

Towards an item bank to measure patient-reported experience of person-centred care

Lena Rosenlund

Institute of Health and Care sciences
Centre for Person-Centred Care
Sahlgrenska Academy, University of Gothenburg



UNIVERSITY OF GOTHENBURG

Gothenburg 2023

Cover illustration: MOSTPHOTOS

Towards an item bank to measure patient-reported experience of person-centred care

© Lena Rosenlund 2023

lena.rosenlund@gu.se

ISBN 978-91-8069-155-0 (PRINT)

ISBN 978-91-8069-156-7 (PDF)

<http://hdl.handle.net/2077/74506>

Printed in Gothenburg, Sweden 2023

Printed by Stema Specialtryck AB, Borås



‘Experience is only as true as the perceptions of those having the experience’

Jason A. Wolf (2017), Patient Experience: The New Heart of Healthcare Leadership, *Frontiers of health services management* 33:3, p.6

ABSTRACT

Person-centred care (PCC) is a key component in high quality care and has been widely promoted as a means of improving patients' experiences of care and health outcomes. Reorienting healthcare towards a more person-centred approach requires new approaches to evaluate care from the patient perspective. The overall aim of this thesis was to explore care from the perspective of people living with long-term conditions, and to develop and psychometrically test Swedish and English items to measure patient experience of PCC.

In Study I, items ($n = 155$) probing patient experiences of PCC were translated, and a mixed-methods design was used for a qualitative item review involving different stakeholders ($n = 84$). The content, relevance and acceptability of the items were evaluated in two validation rounds using questionnaires, a focus group discussion, and cognitive interviews. The item review resulted in 57 Swedish and English candidate items probing person-centred care from the patient perspective. Study II employed individual semi-structured interviews to explore communication and collaboration within a patient-professional partnership from the experiences of persons living with long-term conditions ($n = 15$). Through an inductive thematic analysis, five themes were identified: Adapting and self-managing in daily life, Handling and carrying information, Building trust and continuity, Acting in a flexible and transparent dialogue, and Sharing the way forward. Study III and Study IV were quantitative and used a cross-sectional design. The candidate items retrieved from Study I, were psychometrically tested against the Rasch measurement model in Study III with data gathered from a hospital in Sweden ($n = 140$). Data for Study IV was collected via a web panel in the UK ($n = 501$). Initial analyses revealed poor fit with local dependency and multidimensionality. After the removal of poorly fitting items, a testlet solution with clustered items grouped into dimensions of the conceptual model of person-centred care showed fit to the Rasch measurement model. These items can be used for a future item bank measuring patient experience of person-centred care for use in Sweden and UK.

The findings presented in this thesis contribute to a better understanding how care is perceived as person-centred from the perspective of people living with long-term conditions and provides a solution to how this can be measured in future research.

Keywords: Person-centred care, Person-centredness, Patient experiences, Patient-reported experience measures

SAMMANFATTNING PÅ SVENSKA

Mätning av patienters upplevelse av personcentrerad vård – med sikte på en item-bank

I Sverige och Storbritannien, som i många andra västerländska länder sker en omstrukturering av hälso- och sjukvård för att möta behovet av en åldrande befolkning där allt fler lever med långvariga sjukdomstillstånd. Personcentrerad vård är en viktig del i omställningen och därför behövs nya sätt för att kunna utvärdera om hälso- och sjukvården bedrivs personcentrerad sett ur patienternas perspektiv. Det övergripande syftet med denna avhandling var att utforska vad som gör att vården upplevs personcentrerad för personer som lever med långvariga sjukdomstillstånd, och att utveckla och psykometriskt testa svenska och engelska enkätfrågor för att mäta patienters erfarenheter av personcentrerad vård.

I Studie I användes en mixed-method design i syfte att tillsammans med experter översätta, utveckla och utvärdera 155 frågor för att mäta patienters erfarenheter av personcentrerad inom hälso- och sjukvård. I två valideringsrundor med enkäter, en fokusgrupp och tio intervjuer fick deltagarna värdera varje enskild fråga avseende relevans och begriplighet samt hur innehållet i alla frågor tillsammans täcker personcentrerad från patienters perspektiv. Resultatet blev 57 frågor formulerade som påståenden samt en fyrgradig svars skala. Studie II genomfördes som en kvalitativ studie där 15 personer med långvariga sjukdomstillstånd intervjuades om deras upplevelser av personcentrerad i hälso- och sjukvården, samarbete och kommunikation. Intervjuerna analyserades genom induktiv tematisk analys där fem teman identifierades: egenvård och anpassning i vardagen, hantera och förmedla information, bygga förtroende och kontinuitet, agera i en flexibel och transparent dialog och att dela vägen framåt. Studie III och Studie IV var tvärsnittsstudier i syfte att med hjälp av Rasch-analys psykometriskt testa de 57 frågor som tagits fram i Studie I. Data till Studie III samlades in via webbenkäter på en onkologisk klinik i Sverige ($n = 140$) och till Studie IV via en webpanel ($n = 501$) i Storbritannien. Frågor som inte fungerade psykometriskt togs bort i analysen. Resterande frågor grupperades enligt den teoretiska modellen av personcentrerad vård. Resultatet uppfyllde kriterierna för Rasch-analys.

Den här avhandlingen bidrar med ökad kunskap om vad som är viktigt för patienters upplevelser av personcentrerad i hälso- och sjukvården samt en grund för en Rasch-analyserad item-bank och en hierarkisk modell för mätning av patienters upplevelse av personcentrerad vård.

LIST OF PAPERS

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

- I. **Rosenlund, L.**, Jakobsson, S., Lloyd, H., Lundgren-Nilsson, Å., Hermansson, M., & Dencker, A. (2022). Measuring patient experiences of person-centred care: Translation, cultural adaption, and qualitative evaluation of item candidates for use in England and Sweden. *Scandinavian Journal of Caring Sciences*, 36(1), 235-244.
- II. **Rosenlund, L.**, Jakobsson, S., Lloyd, H., Diffner, A., Lundgren-Nilsson, & Dencker, A. (2022). Patient experiences and prerequisites of collaboration as partners in person-centred care in outpatient settings: An interview study. *Submitted*.
- III. **Rosenlund, L.**, Lundgren-Nilsson, Å., Jakobsson, S., Lloyd, H. & Dencker, A. Initial Rasch analysis of Swedish item candidates to measure patient experience of person-centred care. *In manuscript*.
- IV. **Rosenlund, L.**, Statton R., Close, J., Lloyd, H. & Dencker, A. Patient-reported experience measures for Person-Centred Care: The Development and Testing of a UK-Swedish Measure. *In manuscript*.

CONTENTS

- ABBREVIATIONS..... 12
- DEFINITIONS 13
- 1 INTRODUCTION..... 15
- 2 BACKGROUND 16
 - 2.1 Person-centred care 18
 - 2.1.1 The Gothenburg model of person-centred care 19
 - 2.1.2 The conceptual model of person-centred coordinated care 21
 - 2.2 To measure patient experience of person-centred care 23
 - 2.2.1 Rasch measurement theory..... 26
 - 2.2.2 Item banks and computer adaptive testing 28
- 3 RATIONALE 29
- 4 AIM 30
 - 4.1.1 Overall aim..... 30
 - 4.1.2 Specific aims 30
- 5 METHODS 31
 - 5.1 Design 32
 - 5.2 Participants and data collection..... 33
 - 5.2.1 Study I – Translation and qualitative item analysis.....33
 - 5.2.1 Study II – Interview study 35
 - 5.2.2 Study III – Swedish candidate items 36
 - 5.2.3 Study IV – English candidate items 37
 - 5.3 Data analysis 38
 - 5.3.1 Study I – Mixed methods 38
 - 5.3.2 Study II – Thematic analysis 38
 - 5.3.3 Study III and IV – Rasch analysis 39
 - 5.4 Ethical considerations 41
 - 5.4.1 Ethical approval..... 41
- 6 RESULTS..... 43

6.1	Study I.....	43
6.2	Study II.....	43
6.3	Study III	45
6.4	Study IV	46
7	DISCUSSION	48
7.1	Discussion of main findings.....	48
7.2	Methodological considerations	52
8	CONCLUSIONS	55
	TACK.....	56
	REFERENCES	59
	APPENDIX.....	73

ABBREVIATIONS

GPCC	Gothenburg centre for Person-Centred Care
PCC	Person-Centred Care
P3C	Person-Centred Coordinated Care
PREM	Patient-reported experience measures
RMM	Rasch measurement model
UK	The United Kingdom
WHO	World Health Organisation

DEFINITIONS

Continuity of care	The way in which people perceive their care to be integrated; includes relationships, information, and coordination of care over time
Empowerment	An individual feeling as well as a process in which an individual is supported to take control over her or his health and well-being
Health literacy	The personal knowledge and competencies that are used to promote and maintain good health and well-being
Instrument	A validated questionnaire
Item	A question or statement in a questionnaire
Latent trait	A dimension or construct
Long-term condition	A health condition that lasts over a period of years, or lifetime; includes chronic conditions, disabilities, and congenital diseases
Needs	Conditions that are considered necessary for well-being; can be influenced by an individual's values and perceptions
Patient	(In this thesis) a person living with one or more long-term conditions; a person in her or his role as a patient
Self-efficacy	A person's confidence in her or his ability to look after herself/himself

1 INTRODUCTION

This doctoral thesis is within the scientific discipline of health and caring sciences and focuses on how patient experiences of care are perceived, how these experiences are related to person-centred care (PCC) and how PCC can be measured. The conceptual models of PCC used in this thesis are informed by the University of Gothenburg Centre for Person-Centred Care (GPCC), in Sweden and the Person-Centred Coordinated Care (P3C) model in the United Kingdom. The population of interest in all four included studies comprises people living with long-term conditions.

This thesis is part of the MOSAIC project at the GPCC, and the Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg. The MOSAIC project (<https://www.gu.se/en/research/mosaic-a-rasch-analysed-item-bank-to-measure-person-centred-care>) focuses on the challenges and opportunities of posed by modern technology and modern psychometric measurement methods. It is also part of a collaboration between the University of Gothenburg, Sweden and Plymouth University, UK, with the overall aim of developing future Swedish and English item banks to measure patient experiences of PCC. The project will contribute to a better understanding of patient experiences of care and will perform initial content and psychometric testing of candidate items to measure PCC for people living with long-term conditions. The first steps towards building an item bank measuring PCC from the patient perspective – that is, developing a conceptual model of PCC and identifying and selecting item candidates – were performed ahead of this thesis.

2 BACKGROUND

Like many other Western countries, Sweden is attempting to provide high-quality care to an ageing population with a high prevalence of long-term conditions, including chronic conditions and disabilities. Such conditions require management over a period of years or throughout the person's lifetime and are the result of a combination of genetic, physiological, environmental, and behavioural factors. Some long-term conditions can be immediately life-threatening, while others develop over time, requiring intensive management and often needing complex coordination of care from different healthcare providers (1, 2). The main types of long-term conditions are diabetes, chronic lung diseases, cardiovascular diseases, various cancers and asthma (3, 4). In 2019, nearly two in five adults (38%) in Sweden reported having at least one long-term condition. This proportion increases with age, with 55% of people over 65, reporting at least one long-term condition. Moreover, an increasing number of people live with two or more long-term conditions (5). This situation challenges the definition of health and well-being (6, 7), and requires the healthcare system to shift the focus of its services from acute and hospital-based care to preventive, long-term, and home-based care (8).

Long-term conditions can have multiple impacts on a person's life, including changes in physical health, mental health, autonomy, identity, and socio-economic status (9, 10). Living with one or more long-term condition(s) requires an individual to take responsibility to adopt improved health behaviours, monitor symptoms and side-effects, manage the medications used to treat the condition and undertake daily management to cope with the disease (11, 12). The challenges people with long-term conditions face vary depending on the nature of the conditions, as well as on their personal context, resources, and capacity for self-management (13, 14). Family involvement is common, and can require changes in the lives of family members (9).

From a historical perspective, healthcare has focused on acute injuries and diseases; it has typically been based on an hierarchical structure with healthcare professionals as the experts and patients as the passive recipients of care (15). Swedish healthcare generally ranks well in international comparisons, but it has weaker results in areas involving patients' experience of care, such as patient participation, information, shared decision-making, accessibility, continuity, and coordination of care (16, 17). The healthcare system also has limited resources, with health and social care budgets coming under increasing pressure. Therefore, to maintain or improve the quality of Sweden's healthcare system, changes are ongoing to improve access to

healthcare, to make more effective use of resources (16, 18, 19) and to strengthen the patient's position (20). With an ageing population, the healthcare system must prioritize the prevention of long-term conditions in the first place. Moreover, care for such people must be coordinated, and should foster empowerment, enhance health literacy (21) and support for self-management, engage people in decisions, and offer physical, emotional, psychological, and practical support (22, 23). By focusing on the relationship between people and healthcare services; the health care system are shifting from working *for* people to working *with* them (24, 25).

2.1 PERSON-CENTRED CARE

The National Academy of Medicine (NAM), formerly known as the Institute of Medicine (IOM), has emphasized the importance of incorporating the patient's perspective in defining quality. Today, PCC is established as one of six core components for high quality of care (26) and is perceived as a way to achieve better outcomes for individuals with complex healthcare needs and to address the demands of healthcare systems (27-29).

PCC is grounded in the ethics and philosophy of personhood, and can be seen as a goal and right in itself (15). It has been developed in various areas, including the care of people with dementia (30, 31), and chronic heart failure (32-34), and in different disciplines such as nursing (35), psychology (36), and medicine (37). PCC can be approached from different perspectives (e.g., that of the patient, healthcare professional, or healthcare system); as a result, there are different interpretations of PCC as an ethical approach, a process, an intervention, or a paradigm shift. Also, since person-centredness can mean different things to different individuals and in different contexts, PCC must be holistic, flexible, creative, personal, and unique to the person (38). Within healthcare, there are several conceptions expressing centredness, such as person-centred, patient-centred, child-centred, or family-centred, which contain both similar and different aspects (39-41). There are also several conceptual models or frameworks of PCC (42-48). Nevertheless, despite these different definitions of PCC, it is commonly agreed upon that PCC involves respect for the patient's experiences, needs and wishes (40, 49, 50), rights to being listened to and shared responsibility (41).

From a patient perspective, PCC is described as healthcare that shows compassion, dignity, and respect; it involves listening sincerely and acknowledging patients' experiences and resources, and it takes into account personal preferences, needs and goals for healthcare. Furthermore, a person-centred healthcare system should enable communication, ensure that people can access and understand information, support self-management, and encourage and invite patients to contribute to information and participate in care and treatment decisions based on their preferences and needs. For the care to be person-centred, it must also be coordinated and characterized by continuity, based on the patients' needs and preferences (15).

2.1.1 THE GOTHENBURG MODEL OF PERSON-CENTRED CARE

In Sweden, PCC is informed by the narrative-based model promoted by the GPCC (51). The GPCC model is rooted in the ethics and philosophy of personhood (24). Paul Ricoeur (1913 – 2005) describes the capable person, who can speak, act, give account, and hold herself or himself responsible for her or his own actions; at the same time, he argues that the capable person are vulnerable, and needs others in striving ‘for the good life, with and for others in just institutions’ (52). In a healthcare context, this has been translated to ‘aiming for health and wellbeing with and for patients, relatives, and staff in just institutions’, where ‘institutions’ refers to the community or healthcare settings patient collaborates and builds a partnership with (53, 54). This approach, which views the patient as a capable person, and does not reduce the person to just the role as a patient or the disease, is holistic and represents a shift from a biomedical to a more humanistic and holistic approach (55). PCC also means a shift from a traditional healthcare organization with patriarchal attitudes and hierarchical structures in which patients play a passive role and are at a disadvantage (56). Kristensson Uggla describes patients’ threefold disadvantage as: an institutional, existential, and cognitive disadvantage. Patients may experience an institutional disadvantage because they feel that they are at the bottom of a hierarchical healthcare system. They experience an existential disadvantage due to the vulnerability of having failing health or illness. Finally, patients may experience a cognitive disadvantage as a result of their lack of experience and knowledge of their new health situation (57).

The GPCC model of PCC consists of three key concepts or routines for practicing PCC: initiating a partnership by focusing on the patient’s narrative, working through a collaborative partnership, and safeguarding the partnership through documentation (24, 58-60).

Initiating the partnership – the patient’s narrative

The patient’s narrative plays a crucial role in introducing and perpetuating a person-centred approach. Listening to the patient’s narrative is a key part of a holistic approach, as the focus should not be reduced to the person’s health condition but should encompass the whole person, along with her or his lifeworld and experiences of illness, health, and well-being. The patient’s narrative is important for building trust and allowing the person to be seen, trusted, and believed in. By eliciting the patient’s narrative, that person’s needs and resources, preferences, and priorities are acknowledged and identified (43, 61). Telling their story is also a way for patients to interpret and make sense of

their everyday life; therefore, it can be therapeutic and can help patients to solve problems and cope with their situation (62).

Working in partnership

The patient-healthcare professional partnership is the most central aspect of PCC. Working in a collaborative partnership involves co-creating care between the patient, healthcare professionals and other people of importance in the patient's life, to an extent the patient finds desirable. The partnership aims to empower patients to take control of and handle the challenges related to their health, treatment, and care. Working in a partnership entails sharing information, expertise and decisions to find common ground and combine medical and personal goals in a joint care plan (43, 63).

Safeguarding the partnership

Documentation of the patient's narrative and the shared decisions in a joint care plan is important to safeguard the partnership. The care plan gives legitimacy to the patient's experiences, preferences, beliefs, values, and goals, next to the medical history and goals. The care plan also ensures transparency and information continuity and should be accessible to the patient and to everyone involved (43, 64).

2.1.2 THE CONCEPTUAL MODEL OF PERSON-CENTRED COORDINATED CARE

In the UK, the Person-Centred and Coordinated Care (P3C) model is a conjunction between PCC and the concepts of care coordination; it was established through collaborative action as a potential solution to fragmented care, and to support the implementation of PCC (65). The P3C model is based on the GPCC's philosophy and actions, together with the concepts of care coordination (44) and the person narrative by National Voices (66). The National Voices 'I statements' represent the patient perspective and summed as 'I can plan my care with people who work together to understand me and my carer (s), support my control and autonomy, and bring together services to achieve the outcomes important to me' (66). In the P3C model, five core domains and fourteen sub-domains are identified. The core domains are: Information and communication, My goals and outcomes, Decision-making, Care planning, and Transitions (27, 67).

Information and communication. This domain contains everything concerning the communication of the quantity, quality, availability, accessibility, and clarity of any information related to physical or mental health or well-being; treatment options, side-effects, or efficacy; and service delivery. Here, 'communication' refers to verbal or non-verbal means of exchanging information, thoughts, opinions, values, beliefs, or anything else related to physical or mental health and well-being – whether within a consultation, or in relation to communication between patients and professionals, or in relation to the person's (patient's) mental, physical, or social well-being outside of a consultation. This definition of communication also includes more 'meta' concepts such as treating people with respect and dignity. The sub-domains within the domain of Information and communication are *healthful relationships, information gathering and sharing, and knowledge of person and familiarity*.

My goals and outcomes. This domain covers patients' wishes, desires, lifestyle, treatment or health goals, and ability to manage their health. It can refer to specific treatment, care goals or lifeworld goals. The sub-domains are *goal setting/personal outcomes, empowerment/activation, self-management, and involvement of carers*.

Shared decision-making. This domain relates to decisions between patients and professionals about healthcare, treatment, and support, including situations in which social and mental care are related. A sub-domain is *support for shared decision-making*.

Care planning. This domain comprises the documentation of care and the planning of care in line with information, communication, shared decision-making, goal setting and transitions. The sub-domains within this domain are *co-created plan of care*, *key worker/coordinator*, *responsive and appropriate contact*, *coordination of care* and *medication review/plan*.

Transitions. This includes everything related to transitions between different service providers. A sub-domain is *continuity of care* (27, 67).

2.2 TO MEASURE PATIENT EXPERIENCE OF PERSON-CENTRED CARE

Research in PCC focus on examining how patients and healthcare professionals define PCC, how to practice PCC, and how to measure effects and outcomes of PCC (41, 68). PCC is a complex intervention, and lack of conceptual clarity make the evaluation of PCC difficult in practice (38, 69). A combination of methods and tools are often used; individual or group interviews, questionnaire surveys, observations, or secondary indicators of efficacy, such as safety and costs (68, 70). Interventional studies conducted between 2010 and 2016 ($n = 27$) by GPCC, used a total of, 163 different outcome measures (71). In UK, to evaluate P3C, an evaluation framework with a combination metrics was co-designed to probe healthcare professionals' and patients' experiences, patient participation and well-being and secondary indicators such as mortality, costs, and organizational processes (44).

Engaging patients is essential to PCC, at an individual level but also in the redesign and commissioning of healthcare services. Patient experiences of care are important to stimulate, guide and monitor quality improvement (70, 72-74). Providing a good patient experience is an ethical imperative and is a key component and outcome of high quality of care (7). Research has shown that positive patient experience correlates with better health outcomes for the patient, adherence to self-care and treatment, and less utilization of care (60, 61). The terms 'patient experience', 'patient perspective', 'patient reports', 'patient perception', and 'patient satisfaction' are often used interchangeably. Here 'experience' refers to everything a person understands, perceives, and remembers. Patient experiences include all the interactions that person has with healthcare and include four concepts: perceptions, culture, a cross-continuum view, and interactions. The Beryl Institute defines patient experience as 'The sum of all those interactions, which are shaped by the organization's culture across the continuum of care' (75, p. 5, 76).

To evaluate PCC from the patient perspective, group, or individual interviews or, most frequently, questionnaire surveys are used. Patient-reported measures include validated questionnaires, instruments, or tools that assess patient outcomes and/or experiences of care directly from the patient. Patient-reported outcome measures (PROM) are patient-reported measures that assess patient outcomes such as symptoms, function, or quality of life. In comparison, patient-reported experience measures (PREM) assess patients' experience and perceptions of care. Patient-reported measures are usually administered to the patient either as a paper form or (more commonly today) online. PREM allow

patients to objectively report what has happened to them or to subjectively rate their experiences of care (74). Having feedback systems in place based on PREM data, this provides a potential to use the patient experiences to target quality improvements (77-79). There are several patient-reported measures that have been developed to measure patient perspective of PCC (68, 69, 78). A recent review by Lloyd et al. (2018) identified 328 patient-reported instruments that had been developed to assess experiences and outcomes of PCC from the patient perspective (78). There are approaches to measure PCC or person-centredness holistically, as a unidimensional latent trait, or in the form of specific dimensions, such as shared decision-making, patient participation and for communication between the patient and healthcare professionals (68).

Classical test theory (CTT) has traditionally been used to form patient-reported measures in health sciences, with statistical procedures such as factor analysis, Cronbach's alpha and computing a summed score of raw data. Compared with a linear ratio scale such as the metric scale, raw data from patient-reported measures are typically based on categorical data or rating scales at an ordinal scale (80). Unlike the regular measures between the marks on a metric scale, the differences between levels on an ordinal rating scale tend to be irregular or unknown, which makes it difficult to compare results from different studies using such rating scales; it also hinders the use of parametric statistical tests (80-83). For different scales of measurement, see table 1. To reduce the responders' burden, the number of items in a questionnaire is limited. To account for this limitation, many instruments are either very broad, to cover a large general population, or very specific, focusing on a particular population or disease (83, 84).

Table 1. Scales of measurement

Data	Nominal	Ordinal	Interval	Ratio
Categorical data	Yes	Yes	Yes	Yes
Ranked order	No	Yes	Yes	Yes
Differences are measurable	No	No	Yes	Yes
Zero as starting point	No	No	No	Yes
Examples	Gender	Likert-scale	Temperature	Metric scale

2.2.1 RASCH MEASUREMENT THEORY

Some variables, e.g., weight, can be measured directly by a weighing scale. Other variables, such as person-centredness is a latent variable, which means it cannot be directly measured. Latent variables must be measured using attributes or observed variables – in the present case, items – that represent expressions or manifestations of the latent variable (80, 85). Therefore, creating an instrument starts with defining the latent variable of interest from a theoretical model followed by steps to identify and develop items that together describes or represent different aspects and levels of the latent trait. Thereafter, psychometric properties of the individual items and the items' ability together to measure the latent variable are examined (82).

The aim of modern test theories, such as Rasch measurement theory, is to improve instruments' precision and validate their quality, in addition to measuring the performance of the respondents (82, 86). Rasch analysis means testing of an rating scale against the probabilistic Rasch measurement model (RMM) developed by the Danish mathematician Georg Rasch (87). The Rasch model is built upon fundamental principles of rigorous measurement, such as linearity, invariance, local independency, and unidimensionality, and provides several tests for ascertaining the extent to which these principles are satisfied in a dataset. If the observed data fit the expectations of the RMM, a continuous interval scale can be established with the items sorted according to their difficulty, and the data can be evaluated using parametric statistical tests (82, 88).

To ensure the measurement properties of an instrument, the RMM is strictly unidimensional. A dimension refers to a single underlying latent trait, sometimes called a construct. Rasch analysis offers a strong assessment of dimensionality. It implies that the items examined with a Rasch analysis represent a common latent variable (82).

Linearity is necessary for rating scales to generate rigorous measurements and is one of the fundamental principles of the RMM. The RMM assumes that the probability of a respondent affirming an item is a logistic function of the difficulty of the item and the ability of the respondent on a latent trait. The items and the responders are positioned on a common interval scale or hierarchical map, called a Wright map (i.e., an item-person map). The items are sorted according to their level of difficulty and the responders are sorted according to their ability to affirm the items. The locations of both the items and the responders on the scale or map are given in 'logits', centred by the mean item location and the range from negative infinity to positive infinity.

Logits represent the relative difficulty of each item when compared with each another (82, 89). The distribution of persons and items in a dataset are also visualized in the person-item threshold distribution, centred by the items mean location see figure 1.

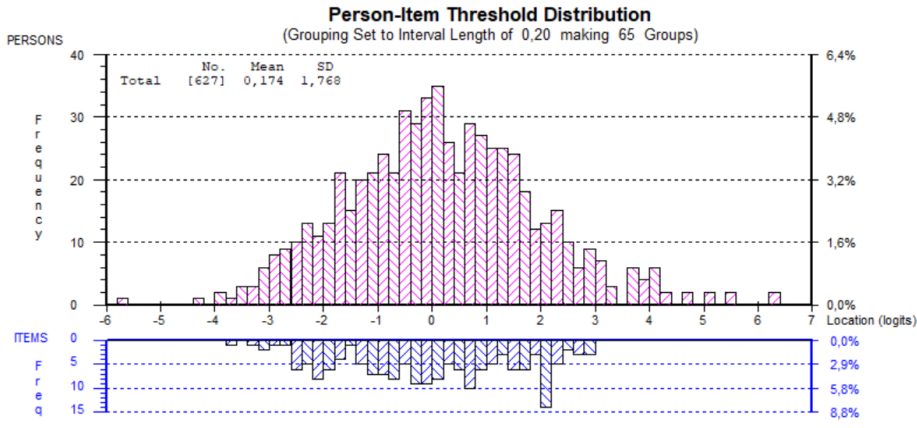


Figure 1. Example of a person-item threshold distribution

Invariance, which is also known as item bias, is another fundamental principle of measurement. A measurement (e.g., a metric stick) should function in the same way between different groups, such as between males and females. This can be examined for each item and different groups in RMM and is known as differential item functioning (DIF) (90).

It is also of importance that the items in a set that are assumed to measure the same latent trait, are not affected by or dependent on the responses to another item in the same set (response dependency); this property is known as local independence. Response dependency and trait dependency – where the latter is multidimensionality – violates the assumptions of local independence. Both forms of violation are known as local dependence (91, 92).

Rasch analysis was recently used in the development of PREM designed to probe PCC, the Patient-Experience Questionnaire (P3C-EQ) (93), the Generic Person-Centred Care Questionnaire (GPCCQ) (94); patient-perceived PCC in nurse-led outpatient rheumatology clinics (95); and patient participation; the Patient Participation in Rehabilitation Questionnaire (PPRQ) (96) and The Patient Preferences for Patient Participation tool (The 4Ps) (97).

2.2.2 ITEM BANKS AND COMPUTER ADAPTIVE TESTING

One of the advantages of using modern test theories such as RMT is the possibility of developing an item bank. An item bank is a collection of items that are sorted and psychometrically calibrated in interval scales for each domain (i.e., latent trait) they are measuring – such as person-centredness. The set of items defines, cover, and quantifies the latent trait of the variable being measured. It also makes it possible to create more flexible and individualized tests that are modified to fit individual people or studies. Such tests are known as computerized adaptive tests (CATs). A CAT is an iterative algorithm that selects items from an item bank based on the responder's previous responses to an item. Moreover, even though the respondents are responding to a different set of items from the same item bank, their results on the same latent trait can still be compared. The score for a CAT is automatically calculated, so results can be obtained in real time (98). Therefore, an item bank using a CAT can improve the relevance of the items to the responders, make the testing less burdensome for the responders, and still collect more information and at a greater precision (88, 99-102).

3 RATIONALE

Each patient's journey is unique, which is why care must be person-centred to be successful. The importance attached to PCC has increased worldwide, reflecting an increasing recognition of the patient's perspective and of PCC as an essential aspect of high-quality healthcare. In PCC, the patients' and caregivers' experiences, knowledge and resources are acknowledged and utilized at all levels in the healthcare system. Because PCC is a complex intervention consisting of many different parts, it is particularly necessary to invest in comprehensive quality measures using modern test theory to measure patients' experiences of PCC. By understanding the latent variable of PCC based on patients' experience and from their perspective, and then by identifying and developing items accordingly, it will be possible to create an item bank for measuring whether care is perceived as person-centred from the patients' perspective. The utility of such an item bank holds great promise, as the item bank will be able to provide the necessary data for feedback systems to visualize whether and how healthcare is delivering care based on the principles of PCC. The item bank will provide a mechanism that use patients' voices to guide, stimulate and monitor quality-improvement efforts.

4 AIM

4.1.1 OVERALL AIM

The overall aim of this thesis was to explore care from the perspective of people living with long-term conditions, and to develop and psychometrically test Swedish and English items to measure patient experience of person-centred care.

4.1.2 SPECIFIC AIMS

This thesis comprises four studies, the specific aims of each study are provided below.

Study I

To translate, culturally adapt and evaluate candidate items to measure person-centred care from the patient's perspective.

Study II

To explore what characterizes communication and collaboration within a patient and professional partnership in outpatient care settings garnered from the experiences of persons living with long-term conditions.

Study III

To investigate the psychometric and scaling properties of 57 candidate items to measure patient's experience of person-centred care against the Rasch measurement model in a Swedish setting.

Study IV

To analyse the psychometric properties of 57 candidate items probing patients' experience of person-centred care in an English setting.

5 METHODS

This chapter presents the methods that were used in the four studies. There are several guidelines and checklists for developing a new valid patient-reported instrument, or item bank (84, 103-106). Several steps, and a multi-methods design combining qualitative and quantitative methodologies are used, together with different expert perspectives from patients, caregivers, healthcare professionals and researchers. The steps include: a conceptual model or description of the variable or phenomena to be measured, an item generation process including a review of the extant measures and the development of new items; a qualitative item review, evidence of reliability, validity (content validity, construct validity, responsiveness) and psychometric and hypotheses testing, (84, 103, 107); determining how scores will be visualized and interpreted; translating the instrument if necessary; and making sure that the instrument is a reasonable length and level of difficulty to avoid overly burdening the responders and researchers (105).

5.1 DESIGN

Table 2 provides an overview of the design, data collection, and data analysis for the four studies included in this thesis. Study I used a mixed methods design for a qualitative item review to evaluate the content and face validity of candidate items with stakeholders. A mixed-methods design uses a combination of methods – usually a combination of qualitative and quantitative data that are collected, analysed, and interpreted together (108). Study II was a qualitative study with interviews designed to generate additional knowledge of patients’ experiences of communication and collaboration within a patient and professional partnership. In Study III and Study IV, a cross sectional design was used, and quantitative data were collected using study-specific questionnaires in Swedish (Study III) or English (Study IV).

Table 2. *Overview of the design, data collection and data analysis in the thesis*

STUDIES	STUDY I	STUDY II	STUDY III	STUDY IV
DESIGN	Mixed methods	Qualitative	Quantitative, Cross sectional	Quantitative, Cross sectional
DATA COLLECTION	Web-based questionnaire, focus group, interviews	Semi-structured interviews	Web-based questionnaire	Web-based questionnaire
COUNTRY	Sweden	Sweden	Sweden	UK
PARTICIPANTS	n = 84	n = 15	n = 140	n = 501
DATA ANALYSIS	Quantitative and qualitative item analysis	Inductive thematic analysis	Descriptive and explorative, Rasch analysis	Descriptive and explorative, Rasch analysis

5.2 PARTICIPANTS AND DATA COLLECTION

The population of interest in all four studies comprised adults diagnosed with one or more long-term conditions that were being treated or followed-up with in an outpatient context. Studies I, II, and III took place in Sweden, while Study IV took place in the UK.

5.2.1 STUDY I – QUALITATIVE ITEM ANALYSIS OF CANDIDATE ITEMS

In Study I, evidence for content validation of the candidate items was gathered by building on the GPCC and P3C conceptual models of PCC and on prior instruments designed to measure PCC.

Selection of item candidates

In a previous comprehensive review, Lloyd et al identified 328 patient-reported measures to evaluate PCC (78). PREM probing PCC, P3C and person-centredness ($n = 63$) with either an overarching or dimensional approach were selected for a shortlist, with all items ($n = 855$) mapped to the core dimensions of P3C (8, 9). From this shortlist, 155 candidate items that best probed the conceptual framework of PCC and P3C were selected for use in Study I (10, 11).

Translation

The candidate items ($n = 155$) and four response options were translated from English to Swedish following the steps provided by Wild et al. (109). Independent professional interpreters were involved and were instructed to use easily comprehensible wording that would be accessible to people with a range of literacy and English and Swedish speaking levels (84).

Validation rounds

To obtain evidence backing the content and face validation, and to culturally and linguistically adapt the Swedish candidate items, various stakeholders and experts in PCC were invited in two validation rounds: persons with experience as patients with various long-term conditions (validation rounds 1 and 2), caregivers (validation rounds 1 and 2); and healthcare professionals and researchers with expertise in PCC and/or questionnaire design (validation round 2).

A study-specific web questionnaire with the translated Swedish candidate items was constructed using Sunet Survey (www.sunet.se). Participants could respond to the questionnaire via cell phone or computer. The items were not sorted in any specific order or domain, and the participants were asked to evaluate each item separately. In the first validation round, the participants rated the comprehensibility, relevance, and importance of each item to PCC (Very important, Important to some degree, or Not important). In the second validation round, a revised questionnaire was constructed with the remaining and rephrased items. In both questionnaires, the responders could comment in free text on each item or come up with new items or suggestions to improve the content. They could also provide comments or suggestions on their overall impression of the content, and on whether something was missing to describe patient experiences of PCC.

In validation round 1, data was collected via the study-specific web questionnaire and a subsequent focus group discussion. Participants were recruited via email after an information meeting at the GPCC Person Council and the patient council of a Regional Cancer Centre. More information on the study and how to participate in the survey was reached via a link in the email. Participants were invited to respond to the study specific questionnaire and to participate in a focus group.

The study questionnaire was also used to introduce the items to the focus group participants prior the focus group discussion. Focus groups are often used in qualitative research to examine persons' experiences. This method can prompt the group members to express their opinions, respond to what other members have to say, and introduce new topics (110). At the start of the focus group, the participants were informed about the purpose of the study (both orally and in writing) and were asked to provide written consent to participate in the study. LR was the moderator, and a research assistant in the project took notes during the discussion. The participants in the focus group discussed the web questionnaire's ratings and comments, appropriate use of language, wording, and the relevance of the items to patient experience of PCC, item by item. They were also asked whether something important to PCC was not covered by the items. Finally, the moderator gave a summary of the discussion to check that the participants' opinions had been accurately noted.

In validation round 2, data was collected via a revised web questionnaire and, in order to further understand the participants' opinions and understanding of the items, 10 participants who had responded to the web questionnaire were asked to participate in either a face-to-face or online cognitive interview with LR (111, 112). For validation round 2, patients and caregivers were recruited

as in the first validation round. Healthcare professionals and researchers in PCC and questionnaire design were recruited via mail sent to researchers and healthcare professionals at the Institute of Health and Caring Sciences at the Gothenburg University and at a hospital. The participants in the cognitive interviews were asked to ‘think aloud’ while reading the instructions and responding to the study questionnaire. LR took notes during the interviews.

Participants

The participants were stakeholders ($n = 84$), who were involved in the two validation rounds ($n = 84$), 20 male and 64 females. One person was below 30 years old; 35 persons were 30 – 59 years old, and 43 persons were 60 years or older. Of the 84 stakeholders, 62 had experience as patients, 43 as caregivers, 36 as healthcare professionals and 27 as researchers in PCC or questionnaire design. The participants had experience with various long-term conditions such as cancer, rheumatic disease, spinal cord injury, stroke, diabetes, asthma, psychiatric disorder, chronic lung disease, dementia, and Parkinson’s disease.

5.2.1 STUDY II – INTERVIEW STUDY

Study II was performed according to a qualitative design; individual interviews using a semi-structured interview guide were carried out to collect the data. Due to the ongoing Covid-19 pandemic, all interviews were conducted via a videoconferencing platform and all the participants attended from their home. The interviews were audio-recorded to enable verbatim transcription.

Inclusion criteria were adult persons with experience as a patient with one or more long-term conditions and an ongoing collaboration with at least one healthcare setting.

Participants were invited via email to the Person Council for patients and caregivers at GPCC and to six different Regional Cancer Centre Patient Council covering all six regions of Sweden. Persons who voluntarily responded to the invitation letter were contacted to schedule time for the interview. All participants were informed, both verbally and by being sent written information, about the study and its purpose.

Participants

Fifteen patients, eight woman and seven men, responded to the invitation and participated in the study. The participants ages ranged between 30 and 78 years (mean = 59 years). All but one person with diabetes had a diagnosis of one or

more cancers or other diseases. Other diseases were multiple sclerosis, and joint and connective tissue disease. The participants had lived with their long-term condition between 7 months and 30 years. Two of the participants also had experience working as healthcare professionals and some of them had experience as a caregiver.

5.2.2 STUDY III – SWEDISH CANDIDATE ITEMS

In Study III, the 57 Swedish candidate items from Study I were tested psychometrically.

The eligibility criteria were as follows: adult persons, diagnosed with cancer and scheduled to attend an oncology outpatient clinic, at a Swedish university hospital.

A study-specific questionnaire was constructed using a web survey tool (<https://www.indikator.org>). The web questionnaire consisted of a total of 82 questions: socio-demographic and disease characteristics of respondents, the 57 candidate items and one section for free comments of their experiences of care and of the design of the questionnaire. All items were worded as positive statements except three which were negatively worded (113). If the item was not applicable, the respondent could skip answering the item and go to the next. The respondents were informed that the study specific items were not sorted in any specific order, and that they should respond to all items individually. The recall period was described as right now or within the last months.

Participants were invited via a cover letter handed out in connection to the person visited the clinic for treatment or routine monitoring of cancer. The cover letter explained the purpose of the study and contained information how to reach the survey. The data collection occurred at three time points during the Covid-19 pandemic: May and November to December in 2020, and March to April in 2021.

Participants

There were 140 patients with various cancer diseases that responded to the study specific questionnaire. There were 105 female (75%) and 35 male (25%) respondents. The participants' ages ranged between 21 and 82 years (mean = 62 years), and 124 (87%) were born in Sweden. Of the 140 participants, 123 (88%) stated that they had access to a contact nurse and 52 (37%) had a written care plan.

5.2.3 STUDY IV – ENGLISH CANDIDATE ITEMS

In Study IV, the English version of the candidate items was tested. Data was collected via a web questionnaire.

Inclusion criteria were adult persons diagnosed with one or multiple long-term or chronic condition and living in the UK.

For this study, the questionnaire was constructed at an online survey platform (Qualtrics XM) and consisted of a total of 86 items; Information and consent, diagnostic and socio-demographics, the 57 PCC items, a brief scale for General Self-Efficacy (114) and a section for free comments. The study specific candidate items ($n=57$) were presented as statements and the response options were scored on the 4-point Likert scale as in Study III (I do not agree, I agree to some extent, I agree to a large extent, I totally agree). Only one response option per candidate item could be chosen and ‘forced responses’ was used for the study specific items. In this study, the order of the candidate items was randomized for the respondent, who was informed that the study specific items were not sorted in any specific order, and that each item should be evaluated individually. The recall period was described as right now or within the last months.

Participants were recruited all over the United Kingdom via the Oxford Prolific Web Panel (115). The data was collected in April – May 2022 and was closed when more than 500 people had responded.

Participants

Out of 540 people, persons who did not consent to the study ($n = 19$) or did not complete the survey ($n = 20$) were excluded, which meant that a total of 501 people were included in the study. There was an even distribution with 248 (49.5%) men and 249 (49.7%) women. The mean age was 49.2, and a range from 20 to 89 years old. Most of the participants had one ($n = 211$) or two ($n = 157$) long-term diseases and 133 had three or more long-term conditions. In this population 996 various longer or chronic condition were reported; diabetes ($n = 182$), mental or psychological disorder ($n = 120$), chronic pain ($n = 131$), allergy or asthma ($n = 98$), autoimmune or rheumatic diseases ($n = 84$), cardiovascular disease ($n = 77$), joint, connective tissue or muscle disorder ($n = 66$), neurological disorder ($n = 53$), kidney, gallbladder or liver disease ($n = 39$), chronic lung disease ($n = 22$), cancer ($n = 16$), congenital disease ($n = 13$) or other ($n = 95$). The number of healthcare contacts per year varied between 0–1 ($n=120$), 2–4 ($n = 228$) and five or more times per year ($n = 153$).

5.3 DATA ANALYSIS

5.3.1 STUDY I – MIXED METHODS

In Study I, both quantitative data and qualitative data were analysed.

Quantitative data – that is, the ratings for the candidate items from the web questionnaire – were summed up and mean and median for each item was calculated to give an overview how all participants together rated the individual items.

The qualitative data - free text in the questionnaire, focus group discussion, and cognitive interviews - such as comments and suggestions for each item was sorted per item (relevance to PCC and importance to experience or perceive person-centredness), and comments of the overall item set or if something was missing for patient experiences of PCC.

Data was analysed to prepare the focus group discussion and for each validation round when the research team discussed the findings. When excluding or rephrasing the items, the research team also considered that the items were to be used in a future item bank with the response option chosen. The items should also be relevant for people with long-term conditions who is treated in outpatient settings and could have multiple healthcare providers.

5.3.2 STUDY II – THEMATIC ANALYSIS

In Study II, the interviews were analysed by reflexive thematic analysis and with an inductive approach. Reflexive thematic analysis is a qualitative method to identify, analyse, organize, describe, and report themes found within qualitative data. An inductive approach means that there were no predefined categories or themes. In this study, the interviews were transcribed in full and analysed according to Braun and Clarke's step-by-step guide to recognize and sort data (116, 117). The first step was to get an overview of the data by reading the transcribed interviews while taking notes. Thereafter, phrases relevant to the study aim, were identified and coded according to their content using NVivo 12 Pro software (118). The third step was to sort the codes into themes and sub-themes and in the fourth step themes were revised. In the fifth step, the themes are further refined and described with a few sentences. The sixth step is to summarize and describe the data for each theme. During the whole

analysis process, all the researchers involved reflected on their pre-understanding of own experiences and presuppositions when analysing the data (119). To strengthen the trustworthiness of the analysis, codes, sub-themes and themes were discussed in the research team until consensus and quotations to strengthen the theme content and credibility was selected (117).

5.3.3 STUDY III AND IV – RASCH ANALYSIS

The psychometric properties, and the construct validity, of the Swedish version of the candidate items (Study III) and the English version of the candidate items (Study IV), retrieved from study I ($n = 57$) were tested against the RMM (87). For a future item bank the aim was to identify items that fit to the RMM. Swedish and English versions of the candidate items are shown in Appendix 1.

The GPCC (58, 60) and the P3C model (44) informed the conceptual model and framework of PCC and was used for the interpretation of the Rasch analysis (87). The analysis in Study IV was also guided by the results in Study III.

For a latent trait representing person-centredness, items on the lower-levels (negative logits) should manifest what does not require a large degree of PCC to be achieved, and at higher-levels (positive logits), the items should manifest a higher degree. Therefore, ahead of the analysis, we predicted that the items would follow the processes in the GPCCs model of PCC, to build and maintain a partnership; starting with the patient's narrative and trust building, to a collaboration with mutual understanding and a partnership where care is co-created and tailored to the person (43).

SPSS Statistics for Windows, version 28 (120) was used for descriptive statistics for the population and items. The software RUMM2030 (121) and the unrestricted partial-credit model for polytomous response options was used for the Rasch analysis (88, 122). The Rasch analyses focused on reliability, overall, item and person fit, testing for item bias (differential item functioning), evaluation of the response options (threshold ordering), targeting of the scale, hierarchical ordering of the items, local independency and unidimensionality (85, 99, 123).

Person separation index (PSI) is the estimate of the internal consistency reliability in RUMM2030. PSI is interpreted in the same way as Cronbach alpha but is calculated on linear logit data (linear person estimate)(124).

Fit of items and persons was evaluated according to fit residuals (± 2.5), chi-square probability (non-significant) and by observing the item characteristic curve for each item. Fit residuals are the discrepancies of the observed data and what was expected by the probabilistic RMM (85). Items which do not fit to the RMM, may indicate multidimensionality, construct-irrelevant variance or that the responders interpret the item differently than intended. Those items that do not work according to RMM, should be removed or rephrased (125).

All 57 items had the same four response options (I do not agree, I agree to some extent, I agree to a large extent, I totally agree) which gives three thresholds per item. Thresholds are the transition point between the response options. If the response options do not work as intended in a ranked order, they are considered disordered. Disordered thresholds can arise due to uncertainty in response options or because respondents have difficulty distinguishing between different choices (85).

There are also analyses to check for invariance or differential item functioning (DIF), by looking if the items responses are influence by external factors such as gender or age (126). DIF was checked for age, gender (Study III and Study IV), education, living situation, number of long-term conditions and number of healthcare contacts per year (Study IV).

Smith's test (included in RUMM2030) was used to examine to what extent the data was unidimensional or not. This includes a series of t-tests of two set of items, identified by Principal Component Analysis to potentially represent subdimensions. The proportion of significant t-tests of person locations should not differ between the two set of items more than 5%, otherwise unidimensionality is violated (127, 128).

Local dependency for items was visualized in the Residual correlation matrix for correlations above 0.2 + the mean value for the residuals of the correlations. Items that cluster violate local independence and can be accommodated for by bringing them together in testlets, also called superitems (129, 130).

Targeting of the items for the population, was examined graphically in the item-person map, and by comparing the mean values. Preferably, mean item location and mean person location are around zero logits, and the items cover all persons on the common scale without any holes where items are missing. The hierarchical ordering of the items, from low to higher levels of perceived person-centeredness, was discussed against the conceptual models of PCC (82).

5.4 ETHICAL CONSIDERATIONS

All included studies were conducted in accordance with the Declaration of Helsinki Ethical Principles for research involving human (131). Each participant (individual or group interview; Study I and Study II) were informed both verbally and in a written form.

Written informed consent was obtained prior to participating in the study, separately or by answering the first question in the study questionnaire. Where questionnaires were used, (Study I, Study III, and Study IV) participants received a written invitation and information including description and purpose of the study, contact details to persons responsible, confidentiality and that participation in the study was voluntary. A question was added in the study questionnaires where the respondents consented or not that their results could be used in the study. The interview situation (Study I and Study II) could be sensitive for the participants. They were informed that the data was handled confidently and no data that could be identified to a specific participant would be used in the manuscript. Participants in all four studies, were informed that they could withdraw from the study at any time without any explanation, and that all data will be processed and presented anonymously and stored on computers in accordance with the General Data Protection Regulation (GDPR) (132).

In Study IV, data was collected from the UK, survey data was downloaded and stored at the University of Plymouth (and deleted from Qualtrics survey platform).

5.4.1 ETHICAL APPROVAL

To do research involving people and handle sensitive personal data, ethical approval was gained for all the included studies in this thesis.

Study I, Study II, and Study III

Ethical approval was provided by the Swedish Ethical Review Authority (Dnr 2019-03996).

Study IV

Ethical approval was approved by the Faculty Research Ethics and Integrity Committee at Plymouth university in the United Kingdom (Project ID 2965).

The Swedish Ethical Review Authority approved the data to be handled and analysed in Sweden (Dnr 2022-05611-01).

6 RESULTS

The results from the four included studies are presented separately.

6.1 STUDY I

In Study I, candidate items ($n = 155$) from the initial pool of 855 items covering the core domains and sub-domains of the GPCC and P3C models of PCC were translated into Swedish and subjected to a qualitative item review.

After the translation process, two validation rounds with questionnaires, a focus group interview, and 10 interviews, 57 candidate items that had been rewritten as statements remained. There were more items covering processes than there were outcomes of PCC. We found that the language used in many questionnaires was outdated and even inappropriate for the core principles of PCC. Moreover, there were few items acknowledging the patient's knowledge, capabilities, or resources. The items were therefore reworded to position patients as actively partnering in their care instead of as a passive recipient, and to cover interactional communication in the co-production of care. In total, 104 items were excluded (due to low ratings, lack of comprehensibility, redundancy, duplication, or over-specificity), 32 items were rephrased (to clarify or to better reflect PCC and the co-creation of care), and an additional six items were included (covering access to care, patient capabilities, mental well-being, and identifying goals). The final list of 57 PCC items covered the ethical approach of PCC, the three key routines in the GPCC model, and the five core domains in the P3C model of PCC. The 57 items are presented in appendix 1.

6.2 STUDY II

In Study II, the participants described both positive and negative experiences of care and in this way described what was person-centred or not.

IP4: 'what would care look like if it wasn't person-centered? Oh, factory with bandages! '

IP10: ' I have a very clear picture but it's difficult to describe it. For me it's about the patient participating, and that it revolves around the patient, and not that one is an object that is not involved. And person-centred for me is also about the whole picture. That you do not break up the disease but look more at what my problems are. Because the body is a whole. '

The results from the interviews were categorized into five themes: Adapting and self-managing in daily life, Handling and carrying information, Building trust and continuity, Acting in a flexible and transparent dialogue, and Sharing the way forward.

Adapting and self-managing in daily life

The participants described their own strategies and actions as a patient or as an individual living with a long-term condition. Personal resources referred to personal qualities, such as being used to physical training, solving problems, being determined, being motivated, and taking a proactive approach. Personal support referred to a mixture of informal and formal care, depending on the patient's network. Important informal resources referred to family, friends, peer patients, and an understanding boss and coworkers at the workplace.

Handling and carrying information

Gaining knowledge about and understanding the disease, treatment options, and self-management were essential for patient well-being and for the patient to be able to participate in decisions or to ask for interventions. In encounters with healthcare professionals, there were situations in which the participants had to balance what they said or needed to coordinate and act as an information carrier between healthcare professionals or different healthcare settings. Most of the participants used their own documentation for a variety of reasons, such as to learn, remember, prepare for meetings, track symptoms, or to keep a diary to mentally process their experiences of having a disease. Shared documentation – such as when the patients had access to their medical records and care plan – enabled transparency and trust.

IP11. 'When I came (to the hospital) in the year 2000 it was awful, I felt that I were treated as a package, you knew nothing, one wasn't an idiot, but you won't understand this, we will do this, like this, you can sit out there (in the waiting room) so you get your chemotherapy and then you can go home'

Building trust and continuity

Healthcare professionals with a person-centred approach enabled communication and trust and were necessary for the patient to be seen, listened to, believed in, and treated respectfully both as a person and as a patient. It was also important with easy access and availability to healthcare professionals, who had knowledge of the patient's condition, beyond scheduled encounters. Personal continuity was emphasized; it facilitated communication and allowed

patients to get help more easily when necessary. The participants appreciated having different ways to communicate with healthcare professionals, such as email, digital platforms, postal letters, or telephone.

IP5: 'And I also think about this with easy access, and availability, that the more I am heard as a patient, the easier it is for myself to cope with it, //, that I feel that they care about me, that I am important.'

Acting in a flexible and transparent dialogue

Collaboration was described as a flexible dialogue with mutual trust, shared learning, and shared problem solving. Prerequisites for collaboration to occur between a patient and healthcare professionals were mutual respect, transparency, accessibility, and continuity. Furthermore, that the healthcare professionals adapted to the patients' preferences, resources, and prior knowledge, acted when needed, gave hope, encouraged, and acknowledged the patient and those important to her or him.

Sharing the way forward

The participants did not always share their personal goals with healthcare professionals. They considered care planning and sharing the way forward – in a dialogue over time – to be part of the collaboration and important in their process of coping with the disease such as what to expect from treatment or rehabilitation.

6.3 STUDY III

In Study III, the 57 Swedish candidate items obtained from Study I were given by healthcare professionals to adults diagnosed with cancer. The responses from 140 people were tested against Rasch measurement theory.

All 57 items analysed together did not fit the criteria according to the RMM, due to a significant summary chi-square value, some misfitting items, and signs of local dependency and multidimensionality. There were few missing responses.

In a first attempt to resolve the fit to the RMT, each item was analysed individually if the residuals were within the expected range (-2.5 to 2.5), if the response options worked as intended (I do not agree, I agree to some extent, I agree to a large extent, I totally agree), for DIF (gender and age), and if local independence was violated (above 0.2 + the mean value for the residuals of the

correlations in the residual correlation matrix). Seven items (40, 41, 42, 52, 53, 55, and 56) 'Important information about what matters to me is missing in my care plan' (item 40), 'I receive contradictory information or advice from my healthcare staff' (item 41), 'I have to repeat myself because healthcare staff do not share information with each other' (item 42), 'I developed my care plan together with healthcare staff' (item 52), 'My personal situation is taken into consideration in my care plan' (item 53), 'Healthcare staff support me to identify activities to improve my health and wellbeing' (item 55) and 'I work with healthcare staff to identify goals to improve my health and wellbeing' (item 56), were identified as psychometrically misfitting and were removed. Those items probed care plans, information continuity and goals.

A new analysis with the remaining 50 items still showed a significant summary chi-square value, as well as signs of multidimensionality and local dependency. In this analysis, three items had fit residuals above 2.5; 'My relatives are involved as much as I want' (item 9), 'I am aware of the next step in my care or treatment' (item 14), and 'I am asked questions about my own goals (or what I want to achieve) to improve or maintain my health' (item 45).

A residual correlation matrix was used to study locally dependent items. Clusters of items were found to be grouped together in a manner similar to the core domains in the P3C model of PCC. To address this issue and to solve the local dependency and multidimensionality, a new analysis with the 50 remaining items divided into testlets (superitems) according to the dimensions of the P3C model (with Information and Communication set as two separate dimensions, and then using the dimensions of Decision-making, My goals, Care planning, and Transitions) was tested. This testlet analysis with 50 items showed fit to the RMM. There were no items with local dependency, no high residuals for the items, no DIF or disordered thresholds, and unidimensionality.

The targeting of the items to the people responding was skewed towards a positive experience of PCC. There were few items covering very high and very low levels of PCC experience. The hierarchical ordering of the items went from items probing rapport and communication (e.g., being treated with respect, listened to, and treated kindly) to items probing shared decision-making, planning and goals.

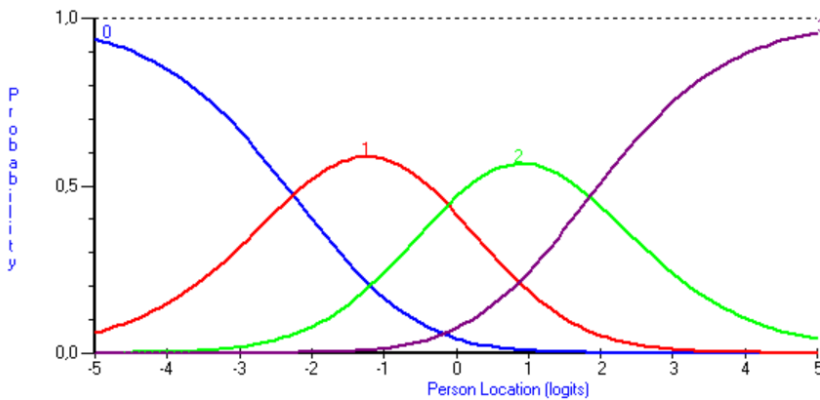
6.4 STUDY IV

In Study IV, the 57 English candidate items were tested in the UK. Participants were invited via the web panel Prolific. A total of 501 persons with one or

more long-term conditions responded to the study survey and consented to participate in the study.

An initial Rasch analysis with all 57 items showed several indicators of misfit, such as items with high residuals, local dependency, and multidimensionality. Three items had DIF for age. There were no disordered thresholds, see example of ordered thresholds in figure 2.

Figure 2. Category probability curve for item 5.



Three analyses were carried out to remove the misfitting items in a stepwise process – from 53 items in a second round to 43 items in a third round and 42 items in a fourth round; however, this did not solve the local dependency and multidimensionality.

A final testlets analysis, informed by Study III, with the items ($n = 42$) grouped into testlets according to the core dimensions in the P3C model of PCC, showed fit to the RMM, with the fundamentals of measurement achieved. This final 42-item model exhibited fit to RMM with no disordered thresholds, no DIF, and no items with extreme fit residuals.

7 DISCUSSION

7.1 DISCUSSION OF MAIN FINDINGS

This thesis explored patient experiences of PCC, what factors patients perceive care as person-centred, and how these can be measured as a common latent trait.

Person-centred care for people with long-term conditions

In Study II, the participants described their experiences in their patient role, and how they self-managed their long-term condition in daily life and their communication and collaboration with different healthcare settings and professionals. The participants were striving for the good life, and an important part were how they adapted and was able to self-manage their long-term condition and balance daily life (Study II). Krahn et al. capture this in their definition of health: 'Health is the dynamic balance of physical, mental, social, and existential well-being in adapting to conditions of life and the environment' (7, p.2) This definition of health show how health is dynamic and how adaption and balance can determine health and well-being for the person (7). Therefore, PCC for people with long-term conditions, aims to enable, and empower the patient. Key factors in this process include sharing information about the condition and promoting the patient's sense of self-efficacy, ability to make changes in her or his situation, and resultant increased feeling of control (133).

Availability and continuity throughout the entire care continuum (Study II), were considered to be important factors in establishing a partnership between a person with a long-term condition and the healthcare professionals (11). Here, continuity consists of three dimensions; personal continuity, information continuity and organisational continuity (134). Among these, personal continuity (i.e. of healthcare professionals) was of high value and appeared to result in informational and organizational continuity for the person's care. For example, personal continuity of staff enabled the patient to receive immediate understanding and help; it also allowed patients to meet healthcare professionals with the right competence, without having to start a relationship from the beginning (Study II).

Depending on the patients' network, family and friends can act as natural supports and resources (135, 136), and may be used interchangeably with healthcare providers to support the person, such as in coordinating care for the

patient, helping to provide a specific diet, or supporting the patient's mental well-being (Study II). Therefore, for a co-created, person-centred outpatient care, it is necessary to acknowledge and collaborate with the patient's team of other healthcare providers (inside and outside our own workplace) and informal caregivers.

Phrasing of items to reflect a person-centred approach

Phrasing of items in an item bank measuring patient experience of PCC should reflect a person-centred approach. In this thesis, there were many considerations in developing items probing patient experiences of PCC or person-centredness.

A main finding was that many of the questions in the original items used to probe person-centredness used outdated language that did not reflect the ethics and core principles of PCC (60). Many items focused on the healthcare professional's performance, approach, and behaviour during the care process instead of on collaboration or teamwork between the patient and the healthcare professional, thereby positioning the patient as a passive recipient (15, 137). In the item selection (Study I), few items reflected the patient as an active partner (15, 138), which was considered in the work with rephrasing items to a more person-centred approach. One explanation to this can be the criticism of patient self-reported experiences to be too subjective for being useful. Furthermore, PREM measuring satisfaction often have ceiling effect that make it difficult to detect changes. Instead some argue to ask patients' to report of what happened, meaning that this is more objectively and easier for the patient, and also more actionable (74). But there are also arguments for the patients' subjective experiences, as an important complement to more objectively clinical or organizational outcomes (139).

Moreover, many of the original items (Study I) mainly reported what happened in a particular meeting with a certain healthcare provider or in a certain healthcare setting. Although such reporting is important, a partnership between a person with a long-term condition and a healthcare professional is also built on the person's narrative and the building of trust over time (Study II). In addition, the items did not reflect the fact that people may have more than one healthcare provider and may be part of several ongoing partnerships. This finding suggests that evaluating PCC for people with long-term conditions should occur over time, across settings, and in the context of both formal and informal care (Study II). The patient experiences do not have any distinct boundaries, experiences reaches outside the clinical settings, in between encounters and across the continuum of care (76). If the focus is limited to

episodic or one-off interactions, there is a risk that this can lead healthcare professionals to only consider their own performance or setting, instead of building a partnership based on the patient's healthcare context and needs (137, 140).

Content: What should be measured?

The content covered by the selected candidate items included areas important to patient experiences of PCC, as described by the GPCC and P3C models of PCC. In the selection of items and in the qualitative item review (Study I), most of the candidate items presented in Study I related to the interaction between the patient and healthcare professionals and concerned a person-centred approach, rapport, and communication. This was confirmed in the validation rounds, where most of the participants (Study I) associated items that probed being respected, being listened to, feeling cared for as a person, and feeling confident in the care situation with PCC.

The 57 items contain both processes and outcomes of PCC. Processes were for example discussions probing shared decisions or shared care planning. Desired outcomes of PCC were feeling respected, being listened to, feeling cared for as a person, being involved, being invited and/or active in shared decision-making, having knowledge, and possessing self-management.

Patient empowerment is one of the sub-domains in the P3C model of PCC and has been highlighted as an important outcome of a patient-professional partnership. For patients, empowerment was important in taking control of their health and coping with the disease (Study II) – findings that corroborate earlier reports of person-centredness in the model by Scholl et al. (48). In this study items probing empowerment were phrased as the patient being encouraged (empowered) by the healthcare professionals and by items probing feelings of being able to self-manage their long-term condition.

In Study III and Study IV, the candidate items were psychometrically tested against the RMM. The Rasch analysis revealed items that did not fit the model, including negatively worded statements that used the term 'care plan' and items that probed information continuity. In Study IV, an item regarding the involvement of relatives did not work psychometrically. A possible explanation as to why the item using the term 'care plan' did not fit could be that not all the respondents had a written care plan or understood what a care plan was. In the development of the GPCCQ, Fridberg et al. had the same experience with items regarding care plans (94). For the item bank, it might be more relevant to place the question about having a written care plan in the

background section or to remove it entirely in favour of an item probing care planning as a shared process rather than as a document. It was also felt that items regarding information continuity and relatives could be rephrased for better clarity in future studies.

Measuring PCC as a latent trait

In both Study III and Study IV, a testlet solution according to the domains in the P3C model of PCC was used to solve the problem with local dependency within the item set. The results support the measurement of patient experience of PCC as an overarching construct, which is an important finding to use in any further development of the item bank. The measurement of patient experiences of PCC as an overarching construct was supported by qualitative findings in Study I and has been supported in the literature by Fridberg et al. (94).

The results provide a hierarchical structure to describe patient experiences of PCC. The hierarchical ordering of items in Study III and Study IV was similar and started with rapport and communication to information sharing, shared decisions, care planning and goals. This order of the items confirmed that a person-centred approach and communication skills are prerequisite for person-centred care and building a partnership. These items were considered easy (lower levels), meaning that many of the participants had experienced this. On the contrary, items regarding a more developed partnership with shared decisions, care planning or goals were items less experienced. The hierarchical order of items followed the process of initiating the partnership, working within the partnership, and documenting the partnership, as described in the GPCC model of PCC (59, 60). Also, in comparison with previous studies using Rasch analysis for patient-reported experiences of person-centredness and participation, the hierarchical ordering of the items was similar (94, 95, 141, 142).

7.2 METHODOLOGICAL CONSIDERATIONS

Study I, Study III and Study IV were part of developing an item bank to measure patient experience of PCC as an overarching, holistic latent trait and as described in the conceptual models and frameworks of GPCC and P3C.

Patient participation

When developing a new patient-reported measure, the population of interest – in this case, people with experience as a patient – should be involved in the whole process (84, 143, 144). In this thesis project, patients were involved in different ways, as participants in focus group discussions (Study I), as interviewees in individual interviews (Study I and Study II), and as respondents to a study questionnaire (Study I, Study III, and Study IV). In Study I, patients' contributions were invaluable for evaluating the relevance, importance, and optimal wording of the items.

The Conceptual models of PCC

A conceptual model that comprises the understanding of and a description of the latent variable is crucial in developing a valid and useful patient-reported measure (82). Even though there is a lack of a universally agreed-on definition of PCC, a strength in this project was its use of two well-described models of PCC – the GPCC and P3C models – with the aim of building a common item bank. The inclusion of both models together provided a wider description of PCC from the patient perspective. Based on a sound philosophical background, the GPCC's conceptual model well describes the three clinical routines of working in partnership for PCC. The P3C model further covers domains in areas that have been described as important to the experiences of PCC of people with long-term conditions. This use of different models is sometimes valuable to describe complex interventions and processes on different levels (71, 145). For example, one model may be appropriate for understanding processes at the healthcare organizations' level while another model better describe the individual perspectives (146).

Even though many different models of PCC exist, the research does not well describe PCC as a latent trait with different levels. The existing models describe areas (i.e., content) and healthcare professionals' approaches, skills, or processes that are important to PCC. The research also contains reasoning on what PCC is and what it is not. To develop an item bank, understanding the latent trait of PCC from the patient perspective should allow a representation of the prediction of item difficulty, such as which items represent easy levels

of PCC, and which represent more advanced levels of PCC. These predictions or hypotheses should then be used to interpret the results from the Rasch analysis (82). Therefore, in this project the hypothesis was that the hierarchical item ordering would follow the process of building a patient-healthcare professional partnership; from initiating a partnership to the co-creation of care and shared care planning PCC (59, 60)

Methodological considerations when measuring PCC for people with long-term conditions

To adapt to the outpatient context for people with one or more long-term conditions, we considered previous studies describing care for people with long-term conditions (67, 147, 148) and findings from Study I and Study II. People with long-term conditions may have complex needs and multiple healthcare services and healthcare providers; however, if such services and providers are integrated, they can function as a unit and provide PCC to the person – emphasizing the need for coordination of care for this population.

We also considered that the needs of people with long-term conditions vary over time, from more intense care being needed at the time of diagnosis or during a recurrence to less intense care being required once the disease stabilizes. In fact, people with long-term conditions often spend relatively little time interacting with healthcare professionals (e.g., a few hours in a year). Most of the time, these people manage their own conditions and care, either alone or with the help of family or other caregivers (12, 23, 149). Therefore, the items did not focus on any encounter, setting, or healthcare professional, but instead captured the person's ongoing and various interactions with the healthcare system and informal caregivers. One of the items 'I can get help when I need' is not addressed to either a healthcare professional or an informal caregiver. Given the diversity of people with long-term conditions, the items needed to work for as many or as few interactions a patient might have with healthcare professionals over the period of a year. They also needed to cover different ways of communicating or interacting with healthcare professionals.

To interpret the results in a future item bank (real-time data), it was considered important to focus on the ongoing patient-healthcare professional collaboration. To account for all this, the respondents' recall period was set to 'right now or within the last three months' (Study III) and to 'right now or within the last few months' (Study IV).

Methodological considerations to develop an item bank

To develop a patient-reported measure, a combination of qualitative and quantitative design is needed (105, 150). Study I used a mixed methods design to evaluate the content and face validity of candidate items to measure PCC from the patient experiences. Qualitative data (Study I) were collected from free text in the questionnaires, a focus group discussion, and individual interviews, while quantitative data was collected from the questionnaire ratings of the candidate items. The questionnaire enabled the collection of both quantitative data (ratings) and qualitative data (free text for every item), and we were able to reach out to many stakeholders. The results from the questionnaires were also used to prepare a focus group and to interpret the quantitative findings in Study I, Study III, and Study IV (151).

The use of existing PREM to measure patient experiences of PCC was valuable in drawing on previous research and the wording of items. Nevertheless, as found in Study I, the language of the original items did not reflect a shift to PCC and had to be rephrased in many cases. As the original items came from different PREMs, they all had different response options. To reduce the respondents' cognitive burden, the items were adapted or rephrased to one response option, with a 4-level Likert scale (I do not agree, I agree to some extent, I agree to a large extent, I totally agree). The candidate items were grouped in domains or categories to identify redundant items and to get an overview of how the items covered PCC according to the conceptual models of PCC. Other considerations in selecting or rephrasing items were that items should contain one aspect at a time, not be semantically redundant, too specific, or difficult to understand. This follows recommendations by De Walt (84).

For the future item bank, and the use of CAT, it was also important that the item could 'stand-alone', and not be presented in any order. Due to this, the participants in the focus group added information to the item regarding shared decisions, as they wanted to feel informed to be able to respond to such item ('I am informed to make decisions in relation to care or treatments'). The responders were asked to evaluate each item separately (Study I, Study III and Study IV). In Study IV, the items were also randomized to the participants.

The Rasch analysis enabled a thorough examination of individual items and how the items worked together as a scale (82). As PCC is complex, the Rasch analysis complemented the content and face validity (Study I) and helped to choose the very best items that also worked psychometrically (Study III and Study IV).

8 CONCLUSIONS

Person-centred care for people living with chronic conditions needs to be based on continuity, with a mutual dialogue over time with healthcare professionals using a person-centred approach to acknowledge and empower the patient. Furthermore, the care needs to be accessible and coordinated to the patient and include the patient's team of both formal and informal caregivers. Patient experiences of PCC are both processes of shared collaboration and outcomes such as feeling respected, listen to and empowered.

This thesis contributes to the field of PCC by providing a pool of items for measuring patients' experiences of PCC. After local dependency has been accommodated, the results support a unidimensional measurement of patients' experiences of PCC and thus add a hierarchical structure to theory and concept of PCC. The results offer insights into how to further refine and restructure a measure to evaluate PCC from the patient perspective. Additional studies are needed to test and validate a CAT for the administration of items in a future item bank. It is also necessary to explore the acceptability of the CAT measurement and to develop a feedback system among patients and healthcare professionals. Nevertheless, measurement itself cannot enhance PCC. Rather, how the results are communicated and visualized to patients and healthcare professionals will be the catalyst to guide improvements in PCC from the patient perspective.

TACK!

Jag vill tacka Institutionen för vårdvetenskap och hälsa på Göteborgs universitet för min tid som doktorand hos er. Här är ingenting omöjligt och jag har träffat så många inspirerande forskare och doktorander här.

Stort tack, Centrum för personcentrerad vård (GPCC), som möjliggjorde det här forskningsprojektet och finansierade min doktorandtjänst. Jag har känt mig stolt över att få vara en del av er forskning. Hos er är det högt i tak och alltid spännande diskussioner.

Innerligt TACK till mina fyra handledare, Anna Dencker, Sofie Jakobsson, Åsa Lundgren-Nilsson och Helen Lloyd, ni har varit fantastiska under dessa fyra år och fyra månader! Stort tack för ert förtroende och att ni valde just mig till det här MOSAIC-projektet. Och tack för era klokheter och stöd. Jag har lärt mig massor från er!

Jag vill ge ett särskilt tack till min huvudhandledare Anna, du har nog inte haft det lätt med mig! Tack för ditt tålamod, att du alltid varit tillgänglig och för all hjälp med struktur och korrektur.

Thank you, Helen, for being so encouraging, and James, Ben, and Ryan at Plymouth university, for the valuable collaboration we have in this project!

Tack Monica Pettersson, som varit min chef under de här åren, för alla trevliga samtal och stöd. Och ni i administrationen, Eva, Karin, Helen, Jeanette och Agnes.

Men vad vore den här tiden utan doktorandkollegor! Jag har ju inte varit i källaren så ofta, men har alltid känt mig välkommen. Särskilt tack till mina rumskamrater och Agneta och Helena, ni är fantastiska! Helena i Falun, tack för att du är du, och precis som jag nästan "Raschian". Och sedan har vi RCCs egna doktorandnätverk, Bodil nu är det din tur snart.

Jag vill också särskilt tacka de patienter som ställde upp i mina fyra delstudier och alla patienter och patientföreträdare jag mött genom åren. Ni har fått mig till en bättre sjuksköterska och forskare.

Stort tack till Eskil Degsell, som var den som hittade doktorandtjänsten och fick mig att söka den. Tack också för ditt stöd och alla samtal. Nu har vi massor att göra!

Varmt tack till Lena Sharp på Regionalt Cancercentrum Stockholm-Gotland, som fick mig att våga tacka ja till doktorandtjänst i Göteborg. Och tack Katja, min nuvarande chef på RCC för jobb, samtal och pepp!

Jag vill också tacka ett stort, mig väldigt kärt, hjärn-gäng, som växt till sig sedan jag började som sjuksköterska på Neurokirurgiska kliniken, Karolinska universitetssjukhuset i Stockholm 1997. Innerligt tack till er alla - Kerubgänget, NONIS och alla kontaktsjuksköterskor, Svenska Hjärntumörregistret, Udatagruppen, Arbetsgruppen för Individuell Patientöversikt, "gamla" CNS planeringsgruppen, och Svenska Hjärntumörföreningen.

Stort tack till min danska kollega som tror på mig, Karin Piil, jag ser fram emot att jobba tillsammans med dig och nya kollegor i European Association of Neuro-Oncology (EANO).

Tack till alla mina fina vänner som hejat på mig; Nynäsgängen, Trollbäcksgängen och Sara, Micke, Ann-Sofie och Staffan.

Tack Kerstin för stöd under de här åren.

Varmt tack till min fina mamma, vad man än gör så är man ju bäst! Och jag vet att du är glad och stolt. Tack till min syster Annika och Janne, som också peppat mig under den här tiden.

Och min familj, Tack älskade Stefan, du som egentligen inte har tålamod, tack för att jag fått göra det här – jag vet att det varit på bekostnad av dig flera gånger. Jag kommer nog aldrig ifatt. Du är bäst!

Ida och Johanna, älskade ungar – människor, unga vuxna. Ni var 13 och 14 år när jag blev doktorand i Göteborg. Jag hoppas att jag inspirerat och inte avskräckt er för detta. Johanna har i alla fall haft en pluggkompis hemma i köket och Ida någon som skjutsar dygnets alla timmar. Jag älskar er!

Tänk vad jag har längtat efter det här! Jag är så tacksam för ert stöd under de här åren. Nu ska jag bli trevlig! Och forskare.

REFERENCES

1. World Health Organization. European Observatory on Health Systems and Policies. Tackling chronic disease in Europe: strategies, interventions and challenges. Copenhagen: World Health Organization on behalf of the European Observatory on Health Systems and Policies; 2010.
2. Lloyd HM, Pearson M, Sheaff R, Asthana S, Wheat H, Sugavanam TP, et al. Collaborative action for person-centred coordinated care (P3C): an approach to support the development of a comprehensive system-wide solution to fragmented care. *Health Res Policy Syst.* 2017;15(1). <https://health-policy.systems.biomedcentral.com/track/pdf/10.1186/s12961-017-0263-z>
3. World Health Organization. Noncommunicable diseases. [cited 2022-11-04]. Available from: <https://www.who.int/news-room/factsheets/detail/noncommunicable-diseases>.
4. Bernell S, Howard SW. Use Your Words Carefully: What Is a Chronic Disease? *Frontiers in Public Health.* 2016;4. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4969287/pdf/fpubh-04-00159.pdf>
5. OECD. Sweden: Country Health Profile 2019. [cited 2022-10-19]. Available from: <https://doi.org/10.1787/2dcb7ca6-en>
6. Huber M, Knottnerus JA, Green L, Horst Hvd, Jadad AR, Kromhout D, et al. How should we define health? *BMJ.* 2011;343:d4163.
7. Krahn GL, Robinson A, Murray AJ, Havercamp SM, Havercamp S, Andridge R, et al. It's time to reconsider how we define health: Perspective from disability and chronic condition. *Disability and Health Journal.* 2021;14(4):101129.
8. Lorenzoni L, Marino A, Morgan D, James C. Health Spending Projections to 2030: New results based on a revised OECD methodology. 2019.
9. Benkel I, Arnby M, Molander U. Living with a chronic disease: A quantitative study of the views of patients with a chronic disease on the

- change in their life situation. Sage Open Medicine, 2020, Vol 8, pp 1-7. 2020;8:1-7.
10. Bonino S. Coping with chronic illness : theories, issues and lived experiences. London: Routledge; 2021.
 11. Hudon C, Fortin M, Haggerty J, Loignon C, Lambert M, Poitras M-E. Patient-centered care in chronic disease management: A thematic analysis of the literature in family medicine. Patient Educ Couns. 2012;88(2):170-6.
 12. Riggare S, Höglund PJ, Hvitfeldt Forsberg H, Eftimovska E, Svenningsson P, Hägglund M. Patients are doing it for themselves: A survey on disease-specific knowledge acquisition among people with Parkinson's disease in Sweden. Health Informatics J. 2019;25(1):91-105.
 13. Coulter A. Patient engagement - what works? J Ambul Care Manage. 2012;35(2):80-9.
 14. Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. Health Aff (Millwood). 2013;32(2):207-14.
 15. Vårdanalys. Från mottagare till medskapare - Ett kunskapsunderlag för en mer personcentrerad hälso- och sjukvård. 2018. [cited 2021-12-30]. Available from: <https://www.vardanalys.se/rapporter/fran-mottagare-till-medskapare/>
 16. Ministry of Health and Social Affairs. Good quality, local health care – A primary care reform (SOU 2018:39). [cited 2023-02-11]. Available from: <http://sou.gov.se/godochnaravard/english-summary-of-the-inquirys-second-interim-report-sou-201839/2018>.
 17. Wallström S, Ekman I, Taft C. Svenskarnas syn på personcentrerad i vården : Larmar och gör sig till (The Swedes' view of person-centredness in healthcare). SOM-institutet Göteborg; 2017.
 18. Vårdanalys. Vården ur patienternas perspektiv : jämförelser mellan Sverige och 10 andra länder : resultat från Commonwealth Fund 2014 International Health Policy Survey. Stockholm: Myndigheten för vårdanalys; 2014.
 19. Vårdanalys. Samordnad vård och omsorg : en analys av samordningsutmaningar i ett fragmenterat vård- och omsorgssystem. Stockholm: Myndigheten för vård- och omsorgsanalys.; 2015. [cited

2023-02-12]. Available from:
<https://www.vardanalys.se/rapporter/varden-ur-patienternas-perspektiv/>

20. Socialstyrelsen. Din skyldighet att informera och göra patienten delaktig : handbok för vårdgivare, chefer och personal : aktuell från 1 januari 2015. Stockholm: Socialstyrelsen; 2015. Report No.: 9789175553078.
21. Farley H. Promoting self-efficacy in patients with chronic disease beyond traditional education: A literature review. *Nursing Open*. 2020;7(1):30-41.
22. Richmond Group of Charities TKF. From vision to action: making patient-centred care a reality. [cited 2022-12-18]. Available from: <https://www.kingsfund.org.uk/publications/articles/vision-action-making-patient-centred-care-reality>; 2012.
23. De Silva D. Evidence: helping people help themselves. The Health Foundation. 2011. [cited 2021-06-16]. Available from: <https://www.health.org.uk/publications/evidence-helping-people-help-themselves>
24. Öhlén J, Björkman I, Siira E, Kirkevold M. Personhood: Philosophies, applications and critiques in healthcare. *Nurs Philos*. 2022.
25. The Health Foundations. Person-centred care made simple. What everyone should know about person-centred care. The Health Foundations; 2016. [cited 2022-11-20]. Available from: <https://www.health.org.uk/publications/person-centred-care-made-simple>
26. Institute of Medicine Committee on Quality of Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington (DC): National Academies Press (US) Copyright 2001 by the National Academy of Sciences. All rights reserved.; 2001.
27. Lloyd H WH, Horrell J, Close JA. Guide for Commissioners on the Use Metrics for Person Centred Coordinated Care for People with Long Term Conditions, Multiple Long Term Conditions and Those at the End of their Life. [cited 2018-03-03] Available from: <https://pearl.plymouth.ac.uk/handle/10026.1/15766>
28. Nolte E, Merkur S, Anell A. Achieving person-centred health systems: evidence, strategies and challenges. Cambridge; Cambridge University Press; 2020.

29. World Health Organization. WHO global strategy on people-centred and integrated health services: interim report. Geneva: World Health Organization; 2015. Contract No.: WHO/HIS/SDS/2015.6.
30. Kitwood TM. Dementia reconsidered : the person comes first. Buckingham : Open University Press; 1997.
31. Mohr W, Rädke A, Afi A, Edvardsson D, Mühlichen F, Platen M, et al. Key Intervention Categories to Provide Person-Centered Dementia Care: A Systematic Review of Person-Centered Interventions. *J Alzheimers Dis.* 2021;84:343-66.
32. Brännström M, Boman K. Effects of person-centred and integrated chronic heart failure and palliative home care. PREFER : a randomized controlled study. *Eur J Heart Fail.* 2014;16(10):1142-51.
33. Ekman I, Wolf A, Olsson LE, Taft C, Dudas K, Schaufelberger M, et al. Effects of person-centred care in patients with chronic heart failure: The PCC-HF study. *Eur Heart J.* 2012;33(9):1112-9.
34. Fors A, Swedberg K, Ulin K, Wolf A, Ekman I. Effects of person-centred care after an event of acute coronary syndrome: Two-year follow-up of a randomised controlled trial. *Int J Cardiol.* 2017;249:42-7.
35. McCormack B. Person-centred nursing, theory and practice. McCormack B, McCance T, editors: Chichester : John Wiley & Sons, Ltd.; 2010.
36. Rogers CR. On becoming a person : a therapist's view of psychotherapy. London: Constable; 2004.
37. Stewart M. Patient-centered medicine : transforming the clinical method. Abdingdon, U.K. :2003.
38. Edvardsson D. Notes on person-centred care: What it is and what it is not. *Nordic Journal of Nursing Research.* 2015;35(2):65-6.
39. Coyne I, Holmström I, Söderbäck M. Centeredness in Healthcare: A Concept Synthesis of Family-centered Care, Person-centered Care and Child-centered Care. *J Pediatr Nurs.* 2018;42:45-56.
40. Håkansson Eklund J, Holmström IK, Kumlin T, Kaminsky E, Skoglund K, Högländer J, et al. "Same same or different?" A review of reviews of person-centered and patient-centered care. *Patient Educ Couns.* 2019;102(1):3-11.

41. Feldthusen C, Forsgren E, Wallström S, Andersson V, Löfqvist N, Sawatzky R, et al. Centredness in health care: A systematic overview of reviews. *Health Expect.* 2022;25(3):885-901.
42. Rathert C, Wyrwich MD, Boren SA. Patient-Centered Care and Outcomes: A Systematic Review of the Literature. *Med Care Res Rev.* 2013;70(4):351-79.
43. Ekman I, Swedberg K, Taft C, et al. Person-Centered Care — Ready for Prime Time. *European Journal of Cardiovascular Nursing.* 2011;10(4):248-251. doi:10.1016/j.ejcnurse.2011.06.008
44. Lloyd H, Pearson M, Sheaf R, Asthana S, Wheat H, Sugavanam T, et al. Collaborative action for person Centred coordinated care (P3C): an approach to support the development of a comprehensive system-wide solution to fragmented care. 2017;15.
45. McCormack B. A conceptual framework for person-centred practice with older people. *Int J Nurs Pract.* 2003;9(3):202-9.
46. McCormack B, McCance TV. Development of a framework for person-centred nursing. *J Adv Nurs.* 2006;56(5):472-9.
47. Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med.* 2000;51(7):1087-110.
48. Scholl I, Zill JM, Harter M, Dirmaier J. An Integrative Model of Patient-Centeredness - A Systematic Review and Concept Analysis.(Research Article). *PLoS One.* 2014;9(9).
49. E Harding SW, J Scrutton. The state of play in person-centred care: A pragmatic review of how person-centred care is defined, applied and measured.; 2015.
50. Moore L, Britten N, Lydahl D, Naldemirci O, Elam M, Wolf A. Barriers and facilitators to the implementation of person-centred care in different healthcare contexts. *Scand J Caring Sci.* 2017;31(4):662-73.
51. Ekman I, Hedman H, Swedberg K, Wallengren Gustafsson C. Commentary: Swedish initiative on person centred care. *BMJ*, 2015, Vol 350. 2015;350.
52. Ricœur P. Oneself as another. Chicago: Univ. of Chicago Press; 1992.

53. Ekman I. Practising the ethics of person-centred care balancing ethical conviction and moral obligations. *Nurs Philos.* 2022;23(3):e12382.
54. Kristensson Ugglä B. What makes us human? Exploring the significance of Ricoeur's ethical configuration of personhood between naturalism and phenomenology in health care. *Nurs Philos.* 2022;23(3):e12385.
55. Jasemi M, Valizadeh L, Zamanzadeh V, Keogh B. A Concept Analysis of Holistic Care by Hybrid Model. *Indian J Palliat Care.* 2017;23(1):71-80.
56. Ekman I. Personcentrering inom hälso- och sjukvård - från filosofi till praktik: Liber; 2020.
57. Kristensson Ugglä B. Personfilosofi - filosofiska utgångspunkter för personcentrering inom hälso- och sjukvård. In: Ekman I, editor. *Personcentrering inom hälso- och sjukvård: Från filosofi till praktik.* Andra upplagan ed: Liber; 2020. p. 58 - 105.
58. Britten N, Moore L, Lydahl D, Naldemirci O, Elam M, Wolf A. Elaboration of the Gothenburg model of person-centred care. *Health Expect.* 2017;20(3):407-18.
59. Ekman I, Ebrahimi Z, Olaya Contreras P. Person-centred care: looking back, looking forward. *Eur J Cardiovasc Nurs.* 2021;20(2):93-5.
60. Ekman I, Swedberg K, Taft C, Lindseth A, Norberg A, Brink E, et al. Person-Centered Care — Ready for Prime Time. *Eur J Cardiovasc Nurs.* 2011;10(4):248-51.
61. Naldemirci Ö, Britten N, Lloyd H, Wolf A. The potential and pitfalls of narrative elicitation in person-centred care. *Health Expect.* 2020;23(1):238-46.
62. Josephsson S, Öhlén J, Mondaca M, Guerrero M, Luborsky M, Lindström M. Using Ricoeur's notions on narrative interpretation as a resource in supporting person-centredness in health and social care. *Nurs Philos.* 2022;23(3):e12398.
63. Wolf A, Moore L, Lydahl D, Naldemirci Ö, Elam M, Britten N. The realities of partnership in person-centred care: a qualitative interview study with patients and professionals. *BMJ Open.* 2017;7(7):e016491.

64. Jansson I, Fors A, Ekman I, Ulin K. Documentation of person-centred health plans for patients with acute coronary syndrome. *Eur J Cardiovasc Nurs.* 2018;17(2):114-22.
65. Rycroft-Malone J, Wilkinson J, Burton CR, Harvey G, McCormack B, Graham I, et al. Collaborative action around implementation in Collaborations for Leadership in Applied Health Research and Care: towards a programme theory. *J Health Serv Res Policy.* 2013;18(3 Suppl):13-26.
66. National Voices. A Narrative for Person Centred Coordinated Care. [cited 2022-02-05]. Available from: <https://www.nationalvoices.org.uk/publications/our-publications/narrativeperson-centred-coordinated-care.>; 2013.
67. Lloyd H WH, Horrel J, Close JA. . Measures for Person Centred Coordinated Care. 2016. How to Use Metrics, Measures & Insights to Commission Person Centred Coordinated Care. 2016.
68. De Silva D. Helping measure person-centred care: a review of evidence about commonly used approaches and tools used to help measure person-centred care: The Health Foundation; 2014. [cited 2022-02-03]. Available from: <https://www.health.org.uk/publications/helping-measure-person-centred-care>
69. Harding E WS, Scrutton J. The state of play in person-centred care - A person-centred approach can transform a person's experience of care, but a lack of common definitions and terminology may hinder its use in practice. [cited 2021-05-06]. Available from: <https://www.healthpolicypartnership.com/project/person-centred-care/>: The Health Foundation; 2015 2020-01-15.
70. Lowe D, Ryan R, Schonfeld L, Merner B, Walsh L, Graham-Wisener L, et al. Effects of consumers and health providers working in partnership on health services planning, delivery and evaluation. *Cochrane Database Syst Rev.* 2021(9).
71. Gyllensten H, Björkman I, Jakobsson Ung E, Ekman I, Jakobsson S. A national research centre for the evaluation and implementation of person-centred care: Content from the first interventional studies. *Health Expect.* 2020;n/a(n/a).
72. Coulter A. Measuring what matters to patients. *BMJ.* 2017. 356 :j816 doi:10.1136/bmj.j816

73. Wang DE, Tsugawa Y, Figueroa JF, Jha AK. Association Between the Centers for Medicare and Medicaid Services Hospital Star Rating and Patient Outcomes. *JAMA internal medicine*. 2016;176(6):848-50.
74. Ahmed F, Burt J, Roland M. Measuring patient experience: concepts and methods. *The Patient - Patient-Centered Outcomes Research*. 2014;7(3):235-41.
75. Wolf JA. Patient Experience: The New Heart of Healthcare Leadership. *Front Health Serv Manage*. 2017;33(3):3-16.
76. Wolf JAN, Victoria; Marshburn, Dianne; and LaVela, Sherri L. Reexamining 'Defining Patient Experience': The human experience in healthcare. *Patient Experience Journal*. 2021;Vol. 8 : Iss. 1 , Article 4.
77. Kingsley C, Patel S. Patient-reported outcome measures and patient-reported experience measures. *BJA Education*. 2017;17(4):137-44.
78. Lloyd H, Wheat H, Horrell J, Sugavanam T, Fosh B, Valderas JM, et al. Patient-Reported Measures for Person-Centered Coordinated Care: A Comparative Domain Map and Web-Based Compendium for Supporting Policy Development and Implementation. *J Med Internet Res*. 2018;20(2):e54-e.
79. Sabina Nuti SDRMB, Anna Maria M. Rethinking Healthcare Performance Evaluation Systems towards the People-Centredness Approach: Their Pathways, their Experience, their Evaluation. *HealthcarePapers*. 2017;17(2):56-64.
80. Hobart JC, Cano SJ, Zajicek JP, Thompson AJ. Rating scales as outcome measures for clinical trials in neurology: problems, solutions, and recommendations. *Lancet Neurol*. 2007;6(12):1094-105.
81. DeVellis RF. Classical Test Theory. *Med Care*. 2006;44(11):S50-S9.
82. Boone WJ. Rasch Analysis for Instrument Development: Why, When, and How? *CBE Life Sci Educ*. 2016;15(4):rm4.
83. Cano SJ, Hobart JC. The problem with health measurement. *Patient Prefer Adherence*. 2011;5:279-90.
84. DeWalt DA, Rothrock N, Yount S, Stone AA. Evaluation of item candidates: the PROMIS qualitative item review. *Med Care*. 2007;45(5 Suppl 1):S12-21.

85. Hobart J, Cano S. Improving the evaluation of therapeutic interventions in multiple sclerosis: the role of new psychometric methods. *Health technology assessment (Winchester, England)*. 2009;13(12):iii, ix.
86. Bond TG, Fox CM. *Applying the Rasch model : fundamental measurement in the human sciences*. London: Routledge; 2015.
87. Rasch G. *Probabilistic models for some intelligence and attainment tests*. Copenhagen: Copenhagen; 1960.
88. Tennant A, Conaghan PG. The Rasch measurement model in rheumatology: What is it and why use it? When should it be applied, and what should one look for in a Rasch paper? *Arthritis Care Res (Hoboken)*. 2007;57(8):1358-62.
89. Hagquist C, Bruce M, Gustavsson JP. Using the Rasch model in nursing research: an introduction and illustrative example. *Int J Nurs Stud*. 2009;46(3):380-93.
90. Rouquette A, Hardouin J-B, Vanhaesebrouck A, Sébille V, Coste J. Differential Item Functioning (DIF) in composite health measurement scale: Recommendations for characterizing DIF with meaningful consequences within the Rasch model framework. *PLoS One*. 2019;14(4):e0215073.
91. Marais I. Local Dependence. *Rasch Models in Health*2012. p. 111-30.
92. Marais I, Andrich D. Formalizing dimension and response violations of local independence in the unidimensional Rasch model. *J Appl Meas*. 2008;9(3):200-15.
93. Lloyd H, Fosh B, Whalley B, Byng R, Close J. Validation of the person-centred coordinated care experience questionnaire (P3CEQ). *International Journal for Quality in Health Care*. 2019;31(7):506-12.
94. Fridberg H, Wallin L, Wallengren C, Kottorp A, Forsman H, Tistad M. Development and evaluation of the measurement properties of a generic questionnaire measuring patient perceptions of person-centred care.(Report). *BMC Health Serv Res*. 2020;20(1).
95. Bala S-V, Forslund K, Fridlund B, Hagell P. Measuring person-centred care in nurse-led outpatient rheumatology clinics. *Musculoskeletal Care*. 2018;16(2):296-304.

96. Melin J, Fornazar R, Spångfors M, Pendrill L. Rasch analysis of the Patient Participation in Rehabilitation Questionnaire (PPRQ). *J Eval Clin Pract.* 2020;26(1):248-55.
97. Luhr K, Eldh AC, Nilsson U, Holmefur M. Patient preferences for patient participation: Psychometric evaluation of The 4Ps tool in patients with chronic heart or lung disorders. *Nordic Journal of Nursing Research.* 2018;38(2):68-76.
98. Petersen MA, Aaronson NK, Arraras JJ, Chie WC, Conroy T, Costantini A, et al. The EORTC CAT Core-The computer adaptive version of the EORTC QLQ-C30 questionnaire. *Eur J Cancer.* 2018;100:8-16.
99. Hobart JC, Riazi A, Lamping DL, Fitzpatrick R, Thompson AJ. Improving the evaluation of therapeutic interventions in multiple sclerosis: development of a patient-based measure of outcome. *Health Technol Assess.* 2004;8(9):i, 1-48.
100. da Rocha NS, Chachamovich E, de Almeida Fleck MP, Tennant A. An introduction to Rasch analysis for Psychiatric practice and research. *J Psychiatr Res.* 2013;47(2):141-8.
101. Cella D, Gershon R, Lai J-S, Choi S. The future of outcomes measurement: item banking, tailored short-forms, and computerized adaptive assessment. *Qual Life Res.* 2007;16(1):133-41.
102. Bjorner J, Kosinski M, Ware J, Qualitymetric I, Washington G, Hwy L. Computerized Adaptive Testing and Item Banking. 2005.
103. Mokkink L, Terwee C, Patrick D, Alonso J, Stratford P, Knol D, et al. The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. *Qual Life Res.* 2010;19(4):539-49.
104. Mokkink LB, de Vet HCW, Prinsen CAC, Patrick DL, Alonso J, Bouter LM, et al. COSMIN Risk of Bias checklist for systematic reviews of Patient-Reported Outcome Measures. *Qual Life Res.* 2018;27(5):1171-9.
105. Reeve BB, Wyrwich KW, Wu AW, Velikova G, Terwee CB, Snyder CF. ISOQOL recommends minimum standards for patient-reported outcome measures used in patient-centered outcomes and comparative effectiveness research. 2013;22:1889-905.

106. Johnson C, Aaronson N, Blazeby J, Bottomley A, Fayers P, Koller M, et al. EORTC guidelines for developing questionnaire modules. EORTC Publication, Brussels. 2011.
107. Rothrock NE, Kaiser KA, Cella D. Developing a valid patient-reported outcome measure. *Clin Pharmacol Ther.* 2011;90(5):737-42.
108. Creswell JW. Designing and conducting mixed methods research. Third Edition. ed. Plano Clark VL, editor: Los Angeles : SAGE; 2017.
109. Wild D, Grove A, Martin M, Eremenco S, McElroy S, Verjee-Lorenz A, et al. Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes (PRO) Measures: Report of the ISPOR Task Force for Translation and Cultural Adaptation. *Value Health.* 2005;8(2):94-104.
110. Krueger RA, Casey MA. Focus groups : a practical guide for applied research. Thousand Oaks, Calif.: Sage Publications; 2015.
111. Wolcott MD, Lobczowski NG. Using cognitive interviews and think-aloud protocols to understand thought processes. *Currents in Pharmacy Teaching and Learning.* 2021;13(2):181-8.
112. Beatty PC, Willis GB. Research Synthesis: The Practice of Cognitive Interviewing. *Public Opin Q.* 2007;71(2):287-311.
113. Rosenlund L, Jakobsson S, Lloyd H, Lundgren-Nilsson Å, Hermansson M, Dencker A. Measuring patient experiences of person-centred care: Translation, cultural adaption and qualitative evaluation of item candidates for use in England and Sweden. *Scand J Caring Sci.* 2021;n/a(n/a).
114. Lorig KR, Sobel DS, Ritter PL, Laurent D, Hobbs M. Effect of a self-management program on patients with chronic disease. *Effective clinical practice : ECP.* 2001;4(6):256-62.
115. Prolific [Available from: <https://www.prolific.co/>].
116. Braun V, Clarke V. Conceptual and design thinking for thematic analysis. *Qualitative psychology (Washington, DC).* 2021;9(1):3-26.
117. Braun V, Clarke VJQRP. Using thematic analysis in psychology. 2006;3.
118. Edhlund BM, McDougall AG. Allt om Nya NVivo Windows. Stallarholmen: Form & Kunskap AB; 2020.

119. Nyström M, Dahlberg K. Pre-understanding and openness – a relationship without hope? *Scand J Caring Sci.* 2001;15(4):339-46.
120. Corp. I. IBM SPSS Statistics for Windows, Version 28.0.1.0. Armonk, NY: IBM Corp; 2021.
121. Andrich D LA, Sheridan B, Luo G. RUMM2030, Rasch Unidimensional Measurement Models. Perth, Western Australia: RUMM Laboratory; 2010.2010.
122. Masters G. A rasch model for partial credit scoring. *Psychometrika.* 1982;47(2):149-74.
123. Andrich D. Rasch models for measurement [Elektronisk resurs]. Newbury Park, [Calif.] ;; SAGE; 1988.
124. Leung Y-Y, Png M-E, Conaghan P, Tennant A. A systematic literature review on the application of Rasch analysis in musculoskeletal disease— A special interest group report of OMERACT 11. *The Journal of Rheumatology.* 2014;41(1):159-64.
125. Pallant JF, Tennant A. An introduction to the Rasch measurement model: An example using the Hospital Anxiety and Depression Scale (HADS). *Br J Clin Psychol.* 2007;46(1):1-18.
126. Andrich D, Hagquist C. Real and Artificial Differential Item Functioning in Polytomous Items. *Educ Psychol Meas.* 2015;75(2):185-207.
127. Hagell P. Testing rating scale unidimensionality using the Principal Component Analysis (PCA)/t-test protocol with the Rasch Model : the primacy of theory over statistics. *Open Journal of Statistics.* 2014;4(6):456-65.
128. Smith EV, Jr. Detecting and evaluating the impact of multidimensionality using item fit statistics and principal component analysis of residuals. *J Appl Meas.* 2002;3(2):205-31.
129. Marais I, Andrich D. Effects of Varying Magnitude and Patterns of Response Dependence. *Journal of applied measurement.* 2008;9(2):105-24.
130. Marais I, Christensen K, Kreiner S, Mesbah M. Rasch models in health. 2013.

131. Association WM. Declaration of Helsinki: ethical principles for medical research involving human subjects. *JAMA*. 2013;310(20):2191-4.
132. European Parliament and Council of European Union. The General Data Protection Regulation (GDPR). [cited 2023-01-03]. Available from: <https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:32016R0679&from=EN2016>.
133. Small N, Bower P, Chew-Graham CA, Whalley D, Protheroe J. Patient empowerment in long-term conditions: development and preliminary testing of a new measure. *BMC Health Serv Res*. 2013;13(1):263.
134. Haggerty JL, Reid RJ, Freeman GK, Starfield BH, Adair CE, McKendry R. Continuity of care: a multidisciplinary review. *BMJ*. 2003;327(7425):1219-21.
135. Blanck E, Fors A, Ali L, Brännström M, Ekman I. Informal carers in Sweden – striving for partnership. *International Journal of Qualitative Studies on Health and Well-being*. 2021;16(1):1994804.
136. Charalambous A. Informal Caregivers: From Hidden Heroes to Integral Part of Care: Springer Nature; 2023.
137. Nuti S, Rosis S, Bonciani M, Murante AM. Rethinking Healthcare Performance Evaluation Systems towards the People-Centredness Approach: Their Pathways, their Experience, their Evaluation. *Healthc Pap*. 2017;17(2):56-64.
138. Vennedey V, Hower KI, Hillen H, Ansmann L, Kuntz L, Stock S. Patients' perspectives of facilitators and barriers to patient-centred care: insights from qualitative patient interviews. *BMJ Open*. 2020;10(5):e033449.
139. Coulter A, Paparella G, McCulloch A. Listening to people: measuring views, experiences and perceptions. 2020. p. 173-200.
140. Wolf JA. The future of patient experience: Five thoughts on where we must go from here. *Patient Experience Journal*. 2019;6(3):1-4.
141. Melin J, Fornazar R, Spangfors M, Pendrill L. Rasch analysis of the Patient Participation in Rehabilitation Questionnaire (PPRQ). *J Eval Clin Pract*. 2020;26(1):248-55.
142. Luhr K, Holmefur M, Theander K, Eldh AC. Patient participation during and after a self-management programme in primary healthcare – The

- experience of patients with chronic obstructive pulmonary disease or chronic heart failure. *Patient Educ Couns*. 2018;101(6):1137-42.
143. Mitchell K-AR, Brassil KJ, Fujimoto K, Fellman BM, Shay LA, Springer AE. Exploratory Factor Analysis of a Patient-Centered Cancer Care Measure to Support Improved Assessment of Patients' Experiences. *Value Health*. 2020;23(3):351-61.
144. US Food and Drug Administration. Guidance for industry: patient-reported outcome measures: use in medical product development to support labeling claims: draft guidance. *Health Qual Life Outcomes*. 2006/10/13 ed2006. p. 79.
145. Katz MH. Evaluating clinical and public health interventions : a practical guide to study design and statistics. Cambridge: Cambridge University Press; 2010.
146. Moore GF, Audrey S, Barker M, Bond L, Bonell C, Hardeman W, et al. Process evaluation of complex interventions: Medical Research Council guidance. *BMJ : British Medical Journal*. 2015;350:h1258.
147. Coulter A. Engaging patients in their healthcare. *Pickier Institute Europe*. 2006;4(3):6-4.
148. Redding D. The narrative for person-centred coordinated care. *Journal of Integrated Care*. 2013;21(6):315-25.
149. Coulter A, Roberts S, Dixon A. Delivering Better Services for People with Long Term Conditions: Building the House of Care. London: The King's Fund; 2013.
150. European medicines agency. Appendix 2 to the guideline on the evaluation of anticancer medicinal products in man: the use of patient-reported outcome (PRO) measures in oncology studies. [cited 2022-03-07]. Available from: <https://www.ema.europa.eu/en/appendix-2-guideline-evaluation-anticancer-medicinal-products-man-use-patient-reported-outcome-pro>: European medicines agency; 2016.
151. Östlund U, Kidd L, Wengström Y, Rowa-Dewar N. Combining qualitative and quantitative research within mixed method research designs: A methodological review. *Int J Nurs Stud*. 2011;48(3):369-83.

APPENDIX

The 57 candidate items in English and Swedish

¹ No	English version of items	Swedish version of items
1	I feel confident communicating with healthcare staff	Jag känner mig trygg i kommunikationen med vårdpersonalen
2	I am treated with respect	Jag behandlas med respekt
3	I am treated kindly	Jag blir vänligt bemött
4	I feel that healthcare staff care for me as a person	Jag upplever att man bryr sig om mig som person
5	Healthcare staff listen to what I am saying	Vårdpersonalen lyssnar på vad jag säger
6	My personal opinions are respected	Mina personliga uppfattningar respekteras
7	I get answers to the questions that I ask healthcare staff	Jag får svar på mina frågor när jag behöver
8	I am involved in decisions concerning my care and treatment (as much as I want and am able to)	Jag är delaktig i beslut kring min vård och behandling (så mycket som jag vill och kan)
9	My relatives are involved as much as I want	Mina närstående involveras så mycket som jag önskar
10	I collaborate with healthcare staff when it comes to my care	Jag samarbetar med vårdpersonalen när det gäller min vård
11	I discuss my care and treatment options with healthcare staff	Jag diskuterar vård- eller behandlingsalternativ tillsammans med vårdpersonalen
12	I have the opportunity to think carefully about decisions about my care	Jag ges möjlighet att tänka igenom beslut kring min vård
13	I get the time I need with the healthcare staff	Jag får den tid jag behöver med vårdpersonalen
14	I am aware of the next step in my care or treatment	Jag känner till nästa steg i min vård eller behandling
15	I am able to discuss the advantages and disadvantages and possible outcomes of treatment with healthcare staff	Jag kan diskutera fördelar, nackdelar och möjliga resultat av behandlingen med vårdpersonalen
16	I am asked how my health condition affects my daily life	Jag får frågor om hur mitt hälsotillstånd påverkar mitt dagliga liv
17	I get the support that I need to manage my health condition (self-care)	Jag har det stöd jag behöver för att kunna hantera mitt hälsotillstånd (egenvård)
18	I am encouraged to take care of my health (self-care)	Jag blir uppmuntrad att ta hand om min hälsa (egenvård)
19	I know how to manage my condition (self-care)	Jag vet vad jag själv kan göra för att hantera mitt hälsotillstånd (egenvård)
20	I know how to manage my symptoms or side effects when I need to	Jag lär mig att hantera symtom eller biverkningar när det behövs

21	We discuss what is important to me about taking care of my health (self-care)	Vi diskuterar vad som är viktigt för mig när jag ska ta hand om min hälsa (egenvård)
22	I am treated with attention and empathy	Jag bemöts med omsorg och medkänsla
23	Healthcare staff understand my situation	Jag känner att vårdpersonalen har förståelse för min situation
24	My concerns are taken seriously	Mina upplevelser och min oro tas på allvar
25	Healthcare staff respect the choices that I make	Vårdpersonalen respekterar de val jag gör
26	I am encouraged to ask questions	Jag uppmuntras att ställa frågor
27	I am encouraged to talk about my experiences with my health condition	Jag uppmuntras att berätta om mina erfarenheter kring mitt hälsotillstånd
28	I feel prepared before any test or treatment	Jag känner mig förberedd inför eventuella provtagningar eller behandlingar
29	Healthcare staff explain things to me in an easy and understandable manner	Vårdpersonalen förklarar saker på ett enkelt och bra sätt
30	I am encouraged to talk about how I experience my symptoms	Jag uppmuntras att berätta hur jag upplever mina symtom
31	I am informed to make decisions in relation to care or treatments	Jag har information för att kunna fatta beslut vid vård eller behandlingsalternativ
32	I have the information that I need about my care or treatment	Jag har den information jag behöver om min vård och behandling
33	I am confident in asking questions about my health	Jag känner mig trygg att ställa frågor kring min hälsa
34	I am listened to by healthcare staff	Jag känner mig lyssnad på
35	I am confident in that healthcare staff know me and my history	Jag är trygg i att vårdpersonalen känner till mig och min historia
36	My care is well organized	Jag upplever att min vård är välorganiserad
37	I can get help when I need it	Jag känner mig trygg i att jag kan få hjälp när jag behöver
38	My knowledge of how to manage my health is taken into consideration	Min kunskap om hur jag hanterar min hälsa tas tillvara
39	Information that is important to me and my situation is documented and shared with healthcare staff	Det som är viktigt för mig dokumenteras så att vårdpersonalen är insatt i min situation
40	Important information about what matters to me is missing in my care plan	Information som är viktig för mig saknas i min vårdplan
41	I receive contradictory information or advice from my healthcare staff	Jag får motstridiga uppgifter eller råd från vårdpersonalen
42	I have to repeat myself because healthcare staff do not share information with each other	Jag är tvungen att upprepa mig eftersom sjukvårdspersonalen inte delar information med varandra
43	I feel well cared for by healthcare staff	Jag känner mig väl omhändertagen av vårdpersonalen

44	I am asked about aspects of my daily life by healthcare staff	Jag får utrymme att berätta hur jag har det
45	I am asked questions about my own goals (or what I want to achieve) to improve or maintain my health	Jag får frågor om egna mål för min hälsa
46	Healthcare staff take time to answer my questions	Vårdpersonalen tar sig tid att svara på mina frågor
47	Healthcare staff involved in my care follow the same care plan	All vårdpersonal jag möter verkar följa samma plan för min vård
48	I am treated in a manner that makes me feel confident in the care I receive	Jag bemöts på ett sätt som får mig att känna mig trygg i vården
49	I am confident in asking for advice	Jag känner mig trygg med att be om råd
50	My capabilities are used in my care plan	Mina förmågor tas tillvara i planeringen av min vård
51	I trust healthcare staff	Jag har förtroende för vårdpersonalen
52	I developed my care plan together with healthcare staff	Min vårdplan är utformad av mig och vårdpersonalen tillsammans
53	My personal situation is taken into consideration in my care plan	Min personliga situation beaktas i min vårdplan
54	I know how to contact my healthcare staff when needed	Jag vet hur jag får kontakt med vårdpersonalen när jag behöver
55	Healthcare staff support me to identify activities to improve my health and wellbeing	Vårdpersonalen stödjer mig i att hitta aktiviteter som förbättrar min hälsa och mitt välbefinnande
56	I work with healthcare staff to identify goals to improve my health and wellbeing	Jag samarbetar med vårdpersonalen för att hitta mål med syfte att förbättra min hälsa och mitt välbefinnande
57	My mental wellbeing is important to healthcare professionals	Mitt psykiska välbefinnande är viktigt för vårdpersonalen

¹The itemlist is published in Rosenlund et al. 2022 in another order.