





The empirical evidence underpinning the concept and practice of person-centred care for serious illness: a systematic review

Alessandra Giusti ^{1,2}, Kennedy Nkhoma ¹, Ruwayda Petrus,³ Inge Petersen,³ Liz Gwyther,⁴ Lindsay Farrant,⁴ Sridhar Venkatapuram ², Richard Harding ¹

To cite: Giusti A, Nkhoma K, Petrus R, *et al*. The empirical evidence underpinning the concept and practice of person-centred care for serious illness: a systematic review. *BMJ Global Health* 2020;5:e003330. doi:10.1136/bmjgh-2020-003330

Handling editor Seye Abimbola

► Additional material is published online only. To view please visit the journal online (<http://dx.doi.org/10.1136/bmjgh-2020-003330>).

Received 6 July 2020

Revised 21 October 2020

Accepted 23 October 2020



© Author(s) (or their employer(s)) 2020. Re-use permitted under CC BY. Published by BMJ.

¹Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King's College London, London, UK

²King's Global Health Institute, King's College London, London, UK

³School of Applied Human Sciences, University of KwaZulu-Natal College of Humanities, Durban, South Africa

⁴School of Public Health and Family Medicine, University of Cape Town Faculty of Health Sciences, Cape Town, Western Cape, South Africa

Correspondence to

Alessandra Giusti;
alessandra.giusti@kcl.ac.uk

ABSTRACT

Introduction Person-centred care has become internationally recognised as a critical attribute of high-quality healthcare. However, the concept has been criticised for being poorly theorised and operationalised. Serious illness is especially aligned with the need for person-centredness, usually necessitating involvement of significant others, management of clinical uncertainty, high-quality communication and joint decision-making to deliver care concordant with patient preferences. This review aimed to identify and appraise the empirical evidence underpinning conceptualisations of 'person-centredness' for serious illness.

Methods Search strategy conducted in May 2020. Databases: CINAHL, Embase, PubMed, Ovid Global Health, MEDLINE and PsycINFO. Free text search terms related to (1) person-centredness, (2) serious illness and (3) concept/practice. Tabulation, textual description and narrative synthesis were performed, and quality appraisal conducted using QualSyst tools. Santana *et al*'s person-centred care model (2018) was used to structure analysis.

Results PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow data: n=12,446 studies screened by title/abstract, n=144 full articles assessed for eligibility, n=18 studies retained. All studies (n=18) are from high-income countries, and are largely of high quality (median score 0.82). The findings suggest that person-centred care encompasses the patient and family being respected, given complete information, involved in decision-making and supported in their physical, psychological, social and existential needs. The studies highlight the importance of involving and supporting family/friends, promoting continuation of normality and self-identity, and structuring service organisation to enable care continuity.

Conclusion Person-centred healthcare must value the social network of patients, promote quality of life and reform structurally to improve patients' experience interacting with the healthcare system. Staff must be supported to flexibly adapt skills, communication, routines or environments for individual patients. There remains a need for primary data investigating the meaning and practice of PCC in a greater diversity of diagnostic groups and settings, and a need to ground potential components of PCC within broader universal values and ethical theory.

Key questions

What is already known?

- Person-centred care has become internationally recognised as a dimension of high-quality healthcare, promoted as a core competency of health workers, a key component of primary care and essential to achieving the Universal Health Coverage goals.
- Ongoing conceptual debates are attempting to determine what constitutes 'person-centredness' and how this concept can be understood and implemented in a variety of settings.
- Serious illness is especially aligned with the need for PCC; the complex clinical scenarios surrounding serious illness usually necessitate the involvement of significant others and depend on high-quality communication and joint decision-making to deliver care concordant with patient preferences, with recognition and management of clinical uncertainty.

INTRODUCTION

Person-centred care has become internationally recognised as a dimension of high-quality healthcare.¹ The Institute of Medicine describes quality care as that which is: "safe, effective, patient-centred, efficient, timely and equitable".² WHO policy on people-centred healthcare highlights person-centredness as a core competency of health workers, a key component of primary care, and essential to achieving the Universal Health Coverage goals.^{3–6}

A variety of terms have been used to denote person-centred approaches. 'Patient-centredness' was first to gain prominence and aimed to challenge the reductionism of the biomedical model and stress the importance of psychosocial factors.^{2,3} Many moved towards use of the term 'person-centredness', suggesting this better articulates the holism of the 'whole person' and a broader conception of well-being.^{7,8} In recent years, the term

Key questions

What are the new findings?

- Included studies largely support the Santana *et al* model of PCC and suggest that additional domains should be given visibility: family and friend involvement and support; promoting continuation of normality and self-identity; structuring service organisation to enable continuity of care and patient navigation.
- The empirical data stresses the importance of patients and families being respected, listened to, understood, given honest, complete and comprehensible information and being engaged in all decisions that affect their daily life, care and treatment. Patients must be supported in their physical, psychological, social and spiritual needs.
- All retained studies were conducted in high-income, Western countries.
- Empirical studies present invaluable data on the meaning and practice of PCC, however none develop this evidence into a theorised framework for implementation of PCC for serious illnesses.

What do the new findings imply?

- Person-centred healthcare must value the social network of each patient, promote quality of life and personal goals not only health status improvement, and implement structural reforms to improve patients' experience of interacting with the healthcare system.
- Health systems must be structured to enable sufficient availability and accessibility of health workers, and support staff to be able and willing to flexibly adapt skills, communication, routines or environments for individual patients.
- There is a need for primary data investigating the meaning and practice of PCC in a greater diversity of diagnostic groups and settings, particularly non-Western, low- and middle-income settings.
- There is a need to consider the theoretical underpinnings of PCC and to ground potential components within broader universal values and ethical theory.

'people-centredness' has also gained prominence, emphasising a focus on "the whole person in their specific familial and community contexts".⁹ Person-centred, patient-centred and people-centred care (PCC) all embody an approach that consciously adopts the perspectives of individuals, families and communities, respects and responds to their needs, values and preferences and sees them as participants in their own healthcare rather than just beneficiaries.^{2 10}

Conceptual clarity is critical to the design, delivery and replication of successful innovations in care.¹¹ Despite the global prominence of PCC as a goal of health systems, the approach suffers from a lack of clarity. Ongoing conceptual debates are attempting to determine what constitutes 'person-centredness' and how this concept can be understood and applied in a variety of contexts.^{7 12-14} While numerous conceptualisations of PCC are presented in existing literature,^{8 15-21} most do not appear to offer empirical origins or practical guidance on the implementation of PCC. The WHO *Global strategy on people-centred and integrated health services* recognises that there is not a single model of PCC to be proposed, but rather that it should be context-specific and that each country should generate its own evidence to enable appropriate, acceptable, feasible practice of PCC.¹⁰ It is currently

unclear what evidence is available to model contextually-appropriate and culturally-appropriate PCC.

The need for a person-centred approach is particularly important in the context of serious illness. The complex clinical scenarios surrounding serious illness usually necessitate the involvement of significant others, high-quality communication and joint decision-making to deliver care concordant with patient preferences, with recognition and management of clinical uncertainty.²²⁻²⁴ As populations age, as infectious disease is better managed, and multimorbidity becomes more prevalent, serious health-related suffering associated with conditions such as cancer, chronic lung disease and dementia is rising fastest in low- and middle-income countries (LMICs).²⁵ Serious illness is also a context in which delivering PCC can be more complex and may require more dimensions to a greater degree than for non-serious illness. Focussing specifically on serious illness is therefore a means of 'stress testing' generalist PCC theory and ensuring it captures 'what matters' in all diagnostic cases. A better understanding of PCC in the context of serious illness would have health-system-wide relevance for other less complex clinical scenarios.

This systematic review aims to aggregate and appraise the empirical evidence underpinning the concept and practice of PCC in the context of serious illness. Specifically, the objectives of the review are to answer the following questions:

1. What is the primary data underpinning conceptualisations and practice-based frameworks of 'person-centredness' in the context of serious illness?
2. What is the quality of this data?
3. What are the key constructs of PCC according to this data?

METHODS

This systematic review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) recommendations.²⁶ The review protocol was registered prospectively with PROSPERO: https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=139259 (registration number 139259).

Definition of terms

To structure this review, literature was considered in line with two frequently cited definitions of PCC, one policy-led (using the term 'people-centredness') and one patient-led (using the term 'patient-centredness'):

1. "An approach to care that consciously adopts the perspectives of individuals, families and communities and sees them as participants as well as beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways." (WHO, 2015)¹⁰
2. "Care that is focussed and organised around people, rather than disease. Within this approach disease prevention and management are important but

not enough to address the needs of person, family and community.” (International Alliance of Patients Organisations, 2007)²⁷

These definitions informed the broad review search strategy.

Numerous terms exist relating to person-centred care, including patient-centred, people-centred, patient-directed and so forth. We acknowledge that these various terms have differences in their origins and connotations.²⁸ However, as they overlap significantly and are often used interchangeably we chose to include all terms in the search strategy and analysis. When referring to this approach we chose to use the term ‘person-centred’. In agreement with Ekman *et al*⁸ and The Health Foundation,²⁹ we take that view that the word ‘person’ avoids reducing the individual to a mere recipient of services and better highlights the whole human being with reason, preferences, needs and a social and cultural background.

The review focuses on serious illnesses in line with the following definition: “Serious illness carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments or caregiver stress. This includes conditions not advanced or high dependency/low function that carry a degree of clinical uncertainty” (Kelley *et al*, 2016).³⁰

According to Kelley *et al*'s broadest definition of serious illness, serious medical conditions include: cancer (metastatic or hematological), renal failure, dementia, advanced liver disease or cirrhosis, diabetes with severe complications, amyotrophic lateral sclerosis, acquired immune deficiency syndrome, hip fracture, chronic obstructive pulmonary disease or interstitial lung disease if using home oxygen or hospitalised, and congestive heart failure if hospitalised for the condition.³⁰

Search strategy

The full search strategy is reported in online supplemental appendix A. The following databases were searched on 18 May 2020 with no date restrictions: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Embase, MEDLINE, Ovid Global Health, PsycINFO and PubMed. Forward and backward reference chaining of included articles was performed.

We included free text search terms (title, abstract and keyword search) related to (1) person-centred care/patient-centred care, (2) serious illness and (3) concept or practice (the meaning of PCC or way in which PCC is enacted). Search terms were adapted to each database subject headings and ‘exploded’ terms. The specific serious conditions included were those listed by Kelley *et al*³⁰ within their broad, operationalised definition of serious illness. Please see online supplemental appendix A for full list of search terms and example search strategy.

Data collection and extraction

All potential references identified were exported to EndNote reference manager and deduplicated. The primary reviewer (AG) assessed the titles and abstracts

against the inclusion and exclusion criteria (detailed in online supplemental appendix A). The full texts of remaining references were then similarly screened. Any reference for which inclusion was unclear was agreed through discussion with the secondary reviewer (KN) or adjudicated by a third reviewer (RH) if consensus was not reached. The following variables were extracted from retained studies into a common table: authors, year of publication, country, setting, aim and objectives, study design and methods, sample and main findings.

Quality assessment

We applied Kmet *et al*'s Standard Quality Criteria³¹ to the primary data. The checklists (quantitative data n=14-items, qualitative data 10-items) score each criterion ‘yes’=2, ‘partial’=1 and ‘no’=0. Items deemed not applicable are excluded from the summary score, which ranges from 1 (highest) to 0 (lowest). Online supplemental appendix A further details the method to calculate scores. We did not exclude studies based on quality score. The primary reviewer (AG) assessed the quality of each study. The secondary reviewer (KN) also assessed the quality of n=5 of the studies and met with the primary reviewer thereafter to compare assessments, resolve any discrepancies and enable reflections to be applied to all other studies’ quality assessments.

For quantitative studies, Kmet *et al* propose a cut-off score of 0.75 as the threshold for including a paper in a review.³¹ As our goal was to assess data quality rather than exclude data failing to meet a quality threshold, we used Lee *et al*'s³² definitions for Kmet *et al*'s quality scores; strong (summary score of >0.80), good (summary score of 0.71 to 0.79), adequate (summary score of 0.50 to 0.70) and limited (summary score of <0.50). For qualitative studies, Kmet *et al* use a threshold of 0.55 for inclusion of a study into their systematic review,³¹ therefore we defined qualitative papers with scores of ≥0.55 as ‘adequate quality’ and ≤0.54 as ‘low quality’.

Data analysis

Retained studies were analysed using narrative synthesis in line with Guidance on the Conduct of Narrative Synthesis in Systematic reviews.³³ The preliminary synthesis was performed by tabulation, grouping and clustering.

To synthesise the extracted data the authors adopted a PCC model developed by Santana and colleagues³⁴ (hereafter referred to as Santana model). The Santana model was selected to structure the analysis of retained studies as it provides comprehensive, practical guidance for implementation of PCC, explicitly linking this guidance to the Donabedian model for assessing healthcare quality.³⁵ Santana *et al*'s model was generated through a narrative review and synthesis of evidence, recommendations and best practice from implementation case studies, as well as existing frameworks. However, besides the consultation of a patient representative, there is limited voice of patients and families informing the model. The model's authors suggest validation of the framework with

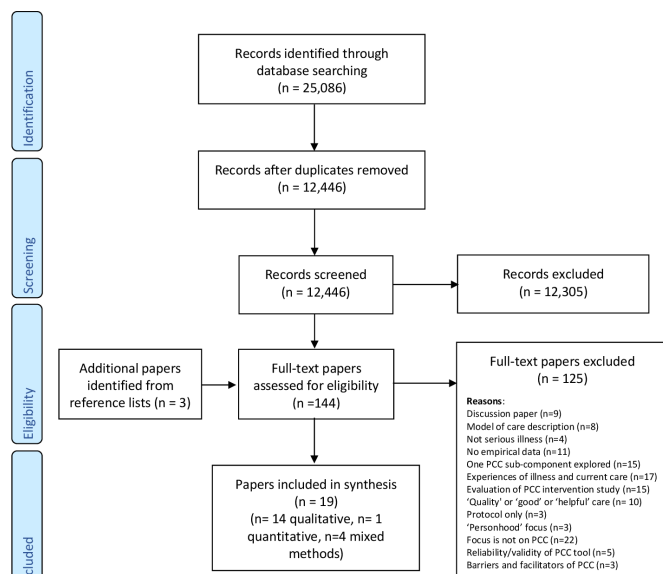


Figure 1 PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2009 flow diagram.

additional diverse patient perspectives and to identify any necessary revisions or additions.³⁴

The components of the Santana model were used to construct an a priori coding frame for deductive analysis of the study findings retained in this systematic review (see online supplemental figure 1 for a priori coding frame). Findings that did not fit into the a priori frame were inductively coded into new codes. The primary reviewer (AG) coded the data using NVivo V.12 software, coding data that did not fit into the a priori frame into additional 'Other' nodes. The primary reviewer reviewed the contents of these 'Other' nodes throughout the analysis, generating new inductive codes where new themes appeared and revising or adding to these as more data was coded. New inductive codes were reviewed by the second and third reviewers (KN and RH), and discussed until consensus on new code meanings and labels was reached.

Patient and public involvement

Patient and public involvement was not conducted as part of this review.

RESULTS

The search summary flowchart following PRISMA guidelines is presented in figure 1. The search yielded 12,446 references following deduplication, and 18 studies/n=19 papers^{36–54} were retained and synthesised in this review. The characteristics of included studies are summarised in box 1. Further detailed characteristics of each included study are presented in online supplemental table 1, with Kmet *et al*'s³¹ data quality score.

Synthesis of included studies' findings

Patient-family-provider relationship

Overall, the findings suggest that PCC encompasses empowerment of both the patient and their family by

Box 1 Characteristics of included studies

Countries and settings

All retained studies (n=18/18) reported data from high-income, Western countries.

- The Netherlands (n=5/18)^{36–40}
- Canada (n=3/18)^{41–43}
- Australia (n=3/18)^{44 45 49}
- USA (n=2/18)^{46 50}
- UK (n=1/18)⁴⁷
- Ireland (n=1/18)⁵³
- Norway (n=1/18)⁴⁸
- Sweden (n=1/18)⁵⁴
- Germany (n=1/18 study reported in n=2/18 papers)^{51 52}

Healthcare settings

- Hospital wards (n=5/18)^{37 38 41 47 48}
- Residential aged care facilities (n=3/18)^{44 45 54}
- Outpatient clinics (n=2/18)^{36 50}
- Nursing homes (n=1/18)⁵³
- Cancer centre (n=1/18)⁴²
- Academic cancer institution (n=1/18)⁴³
- Unknown/combination (n=5/18 studies reported in n=6/19 papers)^{39 40 46 49 51 52}

Diagnostic groups and healthcare professionals

- Cancer (n=10/18 studies reported in n=11/17 papers)^{36 38 39 41–43 48–52}
- Dementia (n=4/18)^{44 45 53 54}
- End-stage renal disease (n=1/18)³⁷
- Palliative or end-of-life care (n=2/18)^{40 46}
- Mixed diagnostic groups experiencing acute care (n=1/18)⁴⁷

Participant groups included

- Healthcare professionals (n=14/18 studies reported in n=15/18 papers)^{37 39–47 49 51–54}
- Patients (n=10/18)^{36–39 42 44 48–50 54}
- Caregivers (n=3/18) studies included^{42 44 49}
- Volunteers working in palliative care (n=1/18)⁴⁰

Study designs

Qualitative designs (n=13/18):

- Semi-structured interviews (n=11/18 studies reported in n=12/19 papers)^{36 38 43–49 51–53}
- Focus groups (n=2/18)^{43 47 50}
- Case studies (interview and observation) (n=1/18)⁴¹
- Mixed qualitative methods (posters and interviews, n=1/18)⁴² interviews and focus groups, (n=1/18)⁴⁹

Quantitative design (n=1/18):

- Survey (n=1/18)⁵⁴

Mixed-methodology designs (n=4/18):

- Q methodology (n=2/18)^{37 40}
- Questionnaire (n=1/18)³⁸
- Delphi method (n=1/18)³⁹

Term used to refer to the PCC approach

- Patient-centred care (n=8/18)^{36–40 48–50}
- Person-centred care (n=7/18)^{42 44 45 47 49 53 54}
- Patient-centred and family-centred care (n=1/18)⁴³
- Client-centred care (n=1/18)⁴⁶
- Individualised integrative care (n=1/18 reported in n=2/18 papers)^{51 52}
- Interprofessional patient-centred care (n=1/18)⁴¹

Kmet Data Quality Scores

Continued

Box 1 Continued

Range=0.35 to 0.95 (possible range: 0 to 1)

Median=0.82

Qualitative studies and qualitative component of mixed-methods studies (n=17/18):

► n=17 scored ≥ 0.55 (adequate quality)

► n=1 scored ≤ 0.54 (low quality).

Quantitative studies and quantitative component of mixed-methods studies (n=5/18):

► n=4 scored >0.80 (strong)

► n=1 scored 0.71–0.79 (good)

Summary of aims and research questions of studies retained in this review

► n=8/18 studies included an objective to investigate what is understood by the term PCC or what PCC should consist of in practice.^{37 40 42 44–48}

► n=3/18 studies focused on patients' experiences and expectations of care in relation to predetermined ideas of PCC components.^{36 49 50}

► n=2/18 studies aimed to develop PCC indicators.^{38 39}

► n=2/18 studies (reported in n=3/17 papers) aimed to investigate how teams that identify as providing PCC practice their care.^{41 51 52}

► n=2/18 studies aimed to investigate clinicians' knowledge and attitudes towards PCC.^{43 53}

► n=1/18 study aimed to identify the organisational, environmental, resident and staff variables associated with aged care units with higher perceived levels of PCC.⁵⁴

being respected,^{40 41 48 50 53} listened to,^{36 37 47 48} understood,⁴⁷ given honest, complete and comprehensible information^{36 37 39–41 43 48 49} and by being engaged in treatment decisions and all decisions that affect their daily life and care.^{36 37 42 46 48 50 51} This requires collaborative, trusting relationships to be developed between patients, families and clinicians,^{40 47 49–51} which rely on clinicians' communication skills,^{39 43 49} attitude⁴¹ and demonstrable compassion,⁴² for example, by comforting nervous patients.³⁶ The studies highlighted specific patient information needs, for example, using diagrams or drawings to aid comprehension, using accessible language, providing information about the possible course of the disease and information about the treatment option of 'no active therapy'.^{38 49} It was also raised that patients should be given the necessary information, education and support to enable self-management.³⁹

A further dominant theme was the importance of involving and supporting the patient's family, friends or significant others,^{36 44 46 47 49} although some patients may deem this a lesser priority.^{37 40}

In addition to physical symptom control, the studies suggest patients must also be supported in their psychological, social and spiritual needs,^{39 40 45 49 51 52} with great attention to all needs and aspects of care that are important to the person.^{36 42 46 47} Sufficient time^{51 52} and availability of staff⁴¹ was identified as crucial to address these needs.⁵⁴ This also requires flexibility and willingness to adapt skills, routines or environments for individual patients.^{44 46}

Several studies' findings placed weight on promoting autonomy, continuation of self and normality and enabling patients to participate in life.^{44 45 52 53} This was particularly highlighted in studies focussed on dementia patients and nursing homes,^{44 53} where a dementia-friendly physical environment was also deemed important.⁵⁴

Organisational level requirements

On an organisational level, PCC was reported to demand a shared philosophy of care,⁵⁴ satisfactory leadership, support from colleagues and continuing education and mentorship of staff.⁵⁴ PCC was seen as requiring interdisciplinary collaboration,^{51 54} and consistency and regularity in collaboration of all members of a care team.⁴¹ Furthermore, all staff (not only front-line) were deemed responsible for providing person-centred care.⁴² Included studies highlighted the importance of the coordination and continuity of patient care^{44 49} and of streamlining care delivery,⁴³ for example, by having nursing staff provide additional teaching following the physician visit,⁴³ or appointing each patient a care coordinator.^{37 39 49} Studies also indicated the importance of enhancing accessibility of healthcare services and considering logistical barriers, such as lack of transport or financial resources.⁴⁹

Complementary findings across participant groups, across countries and across PCC terms

There were no clear discrepancies between the findings of studies incorporating patient participants, caregiver participants or healthcare professional participants. The heterogeneity of studies did not permit analysis to determine difference between countries or regions. However, the study conducted with indigenous Australian populations reported study-specific findings such as the high financial burden of accessing care and the importance of feeling 'culturally safe' within the healthcare system.⁴⁹ There was also no evidence of consistent differences between findings from studies using different terms within the PCC consortium, that is, patient-centred care, patient-centred and family-centred care, client-centred care and so on. Based on the WHO definition of 'people-centredness', we hypothesised that this term has conceptual differences to person-centredness and patient-centredness and wished to investigate what these may be. However, as none of the retained empirical studies used this term we did not have the opportunity to investigate this.

Domains of Santana model supported by included studies' data

The data from included studies largely supported the Santana model components (online supplemental table 2), providing more detail about the specific meanings of subdomains, and suggesting relationships between concepts. This is particularly the case for many of the model's Process dimensions which saw numerous corresponding data codes, for example, *Being responsive to*

Table 1 Santana model domains with no assigned codes from included studies:

Structure	<p>“S1a. Core values and Philosophy of the organisation” subdomains:</p> <ul style="list-style-type: none">▶ “Vision and mission”▶ “Patient and healthcare provider rights” <p>“S1b. Establishing operational definition of PCC” subdomains:</p> <ul style="list-style-type: none">▶ “Consistent operational definitions”▶ “Common language around PCC” <p>“S2. Co-designing the development and implementation of educational programs” subdomains:</p> <ul style="list-style-type: none">▶ “Standardised PCC training in all healthcare professional programs”▶ “Professional education and accrediting bodies” <p>“S3. Co-designing the development and implementation of health promotion and prevention programs” and all sub-domains</p> <p>“S4a. Ensure resources for staff to practice PCC” and subdomain:</p> <ul style="list-style-type: none">▶ “Provide adequate incentives in payment programs; celebrate small wins and victories” <p>“S5. Providing a supportive and accommodating PCC environment” subdomains:</p> <ul style="list-style-type: none">▶ “Collaborate with and empower patients and staff in designing healthcare facilities”▶ “Facility that prioritise the safety and security of its patients and staff”▶ “Spiritual and religious spaces”▶ “Patient-directed visiting hours” <p>“S6. Developing and integrating structures to support health information technology” and all subdomains</p> <p>“S7. Creating structures to measure and monitor PCC” and subdomain: “Co-design and develop framework for measurement, monitoring and evaluation”</p>
Process	<p>“P2b. Providing resources”</p>
Outcome	<p>“O2b Patient-Reported Experiences (PREMs)” and subdomain: “Recommendation or rating of hospital, healthcare provider”</p> <p>“O2c. Patient-Reported Adverse Outcomes (PRAOs)” and subdomains:</p> <ul style="list-style-type: none">▶ “New or worsening symptoms”▶ “Unanticipated visits to healthcare facilities”

preferences, needs and values; Sensitivity to emotional or psychosocial needs; Sharing information; Shared decision-making.

Understanding patient within his or her unique psychosocial or cultural context is an example of a Santana model domain that is better specified through the included studies’ findings. Findings related to this domain suggest that clinicians should show interest in the person as a whole and gain an understanding of their psychological and emotional health, spiritual and existential issues, living conditions, financial situation, social support system, culture, personal identity and daily routines and activities. This knowledge should then be translated into tailored care, perhaps providing emotional support from nurses, referring to appropriate specialists, considering patient convenience and resource availability when ordering investigations and initiating conversations and activities that may be meaningful to a particular patient.^{36 38 39 42–47 49 51 52}

Domains of Santana model left unpopulated by included studies’ data

Table 1 presents domains of the Santana model for which no corresponding study data was found. Predominantly, the Structure components of the Santana model were unpopulated by findings from the 16 studies. This includes domains such as “S3. Co-designing the development and implementation of health promotion and prevention programs”, and “Spiritual and religious spaces”. “P2b. Providing resources” was the only Process domain to

be left unpopulated by the data. Outcome dimensions “O2b Patient-Reported Experiences (PREMs)” and “O2c. Patient-Reported Adverse Outcomes (PRAOs)” were left with no corresponding findings from included studies.

Model adaptation: evidence additional to Santana model domains

Additional units of meaning arose from the included studies that are currently lacking in the Santana model: *Family and friend involvement and support, Promoting continuation of normality and self-identity and Structuring service organisation to enable continuity of care and patient navigation.* Table 2 presents these inductively-identified additional themes with examples of corresponding codes from supporting studies. Table 3 presents an adapted version of the Santana framework incorporating these additional themes.

Specifically, *Family and friend involvement and support* was described as: inviting the patient to bring someone to appointments;³⁹ establishing conversation with family/friends;⁴² involving family/friends in information-sharing and decisions regarding the patient’s care;³⁷ providing family/friends with opportunities to ask specialists and nurses questions;³⁸ respecting the opinions and worries of friends/family;³⁶ acknowledging family/friends in their role as carer for the patient;^{37 44} and involving family/friends at all stages including long-term care, treatment and follow-up.³⁸ Being involved was deemed to

Table 2 Inductively-identified themes additional to Santana model with corresponding codes (see online supplemental table 2 for full table of studies' findings deductively mapped onto Santana model and inductively mapped onto additional themes)

Inductively-identified themes additional to Santana model		Number of supporting studies	Examples of corresponding codes from supporting studies
Family and friend involvement and support	11 36–40 42 44 46 47 49 51		<p>"Involving the family is a massive part of person-centred care, as their family know everything about them; they just know them inside out..." (Registered nurse 4). (Ross et al, 2015, p1228; Quality score 0.8)⁴⁷</p> <p>Welcoming family was described as developing and maintaining trust in that the staff would actively communicate changes and significant events to the family; so that they did not have to constantly seek out information by making phone calls or asking the staff when they visited. Welcoming family was also described by staff as creating opportunities for beneficial teamwork, so that the family's unique knowledge about the person with dementia could be incorporated into care plans.⁴⁴ (Edvardsson et al, 2010, p2614; Quality score 0.8)⁴⁴</p> <p>Respondents in both views state that it is important to attend to the preferences of patients first, and to those of the family thereafter... 'Of course there are some meetings involving the whole family, but ultimately, it is the patient who decides and not the family' (respondent 13).⁴⁰ (Galekop et al, 2019, p4; Quality score 0.95 (qualitative), 0.85 (quantitative))⁴⁰</p> <p>The involvement and respect to the opinions and worries of friends and family was considered very important for the majority of patients.³⁶ (Bisschop et al, 2017, p2250; Quality score 0.85)³⁶</p> <p>(Suggested patient-centred cancer care indicators): Family and friends had opportunities to ask the specialists questions; Family and friends had opportunities to ask the nurses questions.³⁸ (Ouwens et al, 2010, p126; Quality score 0.65 (qualitative), 0.78 (quantitative))³⁸</p> <p>C2. The care provider should gather information on the psychosocial and emotional health status of family and friends of the patient and adequately refer to specialists, depending on the diagnosed problems. (One of final set of approved quality indicators),³⁹ (Uphoff et al, 2011, p35; Quality score 0.8 (qualitative), 0.88 (quantitative))³⁹</p> <p>It was noted that carers undergo sustained periods of dealing with multiple stressors, combined with a lack of attention to their needs and their welfare and little-to-no follow-up, and that this contributed to a sense of being disregarded once the person being cared for had passed away or had reached a less acute stage. "... the carer is the one that carries the load. You know they're the ones that are looking after the sick person as well as trying to manage family." (103 Both).⁴⁹ (Green et al, 2018, p8; Quality score 0.85)⁴⁹</p>

Continued

Table 2 Continued		
Inductively-identified themes additional to Santana model	Number of supporting studies	Examples of corresponding codes from supporting studies
Promoting continuation of normality and self-identity	8 <small>37 38 44–46 49 51 52</small>	Themes and goals centred on understanding “disease as a path/journey”; to “live as a human being” by participating in life despite the disease; to regain activity, control and hope. ⁵¹ (Kienle et al, 2016, p483, Quality score 0.9) ⁵¹
▲ Support for participating in regular personal life activities		The overarching themes of doctors were to help patients live with the disease and find their own way through it; to encourage them to participate in life and regain autonomy and a sense of control and self-efficacy. ⁵² (Kienle et al, 2018, p128; Quality score 0.9) ⁵²
▲ Providing meaningful activities for inpatients		For instance, some patients were not afraid of death but rather of losing certain sensibilities or fine cognitive functions: “For instance a patient with advanced oesophagus carcinoma wished to write several publications; he had a spiritual orientation and rejected chemotherapy because he feared cognitive impairments and emotional constraints; with regular intrasoesophageal mistletoe extract injections the oesophageal stenosis reopened, the patient could eat and kept well for a substantial time with a good quality of life and pursued his writing and publishing activities.” (Gastroenterologist), ⁵¹ (Kienle et al, 2016, p482, Quality score 0.9) ⁵¹
		Individually targeted activities were described not only as providing a meaningful content to the day, but also as a means in reaffirming the residents as individual persons who were able to do the things they enjoyed. Family and staff further described that such activities preferably were adapted to the individual person’s ability so that their self-esteem could be boosted by the successful completion of activities, rather than feeling defeated and demoralised by being expected to undertake something that was beyond their capability. ⁴⁴ (Edvardsson et al, 2010, p2615; Quality score 0.8) ⁴⁴
		Two of the participants suggested that in their client-centeredness they ‘manipulated’ the situation to enable choices, but ones that further occupationally engaged their clients. One participant expressed that the development of the emotional climate or helping people at the end of life engage in full expression of themselves was client-centred and family-centred. ⁴⁶ Pizzi, 2015, p446; Quality score 0.65) ⁴⁶

Continued

Table 2 Continued

Inductively-identified themes additional to Santana model	Number of supporting studies	Examples of corresponding codes from supporting studies
Structuring service organisation to enable continuity of care and patient navigation	10 36–38 41 43 44 46 47 49 51	<i>Using multidisciplinary clinics to decrease wait times and patient anxiety between specialist referrals; Having nursing staff provide additional teaching following the physician visit. (Physician identified patient- and family-centred strategy pertaining to streamlining care delivery.)</i> ⁴³ (Nguyen et al, 2017 (online supplemental table 2); Quality score 0.65) ⁴³
▲ Simplification of care pathways to ease patient navigation		<i>The complex organisation of services could also affect the experience of care. Another family member summarised this: “The system(the oncology clinic) is so complicated that it’s like swimming in molasses. (Family member 3)”</i> ⁴¹ (Bilodeau et al, 2015, p109; Quality score 0.7) ⁴¹
▲ Appointment system structured to allow patients to see same professionals over time		<i>The most prominent negative experiences noted were due to seeing different doctors at subsequent appointments: “We had an appointment with our doctor, but then we received a message that a new doctor was scheduled to help us that day. We really did not like that, especially because he had to tell us new test results and the prognosis. There was no explanation; they only told us our regular doctor was absent.”</i> (Respondent 12) ³⁶ Bisschop et al, 2017, p2250; Quality score 0.85) ³⁶
▲ Structures enabling flexibility in service delivery and care practice. Establishing cooperation pathways across specialisms and institutions		<i>Mostly in data from staff and family, it emanated that to be person-centred, aged care facilities need to have flexible routines adapted to the person with dementia’s needs rather than the needs of staff, especially in relation to staffing, care tasks and activities.</i> ⁴⁴ (Edvardsson et al, 2010, p2616; Quality score 0.8) ⁴⁴
		<i>Some doctors worked in a cancer centre...the others cooperated with oncologists, surgeons, radiotherapists, and other relevant specialists, often referring patients to each other. This cooperation was usually described as positive: “These centres know me all for long... they know that I know exactly what they do... it functions well”</i> (Paediatrician). ⁵¹ (Kienle et al, 2016, p488, Quality score 0.9) ⁵¹

Table 3 Adapted Santana framework incorporating additional themes from the empirical evidence (presented in bold text)

Structure	Process	Outcome
S1. Creating a PCC culture subdomain S1a. Core values and philosophy of the organisation S1b. Establishing operational definition of PCC	P1. Cultivating communication P1a. Listening to patients P1b. Sharing information P1c. Discussing care plans with patients	O1. Access to care O1a. Timely access to care Components O1b. Care availability O1c. Financial burden
S2. Co- designing the development and implementation of educational programs Standardised PCC training in all healthcare professional programs	P2. Respectful and compassionate care P2a. Being responsive to preferences, needs and values P2b. Providing supportive care	O2. Patient-Reported Outcomes (PROs) O2a. Patient-Reported Outcomes Measures (PROMs) O2b. Patient-Reported Experiences (PREMs) O2c. Patient-Reported Adverse Outcomes (PRAOs)
► Training in holistic perception of human organism ► Training for non-clinical staff in providing compassionate and co-ordinated PCC	P2c. Promoting continuation of normality and self-identity ► Support for participating in regular personal life activities ► Providing meaningful activities for inpatients	
S3. Co- designing the development and implementation of health promotion and prevention programs S3a. Collaboration and empowerment of patients, communities and organisations in design of programs	P3. Engaging patients in managing their care Co-designing care plans with patients	
S4. Supporting a workforce committed to PCC S4a. Ensure resources for staff to practice PCC S4b. Ensure strong team leadership around PCC	P4. Integration of care Communication and information sharing for coordination and continuity of care across the continuum of care ► Between healthcare providers ► Referrals to specialist ► Discharge communication ► Providing access to information and resources ► Cooperation across specialisms and institutions	
S5. Providing a supportive and accommodating PCC environment S5a. Designing healthcare facilities and services promoting PCC S5b. Integrating organisation-wide services promoting PCC		
S6. Developing and integrating structures to support health information technology Common e-health platform for health information exchange across providers and patients		
S7. Creating structures to measure and monitor PCC performance Co-design and develop framework for measurement, monitoring and evaluation		
S.8 Structuring service organisation to enable continuity of care and patient navigation S8a. Amplification of care pathways to ease patient navigation S8b. Appointment system structured to allow patients to see same professionals over time S8c. Structures enabling flexibility in service delivery and care practice. S8d. Establishing cooperation pathways across specialisms and institutions	P5. Family and friends' involvement and support P5a. Involving family/friends in information-sharing and decision-making P5b. Addressing the needs of family/friends	

avoid feelings of anxiety among family^{44 49} and aid the patient emotionally, practically and in understanding and reflecting on information provided by clinicians.^{49 51} This domain of PCC also requires healthcare professionals to pay attention to the needs of family/friends of the patient,^{37 46 49} including providing accommodations in or near the hospital during treatment if possible,^{37 49} and gathering information on the emotional health of family/friends and referring to specialists as appropriate.³⁹ It is worth noting that some patients and professionals may place this need as a low priority compared with other PCC domains.^{37 40}

Promoting continuation of normality and self-identity was discussed as requiring encouragement and enablement of persons with serious illness to participate in life despite the disease, and to regain a sense of control and self-efficacy.^{51 52} This requires the clinician to consider a patient's life goals and self-identity when discussing care and treatment options.⁵¹ For long-term inpatients, particularly those with dementia, arranging and enabling meaningful activities was also viewed as a critical part of PCC. Creating individually targeted activities were described not only as providing a meaningful content to the day, but also as a means in reaffirming the residents as individual persons who were able to do the things they enjoyed.⁴⁴

Structuring service organisation to enable continuity of care and patient navigation encapsulates a collection of studies' findings highlighting the importance of streamlining and easing patient navigation, ensuring continuity of care and simplifying the process of multi-specialist care. Suggestions for enabling this included appointing each patient a care coordinator or liaison officer,^{37 41 49} ensuring patients see the same professionals over time^{36 41 44} using multi-disciplinary clinics to decrease wait times and patient anxiety between specialist referrals,⁴³ and arranging for nursing staff to provide additional information or education following a physician visit.⁴³

DISCUSSION

This review has revealed that a number of different constructs underpin the meaning and practice of PCC in the research evidence. These include patient and family empowerment and autonomy through respectful communication, appropriate information sharing and shared decision-making, addressing psychological, social, spiritual and cultural needs and enhancing coordination and continuity of care. The findings of this review indicate that person-centred healthcare must value the social network of each patient, and should promote quality of life and personal goals, not only health status improvement. This implies that person-centred health systems should be structured with flexible health workforce capacity and support staff to adapt skills, communication, routines or environments for individual patients and their families.

The studies' findings largely validate the domains of the Santana framework of PCC, supporting their importance and providing more detail about specific meanings and subcomponents. The empirical findings of included studies also highlight new PCC themes additional to the Santana model. In focussing on serious illness, this review provides insights into the meaning of PCC that other, less severe conditions may not draw attention to.

The additional theme from included studies' findings: *Family and friend involvement and support*, is in line with several other prominent conceptualisations of PCC.^{2 16 55} It particularly aligns with conceptualisations that focus on 'people-centred' care, such as that by the WHO, bringing attention to the health of people within their full social circles and communities.^{56 57} The vast majority of everyday care is often undertaken by patient's families and social networks. Enabling families and friends to be active participants in a patient's healthcare should therefore rightly be a key goal of person-centred health systems reform.

Included studies also indicate PCC as enabling patients to continue to participate in daily life and meaningful activities, promoting continuation of self, personal identity and normality. This finding emphasises that patients' highly value quality of life and continuation of their normal lives, not only health status improvement. This supports the idea that PCC involves striving to avoid damage to personal identities that the person values,⁵⁸ and ties into findings from research with frail populations showing patients value care that supports 'getting back to normal' or 'finding a new normal'.⁵⁹ This finding also overlaps with a dimension of Mead and Bower's patient-centredness framework: the 'patient-as-person', which places focus on the individual's experience of illness and the impact of illness on the individual's life or sense of self.¹⁵

The third additional theme: *Structuring service organisation to enable continuity of care and patient navigation*, places particular weight on the organisational and structural reforms that are needed to enable person-centred, care-continuity processes. It highlights that PCC requires not only aspects of the clinician-patient interaction to reform, but also the experience the patient has in interacting with the wider healthcare system. Continuity of care has been presented within other prominent conceptualisations of PCC^{17 17 18 55 55} however the specific structural features needed to enable this are rarely discussed. This review's findings point towards some practical steps for achieving this, such as appointing each patient a care coordinator or arranging for nursing staff to provide additional teaching following a physician visit.

Strengths and limitations

The literature search conducted was comprehensive, considered numerous synonyms for PCC and involved no country or year of publication restrictions. This review also benefitted from interdisciplinary, multinational co-authors, allowing a range of perspectives and

cultural viewpoints to inform the analysis and discussion. However, the review does suffer some limitations. First, only peer-reviewed studies published in English were included. Second, the review research questions and search strategy relating to 'practice' may have contributed to the lack of supporting data for structure and outcome domains of the Santana model. Third, only publications that included the term 'person-centred' (or synonym) were included. Research has certainly been conducted in non-Western LMICs that could inform models of PCC, for example, studies investigating 'good communication skills' or 'empathetic care'. However, searching terms related to, in addition to near synonyms of, PCC would have deemed this review unfeasible. Our aim was to understand PCC as it is currently described.

CONCLUSIONS; IMPLICATIONS FOR PCC RESEARCH, POLICY AND PRACTICE

This review indicates that there is a stark absence of theoretical models of PCC for serious illness that are grounded in empirical data. Future research should aim to generate theoretically-underpinned empirical frameworks for clinicians and policy makers on how to implement PCC through relevant, appropriate healthcare delivery.

It would also be insightful for future studies to further investigate the aforementioned PCC domains additional to the Santana model to validate whether these domains should constitute PCC components, and if so, what the specific, operationalisable actions within those components should be. One particular additional theme, *Involving and supporting the patient's family and friends*, unsurprisingly surfaced most clearly in studies that included caregivers as participants (n=3). This highlights the importance of including this participant group in further empirical studies.

The included studies add depth and detail to existing Santana model domains, such as: *Understanding patient within his or her unique psychosocial or cultural context*. The findings related to this domain recognise that much of health is determined outside the clinic by social situations beyond the patient-clinician interaction, such as education, employment, income, housing, social support and gender.⁶⁰ Acknowledging and addressing these social determinants of health are critical to delivering PCC. Healthcare professionals must be given the support, tools and structures to actively engage with these social determinants of a person's health and illness. However, this finding also raises the wider question of where the responsibility of PCC lies and how much of this rests with the individual clinic and clinician. Certain socially determined aspects of patient health can be positively influenced by a healthcare professional, others cannot. Consideration is needed about how and when clinicians should go beyond the clinic, and how to involve any external actors in contributing towards better patient health outcomes.⁶¹ We must reflect on how a practice-based theory of PCC

should sit within the broader socio-economic and cultural environment in which a health system operates.

Included studies also strongly support Santana model domains revolving around information sharing, shared decision-making and clinicians taking the time to properly understand each patient's needs. This reaffirms the importance of in-depth holistic assessment of the patient and the need to empower patients and families through health literacy, equipping them with the knowledge to make informed decisions.⁶²

Several Outcome and Structure components of the Santana model were left unsupported by findings from the studies. This is not to say that those subdomains are unimportant, but that evidence to support them is lacking, and that patients, caregivers and professionals are most immediately exposed to, and concerned with, discussing processes. Future primary research with healthcare managers or policy makers should specify important structural and outcome domains. However, we could also perhaps infer that patients and caregivers facing serious illness are as, or even more, concerned with the quality of *processes* than with the outcomes which are most often the focus of healthcare improvement efforts. This suggests we should value process improvements as we value outcome improvements and should value the processes of person-centred care in and of themselves rather than just as a means to a series of outcomes. This supports ethical arguments that we should recognise the intrinsic, not just instrumental, value of PCC, and should pursue it as a valued quality and ethical domain in its own right.^{13 58}

The lack of study findings corresponding to some Structure components of the Santana model may also be a result of the lack of diversity in settings and diagnostic groups of included studies. The components left unpopulated by the studies' findings appear to be those less relevant among the diagnostic groups and high-income settings of included studies. For example, *Facility that prioritises the safety and security of its patients and staff* is less likely to be voiced as a concern in high-income settings with lower rates of violent crime and civil unrest. *Health promotion* is an element of PCC that seems less poignant in cases of patients with end-of-life cancer and dementia; this topic may be of greater relevance in other serious conditions that are more responsive to lifestyle factors, such as chronic obstructive pulmonary disease. More empirical work is needed to confirm whether these components are of importance, what these components consist of and how they should be operationalised in day-to-day practice. This empirical investigation would be most insightful if conducted in a diverse range of contexts within which these components are likely to be more relevant.

PCC is an approach that evolved from high-income countries, and African theorists have questioned the relevance of Eurocentric conceptualisations and noted the absence of data to understand the meaning, feasibility and acceptability of PCC in non-Western LMICs.⁶³ This is

unsurprising given existing biases in healthcare research towards high-income countries, and limited resources and platforms for LMICs to conduct and promote this research. In the context of fewer resources, PCC may also be mistakenly perceived as a ‘nice-to-have luxury’ rather than a ‘need-to-have necessity’ and may be challenging to promote in settings with a history of disease-specific, vertical programmes. However, the lack of diversity in study countries raises questions about how both Santana model domains and additional themes could be conceptualised and operationalised globally, in a diversity of settings. Successful enactment of person-centred care would require a multitude of contextual and cultural factors to be considered and accommodated. For example, as Markus and Kitayama⁶⁴ discuss, the dominant construal of *self* differs between Western and other contexts. Western notions of the ‘self’ are that of an individual independent agent, while in most non-Western societies the ‘individual’ is more integrated with significant others. A patient with more interdependent views of self may be highly concerned with harmonising relationships and views. This has very real implications for the clinician–patient interaction and how to best practice involvement and support of a patient’s family and wider social network. Data from more individualistic cultures, such as that from the included Galekop *et al* study,⁴⁰ may suggest that ‘there are some meetings involving the whole family, but ultimately, it is the patient who decides and not the family’. In a more collectivist culture, however, great importance may be placed on collective decision-making and the impacts of illness on a person’s network,⁶⁵ and thus, person-centred care would need to enable this. We must carefully consider the underlying values and determinants of culture in order to ensure cultural sensitivity in PCC theory.^{58 66} A global theory of PCC and resulting policy would need to accommodate different beliefs and worldviews and centre around a common set of human values.

Twitter Kennedy Nkhoma @KennedyNkhoma6 and Sridhar Venkatapuram @sridhartweet

Contributors AG planned, conducted, reported and submitted this systematic review, and is responsible for the overall content as guarantor. KN assessed the quality of a subselection of included studies and compared assessments with AG. KN and RH reviewed the work as required. RP, IP, LG, LF and SV contributed to design and interpretation. KN, RH, SV, RP, IP, LG and LF approved the manuscript.

Funding This research was partly funded by the National Institute of Health Research (NIHR) Global Health Research Unit on Health System Strengthening in sub-Saharan Africa, King’s College London (GHRU 16/136/54) using UK aid from the UK Government to support global health research.

Competing interests None declared.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as supplementary information. This paper is a systematic review and does not report novel primary data.

Supplemental material This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and

responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution 4.0 Unported (CC BY 4.0) license, which permits others to copy, redistribute, remix, transform and build upon this work for any purpose, provided the original work is properly cited, a link to the licence is given, and indication of whether changes were made. See: <https://creativecommons.org/licenses/by/4.0/>.

ORCID iDs

Alessandra Giusti <http://orcid.org/0000-0003-2667-1665>

Kennedy Nkhoma <http://orcid.org/0000-0002-2991-8160>

Sridhar Venkatapuram <http://orcid.org/0000-0003-3076-0783>

Richard Harding <http://orcid.org/0000-0001-9653-8689>

REFERENCES

- Moore L, Britten N, Lydahl D, *et al*. Barriers and facilitators to the implementation of person-centred care in different healthcare contexts. *Scand J Caring Sci* 2017;31:662–73.
- Institute of Medicine Committee on Quality of Health Care in A. *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, 2001.
- World Health Organization. *People-centred health care: a policy framework*. Western Pacific Region: World Health Organization, 2007.
- World Health Organization, Chronic Diseases and Health Promotion Department. *Preparing a health care workforce for the 21st century: the challenge of chronic conditions*, 2005.
- Veillette AM *et al*. Canadian cancer navigation: an integrative framework. *Psycho-Oncology* 2009;2:S289–90.
- World Health Organization and International Bank for Reconstruction and Development/The World Bank. *Tracking universal health coverage: 2017 global monitoring report*, 2017.
- Mezzich JE, Appleyard J, Botbol M, *et al*. Ethics in person centered medicine: conceptual place and ongoing developments. *International Journal of Person Centered Medicine* 2014;3:255–7.
- Ekman I, Swedberg K, Taft C, *et al*. Person-centered care—ready for prime time. *Eur J Cardiovasc Nurs* 2011;10:248–51.
- World Health Organization. *The World Health Report 2008 - Primary Health Care: now more than ever*, 2008.
- World Health Organization. *Who global strategy on people-centred and integrated health services: interim report*, 2015.
- Kelly EL, Fenwick KM, Barr N, *et al*. A systematic review of self-management health care models for individuals with serious mental illnesses. *Psychiatr Serv* 2014;65:1300–10.
- Cassell EJ. The person in medicine. *Int J Integr Care* 2010;10 Suppl:e019.
- Epstein RM, Street RL. The values and value of patient-centered care. *Ann Fam Med* 2011;9:100–3.
- Harding E, Wait S, Scrutton J. *The state of play in person-centred care: a pragmatic review of how person-centred care is defined, applied and measured, featuring selected key contributors and case studies across the field*. London, 2015: p. 139.
- Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med* 2000;51:1087–110.
- Lawrence M, Kinn S. Defining and measuring patient-centred care: an example from a mixed-methods systematic review of the stroke literature. *Health Expect* 2012;15:295–326.
- Scholl I, Zill JM, Härter M, *et al*. An integrative model of patient-centeredness - a systematic review and concept analysis. *PLoS One* 2014;9:e107828.
- Britten N, Ekman I, Naldemirci Öncel, *et al*. Learning from Gothenburg model of person centred healthcare. *BMJ* 2020;370:m2738.
- Kitson A, Marshall A, Bassett K, *et al*. What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *J Adv Nurs* 2013;69:4–15.
- Jayadevappa R, Chhatre S. Patient Centered Care - A Conceptual Model and Review of the State of the Art. *Open Health Serv Policy J* 2011;4:15–25.

- 21 Hudon C, Fortin M, Haggerty J, *et al*. Patient-Centered care in chronic disease management: a thematic analysis of the literature in family medicine. *Patient Educ Couns* 2012;88:170–6.
- 22 Fox RC. The evolution of medical uncertainty. *Milbank Mem Fund Q Health Soc* 1980;58:1–49.
- 23 McCormick KM. A concept analysis of uncertainty in illness. *J Nurs Scholarsh* 2002;34:127–31.
- 24 Mishel MH. Uncertainty in illness. *Image J Nurs Sch* 1988;20:225–32.
- 25 Sleeman KE, de Brito M, Etkind S, *et al*. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. *Lancet Glob Health* 2019;7:e883–92.
- 26 Moher D, Liberati A, Tetzlaff J, *et al*. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med* 2009;6:e1000097.
- 27 International Alliance of Patients' Organisations. What is patient-centred healthcare? A review of definitions and principles, 2007. Available: <http://iapo.org.uk/sites/default/files/files/IAPO%20Patient-Centred%20Healthcare%20Review%202nd%20edition.pdf> [Accessed 17 Sep 2019].
- 28 Slater L. Person-centredness: a concept analysis. *Contemp Nurse* 2006;23:135–44.
- 29 The Health Foundation. *Person-centred care made simple; What everyone should know about person-centred care*, 2016.
- 30 Kelley AS, Covinsky KE, Gorges RJ, *et al*. Identifying older adults with serious illness: a critical step toward improving the value of health care. *Health Serv Res* 2017;52:113–31.
- 31 Kmet LM, Lee RC, Cook L. Standard quality assessment criteria for evaluating primary research papers from a variety of fields. Conference proceedings 2004.
- 32 Lee L, Packer TL, Tang SH, *et al*. Self-Management education programs for age-related macular degeneration: a systematic review. *Australas J Ageing* 2008;27:170–6.
- 33 Popay J, Roberts H, Sowden A, *et al*. *Guidance on the conduct of narrative synthesis in systematic reviews: a product from the ESRC methods programme*, 2006.
- 34 Santana MJ, Manalili K, Jolley RJ, *et al*. How to practice person-centred care: a conceptual framework. *Health Expect* 2018;21:429–40.
- 35 Donabedian A. The quality of care. How can it be assessed? *JAMA* 1988;260:1743–8.
- 36 Bisschop JAS, Kloosterman FR, van Leijen-Zeelenberg JE, *et al*. Experiences and preferences of patients visiting a head and neck oncology outpatient clinic: a qualitative study. *Eur Arch Otorhinolaryngol* 2017;274:2245–52.
- 37 Cramm JM, Leensvaart L, Berghout M, *et al*. Exploring views on what is important for patient-centred care in end-stage renal disease using Q methodology. *BMC Nephrol* 2015;16:74.
- 38 Ouwers M, Hermens R, Hulscher M, *et al*. Development of indicators for patient-centred cancer care. *Support Care Cancer* 2010;18:121–30.
- 39 Uphoff EPMM, Wennekes L, Punt CJA, *et al*. Development of generic quality indicators for patient-centered cancer care by using a Rand modified Delphi method. *Cancer Nurs* 2012;35:29–37.
- 40 Galekop MMJ, van Dijk HM, van Exel J, *et al*. Views of professionals and volunteers in palliative care on patient-centred care: a Q-methodology study in the Netherlands. *BMC Palliat Care* 2019;18:97.
- 41 Bilodeau K, Dubois S, Pepin J. Interprofessional patient-centred practice in oncology teams: utopia or reality? *J Interprof Care* 2015;29:106–12.
- 42 Calisi R, Boyko S, Vendette A, *et al*. What is person-centred care? A qualitative inquiry into oncology staff and patient and family experience of person-centred care. *J Med Imaging Radiat Sci* 2016;47:309–14.
- 43 Nguyen TK, Bauman GS, Watling CJ, *et al*. Patient- and family-centered care: a qualitative exploration of oncologist perspectives. *Support Care Cancer* 2017;25:213–9.
- 44 Edvardsson D, Fetherstonhaugh D, Nay R. Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff. *J Clin Nurs* 2010;19:2611–8.
- 45 Oppert ML, O'Keeffe VJ, Duong D. Knowledge, facilitators and barriers to the practice of person-centred care in aged care workers: a qualitative study. *Geriatr Nurs* 2018;39:683–8.
- 46 Pizzi MA. Promoting health and well-being at the end of life through client-centered care. *Scand J Occup Ther* 2015;22:442–9.
- 47 Ross H, Tod AM, Clarke A. Understanding and achieving person-centred care: the nurse perspective. *J Clin Nurs* 2015;24:1223–33.
- 48 Kvåle K, Bondevik M. What is important for patient centred care? A qualitative study about the perceptions of patients with cancer. *Scand J Caring Sci* 2008;22:582–9.
- 49 Green M, Anderson K, Griffiths K, *et al*. Understanding Indigenous Australians' experiences of cancer care: stakeholders' views on what to measure and how to measure it. *BMC Health Serv Res* 2018;18:982.
- 50 Chhatre S, Gallo JJ, Wittink M, *et al*. Patient-Centred outcomes research: perspectives of patient stakeholders. *JRSO Open* 2017;8:205427041773851–5.
- 51 Kienle GS, Mussler M, Fuchs D, *et al*. Individualized integrative cancer care in Anthroposophic medicine: a qualitative study of the concepts and procedures of expert doctors. *Integr Cancer Ther* 2016;15:478–94.
- 52 Kienle GS, Mussler M, Fuchs D, *et al*. On caring and sharing-Addressing psychological, biographical, and spiritual aspects in integrative cancer care: a qualitative interview study on physicians' perspectives. *Complement Ther Med* 2018;40:126–32.
- 53 Colomer J, de Vries J. Person-Centred dementia care: a reality check in two nursing homes in Ireland. *Dementia* 2016;15:1158–70.
- 54 Sjögren K, Lindkvist M, Sandman P-O, *et al*. Organisational and environmental characteristics of residential aged care units providing highly person-centred care: a cross sectional study. *BMC Nurs* 2017;16:44.
- 55 Zill JM, Scholl I, Härter M, *et al*. Which Dimensions of Patient-Centeredness Matter? - Results of a Web-Based Expert Delphi Survey. *PLoS One* 2015;10:e0141978.
- 56 World Health Organization. *Framework on integrated, people-centred health services. Report by the Secretariat*, 2016.
- 57 Maeseneer J, Weel Cvan, Daeren L, *et al*. From "patient" to "person" to "people": The need for integrated. *People-centered Healthcare* 2012;2:601–14.
- 58 Entwistle VA, Watt IS. Treating patients as persons: a capabilities approach to support delivery of person-centered care. *Am J Bioeth* 2013;13:29–39.
- 59 Etkind SN, Lovell N, Nicholson CJ, *et al*. Finding a 'new normal' following acute illness: A qualitative study of influences on frail older people's care preferences. *Palliat Med* 2019;33:301–11.
- 60 CSDH. *Closing the gap in a generation: health equity through action on the social determinants of health. final report of the Commission on social determinants of health*. Geneva: World Health Organization, 2008.
- 61 Venkatapuram S. Values-Based Practice and Global Health. In: Loughlin M, ed. *Debates in Values-based medical practice: arguments for and against*. Cambridge: Cambridge University Press, 2014.
- 62 Lowther K, Harding R, Simms V, *et al*. Active ingredients of a person-centred intervention for people on HIV treatment: analysis of mixed methods trial data. *BMC Infect Dis* 2018;18:27.
- 63 De Man J, Olmen JV, Criel B. Patient-Centered care and people-centered health systems in sub-Saharan Africa: why so little of something so badly needed? *International Journal of Person Centered Medicine* 2016;6:162–73.
- 64 Markus HR, Kitayama S. Culture and the self: implications for cognition, emotion, and motivation. *Psychol Rev* 1991;98:224–53.
- 65 Stanford J, Sandberg DM, Gwyther L, *et al*. Conversations worth having: the perceived relevance of advance care planning among teachers, hospice staff, and pastors in Knysna, South Africa. *J Palliat Med* 2013;16:762–7.
- 66 Setlhare V, Couper I, Wright A. Patient-centredness: meaning and Propriety in the Botswana, African and non-Western contexts. *Afr J Prim Health Care Fam Med* 2014;6:E1–4.

Appendix A: Methods

Table 1 lists the free text search terms used for the literature search strategy.

Table 1. Search terms (title, abstract, and keyword search)

Concept 1		Concept 2		Concept 3
person-cent?red*; patient-cent?red*; people-cent?red*; patient-led; patient- directed; patient- focused; patient- oriented; client- cent?red; "values- based care" ; family- cent?red; relationship- cent?red; "individualized care"	AND	"serious illness*"; "serious condition*"; "serious disease*"; "advanced illness*"; "advanced condition*"; "advanced disease*"; "incurable illness*"; "incurable condition*"; "incurable disease*"; palliative cancer; "renal failure"; dementia; "chronic obstructive pulmonary disease"; "advanced liver disease"; "serious diabetic complications"; "amyotrophic lateral sclerosis"; "acquired immune deficiency syndrome"; "hip fracture"; "interstitial lung disease"; "congestive heart failure"; "chronic heart failure"	AND	concept*; practice*; framework; model; theory; meaning; understand*; experience*; needs; views; perspective*; preference*; priorities

Table 2 details an example search strategy carried out on Embase database.

Table 2. Example search strategy

OVID Search Strategy
Database: Embase <1974 to 2019>
1. person-cent?red*.mp. 2. patient-cent?red*.mp. 3. people-cent?red*.mp. 4. patient-led.mp. 5. patient-directed.mp. 6. patient-focused.mp. 7. patient-oriented.mp. 8. client-cent?red.mp. 9. "values-based care".mp. 10. family-cent?red.mp. 11. exp family centered care/ 12. relationship-cent?red.mp.

13. "individuali*ed care".mp.
14. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13
15. "serious illness*".mp.
16. "serious condition*".mp.
17. "serious disease*".mp.
18. "advanced illness*".mp.
19. "advanced condition*".mp.
20. "advanced disease*".mp.
21. "incurable illness*".mp.
22. "incurable condition*".mp.
23. "incurable disease*".mp.
24. palliative.mp.
25. exp palliative therapy/
26. exp palliative nursing/
27. cancer.mp.
28. "renal failure".mp.
29. exp kidney failure/
30. dementia.mp.
31. exp dementia/
32. "chronic obstructive pulmonary disease".mp.
33. exp chronic obstructive lung disease/
34. "advanced liver disease".mp.
35. "serious diabetic complications".mp.
36. "amyotrophic lateral sclerosis".mp.
37. exp amyotrophic lateral sclerosis/
38. "acquired immune deficiency syndrome".mp.
39. exp acquired immune deficiency syndrome/
40. "hip fracture".mp.
41. exp hip fracture/
42. "interstitial lung disease".mp.
43. exp interstitial lung disease/
44. "congestive heart failure".mp.
45. exp congestive heart failure/
46. "chronic heart failure".mp.
47. 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46
48. 14 and 47
49. concept*.mp.
50. concept analysis/ or thinking/
51. practice*.mp.
52. evidence based practice/
53. practice guideline/
54. framework.mp.
55. conceptual framework/
56. model.mp.
57. theoretical model/
58. theory.mp.

59. theory/
60. meaning*.mp.
61. understand*.mp.
62. experience*.mp.
63. needs.mp.
64. views.mp.
65. perspective*.mp.
66. preference*.mp.
67. priorities.mp.
68. 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67
69. 14 and 47 and 68

Table 3 presents details of the inclusion and exclusion criteria used to screen studies.

Table 3. Inclusion and exclusion criteria

Inclusion criteria
<div><div>a. Papers were included if they present primary data of any study design reporting evidence on the meaning, preferences or practices of person-centred care from the perspective of adult patients with serious illness, their family members, caregivers or any individuals who work with patients with serious illness or are responsible for management or policy making for any healthcare settings that provide care to those with serious illness.</div><div>b. Papers were included if 1) investigation of the meaning or practice of PCC is included in the aims or objectives of the study, 2) data concerning meaning or practice of PCC is presented in the results section of the paper, as we understand that this finding may result from a related aim.</div><div>c. Qualitative, quantitative and mixed-method studies of any study design were considered: quantitative studies of all descriptive, correlational, quasi-experimental or experimental designs were included, and qualitative studies of phenomenological, ethnographic, grounded theory, historical, case study, or action research design will be included.</div><div>d. Studies involving the following types of participants were included: adult patients with serious illness (18 years and older); their family members or friends; their caregivers; individuals who work with patients with serious illness (these include general practitioners, specialist doctors, hospital and community nurses, patient representatives, medical students, social workers, and all other clinical staff interacting with such patients); individuals responsible for management or policy making for any healthcare settings that provide care to those with serious illness. Patients with serious illness were restricted to those as defined by Kelley et al [1].</div><div>e. Studies conducted anywhere in the world (low, middle and high-income countries) were included.</div><div>f. Studies published in English were considered for inclusion in this review.</div><div>g. Studies of any publication date were considered for inclusion; no date restriction was applied.</div></div>

1] Kelley, A.S., et al., *Identifying Older Adults with Serious Illness: A Critical Step toward Improving the Value of Health Care*. Health Serv Res, 2017. **52**(1): p. 113-131.

Exclusion criteria
<div><div>a. Published literature other than primary studies (i.e. review articles, books, policy or commentary papers).</div><div>b. Studies focusing on intervention outcomes or effectiveness.</div><div>c. Studies investigating whether patients have a preference for ‘person-centred care’ that do not provide any investigation of the meaning or practice of this concept.</div><div>d. Studies investigating barriers and facilitators for PCC, that do not include any investigation of the meaning, preferences or practices of person-centredness. This review is focused on understanding what PCC means, consists of, and looks like in practice rather than which conditions aid and hinder implementation.</div><div>e. Papers where investigation of the meaning or practice of PCC is neither presented in the aims or objectives of the study, nor in the results section of the paper, and any mention of PCC is merely made in the conclusion as a personal interpretation of the results by the author.</div><div>f. The concept of patient-centred care can be seen as including many subcategories such as patient-centred communication, patient-centred access, patient-centred outcomes, patient-centred diagnosis, shared decision-making, person-centred life-expectancy disclosure etc. Papers focusing exclusively on one deemed sub-component of PCC were not included as this would undermine the feasibility and specificity of this review. We wish to investigate PCC as a broad construct with wide applicability rather than specific constructs such as access and communication, though we recognise that work in these specific areas would be insightful.</div><div>g. Studies claiming to have performed empirical work to inform a ‘person-centred’ intervention that do not report the results of this work.</div><div>h. Studies in which the diagnostic group of focus for the majority of included participants is not a serious illness as defined and listed by Kelley et al.</div><div>i. Studies focusing on ‘personhood’. Personhood is a theoretical and philosophical construct concerned with the self that PCC draws on and is grounded in, rather than a model of care practice in itself.²</div><div>j. Studies focusing on ‘personalised medicine’ or ‘personalised gene therapy’.</div><div>k. Studies published in any language other than English.</div></div>

Table 4 indicates the methods used to calculate quality scores for included studies using the Standard Quality Criteria developed by Kmet et al [3].

Table 4: Methods to calculate summary scores for Kmet et al. quality checklist

Summary score for quantitative studies	Summary score for qualitative study
Total sum = (number of “yes” * 2) + (number of “partials” * 1)	Total sum = (number of “yes” * 2) + (number of “partials” * 1)
Total possible sum = 28 – (number of “N/A” * 2)	Total possible sum = 20
Summary score: total sum / total possible sum	Summary score: total sum / total possible sum

2] Kitwood, T., *Dementia reconsidered: The person comes first*. Open University Press, Buckingham. 1997.

3] Kmet, L.M., R.C. Lee, and L. Cook, *Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields*. Conference proceedings. 2004.

Figure 1. A priori coding frame derived from Santana et al 2018 model of PCC

- ▼ S1. Creating a PCC culture
 - ▼ S1a. Core values and Philosophy of the organization
 - Addressing and incorporating diversity in care, health promotion and patient engagement
 - Patient and health-care provider rights
 - Patient-directed; integrating patient experience and expertise
 - Vision, Mission
 - ▼ S1b. Establishing operational definition of PCC
 - Common language around PCC
 - Consistent operational definitions
- ▼ S2. Co-designing the development and implementation of educational programs
 - ▼ S2a. Standardized PCC training in all health-care professional programs
 - Integration of all health-care sectors and professionals
 - Professional education and accrediting bodies
 - Translating into practice through continued professional education and mentorship
- ▼ S3. Co-designing the development and implementation of health promotion and prevention programs
 - ▼ S3a. Collaboration and empowerment of patients, communities and organizations in design of programs
 - Create patient advisory groups
 - Creating partnerships with community organizations
 - Identify resources
- ▼ S4. Supporting a workforce committed to PCC
 - ▼ S4a. Ensure resources for staff to practice PCC
 - Encourage teamwork and teambuilding
 - Provide adequate incentives in payment programs; celebrate small wins and victories
- ▼ S5. Providing a supportive and accommodating PCC environment
 - ▼ S5a. Designing health-care facilities and services promoting PCC
 - Areas or rooms that will support the accommodation of patients
 - Collaborate with and empower patients and staff in designing health-care facilities
 - Environments that are welcoming, comfortable and respectful
 - Facility that prioritize the safety and security of its patients and staff
 - Spaces that provide privacy
 - Spiritual and religious spaces
 - ▼ S5b. Integrating organization-wide services promoting PCC
 - Patient-directed visiting hours
 - Provide interpretation and language services
- ▼ S6. Developing and integrating structures to support health information technology
 - ▼ S6a. Common e-health platform for health information exchange across providers and patients
 - E-health adoption support through strategic funding and education
 - Electronic Health Record systems with capacity to coordinate and share healthcare interactions across the continuum of care
 - Health information privacy and security
- ▼ S7. Creating structures to measure and monitor PCC
 - ▼ S7a. Co-design and develop framework for measurement, monitoring and evaluation
 - Co-design and development of innovative programs to collect patients and caregiver experiences about care received and providing timely feedback to...
 - Reporting and feedback for accountability and to improve quality of health care
- ▼ P1. Cultivating communication
 - ▼ P1a. Listening to patients
 - Asking questions of what patients want to discuss (concerns, views, understanding)
 - Gathering information through active listening
 - Non-verbal behaviours (eye-contact, listening attentively, proximity or touch, head nodding)
 - ▼ P1b. Sharing information
 - Patients are provided with all the necessary information to make informed decisions in relation to their diagnosis and treatment plan
 - Sharing of information regarding patient's condition and their own impact or influences on their condition
 - ▼ P1c. Discussing care plans with patients
 - Acknowledging and discussing uncertainties
 - Aim and follow-up of treatment or interventions with possible outcomes and adverse events or side-effects
 - Creating a shared understanding
 - Discussing and building capacity of patients for self-management and self-care
 - Responding to patient and caregiver needs
- ▼ P2. Respectful and compassionate care
- ▼ P3. Engaging patients in managing their care
 - ▼ P3a. Co-designing care plans with patients
 - Care plans can be accessed by patients and health-care providers
 - Goal-setting
 - Shared decision making
 - Supporting self-care management
- ▼ P4. Integration of care
 - ▼ P4a. Communication and information sharing for coordination and continuity of care across the continuum of care
 - Between health-care providers
 - Discharge communication
 - Providing access to information and resources
 - Referrals to specialist

- ▼ ● O1. Access to care
 - ▼ ● O1a. Timely access to care
 - During consult, to be seen at emergency community care, pre-hospital, hospital, post-hospital; secondary care; time for patient care
 - Wait times for referrals to see specialists, to receive a consult
 - ▼ ● O1b. Care availability
 - Availability of health-care practitioners during and outside of working hours
 - ▼ ● O1c. Financial burden
 - Affordability of care including complimentary care and therapies, dental, pharmacare, ambulance
- ▼ ● O2. Patient-Reported Outcomes (PROs)
 - ▼ ● O2a. Patient-Reported Outcomes Measures (PROMs)
 - Functionality
 - Health-Related Quality of Life
 - Psychosocial outcomes
 - Symptoms
 - ▼ ● O2b. Patient-Reported Experiences (PREMs)
 - Assessment of care, including appropriateness and acceptability of care (competency, knowledge, skills of staff)
 - Recommendation or rating of hospital, health-care provider
 - ▼ ● O2c. Patient-Reported Adverse Outcomes (PRAOs)
 - Death
 - New or worsening symptoms
 - Unanticipated visits to health-care facilities
- ▼ ● O1. Access to care
 - ▼ ● O1a. Timely access to care
 - During consult, to be seen at emergency community care, pre-hospital, hospital, post-hospital; secondary care; time for patient care
 - Wait times for referrals to see specialists, to receive a consult
 - ▼ ● O1b. Care availability
 - Availability of health-care practitioners during and outside of working hours
 - ▼ ● O1c. Financial burden
 - Affordability of care including complimentary care and therapies, dental, pharmacare, ambulance
- ▼ ● O2. Patient-Reported Outcomes (PROs)
 - ▼ ● O2a. Patient-Reported Outcomes Measures (PROMs)
 - Functionality
 - Health-Related Quality of Life
 - Psychosocial outcomes
 - Symptoms
 - ▼ ● O2b. Patient-Reported Experiences (PREMs)
 - Assessment of care, including appropriateness and acceptability of care (competency, knowledge, skills of staff)
 - Recommendation or rating of hospital, health-care provider
 - ▼ ● O2c. Patient-Reported Adverse Outcomes (PRAOs)
 - Death
 - New or worsening symptoms
 - Unanticipated visits to health-care facilities

Supplementary Table 1. Data extraction table

*The specific aims/research questions relevant to this review are presented in bold text.

Authors; Year of publication; Country	Aim and objectives*	Study design, setting and methods	Sample	Main findings	Quality appraisal score (Kmet et al. scale [29]; possible range: 0-1)
Bilodeau K., Dubois S. and Pepin J. (2014) [41] Canada	<p>Aim: To describe interprofessional patient-centred (IPPC) practice throughout the continuum of cancer care (diagnosis, treatment, recurrence and follow-up).</p> <p>Research questions: 1) How do healthcare teams practice IPPC care at different stages of the cancer care continuum? 2) What are the contextual factors influencing IPPC practice? and 3) What should IPPC practice consist of at different stages in the cancer care continuum?</p>	<p>Qualitative multiple case study. 2 oncology interprofessional teams. Interviews and observations. Data analysed by content analysis.</p>	<p>Two oncology interprofessional teams. Intentional sampling: n=8 cancer patients (4 per team) n=3 adult family members n=20 health care professionals (nurses, doctors, physiotherapists, nutritionist and managers, and a psychologist, pharmacist, social worker and occupational therapist).</p>	<p>Three themes described current IPPC practice: a) Welcoming the person as a unique individual, but still requiring the patient to comply b) Paradoxical coexistence of patient-centred discourse and professional-centred practice; c) Triggering team collaboration with culmination of patient’s situation.</p> <p>Three themes described IPPC practice participants desired: a) Support in line with patient’s experience and involvement b) Respecting patients by not imposing professionals’ values and goals c) Consistency and regularity in collaboration of all members.</p> <p>Patients stressed professionals' availability, sharing of information and professionals' attitude when describing IPPC practice.</p>	0.7

<p>Bisschop J.A.S., Kloosterman F.R., van Leijen-Zeele nberg J.E., Huismans G.W., Kremer B. and Kross K.W. (2017) [36]</p> <p>The Nether-lands</p>	<p>Aim: To investigate the experiences and preferences of head and neck oncology patients at the Oncology Center of MUMC (in relations to the six dimensions of PCC as referred to by the American National Academy of Medicine).</p>	<p>Qualitative research design. Semi-structured interviews with patients.</p>	<p>n=19 patients Patients were included if they had been treated at the MUMC Oncology Center for at least 6 months. Patients who received palliative treatment were excluded.</p>	<p>Three dimensions of the IOM PCC definition predominated the interviews: 1) respect for patients’ values, expressed preferences and needs 2) information, communication and education 3) involvement of family and friends</p> <p>Within these dimensions, patients attached specific importance to three aspects: a) provision of honest and complete information b) an open discussion on decision-making with involvement of the patient c) considering affection with family and friends as a crucial part in the treatment.</p> <p>The dimensions of physical comfort, emotional support, relieving fear and anxiety and coordination and integration of care were of less significance according to the patients. However, comforting nervous patients was considered as crucial for a specialist in this field.</p> <p>Within the coordination of care, remarkably low attention was given to waiting times on the day of appointment. In general, the coordination and planning covers more complex cases that need several appointments and patients expect the waiting times to be longer. The involvement of family and friends was deemed of great significance.</p>	<p>0.85</p>
--	--	---	---	--	-------------

Calisi R., Boyko S., Vendette A. and Zagar A. (2016) [42] Canada	<p>Aim: To investigate the understanding and practice of person-centred care by health care professionals and support staff at a cancer centre and to learn how patients and family members understand and experience person-centred care.</p> <p>Research questions: 1) What does the phrase “person-centred care” mean to health care professionals and front-line staff working in the context of a busy cancer centre? 2) What does the phrase “person-centred care” mean to patients and family members? 3) What does person-centred care look like in practice for frontline and other staff and to patients and families?</p>	<p>Sequential mixed methods approach involving 2 phases:</p> <p>Phase 1 used large wall mounted posters and pens in public areas of the cancer centre to gather comments to answer the question “What does person-centred care mean to you?”</p> <p>Phase 2 used a 6-question, open-ended, paper-based questionnaire for staff and patients.</p> <p>Manual coding technique was used to derive themes from both posters and questionnaires.</p>	<p>As posters were available in public areas the authors assume that staff, patients, family members, volunteers, and visitors had equal access to the posters, but it is not known who provided poster comments.</p> <p>N=44 questionnaires were completed and returned: n=30 front-line staff (n=19 radiation therapists; n=3 nurses; n=2 supportive care professionals; n=2 physicians; n=1 dental assistant n=1 genetic counsellor; n=1 student; n=1 clerk) n=6 non front-line staff (n=2 technical staff, n=2 administrative assistant, n=1 coordinator, n=1 researcher) n= 8 patients and patient and family advisors</p>	<p>97 themes were derived from posters and 134 themes derived from questionnaires. By combining common themes, it was concluded that staff, patients, and family members believe person-centred care to be:</p> <p>1) care that is caring, compassionate, and empathetic 2) person or patient is the centre of focus 3) care is unique to the individual’s needs 4) person or patient is a part of their care.</p> <p>Furthermore, all staff, not only front-line staff, should provide person-centred care.</p>	0.9
Chhatre S. , Gallo J.J., Wittink M., Sanford Schwartz J. and Jayadevappa R. (2017) [50] USA	<p>Aim: To elicit patient stakeholders’ experience and perspectives about patient-centred care.</p>	<p>Qualitative. Discussion group.</p>	<p>n= 4 prostate cancer survivors</p> <p>Patient 1 – age 71; underwent open radical prostatectomy with subsequent radiation and hormone therapy. Patient 2 – age 59; received robotic radical prostatectomy. Patient 3 – age 74; received proton therapy. Patient 4 – age 65; retiree who received radical prostatectomy and subsequent radiation treatments.</p>	<p>The patients perceived patient-centredness to revolve around a theme of respect, engagement and dialogue between physician and patient; Instead of care being centred on one particular individual, be it patient or provider, it must be viewed as a collaborative process.</p> <p>Patients reported wanting to be involved in treatment decisions, not simply told what to do. However, this does not imply that the physician and patient are equal in terms of health knowledge. They agreed that patient-centered care should not mean that patients can demand inappropriate treatments.</p> <p>The degree of patient centredness was observed to be dependent on the situation; High severity conditions warranted a higher level of patient involvement, compared to mild conditions.</p>	0.35

Colmer J and de Vries J. (2016) [53]	Aim: To identify perspectives and experiences of care assistants with PCC in the nursing home in which they worked.	Semi-structured interviews revolving around 11 questions. Setting: 2 nursing homes with a PCC policy (each with more than 100 residents, around 80% of whom had symptoms of dementia) A phenomenological approach was used in the design of the interviews and the qualitative data analysis. Participants' perspectives were extracted, emerging themes and sub-themes were identified. Data analysis utilised the Newall and Burnard (2006) method.	N= 13 care assistants Inclusion criteria: a) the carers had worked for at least one year in this role b) they had been educated and received a diploma in 'Healthcare Support' which is a prerequisite to work as a care assistant in Ireland.	Findings showed considerable disparity between policy and practice, in particular because care assistants lacked clarity on what PCC is and reported that they were not educated in it. Among the 13 participants, 4 had not heard of PCC. Nonetheless, carers' perspectives on 'good care' for people with dementia included elements of PCC which suggested its 'implicit' use in practice, such as respect, personal autonomy, privacy and dignity.	0.75
Cramm J.M., Leensvaart L., Berghout M. and van Exel J. (2015) [37] The Netherlands	Aim: To explore views on what is considered important for Patient-Centred Care (PCC) among patients with end-stage renal disease and healthcare professionals in a haemodialysis department.	Q methodology. Interviews were conducted asking participants to rank-order 35 statements representing 8 dimensions of PCC previously discussed in the literature. Participants explanations given during a follow-up interview, used to interpreted and verify the views found in the quantitative part of the analyses. Views of PCC, and commonalities and differences between them, were explored using by-person factor analysis.	Purposive sampling, n=26 participants: N=14 patients with end-stage renal disease receiving dialysis N=12 healthcare professionals working at the haemodialysis department (n=2 doctors, n=6 nurses, n=4 staff members (i.e. 1 team leader, 1 policy advisor, 1 quality advisor, 1 social worker)).	Four views on what is important for PCC in end-stage renal disease were identified, suggesting that different patients may benefit from different types of care. These four views were: 1) listening to patients and taking account of their preferences in treatment decisions 2) providing comprehensible information and education to patients so that they can take charge of their own care 3) several aspects related to the atmosphere at the department 4) having a professional or acquaintance that acts as care coordinator, making treatment decisions with or for them. All views agreed about the relative importance of certain PCC dimension: the patient preferences and information and education dimensions were generally considered most important, while the family and friends and the access to care dimensions were considered least important.	Qual: 0.9 Quant: 0.85

Edvardsson D., Fetherstonh augh D. and Nay R. (2010) [44] Australia	Aim: To describe the content of person-centred care as described by people with dementia, family members and staff in residential aged care	Qualitative explorative design using conversational interviews (individual, some by telephone) and focus groups. Qualitative content analysis.	N=37 staff working in residential aged care facilities; N=11 people with early onset dementia who had had experience of respite care; N=7 home carers of people with dementia; N=12 carers of people with dementia who lived in residential aged care facilities.	The findings indicated that the core category of person-centred care was promoting a continuation of self and normality. Five content categories emerged as contributing to promoting a continuation of self and normality: 1) knowing the person 2) welcoming family 3) providing meaningful activities 4) being in a personalised environment 5) experiencing flexibility and continuity.	0.8
Galekop M., van Dijk H. M., van Exel J. and Cramm J. M. (2019) [40] The Nether-lands	Aim: To explore professionals’ and volunteers’ views on PCC, and to see whether the views of the volunteers align with or differ from those of the professionals.	Q methodology. Interviews were conducted asking participants to rank-order 35 statements representing 8 dimensions of PCC previously discussed in the literature. Participants were also asked to elaborate on their ranking. A by-person factor analysis was done to identify clusters in the ranking data. For each identified factor a weighted average ranking of the statements was computed, and interpreted and described as distinct views on PCC. Distinguishing statements and consensus statements were identified. Respondents’ explanations of their ranking were used to verify the interpretations. Possible differences in views between professionals and volunteers were inspected using the factor associations of respondents.	N=41 respondents: n=30 professionals (21 nurses, 3 radiotherapists, 2 specialist geriatrics, 2 spiritual caregivers, 1 gastroenterologist and 1 palliative medicine doctor); n=11 volunteers. The participants were recruited from two hospitals and six hospices in the Netherlands.	The factor analysis revealed two distinct views on PCC, explaining 40% of the variance. Both viewpoints were supported by professionals and volunteers. The two main viewpoints identified were: Viewpoint 1: ‘The patient in the driver seat’ – These respondents found it important that patients keep their autonomy during the last phase of life. According to them patients should always be in charge of their own care and professionals and volunteers should act according to the preferences of patients and should primarily support patients to achieve their goals. Viewpoint 2: ‘The patient in the passenger seat’. These respondents found PCC to be best delivered when professionals, volunteers and patients team-up and share control, with the patient in the passenger seat. In this view, whenever possible patients make their own choices, often after consultation with the professional. But when they are not willing or capable to decide themselves at any stage of their care, for example because they lack the energy or capacity to be involved, the professional should step in and decide on their behalf, in their interest.	Qual: 0.95 Quant: 0.85

<div>Green M. , Anderson K., Griffiths K., Garvey G. and Cunningham J. (2018) [49]</div> <div>Australia</div>	<div>Aim: To a) identify the key components of patient experience that should be included in any experience of care measurements for Indigenous patients with cancer; and b) elicit participants' views on the appropriateness and likely acceptability of various data collection approaches for this patient group, from the perspectives of Indigenous people affected by cancer, and health professionals involved in care provision to Indigenous patients with cancer.</div>	<div>Two rounds of semi-structured interviews and focus groups.</div> <div>This study examined patient experiences as guided by the Picker Institute's Principles of PCC. Round One interviews were introduced with the definition of 'good quality cancer care' from the National Aboriginal and Torres Strait Islander Cancer Framework to highlight the person-centred orientation of the study team.</div>	<div>N=17 Indigenous people affected by cancer (either diagnosed with, or have cared for someone diagnosed with cancer) N=28 health professionals (both Indigenous and non-Indigenous, whose work related to the care of Indigenous people diagnosed with cancer, including a broad range of clinical, supportive care, quality improvement and supervisory roles) N=7 individuals in both aforementioned groups.</div> <div>Recruitment occurred through a national web-based network and through four cancer services in urban and regional areas in three jurisdictions across Australia.</div>	<div>Several aspects of cancer care were identified as critical in shaping Indigenous patients' experiences. Key themes included: a) feeling safe in the system b) importance of Indigenous staff c) barriers to care d) the role of family and friends e) effective communication and education f) coordination of care and transition between services.</div>	<div>0.85</div>
<div>Kienle G.S., Mussler M., Fuchs D. and Kiene H. (2016 and 2018) (Two papers reporting data from one study) [51-52]</div> <div>Germany</div>	<div>Aim of 2016 paper: To investigate the concepts, therapeutic goals, procedures, and working conditions of integrative oncology doctors in the field of anthroposophic medicine.</div> <div>Research questions: 1) How are cancer patients cared for within the integrative care setting? 2) What are the underlying concepts and therapeutic goals? 3) What are the procedures? 4) How do expert physicians approach and assess cancer patients and which issues are important? 5) In what way is this treatment approach individualised and what does this mean? 6) What are the organisational working conditions?</div>	<div>Qualitative study, using semi-structured, in-depth, individual interviews.</div> <div>Data analysed using structured qualitative content analysis in combination with techniques from the thematic framework approach.</div>	<div>N=35 highly experienced integrative oncology doctors in the field of anthroposophic medicine, working in hospitals and office-based practices in Germany and other countries; sampled purposively.</div>	<div>2016 paper: The emerging dimensions of the doctors' individualised approaches related to: 1) disease, condition, treatment focus 2) patient 3) doctor 4) therapy Their treatments aimed at both tumour and symptom control and at strengthening the patient on different levels: living with the disease, overcoming the disease, enabling emotional and cognitive development, and addressing spiritual or transcendental issues according to the patient's wishes and anticancer and symptom-relieving treatments. Other external applications, nutrition and lifestyle advice, psychological support, and multiple forms of empowerment. Their approach emphasised good patient-doctor relationships and sufficient time for patient encounters and decision-making. Individualisation appeared in several dimensions and was interwoven with standards and guidelines. The doctors often worked in teams and cooperated with other cancer care-related specialists.</div>	<div>0.9</div>

	<p>Aim of 2018 paper: To explore what role psychological, biographical, and spiritual factors play for experienced doctors working in integrative cancer care.</p> <p>Research questions: 1) What roles do emotional, biographical, and spiritual issues play for physicians practicing integrative medicine? 2) What do physicians observe and experience with regard to these issues in the treatment process? 3) How do physicians support emotional and spiritual needs of patients? 4) What are the underlying treatment goals, concepts and themes?</p>			<p>2018 paper: Prevailing themes identified in this study were:</p> <p>a) enabling patients to participate in life b) promoting autonomy and coping c) stabilising patients emotionally and cognitively d) overcoming the disease e) integrating spiritual issues.</p> <p>Doctors offered conversation, counselling, and time, but also referred to art, music, literature, and nature, so that patients’ ongoing emotional, psychological, and spiritual needs could be explored and addressed. Doctors’ attitudes with regard to existential issues were seen as important, as was maintaining an attitude of openness towards existential issues.</p>	0.9
<p>Kvale K. and Bondevik M. (2008)[48]</p> <p>Norway</p>	<p>Aim: To get insight into patients with cancers’ perceptions of the importance of being respected as partners and share control of decisions about interventions and management of their health problems and the reasons behind their wishes.</p>	<p>Qualitative in-depth interviews. Interviews analysed according to Giorgi’s step-by-step approach to phenomenology.</p>	<p>N=20 cancer inpatients, sampled purposively, with various cancer diagnoses at different stages and with different prognoses (n=10 women; n=10 men).</p>	<p>The units of meaning identified could be clustered into three themes with significance for patient centred care from patients’ perspectives:</p> <p>1) empowerment through being respected, listened to, believed, given honest information, and being valued; 2) shared decision making about the treatment of the disease (discussing treatment, but letting the doctor make the final decision) 3) partnership in nursing care, practiced by inviting patients to be partners in all decisions that affect their daily life and care, such as decisions about how to dress their wounds, administer chemotherapy and with whom they would share their rooms.</p>	0.95

Nguyen T.K., Bauman G.S., Watling C.J. and Hahn K. (2017) [43] Canada	<p>Aim: To explore oncologists’ perspectives on patient- and family-centered care (PFCC) to identify factors that influence their ability to practice PFCC.</p> <p>Objectives: 1) to explore oncologists’ attitudes toward PFCC and 2) to identify factors that influence their ability to practice PFCC</p>	<p>Exploratory, qualitative study. Individual semi-structured interviews. Two focus groups were then facilitated, consisting of previously interviewed participants to confirm and elaborate on the findings.</p> <p>Thematic analysis was conducted, drawing on the principles of grounded theory.</p>	<p>N=18 oncologists (8 radiation, 4 medical, 4 surgical, 2 haematology-oncology).</p> <p>Eligible participants were required to hold full-time staff positions practicing at least in part at the cancer institution. Trainees and general practitioners in oncology were excluded. Each focus group consisted of two radiation oncologists and one medical oncologist.</p>	<p>Three dominant themes emerged:</p> <p>1) Physicians displayed cautious engagement in their approach to PFCC. Collectively, participants understood the general principles of PFCC. Physicians agreed that PFCC meant involving patients and families in care decisions and promoting patient autonomy. Other providers identified that their focus was ensuring patients had sufficient information and understanding for informed decisions. However, there was a limited understanding of the value, implications, and motivation for improving PFCC.</p> <p>2) Both individual and system barriers to practicing PFCC were identified.</p> <p>3) Physicians were able to identify existing and potential PFCC behaviours that were feasible within existing system constraints. These included improving physician-patient communication (e.g. by checking often for patient and family understanding, or consistently inquiring about the patient’s financial situation, social history and support system), and streamlining care delivery (e.g. by having nursing staff provide additional teaching following the physician visit, or adequately informing patients of next steps and wait times between steps).</p>	0.65
--	---	---	---	--	------

<p>Oppert M.L., O’Keeffe V.J. and Duong D. (2018) [45]</p> <p>Australia</p>	<p>Aim: to reveal the level of understanding that aged care workers have of person-centered care (PCC) principles, of the barriers that exist to prevent the practice of PCC and of the facilitators that promote it.</p> <p>Research questions: 1) What do aged care workers understand PCC to mean in the context of their workplace and role? 2) What barriers do aged care workers believe exist to prevent the practice of PCC, and what facilitators do they believe exist to promote it?</p>	<p>Semi-structured interviews (containing 7 core questions), conducted in person or over the phone. Participants were also required to complete a questionnaire that sought demographic information such as age, qualifications and tenure as an aged care worker.</p> <p>Data was analysed using thematic analysis. Furthermore, content analysis was used to quantify responses to enable comparative examination of aged care worker understanding of PCC across participants. The worker's understanding was classified according to how many factors of the VIPS framework (Brooker, 2007) were mentioned.</p>	<p>N=12 aged care workers (n=7 females, n=5 males) who provide direct care to aged residents.</p> <p>All participants had a minimum qualification of Certificate III in Aged Care. Aged care workers who had a minimum 3-months experience in their role at this facility were eligible to participate.</p>	<p>Regarding research question number 1, findings revealed that aged care workers have a “reasonable but incomplete and superficial understanding” of PCC. Of the sample, one participant embraced all 4 of the VIPS elements in their description (i.e. Valuing; Individualised approach; Perspective of service user; Social environment). Approximately three-quarters of the interviewed participants demonstrated a 'moderate to strong understanding' of PCC, in that they included two or three out of the four VIPS elements in their descriptions. A quarter of participants demonstrate 'superficial or limited knowledge' of PCC, in that they mentioned zero or one element of the VIPS framework. (Quotations included in results section illustrate examples of PCC understandings in more detail).</p>	<p>0.75</p>
<p>Ouwens M., Hermens R., Hulscher M., Vonk-Okhuijsen S., Tjan-Heijnen V., Termeer R., Marres H., Wollersheim H. and Grol R. (2009) [38]</p> <p>The Netherlands</p>	<p>Aim: to develop indicators of patient-centred cancer care and test them on a population of patients with non-small cell lung cancer, with the ultimate aim to improve present practice.</p>	<p>Recommendations for patient-centred care were extracted from clinical guidelines and patients were then interviewed (semi-structured) to develop indicators for assessing the patient-centredness of cancer care.</p> <p>These indicators were then tested with regard to psychometric characteristics, with data collected by means of questionnaires.</p>	<p>Interviews</p> <p>N=30 head and neck cancer patients</p> <p>N=7 patient representatives from the Dutch national association of patients with lung cancer</p> <p>Questionnaire</p> <p>N=132 patients with non-small cell lung cancer.</p>	<p>The authors developed 56 indicators for patient centredness covering the eight domains of PCC suggested by the Picker Institute. Interviewees found all the recommendations extracted from guidelines important, so all were included. The criteria for waiting and throughput times came from the interviews as answers to the question of acceptable waiting times.</p> <p>Furthermore, the patients added three specific information items:</p> <p>a) information about the possible course of the disease</p> <p>b) the possibility of a second opinion</p> <p>c) information about the treatment option of “no active therapy”.</p>	<p>Qual section score 0.65</p> <p>Quant: 0.78</p>

Pizzi M.A. (2015) [46] USA	Aim: to examine client-centered care at the end of life as that which enables engagement in meaningful occupation and promotes health and well-being until one dies. (Part of a larger study of health professionals working in end-of-life care).	Open-ended semi-structured interviews conducted by telephone. Thematic analysis.	N=3 occupational therapists Inclusion criteria were being an active, working, end-of-life care occupational therapist for at least two years.	This paper reports the findings from one of the themes that emerged from the larger study: client-centered care. Three sub-themes emerged within this theme: 1) Adaptation - all of the participants discussed how they adapt skills, routines, habits, or environments for people at the end of life, and how it can create a climate of trust, develop rapport, and establish well-being for people. They also discussed the importance of involving and supporting the family or significant others. 2) Client goals - participants expressed their client-centeredness through their descriptions of planning goals and meeting people's needs that were important from the perspective of the client and family 3) Choices - providing and facilitating engagement in daily choices was seen as an important form of empowerment for clients	0.65
Ross H., Tod A.M. and Clarke A. (2014) [47] UK	Aim: to identify nurses' understanding of PCC and what factors facilitate such an approach to care within an acute medical ward. Research questions: 1) What do nurses understand by the term PCC? 2) How is PCC facilitated in the acute hospital medical ward? 3) What are the implications for nurse education?	The study used an action research approach. Individual semi-structured interviews (and follow up group interviews or discussions). Framework analysis was used to analyse the data.	Purposeful sample: N=14 nurses (n=7 registered nurses; n=3 healthcare support workers; n=4 student nurses working on the ward)	Nurses had a 'clear understanding' of person-centred care in the context of their work. They discussed: a) The importance of understanding more about the person and their personal identity, building relationships with the person, their family and within the care team; b) Personal qualities, values and beliefs of staff that were congruent with PCC including listening to and recognising the importance of people's stories c) Respecting the principles of person-centred care including recognising the importance of a person's wishes when considering care decisions and paying attention to all aspects of care that were important to the person.	0.8
Sjögren K., Lindkvist M., Per-Olof Sandman P-O., Zingmark K. and Edvardsson D. (2017) [54] Sweden	Aim: to explore factors characterising residential aged care units perceived as being highly person-centred, with a focus on organisational and environmental variables, as well as residents' and staff's characteristics.	Cross sectional explorative design. Participating staff provided self-reported data and conducted proxy ratings on residents. Data were collected through a resident and a staff survey. The resident survey consisted of demographic variables, measurement scales on ADL-abilities and cognition. Person-centred Care Assessment Tool (P-CAT) was used to measure the extent to which staff perceive care provided as being person-centred. Descriptive and comparative statistics, independent samples t-test, Chi2 test, Eta Squared and Phi coefficient were used to analyse data.	n=1460 residents and n=1213 staff data from 151 residential care units were collected, as well as data relating to characteristics of the organisation and environment, and data measuring degree of person-centred care. The majority of participating care units were special care units for people with dementia (70%), located in rural (26%) and urban (74%) regions of Sweden. The unit size ranged from four to 26 residents, and between 4 and 20 permanent staff members. All residents living in the units were included in the study.	Highly person-centred residential aged care units were characterised by having: a) a shared philosophy of care b) satisfactory leadership c) interdisciplinary collaboration and social support from colleagues and leaders d) a dementia-friendly physical environment e) staff having time to spend with residents f) a smaller unit size Residential aged care units with higher levels of person-centred care had a higher proportion of staff with continuing education in dementia care, and a higher proportion of staff receiving regular supervision, compared to units with lower levels of PCC.	0.91

<p>Uphoff E. P. M. M., Wennekes L., Punt C. J. A., Grol R. P. T. M., Wollersheim , H. C. H., Hermens, R. P. M. G. and Ottevanger, P. B. (2012) [39]</p> <p>The Netherlands</p>	<p>Aim: to systematically develop evidence-based indicators, to be used to measure the quality of patient-centered cancer care as a first step toward improvement.</p>	<p>RAND modified Delphi method. First, key recommendations were identified from literature and were distributed over 5 domains of patient-centered cancer care: communication, physical support, psychosocial care, after-care, and organisation of care. These key recommendations were processed into a written questionnaire. A multidisciplinary panel of patients and medical professionals rated and prioritised these recommendations. Participants were asked “Please rate on a scale from 1-9 to what extent the execution of this action is a good measure for the quality of patient-centered cancer care.” To support their choice, panel members were provided with the source and evidence level of each key recommendation. Subsequently, the panel discussed the recommendations at a consensus meeting.</p>	<p>Multidisciplinary panel of n=14 patients and medical professionals</p> <p>These consisted of: n=2 surgeons; n=2 medical oncologists; n=3 patients/patient representatives; n=1 radiotherapist; n=1 general practitioner; n=1 nurse-practitioner; n=1 nurse; n=1 psychologist; n=2 social workers.</p>	<p>Key recommendations were identified for communication (n=32), physical support (n=13), psychosocial care (n=25), after-care (n=11), and organisation of care (n=11). Merging all 92 key recommendations ultimately resulted in a core set of 17 quality indicators for patient-centered cancer care concerning criteria for communication skills, provision of information, examination of emotional health, appointment of a care coordinator, physical complaints, follow-up, rehabilitation, psychosocial effects of waiting times, and self-management.</p>	<p>Qual score 0.8</p> <p>Quant score: 0.88</p>
--	---	--	--	--	--

Supplementary Table 2. Retained studies' findings deductively mapped onto Santana et al. framework for person-centred care

Santana domains [34]	Number of supporting studies	Examples of corresponding codes from supporting studies
<u>S1. Creating a PCC culture</u>	5 [37,41-43,46]	<i>"Every employee is part of the patient-centred care approach and provides PCC. Sometimes, the focus is too much on frontline, and there is a lack of understanding other's people's roles."</i> Researcher (Calisi, 2016, p313; Quality score 0.9)[42]
S1a. Core values and Philosophy of the organisation	2 [50,54]	<i>"The philosophy should pervade our whole institution. All should keep in mind the holistic nature of our interventions."</i> Physician (Calisi, 2016, p313; Quality score 0.9)[42] <i>A shared philosophy of care ($p < 0.001$, $\eta^2 = 0.090$) (Variable correlated to PCC from Sjogren, 2017, p4; Quality score 0.91)[54]</i>
• Vision, Mission	0	No corresponding findings
• Patient-directed: integrating patient experience and expertise	1 [41]	<i>"The point was raised that patients should be invited to interprofessional meetings."</i> (Bilodeau, 2015, p110; Quality score 0.7)[41]
• Addressing and incorporating diversity in care, health promotion and patient engagement	1 [49]	<i>All participant groups recognised that the presence or absence of an Indigenous care provider is a crucial aspect in shaping the experiences of cancer-affected participants, who described themselves as being "not as guarded" (302 CaAff) and feeling freer to ask questions without feeling silly, with an Indigenous person. As one participant recalled, "It was important to talk with an Aboriginal person – far more important than ...the social worker for me." (303 CaAff)</i> (Green, 2018, p5; Quality Score 0.85)[49]
• Patient and healthcare provider rights	0	No corresponding findings
S1b. Establishing operational definition of PCC	1 [41]	<i>"This is why a number of professionals stressed that interprofessional collaboration should be improved in terms of the process, definitions and formalities."</i> (Bilodeau, 2015, p110; Quality score 0.7)[41]
• Consistent operational definitions	0	No corresponding findings
• Common language around PCC	0	No corresponding findings
<u>S2. Co- designing the development and implementation of educational programs</u>	2 [47,54]	<i>"Students obviously don't know more than the (registered) nurses but sometimes they might have done assignments on different things. I've just done an assignment on dignity and privacy, so sometimes we can bring little bits of things (information) onto the ward...just reminding some staff and other students as well."</i> Student nurse 3 (Ross, 2015, p1228, Quality score 0.8)[47]
Standardised PCC training in all healthcare professional programs	0	No corresponding findings

• Integration of all healthcare sectors and professionals	1 [42]	<i>"Holistic, multidisciplinary approach."</i> Supportive Care Professional (Calisi, 2016, p31; Quality score 0.9) [42]
• Professional education and accrediting bodies	0	No corresponding findings
• Translating into practice through continued professional education and mentorship	2 [39,51]	<i>'Regarding sources of knowledge, the doctors referred to colleagues in their direct working environment, to congresses and meetings (Onkofortbildung), including also discussions of experiences and presenting best and worst cases, to medical books and articles, case reports, guidelines, clinical trials and studies, to general conferences and, most important, to their experiences with patients and patient feedback.'</i> (Kienle, 2016, p489; Quality score 0.9)[51] A3. Communicative skills of all health care providers should regularly be evaluated, and feedback should be given. (One of final set of approved quality indicators) (Uphoff, 2011, p35; Quality score 0.8 (qualitative), 0.88 (quantitative))[39]
S3. Co- designing the development and implementation of health promotion and prevention programs	0	No corresponding findings
S3a. Collaboration and empowerment of patients, communities and organisations in design of programs	0	No corresponding findings
• Identify resources	0	No corresponding findings
• Creating partnerships with community organisations	0	No corresponding findings
• Create patient advisory groups	0	No corresponding findings
S4. Supporting a workforce committed to PCC	3 [41,47,54]	<i>'In addition, the number of staff who received regular supervision was higher in units with high levels of PCC compared to in units with low levels of PCC (p =0.005, phi – 0.09)'</i> (Sjogren, 2017, p4, Quality score 0.91)[54] <i>Flexibility in ward routines was spoken about as a facilitator to PCC; however, for this to occur, the leadership style had to be congruent with PCC: "If you've got a ward manager that is aware of people as individuals and encourages that, then you take your lead from them or your senior nurses...when you get new staff you should be encouraging them and setting a good example."</i> (Research nurse 3) (Ross, 2015, p1228; Quality score 0.8)[47]
S4a. Ensure resources for staff to practice PCC	0	No corresponding findings
• Provide adequate incentives in payment programs; celebrate small wins and victories	0	No corresponding findings

<ul style="list-style-type: none"> Encourage teamwork and teambuilding 	<p>4</p> <p>[37,41,46,51]</p>	<p><i>“Professionals working as a team increase the right mood/atmosphere at the department, which also decreases the chance of making mistakes” (Patient 10) (Cramm, 2015, p7; Quality score 0.9 (qualitative), 0.85 (quantitative))</i>[37]</p> <p><i>“If the team is not ready to work as a team, throughout the process, it’s not a question of asking me to do my job. It’s a matter of being able to work together.” (Professional 4) (Bilodeau, 2015, p110; Quality score 0.7)</i>[41]</p>
<p><u>SS. Providing a supportive and accommodating PCC environment</u></p>	<p>1</p> <p>[49]</p>	<p><i>Participants referred to the hospital environment and surroundings only in the context of cultural safety, including: the intimidating nature of the hospital environment; the presence or absence of Indigenous artwork and flags; the ability to engage in cultural practices, such as smoking ceremonies; space for multiple visitors in hospital (without judgment); and access to garden areas, enabling people to feel more relaxed, able to talk and to receive information. (Green, 2018, p8; Quality Score 0.85)</i>[49]</p>
<p>SSa. Designing healthcare facilities and services promoting PCC</p>	<p>3</p> <p>[36,41,54]</p>	<p><i>A dementia-friendly physical environment, (p <0.001, $\eta = 0.045$) (Variable correlated to PCC from Sjogren, 2017, p4; Quality score 0.91)</i>[54]</p> <p><i>Team members thought proximity facilitated collaboration while physical distance between team members limited it: “I think that the distance between different members of the team can mean less consultation, so that if there were some problem, you deal with it much faster, instead of taking the time to call.” (Professional 7) (Bilodeau, 2015, p109; Quality score 0.7)</i>[41]</p>
<ul style="list-style-type: none"> Collaborate with and empower patients and staff in designing healthcare facilities 	<p>0</p>	<p>No corresponding findings</p>
<ul style="list-style-type: none"> Environments that are welcoming, comfortable and respectful 	<p>5</p> <p>[36,37,41,44,49]</p>	<p><i>Linda, a family member narrated how a personalised environment supported seeing the person behind the disease: “In the facility, the residents are able to bring in their own things, like their photos and pieces of furniture and this makes all the difference. When you walk into the room, you know something about the person by what is there.” (Edvardsson, 2010, p2615, Quality score 0.8)</i>[44]</p> <p><i>“It is important that the department is clean” (patient 5) (Cramm, 2015, p7; Quality score 0.9 (qualitative), 0.85 (quantitative))</i>[37]</p> <p><i>‘Some respondents reported that their physical comfort in the waiting room is of minor importance in comparison to the reason why they were treated.’ (Bishop, 2017, p2250; Quality score 0.85)</i>[36]</p> <p><i>The quality of the environment worried the professionals, who found the premises inappropriate for welcoming patients because they were small and did not foster a warm atmosphere. However, patients and families were much more concerned about the ‘human environment’ than the quality of the physical premises. (Bilodeau, 2015, p109; Quality score 0.7)</i>[41]</p>
<ul style="list-style-type: none"> Spaces that provide privacy 	<p>4</p> <p>[36,39,47,48]</p>	<p><i>It was important for the patients to be able to influence the decision about whom they had to share their room with, but for different reasons. Two reasons are illustrated in the following quotes: “I cannot stay in a dark room. I have to have the light on, night and day, and I have to have fresh air and an open door. I cannot be in the same room as patients who want to turn off the light and have the door closed. I told the nurses, and they tried to find patients who were willing to share the room with me. They never joked about it, and that was important because it is very serious for me. Sometimes the nurses put very</i></p>

		<p><i>ill people in together with more healthy people in the same room. I have suffered much because of this. Lately the nurses have been cleverer by choosing patients that go together. They also ask me how I want things in my room.”</i> (Kvale, 2008, p586, Quality score 0.95) [48]</p> <p><i>A2. The health care provider should guarantee the following preconditions for a suitable conversation: a. providing a room with adequate privacy, with enough time for an accurate conversation.</i> (One of final set of approved quality indicators) (Uphoff, 2011, p35; Quality score 0.8 (qualitative), 0.88 (quantitative))[39]</p>
• Spiritual and religious spaces	0	No corresponding findings
• Facility that prioritise the safety and security of its patients and staff	0	No corresponding findings
• Areas/rooms that will support the accommodation of patients	1 [49]	<p><i>Participants referred to the hospital environment and surroundings only in the context of cultural safety, including: the intimidating nature of the hospital environment; the presence or absence of Indigenous artwork and flags; the ability to engage in cultural practices, such as smoking ceremonies; space for multiple visitors in hospital (without judgment); and access to garden areas, enabling people to feel more relaxed, able to talk and to receive information.</i> (Green, 2018, p8; Quality Score 0.85)[49]</p>
S5b. Integrating organization-wide services promoting PCC	1 [49]	<p><i>Health professionals also spoke about the benefits to staff of having an Aboriginal Liaison Officer (ALO) and/or Aboriginal Health Worker (AHW) in the service, including: helping staff understand why a patient/family member may be responding in a certain way; enabling the patient to trust enough to explain their concerns; and facilitating better linkages with services outside the hospital. “[O]nce they’ve seen that I’ve been able to work with the liaison officer, I’ve been able to build really strong relationships after that……So it’s helped me to be introduced as a safe person…”</i> (HP 205). (Green, 2018, p8; Quality Score 0.85)[49]</p>
• Provide interpretation and language services	2 [37,39]	<p><i>f. Adjusting information to the language skills of the patient and, when necessary, providing information in the native language of the patient</i> (One of final set of approved quality indicators) (Uphoff, 2011, p35; Quality score 0.8 (qualitative), 0.88 (quantitative))[39]</p>
• Patient-directed visiting hours	0	No corresponding findings
<u>S6. Developing and integrating structures to support health information technology</u>	0	No corresponding findings
Common e-health platform for health information exchange across providers and patients	0	No corresponding findings
• Electronic Health Record systems with capacity to coordinate and share healthcare interactions across the continuum of care	0	No corresponding findings

• Health information privacy and security	0	No corresponding findings
• E-health adoption support through strategic funding and education	0	No corresponding findings
<u>S7. Creating structures to measure and monitor PCC performance</u>	0	No corresponding findings
Co-design and develop framework for measurement, monitoring and evaluation	0	No corresponding findings
• Co-design and development of innovative programs to collect patients and caregiver experiences about care received and providing timely feedback to improve the quality of health care (including complaints and compliments, wins and lessons learned)	1 [49]	<i>Most participants indicated that a face-to-face interview with a trusted person would be the best approach to measuring Indigenous patients' experiences of care. There was a clear preference among all groups for an opportunity for 'yarning', with several people suggesting a group or workshop setting.</i> (Green, 2018, p8; Quality Score 0.85)[49]
• Reporting and feedback for accountability and to improve quality of health care	1 [42]	<i>Accountability</i> (Arising theme from questionnaire; Frequency = 1) (Calisi, 2016, p312; Quality score 0.9) [42]
<u>P1. Cultivating communication</u>	11 [36,37,39,41-43, 47-51]	<i>Staff emphasized the importance of...communication between patient, family members and all members of the care team to provide individualized, compassionate care</i> (Calisi, 2016, p312, Quality score 0.9)[42] <i>Per our patient stakeholders, two words characterise the roles of providers and patients – transparency and communication. Patients need to be honest and transparent and the providers need to make sure that patients can trust them. As in any relationship, without good communication, the relationship does not go far.</i> (Chhatre, 2017, p3; Quality score 0.35)[50] <i>Attention to detail in phrasing – subtle changes can impact patient perception. (E.g. Using "What other questions do you have today?" in place of, "Do you have any more questions?")</i> (suggested component of physician-patient communication) (Nguyen, 2017, Supplementary table 1; Quality score 0.65)[43]
P1a. Listening to patients	9 [36-40,42,43,47,48]	<i>There was a clear recognition from participants that listening to and recognising the importance of people's stories were valuable in facilitating PCC</i> (Ross, 2015, p1228; Quality score 0.8)[47] <i>"to be heard, acknowledged and taken care of." Patient</i> (Calisi, 2016, p131; Quality score 0.9)[42] <i>Those holding [Viewpoint 2] indicated that according to their experience patients do want to tell their story several times, because it is part of their acceptance process and thus positively affects their well-being (11;~ 3). "Them telling their story helps them understand what is going and gives some relieve, this is also sometimes the beginning of acceptance" (respondent 21).</i> (Galekop, 2019, p6; Quality score 0.95 (qualitative), 0.85 (quantitative))[40]

<ul style="list-style-type: none"> Gathering information through active listening 	1 [42]	<p><i>“Taking the time to ask questions and actually listening for their answers.” Radiation Therapist (Calisi, 2016, p312; Quality score 0.9)[42]</i></p>
<ul style="list-style-type: none"> Asking questions of what patients want to discuss (concerns, views, understanding) 	4 [42,43,47,51]	<p><i>Ask for the patient and family’s expectations for the current visit and work together to establish an agenda that addresses both patient and provider goals (suggested component of physician-patient communication) (Nguyen, 2017, Supplementary table 1; Quality score 0.65)[43]</i></p>
<ul style="list-style-type: none"> Non-verbal behaviours (eye-contact, listening attentively, proximity/touch, head nodding) 	3 [41,43,44]	<p><i>Patients also commented on professionals’ empathy and attentiveness to them. A patient reported: “The attentiveness they give you. They take the time to speak to you. I often noticed that everyone looked you in the eye.” (Patient 2) (Bilodeau, 2015, p110; Quality score 0.7)[41]</i></p> <p><i>Pay close attention to the body language of patients and their caregivers and acknowledge these observations as appropriate. (suggested component of physician-patient communication) (Nguyen, 2017, Supplementary table 1; Quality score 0.65)[43]</i></p>
P1b. Sharing information	12 [36-42,44,48,49,50,51]	<p><i>Patients attached specific importance to...provision of honest and complete information (Bisschop, 2017, p2250; Quality score 0.85)[36]</i></p> <p><i>“Nothing about me without me.” Patient (Calisi, 2016, p313; Quality score 0.9)[42]</i></p> <p><i>The need for effective communication and education was raised by both cancer-affected and health professional participants. Key points relating to information provision included: the importance of using accessible and appropriate language; using diagrams or drawings to aid comprehension; limiting the amount of information provided at any one time; considering the optimal timing of information provision; and recognising the need to repeat information over the course of the cancer journey. (Green, 2018, p7; Quality Score 0.85)[49]</i></p>
<ul style="list-style-type: none"> Patients are provided with all the necessary information to make informed decisions in relation to their diagnosis and treatment plan 	6 [37,38,42,43,48,50]	<p><i>The patients added three specific information items, namely, ‘information about the possible course of the disease’, ‘the possibility of a second opinion’ and ‘information about the treatment option of “no active therapy”’. (Ouwens, 2010, p124; Quality score 0.65 (qualitative), 0.78 (quantitative))[38]</i></p> <p><i>The provider is responsible for explaining all treatment options and their ramifications, without being biased. (Chhatre, 2017, p3; Quality score 0.35)[50]</i></p>
<ul style="list-style-type: none"> Sharing of information regarding patient’s condition and their own impact/influences on their condition 	3 [38,39,42]	<p><i>Additional suggestions from survey question 4 included...enabling patient access to their own test results... (Calisi, 2016, p313; Quality score 0.9) [42]</i></p> <p><i>Patient knows which activities are allowed at home (suggested patient-centred cancer care indicator) (Ouwens, 2010, p126; Quality score 0.65 (qualitative), 0.78 (quantitative))[38]</i></p>
P1c. Discussing care plans with patients	8 [36,37,39,41-43,47,48]	<p><i>A patient with much pain expressed how important it was for medical staff to take time to discuss treatment with the patient: “The staff did not ask for my opinion the first six months. It was a long time before my pain was taken seriously. Why this was I don’t know. Maybe I was not good enough at telling them, or I looked too healthy. The patient needs to be secure before talking about their needs. The nurses and doctors must have enough time to sit down and find out what the patient’s</i></p>

		<p><i>needs are. When the staff understood how bad it was, they took it seriously. Now I get things the way I want.” (Kvale, 2008, p585; Quality score 0.95)[48]</i></p> <p><i>Participants also identified that involving patients and relatives in care decisions and care delivery in a compassionate manner supported PCC. (Ross, 2015, p1228; Quality score 0.8)[47]</i></p>
<ul style="list-style-type: none"> • Responding to patient and caregiver needs 	<p>11</p> <p>[36-39,41,42,44,46,47,51,53]</p>	<p><i>“PCC...you are looking after their needs opposed to just their physical needs. Like walking, breathing, eating, they need more than that” (Care assistant 3) (Colomer, 2016, p1162; Quality score 0.75)[53]</i></p> <p><i>Care is unique to the individual’s needs (11.3%) (Fifth most common theme arising from poster comments) (Calisi, 2016, p311; Quality score 0.9)[42]</i></p> <p><i>Christina, whose mother lived permanently in a residential aged care facility, described how family should feel welcome at all times: “The family should be told that ‘this is your mother’s home so come and go as you please”. (Edvardsson, 2010, p2615; Quality score 0.8)[44]</i></p>
<ul style="list-style-type: none"> • Aim and follow-up of treatment or interventions with possible outcomes and adverse events/side-effects 	<p>4</p> <p>[36,38,39,50]</p>	<p><i>With the exception of two respondents, sufficient education was provided about the kinds of toxicities and expected adverse effects. (Bisschop, 2017, p2248; Quality score 0.85)[36]</i></p> <p><i>“Specifically, I wanted information on ‘after treatment, this is what you’re going to face in life’, and by ‘this’, I am speaking of the side effects that came with his particular treatment plan.” (Patient stakeholder 2) (Chhatre, 2017, p3; Quality score 0.35)[50]</i></p> <p><i>Specialists discussed aim and follow-up of the treatment with the patient. (suggested patient-centred cancer care indicator) (Ouwens, 2010, p126; Quality score 0.65 (qualitative), 0.78 (quantitative))[38]</i></p>
<ul style="list-style-type: none"> • Discussing and building capacity of patients for self-management and self-care 	<p>3</p> <p>[38,39,46]</p>	<p><i>Patient knows at discharge which medication to take and why. (suggested patient-centred cancer care indicator) (Ouwens, 2010, p126; Quality score 0.65 (qualitative), 0.78 (quantitative))[38]</i></p> <p><i>E5. Depending on the individual patient, the health care provider should stimulate self-management and offer the proper information and support. (One of final set of approved quality indicators) (Uphoff, 2011, p35; Quality score 0.8 (qualitative), 0.88 (quantitative))[39]</i></p>
<ul style="list-style-type: none"> • Acknowledging and discussing uncertainties 	<p>1</p> <p>[39]</p>	<p><i>b. giving verbal information about the possible physical and psychosocial impact of diagnostics and the treatment on the patient (One of final set of approved quality indicators) (Uphoff, 2011, p35; Quality score 0.8 (qualitative), 0.88 (quantitative))[39]</i></p>
<ul style="list-style-type: none"> • Creating a shared understanding 	<p>4</p> <p>[38,39,43,51]</p>	<p><i>Check often for patient and family understanding. (suggested component of physician-patient communication) (Nguyen, 2017, Supplementary table 1; Quality score 0.65)[43]</i></p> <p><i>Medical language had to be made understandable for patients: “Many patients do not understand the language of the doctors and many doctors do not understand the language of the patients...They have to...understand the technical terms. I tell them: translate it... This is very, very important. (General practitioner) (Kienle, 2016, p488; Quality score 0.9)[51]</i></p>

<u>P2. Respectful and compassionate care</u>	13 [36-38,40-42,44-48,50,51]	<p><i>The doctors also described working on their own attitudes toward the patient: having respect, and seeing the side of the patient's personality that impressed them, being dedicated to the care of very advanced and severely ill patients, and always looking for possibilities for providing support and relieving suffering.</i> (Kienle, 2016, p489; Quality score 0.9)[51]</p> <p><i>The interviewer then asked what the nurses said or did that gave them the feeling of being treated with respect. The following units of meaning were identified: "The nurses take me seriously and treat me as an adult and are very good listeners. They encourage me to tell them my wishes, listen to my questions and always give me an answer. They also showed me respect as an individual, not only as a patient, when they remembered my name without looking at my papers when I came back to the ward for treatment. The nurses respect me when doing something extra to help me, for instance finding something that is better for me to eat when I tell them that I cannot have the food they are giving me, rather than saying 'Oh, well...'"</i> (Kvale, 2008, p585; Quality score 0.95)[48]</p> <p><i>"This professional, I took a dislike to him the day they told us he had [cancer]...He told us 'this is important bang bang'. It seems to me that he lacked compassion."</i> (Family member 3) (Bilodeau, 2015, p110; Quality score 0.7)[41]</p> <p><i>Professionals and volunteers consider dignity and respect and quality of life as the foundation of good care-delivery; "People are different, some even rude but they all deserve to be treated with dignity" (respondent 29).</i> (Galekop, 2019, p6; Quality score 0.95 (qualitative), 0.85 (quantitative))[40]</p>
P2a. Being responsive to preferences, needs and values	16 [36-48,51-53]	<p><i>You've got to ensure that, not just the physical aspects of the care are taken, as you're doing your job, but that you're taking the person's wishes into consideration as well."</i> (Care assistant 1) (Colomer, 2016, p1162; Quality score 0.75)[53]</p> <p><i>Respondents with [Viewpoint 1] perspective believed that consideration of patients' preferences was an important aspect of PCC, as evidenced by the importance of treating patients with dignity and respect (item 1; staff member 4 and patient 11 stated that professionals should 'take the patient seriously and respect their choices'), improving quality of life (item 2), and involving patients in decisions about their care (item 4).</i> (Cramm, 2015, p5; Quality score 0.9 (qualitative), 0.85 (quantitative))[37]</p> <p><i>All participants described knowing the history, preferences, needs, interests and particularities of the person receiving care as being fundamental in the provision of person-centred care.</i> (Edvardsson, 2010, p2614; Quality score 0.8)[44]</p> <p><i>Respondents further explained that care should be provided keeping patients' preferences in mind (3;+ 2, 8;+ 2*): "I think the patient needs to express what he or she wants and the care will then be provided according to his or her needs" (respondent 5).</i> (Galekop, 2019, p4; Quality score 0.95 (qualitative), 0.85 (quantitative))[40]</p>
<ul style="list-style-type: none"> • Acknowledge the patient as an expert in their own health and as a part of the healthcare team 	7 [37-42,48]	<p><i>"I am the head of my health care team...ultimately how things progress in my care circle is my decision."</i> Patient (Calisi, 2016, p313; Quality score 0.9)[42]</p> <p><i>[Respondents with Viewpoint 2] especially felt that patients being in charge of their own care (item 28) was very important, as demonstrated by the following statements: "The patient has to make the final decision" (nurse 1); "The patient should be autonomous" (staff member 2); "Everything I can decide, I will decide" (patient 13)</i> (Cramm, 2015, p5; Quality score 0.9 (qualitative), 0.85 (quantitative))[37]</p>

<ul style="list-style-type: none"> Understanding patient within his/her unique psychosocial or cultural context (i.e: awareness of religious, spiritual, lifestyle, social and environmental factors) 	13 [36,38,39,41-47,49,51,52]	<p><i>It referred to informing and shared decision-making, to addressing the mental and spiritual level ("What individualizes and forms a human being are our mental and spiritual forces . . ." [Gastroenterologist]) and to tailoring the whole treatment concept to the patient's condition, constitution, needs, and values: "There are many things that patients bring with them...what is their concept and to start from there, where the patient really stands...which ideas does the patient have about what is good for him/her and how can he/she build up his/her health further." (Internist) (Kienle, 2016, p482; Quality score 0.9)[51]</i></p> <p><i>Consistently inquire about the patient's financial situation, social history and support system. (suggested component of physician-patient communication) (Nguyen, 2017, Supplementary table 1; Quality score 0.65)[43]</i></p> <p><i>Participating staff felt strongly that it was not enough just to know the individual; this knowledge had to be translated into practice and actively used in the provision of care so that it could be person-centred. Knowing the individual was described as essential for initiating conversations, activities and routines that were meaningful for the person. Also, staff could, with such knowledge, provide small extras that the person enjoyed such as sitting in the sun, going for a coffee and/or doing a bit of gardening. (Edvardsson, 2010, p2614; Quality score 0.8)[44]</i></p> <p><i>The context in which cancer occurs is an important factor in shaping how cancer care is experienced. Key contextual factors identified by participants included past and present experiences of racism and discrimination, the underlying patterns of illness in the Indigenous population, health system characteristics and the varied life circumstances of patients. Many participants referred to the lack of open discussion about cancer ("the 'C' word"; 512 CaAff:) in the Indigenous community, for reasons including stigma, large amounts of existing stress, and different ways of dealing with challenges. (Green, 2018, p5; Quality Score 0.85)[49]</i></p>
<ul style="list-style-type: none"> Responding empathically 	2 [42,47]	<p><i>Care that is caring, compassionate, and empathetic (26.8%) (Most common arising theme from poster comments; Frequency = 26) (Calisi, 2016, p311; Quality score 0.9)[42]</i></p>
P2b. Providing supportive care	6 [38,41,45,47,52,53],	<p><i>"It means give them a lot more time. Let them know that you are there for them. That would be my person centred care. To try make them happier." (Care assistant 10) (Colomer, 2016, p1162; Quality score 0.75)[53]</i></p> <p><i>Theme 1: Support in line with patient's experience and involvement (Bilodeau, 2015, p110; Quality score 0.7)[41]</i></p> <p><i>In practice, this might mean what this ACW understands PCC to be, "playing along with those dementia residents and understanding their perspective and adjusting your way in accordance with how they think about things", (ACW5, [Aged care worker 5]). In this instance, ACW5 is aware that the world of the person with dementia is different to that of his own and demonstrates an understanding of the unique perspective (P) of the person with dementia. (Oppert, 2018, p686; Quality score 0.75)[45]</i></p>
<ul style="list-style-type: none"> Building a partnership with patients 	11 [36,38,40-42,44,47-49,51,52]	<p><i>The experience of cancer was demanding for patients and they appreciated developing genuine relationships with the professionals. (Bilodeau, 2015, p107; Quality score 0.7)[41]</i></p> <p><i>The essence that emerged was that the patients wanted to take part in all decisions about their daily life and care. This can be seen as a wish for partnership in nursing care. The following units of meanings were identified: "The nurses ask me to tell them my wishes and they do what I want. This is very good. I want to take part in decision making. When dressing my wound</i></p>

		<p>with bandages and things like that, they ask if it is painful. If I had not agreed with the way the nurses are doing the dressing, they most certainly would have changed it." (Kvale, 2008, p585; Quality score 0.95)[48]</p> <p>Health professionals talked about the importance of developing trusting relationships to overcome this: "I think probably the biggest thing is trust and in palliative care it frequently takes several visits to develop that trust. It's still really important with every individual that we really actively try and engage with the patient and their community." (407 HP) However, this trust could be fragile; if broken it could be critical in defining the person's experience of care: "And they said, "Oh, Aboriginal people don't burn when they have radiation". And that's an outright lie ... Because I was burnt red raw from radiation." (503 CaAff). (Green, 2018, p5; Quality Score 0.85)[49]</p>
• Providing resources	0	NA
• Sensitivity to emotional/psychosocial needs	10 [36,38,39,41,42, 44-46,51,52]	<p>Thirteen respondents reported that emotional/psychological support was not necessary; all stated that the possibilities were explained by the doctors. Four respondents and one partner were given support by a social worker. The respondents and partners who received help from a social worker experienced this as a positive experience: "I have had four appointments with the social worker, and if I needed more it could be arranged. I could count on her, in the beginning I did not think I would need it, but at some point I thought well why not, it is being offered and I could use the help." (Respondent no. 5) (Bisshop, 2017, p2250; Quality score 0.85)[36]</p> <p>Psychological care, such as talking to the patient, psychotherapy, and counselling, was a central part of treatment, particularly in cases of progressive disease: "I actually see my main focus primarily in talking with the patient..." (General practitioner). (Kienle, 2016, p487; Quality score 0.9)[51]</p> <p>"Person-centred care is the person being the centre of the care. So spiritually, physically, mentally looked after as a whole. Making sure that person has holistic care" (Aged care worker 4). (Oppert, 2018, p686; Quality score 0.75)[45]</p>
<u>P3. Engaging patients in managing their care</u>	8 [37,39-42,44,50,51]	<p>Person or patient is a part of their care (12.4%) (Fourth most common arising theme from poster comments and questionnaire; Frequency = 26) (Calisi, 2016, p312; Quality score 0.9)[42]</p> <p>Respondents with [viewpoint 1] felt that patients being in charge of their own care (item 28) and receiving support to achieve this goal (item 29) were less important....[Respondents with viewpoint 2] especially felt that patients being in charge of their own care (item 28) was very important, as demonstrated by the following statements: 'The patient has to make the final decision' (nurse 1); 'The patient should be autonomous' (staff member 2); 'Everything I can decide, I will decide' (patient 13) (Cramm, 2015, p5; Quality score 0.9 (qualitative), 0.85 (quantitative))[37]</p> <p>Respondents holding [Viewpoint 1] strongly believe that patients should be in charge of their own care and that professionals and volunteers should primarily support patients to achieve their goals (28;+ 4* (statement 28; score + 4*), 29;+ 3*). Participants strongly feel healthcare professionals and volunteers should respect patients' autonomy; "Well, I believe that patient autonomy is a priority and we adjust the care we provide accordingly. This means that one can sympathize with others, that 'nothing is set' and everything is well communicated, and that the patient has sovereignty. Sovereignty... well... actually more like autonomy" (respondent 1)... Those holding [Viewpoint 2] considered it most important that patients, volunteers and professionals work together as a team with the patient in the passenger seat...Professionals and volunteers in this viewpoint in a way thus play a central role in the decision-making process in this viewpoint and according to them</p>

		<p>patients are fine with that (28;-2, 29;-1); “In the last phase of life [being in charge of their own care] is not necessary anymore. I think patients are allowed to expect that everything is going alright” (respondent 29), “People who are in the last phase of their life often say: you can make the decisions, I’m tired of doing that. If you make good decisions, I can just ‘be’ ill. Spare me all the choices”(respondent 6). (Galekop, 2019, p5-6; Quality score 0.95 (qualitative), 0.85 (quantitative))[40]</p>
Co-designing care plans with patients	<p>11</p> <p>[36,37,41-44,46-48,50,51]</p>	<p>Patients differ in their willingness and ability to be involved, and thus the physicians have to help them reach the appropriate decision. (Chhatre, 2017, p4; Quality score 0.35)[50]</p> <p>Another way that participants expressed their client-centeredness was through their descriptions of planning goals and meeting people’s needs that were important from the perspective of the client and family. (Pizzi, 2015, p445; Quality score 0.65)[46]</p> <p>The principles of providing PCC involved recognising the importance of a person’s wishes when considering care decisions. Even when the patient him/herself was unable to make the decision, the nurses and multidisciplinary team worked with families to consider what the best interests of the person would be. This often involved supporting the person or their family to ask questions when unsure about treatment or care decisions: “Lots of the times we are advocates for them (patients)...when the doctor walks away we say “Are you alright with everything you have been told, do you want to ask any questions?” They sometimes say they don’t understand what has been said...I think as long as the person has (mental) capacity, then I think it (their view) does get listened to. I think on this ward they are really good, they really try to meet people’s needs and take into account their beliefs and what they want.” (Registered nurse 4) (Ross, 2015, p1229; Quality score 0.8)[47]</p>
• Shared decision making	<p>12</p> <p>[36-43,46,48,51,52]</p>	<p>They were often seen as overwhelmed and under a lot of pressure with conventional treatments planned to start right away. Making time for therapeutic talk with respect to disease circumstances and treatment decisions, including detailed informing about how to understand the disease, stage, therapeutic options, and statistics as well as the emotional and existential dimensions, was thus a practical aspect that doctors emphasized as enhancing autonomy and informed choice-making. For me that [autonomy] is most essential, also in regard to decisions that have to be made right after surgery, namely, chemo-, radiation-, anti-hormone therapy etc ... there the course is already set for non-autonomy. ... I try to slow down and say: ‘First of all, you have time.’... And secondly, I think it is a complete different situation whether they do radiation, because the doctor said so and they didn’t think about it, or because they dealt with the subject and decided: yes, I want this. And to take the time ... this is where I start working on the subject of autonomy. (Gynaecologist) (Kienle, 2018, p128; Quality score 0.9)[52]</p> <p>Two of the participants suggested that in their client-centeredness they “manipulated” the situation to enable choices, but ones that further occupationally engaged their clients. One participant expressed that the development of the emotional climate or helping people at the end of life engage in full expression of themselves was client- and family-centered. (Pizzi, 2015, p446; Quality score 0.65)[46]</p> <p>Some of the patients wanted to put all decisions in the hands of the doctors. The reason for this is illustrated by the following quote: “I do not wish to take part in decision making. The doctors know what they are doing and what they do is right. I have so much respect for their profession that I do not believe that my decision will be better than theirs. I trust them; at least I want to. I leave the decision in their hands. They have not really asked about my opinion, but I have no need of them doing so either.” Only a couple of patients wanted to decide for themselves. This is illustrated by the following quotes. “Yes, yes of</p>

		<p>course I want to decide about my treatment. I belong to the so-called difficult group of patients. There are three types of patients: the ones that have given up and say, 'OK, this has happened to me. It is fate'; the group that believes the doctor is still holy and knows everything and so follows his advice fully; and the difficult ones like me who are asking questions." (Kvale, 2008, p585; Quality score 0.95)[48]</p> <p>'For my questions to be answered and for all my options to be communicated to me. For my decisions to be respected.'" Patient (Calisi, 2016, p313; Quality score 0.9)[42]</p>
• Goal-setting	4 [40,46,51,52]	<p>Another way that [end of life healthcare professional] participants expressed their client-centeredness was through their descriptions of planning goals and meeting people's needs that were important from the perspective of the client and family. In the hospice, the patient and family must agree upon the treatment plan and goals. Setting realistic short- and long-term goals may vary greatly between clients depending on their prognosis. The dying trajectory is individual, and people can optimize function within the limits of the disease process. (Pizzi, 2015, p446; Quality score 0.65)[46]</p> <p>Doctors encouraged patients to actively participate in their existing social network and work life but also to develop new goals and meaningful personal changes by reflecting on biographical aspects, such as dreams and wishes, both new and old, or by asking patients what they would like to experience if their life were to be condensed to only a few years. It also is an overall concept, because it is about the question of meaning, because it is about the question of coping. That is also one of my first questions: what is the main thing that you would do in the time left—no matter how long it is—so that I can tell them that it will be integrated into the treatment so that they do not say, 'Because of chemotherapy, I couldn't do such and such.' (Gastroenterologist) (Kienle, 2018, p129; Quality score 0.9).[52]</p>
• Supporting self-care management	3 [38,39,46]	<p>"You need to get people away from thinking that their wellness is going to come from someone doing something for them. But maybe their wellness is more based on being taught how to take care of themselves – self-management – on many levels." (Occupational therapist 1) (Pizzi, 2015, p445; Quality score 0.65).[46]</p> <p>E5. Depending on the individual patient, the health care provider should stimulate self-management and offer the proper information and support. (One of final set of approved quality indicators) (Uphoff, 2011, p35; Quality score 0.8 (qualitative), 0.88 (quantitative))[39]</p>
• Care plans can be accessed by patients and healthcare providers	3 [40,42,43]	Adequately informing patients of next steps and wait times between steps. (One of physician identified patient- and family-centred strategies pertaining to streamlining care delivery.) (Nguyen, 2017, Supplementary table 2; Quality score 0.65)[43]
P4. Integration of care	5 [36,39,41,51,54]	<p>Interdisciplinary collaboration ($p < 0.001$, $\eta = 0.041$) ...[was] rated significantly higher in units with higher PCC compared to units with lower PCC. (Sjogren, 2017, p4; Quality score 0.91)[54]</p> <p>The complex organization of services could also affect the experience of care. Another family member summarized this: "The system [the oncology clinic] is so complicated that it's like swimming in molasses. (Family member 3) (Bilodeau, 2015, p109; Quality score 0.7)[41]</p>
Communication and information sharing for coordination and continuity of care across the continuum of care	10	First, the communication with the administrative staff was described as respectful with a problem-solving approach with the patient being a central part. Second, internal communication between the HNO department and other medical specialists was generally experienced as being up to date: "All doctors were informed about my story, my operation and the whole

	[36-38,40-42,44, 46,47,49]	<p><i>process. Three surgeons operated on me. There were many different specialists and for me it was one team. I cannot complain.” (Respondent no. 1). (Bisschop, 2017, p2248; Quality score 0.85)[36]</i></p> <p>[Suggested patient-centred cancer care indicators]: <i>Specialists involved knew patient’s history; Patient knew how to reach specialists; Patient knew about being discussed in a multidisciplinary team of specialists; Specialists involved took care of the coordination; Patient knew which specialist is his main contact person; Oncology nurse was present during bad news consultation; Existence of an oncology nurse was known by patient; Patient knew how to reach oncology nurse; Oncology nurse knew patient’s history; Oncology nurses took care of the coordination; Patient knew how to reach paramedic professionals; Paramedic professionals involved knew patient’s history; Paramedic professionals involved took care of the coordination (Ouwens, 2010, p126-7; Quality score 0.65 (qualitative), 0.78 (quantitative))</i>[38]</p>
• Between healthcare providers	2 [38,40]	<p>[As above] [Suggested patient-centred cancer care indicators]: <i>Specialists involved knew patient’s history; Specialists involved took care of the coordination; Oncology nurse knew patient’s history; Oncology nurses took care of the coordination; Paramedic professionals involved knew patient’s history; Paramedic professionals involved took care of the coordination (Ouwens, 2010, p126-7; Quality score 0.65 (qualitative), 0.78 (quantitative) [38]</i></p>
• Referrals to specialist	2 [39,43]	<p><i>Utilizing multidisciplinary clinics to decrease wait times and patient anxiety between specialist referrals. (One of physician identified patient- and family-centred strategies pertaining to streamlining care delivery.) (Nguyen, 2017, Supplementary table 2; Quality score 0.65)[43]</i></p>
• Discharge communication	3 [38,39,49]	<p>[Suggested patient-centred cancer care indicators relating to follow-up]: <i>Home care knows about the patient’s situation; Patient knows which activities are allowed at home; Patient knows which side effects to be aware of; Patient knows when to contact the primary care doctor or specialist; Patient knows at discharge which medication to take and why; The primary care doctor knows about the patient’s situation; Patient follow-up takes place on an agreed schedule; Specialist has enough time during consultations; Patient can reach the specialist between consultations (Ouwens, 2010, p126; Quality score 0.65 (qualitative), 0.78 (quantitative)).</i>[38]</p> <p><i>“I found that I was let down with one of the main services that I really...depended on...(after) being discharged from hospital. I had a bad experience. I was left to fend for myself. I had to maintain my housewhich resulted (in) me getting infected and.. a lot of follow-up with doctors and medication, which could have been avoided..” (305 CaAff). (Green, 2018, p6, Quality score 0.85)[49]</i></p>
• Providing access to information and resources	1 [42]	<p>“Additional suggestions from survey question 4 included allowing enough time for encounters, providing adequate education and resources...” (Calisi, 2016, p313; Quality score 0.9)[42]</p>
<u>O1. Access to care</u>	7 [36,37,39,41-43,49]	<p><i>Furthermore, patients would appreciate having access to the services of the team throughout their entire experience. For example, one patient reported that he would have liked to have access to psychological services a year after his treatments finished because that was when he really felt the need. (Bilodeau, 2015, p110; Quality score 0.7)[41]</i></p> <p><i>Care that is accessible (Theme arising from questionnaire; Frequency = 5) (Calisi, 2016, p312; Quality score 0.9)[42]</i></p>

		<i>Among cancer-affected participants, key challenges, especially for those needing to travel for treatment, included: logistical difficulties and costs associated with transport, accommodation and food; separation from family and support networks during a very stressful time; and costs associated with bringing family support to patients. "Going away and being treated – that's the biggest thing because you know one of the most important things when you're not well is to have your home. I think it's better to be treated at home because you might not have the people around you as you're going through treatment" (304 CaAff). (Green, 2018, p6; Quality Score 0.85)[49]</i>
O1a. Timely access to care	5 [36,38,41-43]	<i>...For care to be consistent and timely: "For appointment times to be accurate; to get tests done in a timely manner; my opinion being respected; to be heard, acknowledged and taken care of." Patient (Calisi, 2016, p313; Quality score 0.9)[42]</i> <i>Adequately informing patients of next steps and wait times between steps. (One of physician identified patient- and family-centred strategies pertaining to streamlining care delivery.) (Nguyen, 2017, Supplementary table 2; Quality score 0.65)[43]</i>
• Wait times for referrals to see specialists, to receive a consult	3 [38,39,43]	<i>E2. The maximal waiting time between the visit to the general practitioner and the first visit to the hospital should be 5 working days. E3. The maximal duration of the diagnostic process should be in accordance with the professional measures for the specific type of cancer. (Two of final set of approved quality indicators) (Uphoff, 2011, p35; Quality score 0.8 (qualitative), 0.88 (quantitative)))[39]</i> <i>Adding patient opinions had added value concerning criteria for waiting times and information supply. The guidelines often recommended speeding up the diagnosis and starting treatment as soon as possible. However, they provided hardly any concrete information about acceptable waiting times. The criteria for waiting and throughput times in our study came from the patient interviews as answers to the question of acceptable waiting times... [Suggested patient-centred cancer care indicator]: Waiting time first visit lung specialist <5 days (Ouwens, 2010, p124-6; Quality score 0.65 (qualitative), 0.78 (quantitative)). [38]</i>
• During consult, to be seen at emergency community care, pre-hospital, hospital, post-hospital; secondary care; time for patient care	4 [36,38,39,42]	<i>D1. The health care provider should guarantee sufficient time and attention to the patient during appointments after the primary treatment has finished. (One of final set of approved quality indicators) (Uphoff, 2011, p35; Quality score 0.8 (qualitative), 0.88 (quantitative)))[39]</i> <i>Within the coordination of care remarkably low attention was given to waiting times on the day of appointment. (Bisschop, 2017, p2250; Quality score 0.85)[36]</i>
O1b. Care availability	4 [44,47,51,54]	<i>Time [for staff] to spend with residents ($p < 0.001$, $\eta = 0.108$) ...[was] rated significantly higher in units with higher PCC compared to units with lower PCC. (Sjogren, 2017, p4; Quality score 0.91)[54]</i> <i>Family members and participants with dementia further described that to be person-centred, staff had to be available and present. This included taking time for a cup of tea or to chat with residents and families. Furthermore, all participants agreed that being with residents had to be prioritised ahead of the completion of tasks in order to promote person-centredness. (Edvardsson, 2010, p2616; Quality score 0.8)[44]</i>
• Availability of healthcare practitioners during and outside of working hours	4 [38,41,44,47]	<i>Patient can reach the specialist between consultations (Suggested patient-centred cancer care indicator) (Ouwens, 2010, p126; Quality score 0.65 (qualitative), 0.78 (quantitative)).[38]</i>

		<i>Patients and families appreciated seeing the same professionals and having ready access to them...Furthermore, the difficulty of contacting some professionals made patients feel that they should only call in case of emergencies. One family member explained: "I am reluctant to call [the professional] ...unless it's a major problem, but if it were for a trivial question ... [I wouldn't call]." (Family member 2) (Bilodeau, 2015, p109; Quality score 0.7)[41]</i>
O1c. Financial burden	1 [49]	<i>"So if a patient needs six weeks of daily chemo and needs to stay there, that's a big financial burden, especially if they've living in the regions and they need to come into the city for appointments, petrol money – you know, that was a big issue too". (504 Both). (Green, 2018, p6; Quality score 0.85)[49]</i>
• Affordability of care including complimentary care and therapies, dental, pharmacare, ambulance	1 [43]	<i>Considering patient convenience and resource availability when ordering investigations. (Physician identified patient- and family-centred strategy pertaining to streamlining care delivery.) (Nguyen, 2017, Supplementary table 2; Quality score 0.65)[43]</i>
O2. Patient-Reported Outcomes (PROs)	2 [42,51]	<i>Accountability (Arising theme from questionnaire; Frequency = 1) (Calisi, 2016, p312; Quality score 0.9)[42]</i>
O2a. Patient-Reported Outcomes Measures (PROMs)	1 [51]	<i>Themes and goals centered on understanding "disease as a path/journey"; to "live as a human being" by participating in life despite the disease; to regain activity, control, and hope; to reduce depression and anxiety; to "choose a new life" by increasing autonomy, resilience, and courage; to reorient toward positive goals, not just "anticancer", to gain "emotional freedom from cancer"; to come to terms with past trauma; and to pursue self-development, lifestyle changes, creativity, and reflecting on relationships with the self and others. (Kienle, 2016, p488; Quality score 0.9)[51]</i>
• Health-Related Quality of Life	6 [37,40,41,46, 49,51]	<i>Treating patients with dignity and respect (item 1), quality of life (item 2), and patients' involvement in decision making (item 4) were also considered to be important aspects of PCC [within Viewpoint 2]. (Cramm, 2015, p5; Quality score 0.9 (qualitative), 0.85 (quantitative)).[37]</i>
• Symptoms	6 [37,38,40,48,49, 51]	<i>Healthcare professionals pay attention to pain management. (Statement was ranked as important by participants within viewpoints 1 and 2) (Cramm, 2015, p5; Quality score 0.9 (qualitative), 0.85 (quantitative)).[37]</i> <i>Previous cancer treatments, tumor response, and side effects were registered, along with the patient's well-being, symptoms, functional abilities, and other disease-related conditions. (Kienle, 2016, p482; Quality score 0.9)[51]</i> <i>[Suggested patient-centred cancer care indicators]: Patient gets support to control physical complaints such as pain, suffocation, nausea, blood coughs, tingling, weight loss and insomnia (Ouwens, 2010, p128; Quality score 0.65 (qualitative), 0.78 (quantitative)).[38]</i>
• Functionality	1 [51]	<i>Other patients did not accept functional losses due to extensive resection (such as partial resection of the hard palate in an 88 year old man), or did not accept the complete loss of sexual function. (Kienle, 2016, p482; Quality score 0.9)[51]</i>
• Psychosocial outcomes	5 [37,49,51-53]	<i>If the patient could not be cured, and particularly if the disease was progressing rapidly, then along with the continuous endeavor to stabilize the tumor situation and control symptoms, the psychological and emotional issues became an increasing focus of treatment: "The primary goal surely is the tumor. But because I know that often it cannot be reached, the</i>

		<p><i>secondary goal becomes the primary, very evidently. So that no matter how it grows or doesn't grow, one can acquire a positive attitude towards life."</i> (General Practitioner [GP]) (Kienle, 2018, p128; Quality score 0.9)[52]</p> <p><i>"When a client is receiving 'good' care or person-centred care, there is a noticeable difference in the behaviour. Almost always the client is happier, calmer, more open with the carer, which makes the carers' job much easier."</i> (Care assistant 1) (Colomer, 2016, p1162; Quality score 0.75)[53]</p> <p><i>Healthcare professionals pay attention to patients' anxiety about their situation.</i> (Statement was ranked as important by participants within viewpoints 1, 2 and 4) (Cramm, 2015, p5; Quality score 0.9 (qualitative), 0.85 (quantitative)). [37]</p>
O2b. Patient-Reported Experiences (PREMs)	0	No corresponding findings
<ul style="list-style-type: none"> Recommendation or rating of hospital, healthcare provider 	0	No corresponding findings
<ul style="list-style-type: none"> Assessment of care, including appropriateness and acceptability of care (competency, knowledge, skills of staff) 	3 [39,42,49]	A3. <i>Communicative skills of all health care providers should regularly be evaluated, and feedback should be given.</i> (One of final set of approved quality indicators) (Uphoff, 2011, p35; Quality score 0.8 (qualitative), 0.88 (quantitative))[39]
O2c. Patient-Reported Adverse Outcomes (PRAOs)	0	No corresponding findings
<ul style="list-style-type: none"> New or worsening symptoms 	0	No corresponding findings
<ul style="list-style-type: none"> Unanticipated visits to healthcare facilities 	0	No corresponding findings
<ul style="list-style-type: none"> Death 	2 [49,51]	<p>For instance, <i>some patients were not afraid of death but rather of losing certain sensibilities or fine cognitive functions</i> (Kienle, 2016, p482; Quality score 0.9)[51]</p> <p><i>Being away from one's own Country or traditional lands, including the possibility of dying off Country, was also a particular source of distress for some participants. "[Aboriginal care provider] really understood where I was coming from being off Country. They understood my fears about being off Country and especially dying off Country – what would happen to my spirit, how would they treat my body and the aunties were able to explain the process of what happened if I did pass off Country and what would happen to my body."</i> (303 CaAff). (Green, 2018, p6; Quality score 0.85)[49]</p>

Inductively-identified themes additional to Santana model		
<p>Family and friend involvement and support</p> <ul style="list-style-type: none"> Involving family/friends in information-sharing and decision-making Respecting the opinions and worries of friends/family Providing family/friends with opportunities to ask questions Addressing the needs of family/friends 	<p>11</p> <p>[36-40,42,44,46,47,49,51]</p>	<p><i>"Involving the family is a massive part of person-centred care, as their family know everything about them; they just know them inside out..." (Registered nurse 4). (Ross, 2015, p1228; Quality score 0.8)[47]</i></p> <p><i>Welcoming family was described as developing and maintaining trust in that the staff would actively communicate changes and significant events to the family; so that they did not have to constantly seek out information by making phone calls or asking the staff when they visited. Welcoming family was also described by staff as creating opportunities for beneficial teamwork, so that the family's unique knowledge about the person with dementia could be incorporated into care plans. (Edvardsson, 2010, p2614; Quality score 0.8)[44]</i></p> <p><i>Respondents in both views state that it is important to attend to the preferences of patients first, and to those of the family thereafter... 'Of course there are some meetings involving the whole family, but ultimately, it is the patient who decides and not the family' (respondent 13). (Galekop, 2019, p4; Quality score 0.95 (qualitative), 0.85 (quantitative))[40]</i></p> <p><i>The involvement and respect to the opinions and worries of friends and family was considered very important for the majority of patients. (Bisschop, 2017, p2250; Quality score 0.85)[36]</i></p> <p><i>[Suggested patient-centred cancer care indicators]: Family and friends had opportunities to ask the specialists questions; Family and friends had opportunities to ask the nurses questions. (Ouwens, 2010, p126; Quality score 0.65 (qualitative), 0.78 (quantitative)).[38]</i></p> <p><i>C2. The care provider should gather information on the psychosocial and emotional health status of family and friends of the patient and adequately refer to specialists, depending on the diagnosed problems. (One of final set of approved quality indicators) (Uphoff, 2011, p35; Quality score 0.8 (qualitative), 0.88 (quantitative))[39]</i></p> <p><i>It was noted that carers undergo sustained periods of dealing with multiple stressors, combined with a lack of attention to their needs and their welfare and little-to-no follow-up, and that this contributed to a sense of being disregarded once the person being cared for had passed away or had reached a less acute stage. "...the carer is the one that carries the load. You know they're the ones that are looking after the sick person as well as trying to manage family." (103 Both). (Green, 2018, p8; Quality score 0.85)[49]</i></p>
<p>Promoting continuation of normality and self-identity</p> <ul style="list-style-type: none"> Support for participating in regular personal life activities 	<p>8</p> <p>[37,38,44-46,49,51,52]</p>	<p><i>Themes and goals centered on understanding "disease as a path/journey"; to "live as a human being" by participating in life despite the disease; to regain activity, control, and hope. (Kienle 2016, p483, Quality score 0.9)[51]</i></p> <p><i>The overarching themes of doctors were to help patients live with the disease and find their own way through it; to encourage them to participate in life and regain autonomy and a sense of control and self-efficacy (Kienle, 2018, p128; Quality score 0.9).[52]</i></p> <p><i>For instance, some patients were not afraid of death but rather of losing certain sensibilities or fine cognitive functions: "For instance a patient with advanced oesophagus carcinoma wished to write several publications; he had a spiritual orientation and rejected chemotherapy because he feared cognitive impairments and emotional constraints; with regular intralesional</i></p>

<ul style="list-style-type: none"> • Providing meaningful activities for inpatients 		<p><i>mistletoe extract injections the oesophageal stenosis reopened, the patient could eat and kept well for a substantial time with a good QoL and pursued his writing and publishing activities.” (Gastroenterologist) (Kienle 2016, p482, Quality score 0.9)[51]</i></p> <p><i>Individually targeted activities were described not only as providing a meaningful content to the day, but also as a means in reaffirming the residents as individual persons who were able to do the things they enjoyed. Family and staff further described that such activities preferably were adapted to the individual person’s ability so that their self-esteem could be boosted by the successful completion of activities, rather than feeling defeated and demoralised by being expected to undertake something that was beyond their capability. (Edvardsson, 2010, p2615; Quality score 0.8)[44]</i></p> <p><i>Two of the participants suggested that in their client-centeredness they “manipulated” the situation to enable choices, but ones that further occupationally engaged their clients. One participant expressed that the development of the emotional climate or helping people at the end of life engage in full expression of themselves was client- and family-centered. (Pizzi, 2015, p446; Quality score 0.65).[46]</i></p>
<p>Structuring service organisation to enable continuity of care and patient navigation</p> <ul style="list-style-type: none"> • Simplification of care pathways to ease patient navigation • Appointment system structured to allow patients to see same professionals over time • Structures enabling flexibility in service delivery and care practice. • Establishing cooperation pathways across specialisms and institutions 	<p>10</p> <p>[36-38,41,43,44, 46,47,49,51]</p>	<p><i>Utilizing multidisciplinary clinics to decrease wait times and patient anxiety between specialist referrals; Having nursing staff provide additional teaching following the physician visit. (Physician identified patient- and family-centred strategy pertaining to streamlining care delivery.) (Nguyen, 2017, Supplementary table 2; Quality score 0.65)[43]</i></p> <p><i>The complex organization of services could also affect the experience of care. Another family member summarized this: “The system [the oncology clinic] is so complicated that it’s like swimming in molasses. (Family member 3) (Bilodeau, 2015, p109; Quality score 0.7)[41]</i></p> <p><i>The most prominent negative experiences noted were due to seeing different doctors at subsequent appointments: “We had an appointment with our doctor, but then we received a message that a new doctor was scheduled to help us that day. We really did not like that, especially because he had to tell us new test results and the prognosis. There was no explanation; they only told us our regular doctor was absent.” (Respondent 12). (Bisschop, 2017, p2250; Quality score 0.85)[36]</i></p> <p><i>Mostly in data from staff and family, it emanated that to be person-centred, aged care facilities need to have flexible routines adapted to the person with dementia’s needs rather than the needs of staff, especially in relation to staffing, care tasks and activities (Edvardsson, 2010, p2616; Quality score 0.8)[44]</i></p> <p><i>Some doctors worked in a cancer center...the others cooperated with oncologists, surgeons, radiotherapists, and other relevant specialists, often referring patients to each other. This cooperation was usually described as positive: “These centers know me all for long . . . they know that I know exactly what they do . . . it functions well” (Pediatrician). (Kienle 2016, p488, Quality score 0.9)[51]</i></p>