The complexities of implementing person-centred care in a real-world setting

A case study with seven embedded units

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Abstract

Background: Implementing complex innovations such as person-centred care (PCC) is gaining international momentum. Studies in real-world settings have the potential to designate factors crucial for large-scale implementation.

Overall aim: To increase the knowledge about the implementation process of PCC in a real-world setting.

Methods: The thesis consists of a case study with seven embedded units conducted between 2016 and 2019. Study I explored the strategies and how they were enacted to support implementation of PCC by triangulating data from activity logs, interviews with change agents, and written documents. Study II explored how the PCC model of the Gothenburg University Centre for Person-centred Care and its underlying philosophical principles were operationalised. Study III explored health care professionals’ perceptions of PCC characteristics by an interview study using focus groups, dyadic interviews, and individual interviews. In study IV a mixed-methods design was applied to develop a generic questionnaire measuring patients’ perceptions of PCC. The study was conducted in three phases and included interviews, a Delphi study and patients responding to the questionnaire, and taking part in cognitive interviews. Data were analysed using Rasch and qualitative content analyses.

Results: The overall results of this case study show the complexity of health care and change processes, focusing the implementation of a new care approach. Specifically, study I revealed how 43 discrete strategies were used in the participating units to support implementation of PCC with wide frequency and dose variation of activities. Strategies used to train and educate HCPs and develop interrelationships between stakeholders were most often reported (78%). A limited number of strategies (4.6%) reported using evaluative and iterative strategies. Study II highlights the challenges of operationalising an abstract ethical approach into concrete core practices. Both similarities and dissimilarities between the participating health care units were identified. In study III, nine constructs from the CFIR were identified as pertinent to describe HCPs’ perceptions of PCC and showed how their perceptions were shaped by diverse factors, including local context and individual understanding of PCC. In study IV, a questionnaire measuring patients’ perceptions of PCC was developed and found to be psychometrically satisfactory.

Conclusions: This case study contributes to an increased understanding of the complexities of implementing PCC in various health care settings. The complexities are apparent in all aspects of the case and contribute with guidance into the different factors that need to be considered during the change process, preferably before organisations embark on implementation of PCC.

Keywords: Person-centred care, implementation, case study, strategies, innovation characteristics, change agents, questionnaire, Rasch analysis

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Två sanningar närmar sig varann. En kommer inifrån, en kommer utifrån och där de möts har man en chans att få se sig själv.

Ur dikten "Preludier II" i Mörkerseende 1970, citerad efter Tomas Tranströmer
List of Papers

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

I  Fridberg H., Wallin L., and Tistad M. Tracking, naming, specifying and comparing implementation strategies for person-centred care in a real-world setting: a case study with seven embedded units. *In manuscript.*

II Fridberg H., Wallin L., and Tistad M. Operationalisation of person-centred care in a real-world setting: A case study with six embedded units. *In manuscript.*


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Abbreviations

CFIR  The Consolidated Framework for Implementation Research
CVI  Content Validity Index
DD  Department for Development
ERIC  Expert Recommendations for Implementing Change
GPCC  Gothenburg Centre for Person-centred Care
GPCCQ  The Generic Person-Centred Care Questionnaire
HCP  Health care professional
PCC  Person-centred care
RCT  Randomised controlled trial
SALAR  Swedish Association of Local Authorities and Regions
WHO  World Health Organisation
Definitions

Change agent  An individual who influences clients’ innovation decisions in a direction deemed desirable by a change agency (Rogers 2003).

Case study  A case study is a research approach that is used to generate an in-depth, multi-faceted understanding of a complex issue in its real-life context (Crowe et al. 2011).

Complex intervention  An intervention might be considered complex because of properties of the intervention itself, such as the number of components involved; the range of behaviours targeted; expertise and skills required by those delivering and receiving the intervention; the number of groups, settings, or levels targeted; or the permitted level of flexibility of the intervention or its components (Skivington 2021).

Context  …”context” is the set of circumstances or unique factors that surround a particular implementation effort (Damshroder et al. 2009).

Implementation  Implementation is an actively planned and deliberately initiated effort with the intention to bring a given intervention into policy and practice within a particular setting. These actions are undertaken by agents who either actively promote the use of the intervention or adopt the newly appraised practices (Pfadenhauer et al. 2017).

Innovation  An idea, practice or object that is perceived as new by an individual or other unit of adoption (Rogers 2003).

Setting  …the environmental characteristics in which implementation occurs (Damshroder et al. 2009).

Implementation strategy  …methods or techniques used to improve adoption, implementation, sustainment, and scale-up of interventions (Proctor et al. 2013).
Introduction

Person-centred care (PCC) is spreading worldwide. One of its primary purposes is to change how people are approached and viewed in health care [1, 2]. A change is encouraged to regard patients as capable, resourceful, and experts in their everyday lives [3]. Patients’ wishes, preferences, and goals should be taken into account when decisions are made between HCPs and patients in health care settings [1, 4]. By referring to patients as partners in the care process, a paradigm shift occurs in which patients are given more agency and responsibility for their health and illness [5, 6]. Implementation of PCC is a complex and challenging endeavour. It involves different stakeholders, including patients, across various settings and healthcare sectors to work in concert to adopt change and transition [1, 4, 7]. There is a lack of knowledge concerning how implementation in real-world environments is carried out without the influence of implementation researchers, i.e. “implementation as usual” [8]. Increased knowledge and understanding of processes and changes in real-world settings, including how different stakeholders tackle change initiatives and perceptions of the new practice, are essential for future implementation efforts [8, 9].

In 2015, the Region Dalarna in central Sweden decided to facilitate the delivery of and increase PCC use in health care practice. The assignment to support PCC implementation throughout the region was given to change agents at the Department for Development (DD). They developed an approach based on their knowledge and experience from previous change initiatives and the local context. This locally produced approach for implementation of PCC created an opportunity to conduct a case study in which different stakeholders (change agents, HCPs, and patients engaging with PCC) could be studied in a real-world setting without being steered or directed by researchers.

This thesis has been conducted within the subject of Care Sciences, and the field of study is Health and Welfare with a focus on evidence-based practice. Care Sciences is characterised as inclusive of various topics of a multi- and interdisciplinary nature to study health, illness, and care in different care environments and settings [10]. A central focus in Care Sciences is research questions exploring functions related to the contact and cooperation between patients and HCPs and the organisational structures to support these functions [10]. The broad subject of Care Sciences allows for an excellent fit with the naturalistic inquiry conducted within this thesis, focusing on increasing the
knowledge of how diverse stakeholders realise the implementation of PCC in a real-world setting. The field of study, Health, and Welfare with a focus on evidence-based practice, details that the co-creation of care between HCPs and patients should be informed from a broad base of evidence sources: current research evidence, HCPs knowledge and clinical experience, as well as patients’ experiences, wishes, and priorities [11]. The source within evidence-based practice that relies on input from patients’ experiences is embedded in the innovation of interest in this thesis, i.e. PCC.
Background

Implementation

Implementation science seeks to bridge the gap between what we know and what we do in practice [12]. Implementation has been defined as “an actively planned and deliberately initiated effort with the intention to bring a given intervention into policy and practice within a particular setting. These actions are undertaken by agents who either actively promote the use of the intervention or adopt the newly appraised practices” [13]. Thus, it is no surprise that stakeholders in various settings worldwide are pushing for more research to increase the success of implementation initiatives [1, 3, 14]. However, implementation research shows that it is a slow, arduous, and unpredictable process with a multitude of factors affecting its success [15-18].

The research evidence or practice implemented, i.e. intervention, is often termed innovation within implementation research and practice [19]. At the same time, context can be defined as “…the set of circumstances or unique factors that surround a particular implementation effort” [20]. Implementation of innovations in a health care context is a complex intervention as it involves an abundance of factors that can affect its outcomes [13, 21, 22]. A health care context accommodates a diversity of stakeholders, including patients, HCPs, leaders, and policymakers at different levels within different healthcare sectors [23]. Moreover, these stakeholders will play various roles in relation to their perceptions of the innovation and if they are at the delivering or receiving end. The stakeholders at the delivery end apply different strategies to drive the implementation and represent another example of a factor in implementation that adds to its complexity [19, 23-25].

To confront the complexities and challenges inherent in implementation, more than 100 frameworks, models, and theories have been developed to aid researchers and practitioners in planning, guiding, and evaluating different implementation initiatives [26, 27]. Process models can be used as a map to assist researchers and practitioners in planning and informing the implementation process. Determinant frameworks, outline factors often denoted determinants, that may hinder or facilitate implementation. Evaluation frameworks point at implementation outcomes advocated to improve opportunities for successful assessment of implementation initiatives [28]. Moreover, to increase the practice of a common and shared language,
the application of taxonomies is encouraged when strategies in planned and enacted implementation initiatives are reported [28]. Thus, multiple frameworks from several theoretical approaches can be used, and different theories, models, and frameworks serve different purposes and targets within implementation research and practice [29]. In recent years, there has been a call to increase consistent language and reporting of implementation initiatives to enable comparisons across implementation efforts, synthesise evidence, and allow replication of implementation initiatives [20, 30, 31]. Unless stated otherwise, this thesis uses the term frameworks to denote theories, models, and taxonomies.

Implementation research

From the field of implementation science, there is no gold standard or silver bullet to help support the implementation of evidence-based innovations [32]. Different methodological approaches in research can serve as pieces in a puzzle that, when put together, give a more holistic understanding of the complexities inherent within implementation [33, 34]. Implementation research carried out as randomised controlled trials (RCTs) can show outcomes that have occurred in a controlled environment [35, 36]. Promising RCT results can then guide further research but may not translate easily in a real-world setting where resources and conditions are often heterogeneous and unpredictable [37]. While more studies are needed to increase knowledge of the effect of research-based implementation programmes tailored for context and various conditions, there is limited knowledge concerning how implementation efforts in usual care are carried out without support from researchers.

Studies in real-world settings have the potential to bridge the gap between RCTs and everyday implementation initiatives in the healthcare sector [9, 37, 38]. Natural experiments whereby the intervention is not controlled and guided by researchers but compared to other real-world alternatives, i.e. “as usual” or “standard,” are often proposed to answer questions of whether an innovation works under standard conditions [38, 39]. Powell states, “…an increased understanding of implementation as usual has the potential to identify leverage points for implementation, specify targets for improvement, and generate useful insights into the types of implementation processes that are likely to be successful in the real world” [8].

Studies of implementation “as usual” can clarify how stakeholders, with in-depth knowledge of their context, implement an innovation. Important insights from implementation as usual in real-world settings can then be compared and merged with results from other studies in implementation research to build a knowledge base of what works for who and under which
circumstances [37, 40]. Increased know-how regarding implementing complex innovations in the real-world is valuable for all stakeholders who wish to embark on similar initiatives. The innovation of focus in this thesis is PCC.

**Person-centred care**

PCC has been defined in several ways. One way offered in the European standard [41] is that PCC is a shared understanding and agreement about 1) what matters to the patient to set care objectives that incorporate what health and quality of life means for the individual, and 2) the professional assessment and guideline-driven care that integrates evidence-based care and national/local routines.

Due to its different origins, PCC has been defined in different ways, which can cause confusion about the concept's actual meaning and make understanding what it involves in practice difficult [7]. The lack of conceptual clarity manifest in PCC, and other similar concepts/terms (such as patient-centered care) can mean that sometimes these concepts share the same meanings [42] or inherent multiple meanings [43]. However, a central and common aspect of the different definitions is a shift from the biomedical paradigm focusing on symptoms and diagnosis to a paradigm recognising patients as persons with resources, needs, values, experiences, and preferences [42, 43].

PCC has evolved from diverse fields within several research areas, some of which are nursing [44], medicine [45], and psychology [46]. The different approaches to the PCC concept have been developed further by focusing on different sectors within health care and society [1, 4, 47]. Thus, research and best practices have evolved in diverse areas, including dementia care [48, 49], cancer care [50, 51], paediatric care [52], and care for people with chronic conditions [53, 54]. Just as PCC has developed from different fields and contexts, so have the approaches to enact the concept in practice between patients and HCPs. Practices such as self-management support [55], shared decision making [56], and personalised care planning [57, 58] are examples of how PCC has been operationalised in practice.

RCTs based on interventions of care in line with PCC have shown positive patient outcomes in individual studies and for specific practices (e.g., shortened hospital stay [54], increased security and satisfaction with hospital care [59], and improved general self-efficacy [60]). PCC initiatives have also been shown to be related to positive outcomes of HCPs' perceptions of their work environment, including increased job satisfaction and personal accomplishments [61].
However, evidence supporting PCC as an overall effective approach in health care is still limited [35, 62, 63]. One dilemma for those who conduct systematic reviews to synthesise evidence of PCC is the methodological variation between research initiatives and a lack of consensus within the literature regarding how to define, conceptualise, operationalise, and measure PCC [35, 44, 47, 48]. To conclude, PCC can be regarded as a dynamic and complex innovation. It spans different health- and social care sectors, involving a range of stakeholders working in concert to adopt a paradigm based on creating a partnership between HCPs and patients [7, 64]. Moreover, adopting a PCC approach means that HCPs and other stakeholders need to use skills and support structures, within and between organisations, to enable a change in PCC practice [20, 21, 65].

Measuring PCC

Outcomes associated with PCC have often been evaluated relative to secondary measures. These measures include patients' increased self-efficacy, reduced anxiety, and decreased health needs (e.g., shorter hospitalisation) [35, 36]. Many questionnaires have also been developed to evaluate patients’ perceptions of PCC (e.g., patients perceiving that they have been a partner in co-creating their care) [66, 67]. However, these questionnaires have most often been created for specific patient groups or HCPs (e.g., nurses and clinicians) and specific contexts [68-70]. Moreover, many initiatives on measuring PCC have been conducted in research and on a one-off basis [4]. We are unaware of any questionnaires aimed at specifically targeting PCC consistent with the University of Gothenburg Centre for Person-centred Care (GPCC) model for use in different healthcare sectors, patient groups, and HCPs.

Implementation of PCC

PCC has often been focused at the individual meeting and partnership between patients and HCPs. However, PCC does not only occur at the micro level within health care settings but also at the meso and macro levels. Focus on the meso level is becoming increasingly prominent in a health care context [1, 4]. On this level, it is acknowledged that managers and policymakers play an important role in the transition towards increased PCC [1, 65, 71]. Also, at a macro level, changes in policy decisions and legal actions are established nationally and globally to increase PCC throughout society [3, 41, 72, 73]. Thus, a whole systems approach is advocated to improve implementation initiatives, including care pathways and transitions over different care sectors within health care and the community [1].
PCC can be regarded as a goal worth striving for in its own right or as a means to reach other goals [4]. The first perspective is grounded in the ethical and philosophical assumption that PCC should be implemented and perceived as an exclusive and undisputed goal. Patients in need of health care should always be ‘treated as persons,’ and their values, resources, and care wishes should be central in care planning and decision making [4]. Another perspective is based on different research initiatives showing that PCC approaches can lead to desirable outcomes for patients, HCPs, and the health care sector [1, 3, 4]. Depending on which perspective is put to the forefront or given primacy, various stakeholders may understand and interpret PCC differently and reach disparate conclusions as to what strategies should be used for implementation of PCC [1].

Implementation of PCC in Sweden has been notably influenced by the GPCC, a government-funded centre formed in 2010 to promote research initiatives on PCC. Ethical and philosophical teachings from philosophers such as Ricoeur underpin the initiative from GPCC. An ethical approach based on seeing the person behind the patient is encouraged and regarded as necessary in any effort to strive for a good and meaningful life for all patients. Relational aspects in which people work in concert with one another, often referred to as a partnership to co-create care between patients and HCPs, hold importance in a model put forward by the GPCC. The model was created to aid HCPs in adopting PCC in different health care settings and for testing in clinical trials. Three core routines (initiating, working, and safeguarding the partnership) outline the model.

*Initiating the partnership* consists of eliciting the patient’s narrative. Listening to patients’ stories can give a glimpse into their lifeworld and its relation to their perceived illness and health. Issues of uncertainty, experiences, wishes, motivation, resources, needs, and what patients value and think are important in their life can be identified if HCPs partner and communicate with patients.

*Working in partnership* means that HCPs and patients co-create care to an extent the patients find desirable. HCPs share their expert knowledge and information about medical care and treatment of the condition from their perspective. The patients contribute with their experiences and knowledge of how it is to live with the condition. The partnership between HCPs and patients aims to find common ground and understanding to create a personalised health plan. The plan is a living document in which the patient’s goals and wishes are prioritised.

*Safeguarding the partnership* requires documenting the agreed health care plan in the patient’s medical record. The patient should preferably have access to the health care plan, and it should be revisited regularly and revised according to new decisions made jointly by the patients and HCPs.
Documenting agreements made in partnership will safeguard the collaboration and ensure the continuity of co-created care [6].

The three cornerstones of the model should not be seen as a process working linearly but as intertwining processes, where HCPs and patients can feed on each other as they move between the routines. For example, the narrative can be built from several encounters over a period with the involvement of different HCPs, and the partnership is thought to be ongoing in all care encounters. In cases where the patient cannot be an active partner in the care process, the next of kin or other stakeholders can act as proxies for the patient based on their understanding of the patient’s lifeworld [6].

Theoretical frameworks

PCC is a complex innovation that needs to be understood and adopted by numerous stakeholders throughout the healthcare sector to cut a path into everyday practice and improve patients’ quality of care. The studies in this thesis have been grounded in different frameworks to enable a structure aimed at guiding data collection, but foremost to aid the data analysis and dissemination of the results [78, 79].

Each framework was chosen based on some overall prerequisites for the overarching case [29, 80]. Frameworks had to fit each study objective and the organisational level of the case, i.e. patients, HCPs, and change agents. Moreover, frameworks were chosen based on the type of data we collected. This meant that the information needed to use the framework was sometimes considered. A final prerequisite was that chosen frameworks were interpreted to fit within a health care context [29, 80].

Study I

To describe what and how different discrete strategies were used to implement more PCC at a regional and a health care unit level in study I, we used two frameworks: recommendations for reporting strategies by Proctor and colleagues [30] and The Expert Recommendations for Implementing Change (ERIC) [31]. Proctor and colleagues' recommendations were advanced to enhance the detailed specification and reporting of implementation strategies in the design phase, during and after implementation [30]. Enhanced elaboration of strategies is thought to make provisions for researchers and practitioners to compare strategies used in implementation initiatives and enable proper replications in future implementation efforts to promote the assimilation of findings [81].
The recommendations include *naming and defining* strategies along with seven dimensions that describe the operationalisation of the strategies: *actors* (who delivers the strategy?), *the action* (how is the strategy operationalised?), *action target* (who are the actors and what are they trying to affect through the action?), *temporality* (when is the strategy carried out?), *dose* (how much time and how many participants are involved in the strategy?), *outcomes affected* (what will the strategy affect/change?), and *justification* (why was this strategy selected?).

Proctor et al’s recommendations have been used in research in different health care contexts [82-85]. As Proctor et al. do not provide guidance on how to name and define strategies, we decided to use the ERIC for this purpose. The ERIC is a taxonomy of 73 implementation strategy terms and definitions [58]. The taxonomy was developed to aid stakeholders in health care to enhance conceptual clarity, applicability, and comprehensiveness by using a common language in research and practice initiatives within implementation [31, 86, 87].

**Study II**

In study II, we wanted to describe how the innovation (i.e. PCC) was operationalised in practice at the participating health care units. We chose to analyse data using the GPCC model of PCC along with recommendations for defining core components of an innovation by Blase, Fixsen, and colleagues [88, 89].

The GPCC model was selected as change agents chose to advocate it at the DD. The GPCC model has been used extensively in Sweden in different health care contexts and research with various designs [74, 77, 90]. Recommendations for defining core components of an innovation by Blase, Fixsen, and colleagues’ have been applied to aid and improve the operationalisation and reporting of the core components thought to be necessary within an innovation to make it efficient [88, 89]. We chose these recommendations to outline how PCC can have as its point of departure ethical principles, including the context, structural elements, and core practices. All these components have been identified as important in relation to research on PCC implementation.

**Study III**

We chose to use the Consolidated Framework for Implementation Research (CFIR) to describe the innovation characteristics as perceived by HCPs in study III. The CFIR is a determinant framework developed to create a compilation of constructs hypothesised to influence implementation outcome...
[20]. Founders of the CFIR synthesised constructs from 20 theories and frameworks into one overarching conceptual framework. The 37 constructs have been categorised into five major domains: intervention characteristics, outer setting, inner setting, characteristics of individuals, and process. The CFIR aims to aid researchers in using a common language along with the consistent use of constructs to guide the assessment of determinants in planning, evaluating, and comparing implementation efforts for different research initiatives [20]. The CFIR was developed for use in health care practice and has been extensively applied in implementation research [91].

Study IV

To guide the development of a questionnaire aimed at measuring patients’ perceptions of PCC we setup some predefined criteria. First we decided to develop a relatively short questionnaire (~15 items) measuring patients’ perceptions of PCC in line with the GPCC model including its ethical foundation for PCC. Moreover, the questionnaire should be generic e.g., work the same way across different health care settings, patient groups and for different health care professionals. Lastly we wanted to use it to evaluate and capture change. To meet our predefined criteria we decided to use recommendations for questionnaire development according to the Rasch measurement model. The Rasch measurement model is increasingly being used in implementation and health care practices to re-evaluate and modify already existing questionnaires [69, 92-96] as well as to guide the construction and development of new questionnaires [68, 97]. The Rasch measurement model enables a researcher to analyse and explore in detail data from a questionnaire on item, person, and scale functioning level [98-100]. The model is particularly relevant in cases where a generic questionnaire is developed aimed at making comparisons across different settings and patient groups [101, 102].
A gap exists between research-based knowledge and clinical practice in health care settings [18]. New evidence-based innovations are challenging to implement and embed in clinical practice. There is a need for novel research approaches to increase the knowledge on supporting implementation in practice [34]. Policymakers across Sweden advocate the implementation of PCC in health care settings to promote high-quality health care throughout the country. Implementation of PCC is a demanding enterprise as it is a complex intervention requiring health care staff to change their knowledge, attitudes, and behaviours. It also demands a change in organisational culture [90].

This thesis aims to broaden the knowledge of how change agents and HCPs in a real-world setting comprehend PCC and take on the challenge of implementing PCC across diverse health care contexts. The thesis also contributes to knowledge on patients’ perceptions of PCC, and how PCC can be measured, understood, and operationalised by change agents and HCPs based on the GPCC model of PCC.
The overall aim of this thesis is to increase the knowledge about the implementation process of PCC in a real-world setting.

The specific aims were:

**Study I:** To explore and compare which and how strategies were enacted at seven embedded units to support implementation of more PCC.

**Study II:** To describe and compare how PCC was operationalised at six embedded units at the level of health care practice.

**Study III:** To describe HCPs' perceptions of PCC in relation to their context through the lens of the CFIR.

**Study IV:** To develop a generic questionnaire measuring patients’ perceptions of PCC and evaluate its content and measurement properties.
Methods

This thesis is part of the larger research project IMPROVE (Implementing person-centred care, process evaluation of strategies, leadership, and health economics). The IMPROVE project explores implementation of PCC from several perspectives, including health economy and policy, in a real-world setting.

Design

The overarching design of this thesis is a case study with embedded units. It allows an in-depth holistic investigation of PCC implementation in a real-world setting where the context is perceived as a natural, uncontrollable, and continuously changing phenomenon [78, 103].

Methodology

This thesis departs from the worldview of pragmatism [104], the philosophical assumption that single and multiple realities can exist and be explored and reported from real-world and practice settings [104]. In pragmatism, the research questions combined with the context of a study will have precedence and guide the choice of research methods. As data collection and analysis in pragmatism are driven by research questions, the researchers can use or combine quantitative and qualitative methodologies to answer the study objectives [78, 105]. Data in this thesis have been triangulated or mixed from different sources and by various methods [104].

In this thesis, the doctoral candidate (HF) has spent many hours collecting data from various sources at each health care unit. Thus, she and her co-authors see themselves as instruments for data collection and co-creators of knowledge through the interaction with the study participants at the embedded units.
Preunderstanding of the researchers

Case studies can be conducted along a spectrum from researchers regarding themselves as objective to the case and its real-world context or taking on the view of being a part of the findings, which are then considered observer-dependent [78, 105]. In this thesis, the researchers' preunderstanding and reflections based on previous knowledge, experiences, perceptions, and assumptions have been acknowledged as a natural part of this inquiry. The thesis author and her co-authors have tried to be transparent about their beliefs and biases throughout the study. At regular meetings, they have also discussed and challenged their views on data collection, analyses, and findings [106]. HF used field notes to keep track of her reflexivity to record perceptions and experiences during data collection [107].

Preunderstanding is not closed but continuously evolves with the researcher's activities in a project and towards a subject [108]. HF has a background in physiotherapy and has worked extensively in in- and outpatient specialist care for people with dizziness. Before entering the PhD project, HF had very little theoretical and empirical knowledge in implementation science or person-centred care. However, HF brought her own experience and preconceptions from being an HCP and what it implies in meetings with patients, their next of kin, and working in teams with and around patients. Moreover, she had experience from various implementation efforts in health care contexts and experiences of sometimes taking the role of patient or acting as next of kin. The supervisors and co-authors have varied and extensive knowledge and expertise from different fields of nursing, occupational therapy and physiotherapy, implementation, person-centred care, questionnaire development, and psychometric evaluations to guide HF throughout the study period. HF and her co-authors use the term patient to refer to persons that need care in a health care context. We acknowledge that patients are persons but take the role as patients when in need of care, just like they can take another role such as HCPs, or change agents, at another time.

Setting

This thesis was conducted in a health care region in central Sweden. Inspired by the patient law and a national movement to increase patient participation in health care, the regional political assembly decided in 2015 to “increase participation in the health care services for patients, relatives, and patient and user organisations” [72, 109, 110]. The model advocated to increase patient participation in health care was the GPCC model for PCC. Staff (i.e. change agents) at the DD at the regional level were assigned to support the transition towards more PCC. The work conducted by change agents is an example of
implementation “as usual,” i.e. implementation is carried out in a real-world setting without the influence of researchers. This real-world setting created an opportunity to obtain a valuable insight into how PCC implementation “as usual” develops across time. The participating region supports about 278 000 people with health care covering 28 000 km². Health care in the region is provided for inhabitants through one large regional hospital, five smaller local hospitals, and approximately 30 primary health care units.

Implementation support strategy by change agents at the DD

Change agents at the DD reached out to all health care units in the region with an offer to participate in a series of three full-day learning seminars. Change agents developed the workshops at the DD to disseminate knowledge and initial support to facilitate a change. The HCPs from each unit then brought home the message to their local context and continued the transition towards more PCC. No fees were charged for those units that opted to participate, and lunch was included for all participants. The senior and frontline managers at each health care unit decided which and how many health care professionals would participate in the seminars. They were asked to enrol several HCPs, preferably with some diversity of vocational roles and teams, to enhance discussions between HCPs and increase buy-in at each local unit.

Participating units

We recruited seven units at two organisational levels: the DD at the meso level and six health care units at the micro level. The health care units were a convenience sample based on 11 units that participated in the first learning seminar conducted by the DD. We also sought to include health care units representing different health care settings. Another prerequisite was senior and frontline managers' willingness to be part of the research initiative and give the researchers access to data collection. Two participating units represented geriatric in- and outpatient care at two hospitals, one nephrology specialist outpatient care unit, one large primary care unit including ordinary primary care, rehabilitation, and family care, and two psychiatric inpatient units. Figure 1 outline the participating units.
Figure 1. The participating units. **LOS: Length of stay, including potential temporary leave.
*Units 5 and 6 were merged between June 2016 and August 2018. 18 beds were available during that period.
Overview of the studies

Four studies, each presenting variation in participants, designs, and data collection, were included in this thesis. An overview of the design, participants, data collection, and analysis used for each study is summarised in table 1.
### Table 1. Overview of included studies with details on design, participants, data collection, and data analysis

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Data collection</th>
<th>Participants</th>
<th>Data analysis</th>
</tr>
</thead>
</table>
| I     | Case study with seven embedded units | Activity logs  
Dyadic interviews and Focus groups conducted twice at all units (n=14)  
Documents | Change agents at seven embedded units (n=26) | Deductive content analysis  
Framework – Recommendations from Proctor et al. and ERIC  
Descriptive statistics |
| II    | Case study with six embedded units | Activity logs (free comments)  
Dyadic interviews and Focus groups conducted twice at all units (n=12)  
Documents | Change agents at six embedded units (n=24) | Deductive content analysis  
Framework – the GPCC model and recommendations from Fixsen, Blase et al.  
Descriptive statistics |
| III   | Interview study | Focus Groups (n=15)  
Dyadic Interviews (n=5)  
Individual interviews (n=22) | HCP (n=97) | Deductive-inductive content analysis  
Framework – CFIR  
Descriptive statistics |
| IV    | Mixed methods involving three phases: construction of a preliminary questionnaire, content validation of items and questionnaire, and psychometric evaluation. | Key informant interviews  
National Patient Survey  
Two Delphi rounds with CVI ratings and expert comments  
Questionnaire  
Cognitive interviews  
Free text comments  
Field notes | Key informants (n=6) | Deductive-inductive content analysis  
Based on three main categories: Dimensionality, words and items to capture PCC, and ratings based on the combined interaction with HCPs vs. individual HCPs.  
Content Validity Index  
Qualitative analysis based on experts’ comments such as readability, comprehensiveness, revisions or suggestion of new items.  
Rasch analyses  
Deductive content analysis  
Based on four predefined categories: response options and anchors, overall content, responses related to Rasch analyses, comprehension of items  
Descriptive statistics |
Participants

We included participants from multiple populations to triangulate different perspectives on the case. Three groups of participants recruited at two organisational levels within the region were included: change agents (studies I and II), HCPs (study III), and patients (study IV). Patients at the six participating health care units were consecutively included and asked to respond to the developed questionnaire. Recruitment of patients was conducted twice at each unit one year apart starting in 2017. A purposeful sample of patients was recruited to participate in cognitive interviews in study IV [111, 112]. Recruitment was based on patients’ gender, age, and care (in- or outpatient) to ensure heterogeneity. Another two groups of participants from outside the region were included: key informants participating in interviews, and experts in two Delphi rounds (study IV). Background characteristics were collected for the patients (gender, age, and form of care), the HCPs (gender, time at the workplace, and form of care), and change agents (vocational roles). An overview of participant characteristics is listed in table 2.

Table 2. Overview of participant characteristics in the four studies of the thesis.

<table>
<thead>
<tr>
<th>Study</th>
<th>Participants</th>
<th>Unit and vocational role</th>
</tr>
</thead>
<tbody>
<tr>
<td>I, II*</td>
<td>Change agents at DD* (n=2)</td>
<td>The DD, Quality developers 2</td>
</tr>
<tr>
<td></td>
<td>Change agents at health care units (n=24)</td>
<td>Unit 1. Frontline manager, Assistant frontline manager 2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unit 2. Frontline manager, Quality developer 2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unit 3. Frontline manager, Assistant frontline Manager, HCPs with different care specialities 6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unit 4. Senior manager, Quality developer, Frontline managers 6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unit 5. Frontline manager, Coordination nurse, Registered nurse, Assistant nurse 4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unit 6. Frontline manager, Coordination nurse, Registered nurse, Assistant nurse 4</td>
</tr>
<tr>
<td>III</td>
<td>HCPs (n=97)</td>
<td>Gender</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Female 80</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Male 17</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Employment at unit</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Years, mean (SD) 7.7 (10.9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Range, min/max 3 months-42 years</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Profession</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Registered nurse 40</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Nursing aid 30</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Medical doctor 10</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Physiotherapist 9</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Occupational therapist 7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other 1</td>
</tr>
<tr>
<td>IV</td>
<td>Key informants (n=6)</td>
<td>PCC informants</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Researchers at GPCC 3</td>
</tr>
</tbody>
</table>
Clinical experts in PCC
Experts

Patients
HCPs
Researchers

PCC experience
Years, median 5
range, min/max 1.5-16 years

Delphi experts (n=8) Patients responding to survey (n=553) Patients in cognitive interviews (n=10)

Age
Years, mean (SD) 66.7 (17.1)
Range, min/max 18-98 years

Gender
Female
Male
Missing

Care
Outpatient
Inpatient

Age
Years, mean 71.5
Range, min/max 54-85 years

Gender
Female
Male

*Data from change agents at the DD were not included in study II.

Data collection study I-III

Data were collected from different periods starting at the end of 2015 and ending in November 2019 (figure 2).

<table>
<thead>
<tr>
<th>Year</th>
<th>2016</th>
<th>2017</th>
<th>2018</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study I</td>
<td>a</td>
<td>b</td>
<td>c</td>
<td></td>
</tr>
<tr>
<td>Study II</td>
<td>a</td>
<td>b</td>
<td>c</td>
<td></td>
</tr>
<tr>
<td>Study III</td>
<td></td>
<td></td>
<td>d</td>
<td></td>
</tr>
<tr>
<td>Study IV</td>
<td></td>
<td>e</td>
<td>f</td>
<td>g</td>
</tr>
</tbody>
</table>

*Figure 2. Data collection timeline. a activity logs; b interviews with change agents; c documents; d interviews with HCPs; e key informant interviews; f Delphi rounds; g questionnaire, cognitive interviews with patients.*
Focus groups, dyadic and individual interviews

All studies in this thesis combined dyadic interviews [113], and focus groups [114, 115]. Study III also included individual interviews [116] with HCPs. In the studies, we chose to combine different kinds of interview data to provide a richer and more comprehensive picture of the aim of each study and the case as a whole [117]. A mix of individual interviews, dyadic interviews, and focus groups was also chosen for pragmatic reasons (e.g., participants’ work schedules).

Written information about the study and the voluntary nature of participation was given to the participants before the study started. Focus groups and dyadic interviews were conducted with HCPs and change agents working at the same unit and often in the same team to increase their ability to discuss and compare their thoughts and experiences on PCC from a shared viewpoint and context [114]. Interviews and focus groups were performed during the working hours of the HCPs and change agents in secluded rooms designated by the managers at the unit. Interview data were based on semi-structured interview guides with open-ended questions targeting the different objectives of each study [118]. Each interview started with information about the study and its aim, followed by an initial inquiry to prepare participants for the study topic. This phase was followed by key questions about the purpose of each study [116, 118]. To avoid directing participants' responses, we avoided using questions based on the frameworks used in the qualitative deductive content analyses. All interviews were recorded and transcribed verbatim by a professional transcriber.

Activity logs

Electronic activity logs were developed for studies I and II to enable the research team to track the activities carried out to achieve more PCC at the DD and the six health care units [83]. These units chose a change agent assigned to regularly log the activities (i.e. weekly to monthly) throughout the study. The reports were focused on naming and describing the type of activity being enacted, its purpose, who was running the activity, how many participants were involved, date and time consumption for the activity, and any clarifying comments that the change agents deemed necessary to understand the enacted activity. Sometimes change agents had difficulties meeting the goal to report regularly due to a high workload. They were encouraged to retrospectively use their calendars to track their activities in those cases. In a few instances, representatives from the research group (HF and MT) had meetings at the units with change agents to help fill out activity logs. Change agents validated all reported logs by the end of the data collection period. Changes were made if errors were identified to represent the performed activities in line with the perspectives of the change agents [78]. The complete reports from the activity logs were used in study I, while change
agents’ clarifying comments (data found to contain information on operationalisations of PCC) were used in study II.

Free text comments, field notes, and documents
We collected written text material based on field notes from HF (studies III and IV) and other documents. These documents were related to different activities regarding implementation or operationalisation of PCC in the form of reports, meeting protocols, plans, and timetables for different educational activities (studies I and II).

Data collection study IV
We collected data in three phases [104]: construction of a preliminary questionnaire [99], content validation of the questionnaire items and the questionnaire [119, 120], and a psychometric evaluation [100]. In this study, we collaborated with the Swedish Association of Local Authorities and Regions (SALAR) who are responsible for administering the largest patient survey in Sweden [121].

Phase one: Construction of a preliminary questionnaire (version 1.0).
A review of the PCC literature and interviews with researchers and clinicians with expertise within PCC were performed to develop a preliminary generic questionnaire [99, 122, 123]. Questions in the interviews explored key informants’ views on the concept of PCC related to its dimensionality, suggestions for terms and items in a questionnaire, and if ratings could be based on patients perceptions of the combined interaction with HCPs.

Phase two: Content validation of items and revision of the questionnaire (version 2.0).
A Delphi study was conducted as a web survey with two rounds [120].
A mixed-methods approach was used [104] with 1) ratings based on the relevance of each item on a scale from one to four and 2) participant comments on the questionnaire items concerning perceived relevance, readability, a new suggestion of items, and dimensions in the questionnaire.

Before entering the study, Delphi experts were given information about what to expect from participating in the study, including the focus of the Delphi study, time consumption, and the timeline between rounds [124]. Ratings were made according to the content validity index (CVI) on a scale from 1 (highly relevant) to 4 (not relevant) [119, 125, 126]. The two middle options were phrased as the item needs minor or major revision to be highly relevant. The responses were dichotomised into two groups. Responses 1 and 2 were
interpreted to mean the item is relevant and valid to keep, and responses 3 and 4 as non-relevant and the item should be discarded. Experts were asked to give free-text comments on each item's relevance, readability, and comprehensiveness in conjunction with each CVI rating. The experts were also asked to provide suggestions of revisions, offer new items, and suggest dimensions that could be added to make the questionnaire more complete [119, 125]. Between rounds 1 and 2, the experts were provided their ratings in relation to the other experts’ ratings and anonymised free-text comments from all participants [120].

Phase three: Psychometric evaluation

Patients were given information about the study by a member of the research group and, in some cases, by HCPs who had been trained in the recruiting process. Patients completed version 2.0 of the questionnaire in paper format and were encouraged to leave comments in free text form. Patients who had problems completing the questionnaire were assisted by a member from the research group who came to the patient’s health care unit at a time chosen by the patient [127].

Cognitive interviews with patients were done to gain insight into patients’ comprehension of and responses to the questionnaire [111, 112]. Interviews were performed at four of the health care units. Patients were given information about the study and asked to complete the questionnaire while thinking aloud [111]. They were asked to read the instructions and questions aloud, and the first author used a protocol based on the same questionnaire to take notes on patients’ comments, responses, and other factors that she noted [111, 112]. Verbal probes were used after the patient had completed the questionnaire to clarify factors the interviewer had picked up on during the think-aloud process [111].
Data analyses

Qualitative content analysis in studies I-III

Qualitative deductive content analysis was used in studies I-II, and qualitative deductive-inductive content analysis in study III in line with teachings by Elo and Kyngäs [128, 129]. All text material was read to gain a sense of the whole. In studies I, II, and III, meaning units of text that belonged to the study objective were first identified. In study I, for example, all data about descriptions of strategies used to implement more PCC in the different units were identified. In a second step, data were coded to unconstrained coding matrixes. Guiding frameworks were used in each study to identify and link data to different predefined categories. Study I used two frameworks, recommendations for reporting strategies by Proctor and colleagues [30], and the ERIC [31, 87]. Study II used the GPCC model of PCC [57], and recommendations for defining core components of an innovation by Blase, Fixsen and colleagues [88, 89]. Study III used CFIR to describe the innovation characteristics as perceived by HCPs [20]. In studies I and III, codebooks were developed to aid the coding process (see table 3 for an example of the construct compatibility in the CFIR).
Table 3. Example from code sheet for the CFIR construct compatibility, general definitions and adapted definition for the IMPROVE project.

<table>
<thead>
<tr>
<th>Construct</th>
<th>General definition</th>
<th>Adapted definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compatibility</td>
<td>The degree of tangible fit between meaning and values attached to the intervention by involved individuals, how those align with individuals own norms, values and perceived risks and needs, and how the intervention fits with existing workflows and systems.</td>
<td>HCPs perceptions in relation to the degree of tangible fit between meaning and values attached to PCC by involved individuals, how those align with individuals own norms, values and perceived risks and needs, and how the intervention fits with existing workflows and systems.</td>
</tr>
</tbody>
</table>

**Inclusion criteria:** Include statements related to existing routines, and perceived values based on individual expressions and the values and norms perceived at the workplace.

**Exclusion criteria:** Exclude statements related to PCC as being difficult to understand or use and code to complexity.

The frameworks were flexible and tailored, i.e. the authors kept an open mind to embrace and report data that did not fit the coding matrixes [129]. After the CFIR codes had been applied to the data in study III, inductive analysis was performed to get an in-depth understanding of the participants' perceptions of PCC in their context [128]. Analysis was performed in NVivo in studies I-III and in Word in study IV.

Study IV

**Phase 1: Development of a preliminary questionnaire**

A qualitative deductive-inductive content analysis of data from key informant interviews using an unconstrained categorisation matrix with three predefined main categories was conducted in Word [128]. Meaning units in the text belonging to the predefined categories were identified, coded, and grouped into subcategories by the first (HF) and last author (MT). The results from the content analysis and relevant literature guided the research group to identify items in the National patient survey [121] to develop a preliminary questionnaire to capture PCC in line with the GPCC concept.
Phase 2: Content validation of items and revision of the questionnaire

The CVI [119] was calculated for each item. A minimum consensus level of 0.78 and positive comments consistent with the GPCC concept of PCC were set as a prerequisite for the retention of an item [126]. The research group analysed, interpreted, and discussed comments on individual items and the questionnaire. Based on the participants CVI values and comments, items were then added or rephrased [104] and then returned to the participants for a new Delphi round. Participant responses from the second Delphi round were analysed by the research group, which led to a revised version of the questionnaire.

Phase 3: Evaluation of the measurement properties of the questionnaire

The data were analysed according to recommendations on Rasch analysis [100, 130]. Analyses were performed in iterative stages, testing data for overall fit to the Rasch model, reliability, threshold functioning, individual item and person fit, targeting, differential item functioning, local dependency, and dimensionality. Analysis was conducted in RUMM 2030 [131] using the partial credit model [100, 132]. For further information about the Rasch analyses in this study see study IV in this thesis.

Qualitative deductive-inductive content analysis was conducted using transcribed data from cognitive interviews, field notes, and free text comments [128]. An unconstrained matrix was used with four predefined main categories consistent with the four overarching concepts in the cognitive interviews. Meaning units in the text were identified, coded, and grouped into subcategories to help clarify the main categories.

Results from the Rasch and the qualitative deductive-inductive content analysis were converged in a mixed-methods design [104] to enable the researchers to compare results and obtain a fuller understanding of the findings, resulting in guided revisions of the questionnaire.

Statistical analyses

Descriptive statistics were calculated according to the data as frequencies (%) for nominal and ordinal data and as means (minimum-maximum) for interval data. Analyses were performed in The Statistical Package for the Social Sciences (IBM SPSS version 26.0) and Excel.

Ethical considerations

This thesis was conducted according to the ethical principles for medical research involving human research in the Declaration of Helsinki [133].

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Ethical approval was granted from the Regional ethics committee in Uppsala (Dnr 2017-195, 2017-195 1B).

Research participants were informed verbally and in writing about the purpose of the project, what was involved in being a participant, that participation was voluntary, and that they were free to withdraw from the project without any explanation and without affecting their current or future health care/workplace situation. Patients were informed that the health care staff at the unit had no access to individual patient survey responses. Moreover, patients and HCPs were told that the research team was conducting the research independently, and the participants’ data would never be shared with the representatives from the region. Participants who consented to participate gave their written consent.

Collected data have been stored on computers and handled according to the General Data Protection Regulation [134]. All data are stored on secure databases with passwords and code keys kept separately from the data. A professional transcription firm performed all transactions of recorded interview data to transcribed text using a locked USB memory that was picked up and returned at the worksite. Confidential data on paper is stored in locked cabinets and code keys are kept separately from the data.

Ethical considerations in implementation research can pose unusual challenges to researchers designing a project and persons reviewing it for its ethical integrity [73]. As the project progressed, we tried our utmost to follow ethical guidelines and discussed the pros and cons of our decisions. We have concluded that participation in the project poses low risks to research participants (i.e. patients, HCPs, and change agents at the participating health care units). Ethical considerations and the type of data collected to ensure that the project complies with ethical codes of conduct were discussed for each group of participants [133]. Below we describe some ethical challenges and the steps taken to meet these challenges.

First, we acknowledge that the choice to participate in this project was made by stakeholders at a regional level and by managers at each health care unit to facilitate access to research participants. This choice poses an ethical dilemma as the participation of units in the project is not made by each individual but by managers higher up in the organisation. To meet this enigma, we have informed all participants of the voluntary nature of participation, that all data are handled with confidentiality, and that no individuals will be identified when the results are presented. Focus groups pose an ethical challenge as participants in a group share views not only with the moderator but also with each other. This ethical conundrum might lead to a breach of confidentiality if sensitive information from a group discussion were shared outside the group. We dealt with this issue by informing participants that confidentiality in a focus group can never be ensured [114]. Participants were informed of
this situation and could decide what they wanted to share in the group discussions.

Second, we made a point of including a heterogeneous population of patients with the opportunity to express their views. However, some patients have serious health issues and may find answering a questionnaire while undergoing intensive care and treatment stressful. The research group has carefully considered this ethical problem and decided that it was crucial that these individuals were not excluded from participating in the study (i.e. the advantages of participating outweigh the disadvantages) [127]. Still, participation is based on an autonomous decision made by each individual. Members from the research group offered assistance with responding to the survey for those patients who were unable to respond but still wished to participate in the study [127].

Third, we presented a case study with specific aims related to the different studies included in this thesis. Case studies can be presented along a continuum from an anonymous entity in which the whole case and its participants are disguised, to total exposure of the case and its participants [78]. As PCC is strongly linked to the context in which it is implemented, it was vital to report on contextual factors related to the region and the participating health care units. We sought a compromise in our reporting whereby the HCPs at the different units were anonymised but where the context underlining the case represented as a region with different health care units could be accurately identified based on background information [78]. Patients have been de-identified in study IV, which aligns with ethical conduct and the study's methodology [133]. However, studies I and II used data based on information from change agents, which intrudes on the individual’s integrity, as some interviews were based on dyads with which participants or other readers can infer the likely source of a comment. We interpret this intrusion as justifiable given that change agents were often the drivers of being part of the research initiative and were informed from the beginning of the nature of the study [78]. Moreover, data from studies I and II were validated by change agents before publication to reduce the risk of describing data at a level of detail deemed to be unacceptable for the individual change agent [78].
Results

A summary of the main results is presented for each study separately.

Study I

Various strategies were used to support the transition to increased PCC over time in the seven embedded units. Forty-three unique discrete strategies were identified through triangulation of the data; of these 43 strategies, 38 (88%) were identified in ERIC. Communication, not included as a strategy in ERIC but suggested as a new strategy by other researchers, was also identified in our data. Additionally, four strategies emerged from the data that could not be connected to previous research using ERIC. These four strategies were Recruit clinicians with competence in the innovation, Provide stakeholders with time to attend educational meetings, Provide stakeholders with resources, and Act as a role model. A total of 782 discrete implementation strategies were identified in the logbooks. These were distributed across the 43 unique strategies with a frequency between 1 and 100. Most reported strategies were found in two clusters in ERIC: Train and educate stakeholders (40%) and Develop stakeholder interrelationships (38%).

Change agents at the DD reported learning seminars in their activity logs. We identified eight discrete strategies contained in these seminars. Change agents described how seminars were created to accommodate the varied preferences of the HCPs to knowledge acquisition and included lectures, workshops, and team discussions. These discussions involved HCPs to reflect and discuss PCC and plan for its implementation at their unit. Different stakeholders ran the seminars, including the change agents from the DD and other health care regions in Sweden, researchers from GPCC with profound knowledge of PCC’s ethical and philosophical underpinnings, HCPs from units in the region, and patients and patient representatives. Another strategy used by the change agents at the DD was to encourage health care units to adapt and operationalise PCC to their particular context. This resulted in many new routines designed to capture the essence of PCC in the different units. Units 5 and 6, for example, changed routines regarding the daily round resulting in revised roles for nurses and nursing assistants, enabling more time to talk with patients rather than talking about patients. HCPs had to change their routines
in a more standardised manner throughout the day to elicit this change. Change agents and specialist student nurses at these units worked together to drive through the change, which involved all HCPs at the workplace.

Few strategies were identified in the cluster *Use evaluative and iterative strategies* (4.6%). Some change agents reported that participation in the research project was a conscious strategy to get feedback on their implementation efforts. Strategies targeting information to patients identified in the clusters *Prepare patients to be active participants* and *Use mass media* had a frequency of three each (0.4%). A total dose of 11076 person-hours was reported in all activity logs between June 2016 and November 2019. Most person-hours focused on strategies targeting HCPs providing PCC at the health care units (81.5%) and less on strategies focused on support functions for PCC (18.5%).

**Study II**

PCC was operationalised into core practices at the six embedded units. We identified core practices in all units that could be linked to the three structural elements from the GPCC model: initiating, working, and documenting the partnership. However, the depth and detail of the core practices and their links to PCC’s philosophical principles and values were sometimes disparate within and between units. Some change agents moved easily forwards and backwards in their descriptions of how core practices could be linked to the GPCC model, their contextual bounds, and the philosophical underpinnings of PCC. On the other hand, others were more ambiguous in their descriptions, making it difficult to identify in what ways these practices were following PCC principles.

Some units had operationalised the narrative by using standardised questions in a protocol when patients were admitted to the health care unit. In contrast, other units described how the narrative was built over time to establish trust and accumulate information successively with one or several HCPs.

Working in partnership with patients contained a broad spectrum of practices among the units. Some approaches to enhance the partnership included improved information about health and illness, treatment alternatives (e.g., home rehabilitation, improved access through videoconference equipment, increased focus on patients' wishes for care, and values in life when goals were set). Although the units used different communication techniques to operationalise PCC, MI was most common.

Documenting the partnership with agreed-upon goals and plans for future care was described as a means of achieving PCC at all participating health care units. In inpatient care, a new law established to increase collaboration
between all stakeholders involved in the transition from inpatient to outpatient care seemed to have more relevance on the core practice of documenting the partnership than on the structural element of the GPCC model of PCC. In outpatient care, documentation was often described relative to individual search words such as the narrative and goals. In contrast, change agents in inpatient care described how the documentation had become routinised and was initiated on admittance as a health care plan or rehabilitation plan, which was revised regularly during the patient's care process.

Study III

Nine constructs emerged in the data analysis to describe HCPs' perceptions of PCC. Eight constructs from the CFIR domains, Intervention characteristics, and Inner setting were identified: Innovation source, Evidence strength and quality, Relative advantage, Adaptability, Trialability, Complexity, Compatibility, and Available resources. One construct, Observability, emerged from the data possessing criteria unique enough to merit it a place as a construct of its own.

The findings show that PCC was perceived as a highly complex innovation, with HCPs showing considerable heterogeneity regarding their perceptions of and willingness to accept the innovation. The innovation was often described as vague and abstract by HCPs. Some staff struggled to understand how and if it differed from how they had worked before, whereas others described how they understood what PCC was about, but that other colleagues did not. Complexity was also discussed in relation to patients’ expectations, wishes, and the possibility of cooperating and participating to co-create care with HCPs. Some HCPs described how they felt frustrated if patients did not wish to participate in their care or if other barriers for working in partnership (e.g., communication problems) arose. Having skills to work in line with PCC was also discussed among HCPs. Such skills included being attuned to patients' needs and wishes and using communication to elicitate the narrative. HCPs described how a PCC approach involved the inclusion of patient and next of kin perspectives, each HCP, and groups or teams of HCPs working with patients. Navigating the different perspectives of all the stakeholders involved with the patient’s care was a sensitive task, especially when norms and values were disparate among stakeholders.

Throughout the data analysis, we identified how the innovation characteristics of PCC were described from two perspectives, which could or could not be interrelated. The two perspectives were the ethical foundation of PCC and the operationalisation into practical work routines. Observability emerged as a separate construct to relative advantage. HCPs described how they could observe patients, team situations, and themselves if PCC was operating. The
results showed that HCPs' perceptions of PCC were shaped by many factors, such as how PCC was operationalised in the specific context and their buy-in to its ethical foundation.

Study IV

Phase 1: Development of a preliminary questionnaire

The results from the qualitative deductive-inductive content analysis based on key informant interviews, items from SALAR’s existing item pool (n=32), and relevant literature laid the groundwork for developing a preliminary questionnaire with 19 items (version 1.0). The key informants were adamant that the ethics of PCC should be embedded in all care practices and, as such, can be regarded as an overarching unidimensional concept. Informants described how this could become a challenge as HCPs are individuals. Thus, some HCPs already had an approach in line with the ethics of PCC, while others needed to become acquainted with this approach for the first time. Moreover, informants described how HCPs and patients together foster a PCC care environment.

PCC was operationalised as one overarching concept targeting the GPCC model for PCC. Each item was rated on a response scale from 1 to 5, retaining the anchors used in the National patient survey. Patients were asked to rate their perceived level of PCC in terms of all HCPs involved in their care (i.e., in an inpatient context where patients meet different HCPs throughout the day and night) or in interaction with one HCP if treatment were conducted by one HCP.

Phase 2: Content validation of items and revision of the questionnaire

Although many of the Delphi experts gave high consensus ratings at the first round, they were also active in their comments, offering suggestions for revisions to improve the wording or adding items to improve the questionnaire and make the instrument more aligned with the PCC concept. The rewording of items was chiefly based on suggestions about increasing the role of the patient as a partner and co-creator of care. Words such as together with and in collaboration with were thought to give more agency to patients in health care. New items were suggested to capture the partnership between HCPs and patients along with items focusing on patients’ resources and capabilities.

Two Delphi rounds with eight experts resulted in excellent consensus ratings for each individual item (>0.88) at the second round. The analysis informed a revised version of the questionnaire with 20 items (version 2.0) to measure patients’ perceptions of PCC.
Phase 3: Evaluation of the measurement properties of the questionnaire

Responses to the questionnaire from the participating units’ 553 patients were analysed using Rasch analysis. Data from the 10 patients who participated in the cognitive interviews, free text comments from patient responses to the questionnaire, and field notes from the first author (HF) were first analysed separately and then converged to guide further revisions.

Thresholds were disordered in 14 items and were rescored in accordance with the best fit of the model. Reliability evaluated with the person separation index was 0.84. There was no differential item functioning by gender, age or care setting. Items 13 (Were your relatives given the opportunity to participate in your care and treatment to the extent you wished?) and 18 (Have you and your caregiver worked together to create a written plan for your future care and treatment?) proved problematic in the fit statistics with large positive fit residuals (suggesting multidimensionality) and high frequencies of missing responses (suggesting low relevance). The qualitative inductive-deductive content analysis corroborated these findings. Thus, items 13 and 18 were deleted sequentially, starting with the most misfitting item, i.e., item 18. After disordered thresholds had been resolved and items 13 and 18 deleted, the questionnaire met the requirements of the Rasch model (see table 4).
Table 4. Summary of the item and fit statistics for items in the initial and revised versions.

<table>
<thead>
<tr>
<th>No.</th>
<th>Item</th>
<th>Initial version with 20 items</th>
<th></th>
<th>Revised version with 18 items</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Location</td>
<td>Fitresid</td>
<td>Chi sq</td>
<td>Missing</td>
</tr>
<tr>
<td>1.</td>
<td>Listen to your experiences of health and illness</td>
<td>-0.550</td>
<td>-0.577</td>
<td>8.212</td>
<td>17 (3)</td>
</tr>
<tr>
<td>2.</td>
<td>Discuss how health and illness affect ADL</td>
<td>0.489</td>
<td>0.539</td>
<td>4.349</td>
<td>39 (7)</td>
</tr>
<tr>
<td>3.</td>
<td>Encouraged to ask questions</td>
<td>0.556</td>
<td>1.765</td>
<td>15.234</td>
<td>36 (7)</td>
</tr>
<tr>
<td>4.</td>
<td>Get responses that you understand</td>
<td>-0.610</td>
<td>-1.167</td>
<td>6.191</td>
<td>18 (3)</td>
</tr>
<tr>
<td>5.</td>
<td>Enough information about care and treatment</td>
<td>-0.336</td>
<td>-0.998</td>
<td>13.295</td>
<td>12 (2)</td>
</tr>
<tr>
<td>6.</td>
<td>Come to an agreement on the next step in care</td>
<td>-0.083</td>
<td>0.273</td>
<td>4.763</td>
<td>57 (10)</td>
</tr>
<tr>
<td>7.</td>
<td>Participate in care-related decisions</td>
<td>0.261</td>
<td>-0.830</td>
<td>8.650</td>
<td>49 (9)</td>
</tr>
<tr>
<td>8.</td>
<td>Important ADLs were considered in planning</td>
<td>0.179</td>
<td>-1.330</td>
<td>16.214</td>
<td>56 (10)</td>
</tr>
<tr>
<td>9.</td>
<td>Important goals set for the planning of care</td>
<td>0.564</td>
<td>-1.705</td>
<td>9.494</td>
<td>79 (14)</td>
</tr>
<tr>
<td>10.</td>
<td>Coordination of contacts within care</td>
<td>0.026</td>
<td>1.413</td>
<td>12.524</td>
<td>97 (18)</td>
</tr>
<tr>
<td>11.</td>
<td>Discuss what you can do for yourself</td>
<td>0.174</td>
<td>-0.105</td>
<td>12.336</td>
<td>46 (8)</td>
</tr>
<tr>
<td>12.</td>
<td>Resources acknowledged and utilised</td>
<td>0.121</td>
<td>-1.190</td>
<td>11.295</td>
<td>50 (9)</td>
</tr>
<tr>
<td>13.</td>
<td>Opportunity for relatives to participate</td>
<td>-0.302</td>
<td>3.941</td>
<td>26.325</td>
<td>157 (28)</td>
</tr>
<tr>
<td>14.</td>
<td>Opportunity to express when concerned and anxious</td>
<td>-0.140</td>
<td>-0.143</td>
<td>8.833</td>
<td>67 (12)</td>
</tr>
<tr>
<td>15.</td>
<td>Feel as an equal person</td>
<td>-0.214</td>
<td>1.117</td>
<td>8.407</td>
<td>13 (2)</td>
</tr>
<tr>
<td>16.</td>
<td>Trust in the staff/caregiver</td>
<td>-0.968</td>
<td>-3.093</td>
<td>28.725</td>
<td>10 (2)</td>
</tr>
<tr>
<td>17.</td>
<td>Treated with respect</td>
<td>-1.047</td>
<td>-3.080</td>
<td>21.371</td>
<td>9 (2)</td>
</tr>
<tr>
<td>18.</td>
<td>A plan written together with the staff/caregiver</td>
<td>2.030</td>
<td>3.934</td>
<td>100.433</td>
<td>153 (28)</td>
</tr>
<tr>
<td>19.</td>
<td>Participate in the development of the plan</td>
<td>0.153</td>
<td>-0.583</td>
<td>9.434</td>
<td>346 (63)</td>
</tr>
<tr>
<td>20.</td>
<td>Understand the written plan</td>
<td>-0.303</td>
<td>0.773</td>
<td>4.434</td>
<td>345 (62)</td>
</tr>
</tbody>
</table>

Analyses have been performed with patients divided into nine class intervals with about 50 persons in each interval for all items, except four items 13, 18, 19 and 20. Items 13 and 18 have approximately 40 persons in each class interval and items 19 and 20 have about 19 persons (class intervals are based on groups within the sample with similar perceived levels of PCC).

Values highlighted in bold in the fit residual column show items with fit residuals outside the recommended range of +/−2.5.

Values highlighted in bold in the chi square column indicate statistical significance at the 0.05 level following Bonferroni adjustment.

Missing responses represented as n (%).
Many patients commented that the questionnaire targets important issues in today’s care. At the same time some argued that they did not have the skills nor wishes to partake in e.g., decision making. A limitation of the questionnaire is the targeting showing that items and persons were not well aligned, creating a ceiling effect. This circumstance means that the items in the questionnaire were unable to match patients’ perceptions of higher levels of PCC at the participating units. The qualitative inductive-deductive content analysis clarified the patients’ responses to some extent. Many patients described how care at the participating units was perceived as exceeding care at other health care units, indicating potential recruiting bias.
Discussion

Discussion in relation to the overarching case

In this section, I discuss findings from the four studies in the context of the overarching case. I have chosen to focus on the totality of the findings that share commonalities which give a richer view of the central case when viewed in an interrelated context.

Ethical principles and core practices of PCC in relation to stakeholder perceptions

The stakeholders' experiences and perceptions on PCC show that PCC is a complex innovation with varied understandings. In study IV, key informants felt that PCC's ethical and philosophical underpinnings should be embedded in all core practices conducted in everyday health care activities. They regarded PCC as a unidimensional construct whereby all practices should be grounded in ethical values and where people use a human growth mindset. Embedding underlying PCC ethics in daily routines is advocated by other research endeavours on PCC and supports the information obtained from key informants in this study [5-7, 135].

The unified understanding of PCC’s basic ethical principles related to core practices among key informants did not fully correspond to how the region's stakeholders understood these principles. In study II, change agents at the different health care units described operationalisation of PCC into core practices with mixed understandings of the ethical foundation. While some change agents quickly linked ethical values in PCC and practices at the different health care units, others had more difficulty explaining this connection. This finding was corroborated by HCPs’ perceptions of PCC in study III. HCPs were even more diverse in their adoption of PCC when they discussed PCC’s perceived characteristics. Some HCPs described PCC as focusing on ethics, whereas others discussed PCC in the context of everyday routines and practices while some HCPs did not recognise that they were supposed to work in line with PCC values. Similar findings have been reported in other research initiatives noting that HCPs report varied understandings of PCC [71].
We chose to develop the GPCCQ based on data from key informants and the literature. Seeing PCC as a partnership between HCPs and patients, we believed it could be measured as a unidimensional concept. The data fit the Rasch model indicating a unidimension, with two exceptions [100]. Relatives and next of kin are often regarded as a crucial element of PCC; however, items measuring involvement of relatives has also shown some misfit in other measures of PCC [68].

A gap between patients and HCPs understanding and knowledge of PCC

In study III, some HCPs reported feeling frustrated and found it difficult when patients showed little or no interest in co-creating care. A clash occurred between some patients’ perceptions and expectations in health care and HCPs trying to facilitate a collaborative climate. In study IV, some patients thought that questions detailing “to the extent you wished” were problematic because they doubted what they could get. This suggests a knowledge gap between HCPs and change agents engaged in increasing the implementation of PCC and patients who have not been informed that a paradigm shift is in progress. Study I revealed a limited number of reported strategies aimed at informing patients of the change leading towards PCC. This finding is corroborated by a recent report in Sweden showing a lack of information to patients about their health care rights [136]. Improving information to patients about why they are asked their opinions and wishes for care can possibly increase the patient-HCP partnership. Such a partnership will place patients on a more equal footing with HCPs if they understand what they are expected to do. Teachings on PCC places great responsibility on the HCPs as autonomous agents to ensure a PCC approach [5, 6]. The HCPs are encouraged to use communication strategies that elicit a narrative and invite the patient to feel secure and positive to co-create care [42, 137]. By informing patients about PCC before a meeting takes place, they can come better prepared to work in partnership with HCPs, i.e., patients and HCPs agree to cooperate to advance their mutual interests.

The approach and understanding of PCC is an individual attribute

Key informants in study IV described that PCC needs to be adopted by all stakeholders in a health care context to ensure continuity and equality for all patients. At the same time, they pointed out that some HCPs seem to have a PCC approach towards patients consistent with PCC principles, while others need support and assistance to attain the required level of PCC. Many HCPs corroborated this finding in study III by noting that to practice PCC effectively requires skills, competencies, and personal qualities. Skills mentioned were
the ability to listen and communicate with patients and colleagues within and between organisations. A universal strategy used at the participating units was to apply different approaches to enhance HCPs' communication skills with patients. Teachings on PCC and other research align with these comments and often stress that this is a vital skill in implementing PCC [5, 42, 137]. While most stakeholders value a PCC approach in health care, understanding of the concept related to core practices and PCC principles was disparate among change agents and HCPs. Similarly, study IV showed that patients had varying perceptions of PCC. Patients described the GPCCQ items as capturing important values that improve the quality of care in health care settings. However, while some patients described the importance of working with HCPs and being involved in care decisions, others stated they did not wish to participate in their care process. Thus, not only do HCPs and change agents have different perceptions of PCC, but patients also show these varying views.

In study IV, we asked patients to rate their perceptions of PCC for the combined interactions with all HCPs who had been involved in their care. In phase three of the development phase of GPCCQ, it became evident that HCPs are viewed as individuals rather than as representatives for a pooled workforce, and thus some patients found it difficult to generalise about all HCPs. Patients’ experiences and perceptions of different HCPs’ adoption of PCC were not described as contingent on vocational roles, which is a finding that distinguishes this study from others, where e.g., medical doctors often place more value on medical parameters than patients’ needs and preferences [138]. However, this finding was also consistent with findings in study III, where the differences between different HCPs' adoption of PCC were outlined. In study III HCPs described a variety of perceptions and experiences to PCC not directly tied to specific health care units or vocational roles.

**Implementation process**

Study I outline which strategies were enacted and how they were introduced into the health care units. The Region and DD used a combined top-down, bottom-up design to process information and increase knowledge. A political decision was taken advocating more PCC in health care (i.e. top-down approach) while managers at health care units could choose to be engaged in the change initiative. Change agents at the DD used several strategies to initiate change throughout the region, where a substantial amount of resources were allocated to arranging learning seminars. The strategies used by change agents at the learning seminars contained many aspects that align with teachings on implementation and PCC [6, 31, 139]. Some of these strategies included encouragement to operationalise PCC to contextual needs for each unit, using different learning activities during the learning seminars (e.g., traditional lectures mixed with group discussions and reflections from HCPs’
Talks and lectures were given covering different factors such as patients giving their perspective of perceived care, HCPs' experiences of working to increase PCC, and researchers from GPCC offering their views on the concept of PCC and the GPCC model.

Because change agents at each health care unit were encouraged to drive their own strategies to achieve change (i.e., bottom-up approach), differences across the health care units were evident in relation to chosen strategies and perceptions of how changes should come about, and the dose and time spent to achieve a change. The units used different changes in routines as strategies to increase PCC core practices at the workplace. Some units included all HCPs in those routines and even revised their roles to support change. Having routines may be of value to remind HCPs of tasks that need to be carried out, but the task's quality may be unclear, e.g., did the patient feel listened to and did the patient feel included in co-creating care? This thesis does not include data on outcomes of the implementation efforts, which precludes conclusions about the efficiency of the different strategies used.

Methodological considerations

This thesis includes four studies in which data from different sources and methods have been triangulated or mixed to enable a broad understanding of the overarching case: Implementation of PCC in a real-world setting. A sample of various health care units representing in- and outpatient care involving different patient groups and HCPs with various vocational roles was included in this study. We regard this as a strength in the sense that it gives a broad spectrum of perspectives on each study objective and the overarching objective. Participants in the role of change agents, HCPs, key informants, Delphi experts, and patients were recruited. They all contributed through their vast experience and perceptions of the different study objectives. The participant’s contributions resulted in activity logs, documents, interview data from focus groups, dyadic, individual and cognitive interviews, free text comments, CVI ratings, and questionnaire responses. In addition, HF used fieldnotes as another data source in the triangulation process.

All research has strengths and limitations that need to be considered in relation to the study objective and the conclusions drawn from the findings. To increase the trustworthiness and transparency of the thesis findings, we have strived to hold high methodological quality in data collection and analysis, as well as our interpretation of the findings. Methodological rigour in research can be explained and verified in different terms whether the study is based on qualitative or quantitative methods [140]. While quantitative methods are characterised by concerns over validity and reliability, qualitative methods use terms related to trustworthiness: credibility, dependability, confirmability,
authenticity, and transferability [129, 141, 142]. Because this thesis uses both qualitative and quantitative methods in a triangulated or mixed fashion, I will apply the corresponding terms to each research strand when I discuss some of the steps undertaken to increase rigour in our studies.

To enhance overall trustworthiness of our findings we have used reporting guidelines for all individual studies to describe and report methodological considerations [102, 123, 143].

All studies have converged multiple sources of evidence to strengthen the trustworthiness, and specifically the credibility, of the findings by reducing possible errors or weaknesses inherent in one data source [78, 104]. To further increase credibility, we have discussed emerging findings ongoing and reported our preconceptions within the research group [78].

A variation of theoretical approaches was chosen to aid the data analyses. The decision to use frameworks with coding matrices to guide the deductive content analyses was made for several reasons. Case studies can overwhelm researchers with tremendous amounts of data [78]. For such situations, guiding frameworks based on empirical knowledge and theory are an essential aid in the data analyses. We also used frameworks to answer the call to increase a consistent use of concepts, definitions and terminology in implementation research [30, 31]. An increased use of a common language by implementation researchers and practitioners has the potential to increase transferability, comparisons, and replication of implementation initiatives. Each framework was carefully identified and chosen with guidance from the literature in regard to the study objectives and in discussions between all authors [29, 80, 98, 102]. We acknowledge that we could have used other frameworks that would have likely yielded different presentations of the results [144-146].

Some researchers propose that frameworks should also guide data collection. We chose to collect data based on our different study objectives to decrease the risk of confirmation bias and missing important factors not included in the frameworks [129]. Moreover, the frameworks were not used inflexibly, i.e. we kept an open mind to embrace and report data that did not fit the coding matrices to ensure that all data that corresponded to the study objective were reported [129]. Thus, from the studies, we could identify data that we interpreted as additional discrete implementation strategies reported by change agents (study I), and constructs that adhere to innovation characteristics as perceived by HCPs (study III).

A possible weakness of this thesis concerns its transferability regarding the extent to which it represents implementation “as usual”. We acknowledge a possible limitation of our case study design in the potential for recruitment bias and the Hawthorne effect [147], the tendency of people to behave
differently because they know they are being evaluated or observed. The strategy of the DD involved inviting health care units to be part of the change initiative voluntarily. Therefore, managers at the participating units who opted to be part of the first learning seminars and accepted the invitation to participate in the studies likely had a positive attitude towards the implementation initiative from the beginning. Hence, these units may not be representative all health care units in the region.

A prerequisite to conducting this thesis in a real-world setting has been managers' willingness to let researchers access data over a period of 4 years. Moreover, several change agents reported that one of their strategies was to be part of the research initiative to acquire feedback on their efforts and increase motivation to work harder to achieve change, possibly creating a Hawthorne effect. Focus groups and interviews with HCPs may have affected how PCC was perceived at the health care units, which several participants corroborated. A typical comment from participants was that they appreciated participating in interviews and focus groups, noting that it was valuable to reflect and discuss PCC among colleagues. HCPs were also aware that questionnaires were used to query patients about their perception of care from a PCC perspective, which may have affected how HCPs transitioned towards more PCC. By showing transparency towards these possible limitations, I hope that each reader of this thesis can assess to what extent the results can be transferred to other settings [78].

The combining of different kinds of interviews and focus groups in the present studies provide data that offer a richer and more comprehensive picture of the study objectives. Individual interviews used in study III have the potential to capture data that may be perceived as sensitive to discuss with other colleagues, especially if individuals views on PCC conflicted with those of others at the workplace [116]. Dyadic interviews and focus groups, on the other hand, are often used to generate data relying on the dynamics that transpire when people discuss a common topic in a dyad or group [113-115]. Participants have the opportunity to compare their views and agree or disagree on the issues raised in the discussion. Mixing interview formats can sometimes be problematic as each format relies on different dynamics to elicit data. However, we did not regard this as a limitation as we sought to analyse and code the manifest content in the data and did not aspire to conduct interaction analyses. Confirmability and authenticity were strengthened by a consistent use of citations from participants [129].

We sought to develop a questionnaire that can be used in different patient populations and healthcare sectors. When a questionnaire is created, it is vital to lay the ground for its construct validity, evaluate its content validity and measurement properties before it can be used as a measurement tool in research studies or clinical work [127, 148]. This evaluation can be conducted
using different methodologies and measurement models [98, 148]. Because our goal was to develop a generic questionnaire that can be used in the future for comparisons in different health care sectors and patient populations, we chose to use the Rasch measurement model [96, 98, 100]. A prerequisite for measurement (e.g., evaluation with the Rasch measurement model) is that data need to capture a unidimensional construct. Therefore, phase one and two in study IV focused on strengthening the construct and content validity and understanding how PCC is conceptualised in the GPCC model [99]. A deep understanding of the concept is needed when a latent construct is operationalised as a tangible item [99]. We used current literature, key informants, and Delphi experts to increase our understanding of the concept and get guidance on how PCC can be operationalised into specific items, where each item is thought to contribute to the unidimensional construct PCC [99]. One of the co-authors (CW) in study IV has extensive knowledge of PCC's philosophical base and the GPCC model, regarded as an invaluable contribution to increasing construct and content validity. In phase three, we carried out Rasch analyses iteratively [96, 100, 102]. Understanding was appreciably strengthened by mixing Rasch analysis with qualitative data from the qualitative deductive-inductive content analysis. The number of Delphi experts (n=8) in phase two was chosen based on Lynn’s recommendations for calculations of CVI [126]. The sample size of 553 patients who responded to the questionnaire in phase three is consistent with recommendations for conducting Rasch analyses [149].

Our goal of developing a generic questionnaire in relation to different patient populations needs to be evaluated further in future studies. Sweden has had a large influx of refugees over the past few years, with people born outside the country representing about 20% of the population as of December 2021 [150]. Patients were included in study IV if they could understand the Swedish language or if they had access to a translator, which was rare (<5 patients). Consequently, few non-Swedish-speaking patients were included. Also excluded were patients <18 years, diagnosed with dementia, a psychiatric condition such as severe psychosis, or other cognitive impairments that refrained patients from responding to the questionnaire. This is a major limitation in our study as it excludes some patient groups in health care settings. However, questionnaires and evaluations of PCC for people with dementia and their relatives have been extensively studied within other research initiatives to explore PCC in those contexts and within these populations [69, 151, 152]. A recent report on health care in Sweden concluded that patients with poor health and foreign-born patients rated health care experiences more negatively than other patient groups [136]. Subsequently we suspect that the responses and results would differ with a broader inclusion criterion of patients who speak other languages.
Conclusion

This thesis demonstrates that implementation of PCC is a complex intervention involving a plethora of factors interacting at different levels within a health care context. Moreover, PCC is a complex innovation with various connotations for all participating stakeholders (i.e., patients, HCPs, change agents, key informants and Delphi experts). Adding to this complexity is the finding that the variations are not described as belonging to specific stakeholder groups, vocational roles, or certain health care units. The results show that linkages between PCC from an ethical and philosophical perspective and core practices varied greatly and were often unclear to change agents and HCPs alike. The complexities of PCC described in this thesis are of utmost importance to all stakeholders who plan to implement PCC. We suggest that stakeholders explore potential barriers to PCC in-depth. They also need to consider barriers in different stakeholder groups, settings, and health care units before choosing strategies for PCC implementation.

The findings from this thesis give a comprehensive account of the stakeholders’ work in a real-world setting. Change agents were asked to meet the challenge of implementing more PCC. From this standpoint, they developed a local strategy based on their experiences and understandings of implementation, PCC, and their particular context. We identified several innovative strategies that can be used in future implementation efforts. We also identified a lack of potential strategies in some areas that should be considered in the future.

This thesis includes the patients’ perceptions of PCC through the development of the GPCCQ. Measuring PCC from the patients perspective is essential as it can contribute to the evaluation process and point to areas in research and clinical care needing improvement. The instrument can be used with other patient-reported outcome measures to evaluate whether the patients perceived that the PCC approach contains the core components of PCC. The questionnaire had some limitations regarding targeting and two items proved unsuitable. However, we believe the questionnaire can be helpful as a generic measure of quality and provide a fair benchmark tool for patients’ perceptions of PCC.

Different theoretical frameworks, taxonomies, and predefined topics were identified to guide data collection and analyses for each study objective. The
frameworks were vital during phases of data triangulation and deductive content analyses and contributed to using a consistent language in implementation research. We strongly encourage other researchers and practitioners within implementation to follow this approach so that we can continue to build a consistent common language enabling replications and synthesis of findings across implementation efforts.
Clinical implications and future research

Findings from this thesis can serve in several ways to provide insights and inspire future implementation research and practice for different stakeholders.

First, the complexities we observed in implementing PCC in a real-world setting can be used to explore determinants for practice in other health care settings. We believe similar barriers can be found in different settings.

Second, improved descriptions of an innovation's core components can aid the implementation process and guide HCPs' understanding of PCC's underlying principles and values, including what it imposes on a granular level. Improved descriptions and reporting of the core components of PCC are also valuable with respect to future replication and generalisation of implementation initiatives.

Third, increased collaboration between researchers and stakeholders concerned with implementing PCC could probably result in a win-win situation (i.e., a solution where everyone benefits). Stakeholders can be assisted in using theoretical approaches to their change initiatives to improve outcomes. Researchers can gain an increased understanding of the experiences that stakeholders inherit from a health care context. Experiences from a real-world context can act to inspire innovative approaches, including using new strategies developed and used in real-world settings to guide future implementation research.

Fourth, the GPCCQ was developed to enable comparisons of patients’ perceptions of PCC across different health care settings. Due to problems identified in targeting, the questionnaire needs to be evaluated further. However, we believe the questionnaire in its current form can be of interest to stakeholders wishing to use it to benchmark PCC.

More studies from the IMPROVE project will be published with the hope that findings from this thesis can be further elaborated: For example, mechanisms of impact, HCPs perceptions of the strategies used for implementation, and outcome measures for the implementation effort.
Svensk sammanfattning

Bakgrund

Forskning för att förbättra människors hälsa och levnadsvillkor sker kontinuerligt. För att nya effektiva metoder och arbetssätt ska komma patienterna till nytta behöver de börja användas i hälso- och sjukvården. Implementering handlar om att på ett systematiskt sätt stödja införandet av nya metoder och arbetssätt i praktiken. Implementeringsforskning handlar om att öka kunskapen om vilka faktorer som påverkar implementeringsprocessen, hur dessa faktorer samverkar och hur processen att implementera nya arbetssätt kan stödjas för att vara framgångsrik.

Idag vet vi att implementering i hälso- och sjukvården ofta är komplicerade processer som är beroende av att personal och patienter på olika nivåer i en sjukvårdskontext jobbar tillsammans för att uppnå en förändring. Arbetet med att implementera nya metoder inom hälso- och sjukvården sker och drivs oftast kontinuerligt av personer som är anställda inom organisationen utan stöd från forskare inom implementering.

Personcenterad vård (PCV) kan ses som ett etiskt förhållningssätt som syftar till att öka kvalitén i vården. PCV utgår från att patienter är unika personer med ovärderlig kunskap om sig själva och sin livsvärld. Genom att se personen bakom patienten kan patienterna bli medskapare av sin vård och deras resurser och möjlighet att ta ansvar tillvaratas. Inom PCV pratar man om att bilda ett partnerskap mellan personal och patient. Implementering av PCV förordas av de flesta regioner i Sverige idag och personal på olika nivåer inom organisationerna får i uppdrag att implementera detta komplexa förhållningssätt.

Kunskap om hur implementering drivs i naturliga kontexter, dvs i ordinarie hälso- och sjukvård utan stöd från forskare är idag bristfällig. Det behövs mer kunskap om hur implementering av komplexa arbetssätt, såsom PCV genomförs som en del av ordinarie utvecklingsarbete. Det övergripande syftet med doktorsavhandlingen är att öka kunskapen om faktorer som påverkar implementeringsprocessen av PCV i en naturlig kontext.
Metod

I Region Dalarna fattades ett politiskt beslut 2015 att öka patienternas delaktighet i hälso- och sjukvården. Det konkretiserades i form av PCV och personal på utvecklingsavdelningen i regionen fick i uppdrag att driva förändringen. Avhandlingsarbetet är en del i ett större projekt som undersöker olika faktorers påverkan på implementeringsprocessen av PCV i en naturlig kontext.


I delstudie I undersökte vi vilka strategier, och hur olika strategier användes för att införa mer PCV på de olika enheterna. Personal som var med och drev implementeringen på varje enhet och på utvecklingsavdelningen intervjuades (26 stycken) vid två tillfällen. På varje enhet fördes loggbok över aktiviteter som genomfördes.

I delstudie II undersöktes hur PCV konkretiserades till praktiska handling på de sex olika vårdenheterna. Analysen baserades på samma intervjuer och loggböcker i studie I.

I delstudie III intervjuade vi 97 personer som arbetade på de olika vårdenheterna. Intervjuerna genomfördes under 2018 och frågorna handlade om hur personalen ser på PCV som ett nytt förhållningssätt som de ska arbeta med i praktiken.

Delstudie IV är baserat på utvecklingen av en enkät för att mäta patienternas upplevelse av vården utifrån ett personcentrerat perspektiv. Utvecklingen skedde i tre olika steg, där det första steget handlade om att ta fram förslag på frågor för att mäta nivå av PCV. I steg två gav forskare, kliniker och patienter (8 sammantaget) återkoppling på dessa frågor tillsammans med förslag till förändringar, tillägg och förbättringar. Steg 2 resulterade i en enkät med 20 frågor som i ett tredje stege besvarades av 553 patienter. För att ytterligare öka förståelsen för hur patienter tänker när de besvarar frågorna rekryterade vi 10 patienter som deltog i intervjuer samtidigt som de fyllde i enkäten.

Resultat

Delstudie I visar att enheterna använde många strategier som syftar till att utbilda personalen i PCV och att skapa samarbeten mellan olika personalkategorier inom regionen och den egna verksamheten. Få enheter rapporterade om strategier för att informera patienterna om att en förändring inom vården höll på att genomdrivas.
I delstudie II identifierades en hel del likheter men också skillnader i hur tillämpningen av PCV beskrivs. Alla enheter arbetade med att patienternas berättelse skulle inkluderas så den låg till grund för utformning av vården, att diskutera mål för vård och behandling med patienten och att skapa en hälsoplan. Skillnader i tillämpning av PCV var till stor del relaterade till de olika typerna av vård som bedrevs på enheterna. Resultaten visade också stora variationer i hur man ser på PCV i relation till den underliggande etiken.

Resultaten från delstudie III visar att PCV är komplext då det beskrivs som luddigt, svårt att förstå hur det ska omsättras i praktisk handling, och att personalen ser med olika ögon på PCV och därmed drar åt olika håll i arbetet. Många deltagare beskrev positiva upplevelser av att arbeta mer i linje med PCV då de såg att det gjorde att patienterna tog mer plats och initiativ i vårdkontexten. Det framkom också beskrivningar av att arbetsklimatet mellan kollegor förbättrades när de jobbade mer enligt PCV.

I delstudie IV visade resultatet att enkätens frågor upplevdes övergripande som viktiga av patienterna för att fånga hur man upplever vården. När mätegenskaperna utvärderades visade resultatet att två frågor inte passade ihop med övriga frågor. En fråga om anhörigas möjlighet att vara delaktiga i patienternas vård och en fråga om man hade gjort upp en skriftlig plan tillsammans med personalen passade inte ihop med övriga frågor. När vissa förändringar hade gjorts i enkäten så kan den anses uppfylla kriterier för att kunna användas som mätinstrument.

**Diskussion**

Det sammanlagda resultatet från avhandlingen visar att många av deltagarna ser på PCV som ett komplext koncept där det gäller för personal och patienter att komma till en samsyn om vad det innebär att arbeta i partnerskap med varandra. Personalen uppsökte en stor heterogenitet när de beskrev PCV där vissa tycker att det är en självklarhet att jobba i linje med konceptet och vissa andra inte upplever att det är någon skillnad jämfört med tidigare arbetsätt. Även patienterna uppsökte skillnader i hur de upplever PCV i vården. Vissa verkar vara ovetandes om sin rätt till att ta mer plats i vården medan andra tycker att det är en självklarhet att de ska vara med och bestämma. Flera patienter uttryckte också att de inte vill vara med om och fatta beslut om sin vård utan att det hör till sjukvårdspersonals roll.

Sammantaget visar avhandlingen att ytterligare förtydligande av hur PCV kan konkretiseras som praktiska handlingar i vården behövs så att personalen i större utsträckning vet vad det är de ska sträva mot för att arbeta mer i linje med PCV. Främst har strategier som fokuserar på utbildning använts för att stödja implementering men andra strategier, t ex strategier riktade till patienter
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