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EMPIRICAL STUDIES

Measuring patient experiences of person-centred care: Translation, cultural adaption and qualitative evaluation of item candidates for use in England and Sweden

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Abstract

Background: To facilitate change for person-centred care, there is a need to invest in measures to assess if and how healthcare systems are delivering care based on the principles of person-centred care. This paper describes the first phase in developing an item bank to measure patients' experiences of person-centred care.

Aim: The aim was to translate, culturally adapt and evaluate candidate items to measure person-centred care from the patient's perspective.

Methods: The Centre for person-centred care at Gothenburg university and the UK Person-centred and coordinated care model informed our conceptual framework. The initial pool of item candidates originated from a previous systematic review where 855 items were identified. In this study, a mixed method design was used involving persons with experience as patients, caregivers, healthcare professionals and researchers in person-centred care or questionnaire design ($n = 84$). The item analysis included two validation rounds using web questionnaires, a focus group and cognitive interviews.

Results: From the initial pool, 155 items covering core domains and subdomains of person-centred and coordinated care were selected for translation and qualitative item analysis. After translation, 44 items were excluded (duplicates). After the first validation round, 21 items were rephrased and 35 were excluded (due to low ratings, lack of comprehensibility, were duplicates or too specifically phrased). To reflect the ethical basis of person-centred care, rewordings were also made to encompass the patient as an active partner in care and where communication and information goes two-ways and care is co-created. After the second round, 11 items were rephrased and 25 items were excluded (for being redundant/repetitive). Six new items were added (covering access to care, patient capabilities, mental well-being and identifying goals).

Conclusion: We have developed a first set of 57 items to proceed towards developing an item bank to measure the patient experiences of person-centred care.

KEY WORDS

person-centred care, patient-reported experience measures, qualitative item evaluation

INTRODUCTION

In many countries, healthcare institutions seek to implement person-centred care (PCC) in order to improve patient experiences, health outcomes, efficacy and the quality of care (1-5). PCC is based on a philosophy of personhood that aims to acknowledge and endorse the individual seeking care to be in control of his or her own health and well-being (6). Although conceptual definitions of person-centred care vary, respecting the individual patient's unique experiences, needs and preferences is paramount (7-9). To provide a bridge between the philosophy and the practice of person-centred care, the Centre for person-centred care (GPCC) at the University of Gothenburg describes three key concepts and routines; (a) listen to the patient's narrative, (b) build a partnership with the patient by sharing knowledge and experiences, supporting individual health management and (c) safeguarding the partnership by communicating and documenting a joint care plan (6,10). In UK, a further development of the framework is person-centred and coordinated care (P3C) including an agreement to act in conjunction with the person and other professionals to coordinate care between different levels of care and care practices (5,11).

For healthcare systems to proceed on the implementation of PCC, there is a need to invest in quality assurance measures and real-time feedback systems to assess if and how healthcare systems are delivering care based on the principles of PCC (7,11,12). PCC is a complex intervention to evaluate and different methods and tools are being used or combined, for example using surveys with patient and healthcare professionals, interviews, observational studies and indicators like efficacy, safety and costs (12). In 27 interventional studies conducted based on the ethics for person-centredness provided by the GPCC, in total, 163 outcome measures (specific questionnaires, health measures or other outcomes), ranging from 1 to 17 measurements per study, were reported (13).

Patient-reported measures, PRMs, usually administered as self-reported questionnaires to the patient is a structured way to obtain the patients perspective of their health or healthcare experience. Patient-reported experience measures, PREMs, are PRMs to describe and assess patient's experiences of care (14) and can provide valuable information to target patient preferences of quality improvements (15,16). Patient experience encompasses the range of interactions that patients have with the healthcare system and can be defined as the sum of all those interactions, which are shaped by the organisation's culture across the continuum of care (17). There are several PREM instruments to measure patient experiences of PCC or person-centredness. Different instrument measure either the broad holistic concept of PCC or specific subcomponents like shared decision-making

and patient empowerment (12,16,18). Despite a growing population living with long-term conditions, two thirds of published research about measuring PCC was conducted in a hospital context (12). PCC for patients with long-term condition/s need to be understood as a set of processes occurring in the interactions between patient and provider, and between multiple providers (19). People with chronic conditions are most often at home and care for themselves and/or have important informal caregivers, family and friends caring for them. Therefore, items need to capture patients' whole experience, collaboration and communication both at the hospital and from home, with both the patient and the caregivers as a team (20).

In UK, to guide and enhance the implementation of person-centred and coordinated care, Lloyd et al. identified 328 PRMs that can be used to assess different outcomes and aspects of person-centred and coordinated care (16). However, to produce a questionnaire, which covers many of the important aspects of PCC and will be responsive to change, there is a risk that the questionnaire would be too long and generic. To improve measurement precision and relevance to patients, questionnaires or measures should ideally be adapted to the individual patient while retaining direct comparability of scores across patients. This is achievable using item banks calibrated with modern test theories, which provide an opportunity to assemble and organise an inventory of items. From a measurement perspective, this offers greater breadth of content coverage, improved precision and flexibility, ability to individualise assessment with computer adaptive tests and reduce respondent burden (21,22). Therefore, an item bank/s can be a logical solution if we can identify items to understand the latent traits of the experiences of person-centred care.

Aims

This paper describes the first phase in developing an item bank to measure patient experience of person-centred care for use in an outpatient healthcare context. The aim of this study was to translate, culturally adapt and evaluate item candidates to measure person-centred care from the patient's perspective.

METHODS**Design**

A mixed method design was used with qualitative evaluations of items using two rounds of web questionnaires, a

focus group and cognitive interviews. The study is a collaboration between the University of Gothenburg, Sweden and Plymouth University, England. The GPCC (6) and the UK P3C framework including coordinated care (16) informed our conceptual framework of person-centred care as a basis for the evaluation of items. The project was approved by a Regional Ethical Review Board in Sweden (Dnr 2019-03996). All participants gave informed consent before any procedures in the study.

Population

To solicit opinions from different experts, this study involved persons with experience as patients with various long-term conditions and their caregivers (validation round 1 and 2) and healthcare professionals as well as researchers in person-centred care and questionnaire design (validation round 2). Patient representatives and caregivers were recruited via the Person Council for patients and caregivers at GPCC and from a Regional Cancer Centre Patient Council.

Item generation process

A multistep process was undertaken to derive items to be included in the item bank. For a previous study, Lloyd et al (15) undertook a systematic identification of PRMS suitable for probing PCC using either a global or dimensional approach. This work was undertaken to produce an online compendium of measures for education, research and practice purposes and resulted in 328 individual measures (p3c.org.uk). Further work for this study scrutinised these measures and identified which ones best represented the P3C model and criteria in a single measure. For example, measures were required to meet the following inclusion criteria for content and application: patient-reported experience items targeting constructs related information/communication, goals/outcomes, decision-making, care planning and transitions/coordination of care and were suitable persons with long-term conditions and in an outpatient context. This mapping exercise resulted in a shortlist of 63 measures that were judged according to their content validity to best represent the conceptual framework of person-centred and coordinated care (P3C) informed by Ekman et al and developed by Lloyd et al (15). For the current study, joint UK and Swedish initiative commenced work on the item bank when 855 items were collated from the 63 shortlisted measures identified by Lloyd et al (15) and thus forming the first iteration of the item bank. All items were reviewed (in pairs of researchers) and kept or excluded based on their appropriateness, simplicity, specificity, bias and relevance to person-centred and coordinated care. Items were sorted by which content they covered to identify repetitions/

duplicates and to identify gaps. Double or multi-barrelled items were excluded or divided into separate items. To be administered one at a time in a web questionnaire, the item also need to be able to stand alone (23). Differences in judgement were discussed until consensus was achieved (22).

Translations

The items were translated from English into Swedish by two independent professional interpreters, both native Swedish speakers, fluent in English, with prior experience of translating questionnaires. Interpreters were instructed to use easily comprehensible language, and translation that conveyed the meaning of the original English version (24,25). The translations were merged into one Swedish version. After the evaluation process in Sweden, the final list of items was back translated into English.

Data collection

Item evaluation process

Two web questionnaires were used where patient representatives, caregivers and researchers were asked to evaluate the items. A web survey tool which allowed the participants to complete the questionnaire electronically at their own computer or mobile phone was used. The web questionnaire was emailed to participants together with a cover letter. The cover letter contained a description of the study, detailed contact information and information that participation in the study was voluntary and that all data collected in the study was processed anonymously and in accordance with the General Data Protection Regulation (GDPR) (26). The aim of the first web questionnaire was both to solicit opinions from patient representatives and to introduce the items to prepare a focus group discussion. The items were not presented in any specific order or dimension, and the participants were asked to rate and comment each item separately. In the first web questionnaire, participants rated comprehensibility, relevance, and importance of each item if used in person-centred care. These aspects were judged as “Very important”, “Important to some degree” or “Not important”.

A focus group discussion was then conducted where the first web questionnaire ratings were presented and the participants were asked to discuss appropriate use of language and relevance of items, item by item.

Following the result from the first validation phase, a second web questionnaire, was produced. In this second phase, participants were asked to rate importance and relevance for person-centred care in relation to each item. Rating was made on a 5-point Likert scale. In both web questionnaires, the

participants were encouraged to comment on each item and add items or aspects if they felt something important to PCC was missing. To further understand how the respondents perceived and responded to the items, some of the participants were invited to answer the second web questionnaire during a face-to-face interview or online cognitive interview (27,28). Those participants received the web questionnaire in conjunction with the interview and were asked to “think-aloud” while rating the items and /or added own comments.

After each web questionnaire, the research team revised the item list according to the results. When revising the items, the research team also made the following assumptions about the items; they could stand alone and not in a specific order to be used one at a time in a future item bank, they could be answered by people in outpatient care, they should be concise and simply worded, use the preferred response options and should not be a duplication.

For a face validity test of the final list of items, the final step was to conduct cognitive interviews with patients recruited via a Patient Council.

RESULTS

From the initial pool of 855 items, 155 items were translated into Swedish. After translation, 44 items were excluded

(duplicates). As the items originated from many different instruments with different styles of language, instructions, recall periods and response options several modifications were made before the translation; The items were re-written as statements and in present tense, standardised for first-person subject, to simplify vocabulary and to fit a 4-point Likert response scale (I do not agree, I agree to some extent, I agree to a large extent, I totally agree). An overview of the item evaluation process is presented in Figure 1.

For the first validation round of the 111 candidate items, participants were recruited from two different patient and caregiver council groups representing various long-term conditions. The two groups ($n = 27$) were informed about the study in one of their regular meetings and thereafter invited by email to respond to the web questionnaire and/or attend a focus group discussion. Thirteen out of 27 persons (48%) with different experiences as patient, caregiver and as healthcare professionals responded to the web questionnaire. Five out of 27 persons agreed to participate in the three hour focus group discussion and three of them attended due to two drop outs the same day. The three participants were all female, above 60 years old and had experience living with long-term conditions, two of them had also experience as healthcare professional and as caregiver. Participants involved in the validation process is presented in Table 1. The four highest rated items among

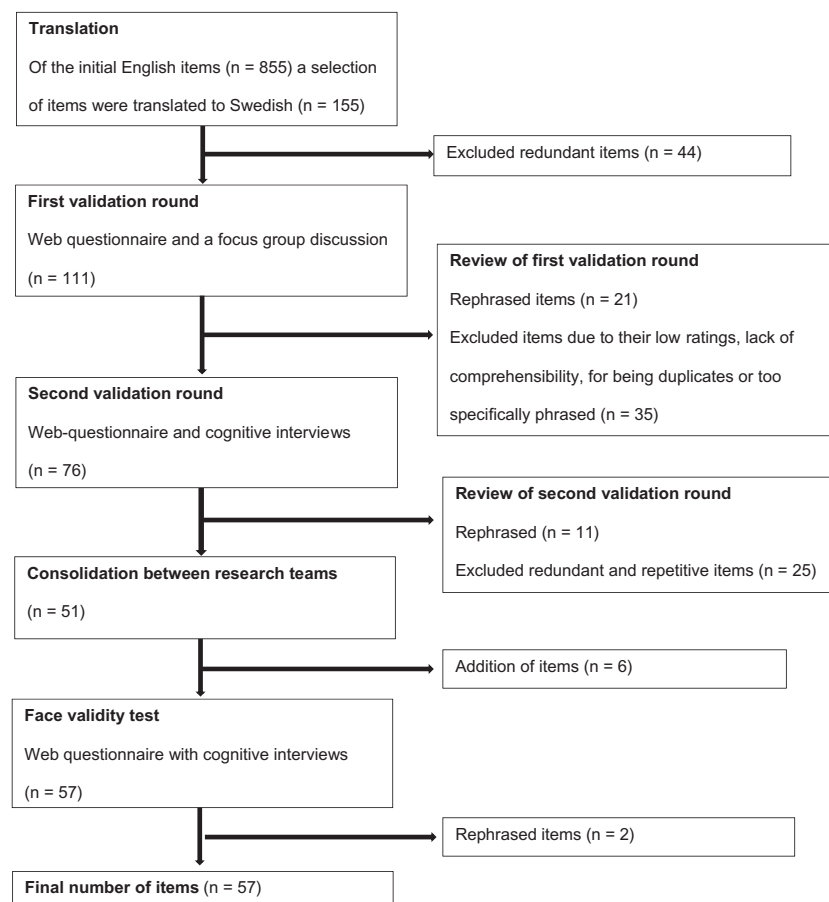


FIGURE 1 Flowchart of the item evaluation process ($n = \text{items}$).

TABLE 1 Participants involved in the validation process of Swedish items.

Background		Round 1		Round 2		Face validity test
		Questionnaire	Focus group	Questionnaire	Interview	Interview
Respondents n		13	3	53	10	5
Gender	Female	9	3	38	9	5
	Male	4	-	14	1	-
Age	<30 yrs	-	-	-	-	1
	30 – 59 yrs	3	-	27	5	-
	60 yrs or older	10	3	26	-	4
Healthcare experience *	Patient	10	3	41	3	5
	Caregiver	10	2	30	1	-
	Healthcare professional	5	2	27	2	-
	Researcher	-	-	23	4	-
Member of a patient association	Yes	9	3	25	2	3
Member of a Patient Council	Yes	13	3	24	1	3

*Can be more than one healthcare experience per person.

the item candidates were given as follows: "I am treated with respect", "My experiences and my concerns are taken seriously", "I am encouraged to ask questions", "I get answers to my questions". The negative ratings were mostly related to comprehensibility and negatively worded items which were clarified in 21 items. Items with low ratings for comprehensibility, relevance or importance were excluded. Items containing complex/rare, reinforcing and emphasising words were discussed and rephrased for clarification purposes. Items that respondents perceived differently or reflected more than one aspect/dimension of PCC were rephrased or removed. When it came to items regarding shared decision-making the participants in the focus group added "informed" to make sure they could respond to that question, "I am informed to make decisions in relation to care or treatments". Some of the terminology was further discussed with the patient representatives for clarification, for example what words to use for "healthcare team", "health care plan", "participation" or "self-care". As one patient said; "Patient participation sounds as if it was a patient who can be allowed to participate in the staff's commitments? I think that in PCC, the starting point is that the staff becomes involved in the patient's health, life and self-management - at least in the case of long-term conditions and more extensive care needs".

Participants in the first web questionnaire (n = 13) and the focus group discussion (n = 3) suggested that the language of some items was outdated and inappropriate for person-centred care. Firstly, this concerned items where patients were presented as passive (e.g. patients obtain, are given, and receive care) instead of active partners in care. Therefore, the research team rephrased the items to reflect

the philosophy in person-centred care, for example "How good was the healthcare professionals at making a plan of action?" was rephrased to "I developed my care plan together with my healthcare team". Secondly, there was an overrepresentation of items of health care professionals "giving" information or the patient "receiving" information, rather than patients providing information, sharing their experience or telling their narrative. Lastly, there were no or few items requesting patients' experiences, goals, capabilities or resources. The review resulted in exclusion of 35 items and 21 items were rephrased, with 76 items remaining. Examples of how the research team excluded or rephrased the items are shown in Table 2.

The second web-based questionnaire with the remaining and rephrased 76 items was emailed to 96 persons of which 53 responded (55%). The responders had different experience of health care as patient (77%), caregiver (56%), healthcare professional (51%) and/or as researcher (43%), see Table 1. Examples of long-term conditions the respondents represented were rheumatic disease, diabetes, stroke, asthma, chronic lung disease, psychiatric disease, Parkinson's disease, spinal cord injury, dementia and various cancer diseases. Ten participants completed the web questionnaire in either a face-to-face or online cognitive interview (Table 1). The interviews lasted between one and two hours. In total, 50 of 76 items received high average scores for importance (4 - 4.5 out of 5). The three highest rated items were "Health care staff listen to what I am saying", "I feel that healthcare staff care for me as a person" and "I am treated in a manner that makes me feel confident in the care I receive". Sixty-seven items received high scores (4 - 4.7 out of 5) when it came to relevance

TABLE 2 Examples of item rephrasing.

Original item/s	Final wording of item
How good was the therapist at making a plan of action?	I developed my care plan together with healthcare staff
Did the HCP help you get all the information you wanted?	I have the information that I need about my care or treatment
I am provided with adequate information about treatment options	I am informed to make decisions in relation to care or treatments
Did the HCP explain how any examinations or tests would take place?	I feel prepared before any test or treatment

for experience of person-centred care. The three highest rated items (4.7 out of 5) were: "I am treated with respect", "Healthcare staff listen to what I am saying", "I feel that I collaborate with healthcare staff when it comes to my care". Several of the participants commented in the questionnaire or interviews that the item list was "very good", "clearly relevant", "good and well thought through" and "captures the essence of personal-centred care". Others perceived some questions not targeted to person-centred care per se, instead exploring a more general healthcare system practice.

Following the results from the second web questionnaire and the cognitive interviews, the item list was revised by the research team and reduced to 51 items. Twenty-five items were excluded most often due to being repetitive and 11 were rephrased. Following participants' suggestions, new six items were added to cover access to care, patient resources and capabilities, mental well-being and support in identifying goals to improve health and well-being.

The final step was five cognitive interviews with patients recruited from a Patient Council. The respondents provided oral feedback and comments about the survey instructions, response options, ease of completing the survey and acceptability of the software. A few technical issues occurred but were resolved and two items were slightly rephrased to avoid misunderstanding. The final list of items is presented in Table 3.

DISCUSSION

Measuring person-centred care is challenging in the absence of a universally agreed definition (7). In this study, our intention was to evaluate patient-reported experience candidate items that probe the three key concepts of the GPCC framework (6) and core domains and subdomains in the P3C framework (5) which are well described elsewhere. Through a thorough evaluation process, a set of 57 item candidates for a future item bank have been evaluated to measure patient experiences of person-centredness and PCC. The items cover the ethical assumptions of PCC such as being seen as a person and that one's experiences,

resources, needs and preferences are recognised and respected. The items cover formal and informal relational aspects and processes of GPCCs three cornerstones by relating to sharing one's narrative, to build a trustful partnership where knowledge, experiences and goals are shared and care co-created and documented. There is also items regarding outcomes like feeling cared for, informed, and involved. For the items to adapt to outpatient care, there are items asking about the impact of health on daily life, involving of relatives, support to self-care, experience of accessibility and coordination of care. For the Swedish healthcare context, the items also cover important aspects of person-centred care from Swedish patient perspective as described in The Swedish Agency for Health and Care Services (4).

A strength of this study was the use of items that originated from existing validated instruments. In the systematic search, instruments were selected because they probed the patient's experience and had been developed to measure person-centred care or a dimension of it (16). This was helpful for guiding words to use in the items. Commonly used words to define person-centred are not words normally used in communication with patients, for example how to ask a patient about his experience of partnership (29) or participation (30,31). Patient engagement was invaluable throughout this study; in the process of identifying which items were important to the experience of PCC, ensuring item relevance to the target population, to find problematic items, and optimising item wording. For the first validation round, we recruited experienced patients who were familiar with working together with health care professionals to improve healthcare and many of the participants were familiar with the concept person-centred care. Due to the amount of items, using the two rounds with web questionnaires was effective and gave the opportunity to involve many stakeholders and produce both quantitative and qualitative data with both ratings and comments for each item. The quantitative data could be interpreted more objectively and provided an indication for the extent to which certain views are shared while the qualitative data provided better understanding of the quantitative findings and discussion (32).

TABLE 3 Final list of the 57 item candidates.

1	I developed my care plan together with healthcare staff
2	I am treated with attention and empathy
3	I am encouraged to ask questions
4	I feel confident communicating with healthcare staff
5	I feel well cared for by healthcare staff
6	I am encouraged to talk about my experiences with my health condition
7	I get the time I need with the healthcare staff
8	I am treated with respect
9	I am asked about aspects of my daily life by healthcare staff
10	I am confident in asking questions about my health
11	I am confident in asking for advice
12	I trust healthcare staff
13	I am treated kindly
14	Healthcare staff understand my situation
15	Healthcare staff explain things to me in an easy and understandable manner
16	I am encouraged to talk about how I experience my symptoms
17	My concerns are taken seriously
18	I feel that healthcare staff care for me as a person
19	Healthcare staff listen to what I am saying
20	I get answers to the questions that I ask healthcare staff
21	Healthcare staff respect the choices that I make
22	I have the information that I need about my care or treatment
23	I know how to contact my healthcare staff when needed
24	I know how to manage my symptoms or side effects when I need to
25	I am involved in decisions concerning my care and treatment (as much as I want and am able to)
26	I am treated in a manner that makes me feel confident in the care I receive
27	My relatives are involved as much as I want
28	I have the opportunity to think carefully about decisions about my care
29	My personal opinions are respected
30	I collaborate with healthcare staff when it comes to my care
31	I am informed to make decisions in relation to care or treatments
32	I discuss my care and treatment options with healthcare staff
33	My personal situation is taken into consideration in my care plan
34	I know how to manage my condition (self-care)
35	I feel prepared before any test or treatment
36	I am asked how my health condition affects my daily life
37	Healthcare staff take time to answer my questions
38	I am aware of the next step in my care or treatment
39	I am asked questions about my own goals (or what I want to achieve) to improve or maintain my health
40	We discuss what is important to me about taking care of my health (self-care)
41	I get the support that I need to manage my health condition (self-care)
42	I am able to discuss the advantages and disadvantages and possible outcomes of treatment with healthcare staff
43	I am encouraged to take care of my health (self-care)
44	Information that is important to me and my situation is documented and shared with healthcare staff
45	I have to repeat myself because healthcare staff do not share information with each other

(Continues)

TABLE 3 (Continued)

46	I receive contradictory information or advice from my healthcare staff
47	I am confident in that healthcare staff know me and my history
48	Important information about what matters to me is missing in my care plan
49	My care is well organised
50	Healthcare staff involved in my care follow the same care plan
51	I am listened to by healthcare staff
52	I can get help when I need it
53	My knowledge of how to manage my health is taken into consideration
54	My capabilities are used in my care plan
55	Healthcare staff support me to identify activities to improve my health and well-being
56	I work with healthcare staff to identify goals to improve my health and well-being
57	My mental well-being is important to healthcare professionals

Limitations in this study were that there was no patient representative in the research team and that there was an overrepresentation of women and people over 60 years evaluating the items. Another limitation could be the amount of items for the responders to evaluate. The items were not presented in any specific domains which made it difficult for the participant to judge if anything was missing. In this study, we did not discuss with the participants how the items would be presented as a “scale” measuring PCC or person-centredness as a higher construct. We also do not know at this stage what items reflect a high quality level of PCC and, conversely what items reflect a low level of PCC? This is an area for future research to explore comparing the results from psychometric testing with a theory of levels of patient perceived PCC.

The results of our data collection confirmed that current measurement of person-centred care identified in earlier instruments lacks an emphasis and relation to the core principles of PCC. We found that existing items were outdated and not representative for a person-centred dialogue or the co-creation of care, for example, in many of the original items patients were addressed as passive recipients of care. There were few items requesting patients’ knowledge, goals, capabilities or resources. To address this, we added new items and reworded existing items to better reflect the ethics in person-centred care where the patient is seen as an active partner in care, resourceful and capable and where communication and information goes two-ways to co-create care (6). One explanation could be that PREMs are often evaluative in that patients are asked to report or provide an account of what happened; “Did the healthcare professionals...?”, “Did you receive information of...?” and that these questions are considered more objective and actionable and less prone to ceiling effects than PREMs that ask patients to rate their experience (33).

One of the challenges we faced was to adapt the items to an outpatient context. Many of the items in our original item list (16) referred to a specific consultation or hospital

visit (16). People with long-term medical condition/s are commonly in contact with more than one healthcare professional, given the importance of collaboration and coordination in between healthcare settings. The “team” around the patient can be various healthcare settings and family/caregivers. Communication may also be via various channels e.g. by mail, telephone call or face-to-face, where the use of remote technology will become increasingly more important. The frequency of contact with their healthcare teams will vary from person to person and over time, hence recall periods require specification. Another challenge in evaluating suitable items were that person-centred interaction and communication in clinical practice will take different forms and mean different things, in different situations, for different individuals. The person responding to the items respond in relation to their own preferences and expectations. For example, a person who needs a lot of information and a person who requires less information should both be able to respond indicating a high score to the question “I have the information that I need about my care or treatment”. A person who wants to be involved in decisions and a person who prefers not to be involved in decisions should both be able to score high on the question “I am involved in decisions concerning my care and treatment (as much as I want and am able to)” because the item is person specific.

CONCLUSIONS AND IMPLICATIONS FOR FUTURE RESEARCH

With the engagement of patients, caregivers, health care professionals and researchers, this study has led to a set of 57 items that has the potential to be used to measure patients’ experiences of person-centred care. The item list can be used in further development of a Swedish and English item bank. Further research and psychometric analysis will show how the items correlate to each other and how

the future item bank will cover a uni- or multidimensional measure of patient's experience of person-centredness and person-centred care.

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Keywords Person-centred care, Patient-reported experience measures, qualitative item evaluation

CONFLICT OF INTEREST

The authors declare that there are no conflicts of interest in this work.

AUTHOR CONTRIBUTIONS

All authors contributed to the study design, conception and development of the manuscript. LR and MH conducted the data collection and the focus group discussion and LR performed interviews and drafted the manuscript. LR and MH made the tables and MH made the figure. All authors were responsible for critical revision and finalising the manuscript.

Ethical considerations

This study was conducted according to the principles of the Declaration of Helsinki and was approved by a Regional Ethical Review Board in Sweden (Dnr 2019-03996).

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