strauss has been a coupling point between symbolic interactionism and STS as a core inspiration for Adele Clarke, Joan Fujimura, and Susan Leigh Star (Bossen & Lauritsen, 2007, p. 13). Central analytical concepts in this tradition are work and its social worlds. Strauss' concept of articulation work (Strauss et al., 1997/1985) is originally developed in relation to tasks and lines of work for an illness trajectory: "Both require 'coordination', for they do not automatically arrange themselves in proper sequences or with proper scheduling. In other words, further work – *articulation work* – must be done to assure that the staff's collective efforts add up to more than discrete and conflicting bits of accomplished work" (p. 151, emphasis in original). It has also been described as: "work that gets things back 'on track' in the face of the unexpected, and modifies action to accommodate unanticipated contingencies. *The important thing about articulation work is that it is invisible to rationalized models of work*" (Star 1991, p. 275, italics in original). Moreover, the concept of invisible work (Star, 1991; Star & Strauss, 1999) is closely related to this and gives attention to the relation between visible and invisible work. The authors consider varieties of visible and invisible work and how it comes to be visible/invisible by different means in different situations (Star & Strauss, 1999, p. 12). Related to the concept of work is the concept of social worlds (Strauss, 1978), which denotes a group of people organized around an activity or subject area of concern carried out in common by the members. Social worlds are dynamic, multiple, and can intersect with each other (Clarke, 1991, p. 131). Moreover, boundary object and negotiated order are core concepts in this line of thinking. A boundary object is an object – abstract or concrete – that makes work across different social worlds possible despite differences between them. Boundary objects denote those objects that inhabit more and intersecting social worlds. They are robust enough to maintain a common identity across sites and plastic enough to adapt to local needs (Star & Griesemer, 1989, p. 393). The concept of negotiated order points to the negotiation of meanings by members of a social world, for example membership through negotiating boundaries and distinctions (Clarke, 1991). The negotiated character of the phenomenon of patient involvement is central to my analysis of how patient involvement is also a managerial concern in the clinic. The negotiated character of what a patient is when inhabiting roles very different from the traditional patient undergoing treatment and care and what ways of knowing this patient that are legitimate are central in the managers' discussions on the topic. This interest in categorizations and standards, and in this thesis especially how new categorizations are negotiated and how, in a field so inhabited by standards as the medical field, involvement activities where no standards or guidelines for action are attached unfold in clinic. I have thus also been inspired by the hidden work that underpins the negotiation, creation, and articulation of classification and standards (Bowker & Star, 1999; Lampland & Star, 2009). These works illustrate how categorizations and standards both enable coordinated action and communication across social worlds but also enforce exclusion of something that is made marginal. In my material, the categorization and standards are less formalized and materialized than those usually studied in this tradition, but the negotiation and meaning making on what the category of "the patient" is when involved in quality improvement work and how to find the "right" way to "reach and know" the patients are all aspects relating to categorization processes.

Science, medicine, and knowledge are other core interests in this line of research (Casper & Berg, 1995; Clarke & Star, 2003). Clarke and Gerson (1990) point out how an interactionist approach to science studies, is built on four basic assumptions: "all scientific facts, findings and theories are socially constructed … knowledge represents and embodies work … science is best approached as a matter of work, organizations, and institutions … scientific work, institutions, and knowledge are not essentially different from other kinds" (pp. 181–182). The emphasis on knowledge as not essentially given, embedded in practices, and requiring socio-material tinkering to bring it about (e.g., Berg & Mol, 1998) is also at the core of the work of Jeannette Pols, and her work on patient perspectives and patient knowledge (Pols, 2005, 2013, 2014; Pols & Hoogsteyns, 2016) has been an inspiration for the second article of this thesis. Pols argues that "the patient perspective" is used as an analytical tool to present patients as knowing subjects in research, but she argues that "subjectivity is linked to situations and interactions, rather than just to individual characteristics; to 'patient positions,' rather than 'patient perspectives'" (Pols, 2005, p. 203). Moreover, she does away with patient knowledge being a certain kind of individual, embodied knowledge based on personal experiences of having lived through something. Instead, she argues that patient knowledge is a practical knowledge that patients use to make medical and technical knowledge useful to their daily lives with disease, not as something that is tied to particular subjects and their individual experiences. By turning to patient knowledge as a practical knowledge of turning medical and technical knowledge into something useful for patients in their daily life with disease, the techniques for doing so are made transferrable to other patients (Pols, 2013, 2014; Pols & Hoogsteyns, 2016).

Moreover, I have taken inspiration from the part of the STS literature addressing that I, with inspiration from Erving Goffman and the way his work has been taken up in STS, call "framing work". Goffman's notion was aiming to explain how people, in order to communicate meaningfully about a phenomenon or an event, adopt certain frameworks: "… indeed a primary framework is one that is seen as rendering what would otherwise be a meaningless aspect of the scene into something that is meaningful" (Goffman, 1974, p. 21). In STS, this idea has been taken up and developed to not only encompass meaning perspectives, cognitive frames, rules, etc. but also material objects such as scientific standards, devices, technology, and the like. The ambition has been to understand how the employment of particular procedures, norms, models, and techniques work to create certain frameworks, within which the phenomena in question are rendered meaningful and manageable. Specifically, I have been interested in the way in which "the patient" and "the patient perspective" through such frameworks (and the work of applying such frames) become constituted as a particular or given thing. More specifically, in the articles of this thesis, I focus upon three types of what can be termed "framing work": contexting, boundary work, and representation work.

Contexting

In an introduction to a special issue of *Science, Technology & Human Values*, Asdal and Moser (2012) use the concept of contexting to suggest "a turn to experiments in contexting. This implies that context is something scholars do, rather than something that is pregiven and passively lying out there, waiting to be discovered" (p. 303). This is related to a debate both in anthropology (e.g., see Dilley, 1999, 2002) and in STS on context and contextualization. However, instead of doing away with the concept of context as suggested by actor-network theory, Asdal and Moser argue for the importance of context despite its problematic history: "context is a troubled notion and straightforward contextualizing a problematic practice, but still something we cannot escape" (Asdal & Moser, 2012, p. 300). They continue:

> Contexting implies a series of moves. First, it acknowledges that the context cannot be seen simply as that which is passively lying "out there", waiting to be discovered. In contextualizing, one often implies that the issues and objects are separated and distinct from their surrounding context. But the point is to link them together in appropriate ways. The patterns will vary. Finally, contexting matters. It takes part in enacting versions of reality, of worlds in progress, and of making some possibilities more real and others less so (Asdal & Moser, 2012, p.303).

Asdal and Moser (2012) also point out that the discussion of context and contextualization is not new. Roy Dilley (1999, 2002) has taken up "the problem of context" in anthropology. He asks the question: "How have social and cultural anthropologists construed as relevant the contexts they deploy in their analyses?" (Dilley, 2002, pp. 440-441) and asks "how contexts might be construed by local social agents with respect to the definitions, negotiations and contestations of meaning within situated contextualizing practices" (p. 441). He continues: "Both analyst and local subject are, therefore, potentially caught in the act of contextualizing: the first in relation to the interpretive practices of an academic discipline; the second in relation to the practical and explanatory concerns of a form of social life" (Dilley, 2002, p. 441). Thus, Dilley (1999) stresses that researchers must have a "heightened sense of awareness about the articulations and connections that we ourselves make in the process of anthropological contextualization" (p. 38) and that this is crucial since "a frame implies a disjunction; it excludes as much as it includes" (p. 38). These ideas in both anthropology and STS on the role of contexts and the act of contexting came very much to my mind during observations and informal talks in the field, and I ended up using the concept of contexting for analysing the work and meaning making that the professionals involved in patient involvement do in order for the phenomenon of patient involvement in quality improvement work to become a doable endeavour. Another concept capable of capturing an element of work going into patient involvement is the concept of boundary work (Gieryn, 1999).

Boundary work

During fieldwork, especially in the managers' meetings, workshops and seminars, and in interviews with managers, issues of boundaries appeared repeatedly. Boundaries are a classical issue in social science: In anthropology, Barth (1969) has argued for not so much looking for the enclosed cultural content of ethnic groups but rather to turn attention to their boundaries and the processes in which these boundaries are maintained. In organization studies, Paulsen and Hernes (2003) argue for a renewed attention to boundaries since they are "intrinsic to the very process of organizing" (p. 11). In healthcare, the theme of boundaries has also gained attention (e.g., Vikkelsø & Kjær, 2008). Lamont and Molnár (2002, p. 177, 178) argue that research on professions and work has been influential in discussions of social and symbolic boundaries (e.g., between professions and other occupations and between experts and laymen). Thomas Gieryn (1999) has coined the concept of boundary work: "The discursive attribution of selected qualities to scientists, scientific methods, and scientific claims for the purpose of drawing a rhetorical boundary between science and some less authoritative residual 'non-science'" (pp. 4–5). He argues that boundary work "is strategic practical action. As such the borders and territories of science will be drawn to pursue immediate goals and interests of cultural cartographers, and to appeal to the goal and interests of audiences and stakeholders" (Gieryn, 1999, p. 23). In line with Gieryn, I am interested in boundary work, but I use the concept to understand the negotiations and meaning making going on in the clinical managers' talk when dealing with how and why to involve patients in quality improvement work and to reach a patient representation found suitable for guiding intervention. These negotiations seldom have an explicit strategic element to them, they are of a more explorative character, reflecting the un-routinized character of patient involvement in quality improvement in the field studied. Gieryn (1999) also points to some characteristics of settings where boundary work on science is done:

> Boundary-work would be expected in settings where tactic assumptions about the contents of science are forced to become explicit: where credibility is contested; where regnant assumptions about boundaries suddenly appear murky or inapplicable; and - most important - where allocations of epistemic authority are decided and consequentially deployed (p. 24).

The settings of the fieldwork especially centre council meetings, seminars, and priority setting workshops are all settings where some of the tacit assumptions about patients' – and their representations' – roles, tasks, and "use" have become explicit during fieldwork and made "natural" boundaries (e.g., between areas of expertise of patients and professionals), relational boundaries, and boundaries between representations and interventions murky.

Representation work

Early on in the process of fieldwork, I was intrigued by the relation between the general notion of "the patient", the professionals' and managers' needs for ways of knowing "the patient" as an abstract category, and the many ways this issue appeared in different situations. In different ways, this interest is at the core of the three articles in this thesis, but different aspects of the question are brought to the fore in each of the articles and through different analytical means, which we will return to later. Now, let us turn to the question of representation and the work it entails.

While representation can be framed as having three dimensions: formal (election, random selection, designation), descriptive (in relation to an "average"), and symbolic (subject perceptions on the origins of consent and legitimacy) (Pitkin, 1967, as cited in Contandriopoulos, 2004), in STS, representation and representing are seen as situated socio-material practices at the heart of scientific work. Representation is thus a central concern in STS, originating in the seminal interests in scientific practices in the laboratory (Latour & Woolgar, 1979) among them, the pragmatic practices of shaping different raw materials into what sometimes come to be scientific facts. Of central concern in this line of work is the interactional and interpretive work going into establishing representations and the technologies, instruments, and devices used for creating visualizations and other representational objects (Coopmans, Vertesi, Lynch, & Woolgar, 2014; Lynch & Woolgar, 1990). In their edited volume, Lynch and Woolgar (1990) focus on representational practices and devise in science, and they argue that no objects are free from representation: “representations and objects are inextricably interconnected; that objects can only be “known” through representation” (p. 13). Moreover, Star (e.g., 1995b; Bowker & Star, 1999) and Hacking (2006) have both in different ways dealt with questions of representation. Aside from his seminal 1983 book *Representing and Intervening*, Hacking (2006) also argues how categorizations also enact what they purportedly innocently represent and “make up people”. Star (1995b) considers the work of “abstracting (removing specific properties), quantifying, making hierarchies, classifying and standardizing, and simplifying” (p. 90) going into creating formal representations and the tension between formal representations and their adaption back to into specific work settings (Star, 1995b, p. 92). The work going into creating formal representations is often invisible and always “valorizes some point of view and silences other” (Bowker & Star, 1999, p. 5).

In his review of two edited volumes on scientific representation and visualization in the STS tradition, Hoeppe (2015, p. 1077) argues for employing what has been learnt about representation in studies of laboratory and expert settings in STS in order to make sense of practices beyond the laboratory (e.g., in contested political, social, and ecological environments). I view the clinic as an environment where representation is an important activity, not just in the scientific cancer research environment but also – albeit in less explicitly material ways – in the different practices of involving patients in quality improvement work. When involving patients in quality improvement activities in the oncology department, no new digital scanning technologies, complex visualization techniques, advanced laboratory equipment, or computer simulations were involved; in fact, the field was only inhabited by “old” technologies such as paper, talking, and involvement methods – film projectors and PowerPoint presentations at the most. However, ideas and practices of representation were very present, e.g. as practical dilemmas of how some patients could represent other patients when participating in involvement activities relating to quality improvement.

With inspiration from Strauss et al. (1997/1985) and their discussion of different kinds of work involved in medical nursing care and the focus in STS on the work, negotiations, and efforts going into making representations (e.g., Bowker & Star, 1999; Hacking, 1983, 2006; Lampland & Star, 2009; Star, 1995b), I use the concept of “representation work” to denote the specific work going into negotiating, sorting out, and deciding whether patients should be involved, what they should be involved in, who is to be involved, and how and what representations can be used for ‘intervening’ in existing practices. The concept of “representation work” puts emphasis on how the work of creating and using patient representations that comes in a plethora of shapes is not necessarily straightforward. However, this is a not particularly articulated aspect of the managerial work going into involving patients in quality improvement. It will be argued, that representation work is a core element of managerial and professional work when involving patients in quality improvement activities.

In the second article of this thesis, representation work can be argued to be the greater frame that tunes in on the empirical concept of “the patient perspective” and how it is used in the field. I draw on Velpry (2008), Pols (2005), and Rowland et al. (2017) and their respective discussions of some of the problems of talking about an individual patient perspective as something existing in a patient waiting to be elicited. I point to the many accounts of the patient perspective and their hinging on diverse representation mechanism and argue that “the patient perspective” as something supposed to represent patients as a general category are shaped in interaction between patients and healthcare professionals in specific situations in relation to specific tasks, they are not found in especially representative patients. Moreover, the form and situation matters – what in some situations are taken to be a suitable patient perspective by the healthcare professionals can in other situations be deemed unsuitable. In the third article of this thesis, the concept of representation work is used to put emphasis on the way patient involvement involves numerous considerations and efforts to represent ‘the patient’ and his or her ‘knowledge’ to be used in quality improvement. This sometimes involves chains of patient representations before it can be accomplished and thus points to the concern that formal or informal involvement methods do not necessarily and effortlessly produce readily usable patient representations and blueprints for action, it requires a lot of managerial negotiation and representation work.

CHAPTER 4. METHODOLOGY

In this chapter, the ethnographic approach, the fieldwork setting, and the empirical anchoring points are presented. In order to give a sense of the process or the meetings central to the specific anchoring points, an empirical description based on fieldnotes introduces each of the three sections on the anchoring points. This is followed by an account of the methods used, the data produced, and the analytical process. Lastly, considerations on access, positioning, ethics, and other fieldwork-related issues are given.

The contours of an ethnographic approach

Before introducing the organizational setting and the three empirical anchoring points in detail, let us first briefly turn to the discussion presented in Article 1 on what organizational ethnography becomes when the phenomenon studied is non-routinized and often episodic in character. In Article 1, I discuss some of the complexities involved in localizing the phenomenon of patient involvement in quality improvement in specific practices in the field. I point to the trope of the everyday in organizational ethnography and discuss the problems encountered when studying a non-routinized, episodic, and non-everyday organizational phenomenon. This will be discussed further in Article 1, but here I will briefly present my ethnographic approach to studying patient involvement in quality improvement.

The fieldwork that this thesis is based on did not draw on a classical ethnographic approach for studying organizations and organizational phenomena based on being present for an extended time in the spatially bounded everyday life of an organization (Ybema et al., 2009). Instead, it has been more in line with a different approach to studying organizational phenomena ethnographically, focusing on organizing as polyphonic, emerging, and processual (Pedersen & Humle, 2016, p. 2). The approach is thus more in line with the fieldwork technique of shadowing (Czarniawska, 2007, 2008), where the shadowed entity is not persons or objects but a phenomenon enacted in specific practices and processes, or with Mol's (2002) praxiography, placing emphasis on following the practices in which a phenomenon is enacted in different situations. I do not purport that patient involvement is one thing and that it is surprising that it is not when studied ethnographically – I just want to point to the approach taken of trying to locate practices of involving patients in quality improvement that could not be done by being in a specific place, by following specific persons (since no category of healthcare professionals with patient involvement in quality improvement as their primary work task existed), or by following particular objects. Furthermore, it was not so easy to locate the activities, since they did not appear in the formal setup of the centre or department, and it did not have formalised functions but was instead episodic in the sense of taking place e.g. as a one-off feedback meeting in one of the teams of the oncology department or episodic in the sense of not occurring very frequently, as was the case for the meetings in the patient panel. Or, that these activities were hard to find due to their informal character (e.g., the feedback-use from patient education sessions that I "found" by accident by getting acquainted with a head of teams nurse by sitting next to her in one of the workshops in the patient-centred care model process). My initial entry was in the encompassing patient-centred care model implementation process that, despite its more formal character, ended up being hard to follow due to the extensive process happening on many different levels of the medical centre (comprised of four departments and a research laboratory each organized in teams, see Figure 1, below) at the same time. I ended up using the oncology department and the processes there as my anchoring, also in the study of the patient-centred care model process in order to be located somewhere, for example, for guiding my mundane but nevertheless important choices such as which of the many meeting tables to sit at or which group discussion to follow at seminars and workshops where both managers and middle managers from the four departments were present. Let us now turn to the empirical setting and the anchoring points in fieldwork.

Organizational setting and anchoring points in fieldwork

The hospital where the fieldwork took place is a university hospital organized in departments clustered in centres (see Figure 1, below). One of these centres was the starting point for this study. It is a medical centre consisting of four clinical departments and a research laboratory:[7] a haematology department, an oncology department, a department of infectious diseases and rheumatology,[8] a department of radiotherapy, and a cancer research laboratory. Each of the four

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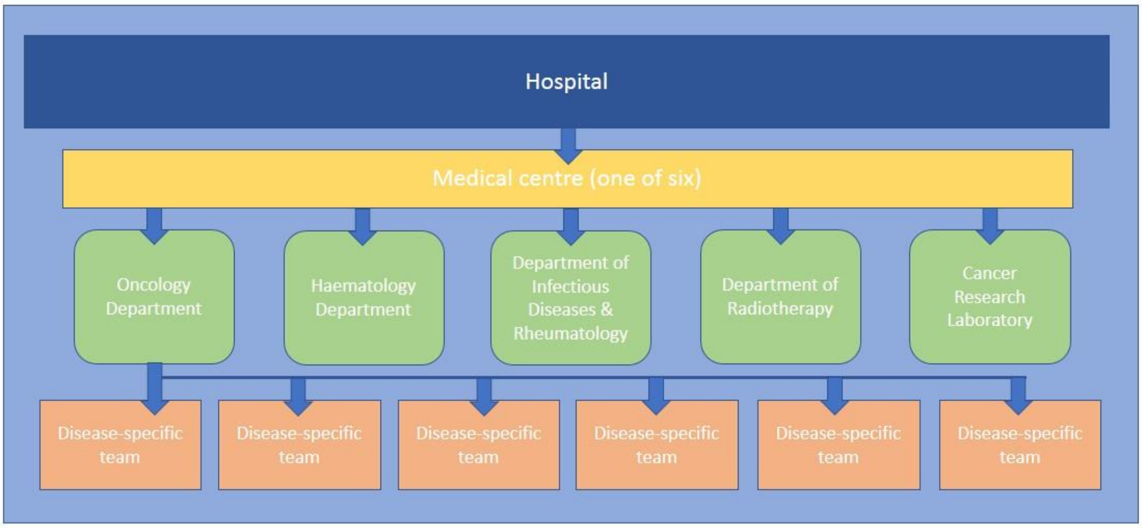
[7] During fieldwork, the oncology and radiotherapy departments were merged.

[8] The rheumatology unit was moved from the department and merged with another department at a late point in fieldwork (1 April 2015).

clinical departments[9] is managed by a head of department and a head nurse, and each of the departments are furthermore divided into units with their own local management.

The oncology department is managed by a head of department and a head nurse and consists of six diagnosis-based teams and four units going across the department: a radiotherapy unit, a palliative unit, a phase 1 unit (experimental cancer treatment), and a clinical research unit. Every year, the department receives approximately 4,000 new patients, has approximately 52,000 visits in the outpatient clinics, and performs approximately 53,000 radiotherapy treatments. Approximately 100 doctors, 300 nurses, and 100 administrative/technical/service staff are employed.[10]

Figure 1. Hospital organization



The formal quality work in the department is organized around a quality council with representatives from each team in the department, the management team of the department, a development nurse working across the teams in the department, the quality coordinator,[11] and the head medical secretary. The issues discussed here were, for example, issues related to the

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[9] During the primary fieldwork period, the centre consisted of four clinical departments, so for the sake of clarity, I will refer to the centre as consisting of four departments.

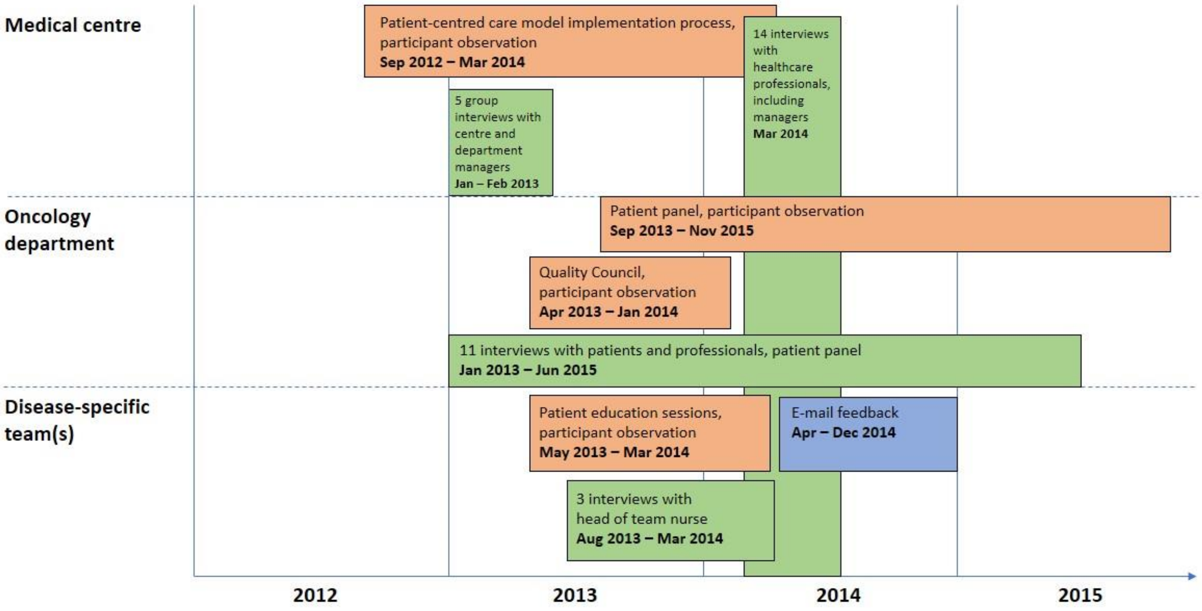
[10] Information from department homepage (19 May 2016).

[11] Who was responsible for more formal quality work (e.g., relating to accreditation, and the work in quality council at the hospital level).

implementation of early warning score in the department, discussing specific unintended incidents reported, working on reducing and informing about waiting time, discussing when there are indications of a need for using x-ray inspection in order to check the placing of feeding tubes, the implementation of a new national rehabilitation programme, and related issues. Furthermore, quality issues and projects are worked with locally in the teams on a department level and also sometimes on a centre level across departments depending on the character of the quality issue in question. The hospital where the fieldwork took place was, at the time of initiating fieldwork, not one with a reputation for being at the forefront when it comes to involving patients in quality improvement. This was mirrored in a meeting between the centre management team and the hospital management team before embarking on the encompassing patient-centred care project. The hospital management team aired a positive attitude towards the project due to several reasons, but partly because the project could meet the requirements from the region regarding user involvement and patient empowerment, issues that were not part of the hospital management's planned strategic initiatives for the coming years.

Let us now turn to the three anchoring points in the fieldwork conducted. The road to the three anchoring points has been described in the introduction to this thesis and to this chapter. For a fieldwork flow chart, see Figure 2, below and for an overview of data, see Table 1, below.

Figure 2. Fieldwork flow chart



	Interviews *Total of 33 hours; 33 interviews*		**Observations** *Total of 230 hours*	**Documents**
Patient-centred care model implementation process	5 group interviews with management teams of the departments and the management team of the medical centre	14 interviews with healthcare professionals/ managers with experience with involving patients in quality improvement*	**120 hours participant observation distributed across 42 occasions**	Agendas, minutes and meeting material related to the patient-centred care model implementation process
Patient panel oncology department	11 interviews in total with patients (7) and healthcare professionals (4) participating in the patient panel		**18 meetings in total, approx. 30 hours in total:** Patient panel meetings (incl. patients' pre-meetings), *8 meetings of 2,5 hours, 20 hours* Pre-meetings healthcare professionals, *6 meetings of 30-60 minutes, approx. 4 hours* Other meetings related to the patient panel, *4 meetings of 60-180 minutes, 7 hours*	Agendas, minutes and meeting material related to the patient panel Activities in the Facebook-group of the patients in the patient panel Email correspondence relating to the patient panel
Patient education sessions in disease-specific team	3 interviews head of team nurse		**7 meetings of 2 hours, 14 hours:** Patient education sessions, *7 meetings of 2 hours, 14 hours* Evaluation meeting, *2 hours* Out-patient clinic, *5 days, 37 hours* Informal meetings with the head of unit nurse, *10 hours*	Email feedback from teacher to head of team nurse after patient education sessions
Quality council meetings in the oncology department			**11 meetings of 1,5 hours, 16,5 hours**	Agendas, minutes and meeting material quality council meetings

* Hereof three interviews with healthcare professionals also participating in the patient panel – therefore the number of individual interviews with professionals in the patient panel is set to six in Article 1.

Patient-centred care model implementation

The patient-centred care model is quite a venture for the centre. The decision to take on the model, taken by the centre council (the centre management team and the management teams of the departments comprising the medical centre) at a study visit to a Dutch hospital working with the same model, needs to be presented to and approved by both the hospital management team and the head of the regional council before it can be initiated. The management team of the medical centre is dedicated to the project; they are preoccupied with the model because it is a way of working with patient involvement in a systematic way. The systematic element is important, since evidence for the effects of patient involvement is lacking; to do patient involvement in a systematic manner is the second-best option in the eyes of the management team, and this is why they find this particular model suitable. The systematic element also gets to be one of the three overall goals of the project, that is, systematically involving patients whenever relevant; the other two being heightened patient satisfaction and heightened employee satisfaction. The management teams of the departments comprising the centre are not equally unanimously enthusiastic about the project, so both enthusiasm and scepticism characterizes the first part of the process.

The patient-centred care model process is a regular item on the agenda of the bi-weekly centre council meetings. A number of different seminars are held during the first year of the process in order to prepare both the department management teams and the middle managers (managers [nurses and doctors] of each of the teams of each department). The initial management seminars held by an American consultant together with consultants from the regional centre become a point of discussion – some of the middle managers are furious that they have spent a whole day away from patients in order to participate, while others are eager to get on with implementing the model in their team or department. During the first year of the process, a comprehensive organizational analysis is undertaken by consultants from the Centre for Patient Experience and Evaluation, a prioritizing seminar is held where areas of priority in the departments and teams are discussed and related to the patient-centred care model process, and a strategy seminar for the centre council is used to make decisions about the focus area of the process. The question of when patients are to be involved more directly in the process is again *raised by one of the head nurses. Halfway in the three-year process a user panel is set up to be part of the work to further the process of getting the selected focus areas – focusing on the reception of patients and making them feel comfortable and on bettering the physical environment – to result in specific changes.*

One of the anchoring points in the fieldwork was the first half of a 3-year process of implementing a patient-centred care model in the medical centre. This process was studied from September 2012 to March 2014[12]. During this period of time, I participated in different kinds of meetings, workshops, and seminars relating to the implementation process and also observed some of the group interviews grounding the organizational analysis (see Appendix B for a list of meetings, seminars and other activities related to the process that I have participated in). The meetings took place both on a centre level and these usually involved the management team of the centre, the department managers and few others, thus app. 15-20 persons. Other meetings and seminars involved both the centre council and the middle managers from the departments. These activities thus involved app. 40 managers depending on the level of absence. A few meetings involved also staff in different ways and was for example organized as open meetings with a limited attendance (seen in relation to the potentially hundreds of people possibly showing up) or took place locally in the departments or was organized to involve the staff committee. Now, a few words on the model. The model stems from an American organization who have developed a model that aims to improve treatment and care by making it more patient- and family-centred and works on the fundamental premise that treatment and care should be organized around the need of the individual patient. In the model, organizational changes are central in order to create an environment where patients can be active participants in their own treatment and care and where the well-being of the staff is also taken into account. The model has 10 components that are considered to be important for how healthcare can become patient-centred, and these components are built on values relating to this. The components, adjusted slightly to fit a Danish context, are: patient-centred organization, respect and choice, information and education of patients, involving

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[12] In addition, I also participated in a seminar planning meeting and a one-day seminar on the experiences with involving patients in quality improvement taking place in the autumn of 2014 – this was included due to the centrality of the theme for this study and because patients were also involved in the planning and as participants in a panel debate in the seminar. The process continued until 2015.

relatives, food and nutrition, architecture and interior design, activities and recreation, spirituality and room for diversity, supplementary treatment and wellbeing, and interacting with the local community. A core element in the first part of the project was an extensive organizational analysis based on a large number of group interviews (43 in total, hereof 22 with patients and relatives and 21 with staff – in total covering 243 persons), and the results from this organizational analysis were used to inform decisions on which change-processes to initiate in the medical centre and departments. Consultants from the Center for Patient Experience and Evaluation, Capital Region of Denmark, have assisted in the process in the medical centre (e.g., in performing the organizational analysis, in education employees and managers, and in planning workshops and seminars). The medical centre has had the overall aims of strengthening the patient-centred culture and of finding new ways of involving patients and relatives in different ways in the centre. In the app. 1½ years I studied the process, the decision to embark on the project and getting started dominated the first half a year. The next half a year had the organizational analysis and the processes of selecting focus areas as the main constituent. The last half a year I studied the process had initiating specific changes on more organizational levels as the centre of attention. For example both setting up a patient panel on a centre level and spurring local engagement and change processes in the departments and teams. During the time I studied the process, patients were involved in different ways: as abstract figures in the many discussions and negotiations in the centre council, as sources of input through interviews in the organizational analysis, and as the resulting interview data. In the user panel that is set up late in the process patients also participated more directly with the staff on issues relating to developing the processes. Also the managers had shifting involvement roles, they were negotiators, initiators, decision makers on the basis of patient data, and some were also interacting in a specific manner with patients on issues to be developed.

The initial management seminars in the patient-centred care model implementation process acquainted me with a head of team nurse from one of the disease-specific teams in the oncology department, a nurse who was experimenting with involving patients in quality-related issues in her team. Her willingness to let me in, and her interest in and experimenting with the phenomenon I was interested in studying, made her team another anchoring point in my fieldwork.

Patient education sessions on late effects of cancer treatment

I meet the nurse and the patients participating in the patient education session in the hallway in the bed unit. The patients are called from the waiting room by the nurse participating in today's session and they flock around her in the hallway. Some of them have brought a relative, some are there alone, still others clearly know some of the other patients present and, from their conversations and their friendly way of patting each other on the back, I quickly learn that they know each other from their treatment in the team or they might even have shared a ward while being hospitalized. I follow the nurse and the patients to the elevators in the hallway and we go to the seventh floor. The meetings take place in the doctors' medical conference room, and the teacher is not wearing a white coat. The room is large, with a big table in the centre and room for 20 persons or so, and at the edge of the room smaller table-and-chair arrangements are placed. I place myself at one of the smaller tables, the patients take their seats around the big table. The teacher is standing at the head of the table with a flip chart beside her.

The session starts with a round of names, diagnoses, when they finished treatment, and what challenges the participants face in terms of late effects of treatment and psychosocial issues. The participants take turns, telling diverse stories of their way through cancer treatment and how it has changed their everyday lives. The teacher takes the problems presented in the round as points of departure for the session on late effects of cancer treatment in order to make the sessions as useful and as relevant as possible for the participants. Henning points to the dilemma of his wife having also been a kind of nurse for him during the months of treatment and how difficult it is to get back to the everyday life they had before the cancer disease. Anne has experiences of problems with getting the necessary rehabilitation with regard to lymph drainage; from the discussion that this point raises, it is evident that the referral practices and possibilities are not uniform for the patients. Mouth dryness is a topic heavily discussed; advice and experiences are exchanged and gum and tiny pocket-sized water spray bottles passed across the table for how to best get through the day or the night. During the session, the teacher notes important points touched upon on the flip chart in order to follow up on them. A short interview film made by the Danish Cancer Society is also shown at every session. In the film, a former cancer patient is telling his story about his journey through diagnosis, treatment, and the impact *cancer has had on him and his everyday life. The film typically gives rise to dialogue on the participants' personal experiences and reflections and breeds the exchange of experiences. Two hours are spent discussing the issues brought to the table together with certain obligatory issues brought up by the teacher if they are not touched upon by the participants. Afterwards, notes are sent to the head of team nurse who discusses relevant points with the chief physician of the team and, if found to be relevant, with the employees, collaborating teams in the hospital, or relevant actors outside the hospital in order to act on the problems surfacing in the patients' conversations.*

The head of team nurse I got acquainted with during the patient-centred care model process was the manager of a disease-specific team in the oncology department. In this team, two patient education sessions were offered to the patients. The first session was obligatory as a part of the "cancer package" – the second session, on late effects of cancer treatment and life after cancer, was optional to patients and took place after they had finished their cancer treatment. The head of team nurse used the sessions on the late effects of cancer treatment and life after cancer for catching quality related problems and issues surfacing during patients' conversations and exchange of experiences during the sessions. Issues were noticed by the teacher who relayed them to the head of team nurse, who in turn discussed relevant issues with staff (e.g., how the feeding tube was presented as an option to the patients by the staff) or attended to concrete problems pointed to by the patients (e.g., problems with getting appropriate reimbursement in connection with frequent dental care after cancer treatment due to unclear communication). The patient education sessions with an incorporated patient feedback mechanism took place once a month, lasted two hours, had between four and ten patients participating and were studied from May 2013 to March 2014.[13]

The above fieldnote-based example of a patient education session points to different kinds of roles for patients and professionals with regard to providing inputs to quality improvement – the unknowing/unaware patients whose inputs have a short distance to travel to reach the head of

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[13] I also received the email correspondence between the head of team nurse and the nurse heading the patient education sessions regarding the feedback from the patients in the remaining months of 2014, since I was not able to attend the meetings due to maternity leave from April 2014 to March 2015. After maternity leave, I discussed the actions taken on the patient feedback with the managing nurse in informal meetings.

team nurse who can take action on it. This raises a core question of involvement: whether the patients' experience of being involved or the use of patient input to improve quality is put in the forefront.

One year into the fieldwork,[14] I gained access to and started observing the meetings of a patient panel[15] already in place in the oncology department in order to localize the fieldwork more closely to the doings of patient involvement where patients were involved in a more active and direct manner than in the other processes studied.

The patient panel

In the doctors' medical conference room, Janet and Anne are seated around the large oval table, ready for the pre-meeting to begin. They chat in an informal tone with each other, "how was your summer?" Janet asks, and Anne talks about her sailing trip together with her husband. I enter the room and the two women greet me in a welcoming way with smiles and a hand gesture signalling "please have a seat". I sit down at the table with them and join the conversation with ease. After a few minutes, the coordinator from the Danish Cancer Society, who facilitates the patients' pre-meetings, arrives together with two more participants, Frank and Amy. On the agenda for the patient panel meeting of the day is three issues: follow-up on issues from the last meeting (i.a., letter boxes for feedback postcards from patients; patient whiteboards and circadian rhythm of the unit scheme; news from patient-centred care model implementation process), presentation from the patient participants on their participation in the monthly introductory programme for new employees in the clinic, discussion of the possibility of using patients in the diagnosis-specific patient education sessions that the department is obliged to offer in all the diagnosis-based teams in the near future. The pre-meeting is formally initiated with a round of introduction since a new member, Amy, is participating for the first time today. She begins by introducing herself, the course of her disease, professional background, and family. Furthermore, she explains that she has chosen to participate in the patient panel because

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[14] I had tried to gain access in the beginning of the fieldwork, but it took some time to get to know the professionals (e.g., through interviews and meeting some of them in the patient-centred care model process) and of in other ways anchoring the fieldwork in the oncology department before I was let in. However, when I was let in, I was met with a very inclusive attitude by both patients and professionals.

[15] The forum was called a "user panel" at the onset of the study but was later renamed "patient panel" because only patients – not relatives – were participating. I will use the term "patient panel" throughout this thesis.

she wants to contribute with her experiences of being a cancer patient because she hopes that future patients can gain from them. The other participants introduce themselves to Amy, talking about the course of disease, professional background, and family. They go on to talk about the issues on the agenda and start by discussing their input to the presentation they are to make at the introductory programme for new employees in the department. They discuss whether the presentation is supposed to be aligned with that of the professionals preceding it or whether they are to present "what we bring as patients", regardless of what the professionals have in their presentation. They discuss elements to go into the presentation – empathy and continuity of doctors and nurses in the course of treatment are chosen as two key aspects. Time is running out and the patients agree to comment on the patient education issue individually in the meeting: "we are allowed to have our individual opinion," Janet says and laughs.

The professionals enter the room and take their seats at the table; it is time for the patient panel meeting to begin. The nurse who is heading the patient panel introduces Amy and a new doctor who is going to participate in the panel to the rest of the participants. Another round of presentations is undertaken and the statuses of follow-up issues from the previous meeting are presented by the professionals (e.g., the status of the boxes for feedback postcards to be introduced in the units where the intention is that the patient panel will be involved in discussing the feedback coming in from other patients). The professionals also relay the status of the patient boards that are to be hung by the beds in the wards with information on the plan for the day, associated nurse and doctor, and more. They go on to discuss the presentation that the patients have prepared and the respective role of the professionals' and patients' presentations. The last point on the agenda is the discussion of the use of former patients in the disease-specific patient education sessions that are to be made obligatory for the teams – some of the patients in the panel think they ought to make their experiences available for other patients, other patients in the panel question the fruitfulness of using specific experiences due to the very different courses of illness for patients and thus question what other patients can use someone's specific experiences for. The time runs out and it is agreed to come back to this discussion at the next meeting.

After the meeting, I follow the professionals to the head nurse's office in order to follow up on the meeting. A theme discussed is the patients' wish to be present at the professionals' presentation preceding their own at the introduction of new employees. The head nurse is firm on *the position that the patients can receive the presentation the professionals are to give but cannot be present at the presentation because she finds it important that the new employees can air their insecurity and what she considers delicate questions (e.g., discussions on prognosis) and that it is important to distinguish between when it is important to include the patients and when they should not be present.*

The oncology department had had a patient panel since 2010. At that time, the department became involved in a pilot project together with an oncology department from another hospital. The pilot project was initiated by the Danish Cancer Society and the purpose was to gain experiences of working with the patient panel method (cf. project description, pilot project). From the oncology department, the head nurse, a rehabilitations nurse, the development nurse (who also headed the quality council), and a chief physician participated together with cancer patients. After the pilot project phase, a new panel was initiated after adjusting the format on the basis of the experiences from the pilot study. The new panel was set up in the early autumn of 2012 and had thus met four times, including the introductory meeting, when I gained access to participate in the panel. During the study period, the only replacement in the group of professionals in the patient panel was the doctor who withdrew and was replaced by another doctor from the department. In the group of patients participating, two remained in the panel for the whole period, three withdrew, and several new patients were recruited, of whom four ended up participating. Moreover, one participant sadly died due to his cancer during the time I participated in the panel. The patient panel was studied from September 2013 until November 2015. Meetings were held 4–5 times a year, and the shared core part of the meeting with both patients and healthcare professionals present lasted 1½ hours. The patients had an initial 30-minute pre-meeting (and often also prepared prior to this either individually or via their Facebook group or through e-mail), the professionals had a 30–60-minute pre-meeting some weeks before in order to prepare and discuss the agenda and also a short follow-up meeting directly after the patient panel meeting in order to reflect on the discussions at the meeting and to delegate tasks to further deal with among themselves.

In addition to the three anchoring points just presented, I also participated in the quality council in the oncology department based on consideration of where I would be able to "meet" other discussions and forms of patient involvement in quality improvement and maybe even some of the input from patients in the patient panel or other involvement processes. These monthly meetings lasted 1,5 hours and had representatives from each team in the department, the management team of the department, a development nurse working across the teams in the department, the quality coordinator,[16] and the head medical secretary as members. Surprisingly, these meetings turned out to contain very little input from or discussions about patient involvement in quality improvement.

Methods and data

During the fieldwork two primary methods were used: participant observation and interview. Documents related to the meetings, seminars, and patient education sessions that were observed were also collected, since they were part of the different meeting settings.

Participant observation

Due to my interest in the specificities of the work that goes into involving patients in quality improvement – the processes of interaction involving patients, healthcare professionals, managers, involvement methods, and tasks in specific situations and contexts – participant observation became the main constituent of the fieldwork. I draw on an interactionist approach to observations and have therefore had the interaction between people and the contexts of interaction as the primary focus (Järvinen & Mik-Meyer, 2005, pp. 98-99). Fieldwork was characterized by taking place largely in meetings of different kinds due to the way patient involvement is organized in the hospital and was thus episodical (see Article 1 for a discussion on this circumstance). Thus, the participant observation carried out during fieldwork was situated in and around these meetings (see Table 1 earlier in this chapter for an overview). Carrying out fieldwork primarily in meetings has some challenges. One of them is that meetings are data-intensive (Sandler & Thedvall, 2017, p.16) in my fieldwork in the sense that a lot of talking was going on in different ways. Either in quite controlled meeting formats with a moderator

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[16] Who was responsible for more formal quality work (e.g., relating to accreditation, and the work in quality council at the hospital level).

facilitating the discussions as in the centre council or in more discussion-based formats as in the patient panel. These meeting forums had 10-20 participants but other meetings had larger set-ups with 40-50 persons participating, as in the large seminars in the patient-centred care model process. These seminars were typically a mix between presentations by individual speakers and different kinds of group discussions. When in the large meeting settings, I followed the managers and staff in the oncology department in order to have a grounding somewhere in the discussions. In the smaller meeting set-ups, I tried to follow the meeting as such through the common dialogues and interactions. Field notes consist primarily of passages of speech and conversations, since this was the primary kind of action in the meetings. Tone of voice, gestures, and other non-spoken elements have also been noted to some extent, either in the situations or in the writing up of the field notes afterwards. When participating in the meetings, I discovered early on in fieldwork that sitting at the meeting table writing field notes on my iPad keyboard was a feasible role to take. It was a role not so different from the other meeting participants, since rather silent meeting participants were quite common in the meeting fora I participated in. A few meetings were audio recorded and transcribed verbatim, but it was primarily the dialogue in the meeting that was captured in field notes, written as close to verbatim as possible during the meetings, and followed up by extending the field notes (Emerson et al., 2011, p. 50) immediately after the meeting or early next day.

During the period of participant observation, my presence came to be a matter of course for the professionals and patients involved in the patient panel. During an agenda preparation meeting for the professionals running the patient panel, the doctor in the panel had not been attending for some time and when he was late for a meeting that had already started – and looking a little confused when he saw me there – the head nurse said: “Oh, and this is Mette. She is a PhD student – we are so used to her being around when it comes to these things that I nearly forgot to introduce her.” In the other kinds of patient involvement activities that I have participated in, I have obviously not attained the same role as a member but more as a detached observer (e.g., during the patient education sessions, where new participants in each meeting made getting to know people difficult, or in seminars with 40 or so managers). My role has thus been quite diverse across the activities studied. However, the kind of participation has, in all instances, been a not very active participation in what was going on in the meetings (e.g., when sitting at the table in the patient panel or in the patient education sessions); here, the passive participation was rather a given, since I had no personal experiences of being a cancer patient. On the other hand, in the centre council meetings, seminars, and workshop, I only participated actively on the very few occasions where someone specifically asked me to give my input on something (e.g., reading through and commenting on written material or helping to recall details from a meeting of which I had also been part).

Interviews

During the fieldwork, 33 interviews were conducted. These interviews lasted 29–129 minutes and were recorded and transcribed verbatim. The interviews were carried out in three rounds: a round of group interviews with department management teams and the centre management team early on in the fieldwork (5 interviews); a round of individual interviews with patients and healthcare professionals participating in the patient panel (11 interviews); a round of interviews with healthcare professionals with experience with involving patients in quality development in different ways (14 interviews); and, lastly, informal interviews with the head of team nurse (3 interviews) (see Figure 2 for a flow chart of fieldwork and Table 1 for an overview of data, both figuring earlier in this chapter). The patient interviews either took place in the interviewee’s home (2), in the meeting room of the hospital prior to a patient panel meeting (1), in a meeting room at Copenhagen Business School (3), or at the patient’s office at his workplace (1) – this was left to the interviewee to decide. The interviews with healthcare professionals all took place in their offices in the hospital. I view the interviews not as moments of extracting pre-existing information but as active interviews (Holstein & Gubrium, 2003) where data is created in an interaction between the interviewee and the interviewer during the interview. This makes the task for the interviewer not to reveal the life worlds of the people but instead to explore the meaning-making through which the social world is created (Mik-Meyer & Järvinen, 2005, p. 16). The interviews were semi-structured and the questions asked were organized around broad themes, such as their specific experiences with involving patients in quality improvement activities, roles and relations when involving patient in quality improvement, the relation between patient involvement in quality improvement and managerial work. However, during the interviews other aspects of patient involvement that were developed during the conversations were readily pursued both due to the conversation-like character of the interviews and due to my interest in discussing elements not necessarily explicated when doing participant observation in the specific involvement activities. Since the field and phenomenon studied did not leave a lot of opportunity for “hanging around”, due to its lack of informal time and everyday-ness (cf. Article 1), I used the interviews as what can be termed “scheduled conversations” around the topic of involving patients in quality improvement. This was useful in order to create opportunities to talk about experiences of specific situations with the interviewee and/or to articulate aspects of the involvement typically not articulated in the meetings, such as asking the patients to talk about their experiences of being a patient panel member. However, they were also – in the initial interviews with department and centre managers – used as a way of gaining insight into the specific involvement activities going on locally that I could not “find” in other ways due to their lack of formal places or functions in the departments. The extent to which the specific interview ended up having the intended informal and conversational character typically depended on my connection with the interviewee – some of them I knew quite well from previous encounters, which made the informal conversation approach very “natural”, while others whom I might never have spoken directly with before usually took more of a formal interviewee position in the conversations. The question of whether I had succeeded in distancing myself from the management and patient involvement agenda – a question I will return to in the section on access and positioning - was also reflected in the interviews. On a few occasions, I experienced the need to clarify my position as a researcher in the beginning of the interview, but on one occasion the interviewee’s very critical stance towards patient involvement and her associating it with my research project was never overcome, which led to the interviewee questioning me and, moreover, associating me with the involvement agenda when answering my questions. In other interviews, such as the interviews with the managers and healthcare professionals that I had met several times and had participated in meetings with many times, the interviews were more conversational and of exploring a common theme of interest – this is not to say that they were all positive towards the involvement agenda, but we shared a space for exploring different aspects of it together. The patient interviews were again different. Even though I did not explicitly ask the interviewees about their disease but rather their experiences relating to the patient panel, the conversation always at some point turned to their illness story, making most of these interviews rather personal, containing serious issues of life and death, living with incurable cancer, the "costs" of having gone through cancer treatment, and so on. This suggests the positioning as interviewee/interviewer as a process of interaction, not as a pre- or well-defined position (Holstein & Gubrium, 2003).

Accounts

I need to make a comment on the role of speech, talk and conversations as the primary kinds of interaction encountered in the meeting settings where the main part of fieldwork took place. The phenomenon of involving patients in quality improvement is to a large extent based on different kinds of spoken interaction – both when patients participate as direct discussion partners and when they participate as more abstract entities spoken about by others (e.g., in managerial negotiations on how to interpret patient data or in discussions about which roles patients can be given); this makes accounts of different kinds central. Hammersley and Atkinson suggest that accounts can both "be read for what they tell us about the phenomenon to which they refer" and that "we can analyse them in terms of the perspectives they imply, the discursive strategies they employ and even the psychosocial dynamics they suggest" (Hammersley & Atkinson, 2007, p. 97). I have used the accounts given in the interviews with regard to both dimensions; for instance, of ways of getting knowledge about what was going on patient involvement-wise in the departments in order to choose which department to delve into, but also in the other way referred to by Hammersley and Atkinson, for example when analysing the healthcare professionals' accounts of "the patient perspective" in Article 2.

From data to analyses

The analytical process does not start when fieldwork ends (Coffey & Atkinson, 1996, p. 6), it is a continuous process of using ideas to make sense of data and using data to push the ideas (Hammersley & Atkinson, 2007, p. 159). The analytical ideas and processes for the articles in this thesis have been developed in a dialogical relationship between fieldwork observations, issues brought up in the patient involvement literature – or were missing – and also the ethnographic approach taken has taken part in shaping the analytical ideas. For example by making the managerial work patient involvement entails visible by taking an ethnographic approach with a strong emphasis on participant observation. My analytical approach is therefore in line with abductive reasoning (Coffey & Atkinson, 1996, pp. 155–156; Timmermans & Tavory, 2012).

The analysis for Article 1, has grown out of the puzzling lack of focus in the literature and in healthcare policy on the work needed in order to get involvement activities in place, discussing and choosing issues to involve patients in, and so forth – which was a large part of what patient involvement in quality improvement was in fieldwork and my data. Article 1 is a book chapter and when writing it the purpose was to explicitly discuss the combination of an organizational phenomenon, a theoretical perspective and a specific ethnographic approach and what organizing then becomes (Pedersen & Humle, 2016, p. 3).

The idea for the analysis of the second article was spurred by the way in which the term "patient perspective" was used in the field as an unproblematic and matter of fact entity to be found and involved. The questions it spurred in the field were, for example, more related to how to access it in the right way and not questioning the entity as such.

The idea for the analysis in the third article emerged from the very first interviews made with the management teams of the departments, where I was intrigued by the negotiations among the interviewees themselves (these were interviews with management teams) that the theme of involving patients in quality work initiated, for example of what patients could be involved in. This unsettledness and negotiated character turned out to be part of most of the management activities (such as workshops, seminars, and meetings) relating to the patient-centred care model implementation process observed during fieldwork and directed my analytical attention to the representation work and negotiations going into making involvement methods work.

In terms of analysis, field notes and interview transcripts were read and reread more times. The analytical work has contained different elements. The analysis for Article 1 was made across the broader data material with the specific interest in the work of healthcare professionals in making patient involvement a doable endeavour. This approach was taken due to the specific setup of the book chapter discussed above. For the analysis in Article 2, the material from the patient panel has been thematically coded guided by the analytical interest in 'the patient' and 'the patient perspective' so often encountered during fieldwork. The coded data was then analysed by identifying both patients' accounts of how to speak on behalf of other patients in the patient panel, professionals' accounts and use of the term patient perspective, and situations where ideas of what the patients are to contribute with surfaced in specific situations in the patient panel. The analysis of Article 3 has been guided by a maximum-variation cases approach to the data material as a whole. In this process, the material data was consulted with the aim of identifying maximum variation in the different involvement activities found in the data. The complexity and lengthiness of the process from patient representation to specific intervention was identified as one dimension and the concreteness of the organizational impact aimed at as another.

Access, positioning, anonymity, and ethics

Access and positioning

My PhD stipend has been co-financed in equal shares by the Department of Organization (Copenhagen Business School) and the Center for Patient Experience and Evaluation (Capital Region of Denmark), and my initial access to the medical centre of the hospital studied was gained through the Center for Patient Experience and Evaluation via their assisting role in the implementation of the patient-centred care model that I was to study. This also implied that my access to the field was given by the management team of the medical centre. In the beginning of the fieldwork, I was by the people in the hospital strongly positioned as part of Center for Patient Experience and Evaluation, because I "arrived" with them and their relation to the centre management team. Early in the patient-centred care model implementation process, a head nurse in one of the other participating departments turned down my request to take part at a meeting in her department where the model and the process was to be discussed with the staff. Her reason for doing so was:

> ... it is crucial that we have room and time to discuss [the model] thoroughly where only the management of the department is present [together with the middle-managers]. We have not had that room yet in the process and there is still scepticism and limited enthusiasm [among the middle-managers] and even though you are only there to observe, you represent the Center for Patient Experience and Evaluation and I fear that the discussions and concerns will not get into the open (personal communication).

Here, it is evident how I was positioned as part of the Center for Patient Experience and Evaluation and subsequently, I would expect, also with centre management. These access-related circumstances – the association with the patient-centred care model, the Center for Patient Experience and Evaluation, and the centre management – accompanied me through the fieldwork. Soon, I realized that I needed to distance myself from the Center for Patient Experience and Evaluation, the centre management team, and the model both in order to get my role as researcher across to the informants and also in order to be able to "travel" to more local involvement activities without being perceived as a someone sent from the management. To dissociate myself from the consultant role that my association with Center for Patient Experience and Evaluation implied, I tried to make it explicit how I was connected to them in order to make my research position stand out. I found this to be important in order for the informants to know who I was and what my aim and role was when participating in meetings, seminars, etc. Another role that I was sometimes ascribed during seminar discussions and other meetings was the role of the researcher from CBS who must know how to make implementation work. On several occasions, I was called upon by one of the team managers as someone able to assist with how to solve the implementation problems – a position that I certainly could not take. To counteract these positions, I made an effort to voice my interest in the specific doings of patient involvement and to clarify that I had no normative position in the question of patient involvement, no interest in promoting and pushing the involvement agenda, or any other agenda of the centre management (e.g., in the information material sent out to the centre council or in the information material handed out when doing interviews with the managers and healthcare professionals).

My attempts to dissociate myself from the centre management and the Center for Patient Experience and Evaluation is also reflected in the way I delineated the field. I deliberately chose to study the Center for Patient Experience and Evaluation only when they were part of the meetings that I studied – since my research interest was in how patient involvement is performed in the hospital and in the relations between patients and healthcare professionals in this kind of work. Therefore, I have not focused explicitly on the work of the consultants from the Center for Patient Experience and Evaluation and their other work of supporting involvement initiatives or their work related to the National Danish Survey of Patient Experiences. However, my affiliation with the Center for Patient Experience and Evaluation and my insight into their other projects and work processes there have of course informed my understanding of the work going on in the hospital.

Access is not something gained once and for all, it is something renegotiated all the way through fieldwork (Bruni, 2006; Hammersley & Atkinson, 2007, p. 61; Wulff, 2000). The many organization and management levels traversed in the fieldwork made this very pertinent. When entering the oncology department, I had consecutive meetings with the head nurse of the oncology department in which I presented my plan for fieldwork, research questions and approach as the project developed, and, moreover, I interviewed her on three occasions. These meetings – and to some extent the interviews too – were a kind of continuous negotiation of access.

Having carried out fieldwork in hospitals before and the fact that I was studying my own cultural context made me wonder, at the beginning of the fieldwork, whether this familiarity would hinder me in asking the stupid questions, would it make me take things for granted? However, fieldwork turned out to relate very little to the everyday treatment and care work in the hospital. Tellingly, I never needed a coat in order to fit in during fieldwork and I spent most of my fieldwork time on the seventh floor of the hospital where the management of the medical centre, the management team of the oncology department, and the oft-used medical conference room and centre management’s conference room were located. The seventh floor was thus a place where no “regular” patients came – only patients participating in meetings in the patient panel, in the patient education sessions, and in other activities not part of the everyday life of treatment and care in the teams of the departments. Moreover, management and quality work were all new areas of study for me and thus helped de-familiarise me from the field.

Anonymity and data protection

The issue of anonymity has been settled with both the head of centre nurse and the head of department nurse who were the primary gatekeepers in the field. Even though they both expressed no need for anonymisation of the hospital, centre, or department, I have chosen to do so nevertheless due to broader considerations of anonymity regarding patients and employees. They are of course anonymised on the personal level, but nevertheless I have found it appropriate to also anonymise the hospital. For people with knowledge of the landscape of Danish hospitals, it will probably not be hard to figure out where the study has taken place due to the specificity of the patient centred-care model implementation process studied.

When participating in meetings, my presence has been mentioned and verbally approved. How genuine the possibility to deny my participation has been can of course be discussed taking the group situation into consideration. As it can be debated whether the participants have actually had a chance to have the full insight of the consequences of letting me participate. I brought one page of written information about my project for people to take at the first meetings and if new people entered the patient panel and at all the patient education sessions where the participants were new at each session. My experience is that not many people have shown any interest in this information and only a few have taken it and no one commented on it.

When interviewing, the interviewees have been informed about the use of the interview data, about anonymisation, the right to withdraw from the study, and were given written and oral information on the project. The study (the patient interview part) has been approved by the Danish Data Protection Agency (file 2013-41-2307).

Ethics

Ethical considerations are a core element of doing fieldwork, and when doing fieldwork in a field where life and death are very much at stake, such as in an oncology department, distinct issues come to the fore. The formal data protection of disease details was handled in the project (see above), but disease details turned out to be considered not very sensitive information for most of the participants who chose to be in the patient panel, at least not in the forum of the patient panel or when relaying their experiences at seminars. The sharing of details or experiences when participating in the panel was actually one of the strongest motivations for participating. So, having actively chosen to share experiences and detailed practical knowledge of being a cancer patient removed or at least lessened the sensitivity of the information and details. As an example, for one of the patients sharing his experiences of serious constipation ending in hospitalization – a side effect of receiving morphine to ease the pain caused by radiotherapy treatment – it was very important for him, since he hoped other patients could avoid having the same situation. What was actually found to be very sensitive for several of the patients was giving critique to the same doctors and nurses responsible for the treatment and care of their cancer disease. So, the fact that the professionals in the panel were not the same professionals they met in their treatment and care was, for several of the patients, a precondition for participating in the panel. This is not an argument for lessening the focus on ethics. Of course, it was important for the informants to protect their personal experiences and information about their disease and otherwise; however, at the same time, the sharing of it was also one of their strongest motivations to participate in the panel. This might instead point to the importance of a situational ethic (Tjørnhøj-Thomsen, 2003, pp. 108–109) in the field, since ethical issues arise in situations, of which many are not possible to plan and sign your way out of. This makes a sensitivity to situations and situational judgments an indispensable element of fieldwork.

CHAPTER 5. THE ARTICLES OF THE THESIS

This chapter consists of the three articles that comprise the analytical part of the thesis. They each relate to one aspect of the overall research question presented in the introduction. The first article concerns the question of how patient involvement in quality improvement is a part of healthcare professionals' work and it shows how they are involved in creating contexts when involving patients in quality improvement. It is published as the book chapter[17]: "Contexting the Patient: A Meeting Ethnography of Patient Involvement in Quality Development" in the book *Doing Organizational Ethnography*, edited by Anne Reff Pedersen and Didde Maria Humle (2016).

The second article concerns the question of how patient perspectives and patient involvement in quality improvement are related and it shows how patient perspectives are not necessarily found in especially representative patients but are shaped in specific situations and through interactions around specific tasks in a patient panel. The article is titled: "Shaping patient perspectives: Balancing representation, authenticity and situated concerns when involving patients in quality improvement work" and was presented at the Organizational Behaviour in Healthcare conference in Cardiff, Wales, in May 2016. It will be submitted to *Journal of Organizational Ethnography* during the winter of 2017/18.

The third article concerns the question of how patient involvement is a part of managerial work and shows how managerial representation work is involved in making involvement method produce patient representations found suitable to guide intervention. It is titled: **"**Patient involvement and managerial work: Juggling representation, intervention and organization" and is to be submitted to *Social Science & Medicine* during the winter of 2017/2018. The article is co-written with Signe Vikkelsø.

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[17] The book chapter was written early in the process and has a slightly different wording than the rest of the thesis; for instance, it denotes the phenomenon studied as patient involvement in quality *development* instead of patient involvement in quality *improvement* – "development" resonating with the empirical wording, "improvement" relating more to the involvement literature. Moreover, the word "clinic" is used instead of "department" to denote the specific setting – in the other parts of the thesis, "department" relates to the specific setting and "clinic" to the abstract concept. Moreover, it should be noted that in the book it is directly followed by a short commentary by Anne Reff Pedersen, since the format of the book is, that all chapters are followed by a commentary by a senior scholar. The commentary has not been included in this thesis.

Article 1: Contexting the patient: A meeting ethnography of patient involvement in quality development (In: Pedersen & Humle (Eds.) (2016): Doing Organizational Ethnography)

Contexting the Patient: A Meeting Ethnography of Patient Involvement in Quality Development

Introduction

In the last decades, government policies concerning increased user involvement have proliferated. Many different welfare sectors are faced with the requirement that users should be involved and heard in relation to the development of services provided. In health care, this is formulated in simple policy and strategy statements such as there is a need for “the patient perspective in quality work” (Sundhedsstyrelsen, 2002, p. 18; the author’s translation) or that the patients’ voice is heard (Terms of reference patient panel, 2015; the author’s translation). But even though patients are in abundance in the daily work in the clinic, it is not given who to actually involve, include or listen to when involving patients in quality development. Also it is also not given what to be involved in and in what ways. So the path from airy policy and strategy statements to the actual work performed in the clinic is long, and in order for patient involvement in quality development to become a consolidated practice, a lot of work is needed. The core interest of this chapter is focused on different aspects of this work. Through ethnographic fieldwork in an oncology clinic in a university hospital, I have studied patient involvement in quality development by looking at concrete activities taking place in concrete settings by concrete people. Through an analysis of empirical material in the form of both meeting observations and interviews with professionals, I will show how an ethnographic approach to patient involvement in quality development elucidates how involving patients in quality development is not a simple method-driven activity assuring the inclusion of ‘the patient’s voice’ in quality development but requires contexting in order to be achieved. Through the use of the concept of contexting, the analysis points to the way tasks and patients continuously need to be related to other work processes and knowledge ideals in the clinic in order for patient involvement in quality development to be a doable endeavour.

Organizational Phenomenon and Setting: Patient Involvement in Quality Development in an Oncology Clinic

The organizational phenomenon taking centre stage in this chapter is patient involvement in quality development. Many methods for patient involvement in quality development exist and the methods are as different as conducting large national patient experience surveys, establishing patient panels with regular meetings, and using patients' photo diaries to gain insight into the patients' experiences in the hospital. All these methods are used in order to involve the patients in discussing and sometimes choosing what needs to be improved in the clinic and how these improvements might be achieved. Patients' roles in these methods varies widely from being quite passive respondents to pre-formulated survey questions to being very active discussion partners with professionals around themes and topics in the patient panel. A core element of these activities is that some patients are involved – directly or indirectly - in developing organizational procedures and practices in order to improve conditions for future patients. Central to this are the ideas that 'the patient's voice' can be used to inform these practices and procedures and that some patients can speak on behalf of other patients and/or in some way guarantee patient interests.

But the largely method-driven character of patient involvement in quality development makes it quite invisible how involving patients is not just a question of choosing and using involvement methods. A whole lot of work is also required from both patients and professionals to actually involve patients in quality development *and* to connect both the concerns of the involvement activities and their outcomes with the practices and procedures in the clinic that it is supposed to inform and improve.

The existing literature on involving patients in quality development[18] is broad but three central themes will be discussed here: issues of representativeness, patient roles and patient-professional relations, and legitimacy relating to the use of patient knowledge and experiences. Regarding representativeness, Martin explores how representativeness is a concept understood in different ways by patients and professionals involved in public involvement in health-service-management (Martin, 2008a). El Enany, Currie, & Lockett show how the professionalization of

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[18] I use the term patient involvement in quality development but in the literature many different terms are used – public participation in health-service management, user involvement in service development, patient participation, patient and public participation, just to mention some of them.

patients participating in these kinds of activities can make it hard to make the participation representative (El Enany, Currie, and Lockett, 2013). From these studies, we can see that understandings of representativeness and their workings in practice and the question of whether some patients can speak on the behalf of others is thus a central theme in the existing literature. This issue relates to the theme of patient roles and patient-professional relations existing in the literature. The policy ideal of equal relations and partnerships between patients and professionals is discussed in the literature and also shown how both patients and professionals contribute to creating the divide between more expert patients and less-expert patients, depending on the knowledge and experiences they draw on (Brooks, 2008; Martin & Finn, 2011; El Enany et al., 2013). This categorization of patients as more or less experts relates to a third theme in the literature: negotiations of legitimacy and the use of patient knowledge and experiences. In this regard El Enany, Currie, and Lockett show that patients regarded as expert patients typically do not solely draw on their patient experiences as the ‘expert knowledge’ used in patient involvement activities. They also draw upon other expertise such as educational background and work experience (El Enany et al., 2013). Solbjør and Steinsbekk show how professionals tend to value patient knowledge most highly when it can either be ascribed a function as an alternative to professional knowledge or when it is in accordance with what the professionals themselves regard as good professionalism, thus supporting professional knowledge (Solbjør & Steinsbekk, 2011). Van de Bovenkamp and Zuiderent-Jerak, in their study of patient participation in the development of evidence-based guidelines (van de Bovenkamp & Zuiderent-Jerak, 2013), show that patients gaining status as legitimate participants (e.g., because of their knowledge of research literature on the subject in question) at the same moment lose their credibility as representing what the professionals regard as ‘true’ patients (van de Bovenkamp & Zuiderent-Jerak 2013, p. 9). As these studies demonstrate, the use of patient knowledge in quality improvement is thus not a straightforward or uncomplicated matter.

Through this short view of the literature, it is thus evident that no simple relationship between what counts as patient knowledge and what kind of involvement this knowledge makes possible exists. Not many of the existing studies have an ethnographic approach to the study of patient involvement in quality development, but Fudge, Wolfe, and McKevitt (2008) and Brooks (2008) are some examples. Fudge et al. (2008) study a modernization programme aimed at improving stroke services in two London boroughs, and Brooks (2008) studies a specific patient council in a UK acute hospital, specifically the nurse-patient relationship. In contrast to these studies, I take the approach of studying ethnographically how patient involvement in quality development is carried out not as one method in isolation but as a phenomenon happening in different ways – and with quite diverse effects - in the same clinic.

In order to study this phenomenon ethnographically, a field site was needed. An oncology clinic in a Danish university hospital was chosen because the healthcare staff in this clinic used different ways of involving patients in quality development. In this oncology clinic, tasks related to patient involvement in quality development is performed mainly by nurses, and more specifically, nurses in managing or specialized functions (a rehabilitation nurse, a development nurse, a head nurse, and managing nurses). Also, this kind of work is largely project-based since involving patients in quality development is not a routinized and compartmentalized part of the organization and thus has no ‘natural’ or evident place or role in organizational life. In the oncology clinic they work with both established and more formal methods for doing patient involvement, and they also experiment with involving patients in ways they develop through specific problems they need to solve in managing the life of the clinic. The established methods used are surveys, a permanent patient panel and occasional feedback meetings. The more experimental and bottom-up driven activities primarily consist of involving patients from the existing patient panel in other tasks. These tasks include being part of a teaching programme for nurses, introducing new employees to the clinic, and using patient panel members for doing presentations on what it’s like to be a patient in the clinic in different fora such as in management seminars or doctors’ meetings. However, in order to explore the ways in which patient involvement in quality development is a lot more than the application of formal methods, I have chosen an analytical approach centred on work in order to widen the object of study.

Patient Involvement in Quality Development Approached Analytically as *Work*

When studying patient involvement in quality development ethnographically, what comes into view is a complex task requiring places, people, meetings, coordination, and considerations that need to be achieved to become an actual work practice, not just an airy policy or strategy statement. The ethnographic approach creates a widened room for understanding the phenomenon in question as something more than just formal involvement methods put into practice, thus complicating the alluringly simple picture of patient involvement methods as 'input-output machines' providing blueprints for action.

Work has become a renewed matter of concern in management and organization studies in the past decade (Barley & Kunda, 2001; Brannan, Pearson, & Worthington, 2007; Philips & Lawrence, 2012). Barley and Kunda plea for bringing work back in to the study of organizations in order to understand what they term 'postbureaucratic organizing' and study work practices and relations in situ in order to give attention to the dynamic aspects of organizing (Barley & Kunda, 2001, p. 84, 88). Even though hospitals can hardly be understood as 'postbureaucratic', it is still worth taking a closer look at some of the new kinds of work gaining prominence in healthcare. With the continuing emphasis on individualization and patient involvement in healthcare (paradoxically coinciding with a strong strive for standardization), involving patients in quality development in the clinic has become a matter of course and a political expectation, but *how* it is done is not, since it is still a relatively new kind of work. This study thus also raises questions about how new tasks can gain a foothold in the landscape of existing ones – the answer being an empirical matter.

Work has also been prominent in ethnographic studies of hospital life and the workings of medicine (e.g. Berg, 1997; Strauss et al., 1997). Strauss et al. stress the importance of attention to the "analytic examination of work itself" (Straus et al., 1997, p. xv) in opposition to work as a background for studying division of labour, professions, careers etc. Through a thorough study of work in hospitals, Strauss et al. (1997) discern different kinds of work inherent in medical-nursing care. Inspired by Strauss et al., I study patient involvement in quality development as work tasks alongside other work tasks in the clinic rather than as formal methods. It is not my purpose here to create new generic categories of work in a hospital setting but solely to use the concept of work to point to the very practical doings of patient involvement in order to escape the heavy focus on formal methods.

One type of work central to the work done in and around patient involvement activities can be conceptualized as contexting. Contexting is a concept used by Asdal and Moser (2012) to discuss the researchers' role in context-making. Asdal and Moser argue that contexts are not out there waiting to be found but instead are constantly being made: "By contexting we mean that contexts are being made together with the objects, texts, and issues at stake" (Asdal & Moser, 2012, p. 303). They point to the researcher's role in contexting, but, as I will argue, contexting is also a core part of the work done by the professionals and patients in patient involvement activities. This is done in selecting/deselecting and assembling relevant contexts for action in specific situations in order to make tasks, patients' knowledge positions, possible actions, and other work processes in the clinic be in accordance.

The two examples of analysis presented later in this chapter each deal with an example of contexting done by the professionals in order to turn patient involvement in quality development into concrete practices in the clinic. The first analysis shows how what is taken to the table in the patient panel needs contexting – both before and after the meetings - in order for the professionals to be able to both connect to and inform the everyday work practices in the clinic. The second analysis shows how the professionals also need contexting in order to create an understanding of what position the knowledge and experiences of the participating patients in quality development can take. This example of contexting is especially important since involving patients in quality development is not yet a routinized part of professional work in the clinic. In sum, the work approach to patient involvement in quality development thus makes it possible to discuss how the phenomenon studied is more complex than merely applying formal involvement methods. Let us now turn to the fieldwork.

Problems of the everyday: How to Study an Episodic and Non-Routinized Phenomenon Ethnographically

A strong ideal in organizational ethnography is striving for studying everyday life in organizations in order to capture the mundane, ordinary, routine, or otherwise unseen details of organizational life (e.g. Ybema et al., 2009; Yanow, 2012). In the oncology clinic studied in the fieldwork grounding this chapter, patient involvement in quality development as an organizational phenomenon has an episodic character since it is not a fully consolidated and routinized part of the organization and clinic in question. This circumstance made it much more difficult to find 'a suitable everyday' to position oneself in as a fieldworker than when the object of study is e.g., consultations or treatments, where everyday work in the clinic occurs in more routinized, localized and schematized ways. Clearly, when the clinic is a large organization with multiple settings and the phenomenon studied is episodic in character, finding out where to be at what time is not a trivial or simple task. Choosing a traditional approach of being in the clinic for 6 months full time would probably not have given me rich data on the workings of patient involvement in quality development or how it relates to other work processes going on in the clinic. Given that phenomenon is not a formalized part of everyday life in the clinic, and that the highly scheduled workday left very little unscheduled time in the daily life of the clinic, the classical fieldwork strategy of 'hanging around' would not have produced sufficient data to study patient involvement in quality development and how it is practiced as an organizational phenomenon. Therefore, the fieldwork was instead planned around three different involvement processes. These processes were identified through an explorative interview on the topic of patient involvement with the head nurse and the head of clinic. The interview was initiated with the question: "Can you tell me, how do you work with patient involvement in this clinic?", and proceeded with elaborations hereof. After this interview and informal talks with a managing nurse in one of the diagnose-related teams in the clinic, I chose the three empirical points of entry: an already established patient panel where patients meet with professionals and discuss issues or solve concrete tasks in order to get the patients' input on specific themes or concrete tasks; an encompassing and, at the time of fieldwork, a newly initiated project aiming at creating a more patient-centred culture in the clinic; and lastly, a collection of data from what was in the clinic termed 'naturally occurring feedback' from patients participating in an already existing patient education forum for cancer patients learning to live with late effects of cancer treatment. What these three processes have in common is that they are episodic in their constitution –they are not a routinized part of the everyday life of the clinic as are the treatment, care and follow-up consultations in the outpatient clinic. Therefore, despite having three processes to study, the fieldwork was hard to conduct in a traditional sense. In order to actually 'meet' the phenomenon I set out to study, the fieldwork has thus – like the phenomenon - been episodic in character. The fieldwork was episodic in the sense that it was largely organized around planned meetings of different kinds: patient panel meetings, preparation meetings, follow-up meetings, patient education meetings, quality council meetings and different kinds of meetings and seminars in the project aiming at creating a more patient-centred culture in the clinic.

Meetings are a very common ‘medium’ for and main constituent of patient involvement in quality development and thus also turned out to be the central observation fora in the fieldwork discussed here. This study thus relates to a line of ethnographic work where meetings are a central object of study (Schwartzman, 1989; Thedvall, 2013; Nyqvist, 2015). While observing the meetings, I positioned myself – and was positioned by the others - as a silent meeting participant, a well-known role in the meetings I observed since the degree of (verbal) participation from the meeting participants varied greatly. I engaged in conversations with the other meeting participants during the breaks and before/after the meetings, but during the meetings, I would typically sit around the meeting table with the other meeting participants and write field notes on my iPad keyboard. The field notes written during the meetings were, as far as possible, the actual wording of the conversations taking place.

In order to go beyond the meetings, interviews with patients, professionals and managers with experience with patient involvement in quality development were conducted during the fieldwork. These interviews can be understood as ‘scheduled conversations’ since there was little non-scheduled time to tap into as a fieldworker. I also view the interviews not as moments of extracting already existing information but as active interviews (Holstein & Gubrium, 2003) where data is created in interaction between the interviewee and the interviewer. I conducted, recorded, and transcribed 32 interviews in total. They can be grouped in three main parts relating to when they were conducted. At the onset of the fieldwork, group interviews with management teams were conducted in order to become familiar with the field and the large hospital centre (of which the oncology clinic was a part). After that, a cluster of interviews were conducted with members of the patient panel – both patients and professionals – and with professionals doing quality work in the clinic. The largest number of interviews was conducted at the end of the fieldwork after I had gained deep insight into the actual doings of patient involvement in quality development. The interviewees were nurses in managing or otherwise specialized functions and chief physicians.

As I mentioned at the beginning of this section, the practical fieldwork-related problem of knowing where to position oneself as a fieldworker when the phenomenon studied is episodic and non-routine in character can give rise to a problematization of the concept of the everyday in organizational ethnography and the trope (Rumsey, 2004) around this concept. When studying something ethnographically, researchers often strive for the informal, the behind the scenes, the everyday, the routine, and the ordinary. But what is this everyday exactly and what consequences does it have for the way we study the organizational phenomenon in question? In anthropology, the question has been pointed out, e.g. as a problem for the study of the lives of refugees in a refugee camp since a refugee camp can be understood as a transitory phenomenon in an 'unnatural' setting where stability, patterns, the ordinary, routine, and everyday-like is not at the centre of attention (Malkki, 1997). But what does studying the non-everyday mean for the study of organizations and organizing? As with the discussion of the refugee camp and the study of extraordinary events instead of patterns, routines, and the ordinary, the struggle to capture the everyday in organizational ethnography can be related to whether the fields studied are place-based or person-centred in their constitution. When studying phenomena that are not day-to-day endeavours, questions of where to actually be as a fieldworker - as has been argued in this section – become very important.

On an ending note, it can be argued that an empirical focus on the non-everyday gives way to considering whether something may or may not *become* everyday-like and routine, thus making the everyday-like an accomplishment rather than something taken for granted or something inherent in spatial conditions of organization or in types of work performed. But one could also go further and argue that when studying phenomena rather than places and a priori categories of work, in some way or other, all phenomena have everyday-like and routine elements in them.

Analysis: Taking a Closer Look at Patient Involvement in Quality Development

Let us now turn to the ethnographic data of the study and an analysis showing the advantages of taking an ethnographic approach to this topic. One advantage is that this approach makes it possible to see that patient involvement in quality development is not a simple method-driven activity assuring the inclusion of 'the patient's voice'. Rather, the analysis brings to the fore the contexting work needed in order for it to be carried out. The focus in the following analysis is thus on some of the work going on outside the formal methods for doing patient involvement, work needed in order to make the task of involving patients in quality development doable for the professionals.

Contexting Work Needed in Order to Go From Everyday Life in the Clinic to Patient Involvement Methods and Back Again

The data excerpts in this section come partly from a series of interviews with healthcare professionals, mainly managing nurses and doctors in the clinic, and partly from observations from different kinds of meetings where discussions on patient involvement in quality development take place. In meetings and in other doings of patient involvement in quality development, competing agendas and requirements complicating this work are prominent, but this is also evident in the way the professionals talk about patient involvement in quality development. The following is an excerpt from a group interview with three nurses involved in the patient panel who talk about the work they do with the patient panel in the clinic and how it is related to other concerns in the clinic:

> NURSE A: Also, it has been a considerable part of the balancing of expectations [with the patient participants in the panel] to make clear that not everything that is brought up [in the patient panel] we can go home and change. Some of it is processes that take time. Some of it is not on our level, it is important to consider, even though the patients are really keen on seeing things happen”
>
> NURSE B: It is also an obligation to *get* all this information, which in some way or the other has to be put into action. Also, there are expectations from the patients that we do something about it and that really demands from us that we make things clear. But we are also aware that it should not necessarily affect our other prioritizing because what comes up in the patient panel should not necessarily override other activities we are doing even though the patient panel have an opinion of it, it is really a fine balancing act. (Interview patient panel professionals, p. 3)
>
> […]
>
> NURSE A: Actually, it requires a whole lot of work, managing and preparation for this group [the professionals] in order to avoid some of the

> shortcomings [of the patient panel method] and also in order to get a connection between what we discuss there and the other things going on in the clinic. So it is both a large responsibility and a comprehensive task for the ones responsible for the patient panel. (Interview patient panel professionals, p. 12)

The ethnographic approach allows for noticing how the work done in the patient panel is not just compartmentalized as an isolated project in the clinic. In the excerpt the nurses' explain how the awareness of both the patients' expectations and their own obligations to take action on issues or their deciding *not* to act on something brought up by the patients is central to the way they work with the patient panel. They say that they have to relate issues taken up or coming out of the meetings to other processes and concerns in the clinic when they decide which issues to take to the meetings and which ones to act upon after the meetings.

I find it fruitful to conceptualize this work as the contexting (Asdal & Moser, 2012, p. 303) continuously needed in order for the patient involvement in quality development to happen. Since patient involvement in quality development is not a 'natural' or routinized part of the work in the clinic, the professionals need to be very explicit in their contexting of issues brought to or coming out of the patient panel meetings. Contexting is a core part of deciding which of the issues to act upon and how to do it, as well as of deciding what not to act upon. Through contexting, the nurses relate specific issues to the broader life and work processes of the clinic. The issues need to be made relevant in relation to other concrete processes and actors in order for the professionals to be able to act on them. These actions might include, for instance, asking someone to fix the wheels of malfunctioning drip stands, sending an e-mail to a regional office in order to pass on patients' comments about a poorly written pamphlet on patient rights, or pass on 'the patient perspective' to the quality council in order to discuss the patients' feedback on how waiting time is experienced from their point of view. Thus bringing together – or keeping apart - what in the specific situations is perceived as relevant contexts and issues is crucial in order to relate issues raised in the patient panel to other things is going on in or outside the clinic. Deciding not to act upon an issue also involves contexting, as this happens through drawing in competing contexts made relevant in the decision situation. Thus contexts are not something to take for granted as background for action but something continuously being created and made relevant in specific situations. Patient involvement in quality development can thus be understood as requiring lot of contexting and making or dissolving connections in order for issues from the patient panel to be related to – or kept separate from – other processes in the clinic.

The Contexting Done by Professionals' in Order to Carve Out Knowledge Positions for Patients in Quality Development

The next empirical excerpts come from fieldnotes from both agenda preparation meetings for the professionals in the patient panel, patient education meetings in one of the disease specific teams in the clinic, as well as interviews with the managing nurses heading each of these two patient involvement activities. In the following excerpt, the managing nurse in one of the disease specific teams in the clinic draws a contour of what constitutes a 'usable' patient for giving feedback.

> *During an informal talk in her office, Louise is telling me about how she uses 'naturally' occurring feedback from patients participating in a patient education to 'catch' quality problems surfacing in the participating patients' exchange of experiences, which heavily structures the patient education sessions. Louise says: "What I like about it is the randomness. The patients have not signed up to participate in a feedback giving session and they are not all really resourceful patients that read all the pamphlets and want to help other patients", and she continues to explain to me that she needs to take care that the patient education sessions keep the format so that she can catch the 'natural' feedback from those patients with experience from the treatment and care in her team. She has considered using the forum to ask patients specific questions but as for now she doesn't want to influence the patients too much by asking pre-planned questions.* (Managing nurse, informal interview)

A certain understanding of task, knowledge and patients meet in this data excerpt. A wish for 'naturally' occurring feedback, a broad range of patients (being close to a wish for a representative patient) and the wish not to influence the patients by asking questions is at the heart of the managing nurse's considerations of what knowledge position patients can have in this kind of involvement. The nurse's ideal of knowledge as something naturally occurring, stemming from patients, and not influenced by pre-planned questions is evident in her explanation of how she uses patients' feedback on the treatment and care in her work. She is contexting the patient involvement activity by drawing on her knowledge ideal, thus also pointing to how the feedback gains its legitimacy and how a certain patient position is carved out through this contexting.

Let us now turn to another situation where contexting comes to the fore in order to see how a quite different patient is described in professionals' discussions of patients' roles when participating in the patient panel. The patient panel is a group of current or former patients in the clinic who meet with professionals four times a year to give their input on issues mostly selected by the professionals in the clinic. The patients decide to participate on the patient panel typically in response to a poster stating the need for new members to join. The patients are interviewed before entering the panel in order to ensure that they are able to 'free' themselves from their own course of disease and illness narrative and participate on somewhat more general terms in the panel. This is the professionals' framing of the primary requirement of the patients participating in the patient panel (Interview patient panel professionals, p. 2, 6).

We enter the professionals' agenda preparation meeting during a discussion of what to put on the next meeting agenda. At the particular agenda preparation meeting, four professionals involved in the patient panel participated. In the discussion, the patients' role in the panel is brought up and during this discussion, contours of what constitutes a 'usable' patient for giving feedback to the clinic emerge:

> *It is most successful when it [the task] is concrete, feedback on pamphlets for example; it is much more difficult when it comes to their subjective stances, things like communication is much more difficult to bring up in [other fora in] the clinic in a concrete way*. (Nurse A, field notes, agenda preparation meeting for the patient panel professionals)

The nurse explains that the results from concrete tasks taken up in the panel are the easiest to use in order to inform other areas of work in the clinic. It seems that when working on concrete problems, it is easier for the professionals to set aside that the patients in the panel participate with a more subjective perspective than when the professionals themselves have to bring a stance from the patient panel along to use in discussions in other fora or situations in the clinic. This fluctuating between the situational need for patients to represent a more general patient or contribute with very specific patient experiences is also central in the next field note excerpt from the same meeting:

> *Another nurse elaborates on the need for insight into the patient panel patients' experiences of concrete situations of treatment and care and the usefulness of this for developing interdisciplinary collaboration and other strategy-related issues [at the time of the meeting a process of renewing the strategy of the clinic was ongoing, and two of the nurses on the patient panel were also heavily involved in this process].* (Nurse B, field notes, agenda preparation meeting for the patient panel professionals)

This nurse calls for the need for insight into the actual experiences of the individual patients, rather than wanting a unified stance from the patient panel when contexting the roles of the patients in relation to other processes in the clinic. This nurse's statement points to the situational character of what is a suitable role for the patients when involved in quality development. So even though one of the criteria for being a member of the patient panel - as before mentioned - is that you can free yourself from your concrete course of disease and participate on more general terms, this is not always the context chosen by the professionals to relate to in the work done in the panel. The nurse heading the panel also talks about another kind of task pointing even further away from a unified stance or a general patient position:

> *I am just really preoccupied with what Thomas [a doctor in the clinic] mentioned yesterday [at a management seminar about patient involvement in quality development], the question concerning the fact that right now we are*

> *arranging a new waiting room and is the furnishing good or bad? Well, why don't we just ask some of the patients there and just skip the question about the truth of it – even though we are in a natural science field – it is just one perspective. As professionals we don't have the absolute truth about the best way to arrange a waiting room either. It is just one perspective on something and the more perspectives we have, the more informed decisions we can make, so there is also a lot of opinion in this [matter].* (Interview, p. 2)

The nurse explains that she is aware of the natural science ideal of knowledge underlying most areas of work in the clinic. However, she also turns away from this knowledge ideal with her reference to that professionals do not have an absolute 'truth' about these kinds of questions either. In this case, the question of how best to arrange a waiting room is pushed outside the realm of both patients and professionals because she frames it as a question of perspective. This makes it more legitimate to have more perspectives on the question when deciding on a solution than when the question is closer to the core issues of treatment and care. In the negotiation of suitable tasks and the roles of the patients, the professionals fluctuate between the wish for a patient representing patients in general, the desire to capture unique patient experiences and the view of patients as carrying just one perspective among many. This fluctuation demonstrates that the ideals of knowledge are situational and are connected to the difficulty of determining which patient is suitable for the task of giving feedback to the clinic. Through contexting, the professionals try to bring together the task, a suitable patient position and a knowledge ideal in order to sort this out.

In sum, these analyses point to some of the contexting and other work required in order for patient involvement to be knit together with the rest of the life of the clinic and in order to carve out knowledge positions for patients in these activities where the patients have quite different positions than when being a patient undergoing treatment and care in the clinic. This analysis is focused on the *professionals'* contexting, so whether the knowledge positions carved out are also taken by the patients in this kind of work is another question lying outside the realm of this chapter.

Conclusion

When studying patient involvement in quality development through ethnographic fieldwork, the more than methods-aspect of involving patients in quality development comes to the fore. With this approach is it becomes clear how patient involvement in quality development is an organizational practice entailing a lot of work in order to fulfil political and managerial demands. When studied ethnographically as concrete practices, it also becomes clear that even though the patient involvement activities studied are not fully consolidated or routinized parts of the daily life in the oncology clinic, they are also not isolated and compartmentalized. The phenomenon calls for the professionals to make new connections and/or change existing ones when dealing with specific questions or situations. Two elements of this have been discussed in this chapter: the contexting necessary for the professionals in order to relate the involvement activities to other work processes in the clinic and the contexting involved in carving out knowledge positions available to patients when involved in quality development activities. This is not straightforward since ‘the suitable patient’ is a situational figure created and configured in different manners, when involving patients in quality development. The contexting of knowledge ideals, patient roles and tasks to be solved is a complex job for the professionals, since no well-established and clear-cut knowledge position exists for patients in this kind of work. In the light of this, it is relevant to point to the ways in which organizing through patients emerge, when involving patients in quality development activities in the clinic. All in all, it is thus not a trivial task to answer the policy call for involving patients in quality development.

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Article 2: Shaping patient perspectives: Balancing representation, authenticity and situated concerns when involving patients in quality improvement work

Shaping patient perspectives: Balancing representation, authenticity and situated concerns when involving patients in quality improvement work

Mette Brehm Johansen

ABSTRACT

The ‘participatory turn’ is well underway in healthcare. Increasingly, involving patients in different aspects of quality development has become a requirement and a concern for hospitals and other healthcare institutions. However, in both policy documents and the practices in the hospital, the ‘who’ of patient involvement is underspecified – the ‘patient perspective’ is most often depicted and used as an unproblematic entity existing in patients that is just waiting to be involved. The quest for the patient perspective in individual patient involvement can be in danger of easily turning into a search for a static, individualized quality inherent in the person waiting to be dug out (Pols, 2005; Velpry, 2008). Turning to the patient perspective as a given entity to be used in quality improvement work, even more pertinent questions must be asked. Rowland, McMillan, McGillicuddy, and Richards (2017) argue that the patient perspective is referred to by patients and professionals as an embodied knowledge of vulnerability. Taking an ethnographic approach provides a way to explore the question: How do patient perspectives figure in patients’ and professionals’ accounts when patients are involved in quality improvement work and how are they related to different mechanisms of representation and the specific tasks performed? The empirical basis of this article is an ethnographic study of patient involvement in quality improvement work in an oncology department in a Danish university hospital. The data used stems primarily from the part of the data relating to a patient panel in the department and consists of meeting observations, interviews, e-mail correspondence, and documents. The findings show how patients’ and professionals’ accounts of patient perspectives are coupled to very diverse mechanisms of representation. Furthermore, what comes to qualify as ‘the patient perspective’ is an interactional, situational, and context-dependent accomplishment related to specific tasks and situations, not something inherent in more or less representative patients. Thereby, this article contributes to the literature on patient perspectives (Pols, 2005; Rowland et al., 2017; Velpry, 2008) by exploring how accounts of the patient perspective link to a range of mechanisms of representation and are always shaped in interaction in specific tasks to be solved. Furthermore, it adds to the discussion of representation in healthcare service development (El Enany, Currie, & Lockett, 2013; Martin, 2008a, 2008b; Thompson, Bissell, Cooper, Armitage, & Barber, 2012) by arguing that the same patients can represent in different manners depending on the specific task – what qualifies as a patient perspective in one situation can come to disqualify in another. Patient representation is not solely tied to persons but also takes its shape from the specific tasks to be solved. This points to the complexity of the representation work that both healthcare professionals and patients face when fulfilling the policy call for involving the patient perspective in quality improvement.

Keywords: Organizational ethnography, patient and public involvement, quality improvement, patient perspective, representation, authenticity, task

Shaping patient perspectives: Balancing representation, authenticity and situated concerns when involving patients in quality improvement work

INTRODUCTION

The ‘participatory turn’ is well underway in healthcare; patients are expected to participate in various ways in different areas of healthcare: service development, quality improvement initiatives, patient safety, guideline development, research, policy development and health technology assessments just to mention a few. A central concern is who is ‘the patient’ that is to be involved in these processes and on what grounds? In policy documents, strategy statements, and in the practices in the hospital ‘the patient perspective’ is formulated and used as a matter of course; for instance, that there is a need for *the patient perspective* in quality work (Sundhedsstyrelsen, 2002, p.18), or the related notion that the *patients’ voice* is heard (Anonymous, 2015). In the literature, ‘the public’ (Barnes, Newman, Knops, & Sullivan, 2003; Degeling, Carter, & Rychetnik, 2015; Felt & Fochler, 2010) and ‘the citizen’ (Lehoux, Daudelin, & Abelson, 2012; Thompson, Bissell, Cooper, Armitage, & Barber, 2014) have been scrutinized, and in a similar vein the patient perspective to be used in quality improvement work in the hospital needs further attention. In the literature, the patient perspective as relating to individual patients has been shown to be situational accomplishments created in interaction between patients and professionals, and not something static based in individual characteristics (Pols, 2005; Velpry, 2008). Furthermore, the patient perspective in patient engagement programmes has been addressed; Rowland et al. (2017) argue that the patient perspective is referred to by patients and professionals as an embodied knowledge of vulnerability. However, there is still a lack of insight into how patients’ and professionals’ accounts of patient perspectives and their workings figure in quality improvement work and how they might depend on other elements than a specific kind of embodied knowledge. This article deals with the research question: How do concerns of speaking on behalf of others and patient perspectives figure in patients’ and professionals’ accounts when patients are involved in quality improvement work and how are they related to different mechanisms of representation and the specific tasks performed? Through an ethnographic study of patient involvement in quality improvement work in an oncology department in a Danish university hospital, this article shows how both patients and professionals have multiple accounts of patient perspectives and how they are supposed to contribute in these processes. The representation mechanisms involved are explored, and it is argued that patient perspectives are situational and context-dependent accomplishments shaped in interaction and in relation to specific tasks; they are thus not something inherent in more or less representative patients. Thereby, this article contributes to the literature on patient perspectives (Pols, 2005; Rowland et al., 2017; Velpry, 2008) by exploring how accounts of the patient perspective link to a range of mechanisms of representation and are always shaped in interaction in specific tasks to be solved. Furthermore, the findings show how the patient story as a generic form and the experiential authenticity and emotional effects associated with it are elements that can both qualify and disqualify what comes to count as legitimate grounds for a patient perspective. What qualifies as legitimate and credible grounds on which to participate as a patient in quality improvement work is thus not static but is situational and assembled in relation to specific tasks and situations by both healthcare professionals and patients participating. This article thus contributes to discussions of representativeness, legitimacy, and credibility in healthcare service development (van de Bovenkamp & Zuiderent-Jerak, 2015; El Enany et al., 2013; Martin, 2008a, 2008b; Thompson et al., 2012) by exploring how patient perspectives and representation mechanisms can be multiple in the same setting and that situational shifting in and out of representation roles in the patient panel is closely connected to the tasks performed. It also points to the credibility of patients participating being based in the ability to shift in and out of these roles with a situational awareness of what input is suitable for the specific situation. Moreover, in line with Renedo and Marston (2015), who point to space as an important constituent for involvement, by coupling patient perspectives and representation to specific tasks, I argue that tasks are involved in defining the situational shape of the patient perspective and the situational representation role to be taken.

LITERATURE ON PATIENT PERSPECTIVES AND REPRESENTATION

Patient perspectives

In the literature, patients are ascribed a proliferation of roles, such as empowered patients (Andreassen & Trondsen, 2010), passive vs. active patients (Armstrong, 2014; Barbot, 2006), expert patients (Fox, Ward, & O’Rourke, 2005; Lindsay & Vrijhoef, 2009), patients as resisting consumers (Fox & Ward, 2006), patients taking part in partnerships (Brooks, 2008), or in lay–expert relations (Prior, 2003; Weiner, 2009). The role of patients involved in quality development is empirically described as patients taking on the role of participating in order to contribute with the patient perspective in these processes. The problem with this conceptualization is that it presupposes the existence of a relatively firm and well-established role for patients in this kind of work and also the existence of a patient perspective as something that can be extracted from individuals taking on this role. Velpry (2008), Pols (2005), and Rowland et al. (2017) open up this seemingly self-evident notion of the patient perspective in different ways. Velpry (2008) shows how the seemingly personal and individual ‘patient’s view’ or ‘patient perspective’ is created through negotiation in interactive processes between patients and staff in a French community mental health centre. She questions the assumptions that the patient’s view is inherently present in the patient and that it is per se empowering to elucidate it (Velpry, 2008, p. 239). On the basis of an ethnographic study of daily care in long-term mental health care in the Netherlands, Pols (2005) argues for going beyond patient perspectives in order to capture the situational and interactional dimensions of patient positions (p. 215) and thus escape the focus on the individual characteristics that the term implies. In a qualitative interview study, Rowland et al. (2017) explore how the concept of the patient perspective is used by both practitioners and patients participating in Canadian patient engagement programmes. They argue that the term ‘patient perspective’ is treated as a particular form of embodied knowledge based in experiences of vulnerability (Rowland et al., 2017, p. 11). In short, the abovementioned studies all open the black box of the patient perspective empirically in different ways. In this article – unlike Pols (2005) and Velpry (2008) – I deal with empirical material where the patient perspective is taken to be a *collective* entity; that is, how some specific patients are to speak on behalf of patients as such and how different accounts of what perspective the patients can contribute with to quality improvement work relate to specific mechanisms of representation, situations, and tasks to be solved. In this article, I thus take the patient perspective to be the overarching point of departure for examining how patients and their accounts come to count as legitimate representations of the patient perspective in different situations, coupled to specific tasks, through different mechanisms of representation. The ethnographic approach taken makes some of the dilemmas and balancing acts involved in this come to the fore.

Representation, legitimacy, and credibility

In the existing literature on patient involvement, the theme of representativeness and the legitimacy and credibility of patient participants' knowledge, experience, and expertise are central concerns (van de Bovenkamp & Zuiderent-Jerak, 2015; El Enany et al., 2013; Epstein, 1995; Martin, 2008a, 2008b; Thompson et al., 2012). Martin (2008a) argues that different understandings and constructions of representativeness exist between users and professionals. El Enany et al. (2013) show how professionalization of users by both professionals and users themselves create what they term unrepresentative involvement. Van de Bovenkamp and Zuiderent-Jerak (2015) show how the professionalization of patients required in order for them to gain credibility to participate in guideline development is also what comes to undermine their credibility as being representatives of 'true' patients (van de Bovenkamp & Zuiderent-Jerak, 2015, p. 9). They point to the unsettledness of how and on what grounds patients can participate in guideline development. These studies thus highlight the importance of considering both patients and professionals as part of the equation when dealing with these questions and how representativeness is built on a variety of grounds when examined empirically.

In this article, I will show that a legitimate and suitable account representing the patient perspective is something that is shaped and reshaped in different situations in relation to specific tasks and purposes and that ideas of representation and authenticity are involved in quite diverse ways. On a more general level, it thus points to what can be termed the representation work that the patients and professionals do in the patient panel; work that can be regarded as a new element of the work of healthcare professionals when they are to involve patients in quality improvement activities.

THE FIELD, METHODS, AND DATA

When interested in the patient perspective and how it figures in patient involvement on a collective level where some patients are to speak on behalf of other patients, an ethnographic approach focusing on the detailed local practices of patient involvement in quality improvement work in the department is suitable. The ethnographic approach makes it possible to notice the details of the work going into patient involvement activities that are important for understanding how the patient perspectives are interactional achievements related to situational concerns and specific tasks. The data used here stem from a larger ethnographic study of patient involvement in quality improvement work where the fieldwork was grounded in an oncology department. The oncology department was chosen as the site for fieldwork because, at the time of study, they were involving patients in quality improvement work in quite different ways and because one of the objectives of the study was to study patient involvement as more than isolated formal involvement methods simply applied in order to elucidate the patient perspective. As a whole, the fieldwork consisted of participant observation (230 hours, primarily meetings of different kinds), interviews (33), documents, and e-mail correspondence. The fieldwork took place from 2012 to 2015 with varying degrees of field engagement during the period, in part due to fluctuation in the intensity of the different processes studied.

In this article, I focus on one of the patient involvement activities studied in the oncology department: the patient panel. The patient panel is a group of both former and current patients in the department (during the time of study, 11 patients participated, with the number of patients participating at the same time ranging from 4 to 7) who meet with four professionals – the head nurse, a rehabilitation nurse, the development nurse, and a doctor – in the department four to five times a year. The meetings last for one and a half hours, and on the agenda are issues relating to different aspects of quality work in the department. Moreover, both the professionals and the patients have pre-meetings prior to the patient panel meetings. The professionals meet some weeks before in order to prepare the agenda for the coming meeting and the patients meet half an hour earlier on the day of the patient panel meeting to discuss the issues on the agenda before they meet up with the professionals. The patients also prepared before this pre-meeting, either individually, through e-mail correspondence, or in a Facebook group depending on the character of the issues on the agenda. During the period of fieldwork, the professionals also established a routine of having short follow-up meetings directly after the panel meetings.

The patient panel has been studied through meeting observations (18 meetings, approx. 30 hours of participant observation) , interviews with patients and professionals (seven with patients, one group interview with three healthcare professionals and six individual interviews with healthcare professionals), e-mail correspondence between patients and professionals, meeting documents, and preparation documents. The meetings observed have been the preparatory and follow-up meetings for the professionals heading and participating in the panel, preparatory meetings for the patients participating in the panel, and the patient panel meetings. Moreover, I have observed some instances where the patient panel members have been used for other tasks in the department (e.g., one of the patients giving a presentation at the introduction programme for new employees in the department and at a management seminar on how to work with patient involvement). The meeting observations have been carried out as participant observation in the sense of the researcher being present at the meeting table but not joining in on the discussions, thus taking a role as a passive meeting participant being present around the table writing on her iPad keyboard and participating in the small talk before and after the meetings. The observations have thus been less participatory than more traditional apprentice-like roles of fieldworkers partly due to my apparent lack of both professional expertise and experience of being a cancer patient that could have opened up for a more active participating role but also due to the primary interest in observing situations of interaction among the participants rather than focusing on the personal life world of the informants.

Interviews were also conducted: one group interview with the professionals early in the study, six individual interviews (with four different healthcare professionals, two were interviewed twice) at two later points in the fieldwork, and seven individual interviews with patients participating in the panel. The interviews were semi-structured and conversational in nature, lasted between 29 and 129 minutes, and were all audio-recorded and fully transcribed. The interviews can be thought of as scheduled occasions for conversation around the topic in question, and the planning was necessary due to the lack of informal time to spend with the informants because of the nature of the involvement activities consisting almost solely of scheduled meetings. Furthermore, the involved healthcare professionals had highly planned and tightly scheduled workdays and the involvement activities were not part of their everyday work (see Johansen & Pedersen, 2016, for a more elaborate discussion of the non-routinized and episodic nature of patient involvement in quality improvement work). The interviews are considered ‘active interviews’ (Holstein & Gubrium, 2003) in the sense that they are not moments of extracting readymade information from the participants but are situations where data is created in interaction between the researcher and the interviewee. Hammersley and Atkinson (2007) suggest that accounts can both ‘be read for what they tell us about the phenomenon to which they refer. Secondly, we can analyse them in terms of the perspectives they imply, the discursive strategies they employ and even the psychosocial dynamics they suggest' (p. 97). It is in this double sense that accounts from both interviews and observations are used here. Field notes and interviews were read, re-read, and thematically coded guided by the analytical interest in the patient and the patient perspective so often encountered during fieldwork. The coded data were then analysed by identifying both patients' accounts of how to speak on behalf of other patients in the patient panel, professionals' accounts and use of the term patient perspective, and situations where ideas of what the patients are to contribute with surfaced in specific situations in the patient panel.

FINDINGS

Evident from the fieldwork is the fact that the patient perspective is not something that is hovering about in the hospital or in or among patients, waiting to be discovered. Rather it is something that is made and remade in different situations in relation to specific tasks in the involvement activities. It takes efforts, arguments, and a lot of work from both the patients and the professionals participating. The interesting question therefore becomes: What goes into making a patient perspective? The analysis consists of two parts that each answer this question in different ways. The first part concerns the patients' accounts of how they are able to speak on behalf of other patients when participating in the patient panel. The second part concerns how the professionals – in contrast to the formal set-up of the patient panel where the individual patient story is not supposed to be central – come to ask for both more or less of a patient story when solving the specific tasks in the patient panel. It all points to different ideas of representation in play when patients and professionals work to involve patients in quality improvement.

'It is not just about me' – how to speak on behalf of other patients

The patients in the panel all have considerations about how they can speak on behalf of other patients in their roles as patient panel participants. They talk about their role as one of being representatives of patients in general in different ways and use different strategies to justify their positions. Three main strategies stand out across the interviews and informal conversations with patients from the patient panel. The first concerns strategies for how to represent not just one's own experiences but a conglomerate of patient experiences. The second concerns rendering probable that the personal experiences are not solely personal but also represent other patients' experiences. The third strategy hinges on a generality ascribed to having been patients going through similar processes in the same department.

Adding of patient experiences for variety

In the following interview excerpt, a patient explains how she tries to be sensitive to other patients' experiences in different ways and to relate this to her own participation in the patient panel:

> **Janet**: Well, in this role I see myself as not just Janet but as a number of patients in some way, it is about trying to be attentive to how people experience things, listen to what they say when they sit in the waiting room, for example. When I sit there, I observe people and hear their frustrations about things […] and I do the same when someone sits on the other side of the curtain [when doctors have conversations with patients in a shared patient room]. I try to listen to what is going on, because it gives some kind of picture of how things work. I have always been very privileged to have my CT scans and get the result the week after, but sometimes I overhear patients who experience having to wait for two or three weeks. Or, sometimes people come in and I can hear that their medicine is not ready – luckily, I have never experienced that – but I can hear that these things happen, and then I try to bring them up here [in the patient panel] when it is relevant (Interview, p. 8).

In Janet's account, she tells of actively collecting other patients' experiences through listening and observing what goes on around her when in the department in order to widen her own base of first-hand experiences as a patient with her own observations of other patients' situations. She explains that different experiences are collected and attempted to be contained and used as a repertoire or pool of experiences to draw from when participating in the panel. This can be understood as a representation strategy of adding. She explains that by adding other patients' experiences to her own, she obtains a *variety* of experiences. Having a *variety* of experiences to draw on is what stands out as the central quality and representation mechanism legitimizing that *she* can speak on behalf of others in the patient panel.

Let us turn to another way of speaking on behalf of other patients, where the central concern is not the variety of experiences but the typicality of experiences.

Screening personal experiences for typicality

Another patient in the panel draws the contours of another way of relating her own experiences to the experiences of other patients:

> **Louise**: … all the way along I have participated in workouts together with other lung cancer patients twice a week. I am also active in the lung cancer online forum, in the alternative cancer association and I am a member of the lung cancer association. I also try to be attentive to how others are doing, what triggers them, what is important to them in order to keep my balance. […] I try to listen to those I know who have cancer, I try to listen to what they say and try to sort out what my personal opinion is and what the more common issues among patients are (Interview, p. 6).

Louise touches upon her efforts to strike a balance between what her *personal* experience and opinion is and what is of a more *typical* character and points to this as a core concern for her when participating in the panel. Louise explains that she uses the collected experiences of others as a screening mechanism in order to estimate the typicality of her own experiences to find out if they are valid to raise and use in the panel. Once again, let us turn to another concern, that of generality of experiences.

Representing general experiences of cancer treatment

Charis has a quite different way of relating her own experiences to those of others:

> **Charis**: … regarding the easy gains I pointed at [at a recent meeting in the patient panel], I am certain that other people are also subjected to the same things. I am also certain that it is just as unpleasant for them as it was for me. It was not just my private matters but administrative issues and hospital routines that affected me […] and these small administrative errors or little practical misses have an enormous effect because you are in such a poor psychological shape – having cancer is like the ultimate life crisis and you are just too sensitive to deal with such inconsiderate bureaucrats (Interview, p. 3).

Charis' starting point is in her own personal experiences but she goes on to make it probable that they are like other patients' experiences, since they are explained as being created by general malfunctions in the 'hospital machine'. She describes that her own experiences are not just particular experiences of an individual patient; other patients go through the same misses and errors and are also affected by it. In making her own experiences with the ‘hospital machine’ and its ‘inconsiderate bureaucrats’ to be of a general nature, she does not need to collect a multitude of experiences in order to have a base from which to speak on behalf of other patients; instead, she extrapolates her own experiences to represent the experiences of patients in general. What comes to be the central representation mechanism is therefore the generality of the experiences that the ‘hospital machine’ is thought to create.

Now, let us move on to consider the professionals in the patient panels’ accounts of patient perspective and representation mechanisms.

Professionals’ accounts of perspectives

This part of the analysis is centred on a specific aspect of the question of what goes in to making a patient perspective; namely, on how both patient perspectives and the patient’s own story play different roles in the professionals’ answers to this question.

On being too much in your own story – when experiential and emotional authenticity disqualifies the strive for a meta-perspective

In the formal set-up of the patient panel, the participating patients are required to be able to lift themselves from their own story in order to be able to reach some kind of meta-perspective.

In an interview with three healthcare professionals in the patient panel, the interviewer asked if the panel members are taught or in other ways prepared for the task of being a patient panel member:

> **Lisa**: Well, they [the potential patient members] have an interview of 1.5–2 hours with the volunteer coordinator from the cancer society, who assesses them and also gets an impression of whether the patient panel is something they want to participate in or not.
>
> **Jane**: The interview also has a focus on how it would be to lift yourself from your own story. It is a lot about that. Are you able to step in on a level where it is not necessarily about the individual patient?
>
> **Leslie**: And about whether you can stay somewhat clear of your own emotions.

> **Lisa**: Yes, are they emotionally ready for this. The volunteer coordinators are used to assess this. They have a lot of volunteers and they use schemas they go through and stuff you need to fill out.
>
> **Jane**: But that does not change the fact that you sometimes have a member – also in this group – where you think 'come on'…
>
> **Leslie**: Is she ready for this…
>
> **Jane**: … because it is really difficult for her to stay clear of her own story, so we get the long version each time a question is asked. We easily understand why it is difficult, for sure. But if it gets to be so much in the detail, 'then I told the doctor', 'then the doctor said' [interrupted]
>
> **Leslie**: Yes, if they get too deep into their own story then there is a long way to a meta-perspective (Interview, p. 6–7).

The position a patient is to take in order to be a member of the patient panel gets carved out in this conversation between the patient panel professionals. It is a matter of emotions, the personal story and of staying clear of and distancing oneself from both – and the goal is a meta-perspective and to participate on a level where it is not about the individual. This is the formal position of the patient perspective in the patient panel – that patients are to participate with a meta-perspective, representing patients in general.

Just one perspective

At other occasions, the professionals also speak of the patients as contributing with 'just one perspective'. In the following interview excerpt, a nurse in the patient panel outlines this position:

> Well, the natural science perspective is voluminous in this culture, but it is only one side of the coin, we need to work with the recognition that some things only patients can tell us about […] Moreover, it is not the truth we get, we get some perspectives, we need to remember that, it is not a truth-panel (Interview, p. 9–10).

The nurse points to how the patients contribute with some perspectives different from those of the professionals' and that it is not a question of a truth about the matter. This stance – that sometimes just other perspectives are what is needed – also pervades in some of the tasks taken up in the panel: when the patients are asked to individually select and prioritize the three most important components of the patient-centred care model being implemented in the department in order to give input to the professionals' further work; when patients are asked to comment on written information material on patients' rights; or when giving input to the content of the information screens in the waiting rooms. The wish for just another perspective allows for internal disagreements and polyphony of the patients, and the question of reaching a meta-perspective and generality is thus bypassed in many situations and tasks taken up in the patient panel. So, when it comes to the specific tasks and interactions in the patient panel meetings, more fluctuating and nuanced versions of what a suitable patient perspective is emerge. It can even turn out that what is in principle deemed unwanted in the formal set-up of the panel – too strong a degree of personal story and the emotions related to it – can be just what is wanted in the situational solving of tasks in the panel. Let us turn to one such situation.

On being too little in your own story – when experiential and emotional authenticity qualifies as a patient perspective

The following field notes show how the fixed starting point in the formal set-up of the patient panel can be unsettled when it comes to the specific tasks performed in the panel:

> One issue on the meeting agenda is the use of patients from the patient panel in the introductory program for new employees in the department. The professionals and the patients discuss how the patients' presentation should be. One of the patients, Charis, asks: 'I find it a bit difficult to understand if we are to talk as a patient panel or as a person with personal experiences and emotions. Are we to talk about how it is – as a human being – to get this diagnosis and what you need in regard to eye contact, the emotional side of it, and the considerations the doctors need to take?' One of the nurses eagerly responds: 'It is just what we have in mind, because it makes a strong impression on the staff when you speak to the human and emotional side of this. We have a lot of factual information about the department. You represent the soft side; things that we [healthcare professionals] cannot get across, because we cannot pass on personal experiences. We can read it aloud but it does not have the same effect as when you tell it.' The doctor in the panel continues: 'Yes, the soft things catch our attention. That you are people standing here right in front of us, and not machines. The personal stories captivate us regardless of professional background.' (Field notes, patient panel meeting, August 2015).

In this account, several important issues are raised: Firstly, the fact that the patient expresses confusion about who she is supposed to be in this specific solving of a task points to it not being evident form where to speak as a patient participating in the panel. Secondly, the professionals say that they want the patient story because of the impression it makes when the patients, via the telling of their personal story, appeal to the human and emotional side of being a patient. This can be understood as pointing to some general human condition – the effect of the patient story does not depend on whether the listener is a nurse or a doctor or a medical secretary – the experiences and emotions conveyed in the story create the effect because the listener is also human. So, the patient story is described as a generic form that can create certain desired effects in the listeners. However, a completely random narrator cannot tell the story. The professionals point to the importance of the story being told by a patient who is physically present in order for it to have the desired effects on the listeners – to catch their attention, make an impression, speak to their (human) emotions – the story in itself is not enough, it needs the right person telling it. Not any narrator, but one who has the personal experience of being a patient – a healthcare professional who has a multitude of patient experiences to relay or a written personal patient story to pass on is not considered to create the same desired effect in the listeners. This makes the patient story a vehicle for conveying personal experiences and the emotions they are to generate in others. The pivotal point is not the concrete specificities of the particular patient's story but the effect that the specificities of *a* patient story is thought to have on the listeners. It is the supposedly generic effects of the patient story as a generic form that become central. As we have seen in this analysis, depending on the task and situation, emotions and the patient's own story can thus both qualify and disqualify participation and what counts as a patient perspective.

DISCUSSION: Balancing tensions between patient perspectives, representation mechanisms, and situationally defined tasks

Taking an ethnographic approach in this study has made it possible to see a detailed landscape of how a variety of concerns exist regarding how some patients are to speak on behalf of other patients and how collective patient perspectives are configured when patients are involved in quality improvement activities in the department. Three kinds of patient accounts of how patients are to speak on behalf of other patients and three kinds of professional accounts of which perspective patients are to contribute with and through which means in the empirical context of a patient panel in an oncology department have been analysed. The results of the analyses are summarized below, please note that for the sake of overview both patients' and professionals' accounts have been categorized as 'the patient perspective':

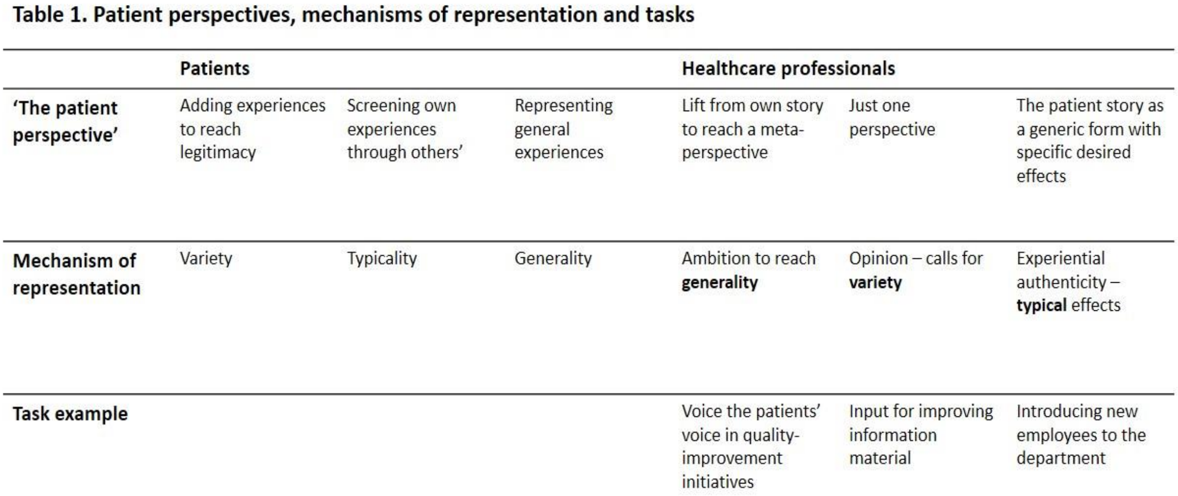

Table 1. Patient perspectives, mechanisms of representation and tasks

	Patients			**Healthcare professionals**		
'The patient perspective'	Adding experiences to reach legitimacy	Screening own experiences through others'	Representing general experiences	Lift from own story to reach a meta-perspective	Just one perspective	The patient story as a generic form with specific desired effects
Mechanism of representation	Variety	Typicality	Generality	Ambition to reach **generality**	Opinion – calls for **variety**	Experiential authenticity – **typical** effects
Task example				Voice the patients' voice in quality-improvement initiatives	Input for improving information material	Introducing new employees to the department

As can be seen, quite different constellations of patient perspective, mechanism of representation and tasks exist when accounts of what perspective the patients can contribute with and how some patients come to represent other patients are explored empirically. As can be seen in the table above, perspectives are related to different situational concerns and specific tasks and very different mechanism are involved.

The table shows how patients' accounts relate to different mechanism of representing other patients and how patient experiences take on different positions in the different accounts. In the first account, the adding of other patients' experiences to one's personal experiences is central and to collect a wide *variety* of experiences comes to be central. In the next patient account, the mechanism is slightly different, since the experiences of other patients are used as a screening device to evaluate the *typicality* of the patient participant's own experiences. Lastly, in a third kind of account, the ability to speak on behalf of other patients is ascribed to the shared and thus *general* nature of the experiences that patients are thought to have when going through the same processes in the hospital.

From the analysis of the professionals’ multiple accounts of patient perspectives and what patients are to contribute with in the work of the patient panel, some distinct mechanisms also stand out. When patients are to contribute with a meta-perspective detached from their own patient story, this involves striving for generality, and this perspective comes to resemble the decontextualized patient perspective, as it is used in policy and in the way it is talked about as seemingly self-evident entity in the hospital. However, when it comes to specific tasks and situations, other versions emerge. Describing the patients as being able to contribute with ‘just one perspective’ points to the need for variety and loosens the aspiration to reach a general stance and turns it more into a matter of opinion. The last part of the analysis pointed to how in some situations coupled to specific tasks, the individual patient story – deemed not central in the set-up of the patient panel – can also become exactly what is asked for due to the effects it is considered to have. The patient story, its emotional effects, and its bearings of authenticity come to take a surprising role as a particular kind of representation, where the patient story as a form, more than specific content, is central. The patient story, the experiential authenticity associated with it, and the emotional effects it is considered to have on the audience can thus both qualify and disqualify it in the situational conception of what a legitimate patient account, and thus a suitable patient perspective, is in the specific situation. The analyses have shown that, when involving patients in quality improvement work, the professionals juggle situational versions of patient perspectives hinged on quite different mechanisms of representation building on generality, opinions or authenticity, and generality, variety, and typicality.

The contribution to the literature on the patient perspective (Pols, 2005; Rowland et al., 2017; Velpry, 2008) thus lies in exploring the collective level, where the patient perspective is not just considered to reside in an individual but as a collective entity somehow able to represent patients as a general category. Rowland et al. (2017) also look into the collective level in their interview study of the use of the concept of the patient perspective; however, in the ethnographic approach taken in this study looking across situations and activities of involvement in addition to interviews, it becomes visible that multiple versions of what a suitable collective patient perspective is exists and that the configuration of it is closely tied to specific tasks and situations.

Existing studies of patient involvement point also to questions of representation and credibility (van de Bovenkamp & Zuiderent-Jerak, 2015; El Enany et al., 2013; Martin, 2008a, 2008b; Thompson et al., 2012). This study adds to two dimensions of these discussions. Firstly, van de Bovenkamp and Zuiderent-Jerak (2015) argue that by gaining epistemic credibility to participate in guideline development, some patients can end up losing their credibility as representatives of ‘true’ patients. This study adds to this by pointing to the kaleidoscopic representation roles patients can come to take on in a patient panel depending on the situation and task – shifting in and out of representation roles depending on specific tasks. Moreover, their credibility can therefore be argued to hinge on their ability to shift in and out of these representation roles and to have situational sensitivity to know, for example, how to use their own story in an appropriate manner or when it is legitimate to draw on their professional background. Secondly, El Enany et al. (2013) show how the professionalization of service users can result in unrepresentative involvement and that both professionals and patients are complicit in the process. The complexity of the representation base, the kaleidoscopic representation roles, and the many strategies of patients for speaking on behalf of other patients found in this study loosens the coupling of patients to fixed bases of representation somewhat implied when talking of unrepresentative involvement. However, this is not to say that the patient participants are not predominantly middle-class, white, middle-aged, and women, but rather to loosen the strong connection between personal characteristics and representation. This study has also shown that the specificity of tasks, the form of patient input, and the interaction between patients and professionals is shaping patient perspectives and representation.

CONCLUSION

In conclusion, this study has shown how patients and professionals are shaping patient perspectives around specific situations and tasks when involving patients in quality improvement work. When doing the specific tasks in the patient panel, different situational versions of the patient perspective are established. Thus, there is not one way of speaking on behalf of others or of framing what the patients are supposed to participate on the basis of in quality improvement work. Some tasks more easily contain internal differences between the patients in the panel and make the differences beneficial (e.g., feedback on a questionnaire to be sent out to new patients before they come to their first appointment), while other tasks are difficult to solve if the panel is not unanimous (e.g., for the professionals to present the panels’ position on a subject in a quality council meeting). The findings show, how the patient story as a generic form and the experiential authenticity and emotional effects associated with it by the professionals are elements that can both qualify and disqualify as a suitable patient account and representation of the patient perspective depending on the situation and task to be solved. A legitimate patient account in quality improvement work can thus be based in both an ideal of detached representation of others and in an ideal of the effects of experiential authenticity and the format of the patient story that becomes a quite different figure of representation. What has been discussed in this article is of course not an exhaustive list of elements and mechanisms of representation when patients are involved in quality improvement work. However, it has been shown how the patient perspective is a situational achievement created in interaction between patients and professionals in relation to specific tasks, not something inherent in more or less representative patients waiting to be involved. What constitutes legitimate patient accounts or suitable patient perspectives thus varies from situation to situation. This points to the potential unfruitfulness of trying to ensure representation by carefully selecting standardized methods for involving patients in quality improvement, by focusing too much on finding the ‘right’ patients to participate, or in training them to become ‘better’ representatives. At least, it bears on a very specific understanding of representation. This also points to the demands put on healthcare professionals, who are often the ones to frame and concretize the involvement activities when representation work becomes an expectation in and of the hospital. In addition, the patients take on complex representation roles where it is not necessarily evident what a legitimate contribution is based in e.g., when to and when not to use one’s own patient story actively. All of this points to the complexity of the representation work that both healthcare professionals and patients can face when fulfilling the policy call for involving the patient perspective in quality improvement work.

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Article 3: Patient involvement and managerial work: Juggling representation, intervention and organization

Patient involvement and managerial work: Juggling representation, intervention, and organization

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ABSTRACT

Patient involvement has become a standard expectation in healthcare and a large body of literature addresses involvement methods, principles, and precautions. Although it is generally agreed that health managers play a role in achieving patient involvement, there is only little research into the required managerial work and decisions. This article offers a systematic analysis of managerial work related to patient involvement in hospitals. Based on an ethnographic field study of patient involvement practices in a Danish university hospital, we present four maximum variation cases covering different types of representational processes and impact. Drawing upon the anthropology of knowledge and sociology of work, we analyse the types of managerial work at play in these cases and the associated types of risk and balancing acts. We synthesize findings in a matrix, which we argue can help to sort patient involvement projects according to the types of managerial work and risks they present. In so doing, we contribute to the literature on patient involvement as well as to notions of healthcare management.

Keywords: Patient involvement, hospitals, quality management, managerial work, representational work, boundary work, articulation work, organization

1. Introduction

Involving patients in their own care as well as in quality improvement of healthcare has become a standard expectation in contemporary hospitals and clinics, and patients are increasingly playing a role in the organization of healthcare (Kjær & Reff, 2010; McDermott & Pedersen, 2016; Zuiderent-Jerak & Berg, 2010). Nevertheless, the organizational and managerial preconditions and consequences of these changes remain largely under the radar. An example in case is the ambition of the Danish Accreditation Programme to involve patients in quality improvement, but with little specification of how this should managerially be handled and carried out locally (National Council for Quality Development in Healthcare (Det nationale råd for kvalitetsudvikling i sundhedsvæsenet), 2002; IKAS, 2012). Likewise, there is a need for investigating the importance of managers for successful adoption of the patient involvement agenda among staff (Armstrong et al., 2013; Coulter, 2012; Wiig et al., 2013).

The role of management in healthcare tends to be addressed in general terms of health governance, as a matter of professional struggle, or from a critical perspective in terms of 'managerialism' and consequences of New Public Management. Despite a rich tradition of ethnographic workplace studies within healthcare, there are only a few studies of managerial work as concrete and organizationally situated practices. In this paper, we investigate patient involvement projects with a particular focus on the decision-making processes and practical work of managers. Taking inspiration from the anthropology of knowledge, sociology of work, and organization theory, we conceptualize patient involvement as involving simultaneously representational practices and intervention practices and investigate patient involvement projects at a medical centre in a Danish university hospital along these lines. We single out four maximum variation cases (Flyvbjerg, 2006) and analyse the representation work (Strauss et al., 1985), boundary work (Gieryn, 1999), and articulation work (Strauss et al., 1985; Strauss, 1988) carried out by health professionals and managers in these cases. On this basis, we propose a matrix in which patient involvement projects can be sorted according to the representational complexity they involve and the concreteness of their organizational impact. We show that managerial work varies across these dimensions and that health managers can use these findings to practically plan, adjust, and organize patient involvement activities.

2. Literature review

The literature on patient and public involvement is vast, but the literature specifically on involving patients in quality improvement is more limited (Groene & Sunol, 2015). The role of healthcare professionals has been explored, for example, in terms of control and power imbalances in the relation between professionals and patients in the involvement activities (Daykin et al., 2004; Fudge, Wolfe, & McKevitt, 2008; Rutter et al., 2004; Solbjør & Steinsbekk, 2011). Furthermore, organizational context and culture is emphasized as important for the involvement processes (Renedo et al., 2015). The role of management for patient involvement in quality improvement, however, is less clear. There have been several calls for studying this particular aspect (e.g., El Enany et al., 2013), but also calls for studying how managers at more general levels help strategic implementation or adoption of the patient involvement agenda among staff (Armstrong et al., 2013; Coulter, 2012; Wiig et al., 2013). Croft et al. (2016) foreground the role of managers in their study of public involvement in the area of healthcare commissioning. They argue that varying degrees of public involvement can be attributed to the role of managers rather than professionals, that ideologies of rational managerial control affect public involvement negatively, and that managerial domination is a reason for why public involvement in service delivery is not more radically accomplished (Croft et al., 2016, p. 132). In this article, we unfold the role of managers beyond these few findings and explore concrete aspects of managerial work and their significance for the implementation and organization of patient involvement in quality improvement. First, however, we need to specify what we mean by patient involvement.

Patient involvement comes in many forms and employs tools and techniques borrowed from the social sciences, psychology, public engagement, and other fields. In our study, we found it useful to sort the methods we encountered into two types of involvement methods. The first type we designate ‘research-like involvement methods’ which seek to capture and represent patients’ experiences and opinions through social scientific methods. This category resembles what others have termed market research methods (e.g., Kreindler, 2009). The second type we call ‘participatory involvement methods’ as they all somehow seek to involve selected patients directly in decision-making processes as representatives of patients in general (e.g., in a patient panel, a working group, and as presenters at seminars). This category somewhat resembles what have been termed ‘deliberative methods’ (Abelson et al., 2003; Martin, 2012), although it covers all methods with direct representation of patients. In the literature, the different involvement methods have been discussed in terms of their different significance and effects. Thus, Kreindler (2009) points to the connection between involvement and the meanings and purpose behind involvement (consumerism versus participatory democracy) and the methods chosen (market research methods versus participatory methods) and, finally, to the differences in complexity and focus of opinions offered by the methods. Rowe and Frewer (2005, p. 285) present a typology of public engagement mechanisms according to the flow of information between the sponsor of the involvement exercise and the participants and argues that efficiency of the exercise can then be ascertained based on efficiency of the flow of information. Tritter and McCallum (2006) criticize a classic model of citizen participation, ‘Arnstein’s ladder’, for only being concerned with the power to act in formal decision-making processes. They argue that it is also relevant to consider the processes as well as the diversity of methods, user roles, and quality of involvement. Thus, meaningful involvement links the participants’ views to actual change in healthcare (Tritter & McCallum, 2006, p. 166). However, several authors have argued that there is only weak and limited knowledge regarding the impact of involvement on the healthcare services in general (Crawford et al., 2002; Mockford et al., 2012; Nilsen et al., 2006) and quality improvement specifically (Groene & Sunol, 2015). In the following, we will contribute to this discussion of effects of different involvement methods by addressing the managerial action and balancing acts required for the methods to work and for their concrete impact. In so doing, we argue that the actual effects of methods depend not simply on their ‘nature’, but just as much on the practical ways in which they are put to life in organizational settings.

3. Theoretical framework and methodology

3.1 Theoretical framework

To guide our analysis of the managerial work related to patient involvement methods and their consequences, we draw on the anthropology of knowledge and the interest in different ways of knowing and the social processes through which knowledge is made (Roepstorff, 2000). In his study of biological and fishery knowledge in Greenlandic halibut fishing, Roepstorff (2000, p.

167) proposes to explore knowledge production through the ‘who’ (whose knowledge), the ‘what’ (what counts as knowledge), and the ‘how’ (how is knowledge produced) of knowledge. We consider this a useful frame for investigating the managerial work involved in using different involvement methods (how knowledge is produced) to gain knowledge on patients in the shape of patient representations (whose knowledge) and the work going into reaching a patient representation found suitable for guiding interventions (what gets to count as knowledge). We supplement this perspective with a microsociological approach to work inspired by Anselm Strauss and colleagues. They suggest that work is an often neglected but highly relevant object of study in itself. Focusing upon the practical work going into the accomplishment of a phenomenon such as patient involvement – “its task sequences, its organization, its many variants and their conditions and consequences, its articulation, its evaluation processes” (Strauss et al., 1985, p. 289) – allows a deeper and more nuanced understanding of this phenomenon. With inspiration from Hacking (1983), we employ the notion of ‘representation work’ to put emphasis on the way patient involvement involves numerous considerations and efforts to represent ‘the patient’ and his or her ‘knowledge’ in quality improvement. We take the term to denote the specific work going into negotiating, sorting out, and deciding whether patients should be involved, what they should be involved in, who is to be involved, and how and what representations can be used for ‘intervening’ in existing practices. Another concept, we have taken inspiration from is Gieryn’s notion of ‘boundary work’. He defines this as: “The discursive attribution of selected qualities to scientists, scientific methods, and scientific claims for the purpose of drawing a rhetorical boundary between science and some less authoritative residual ‘non-science’” (Gieryn, 1999, pp. 4–5). The boundary work foregrounded in this analysis is the work of managers of delimiting what patients are to be/not to be involved in and of establishing a boundary between representation and intervention phases when involving patients in quality improvement activities. The last type of managerial work discussed is ‘articulation work’ (Strauss et al., 1985; Strauss 1988). Strauss et al. (1985) write about articulation work in relation to tasks and lines of work for an illness trajectory:

> Both require ‘coordination’, for they do not automatically arrange themselves in proper sequences or with proper scheduling. In other words, further work – *articulation work* – must be done to assure that the staff’s collective efforts add

> up to more than discrete and conflicting bits of accomplished work (p. 151, emphasis in original).

With inspiration from this, we use the concept of managerial articulation work to give attention to a specific element of managerial work, managerial monitoring, and coordination.

3.2 The organizational setting

The data is gathered as part of an ethnographic study of patient involvement in quality improvement work in a medical centre in a Danish university hospital. The centre consists of four departments and a cancer research laboratory, approximately 900 employees in total. A team of one head nurse and one head doctor manages each department, and the management teams meet in bi-weekly Centre Council meetings with the centre management. Each department comprises several units, for example, the oncology department contains six teams based on the different types of cancer they treat, a phase 1 team (for patients receiving experimental cancer treatment), and a cancer research unit. The other departments of the medical centre are the haematology department, the department of rheumatology and infectious diseases, and the radiotherapy department.[19] The ethnographic fieldwork took place from 2012 to 2015 with varying degrees of field engagement due to fluctuation in intensity of the processes studied. Patient involvement in quality improvement is a not very formalized or institutionalized phenomenon in Danish hospitals (for a more thorough discussion of the methodological consequences of this, see Johansen & Pedersen, 2016), but the fieldwork primarily took place in different kinds of meetings relating to specific activities of involving patients in quality improvement. The fieldwork was thus not a classical organizational ethnography based on being present for an extended time in a spatially bounded everyday life of an organization (Ybema et al., 2009) but followed patient involvement activities across teams and units and implementation processes across organizational and project levels. This is more in line with shadowing (Czarniawska, 2007, 2008), where the shadowed entity is not persons or material objects but a phenomenon, and, with Mol (2002), foregrounding how a phenomenon is not a given stable entity but enacted in specific situations and practices.

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[19] This was the organizational setup at the time of the study; it has subsequently been changed due to reorganizations.

3.3 The patient involvement projects

In order to include patients' opinions and experiences of healthcare services in the adjustment and development of these, surveys and interviews are common methods used, also in the medical centre studied. One general initiative is the National Survey of Patient Experience (LUP), which is mandatory for all Danish hospital departments to be part of. LUP is an annually recurring national survey focusing upon the experiences of patients in the individual departments. The questionnaire is sent out to 250,000 patients and consists of forty questions addressing themes such as admission, course of treatment, staff, information, and overall impression of the stay in the department.[20] The departments are encouraged to work with the results in their quality improvement efforts. Advice on how to do this is available from the regional unit in charge of planning and carrying out the survey, but it is the local management who decides how the results are used locally in the departments. Aside from this national initiative, the centre also used self-initiated surveys (e.g., in the course of the implementation of a patient-centred care model in the centre), where the surveys were used to obtain a baseline from which the project progress could be measured. The managers of the cancer department also used, for example, surveys from the Danish Cancer Society on cancer patients' experiences in the hospital in their quality work. In the managers' choice of involvement methods in the field studied, interviews were also common. These appear in different versions such as focus group interviews, individual interviews, and feedback meeting interviews.[21] At the time of the fieldwork, a large number of group interviews (43 in total, hereof 22 with patients and relatives and 21 with staff – in total covering 243 persons) were conducted as part of an internal organizational analysis informing the implementation of a patient-centred care model in the medical centre. Group interviews were a central element and aimed to guide and inspire decision-making on what changes to initiate in the project. Moreover, interviews were used in a later observation- and interview-based inquiry by external consultants into what patients found most pertinent to improve in the centre.

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[20] The survey was changed in different ways during the time span of fieldwork. Here, we relate to the questionnaires before 2014. Questions are customized for two sub-groups of patients: outpatients and admitted patients. Twenty of the 40 questions are used nationally, while the remaining are region-specific elaborations on different aspects of the themes.

[21] Feedback meetings are meetings where a group of patients is interviewed on a predefined topic area, typically by an external consultant in front of listening staff from the department(s) involved.

In the medical centre, different kinds of participatory methods were used for different occasions: patient presentations at different kinds of meetings and teaching (e.g., an introductory programme for new employees or at seminars), patients as participants in a project steering group or task forces, and patients participating in a patient panel in a department or in relation to a project. The methods were typically facilitated by external consultants (e.g., from the regional unit facilitating patient involvement) or by local healthcare professionals, typically in managerial or specialist functions such as head nurse, rehabilitation nurse, or development nurse. The departments and the managers had very different levels of experience in working with such participatory methods. For example, the Oncology Department had some experience in working with a patient panel and had experimented with using patient representatives for giving presentations (e.g., on their experience with rehabilitation used in a nursing course and in the introductory programme for new employees in the department). Other departments and their managers did not have as much experience with this kind of patient involvement but nevertheless had to relate to it and consider what to establish in their department to meet the patient-centred care project running across the centre.

3.4 Ethnographic data

The fieldwork consisted of 230 hours of participant observation and 33 interviews with managers, healthcare professionals, and patients. In addition, it included the collection of documents and e-mails. The participant observation was conducted in fora relating to patient involvement and quality work: centre council meetings, quality committee meetings, meetings, seminars and workshops relating to the implementation of the patient-centred care model, patient education sessions where patients’ feedback on quality issues was relayed back to the head nurse of the team, and patient panel meetings, including patients’ and professionals’ preparation preceding meetings. The implementation of the patient-centred care model involved all four departments and their managers, and the project was followed both at the shared level and in the oncology department. The rest of the activities studied were located in the oncology department. The role of the fieldworker in the meetings and seminars was primarily that of a silent meeting participant present in the meeting together with the other participants. The interviews were performed with patients, healthcare professionals, and managers involved in quality work and with experience of involving patients herein. The interviews lasted from 29 to 129 minutes, were audio-recorded, and were subsequently transcribed. The interviews were conducted as scheduled conversations' due to the sparse time (and space) in which to talk informally with the informants during fieldwork due to the informants' highly scheduled work day. The interviews were thus quite explorative in nature with open questions about patient involvement in quality improvement and the interviewees' experiences with this phenomenon. The interviews are thus not seen as moments of extracting readymade information from the interviewee but as dynamic interactional conversations on a certain topic (Holstein & Gubrium, 2003). Five of the interviews were made as pair interviews with the management teams of each of the departments and the centre management team. These interviews comprised much dialogue among the interviewees, resembling somewhat the negotiations taking place in the observed meetings and seminars. On the basis of the analysis of data with a focus on managerial work associated with different patient involvement methods, we selected four maximum cases (Flyvbjerg, 2006, p. 230) covering two tensions: process/length of chain of representation and type of impact.

4. Results

In the following, we present four maximum variation cases representing research-like methods and participatory methods respectively. We address two cases from each category: an involvement process requiring rather simple and straightforward managerial work in going from the initial representational activities to intervening in healthcare and another example requiring more complicated and lengthy efforts. We then summarise the differences between cases in terms of representational work, boundary work, and articulation work of the managers.

4.1 Patient involvement through research-like methods

The research-like involvement methods work by producing and analysing data on patients' views and experiences through qualitative and quantitative methods from the social sciences and making them inform the quality of healthcare. In some cases, data and decision context are of a kind where there the patient knowledge is of immediate relevance and spurs concrete action. In other cases, the route from representation to intervention is more convoluted or fails to be made.

A direct route from representation to intervention

Sometimes the data on patient experience feeds directly into decision-making regarding the organization of healthcare. One such example is the input from patients generated in a group interview during a feedback meeting held by one of the teams in the cancer department together with the surgical team. The interview centred on the patients' experiences of the transition from surgical to medical cancer treatment. Seven patients who had recently experienced such a transfer participated, along with a group of healthcare professionals and managers affiliated with the surgical and medical teams. An external consultant from the regional office facilitated the interview, and the questions centred on: How did they experience their course of treatment in the surgical and medical department? And did they experience the transition as coherent? This was supplemented with questions on waiting time, rehabilitation, and relatives. The process from representation to intervention went relatively smoothly in this instance. The interview was carried out, the data was discussed by members of the project group and steering group, and the specific issues to be acted upon were brought to the relevant department. A specialist nurse, who was involved in the planning and follow-up of the feedback meeting, explains how:

> [T]he first cycle of chemotherapy is not given on Fridays anymore. It was something they [the patients interviewed] found problematic, because if they fell ill [due to the chemotherapy], they felt they had no place to turn to because the oncology outpatient clinic does not have a bed unit. They did not feel safe in this. Moreover, if any questions would arise after the first chemotherapy they could not get hold of their contact nurse before Monday … In addition, on the basis of the interview, we listened to the interview again and the heads of department contacted the centre providing rehabilitation and had a meeting with the manager regarding the problem with rehabilitation (Interview, Specialist Nurse).

In this instance, the problems addressed by the patients were regarded as clear and deemed solvable: The start-up of new patients' chemotherapy treatment could be reorganized and external collaborators contacted in order to better organize the patients' course of treatment.

When patient representations create a need for additional representations

At other times, the route from generating data to acting on them is less clear and easy (e.g., if uncertainty arises regarding the generalizability of data). This is evident in the following example. An extensive organizational analysis based on a large number of group interviews of patients was supposed to inspire and guide the managers to make the departments more patient-centred. The interview data was processed by external consultants, who presented the results in department-specific reports as well as a joint centre report. The reports gave a rich picture of the patients' views and opinions regarding 10 pre-defined components of patient-centeredness. The department managers, however, found the amount of data and details overwhelming and that it was not obvious how to use them for making decisions. It was objected that it was unclear how many patients shared the experiences and opinions raised in the interviews: Was it just one single patient who found something to be a problem? Was the issue just one problem among many or was it an *important* problem?

> There are some big challenges since we don't know how many said what, so we can end up changing things in our organization that only one patient has pointed to … and moreover, I do not know if it is a matter of great or little importance for that particular patient (Interview, Head Nurse).

After the report was presented to the managers, they met in seminars to identify and prioritize shared areas to improve in the centre. Here, new questions and issues emerged regarding a shared focus, since the departments comprise rather different types of patients. In addition, they had to balance local results and priorities against general priorities of the hospital and the region. One of the areas they chose to work with was the reception of patients, and a project group and patient panel was established to work with this. However, the need to ask a broader group of patients soon emerged in order to supplement the patients in the panel: What were the *important* issues for patients regarding their arrival in the departments? Did they feel welcome and experience the stay at the hospital as pleasant? The project group decided to have a group of external consultants carry out a new round of data collection including observations and interviews with patients that were hospitalized in two of the departments in order to find out what really mattered to them. The results presented by the consultants centred on seven pain-points' identified in their data material. The pain points should help the project group identify specific improvement initiatives. At a planning meeting, the project manager presented this new data collection as a fine-tuning effort:

> We had some very competent anthropologists who went out to do observations and interviews with the hospitalized patients as well as patients in the outpatient

> clinic in both an oncology unit and an infectious disease unit. We told them that we were up to our ears in data, we had way too much, and that they needed to help us point to what is the most important to work with, what really hurts in the patients' encounter with us, where do we need to concentrate our efforts. And they provided us with seven pain points, that is what they called it, and they are what we are working on, it has been tremendously useful. That way of working is also a way of providing the patient's voice to us, of processing it in a way, and they reach some patients who do not have the strength to sign up for a patient panel. Some of them were very weak and had difficulties expressing themselves, but they [the anthropologists] give them a voice (Field notes, planning meeting).

The anthropologists were delegated a role as navigators in the heap of data in order to single out the 'ordinary, authentic patients' rather than the ones signing up for a patient panel or a group interview. They developed a list of seven specific problem areas anchored in the statements of what was presented as 'authentic patients' in their 'natural settings', which the project group found good to work with.

In this example, one type of patient data creates the need for additional data before specific interventions can be determined. However, sometimes the process from representation to intervention can be even longer and involve several rounds of data gathering before intervention can happen (e.g., if the circumstances of a given issue continue to be unclear or if patient representations contradict each other and it is difficult to decide which one to trust the most). In some instances, patient representations are accumulating on an issue that is not acted upon because managers hesitate or refuse to do so (e.g., regarding the patients' concerns around issues relating to alternative treatment). Finally, it can be difficult to act on patient representations if the local managers are dependent on higher-level managers to approve changes or provide the necessary economic framework. The following is an excerpt from a group discussion among five managers at a managers' seminar regarding the purpose of involving patients in quality improvement in their respective teams:

> Team Nurse: I think that we ask the patients a lot and have many data pointing in the same direction. I really want to do something!
>
> Head Doctor: What you are saying is that we should not do patient involvement in order to create knowledge we cannot act upon. What is the space for

> managerial action? Can we get red chairs or do we need to be content with only getting red combs? … For a long time, we have known that patients experience that they meet too many different health professionals, but if we do not have the possibilities to change it, then we should not keep asking!
>
> Team Nurse: We have data from 2011, 2012, 2013, but nothing happens. We simply cannot keep asking (Field notes, management seminar).

As discussed above, the process from patient representation through data to specific intervention can thus be convoluted due to many different reasons when patients are represented as data. Let us now turn to another type of involvement methods where patients are represented not as data but as participating persons.

4.2 Patient involvement through participatory methods

Participatory involvement methods work by direct representation of patients in selected involvement activities. This entails other questions and concerns than when working with the research-like involvement methods. In the following, we describe two cases of going from patient representation to intervention differing in the character of intervention purported.

Involvement through direct participation in tasks

The following is an example from the patient panel of the Oncology Department of an involvement activity where patient representatives contributed directly to adjusting or developing current practices. The patients in the panel often receive a concrete task to carry out before or at the meeting – a task chosen by the managers and healthcare professionals running the panel. The patients are to prepare either individually (in order to get as much input as possible) or in collaboration (in order to get some degree of shared opinion), depending on the specific task. One such task was to comment on a two-page ‘conversation tool’ that should help cancer patients prepare for conversations with healthcare professionals about their rehabilitation needs. The guide was in its final stage of development before being distributed to patients. At the patient panel meeting, the patients pointed to several issues. One of the patients wanted the category ‘depression’ removed from the list of possible challenges facing a cancer patient. The patients found depression to be a *diagnosis* and were worried that patients cannot distinguish this medical condition from experiences of ‘sadness’, ‘anxiety’ etc., which were other optional categories in the tool. Furthermore, they were concerned with the consequences of ticking the depression box: Will anti-depressants then be prescribed? On the basis of those comments, the category was removed and additional input from the patients used to adjust the final version of the conversation tool.

This way of involving patient representatives in a specific task does not raise a concern for validity or representativeness. Such concerns have usually been dealt with before asking patients to participate, for example, in the selection of patients. However, the involvement in tasks is no guarantee of actual impact. Many obstacles can occur along the way, such as when the patient panel gave feedback on a pamphlet addressing complicated judicial matters. It was anticipated to be a straightforward task, but it turned out to be difficult to implement the suggested changes due to the regional office's pamphlet format requirements. In this way, patient input has to be calibrated against economical, professional and legal standards, and interests.

Participatory methods as diffuse interventions

Patients can also be involved in a more indirect fashion. This can, for instance, be an involvement activity where the participation of patients sharing their experiences was intended to be an intervention in and of itself. This simultaneous representation/intervention is hoped to influence health professionals so that they might change their behaviour or creatively come up with inventions themselves – thus, an intervention of a more diffuse nature. An example illustrates this. The Oncology Department regularly invites patients to be presenters in an introduction programme for new employees. The patients are asked to orally present "What is important for me as a patient in the encounter with the staff in the Oncology Department?" The talks present topics chosen jointly by the patients in the panel but also aim to display some of the specific experiences of being a cancer patient based in the individual patient's own experiences and thus elements of their patient story. The patients of the patient panel take turns in presenting (the seminars are held once a month) and they are free to use details from their own illness case. It is not so much the *particular* details of the individual patient story that are important in this kind of involvement as it is the general effect that the relaying of specific experiences of a patient story is intended to have on the audience (e.g., the healthcare professionals present). A nurse explains:

> … it makes a strong impression on the staff when you speak to the human and emotional side of this. We have a lot of factual information about the department, but you represent the soft side: things that [healthcare professionals] cannot get across, because we cannot relay these personal experiences. We can read them aloud, but that does not have the same effect as when you tell it. A doctor on the panel continues: "Yes, the soft things catch our attention: that you are persons standing here right in front of us, and not machines. The personal stories captivate us regardless of professional background" (Fieldnotes, patient panel meeting, August 2015).

Accordingly, this type of patient involvement seeks to intervene directly in the staff's perception of patients and through communicating elements of the personal story and particular patient experiences to install an awareness of 'patientness' as a human condition. This is hoped to have an effect on the professionals' general approach to patients. Thus, it is an indirect or second order intervention targeted at the general perception of patients and the professional culture and thereby improving patients' satisfaction with the treatment and care received. However, it is also an intervention that is difficult to monitor, control, and ensure.

4.3 Managerial representation, boundary, and articulation work

The four cases represent 'easy' as well as more convoluted involvement processes, just as they outline different degrees and types of impact. No matter what, they all require significant work and balancing acts of the healthcare managers in charge of them. In the following, we analyse this work as, respectively representation work, boundary work, and articulation work.

Representation work

The term 'representation work' designates the practical activities related to defining, selecting, probing, and documenting the viewpoints and characteristics of patients in the effort to involve them. Since patient involvement has become a strong expectation in healthcare, representation work is an increasingly important concern for managers. This implies, for instance, selecting the involvement method fit for the purpose and goal of involvement (and, if the goal is unclear, contributing to clarifying this). It also implies the selection of 'suitable' patients to involve, which is not always obvious. Finally, it also involves finding an appropriate representation form (e.g., numbers, stories, a number of cases) in order to be able to use the representation gained for the specific purpose. What an appropriate form is depends on the situation. A coordinating nurse described, for example, how she collected a list of social security numbers in relation to a specific problem encountered by the patients she was in contact with. She knew that she could get across to the management team with a *list of specific cases*, not with one individual case, even though the problem from her perspective was perfectly valid in itself. This points to form as an important marker of validity, depending on the situation.

The representation work differs from one involvement method to the other. In the research-like methods, a lot is accepted simply as part of a given method's 'scientific nature'. For example, the patient as a category is not questioned in the same way as when patients are directly involved as specific persons. Likewise, a questionnaire produced by external parties tends not to spur discussions of what patients should be asked about. These and other features of the research-like methods work to displace potential disagreements 'downstream' to the specific situations where the data should feed into decision-making. For the participatory methods, the representation work has a different character. Typically, managers are not very familiar with these types of methods, and because they often personally encounter the actual patients, their attention can be drawn to these patients as good or bad personal representatives and to pre-selecting patients on such grounds. In this way, relational aspects and 'impression management' come to the fore in the managers' representation work.

Boundary work

In order to facilitate representation work, the managers must also carry out a certain 'boundary work'. Boundary work can be seen as a question of rational managerial control (cf., Croft et al., 2016) but is better viewed as a broader set of concerns regarding the practical and political demarcation of the involvement activity. Thus, it includes the work of deciding what to include or exclude from patient involvement activities as well as drawing boundaries between representation and intervention. This boundary work frames (and sometimes also enters) the representation work in the sense that it occurs both before embarking on an involvement activity and at the end of an involvement process. For the participatory methods, the managers' boundary work pertains, for instance, to questions of inclusion/exclusion *preceding* the involvement activity (e.g., what roles and relations are possible for patients and professionals) and for example implies the roles of patients in seminars (e.g., as listening participants, active presenters, or discussion partners). It may also involve the types of relations that patients and professionals can have. Finally, boundaries must be clarified regarding the topics of involvement. Can patients, for example, be part of a quality council, and can they have a say regarding the research undertaken in the department? This boundary work may continue after the inclusion of patients, for example, and deciding on the patient input to be acted upon versus left behind (see Johansen & Pedersen, 2016, for a description of the 'contexting' involved in such decisions).

In the research-like methods, the managers' boundary work primarily *succeed* the generation of patient data and revolves around the boundary between this phase and the intervention phase: Do the managers believe they can practically and legitimately act on the patient representations or do they need additional representations? It may, for instance, be decided that data does not have the right 'granularity' (Star, 2010) if it is too general or too specific. Such decisions may be difficult because of disagreement among the managers regarding the 'quality', 'reliability', 'validity' and 'usefulness' of the patient data. They may also disagree on the legitimacy of one representation method over another. Some managers may, for instance, object to patient data because of the specific method chosen or the interpretation of data and their practical implications. Critique of a particular method may even serve to reject the very idea of patient involvement. Thus, some doctors hold that only randomized controlled trials create a legitimate foundation for changing practices.

Articulation work and the management of patient involvement

In order to make patient involvement activities work, we have described several tasks, balancing acts, and questions that managers typically have to address in their representation and boundary work. Together they form bundles of activities and distributed work that requires managerial monitoring and coordination. Taking inspiration from Strauss et al. (1985) and Strauss (1988), we will call this work 'managerial articulation work': the managerial work required to make managerial work work. In some instances, this articulation work is carried out in a very implicit manner or fails to be done. It may be unclear what the precise purpose of a given patient involvement activity is, or it may be discussed as something to do simply “because we have to” and perhaps with as few practical consequences as possible. Such situations, naturally, complicate a purposeful articulation of necessary representation and boundary work.

6. Discussion

What does our analysis of involvement methods and the entailed managerial work suggest regarding the impact of patient involvement processes? In the following, we will discuss our findings regarding the managerial work and consequences of the different types of activities. First, we propose a matrix to help sort patient involvement activities methods according to whether they lead to direct or diffuse interventions and whether they do so by single representational activities or require several and sometimes inconclusive chains of representations. Finally, we outline a number of questions and points of awareness that can fruitfully be considered by management before embarking on patient involvement activities.

6.1 A typology of patient involvement activities

We are not the first to propose models and typologies of involvement mechanisms, as mentioned in the beginning of this article. Rowe and Frewer (2005) base their typology of engagement mechanisms in information flows; Kreindler (2009) on involvement ideology, methods, and participants’ input and perspective; and Tritter and McCallum (2006) argue for multiple aspects and dimensions in a mosaic analogy as opposed to the one-dimensional model that they criticize for being based only on power. A shared focus point is how methods lead to actual changes in service. Tritter and McCallum (2005, p. 166) emphasize that actual effects are important if involvement is to be meaningful and if users are to stay engaged. Kreindler (2009, p. 120) distinguishes between minor changes and fundamental impacts, arguing that the former are more easily identified, while in the literature the latter has been concluded hard to discern. In the following, we supplement these points and distinctions by introducing two other dimensions of importance: a) the specificity of the intervention, and b) the distance between representation and intervention. Both dimensions bring forward a number of basic organizational and managerial questions underpinning patient involvement that are often not asked or discussed, that is: What is the purpose and goal of a specific patient involvement activity? Moreover, what is a legitimate representational basis for organizational decision-making?

In our study, we met instances where the patient involvement methods produced input that immediately gave rise to adjusted practices. However, we also met instances where the involvement method did not result in a direct input to changes or the input was questioned as a legitimate input. For an involvement method to make a difference, it must work to produce a convincing representation of patients; it must strike a good balance between working with a practical selection of patients, ensuring a sufficient breadth of opinions and experiences, and then process these points into as clear and unambiguous input for decision-making as possible. A number of contextual dimensions may complicate the situation. Often, new involvement methods are introduced in order to supplement the first with more ‘nuanced’, ‘generalizable’, or ‘precise’ input. At times, the chain of involvement methods ends without a shared conclusion. In summary, patient involvement covers a spectrum of representational activities running from situations where there is a direct link between involvement and decision-making to situations where there is a series of involvement methods and no clear outcome. We call this a spectrum from short to long chains of representation.

Comparing the involvement method cases, we also found another notable difference across them. Some patient involvement activities result in input to decision-making that is concrete and specific (e.g., a change in the wording of a brochure), whereas in other cases, the resulting effect is not so obvious. Sometimes the knowledge obtained is considered relevant and meaningful, but due to time constraints, competing agendas, or other issues, the practical implications never become clear. In other situations, the patient involvement is not aimed at having a clear and concrete effect but rather to work at what can be called a second order level (e.g., calling attention to foundational premises and assumptions or raising the general level of awareness and reflexivity among healthcare practitioners). We suggest that these different types of effect fall within a spectrum running from direct to indirect interventions. Together, the two spectrums form a matrix in which patient involvement projects can be sorted depending of their representational steps and intervention goals. We show how the four cases addressed above each fall into different areas of the matrix.

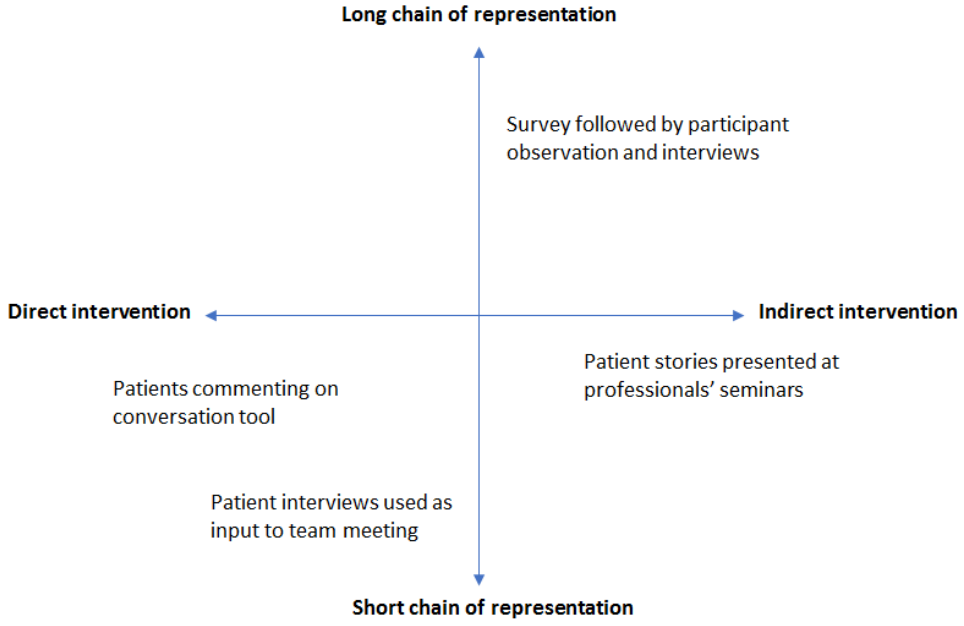

Figure 1. Distribution of involvement activities according to representational steps and intervention goals

The matrix should not be seen as a tool for categorizing specific methods in isolation in terms of their perceived qualities as being easy/successful versus troublesome/complicated. It cannot be predicted in advance how an involvement process will turn out. The specific context, time frame, competing managerial concerns, resources, and attitudes will influence the route patient involvement takes. Thus, it is not simply a matter of selecting 'good' or 'bad' involvement methods but of being aware of the interaction between the many elements at play in the organizational setting. Although systematic and comprehensive comparisons of methods in contexts may prove to indicate that different methods hold different types of virtues and risks, our analysis suggests that the specific organizational circumstances and managerial negotiations are crucial for the actual outcome. In this regard, the matrix can be used to consider the current state and 'fate' of a particular patient involvement project and reflect upon the needed adjustments in terms of representation and goal orientation. Adjustments may involve ‘classic’ representational aspects such as: Have we included sufficiently diverse patients? And have we addressed the right issues? However, it may also involve deeper basic questions regarding forms and purpose of knowledge: Who wants to know what and how? The answer to these questions may work to move an involvement activity ‘upwards’ in the matrix and prolong the chain of representation. However, it may be a necessary investment in terms of moving ‘left’ towards more concrete interventions and impacts. Likewise, adjustments may involve boundary work in terms of deciding on practical, professional, ethical, and economic dimensions of patient involvement. This, in turn, should prompt managers to consider the core purpose of patient involvement. Like many other organizational activities, patient involvement risks becoming a meaningless, frustrating, and even harmful activity if detached from a clear organizational purpose (Vikkelsø, 2015). Thus, patient involvement activities that are diffuse or protracting can usefully be reconsidered in terms of core purpose and appropriate boundaries. Finally, we suggest that sorting patient involvement projects by the matrix may provide an overview of co-existing involvement projects and their potential combination or dissonance. This may be interesting in terms of involvement content and methods: Do they overlap or supplement each other? It may, however, also be interesting in terms of how they are distributed in terms of representational complexity and intervention impact: Do the activities seem to group in some or the other corner of the matrix? And what does this suggest in terms of managerial coordination and awareness? Such questions point to the role of articulation work related to organizing and managing involvement projects.

In order to make patient involvement feed into quality improvement in healthcare, we suggest that it is useful for managers to consider not only representational and boundary aspects of patient involvement, but, fundamentally, what specific questions or practices patient involvement should help to improve: What is the purpose of patient involvement? As patient involvement is spreading fast across the healthcare field as part of broader societal waves of user-driven innovation concepts, empowerment ideas, and citizen involvement efforts, many hospitals and health institutions have had to improvise and cut corners and health managers have found ways to comply with top-down principles by experimenting and learning but also by decoupling patient involvement practices from having a real impact. Today, much experience has been generated and we have presented a portion of this with a special focus upon hidden and invisible managerial work. As with many other managerial tasks, patient involvement is not something that just happens but requires the managers to decide what the purpose is, what tools to use with what effort, by whom, and for how long. In this way, patient involvement requires, perhaps first and foremost, that health managers involve themselves in reflections about who patients are and what they might know best.

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CHAPTER 6. DISCUSSION AND CONCLUSION

In this chapter, I draw the conclusion of the dissertation and answer the research question: *How is patient involvement in quality improvement organized in the hospital? More specifically, how does it relate to the work of healthcare professionals, to patient perspectives, and how is it a part of managerial work in the clinic?* As stepping stones to reach the overall conclusion, I will begin by presenting concluding remarks regarding each of the three more specific questions contained in the research question, concerning (1) the relation between patient involvement and the work of healthcare professionals, (2) the relation between patient involvement and patient perspectives and, finally (3), how patient involvement is a part of managerial work in the clinic. In prolongation to each of these concluding remarks, I will explicate how they contribute to the patient involvement literature. Secondly, I will address three themes that transgress the analytical parts of this thesis. The first is methodological and concerns the challenges of studying episodic and non-everyday phenomena ethnographically. The other two are analytical and concerns, respectively, the many shapes patients can take in patient involvement and the many kinds of work that is involved. On this basis, I will present the thesis' overall conclusion to the question of how patient involvement work is organized at the hospital. The conclusion is followed by reflections on the potential "Danish-ness" of the conclusion. Lastly, I suggest policy implications and implications for healthcare practise, and, finally, I will suggest future areas of research.

Answering the three elements of the research question

The question of how patient involvement in quality improvement relates to the work of healthcare professionals is most directly answered through the first article. In the article, I argue that contexting is a pertinent aspect of professional work when involving patients in quality improvement in a setting where the phenomenon is not a "natural", routinized, and institutionalized part of the hospital. I show how this contexting work can consist of creating knowledge positions for patients that are not given when patients are to be involved in quality improvement. Moreover, I discuss the contexting work going into creating the more practical contexts of relating the tasks solved in the patient panel to - or distancing them from - internal and external processes and demands in the department, the hospital, the region etc. I argue that when very few routinized tasks or routines connect the patient involvement activities with the rest of the department, the connections and contexts need to be created anew. I conclude that contexting is a part of healthcare professionals' work when doing patient involvement.

This conclusion contributes to the patient involvement literature in a general manner by pointing to involving patients in quality improvement work as a new arena of work for the healthcare professionals. Moreover, it points to the new roles and relations that are being negotiated in the wake of the involvement agenda. It unfolds how the healthcare professionals (together with the involved patients who of course do not necessarily "accept" the roles offered) can be left to do the contexting of the phenomenon in the specific involvement activities.

The question of how patient involvement relates to patient perspectives is mainly answered through the second article. Here, I conclude that patient perspectives are not something found in particularly well-selected representative individuals, but that they are situational accomplishments shaped in interaction around specific tasks and purposes. I show how patients' and professionals' accounts of how to speak on behalf of others and the role of patient perspectives are diverse and hinged on different representation mechanisms. The findings show how the patient story as a generic form and the experiential authenticity and emotional effects associated with it by the professionals are elements that can both qualify and disqualify as being a suitable patient account and representation of the patient perspective depending on the situation and task to be solved. The tasks around which patient perspectives are accomplished do not simply appear. The professionals play a subtle role in shaping patient perspectives both by selecting tasks to bring to the table at the meetings; tasks that sometimes come with an expectation of input in a certain form, in addition to the interaction in the discussions during the meetings. The article points to how patients are shifting in and out of representation roles in the patient panel depending on the specific interaction, situation, and task. Thereby the article widens the discussion from ideals and ideas of fixed bases of representation and the existence of a general, abstract patient perspective.

By showing how patient perspectives are situational accomplishments shaped in interaction around specific tasks and purposes, the article contributes to the patient involvement literature by questioning the idea of a fixed and stable representation base residing in more or less representative patients. The understanding of patient perspectives as situational accomplishments also somewhat sidesteps the question of unrepresentative involvement (El Enany et al., 2013). Patients will always represent someone or something in the specific situation, but whether it is a patient’s professional background, a personal experience, a collated experience of a fellow patient, a legitimate input format or something else again, cannot be predicted. These multiple and situated versions of patient perspectives feed into the complexity of the representation roles that the patients are taking on and the demand this puts on their ability to shift in and out of these roles. The article thus adds further nuances to the argument presented by van de Bovenkamp and Zuiderent-Jerak (2015) that patients who, through professionalization, gain credibility as being able to participate in guideline development also lose their credibility as “true patients”. The article adds nuances to van de Bovenkamp and Zuiderent-Jerak (2015) by arguing that patients’ credibility can be argued to hinge on their ability to shift in and out of multiple representation roles in the same setting and on a situational sensitivity to know, for example, how to use their own story in an appropriate manner or when they can legitimately draw on their professional background. In line with Lehoux et al. (2012) and Renedo and Marston (2015), I have tried to go broader than “the patient” by arguing how the specific tasks are also involved in defining the situational shape of a suitable patient perspective and representation role to be taken.

The question of how patient involvement work relates to managerial work is most directly answered through the third article. In the article, we argue that involvement methods do not necessarily readily produce usable patient representations to guide quality improvement intervention and we discuss the managerial representation work, boundary work and articulation work it entails. We argue that patient representations can sometimes come to create the need for new patient representations (e.g., by being in conflict with each other, by being too vague or too solid, or by pointing to not easily solvable or contested problems) and lead to chains of representations necessary before reaching a patient representation found suitable to guide intervention. In addition to the representational complexity, we suggest the degree of concreteness of the organizational impact to be another dimension to be observant of when managing patient involvement. The article contributes to the patient involvement literature by exploring the representation-, boundary-, and articulation work of managers involved in making involvement methods work to produce patient representations found useful to guide intervention. It thus also contributes to patient involvement literature by placing managers and managerial work in the foreground – not as a background element that can secure better and more involvement through strategies or by passing on the value of involvement to employees, as suggested (Armstrong et al., 2013; Coulter, 2012; Wiig et al., 2013). Furthermore, it contributes by foregrounding two dimensions of patient involvement in quality improvement: the complexity of the managerial representation work, and the degree of concreteness of the organizational impact purported as important to be concerned with when managing patient involvement.

Contributions looking across

In the following, I will discuss some of the insights gained by combining the ethnographic approach employed and the analytical concepts pertaining to the work going into involving patients in quality improvement. First, I will emphasize the methodological contribution of this thesis, and then I will discuss two analytical themes going across the thesis: patients and work.

On a methodological note, the contribution of this thesis is the discussion on how to study episodic and non-everyday phenomena ethnographically. Where to find the research object is not necessarily a trivial question and in Article 1, I have discussed how this has consequences for how to conduct fieldwork. It requires of the fieldworker to be episodic and experiment with how to locate the phenomenon. Another methodological contribution of this thesis is that patient involvement in quality improvement is also being shaped and performed where patients in the shape of specific persons are not present. Therefore, limiting the study to arenas of patient involvement in quality improvement where patients are present as specific persons does not necessarily give the most nuanced understanding of the phenomenon. Patients come in many guises and my ethnographic approach made more versions "visible" – paradoxically because I initially sought a specific kind of patient when locating the phenomenon in the field. The ethnographic approach taken made it possible to encounter the ways in which patient involvement in quality improvement is done both through formal methods and in more informal ways, thus widening the understanding of what patient involvement in quality improvement is. Moreover, by taking an ethnographic approach considering patient involvement in quality improvement to be an organizational phenomenon instead of isolated methods and tools, the dynamics between involvement methods also becomes noticeable, for example how involvement methods can come to compete for knowing “the patient” in a department. This was for example the case when the existence of the panel was taken up for reconsideration when the patient-centred care model process was well underway due to plans of setting up panels in that process and due to considerations of whether it would be better to have the department panels on a team level, closer to the treatment and care processes. Or when data on patients gained through different involvement methods is not in accordance and makes them difficult to use for guiding decision-making, as have been touched upon in Article 3.

Patients in many shapes

This thesis is about patient involvement and thus about patients. One of the contributions when looking across this thesis is the plethora of patient shapes and the many other dimensions of what a patient is when involved in quality improvement that has come to the fore in this thesis. It reflects my initial fear of meeting too few patients in an ethnographic study on patient involvement, but it also reflects my initial focus on meeting involved patients as specific persons aware of being involved. Not that I was not aware of or had intentions of disregarding the surveys, the interviews, and other methods where patients were involved in more detached ways, but nevertheless my own initial search for a very specific type of involved patients also led me to many other versions. In the quality council, where I expected to meet the patients indirectly and therefore spent many hours, they hardly appeared. In the patient education sessions, they were in abundance; in the patient panel, they took on shifting and very different roles; in the patient-centred care model process, they were present in the managers’ realm largely as data – as survey percentages, as voices from interviews, at ‘true’ patients relayed through fieldwork - but their data-shape made them negotiable and more easily contested. The multitude of patient representations encountered during fieldwork in different settings points to the potential fruitfulness of moving between spaces and activities and of having patience and staying curious, also when what goes on is not so obviously about involving patients.

Moreover, throughout this thesis a recurring interest related to the patients in many shapes has been the question of what gets to count as patient knowledge, as a suitable patient perspective or usable patient representation and the ways these issues are negotiated. These questions relate to the work of Pols and her interest in patient knowledge and how it needs to be understood as a practical knowledge on how to live with disease in order to be made transferrable to other patients (Pols, 2013, 2014; Pols & Hoogsteyns, 2016). The patient involvement work explored in this thesis can be argued to be concerned with passing on some patients' knowledge and experiences - in very different and more or less explicit ways – to future patients. However, the analytical parts of this thesis have also suggested that capturing and formatting this knowledge is a complex endeavour.

The work of patients, healthcare professionals, managers, and methods

Another analytical interest throughout the thesis has been to explore in different ways the specific work that involving patients in quality improvement entails. In Chapter 2, I explored the Danish healthcare policy context and argued that the policy ideal of involving patients in quality improvement comes with very few specifications for action, leaving it largely up to the local managers to turn the ideal into specific actions. As suggested in Chapter 3, the different analytical concepts used in this thesis can be understood as framing work that, through different means and by different actors, make patient involvement and the abstract notion of "the patient" *something* in different situations and contexts. The patient involvement work explored this thesis can also be argued to be invisible work (Star & Strauss, 1999). However, the work analysed is not invisible in the sense that the persons doing it are invisible due to power and status differences (Star & Strauss, 1999, p. 15) because the work of involving patients in quality improvement largely resides with the managers themselves, as this thesis has shown. Neither, is the work taken for granted or routine and therefore invisible (Star & Strauss, 1999, p. 15), quite the opposite. Patient involvement work can be argued to be invisible precisely due to it being non-routine and only very loosely connected to the primary work of care and treatment in the hospital. Moreover, it does not have its own designated spaces and does not have a crucial for the overall functioning of the workplace.

The term "work" can have the unfortunate connotations of denoting something trivial, everyday, routine somewhat detached from the specificity of the tasks and from the specific persons performing this work. This has by no means been the intention with this thesis, and I hope to have been able to convey the dynamics of the interactions and negotiations going into some of the very specific kinds of work that involving patients in quality improvement entails.

However, the analytical framework centring on work has made it possible to foreground and discuss aspects of patient involvement in quality improvement otherwise left in the background or as the larger frame for action: the work of managers, contexts, methods and patient perspectives. These mundane and seemingly trivial questions and concerns have been explored in this thesis and now it is time to give an answer to the overall research question.

Overall, the thesis contributes to the patient involvement literature by analytically examine some of the aspects that are often ascribed a static role as background for or innocent tools for patient involvement: contexts, the patient perspective, work and involvement methods. It moreover contributes by showing the multitude of patient shapes and the complexity of patient roles involved when patients are involved in quality improvement work. Lastly, it has discussed the often undiscussed and invisible but nevertheless important work it entails to make patient involvement in quality improvement more than a political ideal. Involving patients in quality improvement becomes a specific kind of organizing through patients (Kjær & Reff, 2010), and this thesis has shed light on the complexities of organizing through “the patient” or “the patient perspective” when they are not so evident entities as they might seem. “The patient” and its many representations, sometimes too evasive and sometimes too solid, have become a managerial concern because when organizing healthcare through “the patient” this abstract figure needs to be framed, contexed, formatted, found, made, remade, connected/dis-connected and shaped through specific work practices in the clinic.

The findings of this thesis have implications for other research debates and empirical areas. These include organizing in a hospital context more generally, organizing non-routinized phenomena and processes, and the question of user involvement more generally. Firstly, this thesis has shown that the hospital setting is a particular context for studying ’organizing’. Hospital work is highly professionalized, standardised and regulated, and this shapes any form of organizing taking place as well as what it means to study organizing in this context. Secondly, the thesis illustrates that, in particular, new political demands like patient involvement in quality improvement that is only very loosely connected to the primary work of care and treatment in the hospital can have a hard time in such a setting. Thirdly, the thesis shows that user involvement is a complex phenomenon and far from a straightforward task. The empirical unfolding of the multitude of shapes that patients can have and the multi-facetted work of involving patients in quality improvement are concerns that are not only relevant to patient involvement and healthcare but also to other organizational settings and processes of user involvement more generally, since many public sector organizations face the possibilities and challenges of user involvement.

The Danish-ness of the conclusion

Compared to the situation in other countries, such as the UK (e.g., where patient and public involvement is more formalised and institutionalized in committees and formal fora such as in commissioning group and in local level groups), the Danish situation is, as I have argued in Chapter 2, much less bounded by specific formal requirements. The work and negotiations that involving patients in quality improvement entails might partly be due to the very general statements and vague specifications of the phenomenon in Danish healthcare policy; however, it can also be that these elements are just not “seen” in many other research setups, either due to the methodological approach or the analytical framework. The ethnographic approach taken in this study going across organizational levels and involvement activities and the access to the managerial “engine rooms” on more organizational levels may have contributed to making visible some of the workings needed in order for patient involvement in quality improvement to be carried out.

Implications and future areas of research

The findings of this thesis have implications for healthcare policy and practice. While healthcare policy on involving patients in quality improvement are clearly filled with good intension, this thesis shows that patient involvement is far from a straightforward process. It questions the self-evident and straightforwardness of involving patients in quality improvement and calls for a discussion of patient involvement in quality improvement, as something not necessarily easily accomplished through the application of involvement methods, at least not if the goal extends beyond patient involvement in and of itself. It raises the question of the relationship between formal requirements and informal practices and the organizational level of operation. On the basis of the involvement activities studied in the fieldwork grounding this thesis, it can be argued, that when patient involvement in quality improvement is coupled to the local level of treatment and care, the route from patient input to change of practices is short and change potentially easily accomplished. However, sometimes creating a distance from the local level of treatment and care is what is needed in order for patients to be comfortable giving feedback and input to the development of healthcare. Moreover, quality work often relates to more general questions and processes in the hospital and thus to a different organizational level. So the answer cannot be a general rule, it depends on the situation and importantly on the aims and goals of a particular involvement. The aims and goals of the specific activities are important to discuss locally, because they make a difference in how to go about the task of involving patients in quality improvement. Is it important to be able to measure and document that the involvement is done or that is has an effect? Is it important to make the patients feel involved? Or is it important to involve patient in order to discuss or solve a specific quality problem? This thesis cannot answer the question of what the goals and aims of patient involvement should be, however, it might provide an answer to why patient involvement in quality improvement does not lead to grand impacts by giving an insight into the specific work it requires, which may also be part of the answer - and an answer of another kind than differences in understandings, perspectives, and values or the lack of conceptual clarity – not that these should be disregarded.

Finally, what other interesting themes appear in the data and what questions have been spurred by the literature? One interesting theme of future research to be addressed concerns the quality related issues to be discussed and tasks to be solved when involving patients in quality improvement. What are legitimate quality problems for patients to have a say in, and how is this legitimacy connected to the form of patient input, relational aspects, and organizational spaces? Bringing the quality problems to the fore might lessen the focus on the legitimacy of patients, as often encountered in the patient involvement literature and might give interesting insight into what problems can be solved, with what input, in what organizational spaces. Another question concerns the interesting ways in which patients and ‘patientness’ is negotiated when patients are involved in quality improvement drawing on linear phase understandings of patients and their experiences, e.g. when selecting patients to participate in the involvement activities, in setting time limits for participation or when evaluating involvement initiatives. Inquiring into these matters might broaden the understanding of what patient-ness means when involving patients in quality improvement.

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SUMMARY

Patient involvement has become a part of the political agenda in Danish healthcare. Patients are to be involved not only in questions and decisions relating to their own treatment and care – to involve patients in quality improvement has also become a political expectation of quality work in Danish hospitals. During the last 25 years, patient involvement and quality improvement have become connected in Danish healthcare policy. However, the ideal of involving patients in quality improvement is described in very general terms and with only few specific expectations of how it is to be carried out in practice, as I show in the thesis. In the patient involvement literature, the difficulties of getting patient involvement in quality improvement to have in an impact on the planning and development of healthcare services is, for example, ascribed to conceptual vagueness of patient involvement, differences in perspectives, values and understandings between patients and healthcare professionals, or the lack of managerial attention and prioritization.

My errand in this thesis is to explore how patient involvement in quality improvement is done in the clinic. This thesis concerns the specific work of patients, healthcare professionals, and managers that goes into involving patients in quality improvement in a medical centre in a Danish university hospital. The thesis is based on ethnographic fieldwork anchored in a patient panel, a patient-centred care model implementation process, and patient education sessions with an informal patient feedback mechanism incorporated. This has made it possible to explore the seldom discussed work that goes into involving patients in quality improvement. Theoretically, this thesis is inspired by the sociology of work and science and technology studies, and the central analytical concepts used are: contexting, the patient perspective, boundary work, and representation work. The thesis is article-based and contains three articles that, in different ways and through different analytical means, explore the work that involving patients in quality improvement entails.

The first article discusses how to study non-everyday and non-routinized phenomena – such as patient involvement in quality improvement – ethnographically. Furthermore, it shows how healthcare professionals do contexting work in order to create contexts for patient involvement in quality improvement. One kind of contexting consists of creating the more

practical contexts because no self-evident categories of tasks are established and only few routines that connect the involvement activities with the rest of the work in the department are in place. Another kind of contexting is the contexting involved in creating roles and knowledge positions for patients in quality improvement, since no “natural” or taken for granted understandings of what roles patients can take in this kind of work exist. The article contributes with considerations on what the episodic nature of the phenomenon means for studying these kinds of phenomena ethnographically. Furthermore, it contributes to the patient involvement literature by showing how contexts are not necessarily static backgrounds when patients are involved in quality improvement, healthcare professionals’ contexting work is involved in establishing them.

The second article explores how “the patient perspective” is used in patients and professionals’ accounts and how they are shaped when it comes to solving specific tasks in a patient panel. The article contributes to the patient involvement literature by showing how patient perspectives are not something readymade to be found in especially representative patients but are shaped in specific situations around specific tasks to be solved. The article thus widens the understanding of “the patient perspective” and patient representation and emphasizes the potentially diverse representation roles that patients must navigate between.

The third article takes as its departure the question of how patient involvement in quality improvement is a managerial concern. Through examining four maximum-variation cases of patient involvement activities, the article points to the representation, boundary, and articulation work of managers involved in creating patient representations found useful for guiding specific interventions. The article contributes to the patient involvement literature by examining the managerial representation work involved in negotiating and defining who is to be involved, in what, and how. Furthermore, it contributes by emphasizing that involvement methods do not necessarily easily produce patient representations that are found to be useful in guiding specific interventions – sometimes the road from patient representation to intervention is simple and short, at other times it is long and convoluted.

Overall, the thesis contributes to the patient involvement literature by analytically examining some of the aspects that are often ascribed a static role as backgrounds or passive tools for patient involvement: contexts, the patient perspective, work, and involvement methods. It moreover contributes by showing the multitude of patient shapes and the complexity of patient roles involved when patients are involved in quality improvement work. Lastly, it discusses the often undiscussed and invisible work that is entailed in making patient involvement in quality improvement more than a political ideal.

DANSK RESUMÉ

Patientinddragelse er kommet på den politiske dagsorden i det danske sundhedsvæsen. Patienter skal ikke blot inddrages i beslutninger, der relaterer til deres egen pleje og behandling - at inddrage patienter i kvalitetsudvikling er også blevet en politisk forventning til kvalitetsarbejdet på de danske hospitaler. I den danske sundhedspolitik er patientinddragelse og kvalitetsudvikling i løbet af de seneste 25 år blevet forbundet. Men idealet om patientinddragelse i kvalitetsudvikling er meget overordnet beskrevet, og der optegnes kun få specifikke forventninger til, hvordan det skal ske i praksis. I patientinddragelseslitteraturen diskuteres det blandt andet, hvordan patientinddragelse er præget af upræcise begreber og at dette er en medvirkende årsag til, at det er svært at få omsat patientinddragelse i kvalitetsudvikling til specifikke forandringer. Litteraturen peger desuden på forskellige perspektiver, værdier og forståelser mellem patienter og sundhedsprofessionelle eller manglende ledelse som en del af forklaringen.

Mit ærinde er et andet, nemlig at undersøge hvordan patientinddragelse i kvalitetsudvikling foregår i praksis. Denne afhandling handler om elementer af det specifikke arbejde, der er forbundet med at inddrage patienter i kvalitetsudvikling for patienter, sundhedsprofessionelle og ledere i et medicinsk center på et dansk hospital. Afhandlingen er baseret på etnografisk feltarbejde med empiriske nedslagspunkter i et patientpanel, et patientcentreringsprojekt og patientundervisning med en indbygget patient-feedback mekanisme. Denne forankring har gjort det muligt at stille skarpt på noget af det sjældent diskuterede arbejde, der er involveret i at inddrage patienter i kvalitetsudvikling. Teoretisk er afhandlingen inspireret af arbejdssociologi og Science and Technology Studies, og de central analytiske begreber er ’contexting’, patientperspektivet, grænsearbejde og repræsentationsarbejde. Afhandlingen er artikel-baseret og indeholder tre artikler, der på forskellig vis behandler det usynlige arbejde, som det at involvere patienter i kvalitetsudvikling indebærer.

Den første artikel diskuterer, hvordan man etnografisk studerer et hverken rutinepræget eller hverdagsoptrædende fænomen som patientinddragelse i kvalitetsudvikling. Desuden viser den, hvordan sundhedsprofessionelle er med til at skabe kontekster for patientinddragelsesarbejdet. Den ene slags kontekster, som artiklen peger på, er de praktiske

kontekster omkring patientinddragelsesarbejde, der skal skabes, fordi der ikke er etableret selvfølgelige kategorier af opgaver og kun få fasttømrede arbejdsgange, der rutinemæssigt forbinder inddragelsesaktiviteterne med det, der ellers foregår i afdelingen. Den anden slags konktekstarbejde er det, der er involveret i at definere roller og videnspositioner for patienter i kvalitetsudvikling, da inddragelse af patienter i kvalitetsudvikling ikke er rutinearbejde og fordi der ikke er etableret 'naturlige' og selvfølgelige forståelser af, hvilke roller patienter kan indgå i. Artiklen bidrager til metodelitteraturen ved at pege på det episodiske vilkår, og hvad det betyder, når man studerer denne slags fænomener, samt til patientinddragelseslitteraturen ved at pege på hvordan kontekster ikke er statiske baggrunde, når patienter inddrages i kvalitetsudvikling, men at det involverer de sundhedsprofessionelles kontekstarbejde at etablere dem.

Den anden artikel handler om, hvordan 'patientperspektivet' optræder i patienter og sundhedsprofessionelles beskrivelser af, hvad patienter kan bidrage med i et patientpanel og hvordan patientperspektiver bliver til, når det kommer til løsningen af konkrete opgaver. Artiklen bidrager til patientinddragelseslitteraturen ved at vise, at patientperspektiver ikke er noget færdigstøbt, der kan hentes ud af særligt repræsentative patienter, men er formet i specifikke situationer omkring specifikke opgave, der skal løses. Således udvider artiklen forståelsen af patientperspektiver og patientrepræsentation og peger på de forskellige repræsentationsroller, patienterne må navigere imellem.

Den tredje artikler tager udgangspunkt i, hvordan patientinddragelse i kvalitetsudvikling involverer ledelsesarbejde. Gennem fire 'maximum-variation' cases af patientinddragelsesaktiviteter analyseres det repræsentationsarbejde, grænsearbejde og artikuleringsarbejde, som sundhedsprofessionelle og ledere udfører for gennem forskellige inddragelsesmetoder at skabe patientrepræsentationer, der kan bruges til at guide en specifik intervention. Artiklen bidrager til patientinddragelseslitteraturen ved at undersøge det ledelsesmæssige repræsentationsarbejde, der er involveret i at forhandle og definere, hvem skal inddrages i hvad og hvordan. Desuden bidrager den ved at sætte fokus på, at inddragelsesmetoder ikke nødvendigvis producerer patientrepræsentationer, der bliver fundet egnede til at guide konkrete forandringsprocesser, nogle gange er vejen fra patientrepræsentation til intervention simpel og kort, andre gange er den lang og kompliceret.

Overordnet set og på tværs af artiklerne bidrager afhandlingen til patientinddragelseslitteraturen ved analytisk at behandle nogle af de aspekter, som ofte tilskrives en statisk rolle som baggrund for eller passive redskaber til patientinddragelse: kontekster, patientperspektivet, arbejde og inddragelsesmetoder. Bidraget består desuden i at vise mangfoldigheden af patientformer og kompleksiteten af patientroller, der er involveret i at inddrage patienter i kvalitetsarbejde samt at diskutere det ofte usynlige arbejde det indebærer at gøre patientinddragelse til mere end et politisk ideal.

APPENDIX A INTERVIEWED HEALTHCARE PROFESSIONALS AND PATIENTS

Interviewed healthcare professionals [Interviewed from 2013–2015] [Besides the explicated experience with involving patients in quality improvement they all have been part of the patient-centred care model implementation process studied in different degrees depending on their position]

Louise – nurse, head of team; she has been educated as a nurse for 10 years and has been head of team since 2008. She has some experience with formal and informal ways of involving patients in quality related issues. [Interviewed Mar. 2014; Informal recorded interviews Aug. 2013, Nov. 2013, May 2015]

Lisa – rehabilitation nurse; she is involved in different patient involvement activities and participates in the patient panel. She has also been involved in national development processes where patients have been involved in different ways in service development. [Interviewed Jan. 2013, Jul. 2013, Mar. 2014]

Leslie – development nurse; she works with different areas of development work in the department, primarily in relation to nursing, and she participates in the patient panel. [Interviewed Jan. 2013, Aug. 2013]

Jane – nurse, head of department; she has been educated as a nurse for more than 30 years and has some experience with involving patients in quality improvement activities and she has been involved in establishing the patient panel in her department and heads the patient panel. [Interviewed Jan. 2013, Aug. 2013, Mar. 2014]

Howard – head of department since 2007; he has worked in his medical speciality for more than 30 years and heads the department together with Jane. [Interviewed Jan. 2013]

Penny – nurse, head of department; she has some experience with formal and informal ways of involving patients in quality related issues in her department. [Interviewed Jan. 2013]

Lloyd – head of department; he heads the department together with Penny. [Interviewed Feb. 2013]

Philip – head of department; he has previous but limited experience with involving patients in quality improvement in his field. [Interviewed Feb. 2013]

Michael – head of department; he has limited experience with involving patients in quality improvement but has e.g. asked patients to co-develop a questionnaire [Interviewed Jan. 2013]

Joan – nurse, head of centre; she has been in her position for 15 years and has some experience in involving patients in smaller development projects. [Interviewed Jan. 2013 (together with Chris), Nov. 2013, Mar. 2014]

Chris – head of centre; he has 8 years of experience as head of centre and heads the centre together with Joan. [Interviewed Jan. 2013 (together with Joan)]

Carrie – nurse, head of department; she has some experience with involving patients in quality improvement but mostly in informal ways. [Interviewed Feb. 2013 (together with James and Simon)]

James – head physicist; same department as Carrie and Simon. [Interviewed Feb. 2013 (together with Simon and Carrie)]

Simon – head of department; same department as Carrie and James. [Interviewed Feb. 2013 (together with Carrie and James)]

Peter – chief physician; he has 20 years of experience as a doctor and has been chief physician since 2008. He also participated in the patient panel. [Interviewed Mar. 2014]

Sheryl – chief physician; experience with working with involving patients in guideline development in the Danish Medical Authorities. [Interviewed Mar. 2014]

Bridget – nurse, head of team; she has been educated as a nurse since 2001 and has had managerial positions since 2008. [Interviewed Mar. 2014]

Thomas – chief physician; [Interviewed Mar. 2014]

Justin – chief physician [Interviewed Dec. 2013]

John – chief physician; she has more than 30 years of experience as a doctor and has previously had managerial positions for 20 years at another hospital but recently chose to work directly with patients again. [Interviewed Mar. 2014]

Kathy – coordinating nurse; she has been an educated nurse for almost 20 years and has been in her present position since 2009 where she is also involved in planning and facilitating patient involvement activities. [Interviewed Mar. 2014]

Rose – nurse, head of team; she has some experience with involving patients in quality improvement [Interviewed Mar. 2014]

Alice – staff doctor [Interviewed Mar. 2014]

Patients participating in the patient panel [Interviewed from 2012-2015[22]]

Louise – in her 60s; she was diagnosed with cancer in 2010 (more types, incurable). She is educated as a social worker and has worked in the field for many years but is now on sick pay. She withdrew from the patient panel after having participated for several years and entered another patient panel established in relation to the patient-centred care model implementation process in order to contribute in another setting. [Interviewed Nov. 2013]

Janet – in her 50s; she was diagnosed with cancer in 2010 (incurable) and receives life-prolonging treatment. She has worked as a personnel manager and is now on sick pay. She has been a member of the patient panel since the beginning in 2012. [Interviewed Nov. 2013]

Anne – in her 50s; she was diagnosed with cancer in 2011 but is now cancer free and goes for biannual check-ups. She has worked with marketing and analysis for many years and is now self-employed in the field. She has been a member of the patient panel since the beginning in 2012. [Interviewed Jan. 2014]

Alan – in his 50s; he was diagnosed with cancer in 2009 and is now cancer free. He is educated as a food scientist and has worked in the food industry for 30 years. He withdrew from the patient panel after participating for 2 years due to time concerns and due to experiencing his participation as not having enough impact. [Interviewed Dec. 2013]

Charis – in her 50s; she has an educational background as a psychologist but has worked in the pedagogical area for several years. Entered the panel in early 2015. [Interviewed May 2015]

Paul – in his 70s; he was diagnosed with cancer in 2009. He had worked with human resource management but has now retired. He participated only in a few meetings before withdrawing. [Interviewed Nov. 2013]

Frank – in his 50s; he was diagnosed with cancer in 2011 but is now cancer free. He works in the prison services. Entered the panel in early 2015. [Interviewed June 2015]

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[22] The patients in the patient panel were interviewed during the entire period of fieldwork (of more or less intensity before and after maternity leave April 2014–March 2015) due to new members joining consecutively when others left. The 'now' in the descriptions relates to the time of interview.

[Not interviewed]

Robert – in his 50s; sadly, he died due to a fast relapse during the fieldwork after having participated in the patient panel for half a year. I did not get the chance to interview him.

Amy – in her 60s; she is in experimental cancer treatment for a cancer that has spread and does not respond to standard treatment. She has worked as a schoolteacher and consultant and entered the panel in mid-2015. I did not ask to interview her due to the ending of fieldwork before she had gained much experience of being a patient panel member.

Claire – in her 30s; has been through extensive cancer treatment, also abroad. She is a university student and left the patient panel in early 2014 due to maternity leave. She did not respond to my e-mail and follow-up e-mail asking for an interview.

David – he was screened, accepted, and announced in the patient panel but ended up not being able to participate in any of the meetings, and after a series of cancellations, he withdrew.

Dorothy – in her 60s; diagnosed with cancer in 2007. When stepping into the panel in late 2014, she had more forms of cancer and did not have prospects of being cured. She managed to participate in a couple of meetings before she had to leave due to relapse of her cancer diseases. I did not ask to interview her due to her short time of participation in the patient panel and due to the relapse of her disease.

APPENDIX B PARTICIPANT OBSERVATION IN THE PATIENT CENTRED-CARE MODEL PROCESS

Fall 2012

Study trip to Rotterdam (2 days)

Meetings, e.g. in the centre council and meeting with the management team of the region (6 meetings)

2013

Full day workshops on the patient centred-care model (3 days)

Meetings, e.g. centre council, presentations of results from the organizational analysis, meeting on evidence and patient involvement, preparation meeting before seminar (15 meetings)

Observed interviews with patients and healthcare professionals part of the organizational analysis (7 interviews)

Full day seminars, strategy seminar and priority-setting seminar (2 days)

Winter 2014

Meetings, e.g. centre council meetings, preparation meeting, evaluation meeting (5 meetings)

Half day seminars, e.g. a managers’ seminar on patient involvement in quality improvement (2 half days)

TITLER I PH.D.SERIEN:

2004

1. Martin Grieger
   Internet-based Electronic Marketplaces and Supply Chain Management

2. Thomas Basbøll
   LIKENESS
   A Philosophical Investigation

3. Morten Knudsen
   Beslutningens vaklen
   En systemteoretisk analyse of moderniseringen af et amtskommunalt sundhedsvæsen 1980-2000

4. Lars Bo Jeppesen
   Organizing Consumer Innovation
   A product development strategy that is based on online communities and allows some firms to benefit from a distributed process of innovation by consumers

5. Barbara Dragsted
   SEGMENTATION IN TRANSLATION AND TRANSLATION MEMORY SYSTEMS
   An empirical investigation of cognitive segmentation and effects of integrating a TM system into the translation process

6. Jeanet Hardis
   Sociale partnerskaber
   Et socialkonstruktivistisk casestudie af partnerskabsaktørers virkelighedsopfattelse mellem identitet og legitimitet

7. Henriette Hallberg Thygesen
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How to Multiply Your Crisis

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Om troværdige brand- og virksomhedsidentiteter i et retorisk og diskursteoretisk perspektiv

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Von welchem Österreich ist hier die Rede?
Diskursive forhandlinger og magtkampe mellem rivaliserende nationale identitetskonstruktioner i østrigske pressediskurser

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Sprogpolitik og identitetsdannelse i flersprogede forbundsstater
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Om mellemværendets praktik i en transformation af mennesket og subjektiviteten

29. Sine Nørholm Just
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– A Meaningful Constitution?
Legitimacy, identity, and public opinion in the debate on the future of Europe

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