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Patient participation in cancer care

Different perspectives across healthcare levels

ANNA HULT

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Abstract

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Aim: To explore and deepen the understanding of various experiences of and perspectives on patient participation in cancer care across different settings and levels of the healthcare system.

Methods: Study I explored the role of patient representatives through content analysis of interviews with members of national committees monitoring clinical practice guidelines for cancer in Sweden (n=33). Study II investigated complaints by or on behalf of patients with cancer (n=692) reported to patient advisory committees in four Swedish counties over five years, to describe the frequency and content of communication failures. Content analysis was applied to all the complaints. Study III described different ways healthcare professionals in cancer care (n=16) understood patient participation, through the phenomenographic analysis of the interviews. Study IV explored how healthcare contextual factors, as perceived by contact nurses (n=20), influenced the realization of patient participation in cancer care through focus group interviews, which were analysed with reflexive thematic analysis, using the Fundamentals of Care framework.

Results: In Study I, even though the patient representatives' role was mostly viewed as important, their contributions were hampered by uncertainties about the role and low expectations from other group members, and their representativeness was questioned by some professionals. Study II showed that over half of the patients or their representatives reported communication failures, from diagnostic workup to end of life. In Study III, five descriptive categories of different ways of understanding patient participation were identified, ranging from perceiving participation as conditional on healthcare permission to perceiving it as a collaborative process with a holistic and team-based approach. Study IV found that patient participation was challenged by organizational and cultural conditions as well as by the individual actions of healthcare professionals.

Conclusions: Despite legal support and structural improvements in Swedish cancer care, patients' participatory rights are not always upheld nor are their needs always met. This thesis illustrates how patient participation is not fully embedded in the structure and culture of healthcare organizations, leading to a gap between the policy level and practice. Healthcare organizations, leaders, and professionals need to take responsibility and work together so that patient participation becomes an integrated and shared responsibility. This is necessary to enable and realize patient participation according to policy.

Keywords: Patient participation, Cancer care, Person-centred care, Fundamentals of Care framework, Context of care, Communication, Patient representatives, Patient complaints, Content analysis, Phenomenography, Reflexive thematic analysis

Anna Hult, Department of Surgical Sciences, Nursing Research, Akademiska sjukhuset, ingång 70, 1 tr., Uppsala University, SE-751 85 Uppsala, Sweden.

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To Elvira and Sixten

List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

I. Hult, A., Lundgren, E., Jangland, E. (2021). Patient representatives: Crucial members of health-care working groups facing an uncertain role and conflicting expectations. A qualitative study. *Health Expectations*, 24(4):1197–1206. doi: 10.1111/hex.13249

II. Hult, A., Lundgren, E., Fröjd, C., Lindam, A., Jangland, E. (2023). Patient complaints about communication in cancer care settings: Hidden between the lines. *Patient Education and Counseling*, 114:107838 doi:10.1016/j.pec.2023.107838

III. Hult, A., Lundgren, E., Fröjd, C., Jangland, E. (2026). Different ways of understanding patient participation in cancer care: A phenomenographic study. *Patient Education and Counseling,* 153:109870 doi: 10.1016/j.pec.2026.109870

IV. Hult A, Lorentzson J, Lundgren E, Fröjd C, Jangland E. Patient participation in cancer care and the influence of contextual factors: An interview study using the Fundamentals of Care framework. *(Submitted)*

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Abbreviations

CN	Contact nurse
CPG	Clinical practice guideline
FoC	Fundamentals of Care
HCP	Healthcare professional/provider
NHCR	Northern Healthcare Region
PAC	Patient advisory committee
PR	Patient representative
PREM	Patient-reported experience measure
PROM	Patient-reported outcome measure
RCC	Regional cancer centre
RN	Registered nurse

Preface

'Nothing about us, without us'.

The very first data for this thesis were collected in an interview with a patient representative in a national clinical practice guideline monitoring group. That person cited the historical motto '*Nihil de nobis, sine nobis*' (Nothing about us, without us), meaning that no policy should be decided on without the full and direct participation of members of the group affected by it. For me, this is an important and valuable reminder to truly see the person in front of me in all interactions. As healthcare professionals, our work is a matter of normal daily routine; for the person in front of us, it can be life changing. Since then, this motto has been in the back of my mind during my clinical work and throughout the research process.

Introduction

Patient participation is central to person-centred healthcare policy worldwide (1). According to Swedish legislation (2), all patients have the right to participate in their care, and healthcare should, as far as possible, be planned and provided in collaboration with the patient (2). Patient participation is closely linked to patient safety outcomes (3,4) and can result in better health outcomes (5–8) and greater patient satisfaction (6,8). Patient participation is also central to the 'Choosing Wisely' movement, aiming to reduce low-value care by emphasizing the importance of directing limited healthcare resources towards what truly creates value for patients (9,10). A healthcare aligned with patients' values and priorities may lead to more efficient resource use, which is critical for the long-term sustainability of healthcare systems (5).

In alignment with the rest of healthcare, cancer care has an increased focus on patient participation. Cancer afflicts one in five people during their lifetime (11) and is responsible for one in six deaths globally (12). Cancer imposes immense physical, emotional, and financial strain on individuals and their families (12). As individuals, we see the world through different lenses, which affects how we perceive, comprehend, and interpret situations and events in our lives (13). Nursing as a human science is interested in people's life experiences – the impact they have on people's lives and their implications for health, illness, and death. (13). Healthcare professionals (HCPs) play a key role in enabling support for patients and their needs (14,15), and the need to personalize such support to the individual patient is now well known. Delivering person-centred care meeting the patient's care needs, with patient participation at the core (16,17), has been shown to be important (17). The ability to provide person-centred care has a significant impact on patient participation (18).

Background

Patient participation

The core expectation of patient participation is a healthcare interaction based on mutual partnership with respect for the patient's knowledge gained through experiences of adapting to illness and maintaining health, and respect for the clinical knowledge and expertise of the professional gained through professional practice and formal education (19). A partnership is created when these two perspectives are integrated, and both the patient's and the team's goals form the basis of decision making (20,21). Although patient participation is characterized by the involvement of patients at multiple levels of the decision-making process (22), patient participation is a complex concept (23), with its meaning varying across groups such as HCPs and patients (24). A broader understanding of the concept has been suggested, including sharing experience (25), engaging in self-care activities (24,25), building knowledge of how to manage the illness and its symptoms (24,25), and applying a holistic approach to care in which the patient is viewed as a whole person (26).

The concept of patient participation has been defined in several ways (23,24), but central to all definitions is the dependence on and importance of the patient–provider relationship (23,27). Patient participation relies on learning, the caring relationship, and reciprocity. Learning and reciprocity are parts of the caring relationship (23). A good patient–provider relationship is described as necessary for the patient to feel acknowledged, and for information to be exchanged and transformed into knowledge and understanding. (28). Communication based on respect is a key characteristic of patient participation (24) and is essential in establishing a trusting patient–provider relationship (29). At the heart of a humanistic approach to health communication is meaning shared in dialogue between equal partners, not only the process of delivering and receiving information (30). Reciprocal communication and being listened to are vital for patient participation (25), patient safety, and realizing person-centred care (29,31). Communication that involves the patient as an equal partner reportedly makes a difference between adequate and missed care (32). Person-centred communication and positive patient–provider interactions also positively affect patient well-being (33,34).

Person-centred care

Patient participation is a core element of person-centred care (16,17), and the ability to provide person-centred care has a significant impact on patient participation (18). In healthcare, the concepts of patient-centred care and person-centred care are both used (16), sometimes interchangeably. There are

similarities between them, as they both involve empathy, respect, engagement, relationships, communication, shared decision-making, a holistic focus, an individualized focus, and coordinated care. However, their main goals differ, with the goal of patient-centred care being a *functional* life for the patient, while the goal of person-centred care is a *meaningful* life for the person (16). Using the word 'patient' can encourage objectification and reduce the person to a mere recipient of healthcare (35). Changing the word 'patient' to 'person' also shifts the focus from a passive recipient to an active participant (36), allowing the person to take on a more active role. As each person has specific individual needs, a person-centred environment allows the outcomes to be defined by the person receiving care (37).

This thesis uses the Fundamentals of Care (FoC) framework as the theoretical underpinning of person-centred fundamental care. The framework applies a person-centred focus on the care and a holistic focus on the patient (29,31,38,39). Reflecting its centrality, the patient–provider relationship is at the heart of the framework, constituting the foundation on which high-quality fundamental care is built. The framework describes the integration of physical, psychosocial, and relational care aspects that every person in care requires regardless of, but influenced by, their clinical condition and level of dependence or independence (31). The framework also provides a holistic view of the factors that affect the patient's care, as it also recognizes the context of care, as well as the systems and policy requirements needed to support the delivery of fundamental care (31). The system level includes resources (e.g., physical resources such as equipment and human resources), evaluation and feedback (e.g., processes at the individual, team, and organizational levels providing feedback), leadership (e.g., leadership styles, how roles are defined and supported, and how staff are mentored), and culture (e.g., values and norms of the system). The policy level involves financial management, quality and safety, governance, and regulation and accreditation (31). With its holistic view of the patient and its holistic overview of factors affecting the patient's care, the framework is useful when examining the different aspects of patient participation.

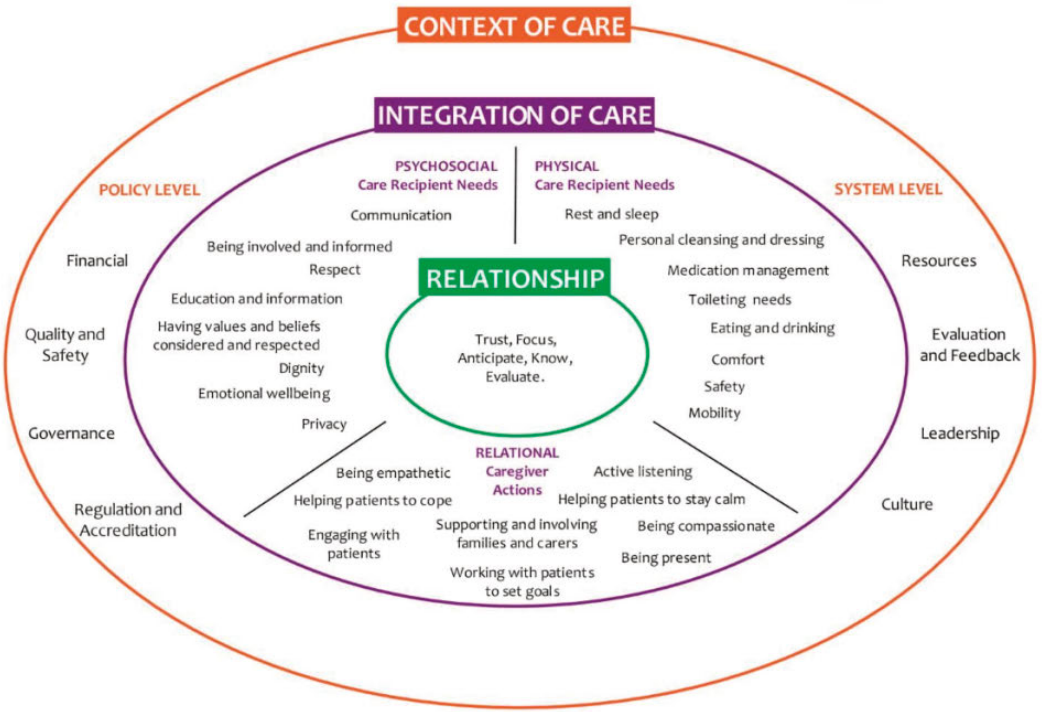

Figure 1. The Fundamentals of Care framework.

Image obtained from https://ilccare.org/the-fundamentals-of-care-framework/ Content within image derived from 1) Kitson, A., Conroy, T., Kuluski, K., Locock, L., & Lyons, R. (2013). Reclaiming and Redefining the Fundamentals of Care: Nursing's Response to Meeting Patients' Basic Human Needs. School of Nursing, The University of Adelaide, Adelaide, South Australia. Available from: https://digital.library.adelaide.edu.au/dspace/bitstream/2440/75843/1/hdl_75843.pdf; and 2) Feo, R., Conroy, T., Jangland. E., Muntlin Athlin, Å., Brovall, M., Parr, J., Blomberg, K., & Kitson, A. (2017). Towards a standardised definition for fundamental care: A modified Delphi study. Journal of Clinical Nursing, 27, 2285-2299. doi: 10.1111/jocn.142

Patient participation across different healthcare levels

The increased focus on involving patients in healthcare reflects a shift in which the authority of expert and professional knowledge is gradually being challenged, implying the questioning of who has the right to make healthcare decisions and in whose interests they are made (40). This shift reflects the reality that technical expertise does not give HCPs the sole right to assess value considerations and make resource allocation decisions, as well as the increased recognition and importance of incorporating patients' knowledge, experiences, values, and preferences (40). Patient participation occurs at the direct care (micro), healthcare organization (meso), and societal and governmental (macro) levels (8,41).

At the *micro level*, the patient–provider relationship and collaboration are central to sharing information and knowledge (8). When HCPs and patients work together, a shift of power occurs, increasing the patient's ability to control their care and enhancing their autonomy (8).

At the *meso level*, patient participation is influenced by the governance and vision of the healthcare organization, and by its organizational flexibility and culture (8). HCPs can work together with patients in determining how to propose, give access to, and deliver care, and in developing services, planning, and care evaluation (18). Working with patient representatives (PRs) in health-service development can foster insights into and a better understanding of patient needs and conditions (41), increase the prioritization of patient-relevant topics (42–44), and identify issues that may be overlooked by HCPs (43).

At the societal and governmental level, *the macro level*, patients and their organizations can collaborate with community leaders and policy makers to shape healthcare policy, set priorities for resource use, and set goals to achieve high-quality patient outcomes (8,18). Patient participation in the development of macro health policies is considered part of people's civil rights (45).

The patient's position in Swedish healthcare

Swedish laws and regulations establish the conditions for healthcare. Healthcare regulations are structured around the obligations of caregivers and HCPs, and the legal text indirectly states what the patient can expect from the care received. The Swedish healthcare system is decentralized and its responsibility is diversified (46). Sweden's 21 regions are responsible for managing the largest part of healthcare by working to promote health and to prevent, diagnose, and treat diseases and injuries. Six healthcare regions, each with one or two university hospitals, have overall responsibility to provide tertiary care (47).

The Swedish Patient Act (2) was introduced in 2015 and aims to strengthen and clarify the patient's position within healthcare activities and to promote the patient's integrity, right to information, and participation (2). The impact of the Act has been evaluated on two occasions, in 2017 and 2021, identifying suboptimal effects and few signs of improvement in compliance with the law over time (48,49). As there are clear shortcomings in the availability, participation, continuity, and coordination of care (49), the purpose of the Act has not yet been fully achieved (48,49).

Privacy in healthcare is traditionally realized through the legal and professional norms of medical confidentiality. HCPs are not supposed to disclose patient information to other individuals or parties, except when legitimized/approved by patient consent, legal obligations, or emergency circumstances (50). All HCPs in Swedish healthcare, both public and private, are bound by confidentiality and professional secrecy. This confidentiality is regulated by the Public Access to Information and Secrecy Act (51) for those working in public care, while those working in private healthcare must comply with the rules on professional secrecy in the Patient Safety Act (52). However, the meaning of these rules is very similar. These two acts imply that not even the patient's relatives have the right to know what is being said and done within the healthcare system if the patient objects to this. The patient should be asked to whom information may be disclosed. Access to medical records is recognized as a key patient right (53), and in Sweden, all patients have had digital access to their own medical records since the late 2010s.

If patients are dissatisfied with their healthcare, they have the ability to file complaints. Patient complaints can reveal problems in healthcare not always identified by reporting systems (e.g., incident reports) (54). There are several ways for patients to register complaints. The addressed healthcare provider can be contacted directly or via the healthcare guide, 1177.se, which is Sweden's national hub for information, advice, and e-services regarding health and healthcare (55). Patients can also address their complaints to a patient advisory committee (PAC). The Swedish Act on Support for Complaints against Healthcare (56) states that each region should have a local, impartial PAC to assist patients and relatives with healthcare complaints and to ensure that questions are answered by the care providers (56). Ongoing follow-up of the complaints should also be conducted (52).

The development and structure of Swedish cancer care

Along with changes in healthcare in general, cancer care is also characterized by an emerging person-centred focus. An official government report from 2009, *A National Cancer Strategy for the Future* (33), focused on future needs

and challenges, paying particular attention to the patient perspective. The report stated that Swedish cancer care usually achieves good medical outcomes, but that there is a general lack of individual patient focus. This problem is not unique to cancer care, but it may be particularly important for patients with cancer as the disease often follows an extended course and its treatment involves many healthcare disciplines (33).

An updated national cancer strategy, published in 2026, has three overarching goals: to reduce the risk of cancer and improve early detection, to increase survival rates, and to ensure the best possible quality of life during and after the disease. These goals can, in turn, be categorized under four focus areas, one of which is person-centred care. These focus areas reflect the fundamental principles that should permeate the implementation of the strategy (57).

Based on proposals in *A National Cancer Strategy for the Future* (33), regional cancer centres (RCCs) were established in each of the six healthcare regions in Sweden, with the aims of improving healthcare quality and results, and making efficient use of health and medical resources (58). A four-year follow-up of the development of the RCCs stated that their establishment, among other factors, had facilitated the use of contact nurses (CNs) in cancer care, multidisciplinary conferences for decisions on treatment, and individual healthcare plans (58). The follow-up of the RCCs also stated that they had strengthened patient participation and person-centring (58).

Swedish cancer care is based on care programmes for each type of cancer and on the comprehensive national cancer strategy. Sweden has approximately 55 national clinical practice guidelines (CPGs) for different types of cancer, with the purpose of providing high-quality and equal care to patients with cancer, regardless of residence, gender, and socioeconomic status. These CPGs contain recommendations on the examination/assessment, treatment, nursing care, rehabilitation, and follow-up of patients with cancer (59). The working group responsible for a particular CPG consists of relevant experts, including PRs, within the specific field (59).

Patients' experience of care is gauged using several systems. Patient-reported experience measures (PREM) gauge the patient's experience of and satisfaction with care, and patient-reported outcome measures (PROM) indicate how the patients experience their illness and health before and after treatment (60). PRs are also included in regional medical process groups, RCC boards/steering committees, local development projects, and nationally in groups monitoring care programmes and CPGs (58).

Patient participation in cancer care

Cancer management is generally more complex than that of other diseases, even other noncommunicable diseases (i.e., chronic diseases, non-transmittable from person to person) (11). Treatment can involve surgery, radiotherapy, and systemic therapy (incl. immunotherapy), and the diagnostic and therapeutic approaches to cancer management should be delivered by a multidisciplinary team, which, according to the World Health Organization, is central to integrated, person-centred care (11).

Patients with cancer have described needing high-quality, comprehensible information in order to understand the illness and treatment options, to know what to expect, and to communicate well with HCPs (61). The patients often struggle to understand the status of their disease and the terminology used when given prognostic information (62–64). Cancer has an emotional impact on those diagnosed, including lack of control over their lives (61), and the psychological distress also extends to their families (12). The role of emotional support throughout the various stages of the disease is emphasized (14). Also, a considerable proportion of people surviving cancer report ongoing concerns about existential challenges and death (65,66). Taken together, this illustrates the complexity of conveying information about and fostering an understanding of the disease in patient interactions.

To participate as a patient, one requires appropriate, credible, and sufficient knowledge provided in a safe and supportive environment (67). Even though patients with cancer often feel that they have the opportunity to ask questions and that HCPs take their preferences into account when planning care (68), they can experience limited opportunities to take part in and influence the care planning (25,68). Cancer survivors particularly emphasize the importance of seeing the person behind the disease, including listening to their changing needs, finding personalized solutions, and applying a holistic approach to planning the cancer care process, an approach that considers the patient's family, social needs, and personal desires (14,69).

Although there are known needs for and benefits from patient participation, there are challenges regarding such participation in cancer care, such as information deficiencies, patients not being taken seriously, and lack of participation in care planning (25,70,71). Also, contextual factors influence clinical factors both positively and negatively (72). Known barriers to active patient participation are time constraints, a paternalistic approach, lack of encouragement, and lack of medical knowledge (3,18,70). Patients may also undervalue their own capacity and expertise: they tend to put great emphasis on medical information and may not always fully recognize, or may undervalue, the complementary expertise that they can bring to decision-making encounters (73).

Rationale

This thesis focuses on patient participation in cancer care. Patients with cancer often need multiple types of treatments and meet with HCPs from multiple medical specialties. Healthcare and HCPs play a crucial role in addressing and supporting these patients with the physical, emotional, psychological, and social needs resulting from their diagnoses. Since these patients often require long-term contacts with healthcare, their needs and preferences for involvement may change over time depending on their health status and well-being. The complexity of the diagnosis and the care process also make patient participation particularly important, so that the patient can understand their disease and the care pathway. The Swedish Patient Act was introduced to strengthen and clarify all patients' positions within healthcare activities and to promote patient participation. With the same goals, the RCCs have structurally developed Swedish cancer care.

However, there are known uncertainties concerning and barriers to patient participation. Also, as shown in evaluations of the Patient Act, improvement in patient participation appears to be slow, despite evidence of its importance. Further investigation based on different sources is warranted in order to understand the reasons behind this slow improvement. Utilizing experiences of patient participation for patients diagnosed with cancer at various system levels and at various disease stages could provide valuable contributions to improving the understanding of challenges and barriers to patient participation. In addition, areas in need of improvement and strategies for enhancing the participation of patients and their relatives could be identified.

Presenting the studies

The overall aim is to explore and deepen the understanding of various experiences of and perspectives on patient participation in cancer care across different settings and levels of the healthcare system.

Aims

Study I

To explore the role of patient representatives in national clinical practice guidelines monitoring groups, to describe their contributions and to identify possibilities for improvement.

Study II

To investigate patient complaints in cancer care settings and to describe the frequency and content of communication failures in all reports.

Study III

To describe different ways of understanding patient participation among healthcare professionals in cancer care.

Study IV

To explore how healthcare contextual factors, as perceived by contact nurses, influence the realization of patient participation in cancer care.

Methods

Design

This thesis is based on four studies, all of which employed a qualitative design based on the philosophical foundation from human sciences that each individual creates their own subjective reality (74). The research questions guided the choice of design, data collection, and analysis (75). An overview of the methods used is presented in Table 1.

Table 1. Overview of methods used in studies I–IV.

	Study I	Study II	Study III	Study IV
Design	Descriptive with an inductive approach	Descriptive with a deductive approach	Interpretive with an inductive approach	Interpretive with a deductive approach
Participants	PRs[1] and HCPs[2], *n* = 33	Patients with cancer reporting complaints to PACs[3], *n* = 692	HCPs[2] in surgical and urological cancer care, *n* = 16	CNs[4] in surgical and urological cancer care, n = 20
Data collection	Semi-structured individual interviews	Reports of patient complaints	Semi-structured individual interviews	Semi-structured focus group interviews
Data analysis	Conventional content analysis (76)	Content analysis with a summative approach (76)	Phenomenography (77)	Reflexive thematic analysis (78,79) using the FoC framework[5] (80) as a theoretical lens

[1] Patient representatives, [2] healthcare professionals (i.e., registered nurses and physicians), [3] patient advisory committees, [4] contact nurses and, [5] the context of care dimension in the FoC framework

In Study II, conventional quantitative analyses, including chi-square testing and logistic regression, were conducted to complement the qualitative

analysis. The logistic regression calculations have not previously been published and are presented only as a supplement to the thesis.

Setting

All studies in this thesis were conducted in cancer care settings in Sweden.

Study I

Healthcare working groups producing national CPGs (n = 7) that make recommendations on diagnosis, treatment, and follow-up of different types of cancer. These groups are coordinated by the Regional Cancer Centres in Collaboration and develop evidence-based guidelines to ensure equitable and effective cancer care in Sweden. They consist of representatives from various professions involved in the patient's care pathway, such as physicians, nurses, and other professionals from both hospital-based cancer care and primary care. Patient and/or relative representatives are also involved in these groups.

Study II

This study investigated cancer care-related patient complaints reported to PACs in the Northern Healthcare Region (NHCR), 2016–2020. The PACs can be contacted in person, by phone, or via written correspondence (i.e., e-mails and postal letters); nowadays, contacts by phone or e-mail are most common. The complaints are summarized by PAC personnel and filed according to national regulations with the use of a guide, coding each complaint according to one category and one subcategory. The category and subcategory are chosen by the PAC personnel, often in consultation with the complainant. The NHCR covers about 52% of the area of Sweden but is sparsely populated with less than 10% of the Swedish population. One of four counties in the NHCR has a university hospital providing tertiary and secondary care; the other three counties each have a county hospital providing secondary care. In addition, the counties have eight local hospitals, although some are very small, also providing secondary care.

Studies III and IV

Studies III and IV were conducted in three Swedish public hospitals: a university hospital, a large and a small county hospital. The larger hospitals are located in central Sweden, while the smaller hospital is situated in a more remote and sparsely populated area of the country.

Participants

Study I

All recruited participants (n = 33) were permanent members of Swedish national CPG monitoring groups for cancer diseases during the period when the interviews were being conducted (i.e., August 2017 to May 2018). CPG monitoring groups were chosen with the aim of including cancer diseases from different medical specialties as well as more or less common cancer diagnoses. CPGs and participants were included until the data were considered saturated (81), resulting in participants from a total of seven CPGs. The participants were registered nurses (RNs), physicians, and PRs (i.e., patients and relatives). The PRs were invited to participate in the groups in the same way as the professionals were. Contact information for group members was provided by the RCCs. The participants were from various locations in Sweden and were contacted via e-mail.

Study II

The participants were patients with a cancer diagnosis (n = 692) who reported complaints to PACs in the NHCR. The reports to PACs contained the patients' gender and age, the addressed healthcare provider, the informant (i.e., the patient, a relative, or another person), the PAC coding, and a short summary of the event(s), sometimes including quotations from the informant. Throughout this thesis, the complaints are described as coming from patients, but individual complaints may have been made by a patient, a relative, another person, or an HCP.

The number of new cancer cases per year (incidence) in the NHCR was higher for men than women during the study period (mean 3027 vs. 2486), but the prevalence was slightly lower for men (24,613 vs. 25,616 by the end of 2020) (82).

Study III

A strategic sample of physicians and RNs (n = 16) working in surgical and urological cancer care at three public hospitals was included. The physicians and RNs all worked in specialized care, either in tertiary care (i.e., a university hospital) or secondary care (i.e., county hospitals). The physicians met patients throughout the care chain, while the RNs worked in either outpatient or inpatient care.

Study IV

A strategic sample of CNs (n = 20) working in surgical and urological cancer care at three public hospitals was included. Swedish CNs are the patient's designated contact person, tasked with ensuring patient participation throughout the care process. They are RNs who have undergone formal or informal training to work as CNs in outpatient care. The national assignment description for CNs states that they should be able to offer care and support from a holistic perspective, which means having a person-centred and health-promoting approach. The assignment is divided into four areas, which means that the CN should have coordinating responsibility, ensure a coherent care process, facilitate availability and continuity, and foster patient participation and influence throughout the care process. The CN should also examine, assess, and manage the patient's individual needs (83).

Data collection

Study I

Semi-structured interviews were all conducted by telephone (except one conducted face to face) using an interview guide with predetermined questions. To encourage participants to clarify and expand on their responses, probing questions were asked. All interviews lasted 20–30 minutes, were recorded, and then transcribed word for word by an administrative assistant. The researchers conducting the interviews listened to most of the interviews again to confirm the transcripts.

Study II

From a total of 909 reports received by the PACs in the NHCR, all obvious multiples were merged. Altogether, 56 patients were excluded for various reasons: malignant disease not explicitly mentioned in the report (n = 25), non-malignancies (n = 23), insufficient information (n = 5), not relevant to malignant disease (n = 2), and from another healthcare region (n = 1). In total, the included reports resulted in complaint material concerning 692 patients.

Study III

Data were collected through semi-structured interviews using a interview guide with open-ended questions. The interviews were conducted in person or through digital video meetings between October 2024 and March 2025, lasted

20–65 minutes, and were audio recorded. The participants were encouraged to describe situations and interactions and to speak freely about their experiences, avoiding descriptions of how things should be or answers considered 'correct'. The interviewer summarized the interview and the interview questions in the last phase of the interview to give the participant the opportunity to elaborate on their earlier responses and give additional examples. A pilot interview was conducted, before data collection, to evaluate the interview guide and technique. This pilot interview was reviewed and discussed within the research team but not included in the final dataset. When four interviews had been conducted, the research team read those interviews and reassessed the interview guide and interview technique, to ensure that the guide was indeed suitable for the phenomenographic method.

Study IV

Six semi-structured focus group interviews were conducted remotely via a digital platform in September–December 2025. In five groups, some participants were physically present in the same room while interacting remotely with other participants via the digital platform. Four short patient stories, based on patient complaints collected in Study II, were used to stimulate discussions of patient participation and contextual factors. The interview guide was designed partially based on these patient stories. After the first interview, the interview guide was evaluated regarding the questions' clarity, comprehensibility, and relevance, while practical and technical aspects of the interview format were considered. The evaluation subsequently led to minor changes in the participants' introduction to contextual factors. At the end of each interview, the observer summarized the interview, offering the participants the opportunity to elaborate on their earlier responses or add content.

The interviews lasted 70–90 minutes and were audio recorded. The aim was to construct focus groups with participants from different hospitals and teams. However, the participants' ability to participate took precedence over the aim of achieving mixed groups. In five focus groups, the participants all worked in the same hospital, although in different teams. All interviews were conducted with the same researchers in the roles of moderator and observer; this ensured that all interviews were performed as similarly as possible and resulted in the researchers becoming increasingly secure in their roles.

Data analysis

Studies I and II

Content analysis was used in studies I and II. Content analysis refers to any qualitative data reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meanings within it. Content analysis generally refers to analysing text, such as interview transcripts, but can also refer to searching text for and counting recurring words or themes (84). This methodological approach can be inductive (i.e., data driven), deductive (i.e., concept driven), or abductive (i.e., complementary) (85).

In Study I, the material was analysed using conventional content analysis (76), an inductive approach without preconceived categories. This method has the benefit of gathering information directly from study participants without imposing preconceived categories or theoretical perspectives (76). Throughout the analytical process, the authors thoroughly discussed each analytical step to confirm its methodological authenticity, including reflecting on whether the authors' backgrounds and experiences might risk biasing the results.

In Study II, the reports were analysed using content analysis with a summative approach (76), for the purpose of exploring the usage of content consistent with the categories and subcategories in the PAC guide. The coding was performed with another member of the research team, and both researchers independently chose up to three categories per report, with no preference for one over another. In the event of disagreement, the categorization was discussed until consensus was reached. The PACs' and authors' codings of the complaints for the two largest groups – i.e., care and treatment (including results) and communication – were compared to validate the coding process. When all complaints in each category and subcategory had been identified, the focus was then on communication failures in all categories, to identify communication complaints (i.e., concerning information, participation, consent, and interactions) related to other categories. To visualize and describe the content of the reports, short summaries of the content of each category and any related communication problems were added. The whole research team met on several occasions to discuss the analytical process and the results based on the reports.

In Study II, complementary conventional quantitative analysis included demographic statistics. Chi-square testing was applied to analyse any differences in the number of complaints about communication during the study period. In the analytical phase, the material was divided into groups according to gender and the Swedish retirement age (i.e., below and above 65 years old). Any

differences in complaints about the categories *care and treatment and results*, *communication*, and *responsibilities in healthcare and organization* were analysed using logistic regression. The results of the logistic regression calculations are previously unpublished, only being presented as a supplement in this thesis.

Study III

In Study III, data were analysed with a phenomenographic method as described by Larsson and Holmström (77) to examine the phenomenon of patient participation, as perceived by HCPs in cancer care. Phenomenographic studies show how individuals experience, understand, or conceive a phenomenon in their surrounding world, focusing on the second-order perspective, not the phenomenon per se (86). The aim of a phenomenographic study is to describe the qualitatively different ways that a group of people make sense of, experience, and understand a phenomenon (87). In phenomenography, the structural and referential aspects of the studied phenomenon are essential. Both the 'what' and 'how' aspects of the phenomenon are studied – in other words, when the informants talk about the phenomenon, what do they talk about and how do they talk about it (77).

Although each participant could embrace more than one understanding, this study focuses on each participant's predominant way of understanding patient participation in cancer care. Preliminary descriptions of these predominant understandings were formulated. Based on similarities and differences among them, the preliminary descriptions were grouped into categories, and final descriptions of these categories were formulated. The internal relationships among the categories were organized into a hierarchical structure, the outcome space. The categories and their descriptions, as well as the outcome space, were read by and discussed with all authors to reach agreement.

Study IV

In Study IV, data were thematically analysed using a deductive reflexive approach with a constructionist perspective (78) as described by Braun and Clarke (78,79), to explore how healthcare contextual factors, as perceived by CNs, influence the realization of patient participation in cancer care. Thematic analysis is a method for identifying, analysing and reporting patterns, themes, within data (88), and this method was chosen to identify patterns of shared meaning across the dataset. As a lens through which to examine the data, care contextual factors outlined in the FoC framework (80) were used; the material was also coded using those same contextual factors (80). Preliminary themes

were sought and reviewed, to then be defined and named through joint discussion by the entire research team. The themes were then verified with the initial coding.

Ethical considerations

Ethical approval was obtained before the studies commenced from the Regional Ethics Review Board for studies I (Dnr: 2017/123) and II (Dnr: 2020-05680). Studies III and IV were approved by the Swedish Ethical Review Authority (No. 2024-01685). The studies conform to the ethics standards and principles outlined in the Guide to the Ethical Review of Research on Humans (89) and the Code of Ethics of the World Medical Association (Declaration of Helsinki) (90).

Participants in studies I, III, and IV were given verbal and written information about the study, explaining that participation was voluntary, that the recorded interviews would be treated confidentially, and that they could withdraw at any time without an explanation. Written informed consent was obtained from all individuals before starting data collection. The PRs' vulnerable position, due to a potentially dependent role relative to healthcare and in the CPG monitoring groups, was considered in Study I. By conducting individual interviews, the participants were given the opportunity to describe their experiences in private, without any involvement of HCPs.

The participating HCPs' dependent role as employees was also considered. In Study III, the participants' contact information was obtained through their department heads, which might have made the participants feel more compelled to participate, although all ongoing contact was with the researcher and withdrawal was possible at any time. The use of focus groups, as in Study IV, prevents researchers from guaranteeing confidentiality. This was described in the information letter and included in the consent form, stating that the participants agreed not to disclose any information obtained from other group participants during the focus group interviews.

The reports received for Study II were anonymized, stating only the patients' gender and age and information about the reported events (i.e., the informants, the addressed healthcare providers, and short summaries of the events), and were therefore not traceable to any specific patients. All data were anonymized and coded upon collection and securely stored with access limited to personnel with permission and authorization. When writing the articles, care was taken to minimize the risk that participants could be identified through demographic information or quotations.

Results

Participants

Some characteristics of the participants in all four studies are presented below (Table 2).

Table 2. Overview of characteristics of participants in all four studies.

	Study I	Study II	Study III	Study IV
Patients	-	692*	-	-
PRs	11	-	-	-
Physicians	9	-	9	-
RNs	13	-	7	20
Men/women	9/24	301/391	6/10	1/19
Age range in years	31–81	4–97	25–63	35–63

* The patient complaints concerned the care of 692 patients, although the complaints could be registered by persons other than the patients.

Study I

Study I explored the role of PRs in national CPG monitoring groups, through interviews with PRs, physicians, and RNs in the groups. Six categories, corresponding to different levels of PR involvement in the CPG monitoring groups, were identified. The categories, which address matters ranging from suitability and representation, through recruitment and aspects of the work, to opportunities for improvement, are presented in Figure 2. The content of each category is briefly presented in Table 3.

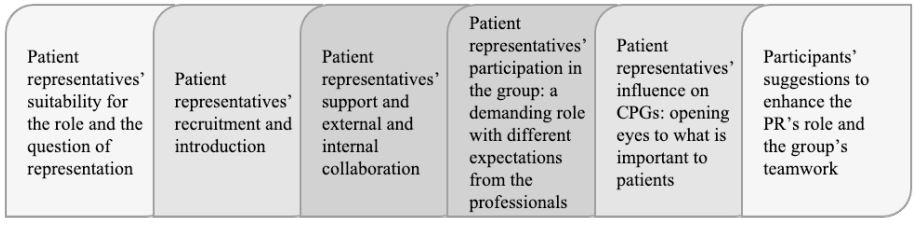

Figure 2. Overview of the categories in Study I.

Table 3. Short presentation of the content of each category in Study I.

Patient representatives' suitability for the role and the question of representation
Identified by professionals: PRs should be in a stable phase with distance from disease PRs could misuse out-of-date facts or their own experiences PRs could view themselves as victims PRs may not be representative of all patients (largest general problem) Identified by PRs: Their opinions not valid for all patients
Patient representatives' recruitment and introduction
Great variation in recruitment and introduction Recruitment of suitable PRs difficult and PR role unattractive due to the workload Poor prognosis or poor health could prevent participation Involving relatives could add another dimension
Patient representatives' support and external and internal collaboration
PRs prepared before meetings and read information even if not understandable Persons were rarely designated to assist PRs Support from patient organizations was appreciated, but could be a source of conflicting views Support from RCCs could help PRs achieve a more professional view PRs experienced walls between medical specialties, consistent with their healthcare experiences
Patient representatives' participation in the group: a demanding role with different expectations from the professionals
PRs took their role seriously and mainly focused on availability of healthcare, nursing, patient–provider interactions, rehabilitation, and self-care PR participation changed attitudes positively in the group Professionals' opinions The PR role viewed as important, but also difficult and unclear Presence of PRs could obstruct discussions Protection of the PRs from sensitive issues sometimes needed Understanding and acceptance of PRs increased over time
Patient representatives' influence on CPGs: opening eyes to what is important to patients
The PRs supplied the group with the patient's perspective Professionals' expectations of and opinions on PRs varied widely PRs wanted an active role, but did not compete with other members PRs had full responsibility for certain parts of the CPGs in some groups Low expectations could impair PRs' performance PRs often felt that their contributions were disregarded
Participants' suggestions to enhance the PR's role and the group's teamwork
Written definitions of PR's role, and professionalizing the PR role PRs should be educated about basic medical knowledge and structure of healthcare Ongoing guidance and support of PRs PRs supported by patient organizations More than one PR in the group All group members should use understandable language Virtual meetings would increase flexibility and reduce travel time Improved economic support

Study II

Study II investigated patient complaints in cancer care reported to PACs in the four northernmost counties of Sweden (i.e., the Northern Healthcare Region) during the five-year period of 2016–2020. Altogether, 692 patients (57% women) made complaints regarding the healthcare received. The complaints concerned outpatient care (77%), inpatient care (16%), or both (6%). The PACs were most often contacted with complaints by the patients (62%), but also by relatives (35%), both (2%), or occasionally other persons (1%). Fourteen per cent of the complaints were made after the patient's death.

The PACs had given each report one code that defined the dominant category of the complaint, following a predetermined list of categories. The material was recoded for this research using the same codes as the PACs used, but with the possibility of choosing more than one code. For an overview of the categories, number of patients with complaints in each category, and number of complaints in each category, see Table 4. Most of the patients (73%) had complaints regarding more than one category, i.e., 39% of complaints concerned two categories and 34% three categories.

Table 4. Overview of the categories, number of patients with complaints in each category, and number of complaints in each category.

Category	No. of patients	No. of complaints*
Care and treatment	454	510
Communication	354	443
Responsibilities of healthcare and organization	168	185
Access to healthcare	108	110
Results	69	69
Administration	60	61
Economic aspects	35	35
Patient's record and secrecy	23	23
In addition**	0	0

* A patient could have one or more complaints in the same category, as well as having complaints in more than one category. Also note that 15 patients had complaints in both the care and treatment and results categories.
** This category was to be used when no specific category applied, but all complaints could be categorized into other categories, hence 0.

More than half of the patients reported communication problems (i.e., concerning information, participation, consent, and interactions), making it the second largest category of complaints after the care and treatment category.

Communication failures were present from diagnostic workup to end of life, often in combination with other complaints (79%). The number of communication complaints did not differ between the years of the study period (data not shown; Chi-square test).

There was a high level of agreement between the coding done by the PACs and the coding in this study concerning the two largest groups of complaints, i.e., care and treatment including results, and communication (see Table 5). However, this study found 216 more patients expressing communication complaints in addition to those identified by the PACs. Complaints about communication were made in relation to all other categories, except economic aspects, and altogether 50 patients had complaints only about communication.

Table 5. Number of patients with complaints within the two largest categories of complaints identified in this study and by patient advisory committees (PACs).

Category	No. patients	PACs, no. patients	Same code, no. patients (%)
Care and treatment, including results	577	388	364 (94)
Communication	354	138	119 (86)

For 47 patients, the PACs did not note any specific type of complaint.

The material was divided according to gender and age under or over the Swedish retirement age of 65 years (see Table 6). As a supplementary analysis, the proportions of the three largest categories of complaints were compared (see Supplement 1). Men under 65 years old reported significantly ($p = 0.016$) lower proportion of communication problems compared to women under 65 years old (reference in all analyses), but no differences were seen for the other groups (previously unpublished data).

Table 6. Gender and age under or over the Swedish retirement age of 65 years.

Gender	Age <65 years	Age ≥65 years
Women	188 (28%)	186 (28%)
Men	103 (15%)	188 (28%)

Age lacking for 17 women and 10 men.

Study III

Study III described the different ways of understanding patient participation among HCPs (i.e., RNs and physicians) in cancer care. The analysis identified five descriptive categories of different HCP understandings of patient

participation in cancer care ranging from perceiving participation as conditional upon healthcare permission (category A), to holistically seeing the patient and, in collaboration with the team, encouraging the person in managing their situation (category E). An overview of the category hierarchy, referred to as the outcome space, is illustrated in Figure 3. The outcome space illustrates the internal relationships among the categories, showing a gradual shift in the understandings from a narrower to a broader and more complex view of patient participation, ranging from healthcare largely shaping participation to gradually increased collaboration and greater patient responsibility and influence (A–E).

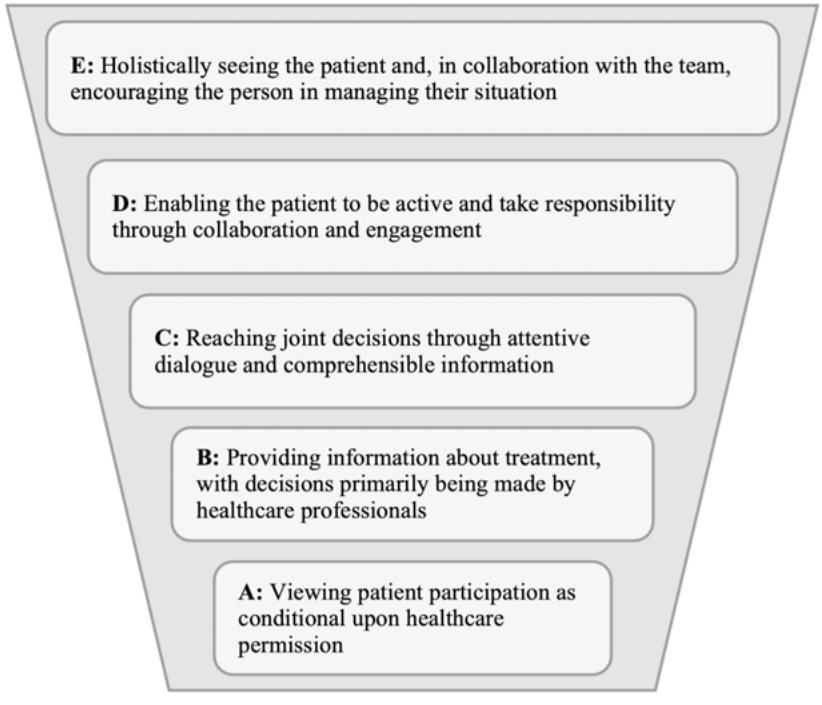

Figure 3. The outcome space: the internal relationships among the categories of ways healthcare professionals understand patient participation. The outcome space ranges from a narrower to a broader view of the concept (A-E), from the bottom up.

According to category A and B understandings, the concept and meaning of patient participation is somewhat unclear and patient participation is viewed in a more restricted way, with healthcare considerably limiting patients' opportunities to participate. In category C, participation is realized through attentive and open communication that enables the patients to make informed choices about their care. In categories D and E, a broader understanding of participation as well as a more active form of participation is evident, with the patients being able to take the initiative and be responsible for their care. HCPs

with an understanding consistent with category E also adopt a holistic view of the patient, considering the team surrounding the patient, including family members, to be central.

Study IV

Study IV explored how healthcare contextual factors influence the realization of patient participation, as perceived by contact nurses in cancer care. The participants were interviewed in focus groups. The analysis identified one overarching theme: Patient participation not fully embedded in the culture and inconsistently realized in everyday practice in cancer care. This overarching theme captures how patient participation was challenged by organizational and cultural conditions, as well as by the individual actions of HCPs. Patient participation was present, but inconsistently realized in everyday practice, reflecting the fact that it was not fully embedded in the culture. Both facilitators of and barriers to patient participation were identified.

Five subthemes were developed, together supporting the overarching theme and reflecting both the system and policy levels of the organization (see Figure 4).

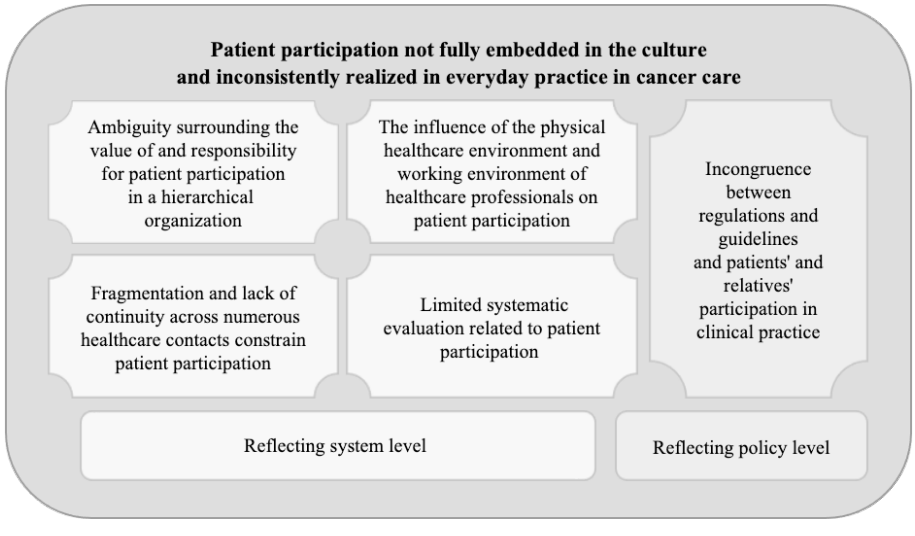

Figure 4. Overarching theme and subthemes in Study IV.

The subthemes are briefly presented as follows:

- *Ambiguity surrounding the value of and responsibility for patient participation in a hierarchical organization* captures how culture and hierarchical structures within the organization affected patient participation.
- *Fragmentation and lack of continuity across numerous healthcare contacts constrain patient participation* addresses the fact that patients with cancer often have numerous healthcare contacts, with continuity across care being essential for enabling participation, while fragmented care involving multiple HCPs often undermined it.
- *The influence of the physical healthcare environment and working environment of healthcare professionals on patient participation* captures how the physical environment and working environment of healthcare staff could influence patient participation.
- *Limited systematic evaluation related to patient participation* captures the limited evaluation of patient participation and feedback available for HCPs in clinical practice.
- *Incongruence between regulations and guidelines and patients' and relatives' participation in clinical practice* addresses patients not always being aware of their legal rights to participate in planning their care or to refuse treatment and how confidentiality sometimes contrasted with participation.

Discussion

This thesis aimed to explore and deepen the understanding of various experiences of and perspectives on patient participation in cancer care across different settings and levels of the healthcare system. The findings present perspectives of PRs, patients, relatives, and HCPs from various parts of cancer care. The findings show that PRs' participation in national CPG monitoring groups for cancer (Study I) was considered important. However, uncertainties and low expectations regarding their contributions were reported. Study II, which analysed a large number of patient complaints to PACs, found that more than half of the patients reported communication failures, many of which were not identified by the PAC coding system. Study III identified widely divergent HCP understandings of patient participation in cancer care, and Study IV identifed that efforts to involve patients in their cancer care were challenged by organizational and cultural conditions, as well as by the actions of individual HCPs.

Despite legal support and structural improvements in Swedish cancer care, patients' participatory rights were not always realized, nor were their needs always met. That full participation has not been achieved, even though it is generally considered important (Study I), illustrates a gap between policy and practice. An initial and prominent explanation for this gap is that HCPs perceive and apply patient participation in widely differing ways. This occurs despite the fact that legislation regarding patients' right to participation (2) has been in effect for more than a decade. Such differences are also evident in studies II, III, and IV. Difficulties in defining and describing the concept, identified in the results of studies III and IV, have also previously been reported (8,22,23,91). This illustrates that the concept of patient participation is neither clear nor well-established for HCPs, which in turn impacts how such participation is realized. In Study III, the findings demonstrate that HCPs' understandings of patient participation varied considerably, ranging from perceiving participation as conditional upon healthcare permission, to holistically seeing the patient and, in collaboration with the team, encouraging the person in managing their situation. How HCPs interact with patients is influenced by their competence, defined as a combination of applied knowledge, skills, and attitudes (92,93). The HCPs' diverse, and sometimes insufficient, competence

regarding participation implies that an act or policy, although important, is not enough, but must also be locally educated, implemented, and repeatedly discussed and followed up within the organizations to create a shared understanding and vision.

Although patient representation is a national priority, the findings of Study I highlight the many challenges associated with the PR role. The same or similar uncertainties and barriers have previously been identified, such as unclear expectations and goals of participation (44), recruiting problems (94), PRs' ability to represent patient groups (44,94), difficulties with scientific and medical language (94), and HCPs' resistance to patient involvement (94). In person-centred healthcare, patients are actively involved in development efforts at all levels, including governance and management (95). PR participation in medical working groups, such as CPG monitoring groups, is one of several ways to achieve such participation. For that to happen, the identified challenges need to be addressed and resolved.

HCPs' opinions of PR influence varied between none or being regarded as essential to healthcare development (Study I), which may reflect differing attitudes regarding patient participation. Studies III and IV illustrate how HCPs view their own responsibility for facilitating participation, which likewise varied greatly. The PRs participating in Study I took their role seriously and wanted an active role, even if it was not always welcomed by the rest of the group. Patients as co-designers of healthcare can challenge traditional roles, forcing HCPs to step out of their comfort zones (96), and the issues of PRs' role description and expectations have been raised in previous studies and reviews (42,43,94,97–100). However, as shown in Study I, acceptance of the PR role did increase over time, especially among physicians. This suggests that the process of implementing patient participation at a structural level has moved faster than the related knowledge-building and cultural changes for HCPs.

Cultural factors can challenge patient participation, as shown in Study IV. Although patient participation did occur, it was not entirely realized in everyday practice, reflecting the fact that it was not fully embedded in the culture. Culture as a contextual factor refers to the values, norms, beliefs, attitudes, and practices of a specific care context (80), ultimately determining the extent to which patient participation is enabled or restricted. Culture in healthcare organizations (including capacity and capability) and readiness for change both affect quality improvement initiatives (101). It is reported to facilitate meaningful participation when the culture of an organization is inclusive, and real attention is paid to the patient perspective (102). However, creating such a culture is seen as challenging (102), and healthcare leaders also argue that

the implementation of patient involvement requires cultural change among HCPs (103). Although HCPs have a responsibility to cultivate a culture that facilitates participation, responsibility for participation does not rest solely with them. Leadership significantly influences the culture of healthcare organizations (104,105). Leadership is a contextual factor affecting quality improvement initiatives (101), and healthcare leaders are considered important facilitators of implementation processes (103). Also, lack of strategy and goals for patient participation has been indicated by patients and HCPs in previous research (106), which could lead to difficulties in understanding what to do and how to do it. Leadership was not brought up as a contextual factor influencing patient participation in Study IV but was not specifically asked about. However, healthcare leaders have responsibility for creating conditions that encourage participation through education, implementation, and continuous follow-up within their organizations.

Regarding collective patient participation, i.e., at the patient-group or citizen level, a recently published government report noted a lack of regulation, monitoring, and oversight, and that the government is perceived as not sending sufficiently clear signals that collective patient participation is a priority (100). Since PRs are increasingly being included in different working groups at various levels within the healthcare system, it is crucial to ensure that their involvement actually leads to meaningful participation in which their knowledge and perspectives are integrated. Overall, it is a joint responsibility for all organizations, their leaders, and HCPs to address shortcomings and together strive to bridge the gap between policy and practice.

In Study II, patients and their relatives shared experiences of situations in their interactions with HCPs where their communication needs were not met, situations that were so important for the individual that they chose to report the shortcomings to the PACs. They reported information deficiencies, not being listened to, feelings of being misunderstood, as well as impersonal and unpleasant interactions. Most patients had more than one complaint about the same event or chain of care, revealing more communication failures than did the PAC statistics. As noted in previous research (107), single-coding systems, such as the PAC coding system, report fewer communication failures than do multiple-coding systems, implying that communication complaints are viewed as less important than other complaints. To facilitate patient participation, a good patient–provider relationship is described as necessary for the patient to feel acknowledged, and for information to be exchanged and transformed into knowledge and understanding (28). This illustrates the importance of all the communication subcategories (i.e., information, participation, consent, and interaction) for achieving full participation. Communication

failures were the second largest category of complaints, congruent with previous national and international studies of patient complaints non-specific to cancer care (107,108). This indicates that, despite structural changes, cancer care faces the same challenges as does healthcare in general regarding participation. In Sweden, the same communication failures have been reported over the years (109,110), even though it is well known that communication is crucial for patient safety (111) and for achieving person-centred care (29,31). Healthcare is changing and improving in so many areas, but regarding communication and patient participation, the changes are progressing far too slowly. Although many communication failures can be individual errors or misunderstandings, the number of reported communication failures suggests that there is also a structural problem with patient–provider communication in cancer care. This could be related to HCP competence, but other factors may also play a role.

Although patients' preferences for involvement in decisions regarding cancer treatment could vary (112), as implied and expressed by HCPs in studies III and IV, the majority of patients still prefer to be involved (112,113). Patients with cancer express the necessity of collaboration that addresses both the disease and the patient having the disease (69). While some patients experience holistic, person-centred care, some patients feel like 'packages' in a fragmented system (69). This corresponds to results concerning a holistic understanding of participation (Study III), and to CNs' views concerning a fragmented cancer care pathway with its negative effect on participation (Study IV). Fragmented care involving many HCPs was described as often undermining patient participation (Study IV).

A powerful healthcare hierarchy was identified in Study IV. The participants said that the hierarchy entailed the patients being in a subordinate position and that this could negatively affect patient participation. Hierarchy has wide-reaching impacts on the delivery of health services (114), and patients with cancer have expressed that their opportunities to take part in and influence their care planning were realized to only some extent (25,68). A broader and more complex understanding of patient participation (Study III) also acknowledges the team around the patient and the interprofessional collaboration among HCPs. Interprofessional teamwork is crucial for delivering optimal care to patients with cancer (115), particularly given that cancer care often involves multidisciplinary teams. The quality of this collaboration also directly influences patient experience, clinical outcomes, and the overall quality and safety of healthcare delivery (116), underscoring its importance. While interdisciplinary collaboration and reflection are vital in healthcare communication and training (117), the findings of all four studies support the need for

increased person-centred care in which all HCPs have both the knowledge (118) and the contextual support (31) to see their patients as persons and to support their care and treatment along the cancer care pathway.

However, patient participation can change hierarchical, provider-driven networks by applying a partnership model (119). Participants in Study I reported weakened hierarchies throughout the group as a result of PR participation. This result suggests that there are more advantages to patient participation than just patient influence, even though that is the main focus. The team around the patient, whether in direct care or at a structural level, can benefit because working together as a team is a necessity for organizational success (120). Effective teamwork also creates more positive and engaging workplaces with improved clinical outcomes and reduced patient risks (116). So, even though a change may seem unclear and perhaps somewhat difficult, it can result in benefits for everyone involved over time. Beyond patient benefits (5–7), increased patient participation is associated with enhanced work engagement and job satisfaction among HCPs (121) as well as economic benefits for healthcare systems (5,122).

HCPs sometimes do not trust or recognize patients' knowledge, capabilities, and abilities, as shown in studies I, III, and IV. HCPs in Study I sometimes felt that they wanted to shield the PRs from issues such as discouraging prognoses. However, none of the PRs mentioned having problems discussing sensitive topics. In studies III and IV, participants addressed the type of involvement patients can handle or be trusted with. HCPs' shielding of patients may also be a factor contributing to the results of Study II, in which patients described failures in communicating information. Although well-intended, HCPs' attempts to protect patients from potentially hurtful or negative information can create difficulties for patients, relatives, and healthcare teams (123). Also, information deficiencies can damage future trust in healthcare (studies II and IV). While cancer patients highly value clarity regarding disease progress (124), prognostic information can be perceived as harmful if poorly timed (125), highlighting the importance of both the patient–provider relationship and contextual factors. Also, as identified in Study IV, patients' having direct access to information via digital medical records can entail problems when they read information that they are supposed to receive at a later scheduled appointment. HCPs are not present to provide explanations and support when they read the information, and sometimes patients blame HCPs for making the information available before a scheduled appointment.

Analysing patient complaints in cancer care does not provide a complete description of the communication between patients and HCPs. However, communication failures and lack of participation appeared clearly in the findings

in Study II, showing a need for improvement in these areas. Moreover, the patients reporting complaints probably represented many 'silent others', as it is unlikely that all patients experiencing communication failures file complaints. As reported in Study IV, patient feedback is not structurally used for learning in clinical practice. Participating CNs acknowledged a lack of knowledge of reported events, noting that there were no structural forums for discussing patient feedback (e.g., patient complaints) or related improvement efforts in their everyday clinical practice. When complaints are treated as isolated events, healthcare fails to identify underlying systemic factors or trigger deeper learning (126). This lack of strategy underlines the need for better policy, tools, and guidance in order to establish a quality monitoring and improvement pathway that is distinct from immediate, case-by-case practice (127). Caring for patients is a team effort, and learning from patient complaints should equally be a collaborative process (126). Also, patient feedback can predict service quality and the effects of quality improvement strategies (128). Using patient feedback as well as allowing patients to actively participate in their care could provide insights that would not otherwise be apparent. While HCPs may often assume that they understand patient needs, Study I and prior research (92) have demonstrated that reflective dialogues can offer eye-opening insights. In previous research, HCPs have expressed belief in the added value of patient participation, since patients have unique expertise that would be missed without their participation (106).

Methodological considerations

To achieve trustworthiness in this thesis, the constituent studies aimed to meet the criteria of credibility, transferability, dependability, and confirmability (129).

To enhance **credibility** and establish that the findings were derived from the data (75), all four studies were conducted through close collaboration within the research team. Its members, informed by their varied and extensive professional experience, discussed both the content and coding process throughout the analysis. The interview guides were designed to encourage detailed responses and to support participants in providing concrete examples. Asking probing questions, to encourage the participants to elaborate on their answers and thereby refine the understanding, strengthened credibility in the data collection. Also, the interview guides (studies I, III, and IV) were evaluated to identify potentially leading questions, clarify ambiguous wording, and ensure that the questions were aligned with the research questions to promote the sharing of participants' experiences and perspectives. The interview

technique was also evaluated. In Study I, each interviewer conducted one pilot interview (included in the material), after which the interview technique was thoroughly discussed and then slightly modified. In Study III, one pilot interview was performed (not included in the material), reviewed, and discussed within the research team. After four interviews had been conducted, parts of the research team read those interviews, and again assessed the interview guide and technique, to ensure that the guide was suitable for the phenomenographic method. In Study IV, the interview guide and format were evaluated after the first interview, leading to minor revisions of the guide regarding the participants' introduction to healthcare contextual factors. In all, interview technique, which entails balancing listening and talking, managing silence, improving probing skills, and maintaining neutrality, needs to be practiced and did improve over time. Also, transcripts were verified against the audio-recordings to ensure verbatim accuracy.

Transferability was sought by providing rich descriptions of participants, contexts, and settings so that readers can assess the degree to which the findings may be relevant to their patients and settings (84). To enable similar studies to be conducted or compared, transparent descriptions of the utilized methods were also striven for (84). Overall, the intention has been to include participants with experiences of different types of cancer and in different contexts in all the studies. This approach captured various experiences, prevented the culture of any particular group from exerting undue influence, and increased the transferability of the findings to other groups (129).

To increase **dependability** (84), the methods were transparently described, detailing both the research process and underlying analytical choices. Also, studies I, III, and IV applied semi-structured interviews that were piloted, evaluated, and audio recorded as ways to strengthen dependability. Having multiple researchers independently perform the analytical steps, as was done in all studies, could be seen as strengthening the dependability of the analytical process (84). This process minimized individual subjectivity, uncovered blind spots, and ensured a more robust, consistent interpretation of the data through subsequent consensus discussions. Although debated by Braun and Clarke (2019), who considered the unavoidable subjectivity of the researcher, the use of multiple perspectives could be seen as contributing positively to the dependability of the interpretation (130).

To enhance **confirmability** (84) and reduce the risk of selection bias (131), all participants were recruited based on predefined inclusion criteria. However, the participants in Study III were identified through their managers, which may have influenced who were invited to participate. As part of all analytic processes, the research team reflected on whether their backgrounds and

experiences might influence the results. In Study IV, a reflexive journal was compiled by the research team members, both individually and collectively. Semi-structured interview guides consisting primarily of open-ended questions were used to avoid leading the participants' answers. Clarifying and probing questions were asked in all interview studies to encourage participants to elaborate on their responses in order to avoid misunderstandings (84). All interviews were audio recorded, which strengthened confirmability (84). Continuously checking the analytical steps in relation to the raw data also strengthened confirmability (84).

All participants in **Study I** were permanent members of CPG monitoring groups. They had varying levels of experience working in the groups, which provided an opportunity to gain insights into different perspectives. All interviews, except one, were conducted by telephone and not in person, which may have affected the participants' responses. Patient participation in healthcare development can be a sensitive subject, as there are challenges in identifying direct impacts and effects (102). It is therefore possible that the telephone interviews allowed participants to speak more freely about the negative aspects of patient participation, although this possibility is merely speculative. Telephone interviews also made it possible to widen the data collection and include more perspectives by including participants from different national CPGs located in different parts of the country. The PRs participated only as informants and not in the research process, although the latter could well have been valuable and which also applies for all the studies.

In **Study II**, the data (patient complaints) were most often written up by PAC personnel, which could mean that participants' perspectives were inadequately reconstructed and that their messages may not have been conveyed as intended. Sometimes the summaries contained quotations or correspondence from the complainant, but mostly they did not. However, the PACs are impartial with the task of helping patients and relatives to address questions and complaints to healthcare, and the choice of data made it possible to include a large volume of data. Despite this large volume, all reports were independently coded by two authors with different professional backgrounds (i.e., an RN and a physician). The statistical calculations were performed in collaboration with a statistician, who was also an author of the published article.

In **Study III**, data were analysed using a phenomenographic method. RNs and physicians working in specialist care at three hospitals were recruited as participants in order to include diverse voices and diverse perspectives (132) on HCPs' understanding of patient participation, based on everyday experience. Physicians care for patients at various stages of the care pathway as a normal part of their work, while RNs normally work in either in- or outpatient

care. Therefore, RNs were recruited from different parts of the surgical and urological care chain to enhance the variation in their experiences. The participants were recruited through departmental leaders, which limited the research team's control of the participants' variations in gender, age, and professional experience, although efforts were made to request such variation in the recruitment information. Despite this lack of direct control, there was variation in age, professional experience, and educational levels among the participants as a whole and within the professions separately. Regarding gender, there was less variation within the professions and there were no male RN participants, which is a limitation. In phenomenographic studies, the number of interviews should ensure sufficient variation in how the phenomenon of interest is viewed (133), but an unmanageable number of interviews should also be avoided (133). Therefore, 20–30 interviews is considered ideal and 10–15 a minimum (134), but interesting patterns of understanding can usually be detected within the first 5–10 interviews (135). In Study III, the inclusion of 16 participants was considered sufficient to provide rich and varied data.

In **Study IV**, CNs, who serve as designated contact persons for patients with cancer, were recruited as participants in focus groups. Focus groups provide the opportunity to collect rich and detailed data, as group discussions can uncover deeper insights and nuanced perspectives (136). The focus group interviews were conducted with mixed groups from three hospitals of different sizes and with different conditions, and the participants were responsible for patients in different teams in surgical and urological cancer care. The variety of organizational contexts was hoped to broaden the participants' perspectives and experiences and lead to more productive discussions. However, the participants' opportunities to participate outweighed the aim of having mixed groups, leading to fewer groups mixing participants from different hospitals than was aimed for. At the information sessions held at one of the hospitals, research team members were not physically present, attending only through a digital platform, which possibly resulted in fewer participants.

The interview guide contained short patient stories, based on real complaints reported to Swedish PACs, to guide the participants to relate to and discuss contextual factors. Not all contextual factors described in the framework (80) were presented in the included short patient stories, which could have influenced the discussions in such a way that certain contextual factors were given greater prominence. In an attempt at counterbalancing, the interview guide contained questions prompting the participants to reflect on contextual factors not illustrated in the presented examples. Also, the participants' differing knowledge and experiences of the framework (80) could have influenced the data.

Conclusion

This thesis aimed to explore and deepen the understanding of various experiences of and perspectives on patient participation in cancer care across different settings and levels of the healthcare system in Sweden. The individual studies concluded the following:

- Although PRs' roles and teamwork varied, most PRs needed to be empowered to engage actively for their knowledge to be fully utilized. Clarifying roles, expectations, and shared goals could enhance collaboration, creating teams that work more effectively to improve healthcare (Study I).
- Communication failures were a common cause of dissatisfaction mentioned in patient complaints, and these failures did not appear clearly in existing reporting systems. Healthcare should utilize the knowledge conveyed by patient complaints and create conditions and environments that support HCPs in delivering person-centred care (Study II).
- HCPs' understandings of patient participation in cancer care differed greatly, ranging from viewing it as an organizationally governed approach to a holistic and collaborative process. Fully realizing participation requires education, continuous follow-up, and a culture that prioritizes participation at all levels from the organization to individual HCPs (Study III).
- Patient participation was inconsistently implemented due to contextual factors. To enable and realize a consistent culture of person-centred care, healthcare organizations, leaders, and HCPs need to strengthen their interprofessional team approaches to make participation an integrated and shared responsibility (Study IV).

Despite legal support and structural improvements in Swedish cancer care, patients' participatory rights are not always upheld, nor are their needs always met. Patient participation is not fully embedded in the structure and culture of the organizations, leading to a gap between policy and practice. Healthcare organizations, leaders, and HCPs need to take responsibility for patient participation and work together so that it becomes a shared responsibility and so that patients' knowledge and perspectives become integral to clinical practice and development.

Clinical implications and future research

This thesis provides knowledge of patient participation from different perspectives and structural levels in cancer care; this knowledge concerns barriers to and facilitators of participation, and how healthcare can support and strengthen patient participation. The results could be utilized in different ways in direct care, healthcare development, education, and professional development to enhance patient participation. The knowledge provided could also be useful in developing organizational strategies and goals to promote meaningful patient participation.

The findings of Study I are of value to clarify the role of PRs in medical working groups, including terms and expectations, and to support improved PR participation through, for example, enhanced introduction to the work, help in overcoming practical obstacles, and continuous support over time. Further studies could evaluate whether collaboration involving all members of the working group, aimed at establishing shared expectations and clarifying roles, could influence the role ambiguity, level of PR participation, and teamwork in the groups. Such approaches could also be applied when implementing PR participation in other healthcare working groups, as it becomes more common at various levels of the healthcare system.

The results of Study II provide an overview of patients' complaints about cancer care, which could serve as a 'wake-up call' about the importance of communication and patient participation. Patient feedback must be utilized at all levels of healthcare, and healthcare leaders have a responsibility to share such information and create opportunities for interprofessional teams to apply patient feedback in improvement efforts. However, identifying failures and implementing improvements are shared responsibilities. In Study IV, short patient stories based on patient complaints were presented to contact nurses; these stories were able to prompt reflection, which in turn could lead to improvement initiatives. Qualitative and mixed-methods studies could explore whether there are factors influencing the patients' ability and willingness to report complaints, resulting in underrepresentation in official statistics. The findings could also be used to improve patient complaint systems by coding for multiple issues within a single report, making the quality monitoring system more reliable.

The different understandings of patient participation presented in Study III are important for healthcare organizations, leaders, HCPs, and educators to understand. This knowledge could be utilized in educational initiatives and professional competence development. Whether structured and recurring educational interventions for HCPs aimed at enhancing competence in patient participation can improve patient experiences and outcomes could be investigated. While implementing such initiatives, patient participation could be measured over time. These findings could also be used in future research to investigate how different understandings of patient participation influence clinical practice, patient experiences, and patient outcomes.

The barriers to and facilitators of patient participation identified in Study IV at both the clinical and organizational levels could be used to improve identified barriers and reinforce the already implemented positive conditions for patient participation in cancer care. Leaders have a responsibility to establish interprofessional forums and educational initiatives in which integrating patient participation in clinical practice is discussed structurally and regularly, helping it become a natural part of ongoing improvement processes.

The findings of Study IV, and of the other studies included in this thesis, could be used as guidance when examining healthcare organizations' own environments and practices regarding patient participation in cancer care. In this process, the FoC framework could provide practical guidance, including a shared language for identifying clinical gaps and for translating abstract goals concerning person-centred care and patient participation into concrete actions at the bedside, in outpatient clinics and within monitoring groups. In such research, patient participation should be measured from a long-term perspective.

In cancer care, as in healthcare in general, technological developments are advancing rapidly. Healthcare systems are constantly striving to become more efficient, and tools such as AI are being introduced to summarize information, to help in diagnosing, determining treatment, and planning care, and to prepare documentation in medical records. These tools are increasingly becoming part of everyday care, and HCPs must be able to handle them appropriately in interactions with patients while maintaining an active role in helping them critically evaluate information from different digital sources, including their own records. How such different sources of information, which may be conflicting, affect patient participation and the patient–provider relationship should be further explored in future studies.

At the very beginning of this thesis, a motto emphasizing that no policy should be decided on without the full and direct participation of members of the groups affected by that policy, was quoted. That motto can also be applied to all situations in patient care to ensure safe, person-centred care, and to

promote reflective dialogues with patients leading to eye-opening insights that could help improve patient participation – ‘Nothing about us, without us’.

Svensk sammanfattning (Swedish Summary)

Patientdelaktighet erkänns alltmer som en integrerad del av hälso- och sjukvården. Kunskap och erfarenheter från patienter uppfattas som viktiga för både planering och utveckling av vården, men även som nödvändigt för säker personcentrerad vård. Patientdelaktighet kan också leda till bättre hälsoresultat, bland annat förbättrad fysisk och psykisk hälsa, samt ökad patientnöjdhet.

Denna avhandlings övergripande syfte är att undersöka och fördjupa förståelsen för erfarenheter av och olika perspektiv på patientdelaktighet i cancervården inom olika verksamhetskontexter och på olika nivåer i hälso- och sjukvårdssystemet. Hälso- och sjukvården och dess personal spelar en avgörande roll i att hjälpa och stödja patienter med cancer med de fysiska, emotionella, psykologiska och sociala behov som uppstår till följd av cancerdiagnosen. För patientdelaktighet är relationen mellan patient och vårdpersonal central. Förväntningen är ett möte som bygger på ett ömsesidigt partnerskap, där respekt såväl för patientens erfarenhetsbaserade kunskap som för vårdpersonalens kliniska kunskap och expertis ingår. En etablerad, välfungerande och förtroendefull relation mellan patient och vårdpersonal är också grundläggande för att uppnå en säker och personcentrerad vård.

Patientdelaktighet ska så långt som möjligt gälla på individnivå, men kan även förekomma på mer övergripande nivåer, så kallade meso- och makronivåer. Mesonivån, nivån för hälso- och sjukvårdsorganisation, kan exempelvis utgöras av förutsättningar för patientdelaktighet i regionala frågor som fördelning av resurser eller interna prioriteringar. Makronivån, samhälls- och myndighetsnivån, handlar om delaktighet i nationella beslut om struktur- och prioriteringsfrågor. Att anpassa vården till patienters värderingar och prioriteringar kan också resultera i en mer effektiv resursanvändning, vilket är avgörande för hälso- och sjukvårdssystemens långsiktiga hållbarhet.

Patientlagen infördes i Sverige 2015 för att stärka och tydliggöra patientens ställning inom hälso- och sjukvården samt för att främja patientdelaktighet. Trots rättsligt stöd och goda intentioner visar dock nationella utvärderingar och forskning att patientdelaktighet inom cancervården inte fullt uppnår den avsedda effekten. För att förstå orsakerna till detta behöver man vidare undersöka patientdelaktighet från flera olika perspektiv.

Studie I undersökte patientrepresentanters roll i nationella arbetsgrupper för vårdprogram för olika cancerdiagnoser. Detta i syfte att beskriva deras roll, bidrag i gruppen och identifiera möjligheter till förbättringar. Data samlades in genom enskilda, semistrukturerade intervjuer med medlemmar i nationella arbetsgrupper för cancer i Sverige (11 patientrepresentanter, 13 sjuksköterskor och 9 läkare) och analyserades med hjälp av innehållsanalys. De flesta deltagarna ansåg att patientrepresentanternas roll var viktig, men flera problem togs upp. Patientrepresentanternas bidrag hämmades av osäkerhet kring deras roll, låga förväntningar från andra gruppmedlemmar och en känsla av att deras bidrag ofta ignorerades. Vårdpersonal ifrågasatte om patientrepresentanterna verkligen var representativa för sjukdomen eller andra patienter och menade också att vissa ämnen inte kunde diskuteras i närvaro av patientrepresentanter.

Studie II undersökte och analyserade patientklagomål inom cancervården som rapporterats till patientnämnder i norra sjukvårdsregionen, dvs. de fyra nordligaste länen, för att beskriva frekvensen av och innehållet i kommunikationsklagomål i ärendena. Innehållsanalys med s.k. summativ approach tillämpades på alla klagomål som rapporterats till patientnämnderna avseende patienter med cancer under en femårsperiod (n = 692). Resultatet visade, till skillnad från de traditionella rapporterna från patientnämnderna, att mer än hälften av patienterna rapporterade kommunikationsbrister. Dessa brister rapporterades från diagnostisk utredning till livets slutskede. Patienterna rapporterade att de fick felaktig eller bristfällig information, inte blev lyssnade till och att de behandlades respektlöst eller opersonligt.

I studie III undersöktes vårdpersonals olika sätt att uppfatta patientdelaktighet inom cancervården. Data samlades in genom semistrukturerade intervjuer med ett strategiskt urval av läkare (n = 9) och legitimerade sjuksköterskor (n = 7) arbetandes inom kirurgisk och urologisk cancervård vid tre olika stora sjukhus. Fem beskrivande kategorier av olika sätt att förstå patientdelaktighet identifierades. Uppfattningarna varierade från att delaktighet kan ske när vården tillåter till att se patienten ur ett helhetsperspektiv och, i samarbete med patienten, närstående och vårdteamet, stödja personen att hantera sin situation.

I studie IV undersöktes hur kontextuella faktorer inom hälso- och sjukvården, så som de uppfattas av kontaktsjuksköterskor, påverkar realiseringen av patientdelaktighet inom cancervården. Semistrukturerade fokusgruppintervjuer genomfördes med ett strategiskt urval av kontaktsjuksköterskor (n = 20), arbetandes inom kirurgisk och urologisk cancervård vid tre olika stora sjukhus. Intervjuerna analyserades med reflexiv tematisk analys, med utgångspunkt i dimensionen ”vårdkontext” i ramverket Fundamentals of Care. Analysen resulterade i ett övergripande tema – att patientdelaktighet inte är fullt

integrerat i kulturen och inte konsekvent tillämpas i den dagliga cancervården. Fem subteman speglar både systemnivå och policynivå inom organisationen.

Trots rättsligt stöd och strukturella förbättringar inom den svenska cancervården tillgodoses inte alltid patienternas rätt till, och behov av, delaktighet. Studie I belyser grundläggande problem som fortfarande återstår att lösa trots att patientrepresentanter länge har deltagit i arbetsgrupper inom hälso- och sjukvården. Även om patientrepresentanternas roll och samarbetet skilde sig åt mellan grupperna, hade de flesta patientrepresentanter behövt stärkas för att mer aktivt delta i arbetet och att deras engagemang och kunskap skulle nyttjas fullt ut. Att förbättra teamarbetet genom att tydliggöra roller och förväntningar skulle kunna leda till mer inkluderande och jämställda team, som kan arbeta mer effektivt mot målet att förbättra cancervården. Studie II visar att kommunikationsbrister är en vanlig orsak till missnöje i patientklagomål men att de döljs ”mellan raderna” och alltså inte framkommer tydligt i befintliga patientnämndsrapporter. Hälso- och sjukvården måste nyttja den kunskap som patienternas klagomål förmedlar och skapa förutsättningar och miljöer som stödjer vårdpersonalen i att tillhandahålla en vård som är personcentrerad och ger möjlighet till delaktighet. I studie III framgick det tydligt att vårdpersonal uppfattar patientdeltagande på väldigt skilda sätt. För att fullt ut uppnå patientdelaktighet krävs utbildning, implementering samt återkommande diskussioner och uppföljning inom organisationen. Studie IV identifierar både hinder och främjande faktorer som påverkar att patientdelaktighet genomförs på ett inkonsekvent sätt under påverkan av kontextuella faktorer. Den beskriver hur insatser för att göra patienter delaktiga i sin cancervård försvårades av organisatoriska och kulturella förhållanden samt av enskilda vårdpersonals ageranden. Studien visade också att patienternas synpunkter inte systematiskt nyttjas i den kliniska verksamheten, vilket – precis som i studie 1 – tyder på att patienternas röster och åsikter inte till fullo tillvaratas och används för att förbättra cancervården.

Att full delaktighet inte uppnås visar på ett gap mellan policy och tillämpning. Gapet påverkas av både organisationernas och vårdpersonalens kunskap och kultur, liksom av kontextuella faktorer. Hälso- och sjukvårdsorganisationer, dess ledare och vårdpersonal måste ta ansvar och samarbeta så att patientdelaktighet blir ett gemensamt ansvar och att patienternas kunskap och perspektiv blir en integrerad del av den kliniska verksamheten och vårdens utveckling. Detta är nödvändigt för att möjliggöra och förverkliga patientdelaktighet i enlighet med lagar och riktlinjer.

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Supplement 1

Patients complaining about *care and treatment including results*, *communication*, and *responsibilities of healthcare and organization*, respectively, in relation to gender and age (years). The material has been divided according to gender and retirement age (65 years), and the group women <65 years is used as reference in all analyses.

All patients (n = 665*)	**NO.**	**%**	**OR**	**CI (95%)**	**P- value women <65 years is used as reference**
Care and treatment, including results (n = 492*)					
Women <65 years	141	29	1.0	-	-
Women ≥65 years	142	29	1.1	0.67–1.73	0.76
Men <65 years	76	15	0.9	0.54–1.63	0.82
Men ≥65 years	133	27	0.8	0.51–1.27	0.35
Communication (n = 345*)					
Women <65 years	110	32	1.0	-	-
Women ≥65 years	94	27	0.7	0.48–1.09	0.12
Men <65 years	45	13	0.6	0.34–0.89	0.016
Men ≥65 years	96	28	0.7	0.49–1.11	0.15
Responsibilities of healthcare and organization (n = 161*)					
Women <65 years	37	23	-	-	-
Women ≥65 years	51	32	1.5	0.95–2.50	0.79
Men <65 years	20	12	1.0	0.54–1.80	0.96
Men ≥65 years	53	33	1.6	0.99–2.59	0.54

* Age is lacking for 17 women and 10 men in the total material, for 11 women and 5 men complaining about care and treatment, including results, for 5 women and 4 men complaining about communication, and for 5 women and 2 men complaining about responsibilities of healthcare and organization. Considering the categories care and treatment and results as one entity explains the difference in number of patients compared with Table 5.

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