Patient participation in value-based healthcare

Towards an integral aspect of value improvement

Jet Westerink

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Henrike Jeltje Westerink

The work presented in this thesis was carried out within the seven collaborating Santeon hospitals. The work presented in this thesis received financial support from the pharmaceutical companies of Johnson & Johnson, and a grant from ZonMw (05160472110004). Financial support for printing the thesis was received from Santeon.

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Radboud Dissertation Series
ISSN: 2950-2772 (Online); 2950-2780 (Print)

Published by RADBOUD UNIVERSITY PRESS
Postbus 9100, 6500 HA Nijmegen, The Netherlands
www.radbouduniversitypress.nl

Design: Proefschrift AIO | Guus Gijben
Cover: Studio Joen
Printing: DPN Rikken/Pumbo

ISBN: 9789465151618
DOI: 10.54195/9789465151618

RADBOUD
UNIVERSITY
PRESS

Patient participation in value-based healthcare

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Proefschrift ter verkrijging van de graad van doctor
aan de Radboud Universiteit Nijmegen
op gezag van de rector magnificus prof. dr. J.M. Sanders,
volgens besluit van het college voor promoties
in het openbaar te verdedigen op

donderdag 4 december 2025
om 14.30 uur precies

door

Henrike Jeltje Westerink
geboren op 25 december 1998
te Beuningen

Promotoren:
Prof. dr. P.B. van der Nat
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Copromotoren:
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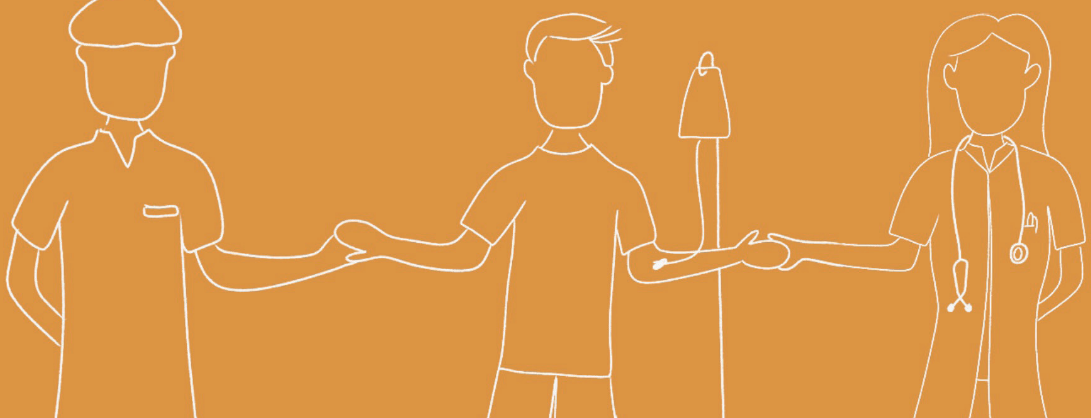


Chapter 1:

General Introduction

The patient's voice is essential for improving healthcare, as their experiences across the full care pathway provide unique insights and expertise. Patients play a key role at the individual patient level by aligning care with their personal preferences, and at the group level by collaborating in care improvement. Although patients are increasingly being involved at these different levels in healthcare, structural involvement of patients at the level of medical conditions remains limited. This is primarily due to the way our healthcare system is organized: around medical specialty departments rather than around the patient journey, leading to fragmented responsibilities for care delivery and improvement. Meanwhile, the input of patients often spans multiple departments and reflects the full scope of the patient journey. Therefore, the transition towards a Value-Based Health Care (VBHC) system provides an ideal context for patient participation, as VBHC aims to redesign and improve care around patient journeys. Yet, in practice, patient participation in VBHC initiatives remains limited. This research project aimed to analyse and improve patient participation in VBHC, offering valuable insights to strengthen patient participation and drive the transformation toward a healthcare system that truly prioritizes patient value.

1.1 Patients are important stakeholders at different levels in healthcare

Over the years, the healthcare system has transformed from a highly paternalistic healthcare system to one where patients' values are central in guiding decisions across the different levels of healthcare [1]. Such a patient-centred healthcare system requires active participation of patients [2]. Two distinct arguments can be made that emphasize the importance of patient participation, i.e. a substantive argument and a normative argument [3]. The substantive argument emphasizes that patients possess important knowledge that is complementary to that of people that work in healthcare, and therefore crucial for improving care. Studies have shown that patient participation can improve quality of care, such as clinical outcomes or patient experience, and increase relevance and impact of research, e.g. by aligning the research outcomes with patients' needs [4,5]. The normative argument stipulates that patients have the right to be involved in decision-making across different levels of healthcare, since they are the end-users of healthcare, and thus important stakeholders.

Patient participation can occur on three distinct levels, the level of direct care, organizational design and governance, and policy making [6]. Patient participation in direct care is also referred to as individual patient participation (e.g. Shared Decision Making, SDM), and patient participation in organizational design and governance, and policy making is also referred to as collective patient participation [7]. Within the individual and collective level of patient participation, patients can partake in different roles, i.e. as listener (is given information), co-thinker (is asked to give opinion), advisor (gives (un)solicited advise), partner (works as an equal partner), or leader (takes initiative, (final) decision). These different roles originated from the different steps of 'the participation ladder' by Arnstein [8]. Arnstein visualized the different roles on a "ladder", thereby implying they have a hierarchal order; i.e. that roles higher up the ladder are superior to those lower down. Over time, this ladder representation has evolved into the participation matrix where the different roles are presented side-by-side rather than hierarchically (Fig. 1) [9]. This shift was made because the ladder representation does not fully reflect the value of all roles [6].

At the individual level, there are multiple examples of how patients participate in various roles, as illustrated in Figure 1. Over the past decade, the main focus has been on shared decision-making (aligning with the partner role). SDM is the process where "health care professionals and patients share the best available evidence and information about personal values when faced with the task of making decisions, and support patients to consider options, to achieve informed preferences" [10]. Other examples of patient participation at the individual level, include patients being involved as co-thinkers, by letting them complete a Patient Reported Outcome Measurement (PROM) questionnaire as preparation for a consult, or as leaders through 'self-management', where patients are empowered to take an active role in managing their personal health [11]. Overall, research has shown that patient participation at the individual level contributes to e.g. improved patient satisfaction and trust, reduced anxiety, and improved quality of care [12].

Beyond the individual level, there are also examples of patients taking on different roles at the collective level (Fig. 1). For instance, patients can be involved as co-thinkers by completing Patient-Reported Experience Measures (PREMs) questionnaires to identify improvement potential based on their experiences. PREMs are increasingly being used by healthcare organizations as a method to standardize the measurement of patient experiences and use the results to improve care [13]. Furthermore, patients can take on an advisory role, such as by participating in patient panels that discuss potential improvement initiatives. In terms of partnership with patients, client councils offer patients a direct voice in policy-making at the organizational level of healthcare organizations. In the Netherlands, each healthcare organization is legally required to have a client council [14]. Lastly, patient organizations are increasingly taking on a leadership role, by initiating projects themselves or lobby in policy-making [15].

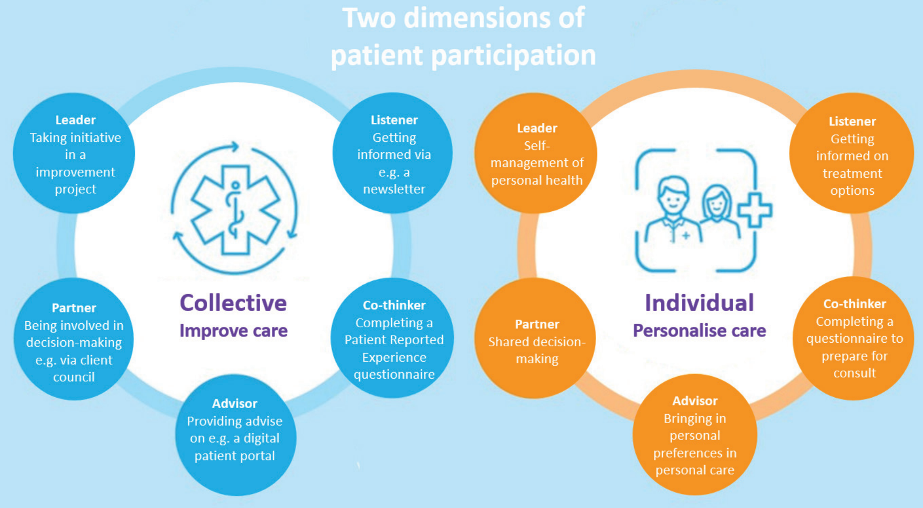


Figure 1| The different levels and roles of patient participation including examples for each role

1.2 The challenges in patient participation in our current healthcare system

While patient participation has gained a lot of attention in practice and in research, the equal involvement of patients at the collective level within the healthcare system remains challenging. Improving care with patients as equal partners requires a cultural shift in the roles and attitudes of patients, but also of healthcare professionals [16]. Multiple barriers relate to this cultural change, such as ambiguity regarding these new roles or struggles with hierarchy between patients and healthcare professionals in these new roles [4,17]. Besides these cultural barriers of patient participation, literature describes barriers in practical organization and resources for patient participation [4]. Such barriers may lead to poorly organized patient participation or even in 'tokenistic' or 'checkbox' participation, i.e. when patients are involved, but only with limited to zero influence. Addressing these barriers is essential to move beyond such tokenistic participation towards meaningful and impactful patient participation. However, while several literature reviews exist on barriers and facilitators to collective patient participation in different settings [4,18–21], an up-to-date overview of barriers and facilitators for collective patient participation is lacking. Such an overview provides healthcare professionals, researchers, policy-makers and patient representatives insights in the key lessons in patient participation from previous studies that they can use to implement meaningful patient participation in new projects.

Another challenge in collective patient participation is that an important intermediate level is often overlooked: participation at the level of patient groups. For example, the ‘continuum of engagement’ of Carman et al. (2013) includes participation at the individual level, the organizational level, and in (inter)national policy-making, but limitedly describes patient participation at the level of patient groups, such as on the level of specific medical conditions [6]. This is striking, as patients can provide unique insights at this level based on their experiences from the entire patient journey. These journeys can vary significantly between different medical conditions, underscoring the importance of improving care at this level. Some examples of patient participation at the level of medical conditions are described in literature, but these are often in the context of projects with very specific goals and end-dates [20,21]. This results in a lack of structural participation of patients at the group-level to continuously improve care based on lived experiences and preferences of patients. This gap might be explained by the fragmented responsibilities for the care for a specific condition across different departments, with no single group having responsibility for the entire patient journey, as hospitals are primarily organized into medical specialty departments. As a result, there is no clear structure where the input of patients can be collected and utilized effectively to improve care at the level of medical conditions [22]. This lack of proper infrastructures around patient groups limits the full potential of patient participation in care improvement [23].

1.3 Value-based healthcare provides a highly suitable context for patient participation

In 2006, Porter addressed this fragmentation in responsibilities for medical conditions and introduces Value-Based Health Care (VBHC) as a solution. Within VBHC, healthcare providers should focus on increasing value for patients, where value is defined as patient relevant outcomes relative to the costs for achieving these outcomes, which is measured over the entire patient journey rather than for isolated interventions [24,25]. To this end, Porter advocates for an organizational redesign towards Integrated Practice Units (IPUs), where care is organized around the patient journey and healthcare professionals share the responsibility for value of care for a specific patient group [26]. However, in daily practice, the uptake of the original IPU concept remains limited [27,28]. Transition towards IPUs requires a full organizational redesign, which is often avoided by healthcare providers. Three alternative organizational structures of condition-based organization (i.e. condition-based units) have been identified: the multidisciplinary project team, the matrix organization, and the independent treatment centre, with differences in e.g. level of responsibilities, independence, and leadership [28]. The alternative structures of multidisciplinary teams and matrix organizations are currently often preferred over IPUs, since these require a less invasive change in organizational design [27,29]. Overall, condition-based units provide the ultimate context for patient participation, because here, the input of patients can be used to shape the care delivery and drive continuous improvement at the patient group-level [22].

To stimulate the implementation of VBHC, Porter and Lee have introduced the "strategic agenda for moving to a high-value healthcare delivery system" [23]. This strategic agenda consists of six components integral to VBHC, i.e.:

1. Organize into IPUs
2. Measure outcomes and costs for every patient
3. Move to bundled payments for care cycles
4. Integrate care delivery systems
5. Expand geographic reach
6. Build an enabling information technology platform

Van der Nat identified that several items were missing from the original strategic agenda, and complemented it with the following four items [30]:

7. Set up value-based quality improvement
8. Integrate value in patient communication
9. Invest in a culture of value delivery
10. Build learning platforms for healthcare professionals

While all ten items of the (extended) strategic agenda are fundamental aspects of VBHC, reviews point out that often only specific items of the strategic agenda are implemented in daily practice [31,32]. Moreover, there are different interpretations of what VBHC truly entails [31,33], with the consequence of healthcare professionals and management 'cherry-picking' the items most attractive to them [31]. In Europe, the main focus of VBHC implementation has been on measuring outcomes and setting up value-based quality improvement [29,32,34–36]. Furthermore, the use of outcome data for SDM mainly originated from European healthcare settings [37,38]. Patient participation is key to the successful implementation of all agenda items, but below, we outline the role of patients in the three major agenda items in the European setting.

Patient participation in measuring outcomes and costs for every patient (agenda item 2)

Since 'value' within VBHC is defined as patient relevant outcomes relative to the costs, patients play an important role in what these patient relevant outcomes are. Within the methodology of the International Consortium of Outcome Measurement (ICHOM), a well-known organization that develops standard sets of relevant outcome indicators, patient participation is the norm [39]. Currently, ICHOM has developed over 40 standard sets for different medical conditions or patient groups [40]. These standard sets are used to benchmark between different healthcare providers, with the goal to learn from each other and to improve value of care [41]. Multiple examples exists where based on the input of patients, specific outcomes were added to the standard set [42,43]. However, research also shows that currently, there is more emphasis on clinical outcomes and process indicators in VBHC initiatives compared to outcomes that matter to patients [44,45].

Patient participation in value-based quality improvement (agenda item 7)

Based on the measurement of outcomes and costs, many healthcare providers have set up value-based quality improvement [32,34–36]. Also here, patients play a crucial role, since they bring unique expertise on potential improvement initiatives complementary to that of the healthcare professionals [34,35,46–48]. However, literature shows that overall, there is limited collective patient participation in VBHC [22,45]. When patients are involved, this mostly includes consultation of patients, e.g. via questionnaires, where the insights from these consultations are typically only discussed among healthcare professionals. This has the risk of resulting in limited impact of patients on the VBHC initiative, or even in the risk of tokenistic patient participation, since healthcare professionals remain in charge of the interpretation and use of the input provided by patients. Consequently, Van der Voorden and colleagues advocate for other levels of involvement of patients in VBHC, such as coproduction and partnership [22].

Furthermore, since VBHC emphasizes that true value of care is created over the entire patient journey [25], it is crucial to gain a comprehensive understanding of these journeys and the patient's experiences throughout the journey to identify improvement potential. Different methodologies for mapping the patient journey are available. In the context of VBHC, the Care Delivery Value Chain (CDVC) methodology was developed, which focuses on mapping the key outcomes throughout the entire care pathway [49,50]. However, the CDVC does not provide insight into the patient experiences and needs, while this provides valuable insights that can lead to targeted improvements in care. To identify relevant improvement initiatives based on patient's experiences, Metro Mapping can be used. The Metro Map consists of five layers, with the top layer called the 'patient experience layer'. In this layer, important themes related to patients' experiences at specific phases in their journey are displayed. The next layer is the 'metro line', where the patient journey is visually presented as a metro line and each 'station' represents a contact point in the care trajectory. The third layer provides insight into the information that patients receive during their patient journey. The fourth and fifth layer provide insight into contextual factors and the healthcare professionals perspectives [51]. The Metro Map was developed to support individual patient participation (Shared Decision-Making), but it can also be used as a tool for redesigning and improving care pathways [52]. However, research has shown that the patient experience layer of the Metro Map is not always developed, and that many Metro Maps have been developed without patient participation [53].

Patient participation in integrating value in patient communication (agenda item 8)

Interestingly, while VBHC aims to enhance value of care for patients, the use of outcome data at the individual patient level was not included in Porter's original strategic agenda, but added by Van der Nat to the extended strategic agenda (i.e. 'integrate value in patient communication') [30]. At the individual patient level, the outcome data that is collected for value improvement can support SDM by providing patients and healthcare professionals insight into patient relevant treatment outcomes of (similar, also referred to as "patients like me") patients [54–56]. For example, access to real-world personalized information may result in patients being less inclined to opt for care with limited impact on patient-relevant outcomes [57]. While there is ample literature available on shared decision-making and the implementation hereof, the use of real world outcome data for SDM is a relatively new application [55]. Over the last years, several studies on the use of (aggregated) outcome data for SDM have been initiated [55,57,58], but there is limited insight into the experiences of healthcare professionals and patients with using outcome data for SDM in daily practice beyond these studies.

Limited patient participation in VBHC

In conclusion, VBHC is increasingly being adopted by different healthcare providers worldwide and multiple articles have been published that describe their organization's approach to implementation of (components of) VBHC [34–36,46,47,59–61]. The involvement of patients in these initiatives remains limited [22]. Although some studies describe their efforts to include patients within their VBHC initiatives, they report significant challenges in meaningful patient participation [35,46,47]. The consequence of such inadequate patient participation is profound; it has the risk to waste valuable resources to improvements that fail to align with patients' actual needs and preferences. This undermines the full potential of VBHC, ultimately compromising the quality and costs of care. Addressing this gap is essential for transforming the healthcare system into a system that truly prioritizes patients' values. Therefore, there is a pressing need for insight into good practices for patient participation in VBHC and effective strategies to improve patient participation within a VBHC system [35,46,47].

1.4 Context

VBHC in the Netherlands

Healthcare organizations within the Netherlands are amongst the early adopters of VBHC [36,59]. This adoption of VBHC has also been embraced by the government, which invested 70 million euro in the 'Outcome based healthcare program' ("Programma Uitkomstgerichte Zorg") focusing on multiple items of the strategic agenda, such as value-based payment models, value-based organizational design, and integrating outcome information in shared decision-making [62]. This was followed up by the Integral Care Agreement ("Integraal Zorgakkoord"), where 2.8 billion euro is made available for transformation of the Dutch healthcare system, in which VBHC and patient participation are put forward as major themes [63].

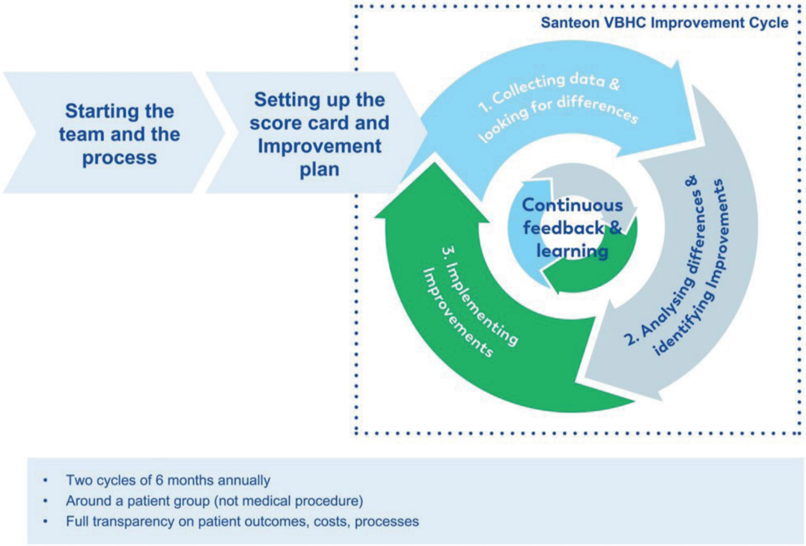
The Santeon hospitals' approach to VBHC

Within the Netherlands, Santeon (a consortium of seven hospitals) has been the frontrunner in VBHC implementation. The Santeon hospitals are seven top clinical teaching hospitals that are working together on VBHC implementation since 2012. These seven hospitals include: Canisius Wilhelmina Hospital in Nijmegen, Catharina Hospital in Eindhoven, Maasstad Hospital in Rotterdam, Martini Hospital in Groningen, Medisch Spectrum Twente in Enschede, OLVG in Amsterdam, and St. Antonius Hospital in Nieuwegein/Utrecht. In 2016, Santeon launched the 'Better Together' program to continuously improve care based on VBHC principles. The

Better Together program currently focusses on 15 different patient groups, and aims to include several more patient groups each year. For each of these patient groups, multidisciplinary project teams have been set up in each of the seven hospitals. For example, each Santeon hospital has a multidisciplinary project team for breast cancer in place, consisting of all relevant stakeholders for breast cancer care within the hospital (i.e. medical specialist, nurses, allied healthcare professionals, data analysts, etc.). These teams structurally collect outcome data (based on the ICHOM standard sets) and use this data to benchmark between the seven hospitals and identify improvement initiatives. To this end, they meet multiple times a year to discuss the collected outcome data and improvement initiatives. This process of the 'value improvement cycle' is followed twice a year (Fig. 2). Within the Santeon hospitals, these teams are referred to as Value Improvement (VI) teams. Some of these multidisciplinary project teams have evolved into the matrix organization archetype, where the VI teams became part of the hierarchical structure and gained formal responsibility for value of care of a specific patient group [59].

Patient participation within the Santeon hospitals' value improvement teams

Within the Better Together program, patients are crucial stakeholders. Their perspectives on relevant outcomes and improvement initiatives are needed to ensure that the efforts of the VI teams contribute to patient relevant improvements in care. To ensure incorporation of the patients' perspective within the VI teams, Santeon aimed to include at least one patient in each VI team at the start of the Better Together program. However, this was experienced as challenging, and questions arose whether this was the best method for patient participation in VI teams. This goal was therefore informally revised to 'incorporate the patients' perspective in the VI team using a method of choice', allowing VI teams to select patient participation methods that best suit their needs and the needs of the involved patient group. This could be for example a yearly questionnaire or setting up a patient panel. However, these relatively open goals in patient participation led to ambiguity regarding the extent to which patients are actually involved in VI teams. Meanwhile, many VI teams kept struggling with finding a meaningful way to include the patients' perspective within their team. As a result, teams were often uncertain whether their efforts to improve care truly contributed to improved care from the patients' perspective, potentially limiting the full potential of the Better Together program. The VI team members therefore expressed the need for the development of a practical guide for patient participation in VI teams. This resulted in the setup of the current research project with the aim to improve patient participation within the VI teams and to develop such a practical guide together with the VI team members.



- Two cycles of 6 months annually
- Around a patient group (not medical procedure)
- Full transparency on patient outcomes, costs, processes

Figure 2| The Santeon Value Improvement cycle

Research within the Santeon hospitals

In order to continuously advance knowledge in the field of VBHC and implementation thereof, Santeon defined a research agenda in 2022 consisting of six main themes on which we want to stimulate research. These six themes are: 1. Implementation and evaluation of value improvement initiatives, 2. Personalisation of healthcare, 3. Implementation and evaluation of digitalization, 4. Steering on outcomes in relation to costs, 5. Evaluation of real world effectiveness of interventions, and 6. Development and implementation of VBHC. All themes directly contribute to solving challenges experienced in daily practice within the hospitals. Therefore, it is essential that research on these topics is conducted in close collaboration with professionals from the field, ensuring it is deeply embedded in the organization rather than led by an 'external' researcher. This approach was also used for the current research project on patient participation in VBHC, to make it highly relevant to everyday practice while also contributing to the research agenda. The present PhD thesis on patient participation is part of the 6th theme of the Santeon Research Agenda.

1.5 Aim of this thesis and research questions:

The aim of this research project was to study how patients can be involved in value-based healthcare in a meaningful manner, with the ultimate goal to ensure that the patients' perspective is well embedded in the value improvement cycle. This was done through the iterative and collaborative development and evaluation of a practical guide for patient participation within value-based healthcare. We formulated the following research questions:

Research questions:

1. What can we learn from the literature regarding collective patient participation?
2. What is the current level of collective patient participation in multidisciplinary project teams?
3. What is the current level of using outcome data at the individual patient level?
4. What are good practices for collective patient participation in multidisciplinary project teams?
5. How can multidisciplinary project teams use patient experiences to identify improvement potential?

1.6 Outline of this thesis:

This thesis is structured in four parts, each answering one or two of the research questions.

Part 1| Insights from the literature

1. What can we learn from the literature regarding collective patient participation?

Part 2| Current level of patient participation

2. What is the current level of collective patient participation in multidisciplinary project teams?
3. What is the current level of using outcome data at the individual patient level?

Part 3| Good practices for collective patient participation

4. What are good practices for collective patient participation in multidisciplinary project teams?

Part 4| Using patient experiences to improve value of care

5. How can multidisciplinary project teams use patient experiences to identify improvement potential?

Part 1| Insights from the literature

Chapter 2 describes the results of a literature review on barriers and facilitators of meaningful patient participation at the collective level in healthcare organizations. A narrative synthesis was used to identify themes in the reported barriers and facilitators, which resulted in five recommendations for collective patient participation that are presented in the discussion of Chapter 2.

Part 2| Current level of patient participation

Part 2 describes the current level of both collective patient participation as well as individual patient participation within a VBHC system. **Chapter 3** outlines the level of collective patient participation within the Santeon VI teams at that moment (2022). Within this study, interviews were conducted with VI team members and questionnaires were completed (Public and Patient Engagement Evaluation Tool, PPEET [64]) by VI team members. Multiple lessons for collective patient participation in VI teams were identified and are presented in this chapter. In **Chapter 4**, the extent to which outcome data were used in individual patient consultations was studied. A mixed methods study design was used to capture a comprehensive view of the topic, combining qualitative insights from healthcare professionals with quantitative data from patients. Healthcare professionals from the Santeon hospitals were interviewed on their use of outcome data at the individual level, and Dutch patients received a questionnaire on their perspectives on the relevance of outcome data for e.g. shared decision-making. This study provided insight into barriers and facilitators for the discussion of outcome data with individual patients in clinical practice, and the patients' perspective on which outcome data they deem relevant to be informed on.

Part 3| Good practices for collective patient participation

Part 3 describes the impact of our efforts to improve collective patient participation within VI teams, and what the good practices for patient participation are. To this end, we used an action research approach. Action research is a participatory research method that aims to tackle complex problems by iterative cycles of observation, planning, action, and evaluation [65]. This approach is highly suitable for answering our research question, since improving patient participation within VI teams requires interventions that are contextually appropriate and co-created with VI team members themselves. We start in part 3 with an explanation of the principles of action research. **Chapter 5** describes the results of our action research and provides insight into barriers and facilitators of implementation of patient participation within VI teams. The insights of the action research study, together with the results from Chapter 2 and 3, shaped the practical guide, which is included in part 3.

Part 4| Using patient experiences to improve value of care

A core principle of VBHC is the establishment of a continuous improvement cycle around the care pathway for a specific medical condition, guided by outcome, process, and cost data. In addition to these data sources, patient experiences are increasingly recognized as valuable input for improving care. However, within VBHC, there is currently no systematic approach for gaining insights into patient experiences and using these insights to inform care improvement. Therefore, in **Chapter 6**, we explore how a VI team can gain insight into patient experiences to improve value of care. We did this through a case study in which, together with the bladder cancer value improvement team, we mapped patient experiences with bladder cancer care at St. Antonius Hospital using Metro Mapping. Metro Mapping is a structured methodology that visualizes the patient journey in five layers: 1. The different steps of a patient journey, 2. The patient's experience throughout the journey, 3. The information that is shared with the patients, 4. The involved healthcare professionals, and 5. The context in which the care is delivered [51].

The thesis concludes with a general discussion in **Chapter 7**.

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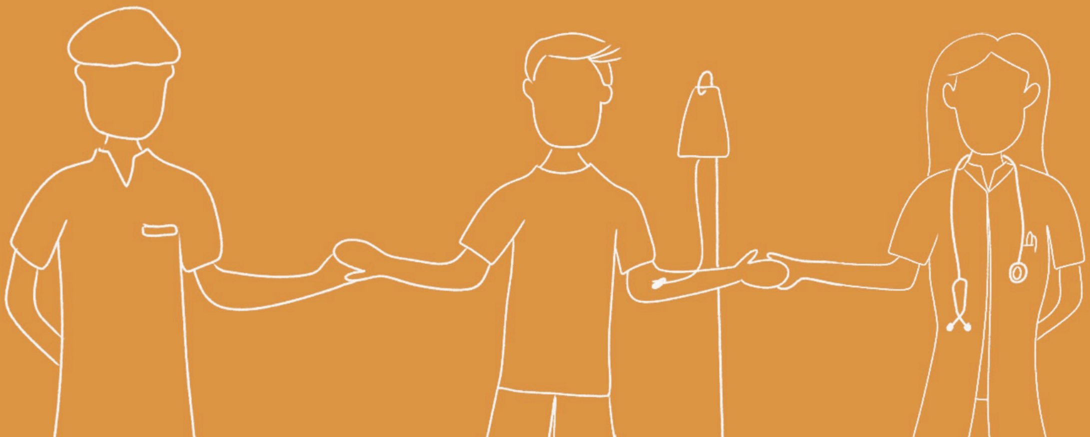
Part 1

Insights from the literature



Chapter 2

Barriers and facilitators of meaningful patient participation at the collective level in healthcare organizations: a systematic review

H.J. Westerink, T. Oirbans, M.M. Garvelink, C.F. van Uden-Kraan, O. Zouitni, J.A.J. Bart, P.J. van der Wees, and P.B. van der Nat

Health Policy, 2023;138:104946

Abstract

Introduction: Collective patient participation, such as patient participation in policymaking, has become increasingly important to achieve high-quality care. However, there is little knowledge on how to let patients participate in a meaningful manner at this level. The aim of this systematic literature review was to provide an overview of barriers, facilitators, and associated impact of collective patient participation.

Methods: PubMed and EMBASE were searched until May 2023 for studies that evaluated collective patient participation. Study characteristics, methods for patient participation, barriers and facilitators, and impact (if measured) of patient participation were extracted from the articles.

Results: We included 59 articles. Identified barriers and facilitators of collective patient participation were grouped into five categories: (1) preconditions for patient participation, (2) strategy for patient participation, (3) preparation of patients and staff for patient participation, (4) support for patients and staff during patient participation, and (5) evaluation of patient participation. Impact of patient participation was reported in 34 included studies at three levels: quality of care and research, the team and organization, and the participants themselves. Only three studies reported quantitative outcomes.

Conclusion: Interestingly, similar challenges were experienced during a period of twenty years, indicating that little progress has been made in structuring patient participation. Our overview of these barriers and facilitators will help to improve and structure collective patient participation.

2.1 Introduction

Over the years, patients have gained a more active role in healthcare, due to a shift from a highly paternalistic healthcare system to a more collaborative system with shared influence of both the patients and the healthcare providers [1]. Patient participation has been acknowledged to be an essential part to achieve high quality healthcare [2,3], both at the individual level and the collective level. The individual level concerns patient participation for their own individual care, for example in shared decision-making [4], whereas the collective level can be defined as patients engaging in activities where the impact extends beyond their individual care [5]. Examples of collective patient participation include patients participating in quality improvement projects, in advisory councils, or in research projects [3,6,7]. Ample research has been conducted on patient participation at the individual level [8–11]. In contrast, there is little knowledge on how to let patients participate in a meaningful manner at the collective level [5].

Patient participation at the collective level is important because of their unique expertise and knowledge, which can be used to e.g. improve quality of care, improve clinical outcomes, improve patient experiences, increase patient autonomy, increase research relevance and impact, and increase public trust in research [3,12–14]. Moreover, the value of collective patient participation is acknowledged by multiple funding institutions and governments by setting up requirements to involve patients at the collective level [15,16]. In addition, it is believed that patients and the public have the moral right to be involved since the project or study has a direct effect on their care, or because the project or study is publicly funded [14,17].

Multiple approaches for collective patient participation can be found in the literature, but due to a lack of formal evaluation, it is unknown what works best [13,18]. This results in researchers, project managers, and policymakers struggling with finding the correct approach for meaningful patient participation, which can result in tokenistic patient participation (i.e. symbolic participation) [19]. Therefore, there is a need for an overview of lessons learned and best practices of collective patient participation. A systematic literature review can help to create such an overview. Existing systematic reviews on collective patient participation are outdated [3,20], have a limited search strategy [21–24], and/or only focus on patient participation in a specific setting or of a specific patient group [25–28].

This review aims to provide a timely and complete overview of the barriers and facilitators and the associated impact of collective patient participation in healthcare organizations. The insights of this study can help researchers, project managers, and policymakers in healthcare organizations to develop the best strategy for collective patient participation in their project in order to achieve meaningful patient participation.

2.2 Methods

Study design

A systematic literature review was conducted to be able to include different types of studies and evidence for barriers, facilitators, and impact of collective patient participation. A comprehensive search for empirical quantitative, qualitative, and mixed-methods studies was undertaken. The Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) and Joanna Briggs Institute (JBI) methodologies were used [29–31].

Search strategy

A preliminary search of PubMed identified applicable articles for this review. The full search strategy was developed based on the MeSH-terms and relevant search terms of the titles and abstracts of the applicable articles (see Table 1). The search strategy was developed with the help of an experienced medical librarian and adapted for the EMBASE database. The search strategy included all articles published between 1 January 2000 and 4 May 2023.

Inclusion process

Following the search, duplicates were removed and the citations were loaded into Rayyan [32]. Potentially relevant studies were screened on title and abstract by two independent reviewers (HJW and TO). Inclusion criteria were: empirical studies on collective participation of adult patients that evaluated their approach for patient participation in a real-world healthcare project and clearly described this approach. Studies were excluded if they did not formally evaluate patient participation or missed information on the evaluation in their method section, if the results were not based on a clearly defined project where patients participated, if they discussed patient participation at the individual level, if patients participated in a trial, if it was not empirical research, if children (<18 years) participated in the project (since this would lead to different barriers and facilitators compared to adults), and if the study was conducted at a low- or middle income country (since these healthcare organizations face different problems in patient participation such as difficulties with reaching indigenous populations).

Table 1| Search strategy

Subject	Search terms
‘Patient participation’	("Patient Participation"[Mesh Major Topic] OR "patient participation"[ti] OR "patient engagement"[ti] OR "patient involvement"[ti] OR "patient partner*"[ti] OR "patient collaboration"[ti] OR "public patient involvement"[ti] OR "patient and public involvement"[ti] OR "public and patient involvement"[ti] OR “patient and family engagement”[ti] OR "user participation"[ti] OR "user involvement"[ti] OR "patient advoca*"[ti] OR "patient representative*"[ti] OR "client participation"[ti] OR "client involvement"[ti] OR "stakeholder participation"[ti] OR "stakeholder involvement"[ti])
AND ‘collective level’	("healthcare organization*"[tiab] OR "healthcare provider*"[tiab] OR "Health Facilities"[Mesh] OR "health facility*"[tiab] OR "hospital*"[tiab] OR "health service*"[tiab] OR "healthcare service*"[tiab] OR "healthcare deliver*"[tiab] OR "clinic*"[tiab] OR "Delivery of Health Care"[Mesh] OR "Delivery of Health Care"[tiab] OR "healthcare system*"[tiab] OR "healthcare decision*"[tiab] OR "healthcare institution*"[tiab] OR "Quality of Health Care"[Mesh] OR “collective”[tiab])
AND ‘participation methods’	("Patient Participation/methods"[MeSH] OR "strateg*"[tiab] OR "patient panel*"[tiab] OR "patient council*" [tiab] OR "patient board*"[tiab] OR "Experience Based Co-Design*"[tiab] OR "Participatory Action Research"[tiab] OR "Patient Advisory Group*"[tiab] OR "patient advisory council*"[tiab] OR "focus group*"[tiab] OR "work group*"[tiab] OR "working group*"[tiab] OR "project group*"[tiab] OR "project team*"[tiab] OR "advisory committee*"[tiab] OR "advisory board*"[tiab] OR "advisory bod*"[tiab] OR “co-creation”[tiab] OR “co-design”[tiab] OR “co-develop*”[tiab] OR “co-produc*”[tiab])
NOT ‘micro-level patient participation’	("shared decision-making"[ti] OR "shared decision making"[ti] OR "Decision Making, Shared"[Mesh] OR "self-management"[ti] OR "selfmanagement"[ti] OR “Self-Management” [Mesh])

Included articles were retrieved in full and their citation details were imported in Mendeley [33]. The full texts of the included articles after title and abstract screening were independently assessed by HJW and TO. Differences between inclusions of the two reviewers were discussed in several meetings and consensus was reached on the final set of included articles. Reasons for exclusion were administrated during full-text screening. The results of each step of the search and selection process are presented in a PRISMA flow diagram [29] (see Fig. 1).

All included studies were subjected to critical appraisal using either the standardized critical appraisal tools from JBI for qualitative or quantitative studies [30,31] or the Mixed-Methods Appraisal Tool (MMAT) for mixed-methods studies [34] to evaluate the trustworthiness, relevance and results of the articles.

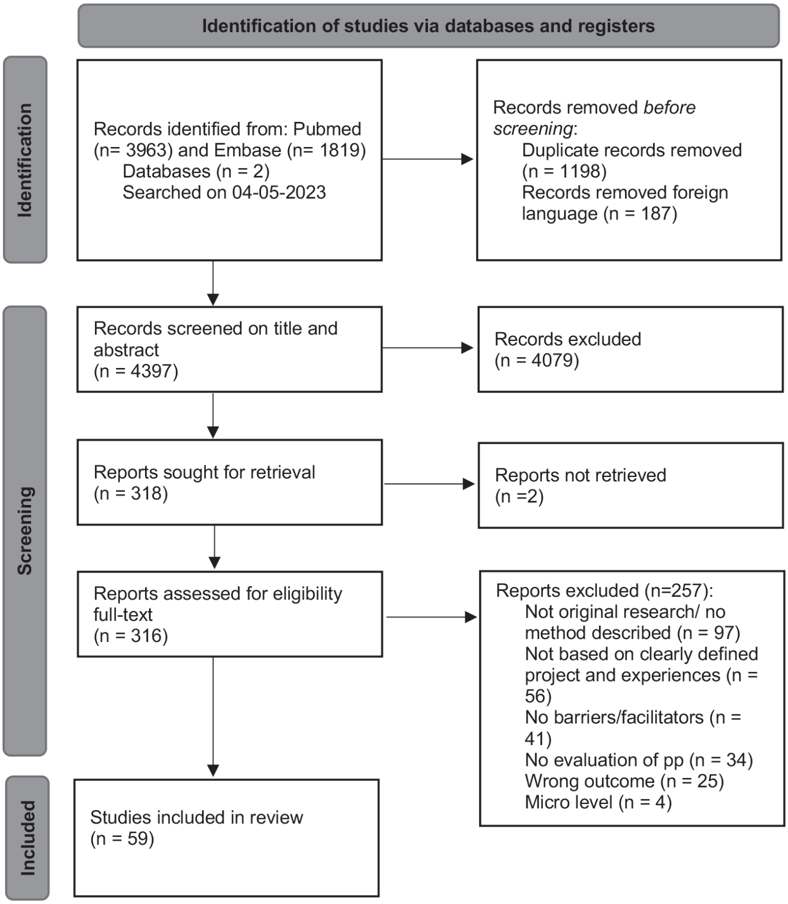


Figure 1| PRISMA flow diagram. [35]

Data extraction

Quantitative and qualitative data from included studies were extracted by HJW using a data extraction tool in Research Electronic Data Capture (REDCap), which is a “secure, web-based software platform designed to support data capture for research studies” [36,37]. The tool was piloted by both HJW and TO to ensure that it captures all relevant data. Ten articles were double-extracted by TO to check for discrepancies, and these discrepancies were solved in three meetings (each meeting was planned after double-extracting 3-4 articles) between TO and HJW in order to increase reliability of data extraction. The data extraction included details about the country of origin, study methods (qualitative/quantitative/mixed-methods), method for patient participation (as described in the article e.g. focus groups and patient panels), setting (primary care/secondary care/research institute/

guideline group/national level/network/other), topic for patient participation (quality improvement/research/guideline development/service planning/hospital redesign/policy-making/tool development/other), medical condition (as described in the article, e.g. lung cancer or chronic diseases), barriers and facilitators, and impact of patient participation. See Appendix A for the full data extraction tool.

Data analysis

Study characteristics, such as country of origin, setting, study design, and patient participation method, were analysed with descriptive analysis. A narrative analysis was used for all other extracted data, due to the heterogeneity of the included studies. The extracted barriers and facilitators and reported impact of patient participation were categorized by HJW and TO. All results were then discussed in several meetings with the co-authors and consensus was reached on the identified categories and results.

Patient and Public Contribution

Two patient advisors were part of the research team and attended the research team meetings. They were involved as research partners in all phases of the study, including drafting the protocol, interpreting the results, and writing this article.

2.3 Results

We retrieved 5782 studies from the search strategy (Fig. 1). After removing duplicates and articles not written in Dutch or English, 4397 studies were left. 4079 articles were excluded after title and abstract screening. We were unable to locate the full-text of two articles, therefore 316 articles were included in the full-text screening. Based on this screening, we included 59 articles. See Table 2 for an overview of all included studies.

Included studies were published between 2001 and 2023, with the majority published after 2017 (n=43). Most studies originated from the United Kingdom (UK; n=18), Canada (n=16), or the United States of America (USA; n=11). In more than half of the studies (n=33), patients participated in a research project. Other topics for patient participation were e.g. quality improvement (n=9) or guideline development (n=4). See Table 3 for a summary of study characteristics.

Different terminology for patient participation was used in the studies, and was often associated with the country of origin. For example, studies from the United

Kingdom mostly used ‘patient and public involvement’, while studies from Canada and the United States of America often used ‘patient engagement’. Furthermore, multiple studies did not use a consistent terminology for patient participation, with some articles using six different terms for patient participation throughout their article (i.e. patient participation, patient involvement, patient engagement, patient partner, stakeholder involvement, and user participation).

The majority of studies set up patient participation by using a combination of different patient participation methods in order to gain insight into perspectives of multiple (and different types of) patients (36%) or by adding a (number of) patients to the multidisciplinary project group/research team (36%). The most commonly seen combination of patient participation methods was including patients in the multidisciplinary project team and questioning a larger group of patients through, for example, surveys or focus groups (32%). Other methods used for patient participation were, e.g. focus groups, questionnaires, interviews, patient advisory boards, and other types of patient panels (see Table 2 and 3).

Table 2| Overview of included studies

Title of publication	**Author**	**Year**	**Country of origin**	**Journal**
Approaches to optimize patient and family engagement in hospital planning and improvement: Qualitative interviews	Anderson, et al [38]	2021	Canada	Health Expectations
Optimizing patient involvement in quality improvement	Armstrong, et al [39]	2012	UK[1]	Health Expectations
Engaging patients and stakeholders in preresearch: findings from the Pipeline to Proposal Awards Initiative	Bayne, et al [40]	2020	USA[2]	Journal of Comparative Effectiveness Research
Patient and researcher experiences of patient engagement in primary care health care research: A participatory qualitative study	Beland, et al [41]	2022	Canada	Health Expectations
Patient involvement in quality improvement - a 'tug of war' or a dialogue in a learning process to improve healthcare?	Bergerum, et al[42]	2020	Sweden	BMC Heath Services Research

Methods	Setting for patient participation	Topic for participation	Medical condition	Methods for participation
Qualitative	Secondary care	Quality improvement	Various	Focus group, interview, patient in multidisciplinary project group, survey
Qualitative	Primary care and secondary care	Quality improvement	Lung cancer, chronic kidney disease, and Abdominal Aortic Aneurysm	Focus group, patient in multidisciplinary project group, patient panel, survey, collaboration with charity
Qualitative	Research institute	Research	Various	Patient in multidisciplinary project group
Qualitative	Primary care	Research	Chronic diseases	Patient in multidisciplinary project group
Qualitative	Secondary care	Quality improvement	Breast cancer, diabetes, neuro, prostate cancer, pneumonia, multi-diagnosed older persons	Interview, patient in multidisciplinary project group, workshop, patient representatives

Table 2| Continued

Title of publication	Author	Year	Country of origin	Journal
A Multilevel Approach to Stakeholder Engagement in the Formulation of a Clinical Data Research Network	Boyer, et al [43]	2018	USA	Medical Care
Value, transparency, and inclusion: A values-based study of patient involvement in musculoskeletal research	Bradshaw, et al [44]	2021	UK	PLOS ONE
People with lived experience (PWLE) of depression: describing and reflecting on an explicit patient engagement process within depression research priority setting in Alberta, Canada	Breault, et al [45]	2018	Canada	Research Involvement and Engagement
Impact of patient and public (PPI) involvement in the Life After Prostate Cancer Diagnosis (LAPCD) study: a mixed-methods study	Brett, et al [46]	2022	UK	BMJ Open
Engaging cancer patients in clinical practice guideline development: a pilot study	Brouwers, et al [47]	2018	Canada	Current oncology
Engaging patients in health care epidemiology research: A case example	Brys, et al [48]	2018	USA	American Journal of Infection Control
From plans to actions in patient and public involvement: qualitative study of documented plans and the accounts of researchers and patients sampled from a cohort of clinical trials	Buck, et al [49]	2014	UK	BMJ open
Sharing space at the research table: exploring public and patient involvement in a methodology priority setting partnership	Burke, et al [50]	2023	Ireland	Research Involvement
Understanding and optimising patient and public involvement in trial oversight: an ethnographic study of eight clinical trials	Coulman, et al [51]	2020	UK	Trials
Patient and public involvement (PPI) in UK surgical trials: a survey and focus groups with stakeholders to identify practices, views, and experiences	Crocker, et al [15]	2019	UK	Trials
What has been the effect on trial outcome assessments of a decade of patient participation in OMERACT?	De Wit, et al [52]	2013	The Netherlands	The Journal of Rheumatology

Methods	Setting for patient participation	Topic for participation	Medical condition	Methods for participation
Qualitative	Research institute	Research	Various	Interview, patient in multidisciplinary project group, survey, patient advisory council
Qualitative	Research institute	Research	Musculoskeletal conditions	Patient board
Qualitative	Research institute	Research	Depression	Patient in multidisciplinary project group, survey, workshop
Mixed-methods	Research institute	Research	Prostate cancer	Patient advisory council
Mixed-methods	Guideline group	Guideline development	Cancer	Patient in multidisciplinary project group, consultation group
Qualitative	Secondary care	Research	Healthcare associated infections	Patient panel
Qualitative	Research institute	Research	Various	Focus group, patient in multidisciplinary project group, patient panel, patient board (multiple studies with varying methods)
Qualitative	Research institute	Research	Various	Patient in multidisciplinary project group
Qualitative	Research institute	Research	Various	Patient in multidisciplinary project group
Mixed-methods	Research institute	Research	Various	Focus group, interview, patient in multidisciplinary project group, survey, consultation group, online forum
Qualitative	Other (conference)	Research	Rheumatic disorder	Patient as attendee of conference

Table 2| Continued

Title of publication	Author	Year	Country of origin	Journal
It's not just 'What' you do, it's also the 'Way' that you do it: Patient and Public Involvement in the Development of Health Research	Devonport, et al [53]	2018	UK	International Journal for Quality in Health Care
Evaluation of Patient Engagement in a Clinical Emergency Care Network: Findings From the BC Emergency Medicine Network	Drebit, et al [54]	2020	Canada	Journal of Patient Experience
Patient Engagement in Health Research: Perspectives from Patient Participants	Easley, et al [55]	2023	Canada	Current Oncology
Patient engagement in patient-centered outcomes research: challenges, facilitators and actions to strengthen the field	Ellis and Kass [56]	2017	USA	Journal of Comparative Effectiveness Research
The dynamic nature of patient engagement within a Canadian patient-oriented kidney health research network: Perspectives of researchers and patient partners	Elliot, et al [57]	2023	Canada	Health Expectations
'Calling executives and clinicians to account': user involvement in commissioning cancer services	Evans, et al [58]	2013	UK	Health Expectations
Involvement of patients with chronic kidney disease in research: A case study	Finderup, et al [59]	2020	Denmark	Journal of Renal Care
Bridge over Troubled Water: Patients' Opportunities for Collective Participation in Substance Use Institutions through Research Circles	Follevag and Seim [60]	2021	Norway	International Journal of Environmental Research and Public Health
The Canadian retinoblastoma research advisory board: a framework for patient engagement	Gelkopf, et al [61]	2020	Canada	Research Involvement and Engagement
Supporting cancer survivors' participation in peer review: perspectives from NCI's CARRA program	Gilkey [62]	2013	USA	Journal of Cancer Survivorship
Patient and public involvement in numerical aspects of trials (PoINT): exploring patient and public partners experiences and identifying stakeholder priorities	Goulao, et al [63].	2021	UK	Trials

Methods	Setting for patient participation	Topic for participation	Medical condition	Methods for participation
Mixed-methods	National level	Research	Obesity	Patient Advisory Groups (PAGs)
Quantitative	Network	Quality improvement, service planning	Various	Patient in multidisciplinary project group
Qualitative	Research institute	Research	Cancer	Patient in multidisciplinary project group
Qualitative	Research institute	Research	Various	Focus group, interview, patient in multidisciplinary project group, survey, Patient Advisory Group (PAG)
Qualitative	Network	Research	Chronic kidney disease	Unknown
Qualitative	Network	Commissioning	Cancer	Patient in multidisciplinary project group
Qualitative	Research institute	Research	Chronic kidney disease	Patient in multidisciplinary project group
Qualitative	Secondary care	Quality improvement	Substance use disorder	Patient in multidisciplinary project group
Mixed-methods	National level	Research	Retinoblastoma	Patient in multidisciplinary project group
Qualitative	Network	Research	Cancer	Patient panel
Qualitative	Research institute	Research	Various	Focus group, patient in multidisciplinary project group

Table 2| Continued

Title of publication	Author	Year	Country of origin	Journal
"They heard our voice!" patient engagement councils in community-based primary care practices: a participatory action research pilot study	Haesebaert, et al [64]	2020	Canada	Research Involvement and Engagement
An empirically based conceptual framework for fostering meaningful patient engagement in research	Hamilton, et al [65]	2017	Canada	Health Expectations
Exploring patient and public involvement in stroke research: a qualitative study	Harrison and Palmer [66]	2015	UK	Disability and Rehabilitation
Engaging patients in primary care design: An evaluation of a novel approach to codesigning care	Hertel, et al [67]	2019	USA	Health Expectations
Patient representatives: Crucial members of health-care working groups facing an uncertain role and conflicting expectations. A qualitative study	Hult, et al [68]	2021	Sweden	Health Expectations
Patient and public involvement in palliative care research: What works, and why? A qualitative evaluation	Johnson, et al [69]	2020	UK	Palliative Medicine
Patient advocates' role in clinical trials: perspectives from Cancer and Leukemia Group B investigators and advocates	Katz, et al [70]	2012	USA	Cancer
'We're passengers sailing in the same ship, but we have our own berths to sleep in': Evaluating patient and public involvement within a regional research programme: An action research project informed by Normalisation Process Theory	Keenan, et al [71]	2019	UK	PLOS ONE
Exploring approaches to identify, incorporate and report patient preferences in clinical guidelines: Qualitative interviews with guideline developers	Kim, et al [72]	2020	Canada	Patient Education and Counselling
'Adding another spinning plate to an already busy life'. Benefits and risks in patient partner-researcher relationships: a qualitative study of patient partners' experiences in a Canadian health research setting	Leese, et al [73]	2018	Canada	BMJ open

Methods	Setting for patient participation	Topic for participation	Medical condition	Methods for participation
Mixed-methods	Primary care	Quality improvement	Various	Patient in multidisciplinary project group
Qualitative	Research institute	Research	Arthritis	Patient board
Qualitative	Other (PPI groups)	Research	Stroke	Patient panel
Qualitative	Primary care	Hospital redesign	Various	Patient in multidisciplinary project group
Qualitative	National level	Guideline development	Various	Patient in multidisciplinary project group
Qualitative	Research institute	Research	Palliative care	Patient in multidisciplinary project group
Mixed-methods	Research institute	Research	Cancer	Patient in multidisciplinary project group
Qualitative	Research institute	Research	Various	Interview, patient in multidisciplinary project group, patient panel, patient board
Qualitative	Guideline group	Guideline development	Various	Focus group, patient panel, survey
Qualitative	Research institute	Research	Arthritis	Patient in multidisciplinary project group

Table 2| Continued

Title of publication	Author	Year	Country of origin	Journal
Assessment of the benefits of user involvement in health research from the Warwick Diabetes Care Research User Group: a qualitative case study	Lindenmeyer, et al [74]	2007	UK	Health Expectations
Involving patients in health technology funding decisions: stakeholder perspectives on processes used in Australia	Lopes, et al [75]	2015	Australia	Health Expectations
Patient and public involvement in hospital policy-making: Identifying key elements for effective participation	Malfait, et al [5]	2018	Belgium	Health Policy
Involving HIV-positive people in policy and service development: recent experiences in England	Maxwell, et al [76]	2008	UK	AIDS care
Enhancing Neurofibromatosis Clinical Trial Outcome Measures Through Patient Engagement: Lessons From REiNS	Merker, et al [77]	2021	USA	Neurology
Transforming the experience of illness into action - Patient and spouses experiences of involvement in a patient and family advisory council	Missel, et al [78]	2020	Denmark	Patient Education and Counselling
Salutogenic service user involvement in nursing research: A case study	Mjosund, et al[79]	2018	Norway	Journal of Advanced Nursing
Whose voices? Patient and public involvement in clinical commissioning	O'shea, et al [80]	2016	UK	Health Expectations
Patient engagement in an online coaching intervention for parents of children with suspected developmental delays	Ogourtsova, et al [81]	2021	Canada	Developmental Medicine & Child Neurology
Emerging Good Practices for Transforming Value Assessment: Patients' Voices, Patients' Values	Perfetto, et al [82]	2018	USA	Value in Health
Go Slow to Go Fast: Successful Engagement Strategies for Patient-Centered, Multi-Site Research, Involving Academic and Community-Based Organizations	Pinsoneault, et al [83]	2018	USA	Journal of General Internal Medicine
Redesigning mental health services: lessons on user involvement from the Mental Health Collaborative	Robert, et al [84]	2002	UK	Health Expectations

Methods	Setting for patient participation	Topic for participation	Medical condition	Methods for participation
Qualitative	Research institute	Research	Diabetes	Patient in multidisciplinary project group, patient panel
Qualitative	National level	Policy making	Various	Patient in multidisciplinary project group, online consultations
Mixed-methods	Secondary care	Policy making	Various	Patient in multidisciplinary project group
Qualitative	Other (Patient organizations)	Policy making, service planning	HIV	Patient in multidisciplinary project group, patient panel, survey, consultations, forum
Qualitative	Other (International level)	Research	Neurofibromatosis and schwannomatosis	Patient in multidisciplinary project group
Qualitative	Secondary care	Quality improvement	Various	Patient advisory council
Qualitative	Network	Research	Mental health	Patient advisory council
Qualitative	National level	Policy making, service planning	Various	Patient in multidisciplinary project group, board meetings that were open to the public
Mixed-methods	Network	Tool development	Parents of children with developmental disability	Patient Advisory Groups (PAGs)
Mixed-methods	National level	Value assessment	Various	Patient workgroup
Qualitative	Research institute	Research	Various	Patient in multidisciplinary project group
Qualitative	National level	Hospital redesign, service planning	Mental health	Patient in multidisciplinary project group, survey

Table 2| Continued

Title of publication	Author	Year	Country of origin	Journal
The involvement of people living with HIV/AIDS in community-based organizations: contributions and constraints	Roy and Cain [85]	2001	Canada	AIDS care
Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London	Rutter, et al [86]	2004	UK	Social Science & Medicine
Organisation, influence, and impact of patient advisory boards in rehabilitation institutions-an explorative cross-sectional study	Sagen, et al [87]	2022	Norway	Musculoskeletal Disorders
Patients, clinicians and researchers working together to improve cardiovascular health: a qualitative study of barriers and priorities for patient-oriented research	Santana, et al [88]	2020	Canada	BMJ open
Patient and public involvement in randomised clinical trials: a mixed-methods study of a clinical trials unit to identify good practice, barriers and facilitators	Selman, et al [89]	2021	UK	Trials
"How Can We Talk about Patient-centered Care without Patients at the Table?" Lessons Learned from Patient Advisory Councils	Sharma, et al [90]	2016	USA	Journal of the American Board of Family Medicine
The impact of patient involvement in research: a case study of the planning, conduct and dissemination of a clinical, controlled trial	Skovlund, et al [91]	2020	Denmark	Research Involvement and Engagement
Evaluation of patient involvement strategies in health technology assessment in Spain: the viewpoint of HTA researchers	Toledo-Chavarri, et al [92]	2020	Spain	International Journal of Technology Assessment in Health Care
Patient participation in cancer network governance: a six-year case study	Tremblay, et al [93]	2021	Canada	BMC Heath Services Research
Monitoring and evaluation of patient involvement in clinical practice guideline development: lessons from the Multidisciplinary Guideline for Employment and Severe Mental Illness, the Netherlands	Van der Ham, et al [94]	2015	The Netherlands	Health Expectations

1: UK = United Kingdom, 2: USA= United States of America

Methods	Setting for patient participation	Topic for participation	Medical condition	Methods for participation
Qualitative	National level	Policy making, service planning	HIV	Focus group
Qualitative	National level	Service planning	Mental health	Patient group and fora
Mixed-methods	Secondary care	Quality improvement	Unknown	Patient board
Qualitative	Research institute	Research	Cardiovascular conditions	Patient in multidisciplinary project group
Mixed-methods	Research institute	Research	Various	Patient in multidisciplinary project group, patient panel, patient board, consultation with local patient group
Qualitative	Primary care	Quality improvement	Various	Patient advisory council
Qualitative	Secondary care	Research	Melanoma	Patient board
Qualitative	National level	HTA	Various	Focus group, interview, patient in multidisciplinary project group, survey
Qualitative	Network	Network governance	Cancer	Patient in multidisciplinary project group
Qualitative	Guideline group	Guideline development	Mental health	Focus group, patient in multidisciplinary project group

Critical appraisal

Details of critical appraisal can be found in Appendix B. Overall, the included studies met most of the critical appraisal criteria (ranging from 53%-100%), except for one study that only met 20% of the criteria. We did not exclude studies based on the critical appraisal.

Barriers and facilitators of collective patient participation

We grouped the extracted barriers and facilitators into five categories. Table 4 shows the five categories of barriers and facilitators including references (the numbers in the text refer to the numbers in Table 4). Underlying text of the original articles can be found in Appendix C.

Table 3| Characteristics of included studies (n=59)

Characteristics	N (%*)
Country	
United Kingdom	18 (31)
Canada	16 (27)
United States of America	11 (19)
Denmark	3 (6)
Norway	3 (6)
Sweden	2 (3)
The Netherlands	2 (3)
Australia	1 (2)
Belgium	1 (2)
Spain	1 (2)
Ireland	1 (2)
Setting	
Research institute	24 (41)
Government/national level	10 (17)
Other	7 (12)
Secondary care	6 (10)
Network	5 (8)
Primary care	4 (7)
Guideline group	3 (5)
Design	
Qualitative	46 (78)
Mixed-methods	12 (20)
Quantitative	1 (2)

Table 3| Continued

Characteristics	**N (%*)**
Topic(s) for patient participation	
Research	33 (56)
Quality improvement	9 (15)
Service planning	6 (10)
Policy making	4 (7)
Guideline development	4 (7)
Other	4 (7)
Hospital redesign	2 (3)
Tool development	1 (2)
Method for patient participation	
Mix	21 (36)
Patient in multidisciplinary project group	21 (36)
Patient advisory panel or board	13 (22)
Other	3 (5)
Focus groups	1 (2)

*percentages may exceed 100% due to the rounding up of numbers

Table 4| Barriers and facilitators of collective patient participation

Category	Barrier (B)/facilitator (F)
1. Preconditions for patient participation	1. Inclusive culture (F/B if that is a challenge to create) and positive attitude of organization towards pp[3] (F). Lack of transparency of organizational structure or exclusion of patients on organizational level (B) 2. Issues with funding for pp (B/F when no issues) 3. High staff turnover or low staff to support pp (B) 4. Use available resources (F) e.g. support from patient organization (F), resources are needed (F)
2. Strategy for patient participation	1. Early involvement of patient (F) 2. Recruitment challenges regarding bias and representativeness (B). Include multiple patients and use different pp methods (F) to have multiple perspectives (F) 3. Clear goals for pp (F) 4. Frequent communication and updates towards patients. Send agenda and minutes in time (F/B if difficult). Challenging when there are long periods between meetings (B) 5. Reward patient / cover expenses, e.g. with money (F). Payment can be received as tokenistic by patients if it does not cover their expenses (B) 6. Have continuous pp and renew patients once in a while (F) 7. Topics that are discussed are too distant for patients / not in line with their needs (B) 8. Have appointed time in meetings for pp (F) time constraints to plan and organize pp (B) 9. Meeting logistics, e.g. finding time and place that suits patients to participate (B if not sufficient/F) 10. Plan pp, but also maintain flexibility (F/ B if flexibility is not possible). Impact of medical condition on patient being able to participate (B)
3. Preparation of patients and staff for patient participation	1. Match patient to project based on knowledge, skills and experience (B). Facilitating when patient is also healthcare professional (F), and patient has understanding of project en health issue (F/B) 2. Training for patients (F/B). Training for researchers/ healthcare professionals (F) 3. Staff feeling unprepared/not confident with patient participation (B), or is hesitant to ask patients to participate (B), or staff has doubts/scepticism about impact of patients or representativeness (B/F when no doubts) 4. Meeting chair with pp skills (F/B if not) 5. Clarity on role, responsibility and expectations/ goals for pp for both patient and staff (F/B if not)
4. Support for patients and staff during patient participation	1. Support (personalized) for patients to participate, e.g. interpreters or childcare (F/B if not) and emotional support for patients (for vulnerable patients), manage disappointment of patients when project is unsuccessful (F) 2. Support for patient by explaining jargon/terminology (F/B if not) 3. Patients have access to extra information (F) 4. Conflict of interest for patient, challenge to stay independent (B). Patient has concerns about being too personal or too critical (B) 5. Hierarchy (B/F if relation is informal). Equality, respect, trust, safe environment (F/B if patient feels isolated) 6. Awkwardness of HCPs to discuss certain topics when patient is also present or challenge to balance patients' input and research objectives (B) 7. Patients that lack the confidence to participate, or compare themselves to other patients participating (B/F when not lacking (anymore))
5. Evaluation of patient participation	1. Effects of pp are not visible, patients' input was perceived as less important, patients felt 'tokenistic' (B) 2. Challenge to use patients' input (B) 3. Show the effects of pp and what is done with input of patient, follow-up with patients so that patients feel valuable and useful (F/B if not) 4. Staff is open towards feedback (F)

3: pp = patient participation

References
1. [5,38,42,52,65,67,69,75,77,82,84,86,87] 2. [5,15,40,55,65,69,83,91] 3. [5,42] 4. [5,43,45,48,54,56,65,68,69,76,82,90]
1. [39,43,46,47,49,50,55,65,69,70,72,82] 2. [15,38,45,47–49,51,52,54–56,64–70,72,74–78,80,82,84,86,88–92,94] 3. [44,46,48,71,77,82] 4. [5,39,43,46,47,49,55,57,72,77,78,90,91] 5. [45,48,49,51,57,58,61,65,77,80,81,83–86,89,90] 6. [47,49,56,64,89–91] 7. [5,38,47,65,77] 8. [5,41,43,46,49,50,56,59,61,64,65,68,80,81,91,92] 9. [56,57,69,72,79,89–91] 10. [5,47,48,57,65,69,71]
1. [38,40,42,46,47,51,52,59,62,64,68,72,74,77,89,92] 2. [5,38,41,43,46,47,49,52,56,62,64,66,70–72,77,80,86,89,90,92] 3. [41,49,52,57,77,86,92] 4. [5,41,46,51,72,76,79] 5. [15,39,41,43,48,49,51,53,56–58,61–63,67,68,70,76,80,82,83,86–90,94]
1. [5,40–42,51,58,62,66,68–71,77,85,88,94] 2. [43,49,63,67,75] 3. [63,77,87] 4. [49,59,61,82,86] 5. [39,40,44,45,48–50,55–58,60,62–66,68,70,73,78,81,88–91,93] 6. [57,68] 7. [5,41,44,46,49,50,53,56,59,60,63,64,66,72,73,81,84,89]
1. [5,44,55,73,93] 2. [41,56,86] 3. [5,44,46,47,54,58,64,65,70,71,76–78,80,82,86,89,90,94] 4. [41,44]

1. Preconditions for patient participation

Four barriers and facilitators were found regarding preconditions for meaningful patient participation within organizations. First, it was found to be facilitating when the culture of an organization was inclusive, with attention for the patient's perspective. However, creating such a culture was seen as challenging, especially when a conflict between caring and collaborating with the patients was being experienced. Furthermore, lack of transparency of the organizational structure and decision-making process, exclusion of patients in organizational decision-making, or lack of a policy on patient participation were identified as barriers of patient participation (1). Secondly, availability of proper resources, such as funding for patient participation and staff to support patient participation were reported facilitators (2). However, high staff turnover and issues with sufficient funding for patient participation were found to be barriers of meaningful patient participation (3). On the other hand, a reported facilitator was to make use of already available resources, such as knowledge of a patient organization, using established advisory councils or other patient networks, or make use of toolkits and social media to gain insight into the patients' perspectives (4). However, one study indicated that collaborating with a patient organization could also lead to conflicting views, which made it challenging for patient representatives to participate.

2. Strategy for patient participation

Regarding the strategy for patient participation, a total of ten barriers and facilitators were found. It was found to be facilitating when: patients were involved early-on in the project (1), multiple methods for patient participation were used to gain insight into multiple perspectives (2), there were clear goals for the patient participation (3), there was a communication plan for frequent communication with the patients (4), the patient was rewarded, e.g. by co-authorship on manuscripts or financially, or their expenses were covered (5), there was continuous patient participation (6), there was appointed time in meetings for patient participation (8), and the meeting logistics (e.g. time and place) were patient-centred (9). On the other hand, identified barriers in patient participation were: recruitment and selection challenges regarding bias and representativeness of patients (2), long periods of time between meetings and inadequate communication towards patients (4), payment that was perceived as tokenistic by patients since it did not cover their expenses (5), not aligning the topics discussed in the meetings with patient's needs (7), time constraints to plan and organize patient participation (8), and not taking the patients' preferences into account in organizing the meetings (9). Lastly, it was found to be facilitating to plan patient participation, but to also allow a level of flexibility, especially when working with a vulnerable patient group where their medical condition can have an impact on their ability to participate (10).

3. Preparation of patients and staff for patient participation

Five barriers and facilitators were found regarding the preparation of patients and staff for the patient participation. Several studies reported that patients should be matched to the project based on their knowledge and experience, and that understanding the project (optionally by training) was a precondition for successful patient participation (1). Furthermore, it was found to be facilitating when patients and staff were trained, for example in skills such as effective communication (2). A described barrier regarding the preparation of staff was when they felt unprepared or not confident in patient participation, when they were hesitant to approach patients, or when there was doubt/scepticism of staff on the added value of patient participation (3). Furthermore, several studies mentioned the importance of having a meeting chair that has patient participation skills (4). Lastly, it was found to be facilitating when both patients and staff were informed about their roles and responsibility within the project (5).

4. Support for patients and staff during patient participation

Regarding the support for both patients and staff in the execution of patient participation, seven barriers and facilitators were found. Identified facilitators were having practical and personalized support for patients such as interpreters, transportation, childcare, and emotional support (1). Furthermore, medical jargon and terminology should be explained (2), and the patient should be able to access extra information (3). Reported barriers of patients to participate are when they were concerned about being too critical or personal during the meetings, or when they experienced a conflict of interest by being on the same team as their healthcare professional (4). Furthermore, an often experienced barrier of meaningful patient participation was the hierarchy between healthcare professionals and patients. To the contrary, having an equal, informal, respectful relationship between patients and staff was a frequently reported facilitator (5). Some studies mentioned as a barrier that staff felt uncomfortable to discuss certain topics with the patient in the team, or that they struggled to find a balance between the patients' input and their research objectives (6). Lastly, multiple studies reported the lack confidence of patients to participate meaningfully, but it was also often mentioned that this confidence grew throughout the project (7).

5. Evaluation of patient participation

Proper evaluation of the added value of patient participation was found important by both patients and staff. Lack of clarity on effects of patient participation, sometimes resulting in a feeling of 'tokenism' (1), and the challenge to incorporate the patient's input were barriers described (2). On the other hand, reporting to patients and staff how the patient's input was used resulted in patients feeling valuable and useful and was found to be important (3). Lastly, it was found to be facilitating when the team was open towards feedback of the patients (4).

Impact of patient participation

A total of 34 studies evaluated the impact of patient participation, of which only three studies identified quantitative effects of patient participation [46,66,70]. Several studies mentioned the challenge to identify direct impact/effects of patient participation on the project's outcomes [58,61,87], and within some studies, the impact was perceived to be different by different project members [75,94]. Impact of patient participation was found at three levels: quality of care and research (1), team and organization (2), and individuals participating (3) (Table 5).

Impact at the level of quality of care and research

Increased quality of care and research due to patient participation was mentioned by 25 studies. In these studies, patients and staff indicated that patient participation has led to more patient-centred care, interventions that better reflect the patients' needs, improved research, and improved communication. Research improved by patients helping to choose relevant outcomes for research, helping with the selection of PROMs, piloting patient questionnaires, supporting data collection and patient enrolment, establishing the research agenda, helping with interpretation and analysis of results, helping with funding, and making research more accessible and transparent.

Impact at the level of the team and organization

At the team level, patients and staff indicated that discussions of teams changed to be more patient-centred, and that co-learning increased as a result of patient participation. Furthermore, patients and staff indicated that because of their experiences with patient participation, the quality of the participation itself improved, since it has led to e.g. sustained partnership with patients, increased patient participation over time, or higher quality of patient participation.

Impact at the level of the individuals participating

Patients indicated that their confidence and knowledge on the healthcare system increased through their participation in quality improvement projects. Furthermore, they indicated that due to their participation, they had the possibility to process their illness, or that they could help others through their participation. Negative impact on the patient was mentioned in one study, where a patient indicated that his participation resulted in a sense of objectifying himself when giving a presentation to an organization about his health condition. Patient participation also had an impact on staff by deepening their understanding of lived experiences, which resulted in more positive views on patient participation. Lastly, patient participation impacted the patients and staff negatively by requiring time investments.

Table 5| Impact of collective patient participation

Level	Impact	References
1. Quality of care and research	1. More patient-centred care 2. Interventions that better reflect patients' needs 3. Improved research, e.g. research that is more in line with patients' needs 4. Communication towards patients improved	1. [67,75,83,84,86,90,93] 2. [59,81] 3. [41,44,45,50,52,55,57,61,63,67,70,74,77,91,92] 4. [43,50,55,57,66,77,81,84,90,91,93]
2. Team and organization	1. Discussions became more patient-centred 2. Co-learning increased 3. Sustained partnership of patients 4. Higher quality patient participation	1. [67] 2. [43] 3. [50,57,64] 4. [40,67,84]
3. Individuals participating	1. Increased confidence of patient 2. Increased knowledge of patient on healthcare (system) 3. Possibility for patient to process personal illness during participation, or helping others 4. Patients objectifying themselves with their illness 5. Staff gained deepened understanding of lived experiences 6. Staff became more positive towards patient participation 7. Time investments required from patients and staff	1. [46,50,57,60,66] 2. [50,57,59,64] 3. [46,78] 4. [66] 5. [45] 6. [52,57,60,64] 7. [63]

2.4 Discussion and conclusion

This review aimed to provide insight into the process and impact of collective patient participation in healthcare organizations. The most common method for collective patient participation was to involve the patient in the project/research team. Evaluation of the process of patient participation identified multiple barriers and facilitators of patient participation, which were grouped into five categories. Based on these categories, five recommendations to set up meaningful collective patient participation can be formulated, which are: (1) ensure that preconditions for patient participation are met, (2) develop a strategy for patient participation, (3) prepare patients and staff for patient participation, (4) support patients and staff during patient participation, and (5) evaluate patient participation with both patients and staff. Half of the studies evaluated the impact of patient participation, and found that patient participation had impact on the quality of care and research, the team and organization, and the individuals involved in the patient participation.

Overall, we found that the emphasis of evaluation of patient participation was mainly on the process. Collective patient participation has been increasingly embraced and accepted the last decade [5], but we would like to argue that little progress has been made in structuring collective patient participation over the years, since similar barriers were found in studies that span over a time period of more than twenty years. Furthermore, the suitability of the chosen method for patient participation was never evaluated, and reasons for the chosen method were also often not mentioned. We believe that different patient participation methods suit different types of questions and projects [95], but based on the included studies we could not make recommendations about which method for patient participation to use when. Therefore, future studies should focus on the selection of the most suitable method for patient participation for specific types of projects or questions.

Even though collective patient participation has been embraced as an important factor to improve quality of care, the impact of patient participation was only studied in half of the included articles. Moreover, these articles mainly described impact based on qualitative data of subjective experiences and beliefs of patients and staff. In addition, multiple studies reported merely secondary effects of patient participation, such as the impact on the individuals involved in the participation. Several researchers mentioned the challenge of drawing causal links between patient participation and its impact on quality of care [58,61,87,96], possibly due to the paucity of formal measurement instruments for the impact of collective patient participation [97–99]. Future studies on collective patient participation should therefore focus more on the development of such a formal measurement instrument, in order to provide more insight into the direct impact of patient participation on quality of care and research.

The majority of the included studies originated from the UK, Canada and the USA. This suggests a variation in the level of patient participation between different countries and research hereon [100], which might be explained by the differences in adoption of patient participation in national policies and programs. For example, the UK was an early-adopter of patient participation via the INVOLVE program [101], and multiple research funders in the UK made patient participation compulsory in grant proposals [102]. As a result, it could be anticipated that patient participation is more firmly embedded in these countries. Consequently, fewer barriers might be encountered in more recent studies originating from these three countries. However, we found similar barriers in these recent studies that already have been addressed multiple times by previous studies (e.g. time constraints and communication difficulties). This suggests that while national initiatives can expedite patient participation, certain aspects may remain unsolved at the national level and may require practical, real-word experiences with patient participation for effective resolution.

We acknowledge three limitations in the search strategy of this systematic literature review. First, since multiple terminologies for patient participation are used in literature [96], we could have missed a few in our search strategy. We tried to overcome this barrier by developing our search strategy with an experienced librarian to capture the majority of terminologies (Table 1). Second, the term ‘collective patient participation’ is not always used in literature, resulting in a challenge to search specifically for this level of patient participation instead of the individual level. We added several search terms to our strategy to only retrieve studies on the collective level (such as healthcare provider or patient participation methods known for the collective level), but do acknowledge that we could have missed some studies that did focus on the collective level, but did not use this terminology. However, data saturation was experienced during data-analysis, indicating that no new information would be found with new search terms. Thirdly, we excluded research conducted in low- and middle income countries and studies where children participated, since we believed that different barriers and facilitators would be addressed in these studies, which could introduce noise into the results. However, it is worth noting that this exclusion may have led us to overlook valuable insights, such as facilitators for including a more diverse sample of participants (e.g. studies involving indigenous populations) or creative participation methods (originally designed for children, but potentially adaptable to other demographics). Future research could investigate whether insights from these excluded studies could be applied in our studied context.

Conclusion

In conclusion, this study provides insight in adopted methods and effects of collective patient participation, and related barriers and facilitators. Interestingly, similar barriers and facilitators were experienced during a period of twenty years of patient participation, indicating that little progress has been made in structuring patient participation. For example, an often-mentioned barrier of patient participation is the lack of clarity on the role of the patient. Based on the barriers and facilitators, five recommendations were formulated to improve the process of collective patient participation. Furthermore, we found (mainly) positive impact of patient participation on the level of quality of care and research, the team and organization, and the individuals participating. However, objective effects of patient participation were understudied in the included articles. Future studies should therefore develop a formal measurement instrument that can help to identify causal effects of collective patient participation. Insights in the causal effects of patient participation together with our recommendations will help to set up meaningful patient participation and will reduce tokenistic collective patient participation.

2.5 Literature

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Appendix A: Data extraction tool

Record ID

____

Date of reviewing

____

Title of publication

____

Authors

____

Date of publication

____

Country of origin

____

Journal

____

Terminology used for patient participation
o Patient participation
o Patient involvement
o Patient engagement
o Patient partner
o Patient advocate
o Patient and Public Involvement (PPI)
o Patient and family engagement
o User participation/involvement
o Patient representative
o Client participation/involvement
o Stakeholder involvement/participation

Setting of healthcare organization
o Secondary care
o Research institute
o Primary care
o National level
o If other, please specify ___________________________________

Subject for participation

- Policy making
- Research
- Quality improvement
- Guideline development
- Tool development (e.g. a dashboard, a decision-aid, or a outcome set)
- Hospital redesign
- Service/healthcare planning
- If other, please specify____________________________________

Please state if the researchers indicate the reason for patient participation, and copy paste this from the article. Otherwise, leave it blank.

____

Method(s) for patient participation

- Brainstorm session
- Delphi method
- Experience Based Co-Design
- Focusgroup live
- Focusgroup online
- Instant feedback (a.k.a. waiting room interview)
- Interview
- Ideabox
- Mystery guest
- Observation
- Participation in project group
- Patient panel
- Patient board
- Shadowing
- Survey/questionnaire
- Not reported
- If other, please specify ____________________________________

Number of participating patients

____

Number of participating non-patients

____

Recruitment of participants

o Purposive sampling
o Snowball sampling
o Quota sampling
o Convenience sampling
o Stratified sampling
o Clustered sampling
o Systematic sampling
o Random sampling
o Other, please specify____________________________________
o Not reported

Copy and paste the text on recruitment of patients

____

Copy and paste the text on selection criteria of patients

____

Disease/condition of participants

____

Copy and paste the text on characteristics of participating patients

____

Preparation of patients for participation

o Information brochure
o Training
o Information call
o None
o Other
o NR

Copy and paste the text on preparation for patients

____

Training for staff?

o yes
o no
o Not reported

If yes, copy paste text here from the article that specifies this

____

Copy and paste the text on barriers of patient participation

____

Copy and paste the text on facilitators of patient participation

____

The following section will contain questions on the impact or effects of patient participation. The classification of Dukhanin et al (2018) is used and is complemented with effects described in literature. Please indicate whether there was a reported effect on the following outcomes (positive/negative/none) or whether they were not reported (NR)

Impact	Positive	Negative	None	Not reported
Improved health outcomes				
Cost-effectiveness				
Quality of services				
Availability of services				
Access to services				
Enhanced patient safety				
User experiences (patient satisfaction)				
Services responsiveness to				
Staff views on engagement				
Participants control of decision process				
Activeness of participation				
Impact on securing funding				
More relevant outcomes in research				
Increased enrolment rates in research				
Decreased hospital admission				
Enhanced communication to patients				
Shift in organizational culture to be more patient centred				
If other, please specify here ____________________				

Please copy paste the text on impact here and make clear (between brackets) to which outcome you classified this impact

____

Please state the authors conclusion here. Use a direct quote if possible

____

Please state wether the authors mention if the participation was a succes

____

Do you have any comments as reviewer left? Please explain here

Appendix B: Critical appraisal

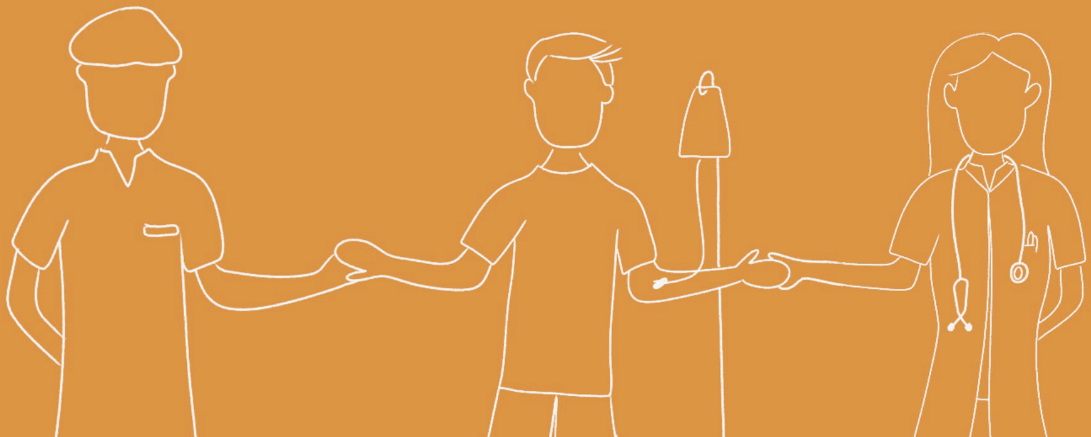
Table can be found via: 10.1016/j.healthpol.2023.104946

Appendix C: Underlying data

Table can be found via: 10.1016/j.healthpol.2023.104946

Part 2

Current level of patient participation



Chapter 3

Evaluating patient participation in value-based healthcare: current state and lessons learned

H.J. Westerink, M.M. Garvelink, C.F. van Uden-Kraan, O. Zouitni, J.A.J. Bart, P.J. van der Wees, and P.B. van der Nat (on behalf of the Santeon Patient Participation Study Group*)

* The Santeon Patient Participation Study Group (collaborators) are:
Annette W.G. van der Velden, Martini Hospital, Groningen, the Netherlands
Sander Koëter, Canisius Wilhelmina Hospital, Nijmegen, the Netherlands
Willem J.W. Bos, St. Antonius Hospital, Utrecht/Nieuwegein, the Netherlands
Diederik H.R. Kempen, OLVG, Amsterdam, the Netherlands
Angelique E.A.M. Weel, Maasstad Hospital, Rotterdam, the Netherlands
Eino B. van Duyn, Medisch Spectrum Twente, Enschede, the Netherlands
Pepijn H. van der Voort, Catharina Hospital, Eindhoven, the Netherlands

Health Expectations, 2024;27(1):e13945

Abstract

Introduction: Value-based healthcare (VBHC) focusses on increasing value for patients. Hospitals aim to implement VBHC via value improvement (VI) teams for medical conditions. To determine the patient's perspective on value, collective patient participation is important in these teams. We therefore evaluated the current state of patient participation in VI teams and share lessons learned.

Methods: This mixed-methods study was conducted at seven collaborating hospitals in the Netherlands. A questionnaire (the public and patient engagement evaluation tool) was tailored to the study's context, completed by VI team members (n=147 from 76 different VI teams), and analyzed with descriptive statistics. In addition, 30 semi-structured interviews were held with VI team members, and analyzed through thematic analysis. Data were collected between February 2022 and January 2023, and data were triangulated by mapping the quantitative results to the interview themes.

Results: 38 of the 76 included VI teams reported to use a form of patient participation. Many respondents (71%) indicated a lack of a clear strategy and goal for patient participation. Multiple VI team members believed that specific knowledge and skills are required for patients to participate in a VI team, but this led to concerns regarding the representativeness of participating patients. Furthermore, while patients indicated that they experienced some level of hierarchy, they also stated that they did not feel restricted hereby. Lastly, patients were satisfied with their participation and felt like equal VI team members (100%), but they did mention a lack of feedback from the VI team on their input.

Conclusion: The results imply the lack of full implementation of patient participation within VI teams. Guidelines should be developed that provide information on how to include a representative group of patients, which methods to use, and how to evaluate the impact of patient participation and give feedback to participating patients.

3.1 Introduction

In the last decade, the concept of value-based healthcare (VBHC) has become a prominent force in healthcare and has been embraced by many countries across the world to improve quality of care and counter rising healthcare costs [1]. VBHC can be defined as a way to organize care that focusses on increasing value for those being cared for, i.e. the patients. Within VBHC, value has been defined as patient relevant outcomes relative to the costs needed to achieve these outcomes [2]. Different strategies to implement VBHC can be found, and an often adopted strategy is to set up multidisciplinary value improvement (VI) teams that are responsible for value improvement in the care for a specific medical condition [1,3]. Patient participation within these VI teams is of great importance to facilitate the incorporation of their perspectives on value [4].

Patient participation can occur on two distinct levels [5], and with different intensities [6]. At the individual level, patient participation is about an individual patient's care, for example in shared decision-making or self-management [7,8]. At the collective level, patient participation is defined as actively involving the patient in organization-wide or (inter)national projects, where the outcome of the project has effect beyond their individual care [5,9]. Patient participation in multidisciplinary VI teams is an example of patient participation at the collective level [10]. Within these VI teams, patients can contribute to identifying and evaluating patient-relevant outcomes and improvement initiatives [11,12].

The focus of literature regarding patient participation in VBHC has mainly been at the individual level, e.g. by using outcome data for shared decision-making [13,14]. However, there is a lack of evidence and examples of best practices for collective patient participation [15], and multiple barriers to participation have been mentioned in literature [16]. For example, a frequently mentioned barrier is that generally higher educated patients are involved at the collective level, resulting in underrepresentation of a large group of (lower educated) patients at this level [17]. These barriers and lack of best practices for collective patient participation often result in tokenistic patient participation [18], which occurs when patients participate but have little to no influence.

Although the impact of collective patient participation in VBHC has been stipulated [4,11,12], thus far, there is a paucity of literature on practical implementation and evaluation of collective patient participation within VBHC [15]. Therefore, the process and impact of collective patient participation needs to be evaluated in order to identify best practices for patient participation in VBHC. In this study, we aimed to evaluate the experiences with collective patient participation within multidisciplinary VI teams using a mixed-methods approach.

3.2 Methods

Context

We conducted a multi-center study between February 2022 and January 2023 in a consortium of seven Dutch hospitals (Santeon hospitals) that collaborate in implementing VBHC by actively measuring, benchmarking, and improving value of care for fifteen medical conditions (e.g. breast cancer, chronic kidney disease, and stroke). Multidisciplinary VI teams per medical condition have been set up in each of the seven hospitals, with a few exceptions when the hospital does not provide care for that condition. These VI teams consist of healthcare professionals, project leaders, managers, and data-analysts who work together to achieve value improvements. For each of the fifteen conditions, outcome, process, and cost data is being collected and compared between the seven hospitals. The VI teams then select improvement initiatives based on the insights from the (comparison of) data. Detailed information on the method of the Santeon VI teams can be found in the articles by Engels et al. and Daniels et al. [12,19]. Since the start of these VI teams, Santeon has strived to include at least one patient in every VI team, but this has been experienced as challenging. Therefore, we aimed to evaluate collective patient participation within the Santeon VI teams in order to identify the lessons learned.

Study design

This study had a mixed-methods design and was based on a case study methodology consisting of questionnaires and two rounds of interviews with VI team members. The first round of interviews was conducted in order to select an appropriate questionnaire based on the experiences of VI team members. Subsequently, this questionnaire was completed by the VI team members. The second round of interviews was conducted to deepen the results of the questionnaire. Questionnaire data were triangulated with interview data to gain in-depth insight into the current state of patient participation in the VI teams. See Figure 1 for a schematic overview of the data collection.

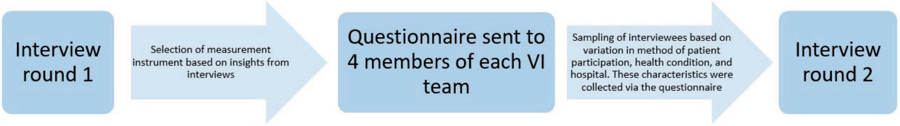


Figure 1 | Schematic overview of data collection

Data collection

Interviews with VI team members

Qualitative data collection and analysis is reported according to the COREQ guidelines [20]. Different VI team members were interviewed in-depth about patient participation within their team in two rounds of semi-structured interviews. We purposively sampled VI team members to be interviewed based on variations in medical conditions, their role within the VI team (e.g. medical specialist, nurse, support staff, and patient), hospital location, and in the second round of interviews also on the method of patient participation within their VI team (identified with the questionnaire). Different VI team members were approached for the two rounds. Three different semi-structured interview guides were used for the two interview rounds (Appendix A), where in round one we used a different interview guide for the patients and staff members. A total of 43 VI team members were invited via email. They had the choice to do the interview face-to-face or via videoconferencing. The interviews were audio-recorded and field notes were made during the interviews. Interviews were performed until data saturation was reached.

Questionnaire:

Based on the first round of interviews, the research team selected a questionnaire from the list of measurement instruments of the Engagement Assessment Toolkit for patients and the public (https://ceppp.ca/en/evaluation-toolkit/) [21] to evaluate patient participation in VI teams. During a meeting with the research team, all measurement instruments from the Engagement Assessment Toolkit were discussed and the domains of the instruments were compared to preliminary findings of the interviews. Based on this discussion, the Patient Participation Engagement Evaluation Tool (PPEET) [22] was selected to be best fitting to the context of VI teams, since this questionnaire addresses subjects that were also discussed during the first round of interviews. The PPEET is a validated questionnaire, and consists of separate questionnaires for patients and staff, each consisting of three modules. Questions of the PPEET can be answered based on a 5-point Likert scale (totally disagree to totally agree) or with yes/no. The Dutch version of the PPEET was used in this study [23].

We selected Module B as the main questionnaire, which focuses on on-going engagement activities. We have added a few questions to both the patient and the staff questionnaire (See Appendix B):

- Patient questionnaire: We added four self-formulated questions (question 4, 9, 10, 14) to tailor the PPEET to the context of the VI teams based on preliminary findings of the first round of interviews.
- Staff questionnaire: We added three questions from module A (focusing on the planning of patient participation) and two from module C (focusing on the impact of patient participation). Furthermore, we added one self-formulated question to the PPEET based on the preliminary findings of the first round of interviews.

The questionnaire was pilot tested with ten VI team members. Respondents were only asked to answer relevant questions, so if a respondent indicated to not have used any form of patient participation, they were not asked any more detailed questions on their experiences with patient participation. Respondents were required to answer all questions that they received to make sure that we did not have any missing data.

The questionnaire was sent out by the project leaders of the VI teams via a data management system (REDCap) to four members of each VI team, i.e. a patient, and three staff members (e.g. a medical specialist, a nurse, and someone with a supporting role such as a project leader or data analyst). Reminder emails were sent after two and four weeks.

Data analysis

The semi-structured interviews of round one and two were recorded and transcribed verbatim using transcription software (Amberscript). The transcripts were then checked and corrected by the first author (HJW), and member-checked by the interviewees. Data were coded with Atlas.ti using open coding with an inductive approach to let themes arise from the data. To increase reliability, all interviews were double-coded by a member of the research team (OW). Agreement between the coding was checked after coding every five interviews, and any discrepancies were resolved by consensus. The two researchers (HJW en OW) analyzed the codes through thematic analysis and discussed the identified themes until consensus was reached.

For the Likert-type questionnaire data, the percentages of respondents who (totally) agreed with the individual questions (score 4 or 5 on the Likert-scale) of the measurement instrument were calculated. For the yes/no questions, the percentages of respondents that answered with ‘yes’ were calculated per question. Data of the pilot test of the questionnaire was also included in the analysis.

Triangulation

The quantitative data were then triangulated (convergence triangulation) with the qualitative data by mapping the questions of the PPEET to the interview themes. Agreements and discrepancies between the quantitative and qualitative data were discussed in the results. A step-by-step guide of the data analysis can be found in Appendix C.

Trustworthiness

We strived for credible results by continuing data collection until data saturation was reached, discussing identified themes with all co-authors, and using data triangulation of the quantitative and qualitative results. Furthermore, participants member checked the transcripts and preliminary results. All interviews were conducted by HJW, who had previous experience and training in conducting and analyzing interviews. Interviewees had no prior relationship with the interviewer. To increase the transferability of the results, the data triangulation was discussed with all co-authors and consensus was reached on the findings of the study. Lastly, confirmability was accounted for by double-coding the interview data.

Ethical approval

This research proposal has been approved by the Medical Ethics Committee (Santeon Beheercommissie SDB2021-014 and the Medical Ethical Commission-Utrecht W22.212). All participating hospitals also received approval from their scientific committee for local feasibility. Participants gave informed consent to use their data for the study.

Patient and Public Contribution

Two patient advisors were part of the research team and attended the research team meetings. They were involved as research partners in all phases of the study, including drafting the protocol (e.g. drafting interview guides and selecting the measurement instrument), interpreting the results, and writing this article.

3.3 Results

Participant characteristics

We interviewed a total of 30 VI team members from 25 different VI teams, of which twelve were patients (response rate=70%). Table 1 shows the participant characteristics. VI team members who refused to participate in the study mainly mentioned time constraints as a reason for their refusal to participate. Data saturation was reached after 22 interviews, but we continued with the other eight interviews since these were already planned. The interviews had an average duration of 26 (±7) minutes, starting from the first interview question.

Table 1| Participant characteristics

Characteristics	**N interviews round 1=**	**N questionnaire=**	**N interviews round 2=**
Total	15	147	15
Role			
Patient	6	15	6
Medical specialist	2	39	2
Nurse	1	36	1
Support staff	4	57	4
Other	2		2
Medical condition			
Birth care	2	14	1
Breast cancer	3	16	2
Chronic kidney disease	2	7	
Colon cancer	1	11	1
Coronary artery disease		6	
Cerebrovascular accident		14	4
Diabetes	2	14	2
Hip fracture		8	
Hip osteoarthritis	1	6	
Inflammatory bowel disease	3	14	
Knee osteoarthritis		7	2
Lung cancer		9	1
Prostate cancer	1	9	
Rheumatoid arthritis		5	2
Vulnerable elderly		7	

Patient participation within VI teams

The questionnaire was completed by 147 VI team members from 76 different VI teams for 15 medical conditions. The results can be found in Appendix B. Of these 76 VI teams, 24 had a patient in their team, 14 used another method, and 18 had no patient participation in their team. In the remaining 20 teams, it was unclear which method was used for patient participation, as respondents of the same team gave conflicting answers. All of the patients that completed the questionnaire were highly educated (university or university of applied sciences degree) and 47% had a full-time job. Most patients were older than 51 years old (67%).

Triangulated interview and questionnaire results

A total of nine different themes were identified from the interviews. Table 2 shows the triangulated results of the PPEET questionnaire results mapped to the interview themes including interview quotes. Overall, we mainly discuss results from teams with (some) experience in patient participation, as these results provide better insight into the lessons learned compared to VI teams where they have not used any form of patient participation. All quantitative results are presented in percentages.

Goals and motivation for patient participation

Patients mentioned several reasons why they were motivated to participate in the VI team: to return something, to improve care, or because they were personally interested in the topics discussed in the VI team meetings. Staff members mentioned that they wanted to let patients participate because they would like to gain more insight into the patients' perspectives on care in order to identify or evaluate improvement initiatives. In interview round one, a few staff members indicated that they did not have a patient in their team since they believed that it was their role to represent the patient perspective, and that no actual patient participation was therefore needed within the VI team.

Furthermore, according to multiple staff members, patient participation had been a low priority for their VI team and was often top-down organized. Only 39% of the staff members indicated that their VI team had a clear statement regarding the objectives of patient participation. In addition, several patients mentioned that they were not aware of the exact goal for their participation or their role in the VI team, while 75% of the staff members of teams in which patients participated indicated that the goals for the patient participation were shared with the patients.

Strategy for patient participation

Overall, staff members believed that patient participation should be discussed more often during their VI meetings. Furthermore, staff members indicated a lack of strategy for patient participation, and they expressed the need for a guideline on patient participation within VI teams. In addition, they mentioned that no one was specifically responsible for patient participation within the VI team. Different staff members were suggested that could be responsible, such as the project leader, medical leader, or marketing department. The lack of strategy was also identified in the questionnaire, where only 31% of the staff had a clear strategy for patient participation.

Moreover, a lack of strategy for the recruitment of patients for the VI team was mentioned. Staff members purposively selected patients based on whether they believe that they are able to participate in the VI team based on their knowledge and skills (e.g. in communication). Quantitative data showed that 29% of the staff indicated to have a clear strategy specifically for the recruitment of patients for the VI team.

Staff members indicated that the method of patient participation should be different for different medical conditions and subjects that are discussed. Other possible methods of patient participation mentioned by staff members included using aggregated PROMs and PREMs data, using a patient panel, sending out questionnaires, conducting interviews, and conducting focus groups. Each of these methods were believed to provide better insight into the perspectives of multiple patients and were therefore seen as more representative than one or two patients in the VI team. However, also downsides to these methods were mentioned, such as having low response rates to questionnaires, or being top-down because the staff members decide what will be asked in the questionnaire or interview. Furthermore, staff members expressed a wish to have more contact with patient organizations to gain insight into the perspective of large groups of patients. A total of 27% of the staff reported that they already collaborated with (external) partners to this end.

Context of VI team influences patient participation

According to the interviewees, several factors related to the context in which the patient participates can influence the level of patient participation. For example, the size of the VI team was mentioned as such a factor, since staff members believed that patients would not feel comfortable in large VI teams. Furthermore, the motivation of the medical lead to let patients participate or having a moderator that ensures that the patient is involved as an equal team member during the

VI meetings were mentioned to facilitate patient participation. Additionally, digital meetings were experienced as challenging by patients, and most patients preferred in-person meetings with the VI team. Interviewees also indicated that the VI team discusses mainly medical subjects, and not so much the patients' experience with care. Opinions differed on whether the VI team should change topics so that they would be more in line with what is relevant to patients.

Resources required for patient participation

Limitations in resources were mainly discussed in round two of the interviews. Staff members indicated time and cost constraints as important challenges in patient participation. Only 38% of the staff that used a form of patient participation believed that patients' needs (such as financial, logistical and information needs) were accommodated. Furthermore, only half of the staff (46%) with experience in patient participation indicated that there was sufficient time allocated for patient participation.

Patients had varying opinions on whether they would like to receive financial compensation for their participation. Some patients indicated that financial compensation would make them feel like a more equal team member, while other patients indicated that they did not need any compensation for their participation in the VI team. The majority of patients indicated that they received sufficient support to participate in the VI teams (89%).

Knowledge and skills in patient participation required from patients and staff

Interviewees, mainly from round one, mentioned a list of characteristics and skills that patients should have to become a VI team member. Among these are being able to discuss in a constructive manner, being critical, being interested in healthcare, being motivated, being verbally strong, having a helicopter view, and having basic knowledge of the healthcare system.

Patients mentioned that they have had some sort of introduction and explanation of the VI team before participation, but sometimes very limited. Additionally, patients indicated that they had previous experience with collective patient participation, and several patients were member of a patient organization and used knowledge that they received from their organization. The patients felt that they are equipped with the relevant skills, characteristics, and knowledge required to be a VI team member. A reported challenge for patients to participate is the use of medical jargon in the VI team. All patients (100%) indicated that they had a clear understanding of the purpose of the VI team and that they had received sufficient information to participate in the team. Lastly, multiple staff members indicated in the interviews to struggle with patient participation, and 44% of the staff who had some experience in patient participation indicated that they would like to participate in a training on patient participation.

Representativeness as barrier for patient participation

The representativeness of patients that participate at the collective level was a much-discussed topic in the interviews. Staff members expressed their concerns about letting patients participate in the VI team, since these patients would never be representative of the entire patient population. Furthermore, several staff members mentioned that it is important to include more than one patient, since "one is none". This argument was mainly mentioned by staff members of VI teams with no form of patient participation. The majority of the staff (74%) believed that the involved patients reflected the targeted patient population of the VI team.

Patients stated that they did not feel like a representative patient, but that they tried to represent multiple perspectives. All patients (100%) indicated that they felt that they could represent the patients' perspectives, and 56% of the patients indicated that they felt more comfortable because they were not the only patient in the VI team.

Relationship among VI team members influences patient participation

Some staff members stated in interview round one that it might be awkward for them to let a patient participate in VI meetings and that it would limit their ability to discuss topics that might be confronting for patients. Of the staff that had experience with a patient in their VI team, 80% indicated that they did not feel restricted in their discussions.

Patients experienced some level of hierarchy in the VI team, but they did not feel restricted by this. Patients did indicate that it was important to them to keep their healthcare professional-patient relationship strictly separate from their relationship as team member. All patients (100%) stated that they felt able to freely express their opinion, and that they felt like an equal team member. Therefore, the subject of hierarchy was not discussed in round two of the interviews.

Feedback and evaluation are important in patient participation

Patients reported that they sometimes missed feedback on what was done with their input. Moreover, both staff members and patients mentioned a lack of evaluation of patient participation within the VI team, resulting in little insight into the added value and effects of patient participation. However, in the questionnaire, both staff members with experience in patient participation (81%) and patients (73%) were positive about the feedback that patients received on their input.

Patients discussed several reasons why they were satisfied with their participation in the VI teams during the interviews, e.g. since they felt taken seriously, of added value, and comfortable in the VI team. Yet, negative experiences with patient participation were also mentioned, for example patients felt tokenistic in the beginning or staff members felt that the input delivered by patients was not very helpful or insightful. Overall, the majority of patients (87%) felt that their participation was a good use of their time and were satisfied with their role in the VI team. On the contrary, only 41% of the staff with experience in patient participation were satisfied with this patient participation in their VI team.

Impact of patient participation

Staff members indicated that they believe in the added value of patient participation, since patients have a unique expertise that would be missed without patient participation. Both patients and staff members stated that patient participation has increased over time, and that steps are being taken to improve patient participation even more within the VI teams. However, other staff members believed that patients should participate on another level than the VI team, because being a VI team member is too burdensome for the patient. This was mentioned several times in round one as a reason for not letting a patient participate in the VI team.

Most patients believed that their input was taken into consideration (93%). In addition, staff members of teams with patient participation indicated that the input of patients was taken seriously (78%), but only half of the staff also believed that the input of patients had influence on the outcomes of the VI team (51%). The majority of the staff members (90%) with experience in patient participation believed that it had added value.

Lastly, in addition to the impact of patient participation on the VI team in general, it can have an impact on the individuals in the VI team. Patients indicated that because of their participation, they were better informed about their medical condition and/or the healthcare system (73%).

Table 2| Evaluation of patient participation in value improvement teams based on qualitative (interview) and quantitative (PPEET questionnaire) data

Theme	Interview subthemes	Example quote from interview
1. Goals and motivation for PP[2]	1.1 Motivation of patient 1.2 Priority of PP 1.3 Role patient/staff	1.1: "I feel like I can give something back, maybe help other patients ... and also the hospital"- patient 1
2. Strategy for PP	2.1 PP as subject of discussion 2.2 Strategy for PP 2.3 Responsibility for PP 2.4 Patient selection for VI[3] team 2.5 PP methods	2.3: "I have always been an assertive patient ... so maybe that's why they asked me if I wanted to join [the VI team] – patient 2 2.3: "I think that the healthcare professionals should be responsible [for patient participation]. Because when you want to improve the care for a specific patient group, then the experts that treat that group should be in the lead" – Staff 1 2.5: "I would really like to have more input from patients. But the method and how to do it, is what I'm struggling with" – Staff 2
3. Context of VI team influences PP	3.1 VI team characteristics 3.2 Process of VI meetings 3.3 Content discussed in VI team	3.2: "I think that everyone is positive towards patient participation. That is due to the medical lead. She is the ambassador and she motivated the rest" – patient 3
4. Resources required for PP	4.1 Resources of team for pp 4.2 Compensation for patients	4.2: "I think that it [patient participation] is a time issue. It can slow down the process when the input [of patients] has to be collected first, and therefore they might be a little bit skeptical of the added value" – Staff 3
5. Knowledge and skills in PP required from patients and staff	5.1 Required skills of patients 5.2 Previous experience of patient with pp 5.3 Characteristics of patient 5.4 Knowledge of patient	5.2: "They [the staff] knew that I was already involved in 'patient partner' projects and then they asked me if I wanted to do this [being a VI member]" – patient 4
6. Representativeness as barrier for PP	6.1 Representativeness of patients 6.2 Number of patients in VI team	6.1: "You will always hear from 1 or 2 highly educated, interested, verbally strong, generally positive patients, otherwise they would not be here. So you get very selective input" – Staff 4
7. Relationship VI team members influences PP	7.1 Relation among VI team members 7.2 Hierarchy in VI team	7.2: "You do notice that the hierarchy, which is common in the hospital, is also present there [in the VI team]" – patient 1
8. Feedback and evaluation are important in PP	8.1 Feedback on input 8.2 Evaluation of PP 8.3 Patient views on PP 8.4 Staff views on PP 8.5 Improvements should be made	8.1: "Sometimes I have the feeling that I'm not sure whether they took the input [given by patient] into account" – patient 6

% of participants that (totally) agree with PPEET[1] question
• Staff: There was a clear statement of the objectives for the engagement: 39% • Staff: The goals for the engagement component were shared with participants: 75%
• Staff: The VI team has a clear strategy to recruit those most affected by the outputs of this project (e.g. relevant lived experience, socio-demographic or geographic communities): 29% • Staff: The VI team has a clear strategy to actively engage patients: 31% • Staff: We worked with other (patient) organizations as part of the engagement component of this project: 27% yes • Staff: We were able to identify shared goals with our partners through this process: 68% • Staff: Do you plan to collaborate with these partners again in the future?: 92% yes
• N.A.
• Staff: The financial, logistical and information needs of participants (e.g., travel, dietary, interpretive, childcare, etc.) were accommodated: 38% • Staff: Adequate time was allocated to plan and implement the engagement component: 46% • Pt[4]: The support I need to participate in the VI team is available (e.g., travel, childcare): 89%
• Staff: I would like to participate in a training on patient participation: 44% yes • Pt: I have a clear understanding of the purpose of the VI team: 100% • Pt: I have enough information to be able to carry out my role: 100%
• Staff: The perspectives of those who will be most affected by the output of this project were reflected through those who participated in the engagement: 74% • Pt: I feel like I can represent the patient perspective: 100% • Pt: I feel more comfortable because I am not the only patient in the VI team: 56% • Pt: The individuals participating in the VI team represent a broad range of perspectives: 87% • Pt: A wide range of views on discussion topics is shared: 80%
• Staff: I can speak freely with the patient at the table: 80% • Pt: I am able to express my view freely: 100% • Pt: I feel like an equal VI team member: 100%
• Staff: Participants were told how the input from the engagement component would be used by the organization: 81% • Staff: Overall, I was satisfied with the engagement component of this project: 41% • Pt: I get sufficient feedback on how my input is used: 73% • Pt: Overall, I am satisfied with the patient participation in this project: 87% • Pt: This initiative for patient participation is a good use of my time: 87%

Table 2| Continued

Theme	Interview subthemes	Example quote from interview
9. Impact of PP	9.1 Added value of pp 9.2 Improvement in PP 9.3 Burden for patient 9.4 Impact PP	9.3: "When you [the patient] are in a crisis [with your health], then you have to be occupied with that, and not with the process and what the hospital is asking from you" – Staff 5

1: PPEET: Public and Patient Engagement Evaluation Tool [24]
2: PP: patient participation
3: VI: Value Improvement
4: pt: patient

3.4 Discussion and conclusion

In this study, we aimed to evaluate patient participation within VI teams. The results showed that currently only half of the 76 included VI teams use a form of patient participation. Nine themes regarding the experiences with patient participation in the VI teams were identified in the interviews, of which we would like to highlight four interesting observations. First, the majority of VI teams lacked a clear strategy and goal for patient participation, which may explain why half of the VI teams had no form of patient participation. Second, we found that specific knowledge and skills are required for patients to participate in a VI team. This leads to the inclusion of patients with these specific skills, which in turn leads to concerns regarding the representativeness of participating patients. Third, patients indicated to have an equal and informal relationship with the rest of the VI team and did not experience 'hierarchy' as a challenge for participation. Fourth, patients mentioned in interviews a lack of feedback on their input, but this was not found in the quantitative results. Meanwhile, staff members indicated in the questionnaire that the input of patients often did not influence the outcomes of the VI trajectory. We discuss these four observations in greater detail below.

This study describes many challenges for patient participation which may be related to the lack of strategy for patient participation that staff members reported. Having a clear strategy, including clarity on the role for the patient, recruitment of patients, and funding and time investments could provide a solution for the

% of participants that (totally) agree with PPEET[1] question
• Staff: The output generated from the engagement component associated with this project influenced the project's outcome: 51% • Staff: The output generated from the engagement component associated with this project were taken seriously by those in a position to act on it: 78% • Staff: The engagement component added value to the project it supported: 90% • Staff: As a result of my involvement in the engagement component associated with this project, I will be comfortable leading future engagement activities: 60% • Pt: I feel that my views are heard: 93% • Pt: I am confident that the VI team takes my provided feedback into consideration: 93% • Pt: I think that the work of the VI team makes a difference to the work of the hospital: 87% • Pt: I think that the hospital is achieving its stated objectives for the VI team: 67% • Pt: As a result of my participation in the VI team, I am better informed about my medical condition and/or the healthcare system: 73%

experienced difficulties in the implementation of patient participation [16,25–27]. Additionally, several practical aspects were mentioned that could stimulate patient participation in VI teams but are currently absent, e.g. 'having a trained moderator to guide the team meetings'. This importance of a moderator trained in patient participation techniques has been stipulated before in the literature [16,28,29]. Furthermore, multiple methods for patient participation can be used by the VI teams. Having a patient as team member is often seen as the highest level of patient participation, and therefore the best possible method. This hierarchy is implied by the frequently used 'ladder of participation' of Arnstein [30]. However, as Carman and colleagues also discuss in their framework, the 'highest' level of participation on the continuum of engagement is not always the best level, but it depends on the question, aim, or project [6]. This was also pointed out by the VI team members, but they indicated to struggle with the selection of suitable patient participation methods for their VI team. Therefore, the VI teams would benefit from guidelines on patient participation which includes the different methods and levels of patient participation. Existing frameworks such as frameworks for patient participation in research [31,32] and the framework of Carman and colleagues [6] could be used to develop such guidelines.

Our results show the importance of paying attention to the knowledge and skills of both patients and staff regarding patient participation. In the interviews, staff members and patients indicated several skills and a certain level of knowledge that a patient should have when participating in a VI team. All patients in our study indicated that they possessed these skills. However, staff members also discussed their concern regarding the required skills for participating patients, since patients with these skills might not be representative for the entire patient population. They indicated that other methods of patient participation, such as focus groups, could help to gain insight into the perspectives of a larger group of patients. Previous research has recommended to combine the two methods, so having both patient representatives as well as using other methods such as patient questionnaires, to learn more about the perspectives of a large group of patients [33]. Furthermore, in literature, there are different opinions on the level of professionalism that is required from patients to participate at the collective level. Some studies stipulate the importance of training the patients [9,34–38], while others criticize this need of training, since this would lead to 'proto-professionalism' of patients participating in such projects and minimizes the representativeness of patients [39]. Training of staff in patient participation is less controversial, and previous studies have shown positive effects of such training [34,35,40,41]. However, only half of the staff in our study indicated that they would like to be trained in patient participation.

Hierarchy is an often mentioned barrier for patient participation [42,43], and while our results show that patients experienced some level of hierarchy, patients also stated that this did not make them feel restricted to express their opinion freely. Almost half of the patients reported that having another patient as a team member did not result in them feeling more comfortable in the VI team. This contradicts a recommendation of a review on patient participation, where it was suggested to have an equal or higher number of patients compared to staff in a project team in order to strengthen patient voices [16]. This contradiction might be explained by the fact that there is a high level of patient empowerment in Dutch healthcare [44], likely resulting in Dutch patients feeling more equal to their healthcare professionals than patients from other countries. Patients did indicate that it is important to maintain their healthcare professional-patient relationship strictly separate from their relationship as VI team member, but that it is possible to participate in a VI team with their own doctor or nurse. This is only partially in line with previous research, where they found that patients should not have a prior relationship with the healthcare professionals in the same panel, since patients would not feel comfortable with that [28]. Not only patients, but also healthcare professionals seem to find it challenging to shift their doctor-patient relationship to a 'colleague' relationship [45]. During the first round of interviews, several staff members mentioned that having a patient in the VI team member would restrict them to express their opinion freely, while results from the questionnaire contradicted this finding. Therefore, we recommend that patients and staff members discuss this topic (‘hierarchy’) prior to becoming team members, since both parties seem to struggle with it on their own.

Patients believed their input was taken seriously and into consideration, but during the interviews several patients indicated that they were not sure how their input was used in practice. Meanwhile, staff members that had experience with patient participation indicated that the input of patients had a limited effect in practice. These results indicate that, also in teams where patients were equal team members, often no full partnership was reached (yet). The lack of identified impact of patient participation might be related to the lack of a clear goal for patient participation. Without a clear goal, it is challenging to determine the effects, since it has not been predetermined how and what to measure as effects. This shortcoming in evaluation and feedback on impact of patient participation has been addressed before in literature. This problem could be tackled by having a coordinator of the patient participation with assigned time for evaluation [46]. Moreover, previous research identified a lack of formal tools to evaluate the effect of collective patient participation [47]. A strategy for patient participation should therefore also include an evaluation plan for the effects of patient participation. Lastly, someone should be assigned responsible for the evaluation of patient participation, since no one currently is.

Some limitations deserve consideration in light of these results. First, only fifteen patients completed the questionnaire, and they were all very satisfied with their participation. We are unsure if our sample was representative, since most patients mentioned during the interviews that they would leave the VI team if they were dissatisfied. Since the questionnaire was only sent out to the patients who were still part of the VI teams, it would also be interesting for future studies to include patients who were less satisfied, for example by inviting patients that have ceased their participation in the VI team. Secondly, since the patients included in our study were all highly educated, we were not able to gain new insights into strategies for enhancing patient participation of patients with more diverse characteristics. Patient participation can be achieved with other (less structural) methods, such as organizing a focus group to gain insight into a specific subject. It would be interesting to evaluate patient participation from the perspectives of these patients as well, and to evaluate whether these methods would stimulate patient participation from patients with diverse characteristics. Thirdly, we were unable to calculate a response rate, since we asked the project leaders to forward the questionnaire to ‘their’ VI team members and we are unsure who they invited. Fourthly, several VI team members of the same VI team gave conflicting answers regarding the method of patient participation used by their VI team. This indicates that not all VI team members are completely up-to-date on patient participation in their teams, which could have resulted in unreliable answers to the questionnaire.

Conclusion

These findings provide both qualitative and quantitative insights into the current state of and experiences with patient participation in multidisciplinary VI teams. The results imply that patient participation is not (yet) fully implemented within current practice of the VI teams. Therefore, we believe that VI team members would benefit from guidelines on how to include a representative group of patients, how to train both patients and staff in patient participation, which methods to use, and how to evaluate the impact of patient participation and provide feedback to participating patients. These guidelines could be based on the findings of this study and existing frameworks and theory on patient participation. Future studies should aim to formulate and implement such guidelines to improve patient participation within VBHC initiatives.

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Appendix A: Interview guides

Interview Round 1:

Interview questions patients:

1. How are patients involved in your Value Improvement (VI) team?
2. Can you tell me something about your role in the VI team?
3. Who invited you to become a VI team member?
4. Why did you chose to become a VI team member?
5. Do you think it is important that a patient is part of the VI team? Why?
6. What do you want to accomplish by being a VI team member?
7. What do you think that the effects are of a patient being a VI team member?
8. What do you need to participate properly in the VI team?
9. What do you expect from other VI team members?
10. Do you have an example of a moment when you felt that the patient participation was successful? Why was that?
11. Do you have an example of a moment when you felt that the patient participation was unsuccessful? Why was that?
12. Having a patient as VI team member is one method for patient participation. Do you have other ideas of how to involve patients in quality improvement projects/programs in healthcare?

Interview questions staff:

1. How are patients being involved in your VI team? Do you have a patient as VI team member? Are patients also being involved in another way?
2. Do you think that patient participation is of added value in the VI team? Why?
3. Do you think it is important to have a patient as VI team member? Why (not)?
4. What do you want to accomplish by conducting patient participation?
5. What do you expect from the patient as VI team member? What is the role of the patient?
6. What can you do to support the patient in the VI team? What do you need to support the patient within the VI team?
7. Do you have an example of a moment when you felt that the patient participation was successful? Why was that?
8. Do you have an example of a moment when you felt that the patient participation was unsuccessful? Why was that?
9. Having a patient as VI team member is one method for patient participation. Do you have other ideas of how to involve patients in quality improvements in healthcare?

Interview Round 2:

1. How are patients being involved in your VI team?
2. Would you like to explain a few answers you gave in the questionnaire? (this question was individually prepared for every interview)
3. How effective do you think that the patient participation in your VI team is?
4. What is going well in patient participation in your VI team?
5. What can be improved in patient participation in your VI team?
6. What is the biggest barrier in patient participation in your VI team?
7. How would you solve this barrier?
8. What do you need from your team or organisation to solve this barrier?
9. Is everyone in your VI team positive about patient participation?
10. Would you like to use other methods for patient participation? If yes, why and which methods?

Appendix B: PPEET results

	Question	Respondent	N score 0
1	I have a clear understanding of the purpose of the VI team.	Patient	0
2	The supports I need to participate in the VI team are available (e.g., travel, childcare)	Patient	0
3	I have enough information to be able to carry out my role.	Patient	0
4	I feel like I can represent the patient perspective	Patient	0
5	I am able to express my view freely.	Patient	0
6	I feel that my views are heard.	Patient	0
7	A wide range of views on discussion topics is shared.	Patient	0
8	The individuals participating in the VI team represent a broad range of perspectives.	Patient	0
9	I feel more comfortable, because I am not the only patient in the VI team.	Patient	0
10	I feel like an equal VI team member	Patient	0
11	I think that the hospital is achieving its stated objectives for the VI team.	Patient	0
12	I am confident that the VI team takes my provided feedback into consideration	Patient	0
13	I think that the work of the VI team makes a difference to the work of the hospital	Patient	0
14	I get sufficient feedback on how my input is used	Patient	0
15	As a result of my participation in the VI team, I am better informed about my health condition and/or the healthcare system.	Patient	0

N score 1	N score 2	N score 3	N score 4	N score NA	N respondents	% agree
0	0	6	9		15	100%
0	1	4	4		9	89%
0	0	7	8		15	100%
0	0	6	9		15	100%
0	0	1	14		15	100%
0	1	2	12		15	93%
0	3	7	5		15	80%
0	2	7	6		15	87%
0	4	4	1		9	56%
0	0	7	8		15	100%
0	5	9	1		15	67%
0	1	8	6		15	93%
1	1	10	3		15	87%
1	3	8	3		15	73%
3	1	7	4		15	73%

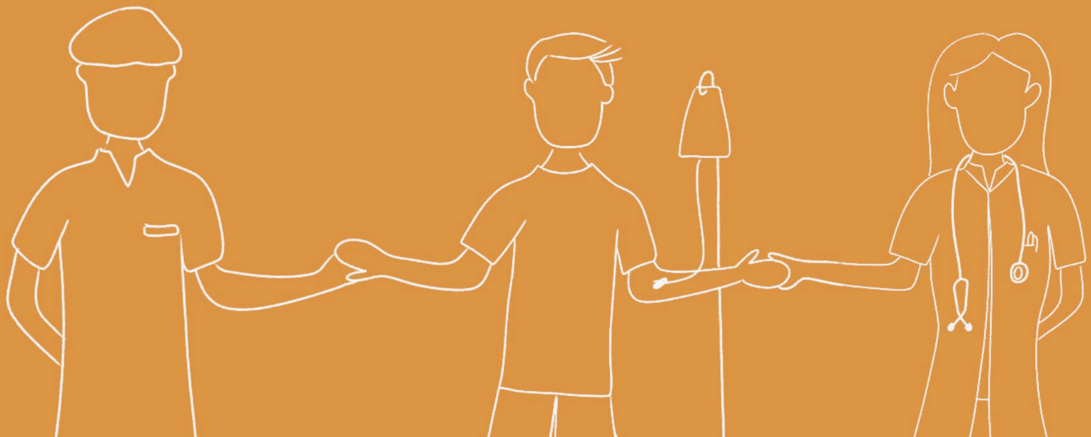
Appendix| Continued

	Question	Respondent	N score 0
16	Overall, I am satisfied with the patient participation in this project.	Patient	0
17	This initiative for patient participation is a good use of my time.	Patient	0
1	There was a clear statement of the objectives for the engagement.	Staff	4
2	The VI team has a clear strategy to recruit those mose affected by the outputs of this project (e.g. relevant lived experience, socio-demographic or geographic communities)	Staff	10
3	The VI team has a clear strategy to actively engage patients	Staff	4
4	The perspectives of those who will be most affected by the outputs of this project were refelected through those who participated in the engagement.	Staff	2
5	The financial, logistical and information needs of participants (e.g., travel, dietary, interpretive, childcare, etc.) were accomodated.	Staff	3
6	Adequate time was allocated to plan and implement the engagement component.	Staff	2
7	The goals for the engagement component were shared with participants.	Staff	1
8	Participants were told how the input from the engagement component would be used by the organization.	Staff	0
9	I can speak freely with the patient at the table.	Staff	1
10	We worked with other (patient)organizations as part of the engagement component of this project. (0=no, 1=yes)	Staff	66
11	We were able to identify shared goals with our partners through this process.	Staff	0
12	Do you plan to collaborate with these partners again in the future? (0=no, 1=yes)	Staff	2
13	Overall, I was satisfied with the engagement component of this project.	Staff	3
14	The engagement component added value to the project it supported.	Staff	1
15	As a result of my involvement in the engagement component associated with this project, I will be comfortable leading future engagement activities.	Staff	0
16	I would like to participate in a training on patient participation (0=no, 1=yes)	Staff	51
17	The output generated from the engagement component associateid with this project were taken seriously by those in a position to act on it	Staff	0
18	The output generated from the engagement component associated with this project influenced the project's outcome	Staff	0

N score 1	N score 2	N score 3	N score 4	N score NA	N respondents	% agree
0	2	7	6		15	87%
0	2	5	8		15	87%
30	41	33	14	5	127	39%
38	37	27	7	7	126	29%
38	42	32	6	6	128	31%
4	15	43	16	1	81	74%
15	17	19	2	1	57	38%
7	29	30	3	1	72	46%
6	11	45	9	1	73	75%
2	12	49	11	1	75	81%
2	4	22	6	1	36	80%
25					91	27%
1	6	14	1		22	68%
23					25	92%
22	26	31	4		86	41%
1	6	52	21		81	90%
9	22	42	4	1	78	60%
40					91	44%
3	14	43	18		78	78%
7	31	34	5	1	78	51%

Appendix C: Step-by-step guide of data analysis:

1. The semi-structured interviews of round one and two were recorded and transcribed verbatim.
2. The transcripts were sent to the interviewees for a member check, and no changes were made by the interviewees.
3. The transcripts were loaded into Atlas.ti. Since the interview guides of round one and two were not very different from each other, we analyzed the interviews of both rounds in the same manner.
4. The first five interviews were independently coded with an inductive approach by both HJW (first author) and OW (research intern).
5. HJW and OW discussed the codes of the first five interviews and reached consensus on the open codes.
6. The next five interviews were open coded independently by HJW and OW and discussed in a consensus meeting.
7. This process was continued until all interviews were coded by the two researchers and consensus was reached on all open codes.
8. All codes were thematically grouped in an session with HJW and OW by printing all the codes and grouping them on different post-its. They reached consensus on the identified subthemes and wrote these subthemes on the post-its. These post-it's were then placed into theme's by grouping them and adding them to envelops with the theme's written on it.
9. These themes and subthemes were then discussed with the co-authors and consensus was reached.
10. These results were then shared with the interviewees. No comments were made that would lead to changing the themes.
11. The data of the questionnaire was analyzed using Excel. The percentages of respondents who (totally) agreed with the individual questions were calculated.
12. HJW then matched the questions to the identified themes. This matching was then discussed in a meeting with the co-authors. This method allows to visualize both the qualitative data and quantitative data in one overview figure (triangulation).
13. The quantitative results were then placed in a schematic overview of all interview themes and subthemes.



Chapter 4

The use of outcome data in patient consultations from the healthcare professionals' and patients' perspectives: a mixed methods study

H.J. Westerink, C.C. Bresser, M.M. Garvelink, C.F. van Uden-Kraan, O. Zouitni, J.A.J. Bart, P.J. van der Wees, and P.B. van der nat, (on behalf of the Santeon Patient Participation Study group*)

* The Santeon Patient Participation Study Group (collaborators) are:
Annette W.G. van der Velden, Martini Hospital, Groningen, the Netherlands
Sander Koëter, Canisius Wilhelmina Hospital, Nijmegen, the Netherlands
Willem J.W. Bos, St. Antonius Hospital, Utrecht/Nieuwegein, the Netherlands
Diederik H.R. Kempen, OLVG, Amsterdam, the Netherlands
Angelique E.A.M. Weel, Maasstad Hospital, Rotterdam, the Netherlands
Eino B. van Duyn, Medisch Spectrum Twente, Enschede, the Netherlands
Pepijn H. van der Voort, Catharina Hospital, Eindhoven, the Netherlands

Patient Education and Counseling, 2024;118:108043

Abstract

Objectives: To gain insight into healthcare professionals' (HCPs') perspectives on the use of outcome data in consultations and to understand which aggregated outcomes patients find important.

Methods: This study had a mixed-methods design and consisted of two steps:

1. HCPs (n=11) were interviewed about the use of outcome data in consultations. Thematic analysis was used for data analysis.
2. Patients with prostate cancer, lung cancer, and inflammatory bowel disease (IBD) completed questionnaires (n=283) to identify important outcomes. Descriptive statistics were used for data analysis.

Results: HCPs indicated that aggregated outcome data are not routinely used in consultations. They pointed out various barriers to using outcome data, e.g., low response rates of PROMs, and suggested actions to address these barriers, including training of HCPs in outcome data usage. Patients rated the majority of aggregated outcomes as important, although preferences differed between the studied health conditions.

Conclusion: Both HCPs and patients underscored the importance of discussing outcome data in consultations. Nevertheless, HCPs encountered several barriers to using outcome data. Furthermore, patients with different health conditions have somewhat different information needs.

Practice implications: The study identified several actionable steps to enhance the collection and application of outcome data in consultations.

4.1 Introduction

Value-based health care (VBHC) is a healthcare model dedicated to enhancing quality of care, while containing or reducing healthcare costs. In the shift toward a VBHC system, the focus is on maximizing value for patients, where value is defined as outcomes relevant to patients relative to the costs needed to achieve these outcomes [1]. With the introduction of VBHC, outcome data at the level of health conditions have become available [2]. These outcome data encompass clinical outcomes, such as blood test results, and patient-reported outcomes, such as quality of life [3–5]. Outcome data can be used at the organizational level for quality improvements and to benchmark between healthcare providers [6], or at the individual level to inform the patient, monitor their health status, and support shared decision-making (SDM) in patient consultations [7].

There are two types of outcome data: 1) individual outcome data, i.e., data from one patient, and 2) aggregated outcome data, i.e., data derived from a group of patients. Patient consultations mainly focus on the patient's individual outcome data to track their personal health status and quality of life. Meanwhile, aggregated outcome data are mainly used in the context of quality improvement and benchmarking, offering insights into group-level outcomes that can be compared across institutions or over time [8]. Moreover, they can be used in patient consultations to support SDM, for instance by developing patient-like-me models that predict personalized outcomes based on data from similar patients [9,10].

To effectively use both types of outcome data in patient consultations, two essential factors come into play: active patient participation and training for healthcare professionals (HCPs). First, active patient participation is needed to select outcomes that are relevant to patients and match their information needs [11]. Current outcome measures are often determined by HCPs without asking patients about their relevance [12]. Moreover, since outcome measures are mostly selected to be used for quality improvement and benchmarking [13–15], these outcomes might not be relevant to discuss in individual patient consultations. Second, training of HCPs on how to use outcome data in a meaningful way is a crucial step in the implementation of outcome data in patient consultations [16,17]. Currently, HCPs often lack the necessary knowledge, skills, and sometimes attitudes for using outcome data in consultations [18].

In recent years, several projects have been initiated in the Netherlands to study and improve the use of both individual and aggregated outcome data in patient consultations, such as the SHOUT study, the QLIC-ON study, and the SOURCE study [17,19,20]. However, it remains unclear whether outcome data are used in consultations outside of these projects, and what the perspectives of HCPs and patients are regarding the use of outcome data in patient consultations.

This study aimed to provide a deeper understanding of the use of outcome data in patient consultations in the Netherlands by addressing the following questions: 1) What are HCPs' perspectives on the use of outcome data in consultations?; and 2) Which aggregated outcomes are important to patients and how does that vary across health conditions? The answers to these two questions will provide an integrated view of outcome data usage at the individual patient level and will guide further steps to enhance the use of outcome data in patient consultations.

4.2 Methods

Study design

This study employed a mixed-methods design. Using a grounded theory approach, we interviewed HCPs about the use of outcome data in patient consultations. Patients were surveyed to identify which aggregated outcomes they consider important.

Healthcare professional interviews

The methodology of the qualitative part is described according to the consolidated criteria for reporting qualitative research (COREQ) guidelines [21].

Context

HCPs from the Santeon hospitals were invited for an interview. Santeon is a collaboration of seven non-academic teaching hospitals that collectively strive to improve their care following the principles of VBHC. They are geographically spread throughout the Netherlands, each serving different patient populations. Each hospital has established multidisciplinary Value Improvement (VI) teams for fifteen specific health conditions. The VI teams collect predetermined outcome-, process-, and cost-data that are used for benchmarking and improving healthcare quality across all Santeon hospitals [22]. For three health conditions (breast cancer, stroke, and chronic kidney disease) the Santeon hospitals have started a study on the use of outcome data to personalize healthcare (SHOUT-study) [17].

Study sample

We contacted 27 HCPs who had previously participated in a study on patient participation in VBHC via email. The inclusion criterion was: medical specialists and nurses who were part of a VI team and thus had experience with using outcome data for quality improvement and benchmarking. The exclusion criteria were: 1) HCPs from recently started VI teams with limited experience in outcome data collection and 2) HCPs who participated in the SHOUT study [17], as their perspectives might be influenced by their role in the study. Participants were given the choice to conduct the interview face-to-face or via video-conferencing.

Data collection

HCPs were interviewed about the use of clinical and patient-reported outcome data, both at the aggregated or individual level, in patient consultations. See Appendix A for the interview guide of these semi-structured interviews. Participants were requested to provide consent to record the interview, and the interviews were transcribed verbatim using transcription software (Amberscript). The first author (HJW) conducted the interviews, made field notes during the interviews, checked the transcriptions, and sent the transcriptions to the participants for a member check. HJW had previous experience with and training in conducting and analyzing interviews. HJW had no prior relationship with the interviewees.

Data analysis

The qualitative data obtained from the interviews were analyzed through thematic analysis. An inductive approach for the coding was used. To ensure the reliability of the analysis, three randomly selected interviews were double-coded by two researchers (HJW and CCB). Any discrepancies were resolved through a consensus meeting after coding these three random interviews. Given the absence of major discrepancies between the two coders, one researcher (HJW) proceeded to code all the interviews, with the second coder (CCB) performing a cross-check. The themes were organized into a schematic overview and discussed with the co-authors. This overview was sent to the interviewees for a member check. Atlas.ti software was used for qualitative data analysis.

Patient questionnaires

Study sample

Patients with one of the following three health conditions, i.e., prostate cancer, lung cancer, and inflammatory bowel disease (IBD), were recruited via Dutch patient organizations and online forums (Crohn & Colitis NL, kanker.nl, Prostaatkanker

Stichting, Longkanker NL, foundation DUOS). The three health conditions were selected based on variations in chronicity and prognosis, with IBD being an incurable chronic disease, prostate cancer being a slow progressive cancer with a high survival rate, and lung cancer being a more progressive cancer with a lower survival rate.

Data collection

Patients were asked to rate the importance of aggregated outcomes on a 5-point Likert-scale. They were also asked whether they preferred merely being informed about the outcome or desired a discussion with their HCP about that outcome. The questionnaires incorporated outcomes that were collected by VI teams for quality improvement of the corresponding health condition. Examples of these outcomes are survival rate, prostate-specific antigen level, malnutrition, patient-reported fatigue, and pain.

The questionnaires were written in Dutch B1 language level (Common European Framework of Reference for Languages) with the assistance of two linguists. An example of a question of the prostate cancer questionnaire is: *'The number of patients that are incontinent after treatment. Do you find this important information?'* Each question on the importance of an outcome was followed by the question *'Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?'* The complete questionnaires and response options are available in Appendix B. Each questionnaire ended with an open-ended question, allowing participants to suggest relevant outcome data that had not been covered in previous questions.

To check whether we had reached an inclusive group of patients with regard to health literacy, the three health literacy questions were added to the questionnaires [23].

Data analysis

Outcomes were considered important if patients rated them with a score of four or five ('important' or 'very important'). Analysis was conducted to examine differences between the three health conditions and the type of outcome data (clinical or patient-reported). Descriptive statistical analysis was performed with Excel. Open text data from the questionnaire were categorized by HJW based on similarities between responses from different patients. To enhance reliability and minimize interpretation, HJW discussed the identified categories with several co-authors.

Inadequate health literacy was determined according to established standards in the literature, where an average score of ≤2 (on a 5-point Likert-scale) of the three health literacy questions indicates inadequate health literacy [24].

Patient and public involvement

Two patient advisors were part of the research team and actively participated in research team meetings. Their involvement spanned all aspects of the study, from grant proposal writing and drafting the patient questionnaire to interpreting the results and co-authoring this article.

Ethical approval

The research protocol for this study was approved by the 'Santeon Beheercommissie' (SDB-2022-004). The Medical Ethical Commission-Utrecht declared that no further ethical approval was needed for this study (W22.213). Each participating hospital also obtained approval from their local scientific committee to ensure feasibility. HCPs provided written informed consent to use and store their data for research. Patients were informed about the use of their answers for research and consented to use and store their data for research by completing the questionnaire. No personal identifiers were collected via the questionnaire.

4.3 Results

Healthcare professional interviews

Eleven HCPs were interviewed; see Table 1 for interviewee characteristics. The main reason for non-participation of the contacted HCPs was due to time constraints. The interviews had an average duration of 23 (±6) minutes, excluding the study's introduction and explanation. Interviews continued until data saturation was reached.

Five distinct themes emerged from the HCP interviews: importance of the use of outcome data, current use of outcome data, barriers to the use of outcome data, proposed actions, and ambitions and future perspectives (see Fig. 1). Illustrative quotes for each theme are presented in Table 2. Overall, HCPs mostly referred to the use of Patient Reported Outcome Measures (PROMs) when discussing outcome data in general.

Table 1| Interviewee characteristics

Characteristics	N (%)
Total	11
Gender	
Male	4 (36%)
Female	7 (64%)
Function	
Medical specialist	6 (55%)
Nurse (practitioner)	4 (36%)
Physician assistant	1 (9%)
Specialism	
Orthopedics	2 (18%)
Inflammatory Bowel Disease	2 (18%)
Lung cancer	1 (9%)
Prostate cancer	3 (27%)
Diabetes	1 (9%)
Birth care	1 (9%)
Coronary artery disease	1 (9%)

Importance of the use of outcome data

The HCPs mentioned several reasons for the importance of using outcome data in patient consultations. First, outcome data aid in treatment decision-making. Second, the use of outcome data empowers patients to actively participate in their care, by allowing them to monitor their own health status and treatment outcomes. Third, HCPs mentioned that collecting outcome data helps to monitor the patients' health status over time. PROMs were considered particularly valuable for providing accurate insight into a patient's health status, since patients can complete the questionnaires at home, which gives a more veracious response of the patient. It was also thought that PROMs facilitate discussions about sensitive topics, since patients do not have to bring these up themselves, and the HCP does not need to carefully introduce the topic. In general, nurses tended to place greater emphasis on the positive aspects of PROMs compared to medical specialists.

Current use of outcome data

There are variances in the current use of outcome data among HCPs. They indicated that aggregated outcome data were predominantly used for quality improvement rather than in patient consultations. The use of individual clinical outcome data, such as monitoring blood values, was seen as common clinical practice, whereas the use of PROMs would require a new way of working according to HCPs. Some HCPs acknowledged that even though PROMs had been implemented for their health condition, they or their colleagues do not consistently discuss them with their patients. HCPs reported the use or development of various tools, such as decision aids or dashboards, to visually present outcome data and to support treatment decision-making based on these data.

Barriers to the use of outcome data

HCPs encountered several barriers to the use of outcome data. First, they noted a lack of practical support, including IT assistance or dedicated staff responsible for PROMs implementation. Second, HCPs pointed out that the quality of aggregated outcome data is often insufficient to use it in clinical practice, as it frequently originates from a small and non-representative sample of patients. Third, several HCPs believed or experienced that the discussion of PROM data is burdensome, as it can consume additional time, while others believed it might save time. A few HCPs considered PROM outcomes as 'too soft' and outside the scope of their responsibilities. Fourth, HCPs mentioned that they prefer traditional conversations with their patient over using tools such as decision aids. Fifth, HCPs indicated that they find it challenging to translate outcome data into treatment decisions. Last, the low response rate of PROMs was cited as a barrier. HCPs identified four possible reasons for the low response rate of PROMs: (1) patients do not see the point of completing PROMs, (2) patients simply forget to complete PROMs, (3) patients lack an incentive to complete PROMs when the HCP fails to discuss them during their consultation, and (4) patients are already burdened with numerous questionnaires.

Proposed actions

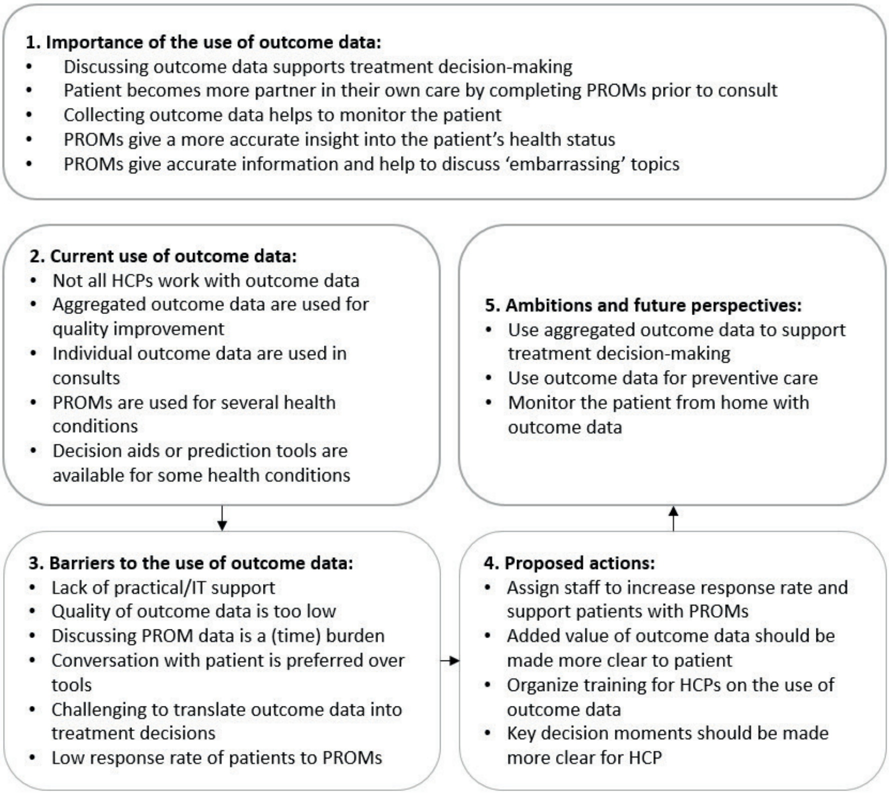
To solve the abovementioned barriers, HCPs reported the need for support staff to coordinate PROMs, as well as to inform and assist patients with PROM completion. In particular, patients that are unable to complete PROMs themselves should be offered support, possibly by having someone (e.g., a nurse) present in the waiting room with a tablet to aid patients in completing the questions. Furthermore, HCPs recommended educating patients about the advantages of discussing outcome data in clinical practice to enhance their motivation for completing PROMs. Additionally, HCPs reported a need to be trained on how to effectively use outcome data in consultations (e.g., by having insight into key decision moments).

Ambitions and future perspectives

All HCPs believed that outcome data will assume a more prominent role in healthcare in the future. They expressed a desire to incorporate aggregated outcome data in patient consultations to support treatment decision-making. They also aspired to use outcome data for preventive care, since it can help them to detect symptoms earlier. HCPs envisioned a future where patients receive more care from home, as outcome data enable the HCP to remotely monitor their patients.

Table 2| Identified themes with quotes from the healthcare professionals interviews (n=11)

Theme	Quote
Importance of the use of outcome data	*"So you can say [to the patient]: 'choose the treatment that you prefer, because now you know what to expect' [based on outcome data]"* – Medical specialist 1
	"The use of a questionnaire that the patient has to complete from home makes it easier [for the patient] to write it [embarrassing symptoms] down, so that I already know this and can bring it up during a consultation instead of the patient [having to bring it up]" – Nurse 1
	"It [outcome data] is very valuable, because you can give the patient insight in the changes over time" – Medical specialist 2
Current use of outcome data	*"I think it [using PROMs] is challenging, because it requires a new way of working. But if you want what is best for the patient, I would recommend using PROMs"* – Physician assistant 1
Barriers to the use of outcome data	*"Currently we are waiting [with sending out PROMs], because the IT doesn't have staff to support us"* – Medical specialist 3
	"Often I do not have PROMs data available (…) People are not very motivated to complete the questionnaire." – Medical specialist 4
	"And it is a little time-consuming to prepare and discuss it [PROMs]" – Nurse 2
	"I do not use it [decision aid] anymore, because the tool was more steering than the conversation with the patient. That did not work for me, to look at the screen with a patient to see what he has answered. I prefer the conversation over the system." – Nurse 2
Proposed actions	*"It will only work if you have a nurse that is responsible for the PROMs, but then the money is often lacking"* – Medical specialist 5
Ambitions and future perspectives	*"When patients can measure their blood sugar from home and send it to us, and they feel fine, that will be advantageous for us, and for the patient too, since they don't have to come to the hospital every time"* – Nurse 1



1. Importance of the use of outcome data:
- Discussing outcome data supports treatment decision-making
- Patient becomes more partner in their own care by completing PROMs prior to consult
- Collecting outcome data helps to monitor the patient
- PROMs give a more accurate insight into the patient's health status
- PROMs give accurate information and help to discuss 'embarrassing' topics

2. Current use of outcome data:
- Not all HCPs work with outcome data
- Aggregated outcome data are used for quality improvement
- Individual outcome data are used in consults
- PROMs are used for several health conditions
- Decision aids or prediction tools are available for some health conditions

3. Barriers to the use of outcome data:
- Lack of practical/IT support
- Quality of outcome data is too low
- Discussing PROM data is a (time) burden
- Conversation with patient is preferred over tools
- Challenging to translate outcome data into treatment decisions
- Low response rate of patients to PROMs

4. Proposed actions:
- Assign staff to increase response rate and support patients with PROMs
- Added value of outcome data should be made more clear to patient
- Organize training for HCPs on the use of outcome data
- Key decision moments should be made more clear for HCP

5. Ambitions and future perspectives:
- Use aggregated outcome data to support treatment decision-making
- Use outcome data for preventive care
- Monitor the patient from home with outcome data

Figure 1| Themes identified from interviews with healthcare professionals (n=11). HCP= healthcare professional, PROM= patient reported outcome measure

Patient questionnaires

A total of 283 patients completed the questionnaire. This included 72 patients with lung cancer, 104 patients with prostate cancer, and 107 patients with IBD. Seven of the respondents had low health literacy.

Generally, patients considered the majority (77%) of the aggregated outcome data (encompassing both clinical and patient-reported data) as crucial to support treatment decision-making. When evaluating individual outcomes, it was evident that lung and prostate cancer patients rated the majority of outcomes, either clinical or patient-reported, as important, while IBD patients tended to prioritize patient-reported outcomes, such as fatigue and pain, over clinical outcomes (see Fig. 2).

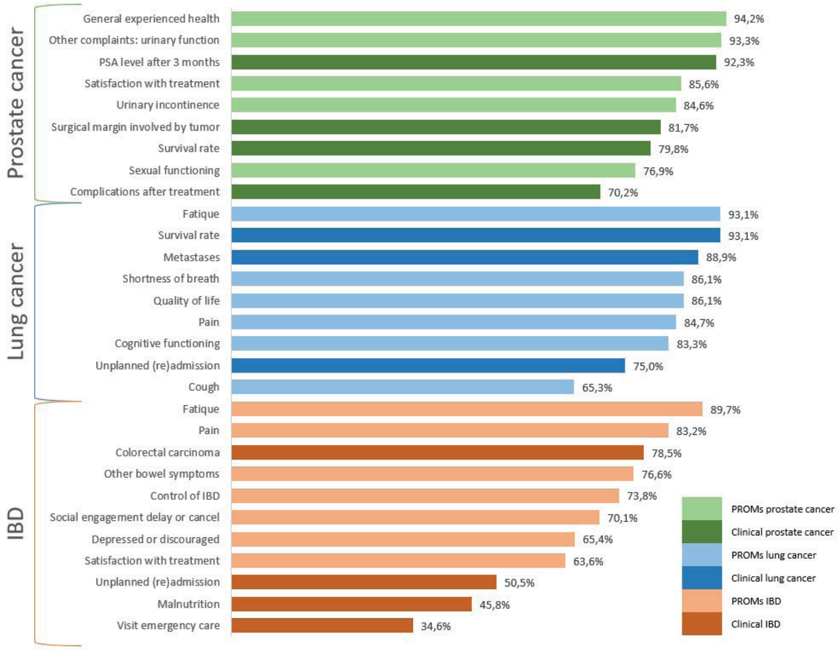


Figure 2| Percentage of patients who rated outcome as important or very important for three health conditions. PROMs= patient reported outcome measure. IBD= inflammatory bowel disease

Prostate and lung cancer patients expressed the need to discuss most of the patient-reported and clinical aggregated outcomes with their HCP (69% and 76% respectively) instead of solely receiving information about it. In contrast, IBD patients indicated that they wanted to discuss only 42% of all patient-reported and clinical outcomes with their HCPs, and for 40% of all outcomes they were content with merely being informed about them. The majority of outcomes that IBD patients wanted to discuss with their HCP were patient-reported (see Fig. 3).

In the open text fields, patients expressed the desire for more insight into alternative treatment options, future perspectives, the treatment process, personalized treatment outcome expectations, outcomes from different hospitals, and relevant research and trials. Lastly, patients wished to discuss the impact of their disease or treatment on their daily lives, including the impact on relationships and work.

An integrated overview of both the qualitative and quantitative results can be found in Appendix C.

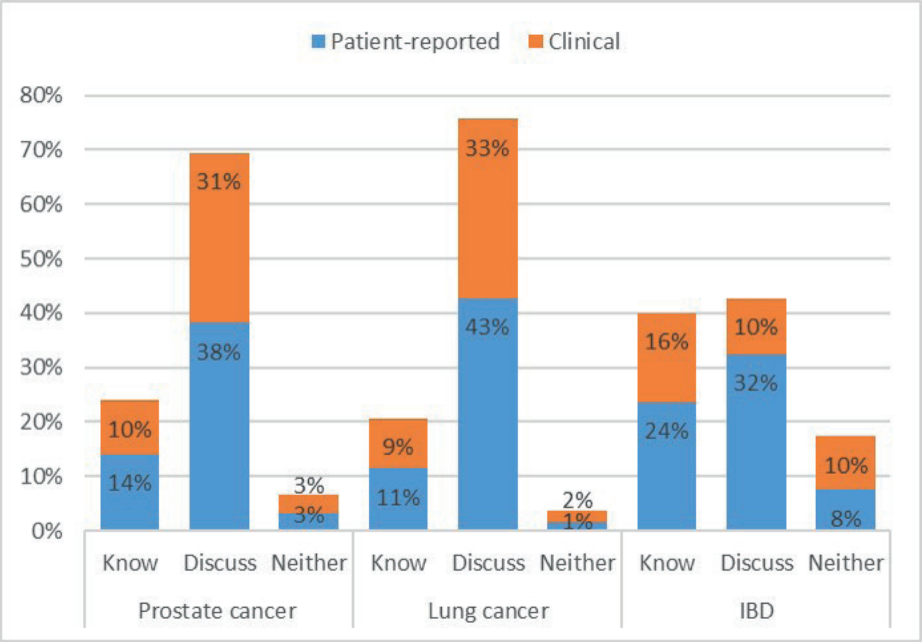


Figure 3| Percentages of total of outcomes that patients want to know or also discuss with their healthcare professional for three health conditions. IBD= inflammatory bowel disease

4.4 Discussion and conclusion

This study underscores the importance of using outcome data in patient consultations from both the HCPs' and patients' perspectives. HCPs emphasized that aggregated outcome data are preliminarily used for quality improvement. Furthermore, since HCPs are used to discussing individual clinical outcomes with their patients, they mainly talked about patient-reported outcome data during the interviews. Patients rated the majority of aggregated outcomes, both patient-reported and clinical, as important. Nevertheless, the information needs regarding these aggregated outcomes varied among the three patient groups. Meanwhile, the HCPs experienced several barriers to using outcome data in patient consultations, such as low response rates of PROMs. They proposed actions to address these barriers, e.g., assigning staff to assist patients in completing PROMs. Last, both HCPs and patients expressed several ambitions and desires to increase the use of outcome data in consultations in the future.

According to HCPs, several barriers limit the use of outcome data in patient consultations. First, discussing outcome data is believed to be time-consuming, which can be linked to the often mentioned barrier in the literature that SDM is time-consuming [25–27]. However, some HCPs in this study believed that discussing outcome data might actually save time in patient consultations, as it ensures that patients are better prepared for their consultation and that HCPs are more up-to-date on the patient's health status. A recent systematic literature review concluded that SDM, in general, does not necessarily prolong consultations, supporting our finding [28]. Moreover, some HCPs highlighted the challenge of translating outcome data into treatment decisions, indicating a potential misinterpretation of HCPs regarding the use of outcome data, since outcome data cannot be directly translated into treatment decisions, but can be used to support conversations hereon [17]. Last, several HCPs expressed a preference for traditional conversations with their patients over using decision aids. This barrier might show another possible misinterpretation among HCPs, as decision aids are not developed to replace the traditional conversation with the patient, but rather to facilitate more structured and coherent consultations. This allows HCPs to engage in more essential conversations with their patients [29].

According to the HCPs, several actions could be undertaken to enhance the use of outcome data in patient consultations and to address the aforementioned barriers. First, the HCPs suggested that staff is needed to increase PROM response rates. However, we believe the issue lies not in staff shortages but in the improper integration of PROMs into the workflow. This leads to HCPs forgetting to discuss PROMs, which in turn leads to patients lacking an incentive to complete them. A systematic review pointed out that this 'design-phase' of PROMs is often overlooked [30]. Furthermore, HCPs stressed the importance of training them on the use of outcome data in clinical practice, which is a recurring recommendation [31–33]. Therefore, widespread training of HCPs in the use of outcome data in patient consultations is imperative. Last, HCPs pointed out the need to have more insight into key decision moments (i.e., important decisions in the patient pathway, such as choosing between surgery or conservative treatment [34]) to recognize when to use outcome data in their consultations. Developing care pathways can aid in identifying these key decision moments [35]. Several of these actions are already undertaken in pending initiatives such as the SHOUT-study [17], indicating that these actions should shift from the research setting to implementation in daily practice. Altogether, these practical suggestions could contribute to improved quality and use of outcome data. Moreover, raising awareness among both patients and HCPs about the importance of using outcome data in patient consultations is essential.

Last, differences in information needs were observed among patients with different health conditions. IBD patients tended to assign lower overall importance to aggregated outcomes compared to lung and prostate cancer patients, possibly because IBD patients often receive personalized treatment [36], rendering aggregated outcome data less informative for them. These patients might benefit from patient-like-me models, where they can gain insight into expected treatment outcomes based on data from patients with similar characteristics and treatments [37,38]. Moreover, prostate and lung cancer patients wanted to discuss the majority of the outcomes with their HCP, while IBD patients indicated that being informed on the outcome data is sufficient. These differences might be explained by the fact that patients with chronic health conditions, such as IBD, are more familiar with self-management than cancer patients [39], and are therefore more used to interpreting and applying information independently. All in all, the different information needs among patients suggest that patients may benefit the most from tailored and personalized outcome information.

There are a few important limitations of this study that deserve consideration. First, our aim was to interview both HCPs and patients, but HCPs were hesitant to recruit patients for the interviews due to their own lack of familiarity with the use of outcome data in consultations. Consequently, our results provide insight into which outcomes are important to patients, but not into how to use and when to discuss them in clinical practice from the patient's perspective. Research has shown that the method of communicating outcome information significantly influences how patients perceive it [40,41]. Second, we aimed to include an inclusive sample of patients, including patients with low health literacy, by simplifying questionnaire language and distributing the questionnaire via different forums and platforms, but only seven patients with low health literacy responded to our questionnaire. However, we believe that having low health literacy does not affect the type of outcomes that is important to these patients, but rather influences the method of how these outcomes should be used, discussed, or provided to them. Future studies should therefore include a larger number of patients with low health literacy potentially by employing more inclusive research methods, such as graphical presentations instead of text-based questionnaires. Third, our study exclusively focused on the use of outcome data in Dutch hospitals. While our findings offer important insights, we recognize that the current state of outcome data collection and usage varies greatly between countries. For instance, a review on the implementation of PROMs in Western countries revealed a significant concentration of relevant articles from the Netherlands, suggesting that the Netherlands might be ahead in the collection of PROM data compared to other countries [42]. Last, we found some differences in perspectives among different types of HCPs, including specializations and roles. We believe that it is a significant topic that warrants further in-depth investigation in future studies.

Conclusion

This study shows that aggregated outcome data are often not used in patient consultations, despite the importance patients and HCPs attach to having insight into this type of data during consultations. Furthermore, the information needs of patients concerning outcome data differs between different health conditions. Currently, HCPs encounter several barriers to using outcome data in patient consultations and propose multiple actions to address these barriers.

Practice Implications

Practical steps to enhance the use of outcome data in consultations include training of HCPs on the use of outcome data, and the integration of PROMs into the workflow to ensure that HCPs consistently discuss them, which in turn would result in an incentive for patients to complete them. Moreover, HCPs should receive better guidance on how to use outcome data in patient consultations, as several misconceptions about their usage were identified. Overall, the results of this study can be used to improve the use of the different types of outcome data in patient consultations. Future studies should focus on patients’ perspectives regarding outcome data selection, collection, presentation, and usage in consultations.

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Appendix A: Interview guide

1. Which outcome data do you have at your disposal?
2. Do you use outcome data within your specialism? Why or why not?

If yes:

3. Which outcome indicators are being collected for health condition X? How is this data collected? Are these indicators the same as the indicators of the scorecard?
4. How do you use this information?
5. Do you use it in a consult with a patient? What do you want to achieve by using outcome data in a consult?
6. What is your experience with working with aggregated or individual outcome data?
7. In what way do you think that the use of outcome data influences your consults? Can you explain why?
8. What are you ambitions for the use of outcome data in a consult? What do you need to accomplish these ambitions?
9. How do you expect that outcome data will be used in the future?

If no:

3. Would you like to make more use of outcome data in your consults?
4. Which outcomes would you like to discuss with your patients? Are the outcome indicators of the scorecard useable at the individual patient level?
5. Are there outcome indicators that you like to discuss with your patient, but that are not part of the scorecard?
6. How would you like to use outcome data? At which moments would you like to discuss outcome data with your patients?
7. What would you need to accomplish this?
8. How do you expect that outcome data will be used in the future?

Appendix B: Patient questionnaires

Each questionnaire started with the 3-HL questions (Chew et al., 2008).

Answer options uneven questions:

0. I do not know
1. Very unimportant
2. Unimportant
3. Neutral
4. Important
5. Very important

Answer options even questions:

0. Neither
1. Only know
2. Also discuss with healthcare professional

Prostate cancer:

1. The number of patients that are incontinent after treatment. Do you find this important information?
2. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
3. The sexual functioning of men after treatment. Do you find this important information?
4. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
5. The general experienced health after treatment. Do you find this important information?
6. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
7. The number of patients that experience complications, for example an infected wound, after treatment. Do you find this important information?
8. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
9. The number of patients that experience complications, such as problems with going to the toilet, after treatment. Do you find this important information?

10. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
11. The overall satisfaction with the treatment. Do you find this important information?
12. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
13. The average PSA level 3 months after treatment. Do you find this important information?
14. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
15. The percentage of surgical margins involved by the tumor after treatment. Do you find this important information?
16. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
17. The number of patients that deceased within 5 years after treatment. Do you find this important information?
18. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
19. Is there any other outcome information that you would like to know or discuss with your healthcare professionals. If yes, what would you like to know or discuss?

Inflammatory Bowel Disease:

1. The average experienced fatigue. Do you find this important information?
2. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
3. The average experienced pain. Do you find this important information?
4. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
5. The overall satisfaction with the treatment. Do you find this important information?
6. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
7. Missing (social) activities due to IBD-symptoms. Do you find this important information?
8. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?

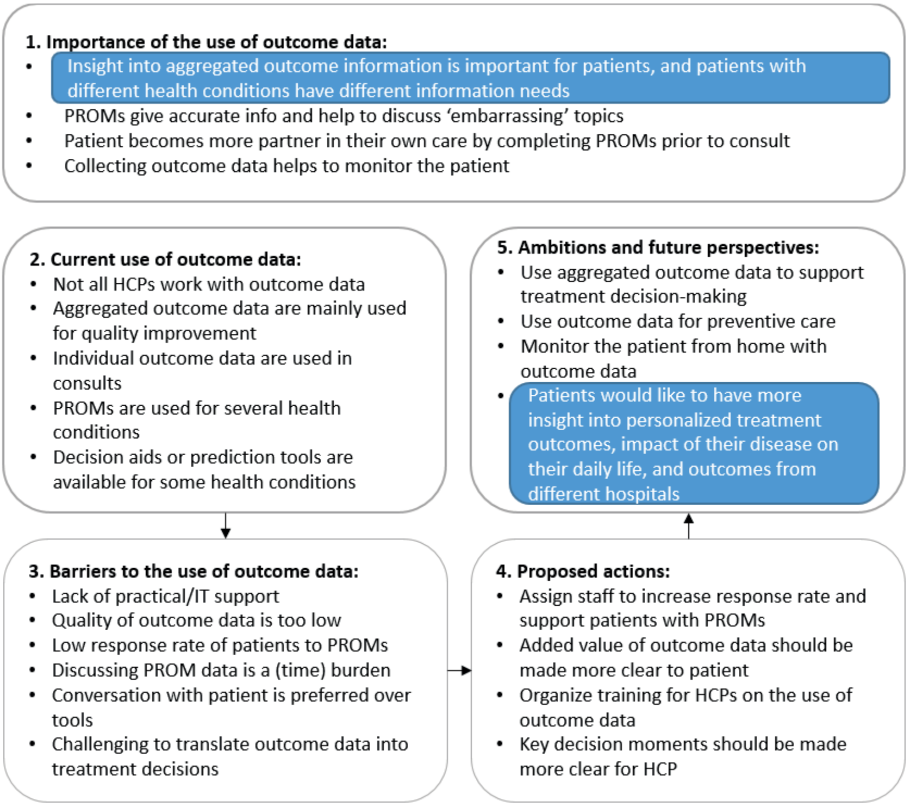
9. The number of patients that experience symptoms, such as having a feeling of needing to go to the toilet or gas production. Do you find this important information?
10. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
11. The average experienced control over IBD symptoms. Do you find this important information?
12. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
13. The percentage unplanned (re)admissions. Do you find this important information?
14. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
15. The percentage of IBD patients that suffer from colorectal cancer. Do you find this important information?
16. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
17. The number of patients that are sick due to malnutrition. Do you find this important information?
18. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
19. The number of patients that suffer from depression. Do you find this important information?
20. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
21. Is there any other outcome information that you would like to know or discuss with your healthcare professionals. If yes, what would you like to know or discuss?

Lung cancer:

1. The average experienced quality of life. Do you find this important information?
2. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
3. The average experienced pain. Do you find this important information?
4. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
5. The average experienced fatigue. Do you find this important information?
6. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?

7. The number of lung cancer patients that experience shortness of breath. Do you find this important information?
8. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
9. The number of times that patients have to cough. Do you find this important information?
10. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
11. The percentage unplanned admissions after treatment. Do you find this important information?
12. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
13. The average cognitive functioning. Do you find this important information?
14. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
15. The percentage of unexpected metastases after treatment. Do you find this important information?
16. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
17. The average survival rate after treatment. Do you find this important information?
18. Do you only want to know this information, or do you also want to discuss this information with your healthcare professional?
19. Is there any other outcome information that you would like to know or discuss with your healthcare professionals. If yes, what would you like to know or discuss?

Appendix C



1. Importance of the use of outcome data:
- Insight into aggregated outcome information is important for patients, and patients with different health conditions have different information needs
- PROMs give accurate info and help to discuss 'embarrassing' topics
- Patient becomes more partner in their own care by completing PROMs prior to consult
- Collecting outcome data helps to monitor the patient

2. Current use of outcome data:
- Not all HCPs work with outcome data
- Aggregated outcome data are mainly used for quality improvement
- Individual outcome data are used in consults
- PROMs are used for several health conditions
- Decision aids or prediction tools are available for some health conditions

3. Barriers to the use of outcome data:
- Lack of practical/IT support
- Quality of outcome data is too low
- Low response rate of patients to PROMs
- Discussing PROM data is a (time) burden
- Conversation with patient is preferred over tools
- Challenging to translate outcome data into treatment decisions

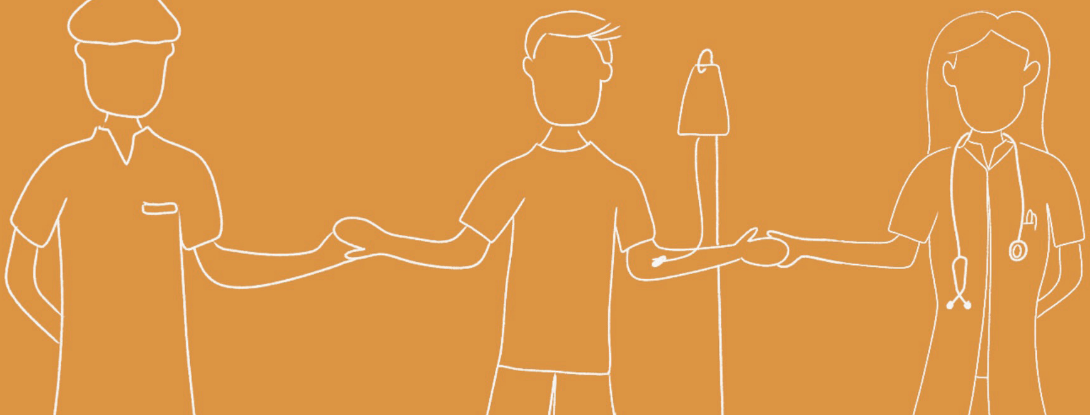
4. Proposed actions:
- Assign staff to increase response rate and support patients with PROMs
- Added value of outcome data should be made more clear to patient
- Organize training for HCPs on the use of outcome data
- Key decision moments should be made more clear for HCP

5. Ambitions and future perspectives:
- Use aggregated outcome data to support treatment decision-making
- Use outcome data for preventive care
- Monitor the patient from home with outcome data
- Patients would like to have more insight into personalized treatment outcomes, impact of their disease on their daily life, and outcomes from different hospitals

Figure 1| Themes identified from interviews with healthcare professionals (n=11) and patient questionnaires (n=283) on the use of outcome data. HCP= healthcare professional, PROM= patient reported outcome measure, SDM= shared decision-making. Text in blue boxes are results from the patient questionnaires integrated into the identified themes from the interviews with HCPs.

Part 3

Good practices for collective patient participation



Methodological Explanation: Action Research

Introduction

This pre-read serves as introduction to Chapter 5. In Chapter 5, the process of action research is used to develop a practical guide for patient participation in Value Improvement (VI) teams. The complexity of action research cannot be fully addressed within the chapter itself. Therefore, the methodology of action research is explained here, and enriched with examples of the action study of Chapter 5 (i.e. the INCLUDE study), as presented in the textboxes and figures.

Action research focuses, as the name suggest, on both action in daily practice and scientific research, and differs from traditional research. Action research has a participatory and context-specific approach, which increases the sustainability of change, as interventions in action research are tailored to the context (e.g. resources or cultural and social norms) and participants are empowered to implement the change themselves [1]. Action research is therefore highly suitable for complex or 'wicked' problems, e.g. when there is not a straight-forward solution to the problem or when social and cultural aspects play a role [2,3] (Textbox 1).

Textbox 1: The 'wicked' problem of patient participation in VI teams
Action research is highly suitable to address the 'wicked problem' of patient participation. Patient participation in VI teams is a 'wicked problem' due to several factors: first, there is no single best approach to patient participation, as effective approaches depend on the specific context and goals of the VI team, and the characteristics of the patient group. Second, the beliefs of VI team members regarding the value and priority of patient participation vary. Third, many VI team members lack the knowledge and skills to improve patient participation. Fourth, also patients sometimes miss the specific and knowledge and skills to be able to participate meaningfully. Last, the time and resources available for patient participation differ significantly between hospitals. All in all, these factors collectively contribute to the complexity and challenges in achieving meaningful patient participation in VI teams.

Core principles of action research

Action research is based on five core principles [4]:

1. Action research has three goals: implement change in daily practice, enhance knowledge and skills of participants, and generate scientific knowledge (Textbox 2). This differs from traditional research, that primarily focusses on generating knowledge [5].
2. Action research is highly participatory. Stakeholders of the project are involved as co-researchers and active participants in all steps of action research. Moreover, the action researcher participates as an equal and active team member, rather than remaining a passive observer. This approach differs from a traditional scientific approach, where research participants are 'subjects' and the researcher tries to be an objective observer in the process [6]. With this participatory approach, action research aims to increase the sustainability of interventions and empower stakeholders to change.
3. Action research follows a cyclical process. The steps of the cyclical process originate from Kurt Lewin, who described that action research constitutes of cycles of planning, action and reflection [7]. More recent reports identify four phases in action research [8]:
    a. Orientation phase: identify the stakeholders, knowledge gap, and change and learning needs.
    b. Planning phase: co-create the action plan and identify goals (Fig. 1).
    c. Action phase: implement actions/improvements (Fig. 2).
    d. Evaluation phase: evaluate actions and processes (Fig. 3).
4. Action research is context-specific. This means that the intervention and implementation approach is tailored to the context, ensuring that they are sustainable in daily-practice [1]. While this aligns to some extent with traditional research (primarily qualitative research), it differs from the mainstream in health sciences, which aims to produce generalizable findings [9].
5. Lastly, action research requires a high level of reflexivity, as the researcher is part of the change process but also in charge of the evaluation of the change. Action researchers should therefore continuously reflect on their role within the process and interventions (Fig. 4). Coghlan and Brannick compare this dual role of an action researcher to an actor who is also the director of the movie they play in [6].

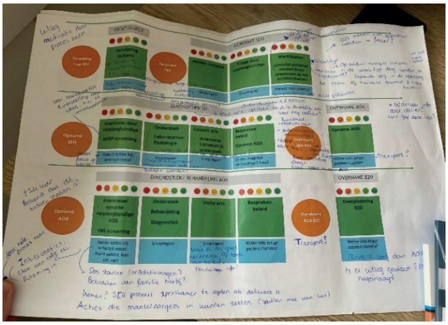


Figure 1| Co-creation of a patient interview guide with the vulnerable elderly team

Figure 2| Patient participation activity

TERUGBLIK SPIEGELGESPREK RALP PATIËNTEN

Op donderdag 1 februari is er vanuit de zorgketen prostaatkanker en het expertteam prostaat van de F2 een spiegelgesprek georganiseerd. Hierbij waren acht patiënten aanwezig die een RALP-operatie hebben ondergaan. Zorgverleners vanuit de keten waren als toehoorders aanwezig.

Het doel van dit spiegelgesprek was om inzichten te verzamelen die kunnen bijdragen aan het verbeteren van de kwaliteit van zorg voor prostaatkankerpatiënten. Het was een hele waardevolle avond.

De belangrijkste verbeterpunten zijn hieronder weergegeven. Hiermee gaan we aan de slag.

- Voorlichting: uitleg van de katheterpleister klopte niet
- Voorlichting: uitleg blijven geven over gang van zaken, proces en wie je wanneer ziet
- Informatie bieden: keuze voor dagbehandeling of nachtje blijven
- Voorstellen: tijdens voorstellen prettig om te weten wie je bent + functie
- Onrust afdeling: zaal op verpleegafdeling is soms erg druk en er wordt hard gepraat in de nacht
- PA gesprek: optie om te vragen wat de patiënt zelf wil?: fysiek/TC/beeldbellen

Figure 3| Snippet from prostate cancer VI team newsletter on the results of the patient participation activity

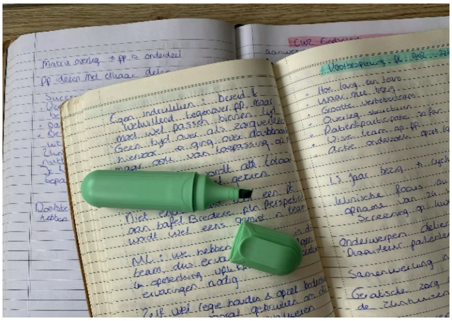


Figure 4| Reflection notes of the action researcher in a research journal

Textbox 2: The three goals of action research in the INCLUDE study

1. **Implement change in practice:** We aimed to implement at least one patient participation activity in each intervention VI team. These activities were selected based on the goals of the VI team, and therefore context-specific. These goals ranged from very specific goals, i.e. 'obtain the perspective of breast cancer patients on the time from diagnosis until treatment', to very broad goals, i.e. 'gain insight into the patient experiences with prostate cancer care'.
2. **Enhance knowledge and skills of participants:** We aimed to increase the knowledge and skills of VI team members by actively involving them in planning, implementing, and evaluating the patient participation activity. Furthermore, we aimed to train the VI team members in patient participation by presenting scientific knowledge on patient participation as well as lessons learned from other intervention teams during the action research meetings.
3. **Generate (scientific) knowledge:** We aimed to gain insight into how to implement/improve patient participation in VI teams and to share our lessons learned through a practical guide and a scientific paper.

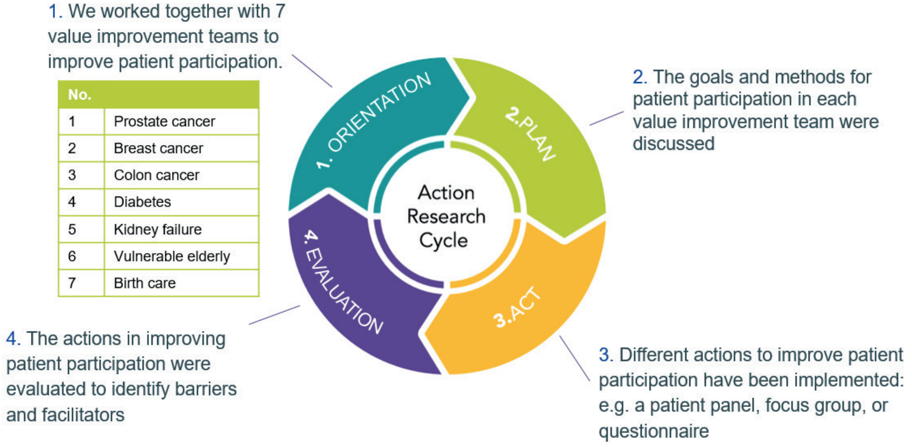
The roots of action research

The roots of action research lie in critical theory and constructivism. Critical theory is a philosophical paradigm that analyses societal structures, power, and inequalities. The goal of critical theory is to use knowledge for social change. Critical theory strives to make people aware of the societal structures they participate in and to emancipate them to change. Constructivism (closely related to the interpretive paradigm) argues that knowledge and reality are constructed through social interactions and personal experiences, where research topics are studied from the perspectives of individuals in their real-life contexts [10]. Action research is grounded in these two paradigms, as action research studies are conducted in real-life contexts and participants are encouraged to gain insight into their context and to get into action. The focus of the early action research studies was mainly on social themes, such as power imbalances and inequalities, and are often referred to as participatory action research [11]. Later on, a new field for action research emerged which addresses practical problems instead of focussing on societal themes [12]. Both types of action research aim to change the situation via a highly participatory approach.

The cyclical steps of action research

One of the five core principles of action research is the cyclical process. This cycle includes four steps, i.e. orientation, planning, action, and evaluation [8] (Fig. 5). During the orientation phase, the problem is identified and clarified. This includes a stakeholder analysis, knowledge assessment, and gaining insight into the change and learning objectives. Also, time must be taken to build relations with the participants, as the quality of the relationship between the participants and the researcher is an important determinant for the success of action research [6]. In the planning phase, the focus lies on the practical aspects of implementing the intervention. Co-creation is central in this phase, as this facilitates stakeholders to be empowered in taking action. It is also important to determine the goals of the action research project, in order to facilitate evaluation later on. The next step is to get into action and to execute the steps from the action plan with the participants. Finally, during the evaluation phase, the actions and the action research process are evaluated. Different quantitative or qualitative data collection methodologies can be used to this end [13]. The outcomes of the evaluations are discussed and reflected on with the participants, which forms the foundation for the next cycle [3]. This is different to traditional research, where the data is normally analysed and reflected on after all data collection has finished [14].

While these steps might seem to be very distinct steps on paper, this is often not the case in practice. Within action research, several cycles might be occurring simultaneously or sometimes steps are skipped or taken back. Following the cycles too strictly could undermine the flexibility and emerging nature that characterizes action research [14].



1. We worked together with 7 value improvement teams to improve patient participation.

No.	
1	Prostate cancer
2	Breast cancer
3	Colon cancer
4	Diabetes
5	Kidney failure
6	Vulnerable elderly
7	Birth care

2. The goals and methods for patient participation in each value improvement team were discussed

3. Different actions to improve patient participation have been implemented: e.g. a patient panel, focus group, or questionnaire

4. The actions in improving patient participation were evaluated to identify barriers and facilitators

Figure 5| The cyclical steps in the INCLUDE study

Challenges of action research

Action research brings some challenges compared to traditional research. One of the challenges in action research is to find a balance between drafting a good and clear action plan, while maintaining flexibility for the cyclical and emergent design [14]. Secondly, the success of the action research is dependent on the social relations between the action researcher and the participants, which adds a subjective factor to the research process [6]. Thirdly, action research is resource-intensive, since co-creation often takes more time than a top-down approach for selecting interventions. Additionally, a large amount of, mostly qualitative, data is collected within action research, which requires thorough analysis that can be time-consuming [3]. Lastly, the context-specific nature of action research makes it challenging to transfer the findings to other contexts. However, a rigorous action research process can yield valid scientific knowledge that, despite its context-specificity, remains applicable and valuable in broader contexts [15]. Textbox 3 provides some examples of the action research challenges we experienced in the INCLUDE study.

Textbox 3: Challenges in the INCLUDE study

Within the INCLUDE study, we encountered several challenges in applying the action research approach. One such challenge was the varying social relationships between the action researcher and the participating VI teams. In some teams, the action researcher was fully integrated and treated as an equal team member, whereas in others, she was only partially included in team meetings. To foster strong connections, the action researcher actively worked on building relationships by attending meetings in person whenever possible. Another challenge was analysing the vast amount of data collected throughout the study, which made a double-coding approach unfeasible. Regardless, as the action researcher was the only person fully immersed in the data, a second coder would have added limited value. To enhance the validity of our findings, we regularly discussed emerging themes with various stakeholders.

Conclusion

In conclusion, action research is a challenging but rewarding research method for addressing complex problems in daily practice. This approach therefore appeared to be highly suitable for improving patient participation in VI teams, since this is a complex, context-dependent challenge. The success of improving patient participation depends on the team's unique context, including its resources, culture, and beliefs. Within the INCLUDE study, we empowered VI team members to actively work on improving patient participation, which increased their knowledge and skills for future participation activities. Lastly, the INCLUDE study resulted in knowledge on how to improve patient participation in VI teams that can be used by other multidisciplinary teams that work on value-based healthcare.

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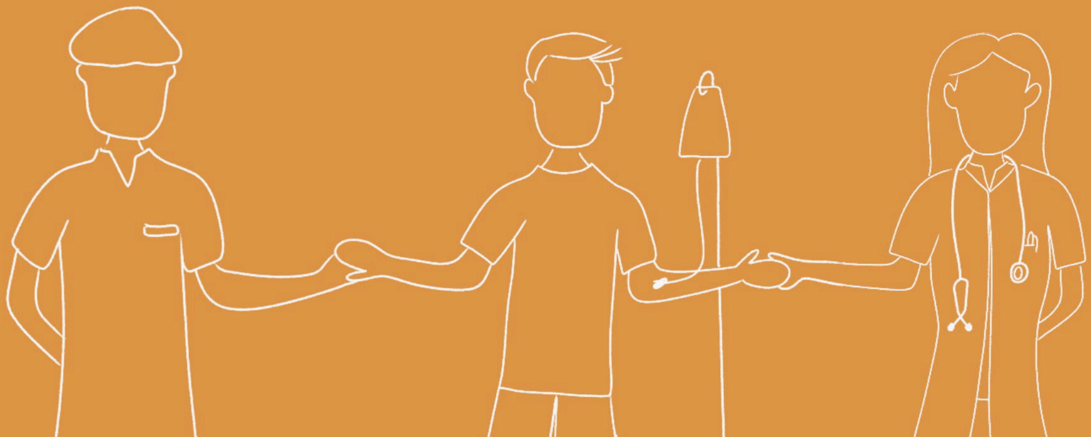


Chapter 5

Development of a practical guide for patient participation in value-based healthcare: an action research study

H.J. Westerink, C.F. van Uden-Kraan, M.M. Garvelink, D. Sprengers, B.J. Hartman, P.J. van der Wees, and P.B. van der Nat, (on behalf of the Santeon Patient Participation Study Group*)

The members of the Santeon Patient Participation Study Group are:
Ilse Arendz, Martini Hospital, Groningen, the Netherlands
Sander Koeter, Canisius Wilhelmina Hospital, Nijmegen, the Netherlands
Myrthe Koops, St. Antonius Hospital, Utrecht/Nieuwegein, the Netherlands
Reinier Groenewoud, OLVG, Amsterdam, the Netherlands
Joke van der Linden, Maasstad Hospital, Rotterdam, the Netherlands
Eino van Duyn, Medisch Spectrum Twente, Enschede, the Netherlands
Anne de Bruijn, Catharina Hospital, Eindhoven, the Netherlands

Under review

Abstract

Background: To deliver Value Based Health Care (VBHC), hospitals are transitioning to an organization centred around medical conditions. To this end, hospitals have set up multidisciplinary project teams that work on improving value of care for specific medical conditions. The patients' perspective in these teams is crucial to identify patient relevant outcomes and improvement initiatives. However, patient participation in VBHC initiatives remains limited. Therefore, we aimed to improve patient participation within multidisciplinary project teams and to develop a practical guide for patient participation using action research.

Methods: This study was conducted in seven Dutch hospitals from March 2023 to November 2024. Seven multidisciplinary project teams were selected to participate in the cyclical action research steps. These included the following patient groups: prostate cancer, vulnerable elderly, breast cancer, diabetes, maternity care, colorectal cancer, and chronic kidney disease. Qualitative observations and minutes of meetings with the intervention teams were collected and thematically analysed. The Public and Patient Engagement Evaluation Tool (PPEET) was completed by multiple members of the intervention (n=7) and control teams (n=94) at three time points (T1=6 months, T2=12 months, T3=end of study) and analysed descriptively. Qualitative and quantitative data were triangulated to create an overview of lessons learned in improving patient participation.

Results: Patient participation goals varied across teams, leading to diverse actions, such as establishing a diabetes patient panel and distributing questionnaires to patients with colorectal cancer. PPEET results show that 71% of intervention team members reported that patient participation had an impact on the team's outcomes compared to 44% in control teams (T3). Furthermore, 80% of the intervention team members initially wanted training in patient participation (T1) which dropped to 29% at T3. Overall, 22 lessons in improving patient participation in multidisciplinary project teams were identified and compiled into a practical guide.

Conclusions: The action research process improved the process and impact of patient participation in the intervention teams. Furthermore, the results indicate that the action research process enhanced the team members' knowledge and skills on patient participation. The practical guide developed in this study can be used to support implementation of patient participation in VBHC.

5.1 Introduction

Value-Based Health Care (VBHC) strives to improve the healthcare system by shifting the focus from volume of care to value of care, i.e. patient relevant outcomes relative to the costs for achieving these outcomes [1]. Since its introduction in 2006, VBHC has gained significant attention worldwide and many healthcare providers have been working on the implementation of various elements of VBHC, such as measuring and improving outcomes and reorganising care around medical conditions [2,3]. In the original literature on VBHC, Integrated Practice Units (IPUs) were suggested as the alternative organizational structure for a condition-based organization [4–6]. Over the years, three other types of Condition-Based Units (CBUs) besides IPUs have been identified: the multidisciplinary project team, the matrix organization, and the independent treatment centre [7].

Within these CBUs, active participation of patients is crucial, as patient participation facilitates the integration of their perspectives into identifying patients' values, relevant outcomes, and important improvement initiatives [8–11]. However, the role of patients within VBHC is often overlooked and value improvement initiatives are rarely coproduced with patients [12]. Healthcare professionals working on VBHC stipulate the importance of patient participation, but they indicate to struggle with finding the correct method of involving patients and experience diverse challenges in implementing patient participation [10,11,13,14]. For example, involving patients requires time investments, while the available time of health care professionals for VBHC activities is often overall limited [8,14]. Furthermore, involving patients as equal team members in value improvement initiatives is often a new way of collaboration for both patients and healthcare professionals, resulting in ambiguity regarding their roles and relationships [11,14]. Lastly, the uptake of patient participation is strongly dependent on the culture within the organization [14,15].

Patient participation has been studied in various contexts, especially within research settings [15–17]. However, the context of VBHC differs fundamentally from these settings, so it is essential to study patient participation within this context specifically. VBHC is not a temporary project or a broad hospital- or department-wide quality improvement initiative; rather, it is a continuous, structural effort to improve the value of care centred around patient groups. This distinct nature of VBHC calls for a better understanding of how to overcome barriers to patient participation and how to improve it within CBUs. As multidisciplinary project teams around medical conditions are most commonly used by hospitals [2,8,13]; this study mainly focused on improving patient participation within such teams. To this end, an action research approach was used, with the ultimate goal to develop a practical guide for patient participation based on the lessons learned.

5.2 Methods

Study design

This study was designed according to the principles of action research, which allowed us to design and implement interventions that are contextually appropriate and co-created with multidisciplinary project team members to increase the sustainability of the interventions [18]. Action research focuses on three key goals: 1. Implementing changes in daily practice, 2. Enhancing the knowledge and skills of participants, and 3. Generate scientific insights. This study is described according to the Standards for Reporting Qualitative Research (SRQR) [19] and the Qualitative Action Research Checklist (QuARC) [20].

Study context and participants

This study was conducted in the seven Dutch Santeon hospitals from March 2023 to November 2024. These hospitals are actively working on VBHC through the program 'Better Together'. The program includes 15 medical conditions, and each hospital has multidisciplinary project teams for these medical conditions (with some exceptions if they do not provide care for that condition). These multidisciplinary project teams are referred to as Value Improvement (VI) teams within Santeon. Some multidisciplinary project teams within Santeon have evolved into a matrix organization archetype, where the VI teams became part of the hierarchical structure and gained formal responsibility for value of care of a specific patient group. A VI team consists of a project leader/coordinator, a data analyst, relevant healthcare professionals (e.g. medical specialists, nurses, dieticians, and physiotherapists), and management (e.g. head of department). The VI teams are continuously improving care by following the steps of the VI cycle, which are: comparing outcome data, identifying an improvement initiative, implementing improvements, and evaluating the improvements by restarting the cycle. More details on the Santeon approach of VBHC can be found in the article of Engels et al [21].

We selected seven VI teams to participate in the action research study (in this article referred to as the intervention teams). Each Santeon hospital participated with one VI team in the action research process, ensuring maximum spread and impact of the action research. Moreover, a maximum variability sample was selected based on current level of patient participation and type of health condition. The project leaders participated in the selection process to include teams that were motivated to improve patient participation. VI teams from the following patient groups were included in the study: prostate cancer, vulnerable elderly, breast cancer, diabetes, maternity care, colorectal cancer, and chronic kidney disease. The prostate cancer VI team can be categorized as a matrix organization archetype, all other are multidisciplinary project teams [7].

Action research process

The action research process is a cyclical process, and consists of four phases: orientation, planning, action, and evaluation [22]. The action researcher joined the seven intervention teams and followed the cyclical steps with each VI team. A first version of the practical guide was drafted before the start of the study, based on insights of an evaluation study of patient participation in the VI teams and a literature review [14,15]. The orientation phase included asking the teams to discuss their current level of patient participation and their goals for patient participation. During the planning phase, the researcher and the team selected a method for patient participation that matched with the goals of the VI team. The researcher encouraged the team to explore methods that would lead to continuous coproduction with patients instead of setting up a one-time consultation with patients. However, the team always remained in charge to choose their preferred method for patient participation. The teams then moved towards the action phase, in which the selected methods for patient participation were implemented. Halfway through the action research process, an updated version of the practical guide was shared with the intervention teams, which helped to determine next steps that teams could take to improve patient participation. In the evaluation phase, the different patient participation activities were qualitatively and quantitatively evaluated with the teams. After this phase, the cycle was restarted. All steps were either executed during already planned VI team meetings or additional meetings with several members of the team. These meetings took place in-person, by videoconferencing, or by phone.

Data collection

Both qualitative data and quantitative data were collected. Qualitative data collection included:

1. Minutes of what was discussed regarding patient participation during each meeting with intervention VI team members. The minutes were made by the researcher and included both the planned VI team meetings as well as the additional meetings.

2. Structured observations of the planned VI team meetings by the researcher and project leader. A structured observation tool was used during planned VI team meetings. The observation tool was developed based on insights from a previous study [14] and included ten themes (e.g. 'equal treatment of patient as team member') which the observer was asked to describe after the VI team meeting. This observation tool was further developed during this study; items were added (n=11) based on themes that emerged during the action research process (Appendix A). The new observation tool was member-checked with several VI team members. After each VI team meeting, the researcher filled out the observation tool and requested the project leader to fill out the tool as well.
3. Reflections from the researcher on her role in the action research process and observations that were not part of the structured observation tool were collected in a research journal.

All qualitative data were compiled in the research journal to create an overview of all minutes, observations, and reflections. The meetings with the VI teams were recorded.

Quantitative data collection included responses to the Public and Patient Engagement Evaluation Tool (PPEET) questionnaire (participant and project questionnaire) [23]. The PPEET was sent out every six months to three or four members (medical specialist, nurse, support staff, and if applicable the patient team member) of the seven intervention teams and all other VI teams (n=94) to act as the control group. The Dutch version of the PPEET was used in this study [24]. The PPEET was sent to the participants three times in total. T1 was after six months from the start of the study, T2 was after one year and T3 was in the final month of the action research process. The PPEET includes questions on design, process, influence, and impact of patient participation. The response choices for the PPEET comprise a 5-point Likert-type scale, ranging from 1 (indicating total disagreement) to 5 (indicating total agreement). Respondents who indicated in the questionnaire that no method for patient participation was used by their VI team did not receive any follow-up questions regarding the process, influence or impact of patient participation.

See Figure 1 for a timeline of the study including the different moments of data collection.

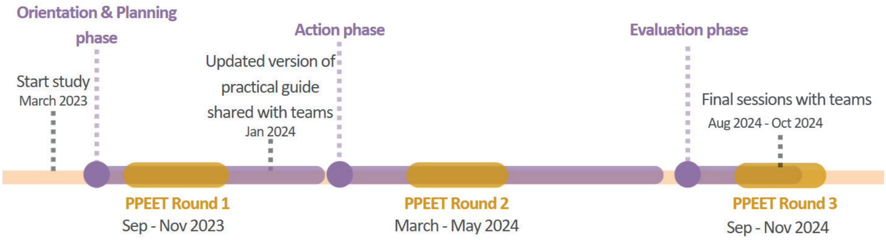


Figure 1| Timeline of action research study. Abbreviation: PPEET= public and patient engagement evaluation tool

Data-analysis

The qualitative data were coded and thematically analysed using theoretical thematic analysis [25]. The coding and analysis were conducted by the first author (HW), who was also the primary action researcher. A single coder approach was used for qualitative data analysis because the action researcher was deeply immersed in the study, making her the most familiar with the context and nuances of the data.

The PPEET results were compared between the intervention and control teams over time using descriptive statistics. Since patients received different questions than the other VI team members (the participant questionnaire, module B), their results were analysed separately.

The qualitative results were triangulated with the quantitative results by mapping them to the five types of barriers and facilitators to collective patient participation (identified in a literature review [15] and tailored to the context) to develop an overview of lessons learned in improving patient participation in VI teams. The five categories are: 'ensure that preconditions for patient participation are met', 'develop a strategy for patient participation', 'prepare patients and VI team members for patient participation', 'put patient participation into action', and 'evaluate patient participation'. Illustrative quotes for the results were identified from the recordings of the meetings with the intervention teams. Figure 2 provides a schematic overview of data collection and analysis.

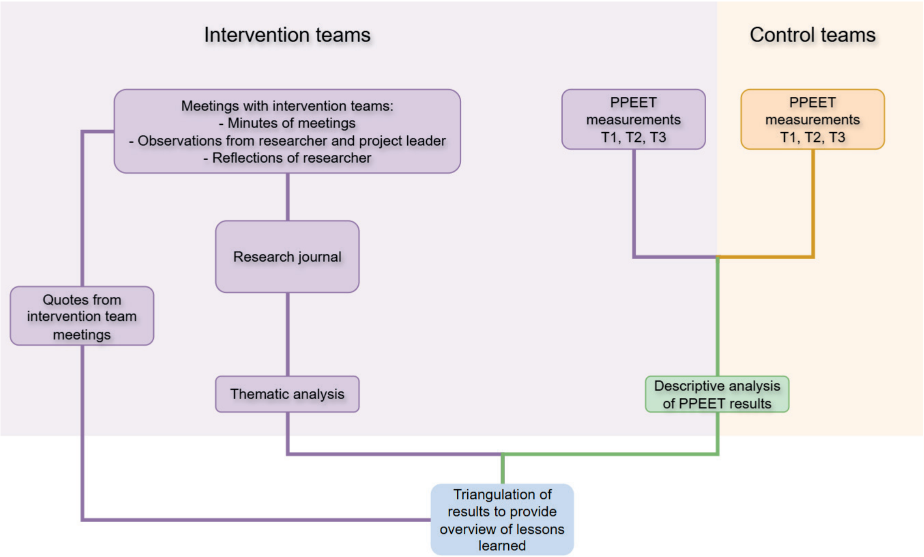


Figure 2| Data sources and analysis. Abbreviation: PPEET = Public and Patient Engagement Evaluation Tool

Trustworthiness

To ensure credibility of the findings, both qualitative as well as quantitative data were collected. Moreover, the action researcher discussed arising themes during quarterly meetings with members of the core research team (CU, MG, PW, PN) including two patient advisors (DS, BH), with the intervention team members, and with the project leaders from the different hospitals. Transferability of the results was enhanced by including seven different VI teams from different hospitals and with different types of patient populations in the study. This diversity in teams increased the applicability of the lessons learned in improving patient participation in a wide range of VI teams. The researcher received training on action research prior to this study and has multiple years of experience in qualitative research. To support confirmability and dependability of the results, the action researcher continuously reflected on her role and influence throughout the action research study and kept track of all reflections in a research journal.

Patient and public involvement

The core research team consistently included two patient advisors, with four different patient advisors being involved over the course of the project. The patient advisors were involved in the study design, research team meetings, and writing of this article.

Ethics approval and consent to participate

Ethical approval for this study was waived by the Medical Ethical Commission Utrecht (W23.022). Participants gave written or verbal informed consent to use and store their data for research.

5.3 Results

Notes were made during 106 meetings with the VI teams as part of the action research study. On average, each team had 15 meetings (ranging from 5-75 minutes) where 1-12 VI team members attended the meetings. The observation tool was completed 42 times. Furthermore, throughout the action research process, 302 PPEET questionnaires were completed by intervention and control team members. Based on triangulation of the qualitative and quantitative data, a total of 22 lessons in improving patient participation were identified.

Action research process results (qualitative)

Table 1 provides an overview of the goals, actions, and the main qualitative findings from the action research process in each of the intervention VI teams.

The goals for patient participation differed between the intervention teams. Some teams had a very specific goal, e.g. gaining insight into the patient's experience during the time from diagnosis to initial treatment, whereas other teams had more broad goals, such as gaining insight into improvement potential from the patient's perspective. Consistent with the goals, different actions in patient participation were implemented during the action phase. For example, a patient panel was set up for patients with diabetes, a focus group was conducted with patients with breast cancer, and questionnaires were sent to patients with colorectal cancer.

PPEET results (quantitative)

The PPEET was completed by 108 VI team members at T1, 99 at T2, and 95 at T3. See Table 2 for an overview of the respondents' characteristics. Figure 3 highlights the results of four PPEET questions, all other PPEET results can be found in Appendix B.

At the end of the action research process (T3), 93% of intervention team members indicated to have clear objectives for patient participation, compared to 38% of the control team members (Fig. 3A). Additionally, at T3, 86% of the intervention team members responded to have taken sufficient time for planning and implementing patient participation, compared to 31% of the other VI team members (Fig. 3B).

However, both the intervention and control VI teams indicated to have insufficient resources for patient participation, which only improved slightly throughout the study period (29% indicated to have sufficient resources at T2, 38% at T3). Notably, at T1, the intervention team members were less satisfied with the level of patient participation in their team (13% was satisfied) compared to the control teams, but the intervention team members' satisfaction increased to 71% after the actions were undertaken to improve patient participation (T3). Of the control VI team members, around 30% was satisfied with the level of patient participation within their team, which minimally changed throughout the study period (Fig. 3C). Moreover, at T1, 80% of the intervention team members responded that they wanted training in patient participation, but at T3 only 29% still wanted to be trained. Lastly, 71% of the intervention team members indicated that patient participation had an influence on the VI team's outcome compared to 44% of the control VI team members (Fig. 3D).

Results from the patients' PPEET questionnaires showed that overall, patients reported to have received sufficient information to participate within the VI team (83-100% (totally) agrees) and that they felt that they can represent the patient's perspective in the VI team (67-100% (totally) agrees).

Table 1| Overview of the action research process in the intervention value improvement teams

Team	Goal(s) for patient participation + rationale	Actions
Maternity care	To regularly consult patients requiring minimal time investments and find a suitable method to this end.	• An online patient panel was set up to consult patients using questionnaires. • The first questionnaire was sent out in April 2024, and the second in September 2024.
Prostate cancer	To evaluate the benefit of their improvement initiatives for patients, and therefore they wanted to consult patients on ongoing improvement initiatives but also gather new ideas from patients.	• The team started with organizing a focus group with healthcare professionals as audience to gather new improvement ideas from the patient's perspective. • A mini focus group was conducted with patients to discuss improvement potential in information provision. • A nurse was appointed to be responsible for patient participation.

Findings
• Only a small number of patients signed up for the panel, the team therefore indicated that someone in the team should be responsible for improving the panel and the number of participants. • Only one staff member (outside of the VI[1] team) had access to the panel and could send out the questionnaires, but when she left for another job no one took over her role, which challenged the continuation of the panel. • Some VI team members expressed that the ownership for patient participation was not clearly allocated to a specific working group or department in their organization, which resulted in discussion on who should be responsible for coordinating the online panel.
• The VI team was positive about the mini focus group, as it was a less time-intensive method compared to the large focus group that they organized earlier, but they also expressed their concerns regarding the representativeness of this group. • The VI team members indicated that they learned more about setting up patient participation and possible methods to gain insight into the patients' perspectives, but that they lack support from the organization in setting up patient participation. • The VI team members indicated that they used to be mainly focused on the individual level of patient participation (where patients are only involved in their personal care) and that the action research process increased their awareness on the positive contribution of patient participation at the level of value improvement.

Table 1| Continued

Team	Goal(s) for patient participation + rationale	Actions
Diabetes	To regularly consult patients without inviting patients to the VI team, since this team did not have separate VI team meetings but integrated into regular team meetings.	• A patient panel was set up. • The first two meetings were held in February and September 2024.
Vulnerable elderly	To gain more insight into the experiences of patients that suffered from a delirium, as the VI team was working on multiple improvements in the care for that patient group	• An interview with a patient and their relative was conducted.
Colorectal cancer	To identify improvement potential from the patient's perspective.	• Questionnaires were sent to patients at different moments in the patient journey.
Chronic kidney disease	This team already had three patients as VI team members and had the goal to improve the collaboration with these patient representatives in order to benefit more from their participation.	• A list of patient-relevant topics was created. Each VI meeting, a topic of this list could be discussed with the team. • A questionnaire on the first topic of the list (i.e. treatment decision-making process) was send to a larger group of patients • An evaluation meeting with the patients was conducted.

Findings
• According to the VI team members, a patient panel, i.e. a focus group that meets structurally, was best fitting to their goals and the characteristics of the patient group, since diabetes patients are chronically ill and would be able to participate in a patient panel for a longer period of time, allowing them to grow into their role. • Patients indicated in an evaluation survey after the first panel meeting that the goal for the panel was not clear to them. By sending the agenda, including the goal, prior to the upcoming panel meeting, this became clearer to patients. • Multiple dates for new panel meetings were scheduled ahead to continue this method of patient participation. The members of the VI team indicated that having these meetings already planned helped them to continue with the patient panel. • The team indicated that they experienced a low priority for patient participation at the management level and missed official requirements for patient participation, which ultimately limited available resources for patient participation.
• The team indicated that they had previously tried to interview a patient, but that limited useful insights were retrieved from that interview. In order to hopefully retrieve more useful input from these interviews, they started with determining detailed questions for the patients. • Based on these questions, the Marketing & Communication (M&C) department was going to conduct the interviews, since they had more experience with this and were responsible for support in patient participation. However, due to staff turnover and shortages, they were unable to provide this support. The team therefore decided to conduct the interviews themselves, but this had led to a delay of six months. • The VI team members indicated that their knowledge about the specific patient group they interviewed and a good preparation for the interviews resulted in rich data, which M&C would possibly not acquire, as they miss knowledge on the patient group. • The team members indicated that they wanted to continue with the interviews, but that they lack the time to do it themselves, so it would be interesting for them to learn from the input of patients in other Santeon hospitals who have more resources for patient participation.
• The team was unsure if patients already received a questionnaire on their experiences with care and tried to find out which patient participation methods were already used for their patient group. After asking multiple staff members within and outside of the VI team, they found that no one could answer this question. They decided to continue with their idea to send out a questionnaire. • After multiple weeks, only a limited number of patients responded to the questionnaire, so the VI team decided to focus on another method for patient participation. However, little steps were taken in setting up the next patient participation activity, since the VI team only met once every three months and a limited number of team members was actively involved in setting up patient participation.
• The team indicated that they work with a very strict agenda for the VI team meetings, which resulted in having limited room to address input from patient team members that falls outside of the scope of their predetermined agenda. Therefore, they wanted to create room on the agenda for such topics and drafted a list with the patient team members of topics that they deemed relevant to discuss in the VI team. • During the evaluation meeting, the patients indicated that they were unsure of the expectations of the VI team regarding their role. • Several improvements were made based on the evaluation meeting: appointing someone responsible for patient participation within the VI team, appointing a contact person for the patient representatives, aligning the expectations of the patients and VI team members regarding their roles, and setting up pre-meetings with the patient representatives to help them prepare for the VI team meetings. • The medical leader pointed out that involving patients as team members took some time to get used to for both the patients and the VI team members, but that he was satisfied with how they were working together at the end of the action research process.

Table 1| Continued

Team	Goal(s) for patient participation + rationale	Actions
Breast cancer	To gain insights into the patients' experiences related to a specific improvement initiative they were working on (reducing the time from diagnosis to treatment).	- A focus group with patients was conducted.

1= VI: Value Improvement

Table 2| Questionnaire respondents

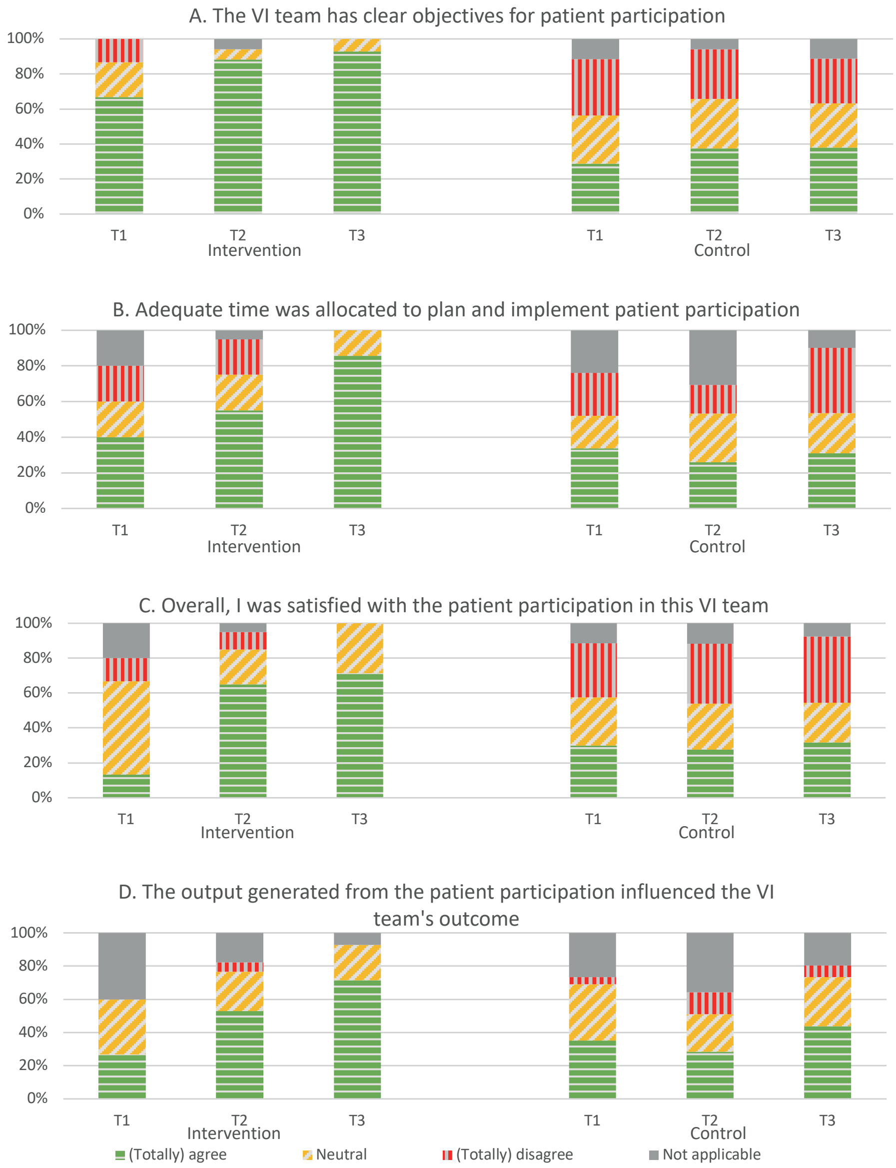
Round	T1 (6 months after start)	T2 (12 months after start)	T3 (final month)
Total (n=)	108	99	95
Intervention team respondents (n=)	17	21	14
Role (n, %)			
Patient (representative)	6 (6%)	3 (3%)	2 (2%)
Nurse / Nurse specialist	29 (27%)	34 (34%)	24 (25%)
Medical specialist	20 (19%)	25 (25%)	21 (22%)
Data-analyst	5 (5%)	1 (1%)	2 (2%)
Project leader	27 (25%)	20 (20%)	35 (37%)
Other, e.g. head of department	21 (19%)	16 (16%)	11 (12%)
VI[1] team (n, %)			
Breast cancer	10 (9%)	7 (7%)	7 (7%)
Prostate cancer	9 (8%)	12 (12%)	8 (8%)
Lung cancer	8 (7%)	7 (7%)	4 (4%)
Colon cancer	5 (5%)	3 (3%)	5 (5%)
Hip osteoarthritis	2 (2%)	5 (5%)	2 (2%)
Knee osteoarthritis	4 (4%)	2 (2%)	2 (2%)
Stroke	14 (13%)	7 (7%)	4 (4%)
Chronic kidney disease	8 (7%)	8 (8%)	8 (8%)
Maternity care	6 (6%)	8 (8%)	9 (10%)
Rheumatoid arthritis	3 (3%)	1 (1%)	4 (4%)

Findings
• The focus group was nearly postponed, because it required too much time to recruit a sufficient number of patients. • During the focus group, the patients mentioned several improvement ideas, but these were not directly related to the topic that the VI team wanted to gain insight on. The medical leader mentioned that the focus group was therefore not very useful for them as the patients provided input outside of the scope of the project. • The researcher indicated that it could be helpful to include patients both by gathering input from a group of patients as well as having them present in the VI team meetings, since now the prioritization of the input of patients was done without patients themselves, but not all team members were open to include patients as team members. • The main challenge that the medical and nurse leader experienced in continuing patient participation was due to difficulties with engaging other departments in the VI team, resulting in a lack of manpower to set up patient participation.

Table 2| Continued

Round	**T1 (6 months after start)**	**T2 (12 months after start)**	**T3 (final month)**
Inflammatory bowel disease	12 (11%)	8 (8%)	10 (11%)
Diabetes	8 (7%)	12 (12%)	14 (15%)
Hip fracture	11 (10%)	11 (11%)	10 (11%)
Vulnerable elderly	8 (7%)	4 (4%)	3 (3%)
Chronic obstructive pulmonary disease	N.A.2	4 (4%)	5 (5%)
Methods used for patient participation (n, %)			
Patient(s) as VI team member[3]	7 (7%)	3 (3%)	4 (4%)
Patient(s) as VI member and other method(s), e.g. focus group	33 (31%)	25 (25%)	32 (34%)
Other method(s), e.g. focus group	50 (46%)	55 (56%)	51 (54%)
None	18 (17%)	16 (16%)	8 (8%)

1: VI = value improvement. 2: This patient group was initiated by the Better Together program during the study period and therefore had no respondents in the first round of the questionnaire. 3: Patient respondents were not asked to indicate if other methods are used and are therefore counted in this category


A. The VI team has clear objectives for patient participation

B. Adequate time was allocated to plan and implement patient participation

C. Overall, I was satisfied with the patient participation in this VI team

D. The output generated from the patient participation influenced the VI team's outcome

Figure 3| Public and Patient Engagement Evaluation Tool (PPEET) results from intervention and control VI teams over time. T1= six months after start action research, T2= 12 months after start action research and T3= final month of action research

Practical guide for patient participation (triangulation of qualitative and quantitative results)

Based on qualitative findings of the intervention teams (minutes, observations, and reflections) and the PPEET results, 22 lessons were identified for improving patient participation. These lessons were grouped into five categories: 1. Ensure that preconditions for patient participation are met, 2. Develop a strategy for patient participation, 3. Prepare patients and VI team members for patient participation, 4. Put patient participation into action, and 5. Evaluate patient participation (Table 3). The numbers in the text below refer to the numbered lessons in Table 3.

Table 3| Lessons learned in improving patient participation in VI[1] teams based on qualitative data of the action research process and PPEET[2] results:

Category	Lessons learned in improving patient participation
1. Ensure that preconditions for patient participation are met	**Individual level:** 1.1 Perspectives of individual team members on impact/ importance/priority patient participation influenced willingness to improve patient participation. **Team level:** 1.2 A certain level of 'maturity' of VI team was needed to improve patient participation, e.g. structural team meetings, multidisciplinary character, enthusiastic team members to improve care. 1.3 Teams working with a very strict agenda had limited room for patient participation, as patient may provide input that falls outside of the scope of their predetermined agenda. 1.4 Having someone with assigned responsibility for patient participation at team level stimulated improvements in patient participation. **Organizational level:** 1.5 No (clear) support and resources for patient participation in the organization limited patient participation. 1.6 Unclear ownership for patient participation in the organization resulted in ambiguity regarding ongoing patient participation and responsibilities for patient participation. 1.7 Limited priority for patient participation at organizational level decreased resources for patient participation. 1.8 Having requirements for patient participation set by hospital or Santeon would stimulate teams to set up patient participation.

Table 3| Continued

Category	Lessons learned in improving patient participation
2. Develop a strategy for patient participation	2.1 Matching the method for patient participation with clear goals and patient characteristics improved usefulness of patient participation. 2.2 Having a fixed structure for patient participation (e.g. yearly focus groups) helped to continue patient participation. 2.3 Using elaborate (high effort) methods or approaches to organize patient participation limited patient participation. 2.4 A low effort patient participation method (e.g. a mini focus group) resulted in patient participation being more approachable. 2.5 Using a combination of different levels of participation would be valuable, since only consulting patients often had a limited impact.
3. Prepare patients and VI team members for patient participation	3.1 Limited knowledge on methods for patient participation hindered setting up patient participation. 3.2 VI team members wanted training in patient participation or experienced training by implementing patient participation. 3.3 VI team members experienced increased awareness for patient participation. 3.4 Patients experienced unclear goals for their participation.
4. Put patient participation into action	4.1 VI team members experienced limited available time to plan and implement patient participation. Meanwhile, VI team members indicated that taking sufficient time to plan patient participation resulted in more meaningful patient participation. 4.2 VI team members experienced a challenge in determining when something is an individual story or a collective problem. 4.3 Multiple VI teams treated patient participation as a separate agenda item instead of an integral aspect of VI, which limited the full potential for patient participation.
5. Evaluate patient participation	5.1 Evaluation of patient participation had impact on improving patient participation. 5.2 VI team members indicated the wish to share insights from patient participation between VI teams.

1= VI: Value Improvement, 2=PPEET: public and patient engagement evaluation tool

These five categories including the 22 lessons-learned, were used to refine the practical guide. For example, the initial version of the practical guide did not include recommendations related to the pre-conditions necessary for patient participation. The final practical guide is included in this thesis after this chapter.

1. Ensure that preconditions for patient participation are met

Several preconditions at different levels (i.e. individual, team, and organizational level) seemed to facilitate or limit patient participation in the VI teams during the study. At the individual level, the team members' perspectives on the importance, impact, and priority of patient participation influenced the willingness to improve patient participation and engagement in improving patient participation (1.1).

At the team level, a low level of maturity of the team, e.g. no structural team meetings, limited involvement of different types of healthcare professionals, or limited (sense of) responsibility for value of care for a specific patient group, seemed to hinder improving patient participation within these teams (1.2).

> *"I think that we're facing the problem that it is difficult to engage other departments in the VI team, so it's not necessarily for this project [=patient participation], but rather that, in general, some departments are a lot less involved than others. That's where the problem lies."* – Medical leader

Some teams worked with a very strict agenda and indicated that this left limited room to address input from patients that falls outside of the scope of their predetermined agenda (1.3). Furthermore, team members pointed out that having someone in the team responsible for patient participation stimulated setting up or improving patient participation (1.4).

> *"It all ultimately comes down to manpower. I really see the potential here [of patient participation] and it could become something very valuable, but there do needs to be someone that takes the lead"* – Head of department

At the organizational level, unclear responsibilities for support or no support in setting up patient participation was experienced as a barrier to improving patient participation (1.5). Quantitative results showed that both the intervention teams and control teams indicated to have insufficient resources.

> "*Everyone emphasizes the importance of patient participation, but we have no available resources, time, and money to set it up."* – Project leader

Meanwhile, a high independence of the VI team to plan and execute patient participation without help from outside the VI team seemed to enable the teams to make more progress in patient participation. Furthermore, VI team members expressed that they experienced ambiguity in who is responsible for patient participation in their organization, also leading in hesitation whether it was their responsibility to set it up (1.6).

> *"It [=patient participation] is allocated across so many places that ownership gets somewhat lost."* – Head of department

While patient participation was included as an important aspect in the vision and mission of all hospitals, a low level of priority at the management level was experienced by the VI team members, mainly because there were limited resources made available for patient participation (1.7). Lastly, some team members expressed the need for hospital-wide requirements for patient participation in VI teams to stimulate them to prioritize it in their team (1.8).

> *"We should agree on a strategy or requirements for patient participation in VI teams; otherwise, it will not be prioritized. This should be decided at the management level."* – Project leader

2. Develop a strategy for patient participation

Teams did not seem to base their method for patient participation on clear goals for what they want to achieve with it. Therefore, one of the steps that was undertaken in the action research was to create awareness of the importance of having clear goals for patient participation and select a method based on these goals (2.1). Quantitative results show that the action research process contributed to improved objectives and strategy for patient participation in the intervention teams. Furthermore, having a fixed structure for patient participation, integrated within the daily practice of VI teams (e.g. via annual plans) stimulated patient participation (2.2).

> *"What I like is that at a certain point I scheduled these moments [=patient panel meetings], and then they're just set, and you have to do it. Otherwise, you keep putting it [= patient participation] off every time."*
> – Nurse leader

Some teams seemed inclined to mainly use very elaborate patient participation methods, such as large focus groups, which were highly time-consuming. As a result, they were less likely to engage in patient participation overall (2.3). Therefore, multiple 'easy to use' methods for patient participation were introduced during the action research, such as mini patient panels or quick surveys, which were perceived as less time-intensive by the team members, making patient participation more feasible (2.4). Lastly, a combination of different levels of patient participation seemed to enhance the impact of patients (2.5). When patients were consulted separately and not actively involved in the team, the team had full decision-making authority over what they would do with the input, which often resulted in reduced impact of the patient participation.

3. Prepare patients and VI team members for patient participation

VI team members seemed to lack the knowledge on different patient participation methods, resulting in limited implementation of patient participation within their team (3.1). Some VI team members indicated a wish to be trained in patient participation, but it was also experienced that patient participation is something that you ‘learn by doing’ (3.2). This was underpinned by quantitative results, where the data showed a decrease in the wish to be trained in patient participation over the course of the action research process.

> *“It [=the action research project] helped to actively work on planning and implementing patient participation, and from there you come up with new ideas [for patient participation].”* – Project leader

The VI team members mentioned that their awareness on patient participation increased throughout the research and that they became more aware of the current limited involvement of patients (3.3). This awareness on the improvement potential in patient participation was also found in the quantitative data, where the intervention team members first indicated to be less satisfied with the patient participation in their team (13% was satisfied at T1), but this improved after actions were undertaken to improve patient participation (71% was satisfied at T3).

> *“Everything that gets attention grows, and we’ve certainly noticed that with patient participation.”* - Nurse

Patients experienced ambiguity regarding their role as team member or in the participation activity and expressed that it was helpful to discuss the expectations regarding their role with the VI team members (3.4).

> *“I think I now have a better understanding of the purpose of the value improvement team, and I've also realized that certain points, especially more practical ones, shouldn’t be discussed within the value improvement team but can be addressed elsewhere."* – Patient representative

4. Put patient participation into action

An experienced difficulty in the implementation of patient participation was the limited time available from VI team members (4.1). Meanwhile, quantitative data showed that the majority of intervention VI team members indicated to have taken sufficient time to implement patient participation at T3. When only a limited number of patients were involved in the patient participation activity, the team members indicated to experience challenges in determining whether the input was representative for a larger group of patients (4.2).

> *"I read the minutes of the patient panel and then can't help but think that many addressed topics are incidents, and I wonder if we should adjust our entire workflow based on that input?"* – Medical leader

Many VI teams seemed to treat patient participation as a separate agenda item instead of an integral aspect to all VI initiatives (4.3). This was found to limit patient participation, since this led to the view that patient participation was something extra on the agenda, which could be skipped, instead of an integral aspect of the improvement initiatives.

5. Evaluate patient participation

VI team members pointed out that the evaluation of patient participation enhanced patient participation, since this provided both VI team members and patients with insight into the added value of and potential improvements in patient participation (5.1). Several team members mentioned that sharing the results of these evaluations and the impact of patient participation among different VI teams was helpful to learn from other teams and the input of patients there, and they indicated that this knowledge sharing should continue after the action research study (5.2).

> *"I'm really curious about the knowledge sharing between different teams in patient participation and how we can learn from their lessons."*
> – Project leader

5.4 Discussion and conclusion

In this action research study, we aimed to improve patient participation within VI teams, increase the knowledge and skills of the intervention team members on patient participation, and develop a practical guide based on the lessons learned. Seven intervention VI teams participated in the action research cycle for 20 months.

Positive outcomes for all three of the action research goals (i.e. implement changes in daily practice, enhance the knowledge and skills of participants, and generate scientific insights) were achieved. Based on the action research process and PPEET results, 22 lessons in improving patient participation in VI teams were identified within five categories: 1. Ensure that preconditions for patient participation are met, 2. Develop a strategy for patient participation, 3. Prepare patients and VI team members for patient participation, 4. Put patient participation into action, and 5. Evaluate patient participation. These lessons, along with insights from previous studies [14,15] were combined into a practical guide.

Our study contributed to the first goal of action research—to drive change in daily practice—by organizing at least one patient participation activity within each intervention team. All teams had different goals for patient participation and therefore, different actions in patient participation were implemented. Some teams completed multiple action research cycles, indicating that multiple actions in patient participation were undertaken in these teams. In the end, the intervention team members indicated to be more satisfied with the level of patient participation in their VI team and experienced a bigger impact of patient participation compared to control teams, implying that the efforts to improve patient participation led to positive changes in daily practice.

Regarding the second goal of action research, this study enhanced the awareness on the actual improvement potential for patient participation and the knowledge and skills related to improving patient participation of the intervention team members. Patient participation is widely acknowledged as an essential aspect of improving care and a cornerstone of VBHC [11,26,27], but many VI team members seemed to be unaware of the limited current engagement with patients. Including patients as equal stakeholders in healthcare requires a cultural shift, redefining their role as equal partners across various levels in healthcare [28,29]. The action research approach was therefore highly suitable, as the participatory strategy supports cultural change by actively involving participants in altering their routines and behaviours [30,31]. Furthermore, the quantitative data suggests that intervention team members developed knowledge and skills on patient participation over the course of the action research, as their need for training in patient participation decreased in each PPEET measurement. Towards the end of the project, the action researcher gradually stepped back from practical tasks in patient participation, enabling team members to carry on with patient participation independently to enhance the sustainability of the outcomes.

Aligned with the last goal of action research, i.e. generate scientific insights, this study offers meaningful lessons and recommendations to improve patient participation in VI teams. The recommendations in the practical guide are divided into five categories. First, it is essential that preconditions, such as having a mature VI team and organizational support for patient participation, are met. Notably, the finding that a certain level of maturity of the VI team is necessary to improve patient participation within the team, is in contrast to the often expressed recommendation that patients should be involved from the start of a project [32]. We believe that this results in two options: either involve patient representatives from the start of the VI team to grow alongside the team as it develops, or when this has not been the case and the team is not (yet) fully functioning, involve patients in alternative ways and include patients as team members when the team is more mature. No standardized method exists to assess team maturity, but general team performance [33,34] or VBHC implementation questionnaires may help [35,36]. Moreover, although patient participation is widely acknowledged as essential in healthcare systems [37–39], there remains a gap between its stated importance and the resources allocated. Hospital management should prioritize allocating resources for patient participation, as these investments are anticipated to lead to more efficient, relevant, and practical improvement initiatives based on the patients' valuable input [40]. Secondly, VI teams should develop a strategy for patient participation. Based on the results of our action research study, a two-method approach to participation is recommended, where each team includes a patient representative in their team (providing a fixed structure for patient participation) combined with consulting patients on specific topics using tailored methods. This two-method approach to patient participation has also been recommended in other contexts [41,42]. Thirdly, patients and VI team members should be adequately prepared for patient participation by developing the necessary knowledge and skills. Training programs from other contexts, such as patient participation in research, could be adapted and used to this end [43]. At the same time, VI team members indicated that patient participation is best learned through practice. Therefore, the cyclical approach of action research is strongly recommended to stimulate this learning through practice [18]. Fourthly, patient participation should be included as an integral aspect of all improvement initiatives the team is working on, rather than being treated as a separate agenda item. This shift reflects the cultural change necessary to recognize patients as equal partners across all levels in healthcare, and such a transformation requires time [44]. Fifthly, the process and impact of patient participation should be evaluated regularly. During this study, we used the public and patient engagement evaluation tool, but other evaluation tools can be used to this end [23,45]. Overall, the identified barriers and facilitators align with often used implementation frameworks such as the Consolidated Framework for Implementation Research (CFIR) [46].

This study mainly focused on improving patient participation in multidisciplinary project teams, as these are the most prevalent condition-based organizational structure [2,13]. However, frontrunner hospitals in VBHC implementation seem to increasingly evolve their multidisciplinary project teams into a matrix organization archetype, including one of the participating VI teams in this study [21]. This type of CBU, with more formal responsibility for the value of care for specific patient groups [7], appears to have supported the implementation of patient participation in our study, as certain preconditions, such as clear ownership and team maturity, were already established. On the other hand, since the value improvement activities of the participating matrix organization were more integrated in everyday practice, it was difficult to identify a specific meeting where patient representatives could participate. Therefore, for each type of CBU, it is important to identify the appropriate setting where value improvement initiatives are discussed, and the recommendations from the guide should be adapted to fit that specific setting.

This action research study has some limitations. First, there is a potential selection bias in the intervention teams. Although the included teams had varying levels of patient participation at the outset, all teams were motivated to improve patient participation, which likely influenced the impact reached with the action research. However, this selection criterion was necessary, as one of the key requirements of action research is that the problem is recognized and experienced by people in the field. Moreover, PPEET data from the previous study on patient participation in the VI teams [14] show that there are no major differences in patient participation between the intervention and control teams before the start of the action research. Secondly, the quality of relationships between the action researcher and the VI team members varied across intervention teams. In some teams, the action researcher was fully integrated as a team member, while in others, she was only involved in discussions about patient participation, excluding her from broader team activities. Moreover, the participation of VI team members as co-researchers also differed between the teams, and mainly focused on identifying relevant lessons learned. Another limitation concerns possible respondent bias in the PPEET questionnaire, as it may be primarily completed by VI team members supportive of patient participation. However, the responses show that the respondents have experience with a wide range of participation methods (from no participation to patients as team members), implying that a diverse group of respondents completed the survey, not just those with substantial experience in patient participation. Lastly, the absence of a second coder for qualitative data analysis may have introduced subjectivity. Double coding was not feasible due to the large volume of data and limited time and resources, but more importantly, the action researcher was the only one that was deeply immersed in the data due to her active role in the action research process, which limited the added value of a double coder. To reduce subjectivity, emerging themes were regularly discussed with the core research team, the intervention teams and the project leaders, and findings were triangulated with quantitative data.

Conclusion

The action research process resulted in improved patient participation within the intervention teams, with greater impact compared to the control teams. Furthermore, the action research process enhanced the knowledge and skills of intervention team members on patient participation. Based on the lessons learned during the action research process, a practical guide for patient participation was developed which aims to support broader implementation of patient participation in VBHC. To our knowledge, this is the first study specifically aimed at improving patient participation in the context of VBHC, addressing the gap in guidance in implementing patient participation highlighted by multiple studies [8,11]. Future research should focus on the implementation of the practical guide and on the impact of patient participation on the value of care. The action research approach is highly recommended for the implementation and evaluation of this practical guide, as this not only makes changes in daily practice and generates new scientific insights, it also increases the participants knowledge and skills. Moreover, it fosters the cultural shift necessary for recognizing patients as equal stakeholders at all levels of healthcare. This will contribute to more meaningful and sustainable patient participation in VBHC initiatives, with the ultimate goal to improve value of care aligning with the patient’s needs and preferences.

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Appendix A: Observation tool patient participation in multidisciplinary team meetings

Included in version	Theme	Observation
1 & 2	Number of patients in meeting	
1 & 2	Level of involvement of patient team members in meeting	
1 & 2	Level of influence of patient team members	
1 & 2	Equality of patient team members, e.g. are they treated similar as all other team members, and do they have an equal role in the discussions?	
1 & 2	Representativity of patient team members	
1 & 2	Patient team members are at ease	
1 & 2	Other methods for patient participation that are used	
1 & 2	Team's perception on importance of patient participation	
1 & 2	Focus on patient perspective in discussions	
1 & 2	Time available for patient participation	
2	Organizational support for patient participation	
2	Previous experience of team members with patient participation	
2	Knowledge of team members on patient participation	
2	Level of patient participation in all improvement initiatives	
2	Team's perception on the role of patients (from collecting input to partnership)	
2	Is the patient participation structural or one-time?	
2	Scope of team	
2	Social interactions in team	
2	Level of involvement of team members in patient participation	
	Other observations:	

Appendix B: PPEET results

The entire PPEET dataset will be made available as appendix to the published article.

Practical guide for patient participation

For members of multidisciplinary project teams that are working on Value-Based Health Care

For whom?

This practical guide is developed for multidisciplinary teams that work on improving value of care for a specific patient group or care pathway. The recommendations are based on a literature review[1], the results of research on patient participation within multidisciplinary value improvement teams[2], and the action research study. Furthermore, several patient representatives contributed to the development of this guide.

Why a practical guide?

The perspectives of patients are crucial to improve care, as patients are best positioned to indicate which outcomes matter to them and where care could be improved. Patient participation provides insight into the perspectives of patients, and can occur on two different levels: the individual level (the patient is involved in their own care, such as with shared decision-making) and the collective level (the patient is involved in a project of which the outcomes have an impact on multiple patients). In practice, however, it can be challenging to engage patients actively and meaningfully in multidisciplinary (project) teams that work on improving care. Additionally, many teams lack a structured approach or strategy for patient participation. To support teams in setting up meaningful patient participation, we have developed a guide on patient participation.

The five steps for patient participation

This practical guide includes five steps. Each step comprises of several themes and a brief checklist on that theme. Appendix 1 contains the complete checklist.

1. Ensure that preconditions for patient participation are met

Ensure a team with the right maturity and culture for patient participation

Any team can get started with patient participation, but the “maturity” of a team affects patient participation within the team. By “maturity” is meant, for example, the extent to which the team meets structurally, has a multidisciplinary character, has and experiences responsibility for improving care for a particular patient group and understands the importance of patient participation. The more “mature” a teams is, the easier it is to implement structural and meaningful patient participation within the team.

The team chair plays a crucial role in the team's "maturity" and in driving patient participation. They can inspire the team, emphasize the importance of patient involvement, and draw on insights from other teams to shape patient participation within the team.

Checklist team:

☐ The team recognizes the importance of patient participation

☐ The team is open to suggestions for improvement from patients

Assign responsibility for patient participation within the team

It is important to designate someone responsible for implementing patient participation within the team. This person can ensure that the team considers how patients can be involved for relevant agenda items, and take charge of organizing patient participation activities. Furthermore, it is important to designate someone responsible for supporting the patient representatives in the team and to be their point of contact.

Checklist responsibility in team:

☐ Someone in the team is responsible for patient participation

☐ Someone in the team is responsible for supporting the patient representatives in the team

Assign responsibility and establish a clear policy for patient participation at the organizational level

Responsibility for patient participation should also be assigned at the organizational level and it should be clear where teams can turn to for support in patient participation. In addition to clarity in support for patient participation, clear policies regarding patient participation are needed. Without clear policies, there is confusion about the ways and places in which patients from a specific patient group are, or should be, involved. However, regardless of these organizational level preconditions, an individual team can always get started with patient participation in their team.

Checklist responsibility in organization:

☐ It is clear within the organization who is responsible for supporting patient participation

❒ There is a policy for patient participation within the organization

❒ Someone in the organization is responsible to further develop policies to improve patient participation

2. Develop a strategy for patient participation

Patient participation can best be approached using a two different roles for patients: involve patient representatives in the team itself, and consult larger groups of patients using a fitting method for the specific question.

Involve patient representatives as team members

Results from interviews and surveys show that having a patient representative in the team has a significant impact on the rest of the team and the improvement initiatives being undertaken. Patient representatives are patients who can rise above their personal experiences and represent the patient's voice during meetings. A patient representative does not speak for all patients but can indicate when it is important to address topics together with patients and when to gather input from a larger (diverse and representative) group of patients. By involving patient representatives in the team, issues can be raised that might otherwise be overlooked, and it can help to maintain focus on the patient perspective when needed. This patient representative can be recruited via your own healthcare organization, or via national patient organizations. Below are several key points for involving patient representatives in the team:

- Invite at least two patient representatives to your team. These two patient representatives can support and complement each other. Additionally, this ensures input from two (possibly different) perspectives, providing a better balance.
- During meetings, ensure that as little medical jargon as possible is used, as this can make it difficult for the patient representatives to follow the discussions.
- Discuss with the patient representatives whether they would appreciate having designated "speaking time" in each meeting. This gives patients the opportunity to raise issues that might otherwise not be discussed. You can also create a list of topics that are important to patients with the patient representatives and discuss one topic from this list in each team meeting.
- Agree with the patient representatives whether they would like to speak to someone from the team prior or after the team meeting for extra clarification or explanations on specific topics.

- Set a term for the participation of the patient representatives in the team. This creates a natural end to their involvement and allows you to seek input from other patients. It also sets clear expectations for the patient representatives. Keep in mind, however, that working with patient representatives can take some time from patient representatives and the team members to grow into these new roles and ways of working. Therefore, the term should not be too short.
- Discuss with the patient representatives whether they prefer to join the meeting online or in person.

Checklist patient representatives:
☐ Two patient representatives are included as team members

☐ The needs from the patient representatives to join the team meeting are discussed (e.g. speaking time or term for participation)

Use other methods for patient participation to gain insight into the perspectives of a group of patients

There will pop up questions that cannot be answered by the two patient representatives in the team. Additionally, the team may work on improvement initiatives where they feel the need to gain insight into the perspectives from a larger group of patients. In these cases, other methods for patient participation can be utilized, such as questionnaires, focus groups, or interviews.

When choosing the method for patient participation, it is important to first think about the goal you aim to achieve with the patient participation. Once the goal is defined, consider what 'type' of patient you need to involve to reach that goal (e.g., age, health literacy, gender). Based on the goal and the type of patient you want to engage, you can choose the patient participation method that is best fitting. Sometimes a less elaborate method, such as asking the question to a number of patients during the workday, is enough to answer your question. See Appendix 2 for a decision tree on which method for patient participation best suits your issue. The decision tree includes examples of common methods, but is not exhaustive. Finally, tailor your recruitment method to the target group (e.g., personal approach or email invitation).

Discuss with the patient representatives in your team in advance how they would like to be involved in a broader form of patient participation. For example, they can help design a questionnaire or co-chair a focus group.

Checklist gaining insight into the perspectives of a group of patients:

☐ Different methods for patient participation will be/have been used to gain insight into the perspectives of a group of patients

☐ The goal for patient participation is clear before selecting the method for patient participation

☐ The recruitment method fits with the patients' characteristics

Ensure appropriate recognition and compensation for patients

Patients should be rewarded for their participation in a team or a participation activity. This does not always have to be financial (a parking exit ticket is a minimum), but can also take other forms of appreciation, such as giving patients the opportunity to attend a symposium.

Checklist recognition and compensation:

☐ Appropriate recognition or compensation for patients has been agreed upon with patients

☐ Participating patients receive at least a parking exit ticket after participating in a team meeting or participation activity

3. Prepare patients and team members for patient participation

Train patients and team members in patient participation

A key aspect for meaningful patient participation is to provide training to both the patient representatives and the rest of the team members on patient participation. To this end, the participation game can be used[3]. In this game, team members work on designing patient participation based on a case study and discusses it using conversation cards (Appendix 3). This game helps the team think about the possibilities for patient participation, raises awareness about patient participation, and helps to make agreements to address it within the team. The participation game can also be used for step 2, i.e. creating an action plan for patient participation by taking a real-life improvement initiative as case.

Checklist training:

☐ The patient representatives have been trained in patient participation and received an explanation of the team (including its purpose, any jargon, etc.)

☐ The team members have sufficient knowledge / have been trained in patient participation

Ensure clarity in the goal of patient participation and the role of patient representatives

Make sure that both patients and other members of the team clearly understand the goal of patient participation and the role of patient representatives within the team. Discuss this together to align expectations.

Checklist clarity goal:

☐ The goals for patient participation has been coordinated with, and are clear to the patients and patient representatives

☐ The role for the patient representatives has been coordinated with, and is clear to them

4. Put patient participation into action

It is important not to treat patient participation as a separate agenda item but to view it as an integral part of the various improvement initiatives of the team. When gathering input from patients on how to improve care, it is also essential to take this input seriously and follow up on it. Sometimes, patients may raise entirely different points than expected. Ensure there is room to address these points, or explain to patients why certain suggestions won't be pursued (e.g., if they fall outside the influence of the team).

Checklist execution patient participation

☐ Patient participation is an integral part of the VI cycle

☐ There is room to address the points raised by patients or it has been communicated why not

5. Evaluate patient participation within the team

The team should continuously evaluate patient participation. Schedule this evaluation structurally (e.g. annually) on the team's agenda. For evaluating patient participation, you can use both a qualitative approach (conversations with patient representatives and team members; see Appendix 4 for a list of evaluation points) and a quantitative approach (a questionnaire on patient participation; such as the Public and Patient Engagement Evaluation Tool[4]). Additionally, it is valuable to discuss how other teams approach patient participation to learn from each other in this area as well.

Provide feedback to patients

Finally, it is important to continuously evaluate what has been done with the patient's input and to provide feedback to (participating) patients. For other team members, this is often more visible, as the improvement initiatives directly impact their work. Patients may not be aware of this without feedback.

Checklist evaluation:

❐ Patient participation is structurally evaluated with the team

❐ The insights from patient participation have been shared with other teams

❐ Patients have received feedback on what has been done with their input

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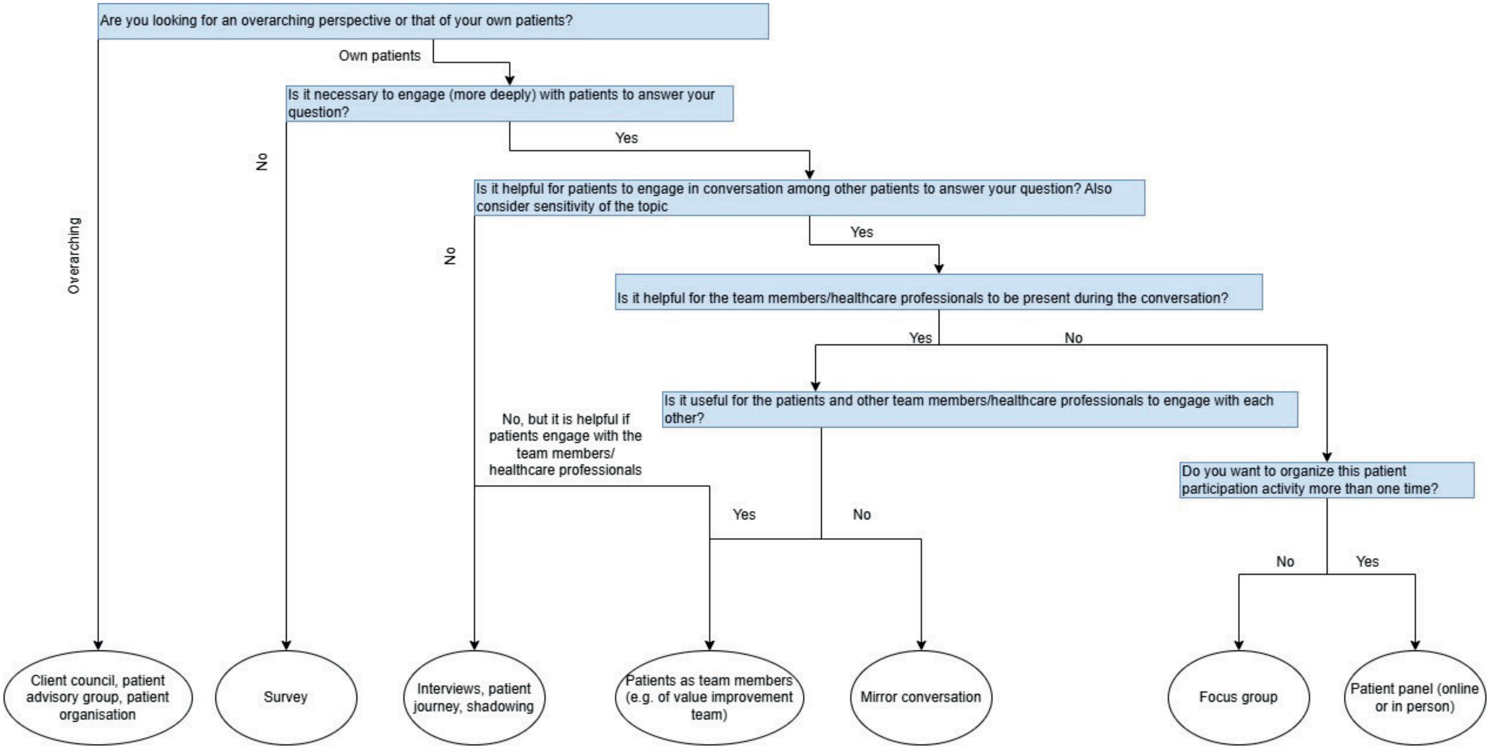
Appendix 1: Checklist for patient participation in a multidisciplinary project team

Step	Checklist
1. Preconditions for patient participation	☐ The team recognizes the importance of patient participation ☐ The team is open to suggestions for improvement from patients ☐ Someone in the team is responsible for patient participation ☐ Someone in the team is responsible for supporting the patient representatives in the team ☐ It is clear within the organization who is responsible for supporting patient participation ☐ There is a policy for patient participation within the organization ☐ Someone in the organization is responsible to further develop policies to improve patient participation
2. Strategy for patient participation	☐ Two patient representatives are included as team members ☐ The needs from the patient representatives to join the team meeting are discussed (e.g. speaking time or term for participation) ☐ Different methods for patient participation are used to gain insight into the perspectives of a group of patients ☐ The goal for patient participation was clear before selecting the method for patient participation ☐ The recruitment method fits with the patients' characteristics ☐ Appropriate recognition or compensation for patients has been agreed upon with patients ☐ Participating patients receive at least a parking exit ticket after participating in a team meeting or participation activity
3. Preparation for patient participation	☐ The patient representatives have been trained in patient participation and received an explanation of the team (including its purpose, any jargon, etc.) ☐ The team members have sufficient knowledge / have been trained in patient participation ☐ The goals for patient participation has been coordinated with, and are clear to patients and patient representatives ☐ The role for the patient representatives has been coordinated with, and is clear to them
4. Put patient participation into action	☐ Patient participation is an integral part of the VI cycle ☐ There is room to address the points raised by patients or it has been communicated why not
5. Evaluation of patient participation	☐ Patient participation has been evaluated with the team ☐ The insights from patient participation have been shared with other teams ☐ Patients have received feedback on what has been done with their input

Appendix 2: Decision tree patient participation



Appendix 3: Participation game

Game rules participation game

Purpose of the game:
Goal: To define the roles for patients during the different steps of the improvement cycle.

Start of the game:
Before the game can be played, you should fill in the rows of the 4rd column based on the details of the case that you want to use. We have included an example of a case study for the prostate cancer value improvement team below. In this case study, the team was working on shortening the length of stay after a prostatectomy.

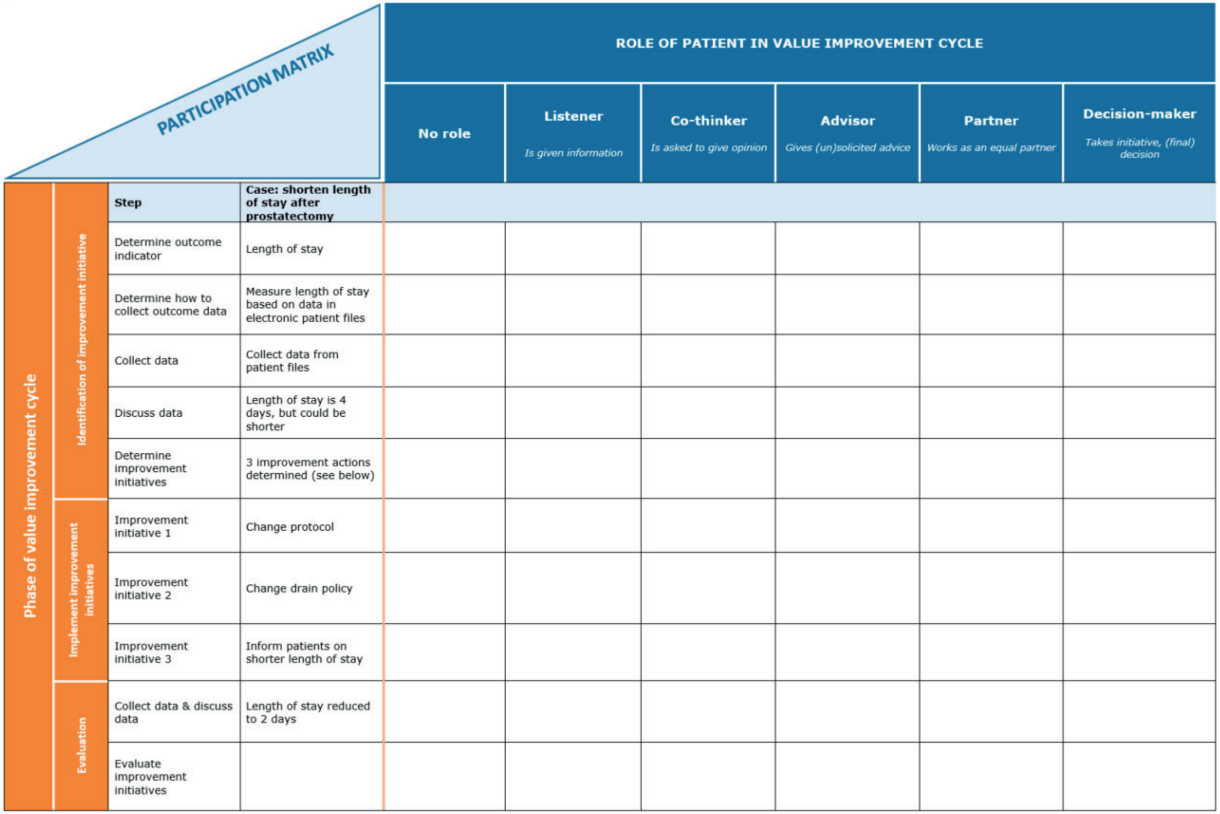
Game Mode:

1. Players are going to figure out for each step of the improvement cycle (row) how to involve patients (column). Players fill in the rows 1 by 1 by placing pawns in the columns with the different roles for patients. So player 1 starts by placing pawns at row 1 at which level he/she wants patients to participate here. There are 6 options, including the five roles for the patients, or no role at all.
2. It is possible to place multiple pawns in several squares per row. Meanwhile, the player explains why they placed a pawn there.
3. It is also possible to add things to the case column, e.g. if you would like to collect other (additional) data. You can write this down on the matrix.
4. After completing 1 row, the first discussion question is read by player 1 and answered. The team can discuss this answer.
5. After this, it is player 2's turn and repeats the same steps but for row 2. This continues until all rows are completed.

End of game:
The game ends when all rows have been completed and the last question has been addressed.

Discussion questions:

1. Who on your team is responsible for patient participation?
2. What is your goal here of involving patients?
3. How will you engage patients? What method of patient participation will you use?
4. What group or “type” of patients do you need to achieve your goal?
5. How will you handle differences of opinion between patients and health care providers?
6. How will you recruit patients to reach your goal?
7. How will you evaluate whether you have answered your question/goal here?
8. Looking at the 'lowest' 3 levels of patient participation (none, listener & co-conspirator), do you see any added value in increasing the role of the patient anywhere?
9. Looking at all the pawns set so far, what is a priority for you? What moments of patient participation are critical to the success of the improvement initiatives?
10. Snap a picture of your completed participation matrix. What (preconditions) do you need to make this a reality?



PARTICIPATION MATRIX

Phase of value improvement cycle		Step	Case: shorten length of stay after prostatectomy	ROLE OF PATIENT IN VALUE IMPROVEMENT CYCLE					
				No role	**Listener** *Is given information*	**Co-thinker** *Is asked to give opinion*	**Advisor** *Gives (un)solicited advice*	**Partner** *Works as an equal partner*	**Decision-maker** *Takes initiative, (final) decision*
Phase of value improvement cycle	Identification of improvement initiative	Determine outcome indicator	Length of stay						
		Determine how to collect outcome data	Measure length of stay based on data in electronic patient files						
		Collect data	Collect data from patient files						
		Discuss data	Length of stay is 4 days, but could be shorter						
		Determine improvement initiatives	3 improvement actions determined (see below)						
	Implement improvement initiatives	Improvement initiative 1	Change protocol						
		Improvement initiative 2	Change drain policy						
		Improvement initiative 3	Inform patients on shorter length of stay						
	Evaluation	Collect data & discuss data	Length of stay reduced to 2 days						
		Evaluate improvement initiatives							

Involvement Matrix adapted from Smits et al, 2020[5]

Appendix 4: Evaluation topics for patient participation

Was the patient's perspective included during the improvement cycle?

- When during the improvement cycle did we gather the patient perspective? Was this the right moment?
- At which specific moments was patient input crucial for decisions or changes?

Did we use appropriate methods for patient participation?

- What methods did we use to involve patients in the improvement team?
- Have these methods been effective in gathering valuable input from patients?

Did we involve the right groups of patients?

- Which specific groups of patients did we involve in the improvement team (or focus group, survey, etc.)?
- Was the recruitment approach suitable for this patient group?
- Are there other groups of patients we should have involved for a more complete perspective?

Is the role of patient representatives in the improvement team still clear, and is this role being fulfilled? (Optional: discuss this separately with the patient representatives)

- Are the responsibilities and expectations of the patient representatives within the team clearly defined?
- Have the patient representatives actively participated in discussions and decision-making?
- Are the patient representatives equal members of the improvement team?
- How do the patient representatives feel about their role and position on the team?

What did we do with the input from patients? What was the effect of patient participation?

- How did we integrate patient input into the improvement actions or decisions?
- What were the concrete outcomes or changes that directly resulted from patient participation?
- Did we also share this with the participating patients?

What have we learned, and what do we want to do differently next time?

Part 4

Using patient experiences to improve value of care

Chapter 6

The patient experience layer of the Metro Map to improve value of care: a bladder cancer case study

H.J. Westerink, M.M. Garvelink, C.F. van Uden-Kraan, A. van de Lindeloof, P.E.F. Stijns, N. Hanzen, B.J. Hartman, D. Sprengers, P.J. van der Wees, and P.B. van der Nat

Under review

Abstract

Background: Value-based healthcare focuses on continuous value improvement using outcome, process, and cost data. Currently, it lacks a structured approach to include patient experiences in value improvement. This case study explored how Metro Mapping can be used to improve value of care based on patient experiences. Metro Mapping includes the following layers: the care pathway (metro line), patient experiences, information, context, and companions.

Methods: This study has a case study design, in which the bladder cancer Metro Map was developed by the bladder cancer value improvement (VI) team at a top-clinical hospital in the Netherlands. To develop the patient experience layer, interviews were conducted with patients and their partners based on the metro line, followed by a questionnaire to validate the findings, and two sessions with the VI team and patient representatives to discuss the insights. Finally, a focus group was conducted to evaluate the usefulness of the patient experience layer to improve value of care. Data were thematically analysed.

Results: 20 interviews with patients and partners were conducted and a questionnaire was completed by 57 patients. In total, nine important topics for bladder cancer care improvement were identified and included in the patient experience layer, such as improving shared decision-making and having a designated contact person. The VI team indicated that the patient experience layer was useful to identify improvement initiatives from patient experiences. They indicated several facilitators of the development of the patient experience layer of the Metro Map, such as collecting patient experience data via an independent person instead of by a healthcare professional. Furthermore, several recommendations were made to use the patient experience layer to improve care, such as having highly engaged staff in the VI team and involving patient representatives.

Conclusions: Overall, the patient experience layer of the Metro Map appears to be a valuable approach to support value improvement based on patient experiences. Several facilitators and recommendations were identified for the development and use of the patient experience layer of the Metro Map to improve care based on patient experiences.

6.1 Introduction

Value-based healthcare (VBHC) is a prominent approach in healthcare that focuses on improving patient relevant outcomes relative to costs, ultimately aiming to increase value of care for patients [1]. A core principle of VBHC is setting up a continuous improvement cycle focused on the care pathway for a specific medical condition, driven by outcome, process, and cost data [2]. To support this process, the care delivery value chain has been proposed within VBHC as a tool to systematically map each step in the care pathway and link these steps to patient-relevant outcome, process, and cost indicators [3]. Besides this outcome, process, and cost data, patient experiences are increasingly recognized as vital input for care improvement [4,5]. However, VBHC currently lacks a systematic approach to gain insight into patient experiences over the care pathway in order to improve value of care based on these insights.

Insight into patient experiences over the care pathway can be achieved by patient journey mapping. Patient journey mapping is a widely used approach to understand the patient experience throughout the healthcare system [6,7]. Patient journey maps provide a structured overview of all steps of a care pathway and help to identify opportunities for improvement in care delivery [8]. A recently developed method for mapping the patient journey is Metro Mapping [9]. In Metro Mapping, the patient's care pathway “as is” is visualized as a metro line, where each 'station' represents a contact point in the care trajectory [9]. Besides this metro line layer, the Metro Map consists of four other layers, i.e. the experience layer, the information layer, the companion layer, and the context layer (Fig. 1). In the experience layer, themes related to experiences of all stakeholders at specific phases in their journey are elicited. The information layer provides insight into the different types of information that patients receive during their patient journey. The context layer provides insight into the locations where healthcare services are provided and physical elements that patients may come into contact with, and the companion layer provides insight into the companions (e.g. involved healthcare professionals, and loved ones of the patient) throughout the patient journey [10].

The Metro Map “as is” can be used to redesign and improve care based on the insights from the five layers [10]. A Metro Mapping project begins by gaining insight into the current state of care for the five different layers of the Metro Map and visualizing the Metro Map based on these insights. Subsequently, stakeholders discuss the Metro Map to identify improvement potential and possible solutions. Next, the different solutions are discussed and combined into an integrated solution, resulting in the improved "to be" version of the Metro Map that illustrates the desired future state [10]. Within this process, the stakeholders' experience layer offers valuable insights on improvement potential based on patients' needs and preferences. However, research has shown that patients are limitedly involved in the experience layer of the Metro Map [11]. Our study assesses the usefulness of involving patients in the experience layer (from now on "patient experience layer") to improve value of care based on patient experiences. To this end, we used a case study design.

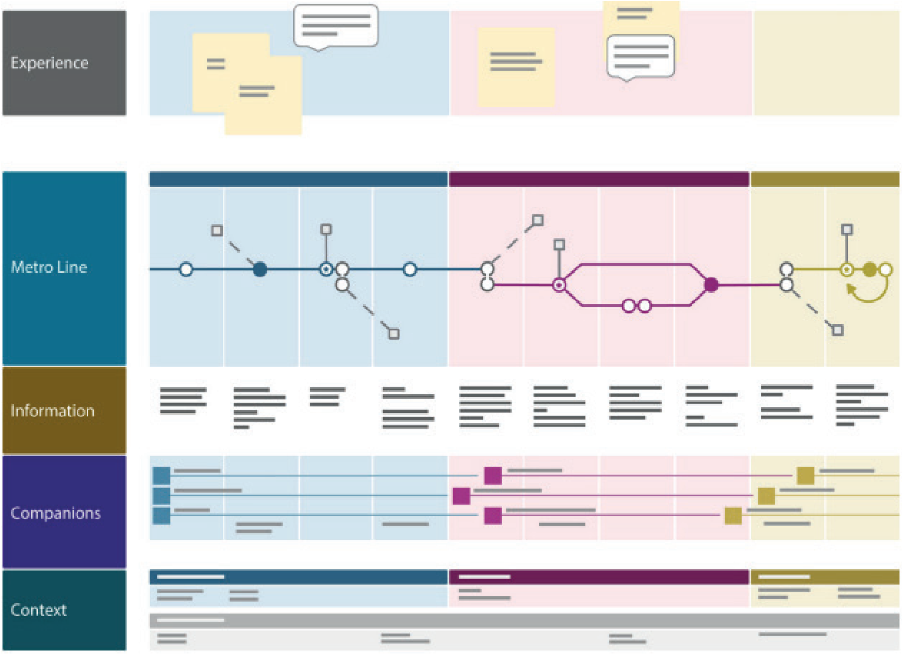


Figure 1| The five layers of the Metro Map. Image retrieved from Stiggelbout et al. (2023) [9]

6.2 Methods

Study design

This study used a case study design, where the development of the patient experience layer for the bladder cancer Metro Map by the bladder cancer Value Improvement (VI) team in a top-clinical hospital (St. Antonius Hospital) in the Netherlands was used as the case. This case was selected since this VI team was already working on developing the metro line of the Metro Map and they were interested in gaining insight into the patient experiences throughout the care pathway to identify improvement potential. The study was conducted between

April 2024 and March 2025. In this study, we focussed specifically on the patient experience layer of the Metro Map. Therefore, when referring to 'Metro Mapping', we primarily refer to the patient experience layer of the Metro Map.

To develop the patient experience layer of the Metro Map, we interviewed patients with bladder cancer and their partners to gain a deep understanding of their experiences with (care for) bladder cancer. Next, based on the qualitative insights, we selected and tailored a Patient Reported Experience Measure (PREM) questionnaire to validate and complement the qualitative insights with a larger group of patients. The findings from the interviews and questionnaires were discussed in two sessions with the bladder cancer VI team and two patient representatives from the Dutch bladder and kidney cancer patient organization. We deliberately chose to involve patient representatives in these sessions, as they are trained and equipped with the knowledge to speak on behalf of the wider patient community, rather than solely from personal experience. During these sessions, the patient experience layer was developed by collaboratively identifying improvement topics from the insights from the interviews and PREM.

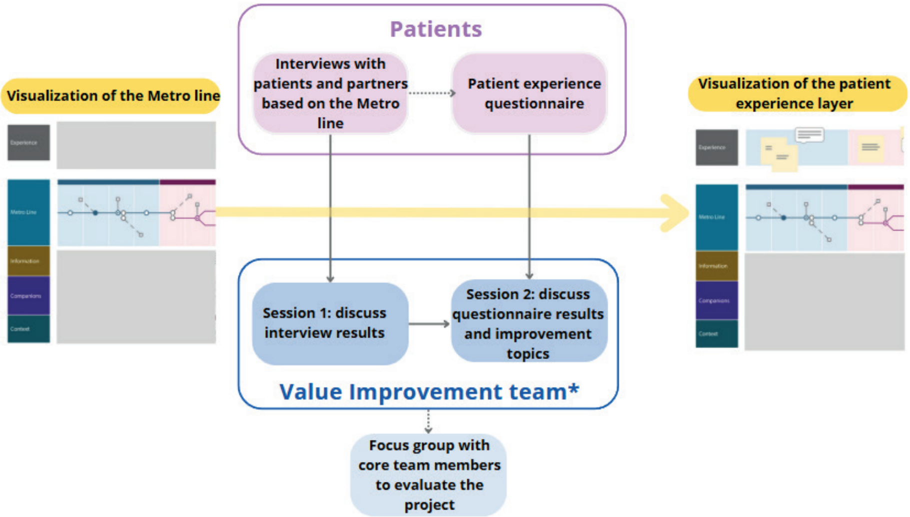


Figure 2| Schematic overview of study design. *The VI team consists of physicians, nurses, allied health professionals, management, and support staff (among which a project leader and a data analyst from the central VBHC department). The bladder cancer VI team has a core team consisting of a project leader, a data analyst, a medical leader, and three nurses

Finally, several VI team members and the patient representatives were invited to participate in a focus group to discuss their perspectives on the usefulness of the patient experience layer of the Metro Map to improve value of care.

See Figure 2 for a schematic overview of the study design. This study is reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guideline [12].

Context

The St. Antonius hospital has VI teams for 28 medical conditions that work on improving care based on the principles of VBHC [13]. These teams meet regularly with all relevant healthcare professionals (and sometimes patients) to discuss improvement initiatives for a specific patient group [14]. The improvement cycle of VI teams includes four cyclical steps: 1. Monitoring outcomes, 2. Identification of improvement potential, 3. Selection of improvement initiatives and 4. Implementation of improvement initiatives [15].

Approximately 45 staff members are invited to the bladder cancer VI team meetings, including physicians, nurses, allied health professionals, management, and support staff (among which a project leader and a data analyst from the central VBHC department). The bladder cancer VI team has a core team consisting of a project leader, a data analyst, a medical leader, and three nurses. The VI team does not structurally include patient team members, but has experience with other methods for patient participation, such as focus groups.

The Metro Map project focussed on localized bladder cancer, both non-muscle invasive and muscle invasive. Treatment options differ according to tumour stage (T-stage) and included endoscopic resections and intravesical chemotherapy or immunotherapy (bladder instillations), radical cystectomy (with or without neo-adjuvant chemotherapy), or chemo-radiotherapy [16]. For the development of the metro line of the Metro Map, a first version was made based on the national guidelines for bladder cancer care [17]. Subsequently, this metro line was discussed with the medical leader of the VI team and adapted based on the context of the St. Antonius hospital.

Data collection and analysis

Interviews with patients

Semi-structured interviews were held with patients and partners. Interviews were chosen to allow a deep dive into the personal story of the patient and their partner regarding their patient journey and to allow them to discuss sensitive topics which may not be addressed during a focus group with other patients or healthcare professionals. The interview guide was developed with the core VI team members (Appendix A). During the interview, a printed version of the metro line was used as a guide to discuss the patient's experiences in each step of their journey. Patients were recruited by nurses using consecutive sampling, i.e. all patients that met the inclusion criteria were approached until the desired sample size was reached [18]. Inclusion criteria were: patients older than 18 years that underwent treatment for organ confined bladder cancer without metastases and that were Dutch speaking. Patients with non-muscle invasive bladder cancer were recruited after 6 months from their first intravesical therapy or when applicable, following their follow-up appointment after cystectomy. Patients with muscle-invasive bladder cancer were recruited following their follow-up appointment after cystectomy. Patients that were treated with chemo-radiotherapy were excluded from this study, as this comprised a small group in the St. Antonius hospital. Furthermore, patients were excluded if their cystectomy or last intravesical therapy had taken place more than one year ago. We aimed to interview an equal number of cystectomy and intravesical therapy patients and a representative number of males/females (approximately 80%/20% respectively [19]). Patients were encouraged to invite their partner to the interview. A total of 25 patients were invited for an interview.

The interviews were conducted by HJW and were held face-to-face, either in the hospital or at the patient's home, based on the patient's personal preferences. The interviewer had no prior relation with the interviewees. HJW has multiple years of experience in qualitative research. Interviews were audio-recorded and transcribed.

The interviews with patients and their partners were open coded via an inductive approach and thematically analysed [20] using Atlas.ti software. The coding and analysis were executed by the first author (HJW). A single-coder approach was employed for coding the interviews, given that this part of the study focuses on the practical use of Metro Mapping, where in daily practice, a single coder would typically be chosen for pragmatic reasons. The results of the thematic analysis were shared with the interviewees.

Patient experience questionnaire

Based on the qualitative findings, the PREM questionnaire from the Dutch Federation of Cancer Patient Organizations [21] was selected to align with the themes identified in the interviews and was refined with eleven tailored questions, mainly on the provision of information (Appendix B). The goal of the questionnaire was to validate and complement the qualitative insights with a larger group of patients.

Patients were again recruited by nurses and identical inclusion and exclusion criteria as for the interviews were used. Patients that participated in the interviews were not contacted to fill out the questionnaire. The questionnaire was sent to 100 patients, which included all eligible patients (n=43) with muscle invasive bladder cancer that underwent cystectomy over the past year (September 2023-September 2024) and a similar number of patients (n=57) with non-muscle invasive bladder cancer that received intravesical therapy. The questionnaire results were analysed with descriptive statistics.

VI team sessions

Two sessions were organized to discuss the findings of the interviews and questionnaires with VI team members and two patient representatives from the Dutch bladder and kidney cancer patient organization. During the first session, the interview results were discussed, and during the second session, the questionnaire data were discussed. Based on these discussions, the various topics for care improvement were identified and mapped on the Metro Map. This resulted in the patient experience layer. After these sessions, the patient experience layer was visualized in the Metro Map using Microsoft Visio (version 2016).

Focus group with VI team members

The core VI team members and the patient representatives were invited to participate in a focus group to discuss their perspectives on the usefulness of the patient experience layer of the Metro Map to improve value of care. The interview guide was based on the Consolidated Framework of Implementation Research (CFIR) [22]. See Appendix C for the interview guide. HJW conducted the focus group. At the time of the focus group, she had been working with the VI team members for several months.

The focus group was audio-recorded and transcribed verbatim. The transcription of the focus group was coded using both a deductive approach (based on CFIR) and inductive approach. The codes were thematically analysed [20] using Atlas.ti software. A double-coding approach was used, where HJW and CCB individually coded the focus group. Next, HJW thematically analysed the codes and discussed the codes and themes during a consensus meeting with CCB. Lastly, the themes were discussed with and approved by the research team.

Patient and Public Contribution

Two patient advisors were closely involved in the research project and participated in the research team meetings. They contributed as research partners across all stages of the study, including protocol development, data interpretation, and manuscript preparation. In addition, two patient representatives were invited to take part in the VI team sessions and the focus group.

6.3 Results

Participants

Of the 25 invited patients, 20 patients accepted to be interviewed, of which seven patients brought their partner to the interview. The patients that declined to participate in the interview mainly reported time constraints as reason. Data saturation was reached after 16 interviews, but the researcher continued with the other four interviews since these were already planned. The interviews had an average duration of 50 minutes. A total of 57 patients completed the questionnaire. Patient characteristics can be found in Table 1.

On average, 17 VI team members attended the sessions to discuss the insights from the patient interviews and questionnaire. One patient representative participated in the first session, and two in the second session. The sessions had an average duration of 90 minutes.

Four VI team members participated in the focus group, i.e. the project leader, the medical leader, a nurse, and the patient representative that participated in both VI team sessions. The focus group had a duration of 68 minutes.

Table 1| Patient characteristics

Characteristic	Interview participants	Questionnaire participants
Total (n)	20	57
Male (n, %)	17, 85%	48, 84%
Partners that participated (n)	7	N.A.
Mean age (range)	70 years (41-80)	70 years (51-83)
Type of bladder cancer:		
Muscle invasive bladder cancer (n, %)	6, 30%	23, 40%
Non-muscle invasive bladder cancer (n, %)	14, 70%	34, 60%
Treatment:		
Intravesical therapy (n, %)	11, 55%	29, 51%
Cystectomy[1] (n, %)	9, 45%	28, 49%

[1] Patients that underwent cystectomy sometimes had received intravesical therapy prior to this treatment

Patient experiences with bladder cancer care

A total of nine topics to improve value of care for patients with bladder cancer were identified based on the discussion of the results of the interviews and questionnaires during the VI team sessions. The nine topics were mapped onto the Metro Map, resulting in the patient experience layer (Fig. 3). Besides these improvement topics, overall, patients were satisfied with the care for bladder cancer. For example, patients indicated in the questionnaire that they would recommend the hospital to other patients with bladder cancer (average rating = 9/10). The nine topics that were identified for improving bladder cancer care are:

1. Provision of information: patients pointed out in interviews and questionnaires that overall, the quality of the information was good (average rating was 8.8/10), but that some information was missing or that they received contradictory information from different healthcare professionals or in flyers. Some patients pointed out during the interviews that they did receive an overwhelming amount of information at the beginning of their patient journey, but this was not validated by the questionnaire results (89% indicated that the amount of information was sufficient, i.e. neither too much nor too little). Furthermore, during the interviews, several patients mentioned that they missed an overview of the care pathway at the beginning of their patient journey. They indicated that a less detailed version of the metro line would have been helpful to this end.
2. Observing cystoscopy procedure: Several patients found it confronting to observe the screen while undergoing the cystoscopic diagnostic procedure

and expressed the desire to be better prepared for it before undergoing the procedure.

3. Shared decision-making: while 80% of the patients reported in the questionnaire that they received information about different treatment options, in the interviews, multiple patients with non-muscle invasive bladder cancer pointed out that only one treatment option was discussed with them. Most patients did not experience this as a problem, but they did point out that they lacked information on e.g. the impact of this treatment on their daily life. Furthermore, only 11% of all patients indicated in the questionnaire that the option for watchful waiting was discussed with them. In addition, in the questionnaire, only 35% of the patients with non-muscle invasive bladder cancer indicated that they discussed their personal preferences with their healthcare professional when making treatment decisions. Moreover, 36% of the patients with non-muscle invasive bladder cancer indicated that they did not play a role in treatment decision-making.
4. PROMs: 55% of the patients indicated that they completed a patient-reported outcome measurement (PROM) questionnaire, of which 23% discussed their results with a healthcare professional. In total, 38% of patients with non-muscle invasive bladder cancer who completed a PROM questionnaire reported that they did not discuss its results with their healthcare professional, though they would have liked to.
5. Contact person: in the questionnaire, 87% of the patients with muscle-invasive bladder cancer indicated to have a designated contact person for their questions regarding their bladder cancer care, compared to only 50% of the patients with non-muscle invasive bladder cancer.
6. Contact moments during intravesical therapy: patients that were treated with intravesical therapy pointed out that they missed time to discuss their questions and complications during the treatment phase. Even though they had multiple visits to the hospital to receive treatment, they felt that these were not suitable moments to discuss personal matters, because during these visits they were physically exposed and focused entirely on undergoing the procedure. This did not offer an appropriate environment for engaging in personal conversations.
7. Information after cystectomy: during the interviews, several patients pointed out that they lacked information on what they could and could not do after their cystectomy. They indicated that they received a clear schedule for physical therapy during the first week after surgery, but that this information was insufficient after discharge from the hospital.

8. Sexual consequences: Patients that underwent a cystectomy pointed out that there is limited attention for the possible complications regarding sexual functioning. In the questionnaire, 22% of patients that underwent a cystectomy experienced problems with sexual functioning due to the bladder cancer (treatment).
9. Peer support: only a limited number (25%) of patients indicated that they have received information about the patient organization for bladder cancer. During the interviews, multiple patients mentioned that they searched for online forums to learn about other patient experiences with bladder cancer and their treatment.

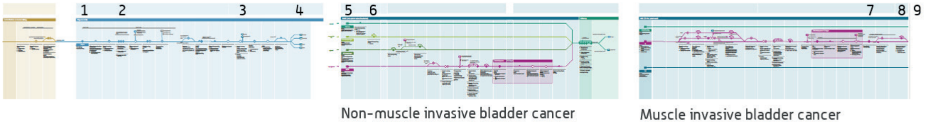


Figure 3| The bladder cancer metro line including the improvement topics. The detailed Metro Map can be retrieved via the Radboud Data Repository (https://doi.org/10.34973/z69z-0n39). The colours represent the different phases in the care pathway, i.e. yellow is the first complaints and referral, blue is diagnosis, green is treatment including follow-up.

VI team members' perspectives on the usefulness of the patient experience layer

The usefulness of the patient experience layer to improve value of care was evaluated with the VI team members and the patient representative during a focus group. The themes identified from this focus group were grouped into three domains, i.e. 'evaluation of the patient experience layer', 'recommendations for the patient experience layer', and 'next steps for the VI team'. See Table 2 for an overview of the domains and themes, including illustrative quotes.

Table 2| Domains and themes identified from the focus group with illustrative quotes

Domain	Theme	Quote
Evaluation of the patient experience layer	(Relative) advantage of the project	*"The Metro Map provides a clear overview of the entire care pathway, which makes it possible to incorporate many different facets of the patient journey. While it's not feasible to improve everything at once, it does offer valuable insights into patient' experiences throughout the entire process"* – PR[1]
	Critical notes on the project	*"Somewhere my question is still: suppose you had purely just the information from the interviews or the information from the questionnaire, would that have made it very different?"* – PL[2]
	Facilitators of the project	*"I think it's actually a very pleasant and independent way to gather feedback. In contrast to, for example, a focus group, where healthcare professionals are present at the moment when the patients say, "This is how I experienced it" both in a positive and in a negative sense, despite the fact that they don't actually say anything. Now we had an impartial intermediary without the presence of the healthcare professional in those interviews. So, I think that was a pretty pure form of getting that feedback"* – ML[3]
Recommendations for the patient experience layer	Time and resources	*"I think that you have to realize that you can collect a lot of improvement topics, and that you need the time and resources to do something with them"* – PL
	Independency	*"How we've done it before and still do it, also for example with the PROMs, is that patients fill it out, but the healthcare provider then discusses it with the patient. I believe it adds real value to have an independent person act as an intermediary, offering an objective perspective [on the patient feedback]"* – ML
	Engagement of healthcare professionals	*"The engagement of healthcare professionals, such as from the nursing ward or outpatient clinic, helps to enthuse them to see the added value of improving things. In the end, it makes your work a lot more fun"* – Nurse
	Aim and scope	*"I think it depends on which questions you want to pursue. Do you want to do more than just the medical content part, or do you want to broaden your scope a bit more? That could be something that a team should think about"* – ML
	Patient representatives	*"It would have made sense for us to have been involved in that [development of metro line] as well. And then it might also have been a little easier to follow the project a little better. Certainly, when it comes to mapping decision moments in a care pathway, we have knowledge about this from other projects, so perhaps we could have given some input there as well"* – PR

Table 2| Continued

Domain	Theme	Quote
Next steps for the VI team	Upcoming actions	*"We talked about that [prioritization] last time, didn't we, because a lot of topics came up, and I think that we have the task as a core team to actually make a preliminary suggestion of well this seems to us, name it, the top three or five things we would like to work on"* – ML
	Sharing insights	*"And what we did say at the beginning when we were asked to participate, we said 'this is very nice that this is happening here [St. Antonius hospital], but we also think it is very relevant to share the insights gained here more widely'. So that perhaps others can benefit from this"* – PR
	Evaluation of improvement initiatives	*"I would imagine that as an evaluation you will indeed do interviews in the same way, and you will look again at that metro line to see where there have been interventions and what the impact has been"* – ML

1: PR = patient representative, 2: PL = project leader, 3: ML = medical leader

Evaluation of the patient experience layer

Several aspects were mentioned regarding the relative advantage of developing the patient experience layer of the Metro Map compared to other methods to gain insight into the patient experiences. First of all, the focus on the entire patient journey (including steps that occur outside the hospital) was experienced as an advantage over other patient participation methods that have previously been used by the VI team. Secondly, the visual and structural approach of Metro Mapping was indicated as an advantage, as this provided a clear overview of the different improvement topics which helps to tackle them step by step. Thirdly, the development of the patient experience layer gained insights into many improvement topics, and therefore was experienced to provide a good overview of improvement topics for long-term use.

Besides the advantages of the project, a few critical notes were made during the focus group. Some VI team members questioned whether the Metro Map approach was essential for obtaining the results or if the same results would have been achieved if the patient interviews were conducted without using the metro line during the interviews and without the visualization of the results in the Metro Map. On the other hand, some VI team members indicated that the metro line was essential during the interviews to obtain insights over the entire patient journey. Furthermore, not everyone was convinced that the Metro Map would be used long-term, and some VI team members indicated that other tools (such as roadmaps for patients) would be more useful in daily practice. Lastly, the VI team indicated to have more responsibilities besides this project, which restrained the available time to work on the improvement topics.

During the focus group, several facilitators of the approach to develop the patient experience layer of the Metro Map were mentioned. For example, the use of an independent researcher to collect patient feedback, the combination of a qualitative and quantitative approach, and the inclusion of partners of patients in the project were seen as advantages of the project. Furthermore, support for developing and utilizing the patient experience layer to identify improvement potential was experienced as essential for the progress. Moreover, the VI team indicated that they were well-functioning, with engaged and enthusiastic VI team members, which helped the progress of this project. Lastly, the involvement of the patient representatives was seen as a facilitator of the project, as they provided valuable insights during the VI team sessions.

Recommendations for the patient experience layer

Overall, the VI team members would recommend the development of the patient experience layer of a Metro Map to other VI teams, as it was a useful method to gain insight into improvement potential from the patient perspective. The VI team members mentioned several recommendations regarding the use of Metro Mapping to improve value of care based on patient experiences. First of all, a VI team should only start a Metro Mapping project if they have sufficient time, commitment, support, and resources for the project, as a large list of improvement topics will follow from it. Secondly, independency was mentioned to be an important aspect in Metro Mapping, both for collecting the patient feedback (an independent person to collect the patient feedback) and in collaborating with external parties (no influence of external parties on results of the Metro Map and the improvement initiatives). Thirdly, an engaged VI team is needed to ensure implementation of improvements in daily practice. Fourthly, the aim and scope of the project should be clear before the start, as the Metro Map can be used for various aims and the scope can be either limited (only the patient pathway within the hospital) or very broad (including the steps outside of the hospital), which also requires participation of other stakeholders. Lastly, the patient representatives should be involved early on in the project, including in drafting the metro line.

Next steps for the VI team

The VI team members indicated that the first next step would be to draft a top three to five priorities from the nine improvement topics. Furthermore, they expressed interest in continuing collaboration with patient representatives in the improvement initiatives that follow from the insights. For the patient representative, an important next step would be to share the insights with other hospitals. Meanwhile, the medical leader leaned towards sharing insights after working on the improvement initiatives to demonstrate how to improve, but also believed that others could already benefit from the insights in what could be improved.

The VI team members indicated that on the long term they want to evaluate the impact of the improvement initiatives that originated from this project, to study whether these have led to e.g. higher patient satisfaction, improved shared decision-making, or increased quality of life. They indicated that this can be done by updating the patient experience layer and comparing these insights with the current patient experience layer. In the end, VI team members indicated that insights into the impact would stimulate healthcare providers to continue collecting patient experience data and improving care based on this data.

6.4 Discussion and conclusion

This study aimed to assess the usefulness of the patient experience layer to improve value of care based on patient experiences. Overall, nine topics for bladder cancer care improvement were identified and included in the patient experience layer. In terms of development of the patient experience layer, the VI team members and patient representatives identified several facilitators, e.g. use an independent person for collecting the patient experience data, combine qualitative and quantitative data, and include the patients' partners. Recommendations for future development of the patient experience layer were, for example, having a clear goal and scope, and include patient representatives early-on. Next steps for the VI team to use the insights to improve value of care would be to prioritize the improvement topics, collaborate with the patient representatives on the improvement initiatives, and evaluate the impact of the improvement initiatives on the value of care.

The patient experience layer was positively received by the VI team members and yielded valuable insights for improving care based on patient experiences. While Metro Mapping was originally developed to support SDM at the individual patient level [9,23,24], our results show that the approach can also be used to improve value of care at the collective level. Some VI team members questioned the added value of Metro Mapping, but others emphasized the benefits of the approach for collecting and using patient experience data to improve value of care. Regarding the collection of patient experience data, it was experienced that Metro Mapping was of added value since the metro line provided patients with a structured visual aid that helped them recall and articulate their experiences across the full care pathway. Without this visual support, it could have been difficult for patients to remember specific steps of their journey, especially those that occurred earlier in the process or when impactful events occurred in-between [25]. Regarding the use of the patient experience data to improve care, the VI team members indicated that Metro Mapping helped in making sense of patient input by structuring and visualizing improvement topics identified from patient experiences. The detailed, yet clear, layout of the Metro Map helped team members to translate the insights into a structured overview of improvement topics. While this visualization is a characteristic of patient journey mapping in general [7,26–30], Metro Mapping stands out by using a standardized methodology that offers a high level of detail while maintaining clarity and structure.

Our approach and the recommendations for the patient experience layer can support others to develop the patient experience layer in order to improve value of care. However, as indicated during the focus group, this approach does require significant time investment. Moreover, Metro Mapping requires specific expertise of service designers, or trained quality staff, for the visualization [10]. Notably, several of the improvement topics identified through the patient experience layer align with findings from previous studies on patient experiences, such as the need for clearer information on treatment options and a better overview of the care pathway [26–28]. Given this overlap, we suggest that future research explores the development of a generic patient experience layer based on these ‘generic’ themes in patient experiences with oncologic care. Such a generic patient experience layer allows VI teams to leverage insights from other (Metro Mapping) projects without the need for extensive new data collection. At the same time, it offers the flexibility to tailor the layer to condition-specific experiences or variations in the care pathway, for example, by focusing only on those specific topics when gathering patient experience insights.

As for the usefulness of the patient experience layer, insights were gained into how it can be applied to support care improvement efforts. An important facilitator for using the patient experience layer of the Metro Map to improve value of care was having highly engaged healthcare professionals within the VI team to work on the improvement initiatives. Interestingly, a recent study was conducted in the same department involved in this case study and explored nurses’ perspectives on their work experience with that department, focusing on the factors that contribute to engaging, binding, and retaining nurses. The study found that nurses valued the existing strong support structures, the optimal work environment, and the robust team culture [31]. While this study specifically focused on the context of care delivery, we believe that these factors may also contribute to active involvement of healthcare professionals in value improvement efforts, as the VI team members experienced strong engagement within their VI team.

Lastly, VI team members emphasized the importance of evaluating the impact of improvement initiatives derived from the patient experience layer. However, the Metro Map is a static document, meaning that changes in the patient experience layer are not automatically tracked. To assess the impact of the improvement initiatives on patient experiences, the team has to perform an identical post-measurement, which is time-consuming. To address this, we propose enhancing the Metro Map methodology by incorporating patient experience indicators, such as PREMs, into the Metro Map. Doing so would allow for targeted and structured measurement of patient experiences at specific points along the care pathway, making it possible to evaluate the impact of improvement initiatives more efficiently. In addition, outcome, process, and cost indicators could also be mapped to the Metro Map. This integration would result in a Metro Map that provides a comprehensive overview of all types of data relevant for VI teams to effectively shape and drive their continuous improvement cycle. This proposal essentially entails an integration of the care delivery value chain with the Metro Map. The care delivery value chain focuses on mapping outcome, process, and cost indicators across the care pathway to identify value improvement opportunities [3,32], to which the Metro Map adds complementary insights from the other layers (e.g. the patient experience layer).

Three limitations should be taken into consideration when interpreting the results of this study. First, the focus group with the VI team was conducted by the researcher who had been closely involved in the development of the patient experience layer. This could have introduced bias, as team members might have felt inclined to provide positive feedback about the Metro Mapping project to this particular researcher. However, the focus group results show that participants shared both positive and critical views, suggesting that any potential bias was likely limited. Second, the focus group was conducted with a small group of VI team members, which may have influenced the results, as these team members were highly involved in the Metro Mapping project. Thirdly, we did not evaluate the experiences of patients that participated in the interviews and questionnaire with Metro Mapping. Meanwhile, we did receive informal feedback on the added value of the use of the metro line during the interviews from patients.

Conclusion

The Metro Mapping project was positively experienced by VI team members and patient representatives and resulted in multiple improvement topics. Several facilitators and recommendations were identified for the development and use of the patient experience layer of the Metro Map to improve care based on patient experiences. In the end, improving care based on patient experiences is essential to deliver high-value care, and the patient experience layer of the Metro Map appears to be a valuable approach to support this.

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Appendix A: Interview guide patient experiences with bladder cancer (care)

Introduction:

- Can you briefly tell me about yourself? Your daily life, family situation (also introduce partner if present during interview), work, and hobbies?
- How are you doing physically and mentally?

Diagnosis Phase (place pawn on metroline):

- Can you tell me how you found out you had bladder cancer?
    - o What were your first symptoms? When did this happen?
    - o How long did it take from your first symptoms and seeing your GP to getting referred?

- How did you experience the referrals?
    - o How did you end up at this hospital?
    - o How was the referral process between different healthcare providers? What did you think about the length of this process?

- How was the process of receiving your diagnosis?
    - o What did you think about the waiting times for diagnostic tests like scans? How was the support you received, both practically and emotionally?
    - o Was it clear to you what your treatment path would look like and why certain tests/appointments were scheduled?
    - o How did you find the guidance and information provided by the healthcare providers during this process (clarity/appropriateness at the right times)?
    - o How were you and your loved ones involved during the diagnosis process? What did you think about this?

If a partner is present: How was this diagnostic process for you?

- What impact did it have on your life? Where did you notice this impact?
- What support and information did you receive from the healthcare providers? What did you think about this? Did it meet your needs and was it sufficient?

Treatment (move pawn):

- Can you tell me about the process of choosing your treatment?
    - Who provided you with information about the different treatments?
    - What did you think about the information provided to help you make a choice? Was it clear to you what the pros and cons (side effects) of the different treatments were?
    - Why was the particular choice made? What were your personal preferences for this treatment? Do you remember the considerations you had?
    - Who was involved in this decision-making process? What role did your family play in making a choice?

- What treatments did you receive for bladder cancer?
- Was it clear to you how this process of treatment would unfold?
- How did you find the treatments? What did you like and not like?
- Looking back, was your chosen treatment the right choice? Do you feel you lacked any information when making the decision?

If hospitalized:

- Which healthcare providers were involved in your care? Was this clear to you?
- What did you think about the discharge process? How soon were you allowed to go home? How far in advance did you know? Who and how was this communicated to you? How did you feel about going home?

If a partner is present: How was this treatment process for you?

- What did you think about the information/explanation/support during the treatment process?
- How were you involved in making a choice for treatment? What information helped with this decision? What role did you play in the decision-making process?

Aftercare and follow-up (move pawn):

- How did you experience the time after treatment (aftercare)?
- What were your expectations before treatment regarding the treatment and the follow-up process? Did this match reality?
- Did you have a clear point of contact? Who was this for you?

- What did you think about the support you received during rehabilitation and reintegrating into daily life?

If a partner is present: How was this process for you?

- What did you think about the information/explanation/support during this phase?
- What was the impact on your daily life?

Reflecting on the entire journey (let patient move pawn for each question):

- What was particularly important to you during your journey?
  - Which moments?
  - What emotions were involved?
  - Which people were involved?

- Which moment was the most challenging/frustrating/stressful for you?
  - What emotions were involved?
  - Which people were involved?
  - Did you feel you received enough support?

- What were important decision-making moments for you?
  - What choices needed to be made?
  - What choice did you make?
  - What was the impact of this choice?

- What did you think about the healthcare providers throughout your journey?
  - Were they friendly, knowledgeable, clear, and did they listen to your personal story?
  - Was there enough attention given to both physical and mental well-being?

- Looking back on the entire experience, what would you or your partner have liked to have done differently, knowing what you know now?
- What impact has your illness and treatment had on your daily life? Think about diet, work (volunteering), sexuality.
- What advice would you give to a future patient at our hospital?
- What advice would you give to the hospital or your healthcare providers?

Appendix B: Patient experience questionnaire

No.	Question	Answer options
1	Are you currently receiving treatment for bladder cancer?	Yes; No, I have not yet started treatment; No, it was decided to wait and see; Treatment is completed, but I still have follow-up appointments; Treatment is completed, I no longer have follow-ups; Other, namely: [open text field]
2	What is the current status of your bladder cancer?	I no longer have bladder cancer; I have bladder cancer, but recovery is possible; I have bladder cancer and recovery is not possible; I have bladder cancer and don't know if recovery is possible; Other, namely: [open text field]
3	What is your gender?	Male; Female; Other
4	In which year were you born?	[Open text field – enter 4-digit year]
5	What is your highest level of education?	Practically educated; Secondary education; Higher education; Other, namely: [open text field]
6	What care did you receive at St. Antonius Hospital for bladder cancer?	Multiple answers possible: Diagnostics; Second opinion; Surgery; Chemotherapy; Radiation; Hormone therapy; Immunotherapy; Targeted therapy; Stem cell transplant; Watchful waiting; Active surveillance; Symptom/pain management; Aftercare; Other, namely: [open text field]
7	Why did you choose St. Antonius Hospital?	Multiple answers possible: Recommended by GP; Referred by doctor from another hospital; Own choice; Advised by someone in my environment; Received second opinion here; Received specific treatment not available elsewhere; This hospital is a bladder cancer expert; Part of a bladder cancer network; Close to home; No specific reason; Don't know / not applicable; Other, namely: [open text field]
8	How satisfied were you with the bladder cancer doctors at St. Antonius Hospital?	Rate from 1 (very dissatisfied) to 10 (very satisfied): • Expertise; • How seriously you were taken; • Time they had for you; • Friendliness; • Feeling supported; • Attention for family/partner/ important others
9	Number of different doctors you saw for bladder cancer at St. Antonius Hospital?	1 doctor; 2 doctors; 3 doctors; More than 3 doctors
10	How satisfied were you with the number of different doctors you saw?	Rate from 1 (very dissatisfied) to 10 (very satisfied),

Appendix B| Continued

No.	Question	Answer options
11	How satisfied were you with the nurse specialists or oncology nurses for bladder cancer at St. Antonius Hospital?	Rate from 1 (very dissatisfied) to 10 (very satisfied): • Expertise; • Feeling taken seriously; • Time available; • Friendliness; • Feeling supported; • Attention to family/partner/ important others
12	How satisfied were you with other hospital staff?	Rate from 1 (very dissatisfied) to 10 (very satisfied): • Collaboration between staff; • Friendliness of staff
13	Did you have a fixed contact person for bladder cancer at St. Antonius Hospital?	Yes; No; Don't know / not applicable
14	Who was your fixed contact person?	My oncology nurse; My doctor; My nurse specialist; Don't know; Other, namely: [open text field]
15	How satisfied were you with your fixed contact person?	Rate from 1 (very dissatisfied) to 10 (very satisfied)
16	How satisfied were you with the following tasks of your fixed contact person?	Rate from 1 to 10: • Overview of my illness; • Support when needed; • Support for family/partner; • Knows me personally; • Easy to contact
17	Did hospital appointments take your preferences into account (e.g., convenient time/days)?	Yes; Sometimes; No; Don't know / not applicable
18	Could you choose for remote appointments (e.g., video call, phone) if desired?	Yes; Sometimes; No; Don't know / not applicable
19	Did you have enough time to ask questions during appointments?	Yes; Sometimes; No; Don't know / not applicable
20	Were you given a choice in which treatment you received for your cancer?	Yes; No; Don't know / not applicable
21	How clear was the explanation about the different treatment options?	Very unclear – Very clear (10-point scale)

Appendix B| Continued

No.	Question	Answer options
22	Did someone from St. Antonius Hospital talk to you about the following topics?	Multiple answers possible: Chances of longer life and/or recovery; Relief from symptoms; Side effects and problems caused by treatment (e.g., nausea, tingling, fatigue, pain, diarrhoea, re-operation); Long-term or delayed effects (e.g., fatigue, sexual problems, eating/drinking issues, memory/concentration issues, lymphedema, incontinence, tingling); The option of choosing not to be treated; None of the above
23	Do you trust that your care providers have discussed all treatment options with you for bladder cancer?	Rate from 1 (no trust) to 10 (complete trust)
24	How satisfied are you with the help you received from St. Antonius Hospital in choosing a treatment?	Rate from 1 (very dissatisfied) to 10 (very satisfied
25	Has someone discussed with you what is important in your life?	Yes; No; I don't know / Not applicable
26	What was your role in choosing a treatment?	Multiple answers possible: I had a role; I made the decision alone or with my partner/family; I had a role; I made the decision with my care provider; I had no role; care providers decided for me; I had no role because I didn't want to choose; I don't know / Not applicable
27	What did you think of the information you received from the hospital about bladder cancer?	[Open text field]
28	Was the information clear?	Very unclear – Very clear (10-point scale)
29	Was the information complete?	Yes, missed nothing; No, but didn't miss anything; No, I missed information; I don't know
30	Were there differences in the information you received (e.g., between leaflets or care providers)?	Yes; No; Sometimes; Not applicable
31	What did you think of the amount of information?	Too little; Sufficient; Too much
32	Did you receive the information at the right time?	Yes; No; Not applicable
33	In what way would you prefer to receive information?	Multiple answers possible: In conversation; On paper (text only); On paper (with images); Digitally (text only); Digitally (with images/videos); I don't mind
34	How clear was the information about your treatment and what was going to happen?	Very unclear – Very clear (10-point scale)

Appendix B| Continued

No.	Question	Answer options
35	Were you asked by St. Antonius Hospital to complete a questionnaire about your health (e.g., fatigue, pain, anxiety)?	Yes, I completed it; Yes, but didn't complete it; No; I don't know / Not applicable
36	Did someone from the hospital talk to you about your questionnaire answers?	Yes; No, but I wanted to; No, and I didn't want to; I don't know / Not applicable
37	How satisfied were you with that conversation?	Rate from 1 (very dissatisfied) to 10 (very satisfied); Don't know / Not applicable
38	What problems have you experienced due to bladder cancer?	Multiple answers possible: Emotional issues (e.g., anger, anxiety); Physical issues (e.g., pain, fatigue); Eating/drinking/weight issues; Sexual/intimacy issues; Family/relationship issues; Work problems; Financial problems; Existential questions; No problems; Other, namely: [open text field]
39	Did St. Antonius Hospital offer you contact with other cancer patients (peer support)?	Multiple answers possible: Bladder cancer patient organization; Information evenings; Buddy contact (experienced patient); Cancer support centre; Yes; No; I don't know / Not applicable
40	Would you recommend St. Antonius Hospital to others with bladder cancer?	Rate from 1 (definitely not) to 10 (definitely yes)
41	What compliment would you like to give St. Antonius Hospital for the care you received?	[Open text field]
42	What could St. Antonius Hospital improve in the care for bladder cancer?	[Open text field]
43	This is the final question of this questionnaire. Is there anything else you would like to share?	[Open text field]

Appendix C: Interview guide to evaluate the patient experience layer

Development of Metro Map

The innovation:

- Why did your VI team initiate the Metro Map project?
- To what aligns gaining insight into patient experiences, using Metro Mapping, with the responsibilities of a VI team according to you?

Individuals:

- What was your role in the development of the Metro Map?

Implementation process:

- How did you experience the process of the development of the Metro Map?
- To what extent are patients adequately represented in the development of the Metro Map according to you?

Use of Metro Map (co-creation sessions)

The innovation:

- To what extent did the Metro Map help you to gain insight into patient experiences and improvement potential? Can you give an example?
- There are multiple methods known to gain insights into patient experiences (e.g. focus groups). To what extent was the Metro Mapping approach of added value for your VI team?
- How are you going to use the Metro Map in your VI team to improve care?
- How easy (or not at all) is it to use the insights of the Metro Map in daily practice?

Individuals:

- What is (or is going to be) your role in using the insights of the Metro Map to improve care?

Implementation process:

- What do you think of the process of using the Metro Map, e.g. the co-creation sessions?
- How are patients (going to be) involved in using the insights of the Metro Map to improve care?

Inner setting:

- Which organizational preconditions or resources are needed to improve care based on the insights of the Metro Map?

Future use of Metro Map

The innovation:

- How do you think that the Metro Map will be used on the long term within our outside of your VI team?
- Which changes to the Metro Map would stimulate or improve long term use of the Metro Map?

Individuals:

- What do you think that your role will be in future use or development of the Metro Map?

Implementation process:

- How do you think that the implementation process can be improved for other teams or organizations that want to work with the Metro Map?
- Do you want to improve the involvement of patients in future use or development of Metro Maps?

Inner setting:

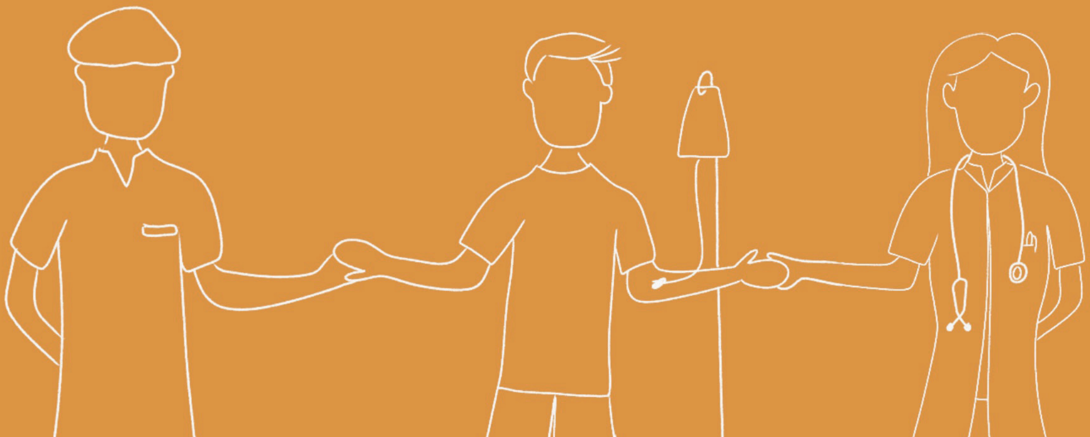
- Which organizational preconditions or resources are needed to improve future use of the Metro Map in your team?

Recommendations innovation:

- To what extent would you recommend other VI teams to develop a Metro Map? For which goal?
- If you would recommend other teams to develop a Metro Map, which recommendations would you make to ensure a positive experience?
- What do you think is needed to stimulate other teams or organizations to successfully work with Metro Mapping? Are specific resources, training or preconditions needed?

Final remarks

- Do you have any final remarks regarding the development, use or future improvement of Metro Mapping?



Chapter 7

Summary and general discussion

The central aim of this thesis was to study and improve patient participation in the context of value-based healthcare (VBHC). Involving patients, i.e. patient participation, is essential for improving healthcare, as patients provide unique insights based on their lived experiences throughout the entire care pathway. However, structural involvement of patients in the improvement of care at the level of medical conditions remains limited. This is due to a healthcare system that is organized around medical specialties rather than around medical conditions, leading to fragmented responsibilities for (improvement of) care for a specific medical condition. This fragmentation makes it difficult to establish meaningful and structural patient participation at the level of medical conditions, as there are often no dedicated groups focused on the care improvement of specific medical conditions. The transition to a VBHC system creates a suitable context to better integrate patient participation in care improvement, as VBHC involves redesign around care pathways and continuous improvement of value of care [1]. Yet, as highlighted in the introduction, there is a lack of involvement of patients in VBHC initiatives and multiple studies have addressed the need for insight into good practices for patient participation in VBHC [2–5]. Therefore, the main goal of this thesis was to study how patients can be involved in VBHC in a meaningful manner.

The following research questions were formulated:

Part 1| Insights from the literature
1. What can we learn from the literature regarding collective patient participation?

Part 2| Current level of patient participation
2. What is the current level of collective patient participation in multidisciplinary project teams?
3. What is the current level of using outcome data at the individual patient level?

Part 3| Good practices for collective patient participation
4. What are good practices for collective patient participation in multidisciplinary project teams?

Part 4| Using patient experiences to improve value of care
5. How can multidisciplinary project teams use patient experiences to identify improvement potential?

The majority of the studies were conducted in the Santeon hospitals. Santeon is a collaboration of seven top clinical teaching hospitals in the Netherlands that jointly work on VBHC via the 'Better Together' program. For fifteen medical conditions, multidisciplinary Value Improvement (VI) teams have been set up at each hospital that collaborate on improving care based on the VBHC principles.

This chapter starts with a summary of the research chapters of this thesis. A reflection on the findings from the different chapters is presented in the general discussion. In the next section, several methodological considerations of this thesis are discussed. Based on the implications of the findings and the methodological considerations, recommendations for daily practice and future research are provided. Finally, this chapter closes with the overall conclusions of this thesis.

7.1 Summary of the chapters

Part 1| Insights from the literature

In **Chapter 2**, we report the findings of our systematic review on barriers and facilitators for meaningful patient participation at the collective level in healthcare organizations. We searched two literature databases for scientific articles that evaluated collective patient participation and included 59 articles in our review. The analysis of the included articles showed that the most common method for collective patient participation was to involve patients in a project or research team. Based on narrative analysis of the reported barriers and facilitators of patient participation, five recommendations were formulated to set up meaningful collective patient participation. These are: 1. Ensure that preconditions for patient participation are met, 2. Develop a strategy for patient participation, 3. Prepare patients and staff for patient participation, 4. Support patients and staff during patient participation, and 5. Evaluate patient participation with both patients and staff. Interestingly, we found that similar barriers and facilitators were experienced over a period of twenty years of patient participation, indicating that little progress has been made in structuring patient participation. Half of the included studies evaluated the impact of patient participation and reported that patient participation had (mainly positive) impact on the quality of care and research, the team and organization, and the individuals involved in the patient participation.

Part 2| Current level of patient participation

In part 2, we evaluated collective patient participation (**Chapter 3**) and individual patient participation (**Chapter 4**) in the context of VBHC. In **Chapter 3**, a mixed-methods approach was used to evaluate collective patient participation in the Santeon hospitals. We interviewed 30 VI team members, including 12 patients, and the Public and Patient Engagement Evaluation Tool (PPEET) [6] was completed by 147 team members of 76 different VI teams. The results showed that only half of the 76 included VI teams used a form of patient participation. Nine themes regarding the experiences with patient participation in the VI teams were identified in the interviews and questionnaires. For example, we found that the majority of VI teams lacked a clear strategy and goal for patient participation, which could explain why there was no patient participation in half of the VI teams. Furthermore, VI team members indicated that specific knowledge and skills are required for patients to participate in a VI team. This led to the inclusion of patients with such specific skills, which in turn led to concerns regarding the representativeness of participating patients in VI teams. VI team members also indicated that the input of patients often did not influence the outcomes of the VI trajectory. Overall, the results implied that patient participation had not yet been fully embedded in the practice of the VI teams.

In **Chapter 4**, we evaluated the use of outcome data at the individual patient level, for example to support shared decision-making (SDM). Healthcare professionals from the Santeon hospitals with experience in using outcome data to improve value of care were interviewed (n=11) and Dutch patients were invited to complete a questionnaire. We asked the healthcare professionals to which extent they used outcome data at the individual patient level during their consultations. Healthcare professionals emphasized that aggregated outcome data are limitedly used at the individual patient level, and they experienced several barriers to this end. An example of a barrier is the low response rate of patient reported outcome measurements (PROMs). They mentioned multiple actions to address the barriers, e.g. assigning staff to assist patients in completing PROMs. Notably, we identified a few misconceptions of healthcare professionals regarding the use of outcome data at the individual patient level, one of them being the perception that decision aids replace the ‘traditional’ SDM conversation between a patient and their healthcare professional. Within the patient questionnaire, patients were asked to rate the importance of different outcome indicators and to indicate whether they want be informed on the outcome or discuss it with their healthcare professional via a questionnaire. This questionnaire was completed by 283 Dutch patients with either prostate cancer, lung cancer, or inflammatory bowel disease (IBD). Generally, patients considered the majority (77%) of the outcome indicators (encompassing both clinical and patient-reported outcomes) as important to support treatment decision-making. When zooming in on the specific patient groups, it became evident that patients with lung and prostate cancer rated the majority of indicators, both clinical and patient-reported, as important, while patients with IBD tended to prioritize patient-reported outcomes, such as fatigue and pain, over clinical indicators. Overall, this study underscored the importance of using outcome data in patient consultations from both the healthcare professionals’ and patients’ perspectives.

Part 3| Good practices for collective patient participation

The findings of the literature review (**Chapter 2**) and the evaluation of collective patient participation in VI teams (**Chapter 3**) formed the foundation for the action research study of **Chapter 5**. In this action research study, we had three goals: (1) to improve patient participation within VI teams, (2) to increase the knowledge and skills of these intervention team members on patient participation, and (3) to generate scientific insights based on the lessons learned. Seven VI teams (i.e. the intervention teams) participated in the action research for a period of 20 months. In this period, we sent the PPEET questionnaire three times to both the seven intervention teams and all other VI teams in order to have a control group. A total of 106 meetings with the intervention teams were conducted as part of the action research study, and the PPEET was completed 302 times. Positive outcomes for all three of the action research goals (i.e. improving patient participation in daily practice, enhancing the knowledge and skills of participants, and generating scientific insights) were achieved. For example, PPEET data showed that 71% of intervention team members reported that patient participation had an impact on the team's outcomes compared to 44% in control teams at the final PPEET measurement. Furthermore, 80% of the intervention team members initially wanted training in patient participation, which dropped to 29% at the end of the study. Overall, 22 lessons in improving patient participation in multidisciplinary project teams were identified. These lessons, along with insights from **Chapters 2 and 3** were combined into a practical guide for patient participation in VBHC (**Intermezzo**). This practical guide provides recommendations for patient participation in multidisciplinary teams that work on improving care for a specific patient group.

Part 4| Using patient experiences to improve value of care

A core principle of Value-Based Healthcare (VBHC) is the establishment of a continuous improvement cycle around the care pathway for a specific medical condition, guided by outcome, process, and cost data. In addition to these data sources, patient experiences are increasingly recognized as valuable input for improving care. However, VBHC currently lacks a systematic approach to capturing these experiences and using them to inform care improvement. To explore how patient experiences can be effectively integrated into this improvement cycle, we conducted a patient participation case study, where the bladder cancer VI team aimed to identify improvement potential based on patients' experiences using Metro Mapping (**Chapter 6**). Metro Mapping is a recently developed method for patient journey mapping that includes five layers: 1. The different steps of a patient journey, 2. The patient's experience throughout the journey, 3. The information that is shared with the patients, 4. The involved healthcare professionals, and

5. The context in which the care is delivered [7]. In our study, we focussed on the 'patient experience layer' of the Metro Map and evaluated the experiences of VI team members with this approach to identify improvement potential based on the patients' perspectives. Through 20 interviews with patients and a questionnaire completed by 57 patients, nine important topics for bladder cancer care improvement were identified, for example improving information on complications and risks after cystectomy or having a clear contact point for patients with non-muscle invasive bladder cancer. These improvement topics were discussed and prioritized during two co-creation sessions. Finally, the VI team members' experience with the development and applicability of the patient experience layer of the Metro Map was evaluated through a focus group. Overall, the project was positively experienced by VI team members and resulted in relevant insights for potential improvement initiatives. Moreover, several recommendations regarding the development and applicability of the patient experience layer of the Metro Map were made. For example, the role of the independent researcher to gain insight into patient experiences was experienced as an essential aspect for the development of the patient experience layer, and the engagement of VI team members and patient representatives was indicated as important for the applicability of the Metro Map to improve care.

7.2 General discussion

This thesis identified five steps for meaningful patient participation from literature, further developed these steps using insights from evaluation of (individual and collective) patient participation in the VBHC context, and tested and refined these in practice within VI teams using an action research approach. The five refined steps for meaningful patient participation are: 1. Ensure that preconditions for patient participation are met, 2. Develop a strategy for patient participation, 3. Prepare patients and staff for patient participation, 4. Put patient participation into action, and 5. Evaluate patient participation with both patients and staff. These five steps and the underlying practical recommendations are included in the practical guide for collective patient participation within multidisciplinary teams that work on improving value of care (**Intermezzo**). In this section, we would like to reflect on the five steps by combining the insights from the five studies of this thesis and insights from literature.

1. Ensure that preconditions for patient participation are met

In **Chapter 2**, several preconditions that are necessary to set up meaningful collective patient participation were identified based on existing literature, e.g.

the importance of having a positive attitude of the organization towards patient participation and having sufficient resources for patient participation. These were further complemented in **Chapters 3 and 5** with preconditions specific to the VBHC context, such as having a mature VI team. Additionally, in **Chapter 4,** several preconditions for the use of outcome data at the individual patient level were identified. Some of these align with preconditions required for collective patient participation, such as having adequate support and time for patient participation, and others were unique to the context, such as better engaging patients to complete PROMs to obtain meaningful data. Below, we will reflect on three key preconditions. Meanwhile, we want to stipulate that while our studies show the importance of these preconditions, it does not mean that patient participation is not possible without these preconditions.

One of the most important preconditions identified in our studies was having a mature and engaged VI team that feels responsible for patient participation. Our studies showed large differences between the maturity of VI teams. Previous studies have identified factors that influence the maturity of VI teams, such as the presence of motivated and enthusiastic medical leaders and project leaders [3,8]. Furthermore, a low sense of responsibility for patient participation might also be explained by the lack of a formal position that a VI team has within an organization, since VI teams are positioned as project groups additional to the traditional departments [9]. The more formally integrated the team is within the organization, the more responsibility it will naturally assume for patient participation, since they are then the only group dedicated to this patient group. This implies that that the shift towards more embedded forms of condition-based organization, i.e. matrix organization or integrated practice units, could positively influence more structural patient participation, as certain preconditions, such as formal responsibility for value of care, are key aspects of the setup of these condition-based units (CBUs) [9].

In our studies, the practical preconditions for implementation of patient participation were often lacking. While patient participation is widely acknowledged as a cornerstone of modern healthcare [10], and many hospitals have included patient participation within their vision and mission [11,12], the lack of resources for patient participation has repeatedly been reported as a barrier for both individual as collective patient participation [13,14]. Therefore, to truly transit to a healthcare system where patient values are integrated at all levels, hospital management must take an active role in facilitating patient participation [15]. This goes beyond including patient participation within the vision and mission. For instance, hospital management should allocate the necessary resources and support to set up and improve patient participation.

Besides the importance of practical preconditions, our results emphasize the importance of a supportive culture within the organization and VI teams to successfully implement patient participation. Our healthcare system is rooted in a ‘paternalistic system’, resulting in a power-imbalance between healthcare professionals and patients [16]. Since the introduction of patient-centred care in the 1950’s [17], this relationship started shifting towards a more equal partnership, primarily with regard to the individual patient level [16,18]. The equal role of patients at the collective level evolved later on [19,20]. This shift in roles from patients and healthcare professionals requires behaviour change of both patients and healthcare professionals. In order to understand and stimulate behaviour change, the behaviour change wheel has been developed. The behaviour change wheel includes nine types of interventions that stimulate behaviour change, e.g. training, education, enablement, and modelling [21]. Within the literature, several examples exists of the use of such interventions to support implementation of patient participation. For example, SDM is increasingly integrated into medical education and training for healthcare professionals, with studies suggesting positive impacts on their SDM skills [22]. Furthermore, patients and patient advocacy groups have played an important role in accelerating patient participation by raising awareness and educating patients about their ‘new’ role [23]. Moreover, the advancement of patient participation in other contexts may contribute to the ‘modelling’ intervention, i.e. share examples of meaningful patient participation for VI teams to aspire or imitate. However, there are only a few concrete examples of meaningful patient participation in the context of VBHC for VI teams [2]. **Chapter 2** indicates that collective patient participation has primarily advanced within the research context, possibly driven by mandates from funding agencies, medical ethics boards, journals, and national guidelines [24,25]. The wide range of frameworks that have been developed to support patient participation in the research context [26] could provide useful examples for patient participation in the context of care improvement. Finally, similar to patient participation in research, collective patient involvement in care improvement may also benefit from formal mandates and national guidelines to stimulate implementation.

2. Develop a strategy for patient participation

Chapters 2, 3, 4, and 5 provide multiple lessons and recommendations regarding the development of a strategy for collective and individual patient participation. In **Chapter 2 and 3,** we emphasized the importance of providing guidelines in when to use which collective patient participation method, but during the action research, it was found that development of such specific guidelines is not feasible. Patient participation requires a tailored approach based on the patient (population), the context (e.g. the characteristics of the VI team), and most importantly, the goal for patient participation. While many VI team members treated collective patient participation as a goal in itself, we identified two primary goals for collective patient participation in VI teams: 1. To identify improvement potential from patients' experiences, and 2. To gain their perspectives on improvement potential that is identified from process, outcome, or cost data, for example to interpret the data or to design, implement, or evaluate the intervention. Below, I would like to reflect on these goals and provide general recommendations for the strategies for patient participation that align with these two different goals for patient participation.

VI team members primarily mentioned the first goal, gathering improvement ideas from the patient perspective, when discussing patient participation. While this is an important goal for patient participation, it suggest that some VI team members confused this goal to be the overall purpose of patient participation. Meanwhile, VI teams traditionally identify improvement potential based on comparing and benchmarking different types of data [27], which is limitedly possible for patient experiences as these are not always quantitatively measurable. Subsequently, this led some VI teams to question whether this goal for patient participation aligned with their core responsibilities. This perspective suggests the importance of a cultural shift in some VI teams, in which improving patient experiences is considered equally important to improving outcome data. This is also stipulated in **Chapter 6,** where gaining insight into patients' experiences appeared to be essential for VI teams to identify improvement potential, with Metro Mapping being a useful approach to this end.

Interestingly, VI teams appear to have limited awareness of the second goal for collective patient participation, i.e. involve patients in improvement initiatives arising from data. To enhance this awareness, I recommend a two-method approach to participation, where each team includes one or two patient representative(s) in their team (providing a fixed structure for patient participation) and combines this with consulting groups of patients on specific topics using tailored methods for patient participation based on the goal and context. The patient representative within the team plays a key role in raising awareness about the importance of involving patients in improvement initiatives derived from different types of data. This two-method approach has also been recommended in other settings, such as research projects [28,29]. Notably, the method for consulting groups of patients can, depending on the topic and context, require minimal effort for the VI team and patients. In some cases, simply asking a few patients a targeted question during routine consultations may be sufficient.

Lastly, hospitals often seem to limit themselves to traditional patient participation methods, such as questionnaires and interviews, which are mainly language-based methods. This means that that they rely on verbal or written communication to gather input from patients. Research has pointed out that these methods potentially exclude a large group of patients that are less comfortable with such language-based methods [30]. This has led to a movement, mainly in mental healthcare, that uses more creative methods to involve patients that do not involve language. An example of this is photo voice, which is a method where patients use photographs to capture and communicate their experiences. Such art-based approaches can result in more meaningful and richer data compared to traditional qualitative methods, especially when exploring sensitive topics or including vulnerable groups [31].

3. Prepare patients and staff for patient participation

Within **Chapter 2**, several items are reported that help to prepare patients and staff for collective patient participation, such as training in patient participation and having a clear role for patients. In **Chapter 3**, VI team members primarily discussed the skills needed from patients to participate in a VI team. In **Chapter 5**, the focus shifted to describing the knowledge and skills required from VI team members to set up meaningful patient participation. This transition highlights that while *evaluating* collective patient participation, VI team members emphasize the importance of patients' skills for meaningful participation, but during actual *implementation*, they recognize the importance of their own skills in enabling this process. This shift is also evident in the initial increase in demand for training among intervention VI team members in the action research study. Furthermore, **Chapter 4** shows that healthcare professionals had several misconceptions regarding the use of outcome data at the individual level, and they indicated that they need to be trained in the use of outcome data at the individual level. This need for training on the use of outcome data in clinical consultations, e.g. regarding risk communication, has been stipulated before [13] and the literature underscores the importance of complementing theoretical knowledge with practical skills training to enhance the implementation of SDM [32]. Interestingly, VI team members seemed less eager to be trained in collective patient participation (**Chapter 3 and 5**), and they indicated that collective patient participation is something that you learn by doing. I therefore believe that VI team members would mainly benefit from actions to increase their awareness on patient participation and stimulate them to get into action instead of theoretical training. The action research approach proved to be highly suitable to this end.

The opinions on the need of training of patients in collective patient participation are dispersed in the literature. Some studies underpin the importance of training [28,33–35], while others criticize it, as this would lead to 'proto-professionalism' of patients [36]. 'Proto-professionalization' of patients refers to the process in which patient representatives increasingly adopt professional language, behaviours, and norms. This has the risk of non-patient team members questioning whether such 'proto-professional' patients still authentically represent the experiential insights they were meant to bring to the table, and therefore taking their input less seriously [36,37]. Based on our findings and the perspectives of interviewed patient VI team members, we would recommend training of patients in skills to participate meaningfully but limit theoretical training to counter 'proto-professionalism'. Such training in participation skills is mainly important for patients that are involved in structural patient participation activities, such as participating in the VI team or in a panel, and less for patients who are involved in one-time participation activities. For this latter group, it is primarily important that they are aware of the goal for participation.

Lastly, results of **Chapter 3** show that healthcare professionals and patients both seem to struggle with shifting their doctor-patient relationship to a 'colleague' relationship and do not discuss these struggles with each other. This could be due to the traditional hierarchy between healthcare professionals and patients, creating a more formal relationship and therefore inhibit open, equal conversations about role expectations and shared responsibilities [37,38]. Future implementation and improvement of collective patient participation should therefore focus on joint training and dialogue to enable healthcare professionals and patients to grow into their new roles together.

4. Put patient participation into action

In the literature review, we described the fourth step for meaningful patient participation as 'support patients and staff during patient participation' (**Chapter 2**). However, based on the findings during the action research study (**Chapter 5**), we changed this to ‘put patient participation into action’. The reason for this change was that we noticed that, even if the previous three steps were undertaken, there remained a gap between talking about patient participation and actually putting it into action. This appeared for example from **Chapter 5,** where limited improvements in collective patient participation were made by the control teams compared to the intervention teams over a period of twenty months, and **Chapter 2** where we found that overall, little progress in structuring collective patient participation has been made over the last twenty years. The same hesitation seems to hold true for individual level patient participation, as shown in **Chapter 4** and discussed in the literature [32]. During the study period, the use of outcome data at the individual level was a key focus in Santeon hospitals as part of the 'Experiment Outcome Indicators' [39], but **Chapter 4** indicates that beyond the three pathways included in this initiative, progress in utilizing aggregated outcome data at the individual patient level remained limited.

Several factors contributed to the hesitation to take action in patient participation in our research, but one of the most prevalent was the limited availability of time among VI team members. This is a recurring theme in the context of VBHC and patient participation [3,5,15,40,41]. In my view, the ‘lack of time’ argument implies that, currently, patient participation is still considered an additional task instead of the standard approach to value improvement and care delivery. As well, I think that in the end, patient participation can even save time, as this helps to take on improvement initiatives and deliver care that aligns with patients’ needs and preferences [42,43], suggesting that no time would be wasted on less valuable care (improvements).

5. Evaluate patient participation with both patients and staff

Chapters 2, 3, and 5 describe the importance of the evaluation of collective patient participation with both patients and staff. In these chapters, we mainly focused on evaluating the *process* of patient participation, and to a lesser extent on the evaluation of the *impact* of patient participation. We considered this a necessary first step, as assessing the impact of patient participation is only meaningful once proper implementation has been ensured. The PPEET questionnaire that was used in **Chapter 3 and 5** does measure the impact of patient participation, but only based on (subjective) experiences of VI team members regarding the impact. Meanwhile, there is an increasing demand for the objective evaluation of the impact of patient participation, also highlighted in **Chapter 6**.

Currently, the evaluation of the *process* of collective patient participation is prominent in the literature [44], and the evidence for the *impact* of collective patient participation is minimal [45]. There is even less insight into the cost-effectiveness of patient participation at the collective level [20,46]. This might be due to the limited availability of (validated) evaluation tools for the impact of patient participation, as most of them mainly focus on the process of patient participation [47,48]. When impact is measured, it often concerns the effect on participating individuals [47], or the outcomes are largely based on self-reported data and (subjective) experiences of both patients and healthcare professionals [6]. This lack of insight into the impact of patient participation might also be a reason for the hesitation of hospitals to allocate resources for patient participation, as they are uncertain about how these costs compare to the benefits of patient participation. While the evaluation of the impact of patient participation might help to build broader support and address scepticism towards collective patient participation in care improvement, I would also like to stipulate that the implementation of patient participation should never be solely dependent on the evidence of its impact, since the normative argument (i.e. patients have the right to be involved) is evenly important as the impact argument [49].

7.3 Methodological considerations

This thesis involves several overarching methodological considerations, both strengths and limitations, that are important for interpreting its results. In this paragraph, four overarching methodological considerations are highlighted and some reflections on the action research process (**Chapter 5**) are discussed.

First, during the study period, I had a dual role, i.e. that of an advocate/advisor in patient participation and of an objective researcher. I believe that this dual role was essential to the success of the research project. The advocacy role helped to raise awareness and foster a more positive attitude of VI team members toward collective patient participation, which was a crucial step in driving meaningful patient participation. However, this could have introduced bias in the collected data. For example, I advocated for patient participation in meetings and events outside of the research project, but at the same time conducted interviews on patient participation. This could have influenced my view and interpretation of the results of the studies and participants could have been inclined to provide socially desirable answers towards me [50]. This potential bias was limited by double-coding the data, discussing the results with different stakeholders throughout the research project, and explicitly encouraging participants to share their honest opinions and experiences regarding patient participation. Since the results include participants' critical perspectives on patient participation, we are confident that the influence of this bias was limited.

Secondly, a major strength of this research was the continuous involvement of patient representatives throughout the different studies, from design to publication. We worked closely with one patient representative from the client council of St. Antonius Hospital (one of the Santeon hospitals) and one from the Dutch Patient Federation, a combination that brought valuable and complementary perspectives and expertise. They provided essential input from their perspectives on different levels, e.g. on the information materials for patients, the design and protocols of the studies and interpretation of the results. Their perspectives helped to continuously remain aware of the patients' viewpoint. For example, it was one of the patient representatives that pointed out that it was interesting that we were discussing the evaluation of the impact of patient participation in VI teams, while the involvement of e.g. nurses and medical specialists in such teams is generally assumed to be self-evidently valuable. Midway through the studies of this thesis, there were some changes in patient representatives, which posed some challenges, especially when new patient representatives joined an ongoing study and lacked prior context or were unable to influence earlier decisions due to fixed study protocols. To address this, I initiated one-on-one conversations with the patient representatives to provide additional background before joining broader research meetings. In addition, I conducted annual one-on-one evaluation meetings to reflect on the collaboration over the past year and what could support effective collaboration going forward.

Thirdly, we would like to discuss the limitations in transferability of the results of our studies. Most studies were conducted in the context of the Santeon hospitals, which are frontrunners in VBHC implementation in the Netherlands. The results of our studies are therefore mainly relevant for CBUs with a similar context as the Santeon hospitals [9]. Four archetypes of CBUs have been identified, i.e. multidisciplinary project teams, matrix organization, integrated practice units, and independent treatment centres. These different archetypes differ in levels of responsibilities, independence, and disruption of the 'traditional' organizational structure around medical specialties [9]. Most of the Santeon hospitals work with multidisciplinary project teams, i.e. the VI teams, and a few have set up a matrix organization archetype around specific patient groups. Importantly, there is considerable variation among the Santeon hospitals themselves in organizational structures and approaches to the VI teams, which strengthens the transferability of our recommendations. We therefore believe that our recommendations for patient participation can also be transferred to other types of CBUs, e.g. by identifying a group or meeting within the CBU where value improvement initiatives are discussed (so resembling the Santeon VI team context).

Fourthly, there was limited participation of vulnerable patient groups in our studies. Despite our efforts to include diverse patient populations, e.g. using plain language in the questionnaire, our results indicate that participation of vulnerable groups (such as with low health literacy) remained low. This might be due to the use of traditional, language-based participation methods, such as questionnaires, interviews and focus groups, which limitedly reach patient populations that feel less comfortable with these methods [30].

Reflection on the action research process

At the beginning of the action research study, I became aware that both the VI team members and I (the action researcher) needed time to get used to the highly participatory role within the action research project. For example, during the first few meetings with the intervention teams, I noticed that the VI team members expected that I would have a thought-out intervention ready for them, instead of co-creating the intervention together. Adapting to this participatory approach required a shift for me (as action researcher) as well, since I was previously used to adopting a more observational role in research. This adjustment in roles may have initially slowed progress or strained relationships. Throughout the study period, both the VI team members and I became more acquainted with our roles, which positively influenced the progress of the action research. Even though I had received training in action research prior to the start of the study, I experienced that action research is, similar to patient participation itself, something that you mainly learn by doing.

Furthermore, we described in **Chapter 5** that some teams completed a single action research cycle, while others went through multiple cycles. However, in practice, the cyclical nature of action research is often more fluid than it appears on paper [51]. The action research process can therefore better be visualized as a series of smaller cycles nested within a larger cycle. The larger cycle represents the overarching process of co-creating, implementing, and evaluating the main intervention (in our case patient participation activities) and within this larger cycle, smaller learning cycles continuously take place. For example, nearly every meeting with the intervention teams involved elements of planning, action, and evaluation, indicating that a small learning cycle was completed within each session. This resembles the ‘spiral of action research’ as explained by McNiff, who indicates that action research is an ongoing spiral of action and reflection, where each cycle builds on the learning from the previous one [52].

7.4 Recommendations for practice and research

The results of our studies have been combined into a practical guide for collective patient participation. This practical guide includes the five steps for patient participation, and can be used in daily practice by multidisciplinary project teams that work on improving care. Here, I would like to discuss four overarching recommendations for practice and research that transcends these individual multidisciplinary project teams and are essential for further implementation and improvement of patient participation in care improvement.

Recommendation 1: Increase awareness on the importance of collective patient participation in care improvement

During the course of this research project, we observed that awareness of collective patient participation was limited within VI teams. For instance, when the term patient participation was mentioned, VI team members often primarily associated it with individual-level participation, such as shared decision-making in clinical encounters. Moreover, many VI team members were often unaware of the potential roles patients can play in identifying, designing, and implementing value improvement initiatives. Therefore, raising awareness is essential for fostering collective patient participation.

In 2024, we launched a national working group on collective patient participation, as part of the Linnean Initiative. The Linnean initiative is a Dutch network that focusses on the acceleration of implementation of VBHC within the Dutch healthcare system and has multiple workgroups [53]. The primary goal of the Collective Patient Participation working group is to increase awareness around collective patient participation and to support hospitals in implementing meaningful and structural collective patient participation within their organization.

Ultimately, collective patient participation is not only essential for VI teams, but also for addressing broader challenges and transformation projects within healthcare. As emphasized in the Integral Care Agreement (Dutch: Integraal Zorgakkoord, IZA), patient participation is a critical component in preparing our healthcare system for the future. The system currently faces significant pressures to remain sustainable, requiring a fundamental shift in how care is delivered. This includes moving care away from hospitals where possible, increasing patients' self-management responsibilities, and accelerating the use of digital health solutions [10]. In all of these transitions, meaningful patient participation is indispensable to ensure that changes align with patients' needs, preferences, and lived experiences. Our recommendations can contribute to improved patient participation in these transitions, also when there are no VI teams or other CBU types in place.

Recommendation 2: Set up organizational policies for patient participation

The Santeon hospitals collaboratively developed a general vision on patient participation, which indicates the importance of structural and meaningful involvement of patients in VI teams. Throughout the action research study, efforts were made to translate this vision into practice. However, the absence of organization-wide policies, regulations, and clear requirements seemed to create a disconnect between the vision and its actual implementation in practice (within both the intervention as well as the control teams). The 8-Step Change Model of Kotter also indicates that creating a vision is only one of the eight steps to effectively implement transformation, where other steps include empowering staff to take action to incorporate changes and integrating the change in the culture, systems, and processes [54]. Multiple VI team members outed their wish to have clear organizational policies and requirements for patient participation, also to stimulate themselves to prioritize patient participation in their team. Such policies should include e.g., minimal requirements for patient participation and clear agreements on compensation for participating patients. It would be helpful if hospital-wide policies and agreements for patient participation in care improvement align as much as possible with those for patient participation in research (e.g. similar compensation for participating patients), although differences may exist due to the different contexts. Such alignment fosters a consistent approach to patient participation within the hospital setting, reducing confusion for patients for whom the difference between involvement in research versus care improvement initiatives is less evident.

Furthermore, organizational policies should clearly define who is responsible for the support in organizing patient participation activities, implementation, and further improvement and development of patient participation. These responsibilities can be distributed across departments, for example, the marketing and communication team may be responsible for support in organizing patient participation activities, VI team members may handle implementation, and the VBHC advisory team may lead further development and innovation. Currently, many Santeon hospitals lack formal agreements on these roles, or only assign responsibility for support in organizing patient participation activities. Our research shows that without clear ownership for implementation and improvement, patient participation remains limited and underdeveloped. There is a need for dedicated capacity for implementation and improvement of patient participation, particularly during the transition phase toward a more mature and embedded form of participation. Initially, this requires a higher level of capacity and support, which can be scaled down once patient participation is integrated into routine practice of the VI teams. These different levels of capacity can be compared to the St. Antonius Hospital's (one of the Santeon hospitals) approach for setting up VI teams, where central advisors temporarily support VI teams as project leaders of the teams, followed by more remote support once the team is embedded into routine practice.

Recommendation 3: Implement patient participation

During the action research study, the level of patient participation improved within the intervention teams, but the results show that still limited progress was made in the control teams. In addition, the intervention teams were selected based on their motivation to improve patient participation, and this motivation may lack in some of the control teams. The previously suggested organizational policies will hopefully help to increase implementation and improve patient participation, but we believe that there is still a need for active support (e.g. by appointing a project leader) for large-scale implementation of patient participation in VI teams based on the recommendations in our practical guide.

Participation of vulnerable patient groups

While many lessons regarding the implementation of patient participation were learned throughout the different studies, knowledge on several specific topics is still missing. For example, there is still need for more insight into the participation of 'easy to neglect' patient groups, such as people with low health literacy of people with different cultural backgrounds. During our action research study, there was limited involvement of such patient groups, possibly due to the use of traditional, language-based participation methods, which often excludes these patients. Therefore, future research should dive into the participation of vulnerable groups of patients in value improvement initiatives, e.g. by studying whether more creative methods for patient participation would contribute to this end.

Patient participation in other types of condition based units

Future studies should also focus on the implementation of patient participation in VBHC in settings beyond the Santeon hospitals, including nationally and internationally, and across different types of CBUs, as literature shows an overall limited level of international implementation of patient participation in VBHC initiatives [2]. Our lessons learned are primarily based on the context of the Santeon hospitals and the multidisciplinary project team type of CBU. For example, we identified the importance of having a mature multidisciplinary project team to improve patient participation. However, as mentioned previously, the maturity of a VI team also depends on the formal position that these teams have within the organization. This implies that patient participation is easier to embed in the other types of CBUs (e.g. the matrix organization). On the other hand, we also noticed that it is more difficult to appoint a specific setting where patient representatives could participate in these different CBU types, as there is not one specific meeting where value improvements are discussed because improvements are more integrated in daily practice. Therefore, there is a need for insight into the applicability of our recommendations and practical guide in other VBHC settings. Strengthening patient participation in CBUs is not only vital for the value improvement cycle itself, but also for driving broader innovation and improvement efforts. Within a condition-based organization, CBUs are the dedicated units for implementing innovations tailored to specific patient groups. By embedding patient participation within these units, there is potential to enhance patient participation in a wide range of improvement initiatives, for example the implementation of digital care pathways, setting up regional collaboration, and the implementation of Appropriate Care initiatives.

Based on the results of our action research study (**Chapter 5**), I would recommend an action research approach for the further development of knowledge on patient participation. For example, during our action research study, the VI team members indicated that patient participation is best learned through practical experience. Moreover, VI team members noted that a key facilitator of the study was the action researcher. This action researcher encouraged teams to take action, helped to identify opportunities for improvement in patient participation, and facilitated horizontal learning across VI teams by sharing insights and good practices from other teams. These aspects can contribute to larger scale implementation and improvement of patient participation. Importantly, in hospital settings, scientific research remains the standard for demonstrating the added value of new approaches. An action research design not only supports practical change, but also provides the rigorous, scientific insights needed to justify and sustain such changes within the healthcare system.

Recommendation 4: Evaluate the impact of patient participation

As described previously, our studies mainly focused on the evaluation of the *process* of patient participation, and limitedly on the *impact* of patient participation. This evaluation of the process is particularly crucial at the team level, where it can reveal opportunities to improve patient participation within the VI team. At the organizational level, there is a need for insight into the impact of patient participation. Such understanding is essential since questions regarding the impact of patient participation continue to arise and hospitals struggle with determining which investments they are willing to make in collective patient participation while they are unsure of the (potential) impact. That said, decisions about investments in patient participation should not be based solely on measured impact. The right of patients to have a voice in healthcare improvement remains a core principle regardless of the impact. Furthermore, when evaluating impact, it is vital to recognize that the impact is always the result of joint efforts between patients and healthcare professionals, rather than the input of patients alone.

The evaluation of the impact of patient participation should be tailored to the goal for patient participation. As stated previously, VI teams can have two distinct goals for collective patient participation. For the first goal, to identify potential improvements based on the patient experiences, the Metro Mapping approach may offer a suitable impact evaluation strategy. This method includes a baseline measurement of patient experiences, which can be repeated after implementing the interventions to assess their impact. In this case, the VI team is actually not evaluating the impact of patient participation itself, but of the improvement initiatives that have been identified and implemented through patient participation.

For the second goal of patient participation, i.e. involve patients in improvement initiatives that are identified from insight in outcomes, processes, or costs data, evaluation of the impact of patient participation is more difficult. This is due to the challenge of proving a causal relation between patient participation and the outcomes of interest, as multiple factors interact (e.g. the context of the VI team), and patient participation cannot be isolated from other influences. For example, even if patients provide valuable input on the design of an improvement initiative, the resulting impact may remain limited if the VI team does not act on this input, either because it is not taken seriously or because external constraints, such as national guidelines, prevent the use of the patient’s input. The Theory of Change can support the evaluation of such a complex intervention. This theory outlines how a complex intervention is expected to lead to its intended impact by clarifying the steps and underlying assumptions that connect the intervention to long-term outcomes. It distinguishes between the following phases: input, activities, output, and expected outcomes/impact [55]. These phases allow for the development of an 'impact pathway.' Within such an impact pathway, several (intermediate) outcome indicators for collective patient participation could be determined. The outcome indicators could be based on the qualitative evidence of the impact of collective patient participation. For example, studies reported that collective patient participation has led to increased patient-centricity in healthcare services or increased uptake of an intervention as it better reflected patients' needs [56,57]. In these cases, outcome indicators might be measurements of patient-centred care [58] or the percentage uptake of the intervention. Moreover, an evaluation toolkit for the impact of patient participation in care improvement has been developed by Abelson and colleagues, that discusses eight domains of impact of patient participation (e.g. cultural change and patient outcomes and experience) and provides guidance in the evaluation thereof [59]. Lastly, an impact pathway addresses the role of the input and activities in the final output and outcomes of an intervention. This requires continuous evaluation of the process of patient participation and the VI teams, to evaluate the actual input and activities that have been undertaken in patient participation in practice. To this end, evaluation tools for the process of patient participation or VI teams can be used [47,60].

7.5 Conclusion

In this thesis, we explored how to improve patient participation within the context of VBHC. While previous studies have highlighted the challenges of patient participation and called for practical guidance, our research aimed to bridge this gap by offering concrete lessons and insights in individual and collective patient participation in the context of VBHC. Overall, our findings highlight opportunities to more fully integrate patient participation as an integral aspect of value improvement and care delivery. Based on the insights of the studies in this thesis, we derived five steps to help to ensure structural and meaningful patient participation in VBHC:

1. Ensure that preconditions for patient participation are met
2. Develop a strategy for patient participation
3. Prepare patients and staff for patient participation
4. Put patient participation into action
5. Evaluate patient participation with both patients and staff

In conclusion, this thesis offers valuable lessons to improve patient participation. Wide adoption of these lessons contribute to healthcare improvements that genuinely reflect patient needs and preferences.

7.6 References

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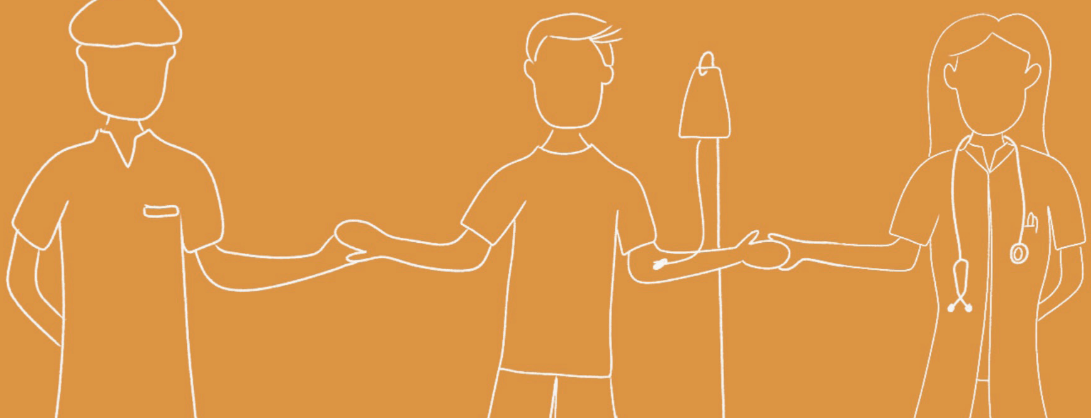

Appendices

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Nederlandse Samenvatting

De stem van de patiënt is van cruciaal belang voor het verbeteren van zorg, omdat patiënten unieke kennis bezitten op basis van hun ervaringen in het gehele zorgtraject. Op individueel niveau spelen patiënten een essentiële rol bij het afstemmen van zorg op hun persoonlijke voorkeuren. Op collectief niveau bieden zij waardevolle inzichten om samen met zorgmedewerkers te werken aan zorgverbetering. Ondanks toenemende betrokkenheid van patiënten op verschillende niveaus in de zorg, ontbreekt structurele collectieve patiëntparticipatie op het niveau van aandoeningen vaak. Dit komt mede doordat ons zorgsysteem is gericht op medisch specialismen, wat leidt tot versnipperde verantwoordelijkheden voor de (verbetering van) zorg voor specifieke aandoeningen. De overgang naar een waardegedreven zorgsysteem biedt een oplossing door de zorg te reorganiseren en verbeteren rondom het zorgproces van de patiënt. Dit gebeurt bijvoorbeeld door multidisciplinaire verbeterteams op te zetten die samen werken aan verbeteringen in de zorg voor een specifieke aandoening. Toch blijkt uit onderzoek dat patiënten nog minimaal worden betrokken, en verschillende studies geven aan dat er behoefte is aan inzicht in hoe je patiënten op een betekenisvolle manier kan betrekken binnen waardegedreven zorg. De hoofdvraag van dit proefschrift luidt daarom: “Hoe kunnen patiënten op een betekenisvolle manier worden betrokken in waardegedreven zorg?”

De volgende onderzoeksvragen zijn geformuleerd om de hoofdvraag
te beantwoorden:

Deel 1| Inzichten uit de literatuur
1. Wat kunnen we leren uit de literatuur met betrekking tot collectieve patiëntparticipatie?

Deel 2| Huidige situatie
2. Hoe wordt op dit moment collectieve patiëntparticipatie in multidisciplinaire verbeterteams vormgegeven?
3. Hoe wordt op dit moment uitkomstdata op het niveau van individuele patiënten gebruikt?

Deel 3| Good practices voor collectieve patiëntparticipatie
4. Wat zijn *good practices* voor collectieve patiëntparticipatie in multidisciplinaire verbeterteams?

Deel 4| Verbeteren van zorg op basis van patiëntervaringen
5. Hoe kunnen multidisciplinaire verbeterteams patiëntervaringen gebruiken voor het verbeteren van zorg?

Context:
De meeste onderzoeken die zijn uitgevoerd om deze onderzoeksvragen te beantwoorden, vonden plaats in de Santeon ziekenhuizen. Santeon is een samenwerking van zeven grote topklinische ziekenhuizen in Nederland die werken aan waardegedreven zorg via het programma ‘Samen Beter’. Voor vijftien medische aandoeningen zijn er in elk ziekenhuis multidisciplinaire verbeterteams opgericht die samenwerken om de zorg te verbeteren.

Hieronder zullen we de verschillende hoofdstukken samenvatten en antwoord geven op de onderzoeksvragen. Tot slot bespreken we de conclusies van dit proefschrift.

Deel 1| Inzichten uit de literatuur

Om de eerste onderzoeksvraag te beantwoorden hebben we een systematisch literatuuronderzoek uitgevoerd naar bevorderende en belemmerende factoren voor betekenisvolle patiëntparticipatie op collectief niveau in zorginstellingen (**Hoofdstuk 2**). We hebben in twee literatuurdatabases gezocht naar artikelen die collectieve patiëntparticipatie evalueerden (n=4397) en 59 artikelen in ons literatuuronderzoek geïncludeerd. De meest voorkomende methode voor collectieve patiëntparticipatie was patiënten te betrekken in het project of onderzoeksteam. Door middel van narratieve analyse van de gerapporteerde bevorderende en belemmerende factoren voor patiëntparticipatie hebben we vijf aanbevelingen voor betekenisvolle patiëntparticipatie verwoord. Dit zijn: (1) zorg voor de juiste randvoorwaarden voor patiëntparticipatie, (2) ontwikkel een strategie voor patiëntparticipatie, (3) bereid patiënten en medewerkers voor op patiëntparticipatie, (4) begeleid patiënten en medewerkers tijdens patiëntparticipatie, en (5) evalueer patiëntparticipatie met patiënten en medewerkers. Wat opviel was dat dezelfde belemmerende factoren voor patiëntparticipatie werden genoemd gedurende een periode van 20 jaar, wat impliceert dat er weinig voortgang is gemaakt in het borgen van patiëntparticipatie. De helft van de geïncludeerde studies hebben de impact van patiëntparticipatie geëvalueerd, en rapporteerden dat patiëntparticipatie voornamelijk positieve impact had op de kwaliteit van onderzoek en zorg, het team en de organisatie, en de individuen betrokken bij de patiëntparticipatie.

Deel 2| Huidige situatie

In deel twee onderzochten we de huidige situatie (2022-2023) van patiëntparticipatie in de context van waardegedreven zorg. In **Hoofdstuk 3** evalueerden we de mate van collectieve patiëntparticipatie in de verbeterteams van de Santeon ziekenhuizen middels een mixed-methods aanpak (onderzoeksvraag 2). We hebben 30 verbeterteamleden geïnterviewd, waaronder 12 patiënten, en 147 verbeterteamleden van 76 verschillende verbeterteams hebben de Nederlandse vertaling van de ‘Public and Patient Engagement Evaluation Tool (PPEET)’ ingevuld. Het oorspronkelijke doel van Santeon was om in elk verbeterteam een patiënt te betrekken, maar de resultaten van onze studie lieten zien dat op dat moment maar de helft van de 76 geïncludeerde verbeterteams een vorm van patiëntparticipatie gebruikten. Negen thema’s werden geïdentificeerd middels de interviews en vragenlijsten. We vonden onder andere dat veel verbeterteams geen duidelijke strategie en doel voor patiëntparticipatie hadden, wat ook het gebrek van patiëntparticipatie in veel verbeterteams kan verklaren. Daarnaast noemden verbeterteamleden dat specifieke kennis en vaardigheden nodig zijn van patiënten om deel te nemen in een verbeterteam. Dit leidde tot het betrekken van patiënten met deze kennis en vaardigheden, wat vervolgens weer tot zorgen met betrekking tot de representativiteit van deze betrokken patiënten leidde. Tot slot gaven verbeterteamleden aan dat de patiëntparticipatie weinig impact heeft gehad. Over het algemeen laten deze resultaten zien dat patiëntparticipatie (nog) niet volledig is geborgd in de huidige werkwijze van verbeterteams.

In **Hoofdstuk 4** hebben we het gebruik van uitkomstdata op het niveau van individuele patiënten geëvalueerd (onderzoeksvraag 3). Zorgverleners van de Santeon ziekenhuizen die ervaring hadden met het gebruik van uitkomstdata voor het verbeteren van zorg zijn geïnterviewd (n=11). We hebben deze zorgverleners gevraagd in welke mate zij dezelfde data gebruiken in de spreekkamer voor individuele patiëntparticipatie, bijvoorbeeld bij het maken van een behandelkeuze. Zorgverleners gaven aan dat geaggregeerde uitkomstdata nog weinig op het niveau van individuele patiënten worden gebruikt en dat ze verschillende belemmeringen daarin ervaren, zoals de minder betrouwbare data door de lage responspercentages van patiënt gerapporteerde uitkomsten metingen (PROMs). Ze noemden verschillende acties die ondernomen kunnen worden om dit te verbeteren, zoals het ondersteunen van patiënten bij het invullen van PROMs. Het viel daarnaast op dat zorgverleners een aantal misvattingen hadden met betrekking tot het gebruik van uitkomstdata in de spreekkamer, bijvoorbeeld dat keuzehulpen de ‘traditionele’ gesprekken tussen zorgverleners en patiënten vervangen. Vervolgens is een vragenlijst ingevuld door 283 patiënten uit heel Nederland met prostaatkanker, longkanker of inflammatoire darmziekte (IBD). In deze vragenlijst hebben we patiënten gevraagd hoe belangrijk ze bepaalde uitkomstindicatoren vinden en in hoeverre ze deze uitkomsten willen weten of bespreken met hun zorgverlener. Over het algemeen vonden patiënten informatie over de meeste uitkomsten (77%) (zowel klinisch als patiënt gerapporteerd) relevant voor het maken van een behandelkeuze. Patiënten met long- of prostaatkanker vonden alle uitkomsten belangrijk, terwijl patiënten met IBD met name de patiënt gerapporteerde uitkomsten, zoals vermoeidheid en pijn, als belangrijk scoorden. Deze studie benadrukt hoe belangrijk het is om uitkomstdata te gebruiken voor individuele patiëntparticipatie, zowel vanuit het oogpunt van zorgverleners als van patiënten.

Deel 3| Good practices voor collectieve patiëntparticipatie

Om inzicht te krijgen in de *good practices* voor collectieve patiëntparticipatie in multidisciplinaire verbeterteams (onderzoeksvraag 4) hebben we een actieonderzoek uitgevoerd (**Hoofdstuk 5**). De bevindingen uit het literatuuronderzoek en de evaluatie van collectieve patiëntparticipatie in verbeterteams vormden de basis voor het actieonderzoek. Dit actieonderzoek had drie doelen: (1) patiëntparticipatie verbeteren in de verbeterteams, (2) de kennis en vaardigheden van de deelnemende teamleden op het gebied van patiëntparticipatie vergroten en (3) een handreiking voor patiëntparticipatie ontwikkelen op basis van de geleerde lessen. Zeven verbeterteams (de interventieteams) deden mee aan de cyclische stappen van actieonderzoek gedurende 20 maanden. Tijdens deze 20 maanden hebben we drie keer de PPEET-vragenlijst verstuurd naar alle Santeon verbeterteams, zowel de interventieteams als alle overige verbeterteams. In totaal zijn in het kader van het actieonderzoek 106 afspraken geweest met de interventieteams, en is de PPEET 302 keer ingevuld. De resultaten laten zien dat voor alle drie de doelen van dit actieonderzoek positieve uitkomsten zijn bereikt. De PPEET-data toonden bijvoorbeeld aan dat 71% van de interventieteamleden heeft ervaren dat patiëntparticipatie impact had op het team, ten opzichte van 44% in de controle teams. Daarnaast had 80% van de interventieteamleden behoefte aan training in patiëntparticipatie na de eerste zes maanden in het actieonderzoek; dit daalde naar nog maar 29% in de eindfase van het actieonderzoek. In totaal zijn er 22 lessen geïdentificeerd met betrekking tot het verbeteren van patiëntparticipatie in verbeterteams. De lessen, samen met de inzichten uit hoofdstuk 2 en 3 zijn gebundeld in een handreiking voor patiëntparticipatie bij waardegedreven zorg. Deze handreiking bevat aanbevelingen voor patiëntparticipatie in multidisciplinaire teams die werken aan het verbeteren van zorg.

Deel 4| Verbeteren van zorg op basis van patiëntervaringen

Een kernprincipe van waardegedreven zorg is het opzetten van een continue verbetercyclus rond het zorgtraject van een specifieke aandoening, gestuurd door uitkomst-, proces- en kostendata. Naast deze data worden ook patiëntervaringen steeds vaker erkend als waardevolle input voor het verbeteren van zorg. Toch ontbreekt er binnen waardegedreven zorg een systematische aanpak om inzicht te krijgen in patiëntervaringen en om deze inzichten te gebruiken voor het verbeteren van zorg. We onderzochten daarom in **Hoofstuk 6** hoe een verbeterteam inzicht kan krijgen in patiëntervaringen voor het verbeteren van zorg (onderzoeksvraag 5). Dit deden we aan de hand van een casestudy, waarbij we samen met het blaaskanker verbeterteam de patiëntervaringen met de zorg voor blaaskanker in het St. Antonius Ziekenhuis in kaart hebben gebracht middels Metro Mapping. Metro Mapping is een recent ontwikkelde methode en richt zich op vijf verschillende lagen: 1. de stappen van een patiëntenreis (de metrolijn), 2. de ervaringen van patiënten tijdens deze reis, 3. de informatie die aan patiënten wordt gegeven, 4. de betrokken zorgverleners, 5. de context waarin de zorg wordt geleverd. Op basis van 20 interviews met patiënten en naasten (met gebruik van de metrolijn) en 57 ingevulde vragenlijsten van patiënten hebben we negen belangrijke verbeterpunten in de zorg voor patiënten met blaaskanker geïdentificeerd, zoals het hebben van een duidelijk aanspreekpunt, en gevisualiseerd in de Metro Map. Vervolgens hebben we de ervaring van de verbeterteamleden met Metro Mapping geëvalueerd in een focusgroep. Het project werd over het algemeen positief ontvangen en leverde waardevolle inzichten op voor mogelijke verbetertrajecten op basis van ervaringen van patiënten. Daarnaast werden er diverse aanbevelingen gedaan voor het inzetten van Metro Mapping om verbeterpunten op basis van patiëntervaringen te identificeren. Zo werd de inzet van een onafhankelijke onderzoeker, die inzicht biedt in de beleving van patiënten, als een cruciale factor voor het succes van het project benoemd.

Discussie en conclusie

In dit proefschrift hebben we onderzocht hoe patiëntparticipatie binnen de context van waardegedreven zorg verbeterd kan worden. Eerdere studies hebben de uitdagingen van patiëntparticipatie benadrukt en opgeroepen tot praktische handvatten. Ons onderzoek heeft deze kloof proberen te overbruggen door concrete lessen en inzichten te bieden over zowel individuele als collectieve patiëntparticipatie binnen waardegedreven zorg. De inzichten in collectieve patiëntparticipatie leiden tot vijf concrete aanbevelingen (gebundeld in een handreiking) die gebruikt kunnen worden in de dagelijkse praktijk door multidisciplinaire verbeterteams die samen met patiënten willen werken aan waardegedreven zorg:

1. Creëer de juiste condities en randvoorwaarden voor patiëntparticipatie
2. Bedenk je plan van aanpak voor patiëntparticipatie
3. Bereid de patiënten en het team voor op patiëntparticipatie
4. Ga aan de slag met patiëntparticipatie
5. Evalueer patiëntparticipatie op vaste momenten binnen het team

Op basis van de resultaten uit de studies en de bestaande literatuur zijn vier aanvullende aanbevelingen geformuleerd voor organisatiebeleid, (inter)nationaal beleid en toekomstig onderzoek, die van belang zijn voor het verder versterken van patiëntparticipatie. Ten eerste moet er meer aandacht en bewustwording komen voor het belang van collectieve patiëntparticipatie. Ten tweede zouden ziekenhuizen duidelijke richtlijnen en randvoorwaarden moeten vastleggen voor patiëntparticipatie, bijv. over de verantwoordelijkheden en beschikbare middelen voor patiëntparticipatie. Ten derde bevelen we bredere toepassing van onze bevindingen aan, zowel binnen de Santeon-ziekenhuizen als daarbuiten. Daarbij is het belangrijk om te onderzoeken of onze aanbevelingen ook werken binnen andere aandoeningsgerichte organisatievormen, zoals matrixorganisaties of 'integrated practice units'. Ook moedigen we ziekenhuizen aan te experimenteren met alternatieve vormen van patiëntparticipatie, bijvoorbeeld via creatieve methoden, met name om de betrokkenheid te vergroten van patiënten die door bijvoorbeeld door beperkte gezondheidsvaardigheden, taalproblemen of laaggeletterdheid moeilijker bereikt worden. Ten vierde pleiten we voor vervolgonderzoek naar de (kwantitatieve) impact van collectieve patiëntparticipatie. In onze studies lag de nadruk vooral op het evalueren van het *proces* van participatie en minder op het *effect* ervan. Hoewel het 'ethische argument' (patiënten hebben het recht om betrokken te worden) voor patiëntparticipatie belangrijk blijft, denken we dat het kunnen aantonen van objectieve impact essentieel is voor bredere acceptatie. Op dit moment hangt de toepassing van patiëntparticipatie namelijk sterk af van de motivatie van individuele verbeterteamleden.

Al met al biedt dit proefschrift waardevolle inzichten om patiëntparticipatie te verbeteren. We hopen dat een bredere toepassing van deze lessen bijdraagt aan zorgverbeteringen die nog beter aansluiten bij de behoeften en voorkeuren van patiënten.

Research Data Management paragraph

Ethics and privacy

This thesis is based on the results of research involving human participants and existing data from published papers, which were conducted in accordance with relevant national and international legislation and regulations, guidelines, codes of conduct and Radboudumc policy. A statement that the study was not subject to the Dutch Medical Research Involving Human Subjects Act (WMO), was obtained from the recognized Medical Ethics Review Committee 'MEC- Utrecht' for chapter 3 - 6 (chapter 3: W22.212, chapter 4: W22.213, chapter 5: W23.022, chapter 6: W24.033). Chapter 2 is a literature review and therefore did not require an ethics review.

The privacy of the participants in the studies involving human participants was warranted by the use of pseudonymization (chapter 3, 4, 5, 6) or anonymization (chapter 4 and 6). The pseudonymization key was stored on a secured network drive that was only accessible to members of the project who needed access to it because of their role within the project. The pseudonymization key was stored separately from the research data.

Informed consent, either written or verbal, was obtained from participants of research chapters 3-6 to collect and process their data for this research project. The sensitivity of the raw qualitative data (i.e. interviews and observations) and questionnaire data of chapter 3 and 5 makes sharing of the data without compromising confidentiality and privacy impossible, therefore consent for sharing of the data was not asked from the participants.

Data collection and storage

Data for chapter 3, 4, 5, and 6 were obtained through interviews, observations and online questionnaires. Data from chapter 2 was obtained through literature research. REDCap was used for secured online data collection of the questionnaires and data collection for the literature review. Data from all chapters were stored and analysed on the department server and in REDCap and are only accessible by project members working at the St. Antonius Hospital. Hardcopy informed consent forms are stored in locked cabinets on the department. These secure storage options safeguard the availability, integrity, and confidentiality of the data.

Data sharing according to the FAIR principles

See table 1 for an overview of the findability and accessibility of all data collected. All studies are or will be published open access. The St. Antonius Hospital is owner of all data. All data, including descriptive files of the data, will be archived for 15 years on the department server of the St. Antonius Hospital or in REDCap of the St. Antonius Hospital.

Chapter 2 was based on existing data (literature review). The raw data underlying chapter 3 and 5, and the qualitative data underlying chapter 4 and 6 are not publicly available due to privacy or ethical restrictions. The metadata of chapter 3 to 6 is findable via a Data Acquisition Collection of the Radboud Data Repository (RDR); the raw data is archived with closed access at the St. Antonius hospital. The anonymized data underlying chapter 4 and 6 are available from the RDR with restricted access. Requests for access will be checked by Prof.Dr. Paul van der Nat, against the conditions for sharing the data as described in the signed Informed Consent. All data can be opened with generally available software tools.

Table 1| Overview of findability and accessibility of data collected for this thesis

Chapter	DAC	DSC	DSC License
3	10.34973/xm23-zc14		
4	10.34973/trwh-bz50	10.34973/t6p9-wb65	*RUMC-RA-DUA-1.0*
5	10.34973/dy13-h870		
6	10.34973/zdtw-df87	10.34973/z69z-0n39	*RUMC-RA-DUA-1.0*

DAC = Data Acquisition Collection, DSC = Data Sharing Collection

PhD portfolio of Jet Westerink

Department: **IQ Health**
PhD period: **14/06/2021 – 14/06/2025**
PhD Supervisor(s): **Prof. P.B. van der Nat and Prof. P.J. van der Wees**
PhD Co-supervisor(s): **Dr M.M. Garvelink and Dr C.F. van Uden-Kraan**

Training activities	Hours
Courses	
• REDCap workshop (2021)	3.00
• RIHS - Introduction course for PhD candidates (2021)	15.00
• Literature review workshop (2021)	4.00
• Radboudumc - eBROK course (for Radboudumc researchers working with human subjects) (2021)	26.00
• RU - Qualitative Research Methods and Analysis (2022)	84.00
• Radboudumc - Scientific integrity (2022)	20.00
• RU - Writing Scientific Articles (2022)	96.00
• Data visualisatie (2022)	8.00
• RU - Projectmanagement voor Promovendi (2022)	45.00
• Actieonderzoek training (2024)	8.00
• RU - Art of Finishing Up (2024)	10.00
• RU - Analytic Storytelling (2024)	20.00
Conferences	
• ICHOM (2022): poster presentation	20.00
• Landelijk congres Uitkomstgericht Zorg (2022): oral presentation	8.00
• CaRe days (2023)	16.00
• ZonMw Implementatie congres (2023)	5.00
• CaRe days (2024): oral presentation	8.00
• ISDM (2024)	32.00
• ISQUa (2024): oral presentation	36.00
• ICHOM (2024): poster presentation	20.00
Teaching activities	
Supervision of internships / other	
• Supervision internship (2022)	40.00
• Supervision internship (2023)	40.00
Total	**564.00**

List of publications

Publications included in this thesis

- Westerink HJ, Oirbans T, Garvelink MM, van Uden-Kraan CF, Zouitni O, Bart HAJ, van der Wees PJ, van der Nat PB. Barriers and facilitators of meaningful patient participation at the collective level in healthcare organizations: A systematic review. Health Policy. 2023 Dec;138:104946. doi: 10.1016/j.healthpol.2023.104946. Epub 2023 Nov 17. PMID: 38000333.
- Westerink HJ, Garvelink MM, van Uden-Kraan CF, Zouitni O, Bart HAJ, van der Wees PJ, van der Nat PB; Santeon Patient Participation Study Group. Evaluating patient participation in value-based healthcare: Current state and lessons learned. Health Expect. 2024 Feb;27(1):e13945. doi: 10.1111/hex.13945. PMID: 39102682; PMCID: PMC10797212.
- Westerink HJ, Bresser CC, Garvelink MM, van Uden-Kraan CF, Zouitni O, Bart HAJ, van der Wees PJ, van der Nat PB; Santeon Patient Participation Study Group. The use of outcome data in patient consultations from the healthcare professionals' and patients' perspectives: A mixed methods study. Patient Educ Couns. 2024 Jan;118:108043. doi: 10.1016/j.pec.2023.108043. Epub 2023 Oct 31. PMID: 37925975.
- Westerink HJ, van Uden-Kraan CF, Garvelink MM, Sprengers D, Hartman BJ, van der Wees PJ, van der Nat PB; Santeon Patient Participation Study Group. Development of a practical guide for patient participation in value-based healthcare: an action research study. *Under review*
- Westerink HJ, Garvelink MM, van Uden-Kraan CF, van de Lindeloof A, Stijns PEF, Hanzen N, Hartman BJ, Sprengers D, van der Wees PJ, van der Nat PB. The patient experience layer of the Metro Map to improve value of care: a bladder cancer case study. *Under review*

Other (co-authored) publications

- Westerink HJ, Kosse LJ, Jessurun NT, Tubergen AV, Vonkeman HE, Nurmohamed MT, van den Bemt BJF, de Vries M. Patients' and health-care professionals' perspectives on adverse drug reaction burden attributed to the use of biological DMARDs: a qualitative study. Expert Opin Drug Saf. 2023 Jan-Jun;22(5):417-424. doi: 10.1080/14740338.2023.2134344. Epub 2022 Oct 24. PMID: 36269284.
- Westerink HJ, Steinmann G, Koomans M, van der Kemp MH, van der Nat PB. Value-based healthcare implementation in the Netherlands: a quantitative analysis of multidisciplinary team performance. BMC Health Serv Res. 2024 Feb 21;24(1):224. doi: 10.1186/s12913-024-10712-x. PMID: 38383368; PMCID: PMC10882801.
- Bresser CC, Duarte-Díaz A, Gonález-Pacheco H, Rivero-Santana A, Ramallo-Farina Y, Westerink HJ, Dijksman LM, van Melick HHE, van der Nat, PB, Légaré F, Elwyn G, Garvelink MM, Perestelo-Pérez L. Assessing Shared Decision-Making in Clinical Practice: A Systematic Review and Meta-analysis of Studies Using OPTION-12 and OPTION-5. BMJ EBM. *Under review*

Curriculum Vitae

Henrike Jeltje (Jet) Westerink was born on December 25th, 1998, in Beuningen, the Netherlands. She completed her secondary education at Christelijk College Nassau-Veluwe in Harderwijk, graduating in 2016. Following high school, Jet pursued a Bachelor's degree in Medical Biology at Radboud University in Nijmegen, completing her studies in 2019. Her Bachelor's thesis investigated factors contributing to weight gain during treatment with antidepressants.

Jet obtained a Master's degree in Medical Biology, with a specialization in Science, Management, and Innovation. During her Master’s, she undertook two research internships. Her first focused on genetic variations in the kynurenine enzyme pathway and their implications for major depressive disorder. Her second, her graduation project, explored the burden of adverse drug reactions from biologicals, which was published in a peer-reviewed journal and was awarded the Leo Meijler Thesis Prize.

In parallel with her studies, Jet worked for the National Association for Rheumatology Patients (Nationale Vereniging ReumaZorg Nederland), where she gained valuable insights into patient participation and its importance in healthcare and research.

Her PhD research, which commenced in 2021 at St. Antonius Hospital in collaboration with Radboudumc and the Santeon hospital network, focused on strengthening the role of patients within value-based healthcare.

Building on this work, Jet took on the role of chair of the Linnean Working Group on Collective Patient Participation in 2024. Through this position, she contributes to expanding national collaboration and knowledge in the field of patient participation.

As per April 2025, Jet started as Project Lead for Collective Patient Participation at Radboudumc, where she applies the insights from her PhD research to embed meaningful patient participation into quality improvement at different levels of the Radboudumc.

Dankwoord

Aan het begin van mijn studie had ik nooit gedacht dat ik aan een promotietraject zou gaan beginnen, maar ik ben toch echt het dankwoord van mijn proefschrift aan het schrijven. Ik heb afgelopen jaren ervaren als een waardevolle en leerzame periode, waarin ik met veel plezier heb gewerkt aan dit onderzoek. Ik ben heel blij met alle mensen die op welke manier dan ook betrokken zijn geweest bij mijn promotietraject, en ik wil hen hier graag bedanken.

Paul, ontzettend bedankt voor jouw fijne begeleiding afgelopen jaren. Jouw enthousiasme voor waardegedreven zorg werkte aanstekelijk. Je scherpe vragen en aanmoedigingen om de resultaten van mijn onderzoek levendiger en overtuigender op te schrijven hebben een belangrijke rol gespeeld bij het schrijven van dit proefschrift. Daarnaast waren onze wekelijkse RO's niet alleen nuttig, maar ook zeker gezellig.

Philip, ontzettend bedankt dat ik altijd bij jou terechtkon met mijn vragen over wetenschappelijke theorieën, methoden en alles daartussenin, jouw kennis hielp me vaak om helderheid te krijgen wanneer ik zelf even vastzat. De sessies die je organiseert voor jouw onderzoeksgroep waren daarin ontzettend waardevol, niet alleen vanwege de inhoudelijke verdieping, maar ook omdat ze mij meer verbondenheid gaven met het Radboudumc als buitenpromovenda.

Mirjam, dankjewel voor je betrokkenheid bij zowel de inhoud van mijn onderzoek als bij alles wat daarbuiten speelde. Ik heb ontzettend veel geleerd van je nieuwsgierigheid en creativiteit bij het doen van wetenschappelijk onderzoek. Hopelijk kunnen we nog eens een van onze creatieve ideeën oppakken (project Utopia, fictieve patiënten in vergaderkamers plakken, etc.).

Nelly, heel fijn dat je aan het begin toch hebt besloten om echt onderdeel te worden van mijn promotieteam, want zonder jou had ik me nooit zo betrokken gevoeld bij Santeon. Je kritische blik en ruime ervaring en sterke verbondenheid met de Santeon ziekenhuizen hebben ervoor gezorgd dat mijn onderzoek beter aansloot bij wat er écht nodig was, en daarmee relevanter en bruikbaarder werd voor de verbeterteams.

Ik bedank ook graag de leden van de manuscriptcommissie voor het lezen en beoordelen van dit proefschrift: Prof.dr. Jeroen Hasselaar, Prof.dr. Anne Marie Weggelaar en Prof.dr.ir. Kees Ahaus.

Hans, Ouisam, Dominique en Bart, ontzettend bedankt voor jullie betrokkenheid de afgelopen jaren bij de sparsessies, het meedenken over protocollen en artikelen, het helpen bij de presentaties en zelfs als mede-gast in een podcast. Dankzij jullie had ik een constante reminder waarom ik met patiëntparticipatie bezig was. Jullie perspectief hielp om dingen van de andere kant te blijven bekijken, en niet 'vast' te blijven zitten in een ziekenhuisperspectief.

Roos, Joost, Tobi, Nathascha, Laurence en andere betrokkenen vanuit Johnson& Johnson, bedankt voor de fijne samenwerking. Ik heb genoten van onze brainstorms tijdens de kwartaalbijeenkomsten. Alle voortgangsklokjes zijn nu rond, maar hopelijk kunnen we in de toekomst blijven samenwerken om patiëntparticipatie weer een stukje verder te brengen.

Aan alle projectleiders, adviseurs, zorgverleners en patiënten vanuit het Santeon programmabureau en de Santeon ziekenhuizen die betrokken zijn geweest bij dit onderzoek, bedankt voor alle tijd en energie die jullie in dit onderzoek hebben gestoken!

Kirsten en Anna Roos, bedankt voor jullie warm onthaal en dat jullie mij op weg hebben geholpen als PhD'er. Tom, bedankt voor je hulp bij het literatuuronderzoek. Cato, ik heb heel erg genoten van het samen optrekken tijdens onze PhDs, zonder jou was dit promotietraject nooit zo gezellig geweest! Femke, ontzettend leuk dat je in mijn laatste jaar nog onderdeel bent geworden van de onderzoeksgroep, heel erg bedankt voor de gezelligheid tijdens de ontelbare koppen koffie. Lian, Sara, Dorine, Linda, en alle andere onderzoekers en stagiaires die afgelopen jaren onderdeel hebben uitgemaakt van de 'WGZ-onderzoekers', dank voor de fijne tijd samen en wat ik van jullie heb mogen leren. Heel veel succes met jullie onderzoeken!

Enny en Joliene, super leuk dat wij vorig jaar samen zijn begonnen met de Linnean werkgroep Collectieve Patiëntenparticipatie. Jullie zijn geweldige powervrouwen om mee samen te werken! En natuurlijk de rest van de Linnean kerngroep en werkgroep, jullie ook ontzettend bedankt voor jullie betrokkenheid en fijne samenwerking. Ik hoop de komende tijd nog veel samen te mogen werken aan collectieve patiëntenparticipatie in de Nederlandse ziekenhuiszorg.

En dan aan iedereen die vooral voor de nodige afleiding heeft gezorgd de afgelopen jaren:

Allereerst de Circle (ook bekend als 'Zuurkool'), bedankt voor jullie vriendschap en de gezelligheid tijdens de Circle avonden, weekendjes weg en wintersportvakanties. En in het bijzonder Lau, Diex, Els (aka de jaarlaag), wat ben ik blij met jullie als vriendinnen. Onder het genot van een goed glas wijn is geen gespreksonderwerp te gek, en kan ik altijd mijn hart bij jullie luchten (Pour it out!). Aan de buurtjes; wat een droom dat jullie zo dichtbij zijn komen wonen. Bedankt voor al jullie culinaire creaties tijdens de kookclubavonden, het lenen van gereedschap, de BZV-avonden, en alle (spontante) momenten samen.

Wies, waar we ooit begonnen als lab-partners in Nijmegen, zijn we inmiddels allebei een hele andere weg ingeslagen met onze studie. Extra leuk dat je nog een tijdje in Utrecht hebt gewoond en mij de sportschool in hebt gekregen (dank daarvoor, dit heeft goed geholpen om even mijn onderzoek uit mijn hoofd te krijgen). Inmiddels hebben we het spinnen bij DJ Jean-Mark ingeruild voor wijnavondjes, waar ik natuurlijk nog meer van geniet.

Esther, wij gaan natuurlijk echt way back! Ooit samen bruggen van papier gebouwd in de kelder van het CCNV, en nu allebei een (soort van) grotenmensen leven. Ontzettend leuk dat we elkaar nog steeds spreken, en helemaal leuk dat ik tijdens mijn onderzoek de bezoekjes aan het Maasstad vaak kon combineren met een etentje bij jou.

En dan de Kopjes! Wat ben ik jullie dankbaar voor jullie oprechte interesse in mijn onderzoek en het enthousiaste meeleven bij de (kleine) mijlpalen. Maar nog veel meer dank voor jullie warmte, vrolijkheid, gezelligheid en borrelplankjes. En hoe leuk was het dat we, Suus & Yami, heel even alledrie Antoniaan waren. Lieve Kopjes, laten we nog lang en vaak de mooie dingen in het leven samen vieren!

Lieve pap en mam, dank voor alles wat jullie mij hebben meegegeven en geleerd. Pap, dank dat je mij hebt geleerd om dingen echt te willen begrijpen. 'Als je het niet simpel kan uitleggen, dan snap je het ook niet', heb ik nog vaak gehoord in mijn hoofd tijdens dit promotietraject. Lieve mam, dank dat ik je organisatieskills heb mogen erven, die kwamen goed van pas bij een PhD. Je bent een echte aanpakker en doorzetter, en dat heb je maar weer keihard bewezen afgelopen jaren. Wat ben ik dankbaar dat het inmiddels weer zo goed met je gaat en dat je weer helemaal gezond bent.

Lieve baby Jens, ook al ben je allang niet meer zo klein, je blijft mijn babybroertje. Ik vind het heel leuk dat je in Utrecht bent komen studeren en om je zo zien te ontpoppen als echte student. Mooi om te merken hoeveel interesse je hebt in je studie, en stiekem ook wel grappig dat we nu gesprekken kunnen voeren over dingen als kwalitatieve dataverzameling. Lieve Tijn en Lon, in de tijd dat ik dit boekje heb geschreven zijn jullie een heus gezin geworden. Dank voor jullie gezelligheid, heerlijke BBQ-avonden, maar vooral voor het feit dat jullie mij tante hebben gemaakt. Jidde en Steyn, jullie zijn de allerliefste neefjes die een tante kan wensen.

En dan de allerbelangrijkste van allemaal: Lieve Wout, dank voor al jouw steun afgelopen jaren. Dank voor het eindeloos aanhoren van mijn onderzoeksstruggles, het geduldig doorstaan van mijn zogenoemde 'mental breakdowns', het meedenken bij het net wat tactischer formuleren van mijn e-mails, maar vooral voor alles wat niet met mijn onderzoek te maken had. Bedankt voor de heerlijke date-avonden, tuinsessies, vakanties, en alle momenten daartussen die we samen hebben gespendeerd. Ik kijk enorm uit naar alles wat de toekomst ons gaat brengen. Met jou aan mijn zijde weet ik zeker dat er nog veel mooie hoofdstukken zullen komen.

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