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Measuring patient-centred system performance: A scoping review of patient-centred care quality indicators

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Abstract

Objectives: The shift to the patient-centred care model as a healthcare delivery paradigm, calls for systematic measurement and evaluation. In an attempt to develop patient-centred quality indicators (PC-QIs), we embarked on this study with the aim to identify quality indicators that can be used to measure patient-centred care. The objective of this scoping review was to identify existing PC-QIs that have been developed and implemented across various care sectors.

Search Strategy: Studies were identified through searching seven electronic databases and the grey literature. Search terms included: quality improvement, quality indicators, healthcare quality, patient-centred care. Articles were included if they mentioned development and/or implementation of PC-QIs.

Results: This review revealed the heterogeneity describing and defining the nature of PC-QIs. While PC-QIs, defined by Agency for Healthcare Research and Quality (AHRQ) are a quantifiable unit of measurement of the performance of the healthcare system, most PC-QIs were presented as patient-centred care (PCC) measures and identified as guidelines, surveys, or recommendations. Our search yielded 502 proposed ways to measure PCC, only 25 of which were actual PC-QIs. An example of a PC-QI identified was "percent of hospital patients who said they had been sufficiently involved in decisions about their care as much as they wanted to be".

Conclusion: There is a lack of evaluation and implementation of PC-QIs in the literature. The identification of PC-QIs is a key first step in laying the groundwork to develop evidence-based PC-QIs. Research is needed to continue the development and implementation of PC-QIs for healthcare quality improvement.

Keywords: patient-centred care, quality indicator, healthcare quality, quality improvement

What is already known on this subject:
There has a been a shift in delivery of healthcare to a patient-centred care model. Measurement of patient-centred care is necessary to improve the quality of care
What this study adds:
From our scope of the literature, we identified quality indicators and measures to inform the development of evidence-based patient-centred quality indicators.

Strengths
- Transparent and rigorous search strategy
- Involvement of our patient partner in the study
- Study informed by a previously published protocool[9]

Limitations
- Search strategy using only English terms
- We did not assess the quality of the measures and/or indicators identified

INTRODUCTION

Patient-centred care (PCC) is an approach that has become central to policies and programming to improve healthcare inefficiencies and address patient safety issues.[1] PCC is one of the six dimensions of healthcare and was formally described by the Institute of Medicine in 2001 as *"healthcare that respects and responds to the preferences, needs and values of the individual patients throughout all healthcare decisions"*.[2] PCC is a model in which healthcare providers are encouraged to partner with patients and families to design and deliver individualized care. PCC models have been linked to positive patient experiences and improved outcomes, such as increased adherence to care and treatment.[3-5]

The adoption of a PCC model requires first, the identification of appropriate indicators to measure the quality of PCC, and second, the assessment of the impact of delivering PCC on healthcare system and patient outcomes. Quality indicators are a key mechanism for measuring system performance and healthcare quality, and demonstrating the extent to which improvement efforts have led to desirable change, or contributed to unintended results.[6] As identified from the Agency for Healthcare Research and Quality (AHRQ), a quality indicator consists of: a specific aspect of quality being captured, and a method for how concepts of quality are captured (which includes: data source, measure type, observable event, specification and risk adjustment).[7] While various quality indicators have been developed to measure healthcare safety, effectiveness and access,[8] they typically do not incorporate the priorities and experiences of patients and family caregivers. To truly evaluate the impact of patient-centredness, indicators must reflect the patient and family caregiver perspective.

This scoping review aimed to synthesize existing literature on quality indicators used in the evaluation of patient-centred care. The search was guided by the questions: "How is patient-centred care measured?" "Is this a patient-centred quality indicator?" and "Have existing patient-centred quality indicators been implemented and evaluated across various points-of-care settings, processes of care, and at the systems level to measure patient-centred care?" The information gained from this study will inform the development of patient-centred care quality indicators that could be implemented to drive healthcare improvement valued by patients and families.

METHODS

We employed a scoping review protocol that was previously published, [9] using methodology based on Arksey and O'Malley's scoping review framework[10] and Levac *et al.*'s methodological enhancement.[11] We searched the peer-reviewed published and grey literature for either proposed or existing quality indicators that have been developed and/or implemented across various points-of-care settings to measure patient-centred care. For this scoping review, the Agency for Healthcare Research & Quality (AHRQ)[12] definition of a quality indicator was adapted to incorporate a patient and family focus. Specifically, a patient-centred quality indicator (PC-QI) was defined as *a unit of measurement of the performance of the healthcare system, which reflects what matters to* *patients and families, and to any individual that is in contact with healthcare services.* In contrast, PCC measures inform the development of indicators to measure patient-centred care, and are often in the form of a survey, guideline, or recommendation.

Data sources and search strategy

In order to identify studies assessing quality indicators for patient-centred care, search strategies were developed that combined terms from two concepts: patient-centred care and quality indicators (supplemental file 1). The Cochrane Library, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), EMBASE, MEDLINE, PsycINFO, Social Services Abstracts, and Social Work Abstracts were searched from inception to May 2017. A search of the Google search engines, and the websites of relevant quality improvement and patient-centric organizations enabled the identification of relevant grey literature. Grey literature searches were conducted in duplicate by both a researcher and patient partner. The reference lists of included studies were also scanned to identify any other studies of relevance.

Citation management

All references were imported into a custom-written Java software application, Synthesis for reference management and data collection.[13] Duplicate citations were removed automatically by the software, with any mismatched duplicates removed manually if detected.

Study selection and data abstraction

To be eligible for inclusion, the study/article had to 1) identify quality indicators for PCC and/or 2) identify PC-QI in performance measurement (e.g., validation). The title and abstract of each citation identified was screened for eligibility independently by two reviewers (MJS, ML). The full-text of any abstract selected by either reviewer was retrieved and assessed for eligibility. Any full-text articles for which there was inter-rater discord were reviewed a second time, and final disagreements about study eligibility were resolved through discussion.

Data collection and Classification of Indicators

A data collection tool was developed and tested on a sample of papers to determine its practicality prior to the full review (supplemental file 2). Extracted data included study characteristics (country, year of publication, type of study/article), patients' inclusion in the development of indicators, and type of patient populations and point of care if applicable (e.g. in-patient, out-patient, primary care).

All extracted indicators were classified according to a person-centred care framework[14] developed by the team and guided by the Donabedian model of quality of care.[15] This framework provides a roadmap for healthcare systems to implement and measure PCC at the level of structure (the health care system/organizational level); process (the patient-healthcare provider interaction level), and outcome (the patient-health care provider, healthcare systems interaction level).[14]

RESULTS

A total of 36,643 citations were retrieved, and upon duplicate removal, a total of 16,173 citations were reviewed at the title and abstract stage for inclusion (Figure 1). A total 184 full-text peer-reviewed articles were assessed for eligibility for inclusion; of these, nine articles were included in this review (Figure 1). From the non- peer-reviewed literature, following the title and document review, eight documents met the criteria for inclusion in this study (Figure 1). The most common reason for excluding articles (n=15,905) was the absence of indicators for PCC.

Article Description

Table 1 presents the characteristics of the full text articles included in the study. The years of publication ranged from 1996 to 2015. Included studies were published in Belgium (n=1), United States of America (n=2), Canada (n=3), United Kingdom (n=4), the Netherlands (n=4), and three sources did not include a country of publication. Sources were varied and included original peer reviewed research (n=8), guest editorial (n=1), reports (n=4), discussion paper (n=1), working paper (n=1), literature review (n=1), and a website (n=1). The study populations varied in the peer reviewed literature (e.g., cancer, fertility care, HPN, etc.) and no specific populations were identified in the non-peer reviewed literature.

Table 1. Characteristics of Articles on Patient-Centred Quality Indicators

Study identifier (first author)	**Country**	**Year**	**Study Type**	**Population**	**Patients involved**	**Number of Indicators & ways to measure PCC**
Peer reviewed literature (n=9)						
den Breejen et *al.*[38]	Netherlands	2013	Focus groups/interviews/ consensus meetings	Fertility care	Yes	34
Dreesen et *al.*[25]	Belgium	2014	Focus groups/interviews/ consensus meetings;	Home parenteral nutrition (HPN) patients	Yes	33
Ouwens et *al.*[26]	Netherlands	2010	Focus groups/interviews/ consensus meetings;	Cancer- Non-small cell lung carcinoma	Yes	54
Sewitch et *al.*[39]	Canada	2013	Focus groups/interviews/ consensus meetings; Surveys	Colonoscopy patients - adult	Yes	20

Uphoff et *al.*[27]	Netherlands	2012	Focus groups/interviews/ consensus meetings	Cancer	Yes	21
Wensing et *al.*[16]	Netherlands	1996	Focus groups/interviews/ consensus meetings; Surveys	Chronically ill patients (chronic obstructive pulmonary disease, diabetes, cardiovascular disease, migraine, chronic disease of locomotor system)	Yes	41
Zimmerman et *al.*[28]	USA	2014	Focus groups/interviews/ consensus meetings	Community-based, assisted living support patients	Yes	43
Cox et *al.* [40]	United Kingdom	2014	Guest editorial	-	-	4
Carinci et *al.* [24]	United Kingdom	2015	Modified Delphi approach/consensus meeting	-	-	12
			non-peer reviewed Literature (n=8)			
Steven Lewis[22]	Canada	2009	Discussion paper	-	-	6
RNAO[21]	Canada	2002	Guidelines document/report	-	-	18
Silow-Carroll et *al.*[41]	USA	2006	Report	-	-	6
Kelley & Hurst (OECD)[20]	-	2006	Working papers	-	Yes	7
OECD[23]	-	2006	OECD website	-	Yes	8
Essence of Care- Patient Focused benchmarks for clinical governance (NHS)[18]	United Kingdom	2003	Report	-	Yes	116
Davies et *al.*[19]	United Kingdom	2009	Report	-	-	10
IAPO[17]	-	2012	Literature review	-	-	69

PCC, Patient-Centred Care; OECD, Organization for Economic Co-operation and Development; NHS, National Health Services; RNAO, Registered Nurses Association Ontario; IAPO, International Alliance of Patients' Organizations

How is patient-centred care measured?

From the sources included, a total of 502 ways of measuring PCC were identified, of which 25 identified were actual indicators. PCC measurement varied between articles.

Most sources presented the measurement as guidelines or recommendations for healthcare practitioners. Wensing *et al.* presented indicators as questions similar to items in a survey, such as “Does the GP pay attention to patients' needs?”[16] Actual indicators were presented as percentages and proportions, and identified from six grey literature sources.[17-22] For instance, one study outlined an example of a structure indicator - “Percent of nurses attending education sessions (orientation, organization professional development opportunities) on client centred care.”[21]

Study populations included cancer patients (n=2), colonoscopy patients (n=1), home parenteral nutrition patients (HPN) (n=1), chronically ill (n=1), fertility care (n=1), and assisted living support patients (n=1) (Table 1). For the development of PCC measures, seven studies used focus groups, interviews, and/or consensus meetings, ten studies included patients and family caregivers in the development of PCC measures, and one article developed measures through the authors’ clinical and research work. Two sources developed ways to measure PCC from patient reported experience surveys,[20 23] and two studies used a framework.[21 24]

Some studies grouped ways to measure PCC according to domains of patient-centred care that were based on previously defined frameworks or through consensus (e.g., access to care, communication and information). We classified actual indicators and other ways of measuring PCC according to the person-centred care framework.[14] Domains identified from the person-centred care framework are categorized according to structure, process, and outcome.[14] Table 2 presents examples of measuring PCC classified according to the person-centred care framework,[14] and Table 3 presents the actual indicators classified according to the same framework.[14]

Table 2. Examples of PCC measurement classified according to the person-centred care framework.[14]

PCC Measure Classification	**Domain**	**Example of ways to measure PCC**
Structure (n=80)	Supporting a workforce committed to Patient-Centred Care (PCC)	• The development needs of health care personnel are met by ongoing review through supervision, appraisal and individual development plans[18] • Percent of nurses attending education sessions (orientation, organization professional development opportunities) on client centred care[21]. • All staff and volunteers can articulate person-centred principles and practices applicable to their role(s) and demonstrate their implementation[28]
	Providing a supportive and accommodating PCC environment	• Residents have a choice of a private room[28] • Patient satisfaction survey translated into Spanish[40]
Process (n=343)	Cultivating Communication	• (Regular) doctor involving patients in decisions about care or treatment[23]

		- Making use of open-ended questions in a conversation with the patient[27] - Patient had the knowledge and support to make decisions[26] - Regular doctor providing easy-to-understand explanations[24]
	Respectful and compassionate care	- Patient received emotional support from nurses if needed[26] - Giving confidence to the patient[25] - Does the GP pay attention to patients' needs?[16]
Outcome (n=79)	Patient-Reported Outcomes (PROs)	- Measures are in place to assess and provide feedback on the interpersonal skills of health care personnel[18] - Does patients' health improve or stabilise?[16] - Regarding infertility treatment, patients would like to see all members of the infertility treatment team following the same policy[37]

Table 3. Patient Centred Care Indicators classified according to the person-centered care framework[14]

Type of Indicator	**Domain**	**PCC Indicators (n=25)**
Structure	Creating a PCC Culture	- An induction programme is in place which promotes the philosophy of care [18] - % of PHC organizations who currently have processes to involve community input for planning the organization's services (e.g. advisory committees, focus groups[17] - Clear policies are in place on how services are offered to patients[17]
	Supporting a workforce committed to PCC	- Percent of nurses attending education sessions (orientation, organization professional development opportunities) on client centred care[21] - Percent of non-nursing staff attending education sessions (orientation, organization professional development opportunities) on client centred care[15]
Process	Cultivating Communication	- % of patients with access to an on-line HER a) By region b) By practice[22] - Proportion of service users who stated that the district nurse provided health advice or information about his/her condition[19] - Proportion of service users who stated that they

		were involved as much as they wanted to be in decisions about their care and treatment[19]
	Respectful and compassionate care	• Proportion of service users who stated that their district nurse treated them with respect and dignity[19] • % of inpatients who said they were always treated with respect and dignity while in hospital/primary care[17]
	Engaging patients in managing their care	• % of PHC clients/patients, 18 years and over, with a chronic condition(s), who actively participated in the development of a treatment plan with their PHC provider over the past 12 months[17] • % of hospital patients who said they had been sufficiently involved in decisions about their care as much as they wanted to be[17] • Percent of nurses self-reporting: Adequate assessment of a client's perceived needs for care, adequate assessment of a client's goals for care, adequate documentation of a client's personal goals for care, sharing client's concerns/choices with other members of the health care team, discharge teaching guided by the client's goals for managing their care at home[21]
	Integration of Care	• % of hospital patients taking medicines home after discharge who were told completely about the purposes of the medicine in a way they could understand[17]
Outcome	Access to Care	• % of patients who can get all diagnostic work ordered by their primary care doctor done the same day in the same location (excluding certain high-technology procedures such as CT and MRI)[22] • Percentage of outpatients seen within 13 weeks of GP referral[20] • Percentage of those on waiting list waiting 12 months or more[20] • Proportion of service users who were able to contact a district nurse when needed, including outside of normal working hours[19] • The percentage of patients who, in the appropriate national survey, indicate that they were able to obtain a consultation with a GP or appropriate health care professional within 2 working days (NHS Confederation, UK)[17] • % of PHC clients/patients, 18 years and over, with a chronic condition(s), who had sufficient time in

		most visits to confide their health-related feelings, fears and concerns to their PHC provider[17]
	Patient-Reported Experiences (PREMs)	• Proportion of service users who stated that the district nurse had all the necessary information about the service user and his/ her health needs[19] • Proportion of service users who stated that the district nurse had all the equipment and dressings needed[19] • Proportion of service users who stated that the district nurse was knowledgeable and competent[19] • Proportion of service users who rated the district nurse service as very good or excellent[19] • Proportion of children whose parents routinely received all aspects of family centred care (Child and Adolescent Health Measurement Initiative)[17]

PHC, Primary Healthcare; HER, Health Electronic Record; CT, Computed Tomography; MRI, Magnetic Resonance Imaging; GP, General Practitioner; NHS, National Health Services; UK, United Kingdom

Is this a patient-centred quality indicator?

The definition of a PC-QI was not clearly articulated in the studies identified (Table 4). Ten of the included studies provided no such definition of a quality indicator (Table 4). Sources where the definition of a quality indicator was mentioned defined indicators as something to be measured, and developed through consensus (Table 4).[19 25-27] Of those four sources where the definition of a PC-QI was clear, two included actual indicators.[17 19] The National Health Services (2003) report described indicators as 'items that patients, carers and professionals believed were important in achieving the benchmarks of best practice."[18]

Table 4. Definition of quality indicator used by authors

Study Identifier (First Author, year)	**Definition of quality indicator used**
(den Breejen et *al*, 2013),[38] (Sewitch et *al*, 2013),[39] (Uphoff et *al*, 2012),[27] (Zimmerman et *al*, 2014),[28] (Cox et *al*, 2014),[40] (Lewis, 2009),[22] (RNAO, 2002),[21] (Silow-Carroll et *al*, 2006),[41] (Kelley & Hurst, 2006),[20] (OECD website, 2006),[23] (Carinci et *al*, 2015)[24]	Definition not included
(Dreesen et *al*, 2014)[25]	A quality indicator as a measurable element of practice performance for which there is evidence or consensus that it can be used to assess the quality of care, and hence change the care provided.[42]
(Ouwens et *al*, 2010)[26] (Uphoff et *al*, 2012)[27]	Quality indicators are 'measurable elements of practice performance for which there is evidence or consensus that they can be used to assess the quality of care'[43]
(Davies et *al*, 2009)[19]	An explicit measureable statement of the

	quality of care given. Relates to a single outcome or process of medical care. Clearly defined and unambiguous.[43 44]
(NHS, 2003)[18]	Items that patients, carers and professionals believed were important in achieving the benchmarks of best practice.[18]
(IAPO, 2012)[17]	Can be measures of structure, process and outcome, either as generic measures relevant for all diseases, or disease-specific measures that describe quality of patient care related to a specific diagnosis.[45]

OECD, Organization for Economic Cooperation and Development; NHS, National Health Services; IAPO, International Alliance of Patients' Organizations

Have the existing patient-centred quality indicators been implemented and evaluated across various points-of-care settings, processes of care and at the system level to measure patient-centred care?

None of the articles mentioned actual implementation of indicators in the settings for which they were developed. Similarly, many of the sources did not evaluate the indicators according to any set criteria. The study by Ouwens et *al.* assessed guidelines for psychometric characteristics and only 26 out of 56 guidelines were found to be reliable.[26] The study by Carinci et *al.* used a modified Delphi approach with expert Organization for Economic Co-operation and Development (OECD) members to rate the PCC measures, using validity, reliability, relevance, actionability, international feasibility, and international comparability as the criteria.[24] Uphoff et *al.*, recommended using the Gol & Grimshaw model for evaluating indicators,[27] while a future direction for Zimmerman et *al*. was the evaluation of the indicators.[28] The working paper by Kelley and Hurst presented criteria that can be used to select indicators.[20] These included the importance of what is being measured (which includes policy importance), scientific soundness, and feasibility of the measure.[20]

DISCUSSION

This review specifically examined existing ways to measure PCC. Patient-centred care has been increasingly adopted by many jurisdictions, however this review revealed there to be gaps in the measurement of PCC. Few articles met the inclusion criteria in the literature. Out of the 17 articles that met the inclusion criteria, only 9 were peer reviewed, and looked at specific conditions. Additionally, the heterogeneity of the PCC literature relates to the variety of definitions on PC-QIs, and a diverse type of indicators developed for different patient population and care-settings. For instance, all included articles in the review used the term 'indicator,' but not all presented indicators as defined by the Agency for Healthcare Research & Quality (AHRQ).[12]

The absence of a standard definition of what a PC-QI is in the literature has posed challenges in identifying the literature sources for inclusion in this review. 'Quality' means different things to different people, and despite the standard definition of PCC by the Institute of Medicine, PCC continues to be operationalized and measured differently.[2] Most sources identified in the literature did not explicitly define what a quality indicator is, which may explain the differences in approaches to indicator development. The absence of a definition for quality indicators results in inconsistencies for how an indicator should be presented and also what makes for a good indicator. Previous reviews have also found variability in quality indicator definitions, such as indicators for hip fracture patient care.[29]

In compliance with quality improvement agencies, quality councils and organizations such as the AHRQ, quality indicators should be presented as a unit of measurement - as a percentage or proportion.[12] Our review revealed inconsistencies in the definition of indicators. Only few sources in the non-peer reviewed literature included PC-QIs as quantifiable units, such as percentages, incorporating a numerator and denominator in the unit of measurement.[30] Most of the identified indicators were actually domains included in PCC measures and guidelines. The lack of defined units of measurement impedes comparisons across facilities, and benchmarking, and doesn't allow for longitudinal evaluation and overall measurement of care that is patient-centred. Without this unit of measurement for PC-QIs, it is difficult to target specific improvements needed for PCC.

The review revealed that when incorporating the patient and caregiver perspective in quality improvement, a difficulty exists in translating perceptions and subjective experiences into standardized objective indicators. Measures of well-being are both necessary and important to incorporating a PCC model of care. The study by Carr et *al.* suggests that perceptions of health and its meaning vary between individuals and across time, as do their experiences and expectations of healthcare.[31] In order to capture various perspectives on quality care, it is vital to include patients and families. Including the patient and family perspective is necessary to ensure quality patient-centred care

Additionally, this review found large variances for domains to categorize approaches to measuring PCC. In an attempt to organize our findings and understand the ways of measuring PCC, we used a previously published person-centered care framework[14] to classify them into healthcare quality domains. From this classification, most strategies for measuring PCC were found to relate to domains associated with healthcare processes (e.g. cultivating communication). These findings are consistent with the current measurement landscape, for instance trauma indicators,[32] and AHRQ PC-QIs[33] which mainly assess processes and outcomes. For PCC, structures, such as policies and education programs can provide an important basis to improve PCC practice. In this review, structure indicators, were lacking.

Finally, there is scarce evidence in the literature on how to implement indicators for PCC, and how to evaluate their implementation. PCC measurement has, to date, primarily focused on specific disease conditions and healthcare sectors. However, recent initiatives, (National Health Services) reveal a more generic approach to measurement (Family and Friend Test).[34] In order to create a standardized set of PC-QIs, indicators must be developed across the continuum of care. Stelfox et *al.* also found a lack of implementation of indicators in care settings in their review.[32] Before indicators are implemented, they must be evaluated according to standard set criteria. What constitutes as a good indicator has been outlined by health quality organizations, such as National Quality Forum. As outlined by the National Quality Forum, quality indicators should be evaluated through a set criteria including: importance, scientific acceptability, feasibility, and usability and use.[35] Our review did not identify any studies where such evaluations were implemented. In the development and implementation of quality indicators, the guideline set by the National Quality Forum should be adhered to.

Strengths and Limitations

Our scoping review used robust and transparent methods guided by a protocol previously published,[9] and supported by a research librarian with expertise in knowledge synthesis and scoping reviews (DLL).

This review may not have identified all relevant sources in the published and grey literature despite the support of experts on the team and processes implemented to ensure search comprehensiveness. A further risk of bias may have been enhanced by the fact that we conducted the search using only English terms.

The findings from this study will be used to inform the development and refinement of PC-QIs that may be used for implementation, as recommended by Stelfox & Straus (2013).[36] This includes a consensus process (modified Delphi)[37] – that will be conducted to evaluate the quality of the indicators and identify a core group of PC-QIs that can be implemented and evaluated at the system level. With this review, our aim is to inform the development of standard PC-QIs that can be implemented at various healthcare settings, around the world. A universal set of PC-QIs is needed to guide systematic monitoring and evaluation of patient-centred care nationally and globally.

In summary, our review is the first to examine the literature pertaining to quality indicators that are patient-centric. The identification of ways of measuring PCC in this scoping review is a key first step in laying the groundwork for developing evidence-based PC-QIs. Our findings will further the development of validated healthcare tools assessing healthcare quality from a patient-centred approach. Future research should focus on developing and refining PC-QIs that are ready to implement and evaluate following the criteria set forth by the National Quality Forum.[35]

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Details of contributors:

MJS conceived the study, and all authors identified key literature to be included in the review. MJS led the drafting of the manuscript and key discussion points with support from DL, RJJ, SA, ML and KM. SA managed the design of the tables (with feedback from all authors), and management of references. All authors provided important intellectual contribution and guidance throughout the development of the manuscript. HQ, DL, SZ, and ML provided guidance on the presentation of the findings and guidance on final revisions. All of the authors contributed to critical review and revisions to the manuscript, agreeing on the final version.

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All authors had access to the data (literature identified and tables) in the study and assume responsibility for the integrity of the data and the accuracy of the data analysis.

The lead author* affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

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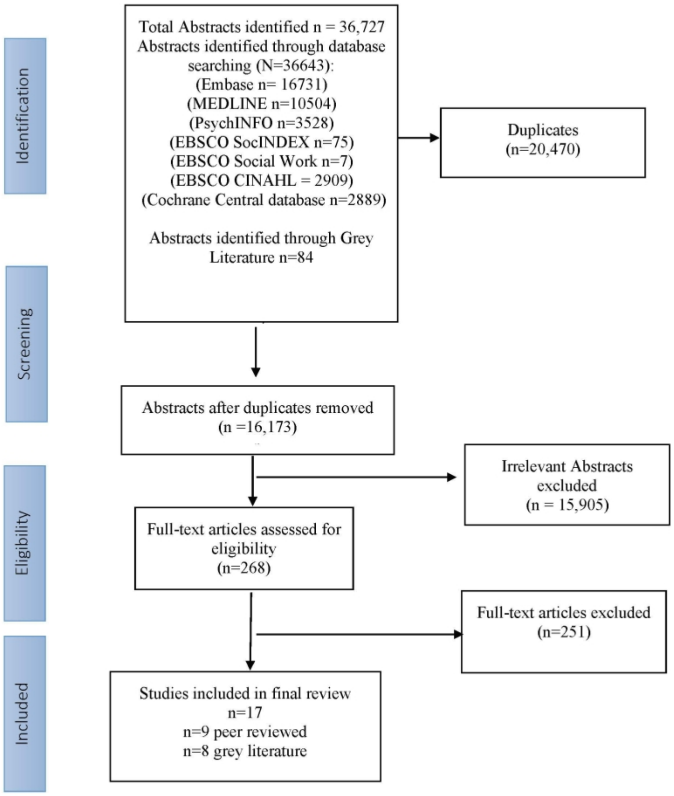
Figure 1- Flow Diagram for study inclusion



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Patient-Centered Quality Indicators Search Strategies
Jan 17 2017
MEDLINE

1. exp patient-centered care/
2. Culturally Competent Care/ or exp ethnic groups/
3. ((carer* or care giver* or caregiver* or client* or culture* or cultural* or ethnic* or family or families or indigenous or parents or patient* or person or racial* or ethnocultural* or immigrant* or refugee* or migrant*) and (centered* or centred* or focused) and (care or healthcare or nursing or medical or medicine)).kw.
4. ((carer* or care giver* or caregiver* or client* or culture* or cultural* or ethnic* or family or families or indigenous or parents or patient* or person or racial* or ethnocultural* or immigrant* or refugee* or migrant*) adj5 (centered* or centred* or focused) adj5 (care or healthcare or nursing or medical or medicine)).tw.
5. cultural competency/ or patient satisfaction/ or patient preference/
6. exp Patient Rights/
7. ((carer* or care giver* or caregiver* or client* or cultural* or culture* or ethnic* or family or families or indigenous or parents or patient* or racial* or ethnocultural* or immigrant* or refugee* or migrant*) adj5 (advocacy or autonomy or beliefs or choice or perspectives or preferences or rights or satisfaction or values or views) adj5 (care or healthcare or nursing or medical or medicine)).tw.
8. ((cultural* or ethnic* or racial* or ethnocultural* or immigrant* or refugee* or migrant*) adj10 (competency or competent care)).tw.
9. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8
10. exp Quality Indicators, Health Care/
11. benchmarking/ or clinical audit/
12. (performance measure* or (healthcare adj3 monitor*) or performance reporting or QI or PQI or (quality adj3 criteria) or (quality adj3 indicator*) or (quality adj3 measure*) or (quality adj3 scale*)).tw,kw.
13. Guideline Adherence/
14. 10 or 11 or 12 or 13
15. 9 and 14
16. limit 15 to yr="1990 -Current"
17. limit 16 to yr="2015 -Current"

Patient-Centered Quality Indicators Search Strategies
Jan 17 2017
EMBASE

1. cultural competence/ or exp ethnic group/ or exp "ethnic or racial aspects"/
2. patient satisfaction/
3. patient preference/
4. exp patient right/
5. ((carer* or care giver* or caregiver* or client* or culture* or cultural* or ethnic* or family or families or indigenous or parents or patient* or person or racial* or ethnocultural* or immigrant* or refugee* or migrant*) and (centered* or centred* or focused) and (care or healthcare or nursing or medical or medicine)).kw.
6. ((carer* or care giver* or caregiver* or client* or culture* or cultural* or ethnic* or family or families or indigenous or parents or patient* or person or racial* or ethnocultural* or immigrant* or refugee* or migrant*) adj5 (centered* or centred* or focused) adj5 (care or healthcare or nursing or medical or medicine)).tw.
7. ((carer* or care giver* or caregiver* or client* or cultural* or culture* or ethnic* or family or families or indigenous or parents or patient* or racial* or ethnocultural* or immigrant* or refugee* or migrant*) adj5 (advocacy or autonomy or beliefs or choice or perspectives or preferences or rights or satisfaction or values or views) adj5 (care or healthcare or nursing or medical or medicine)).tw.
8. ((cultural* or ethnic* or racial* or ethnocultural* or immigrant* or refugee* or migrant*) adj10 (competency or competent care)).tw.
9. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8
10. quality control/ or medical audit/
11. performance measurement system/
12. (performance measure* or (healthcare adj3 monitor*) or performance reporting or QI or PQI or (quality adj3 criteria) or (quality adj3 indicator*) or (quality adj3 measure*) or (quality adj3 scale*)).tw,kw.
13. 10 or 11 or 12
14. 9 and 13
15. limit 14 to yr="1990 -Current"
16. limit 14 to yr="2015 -Current"
17. limit 16 to yr="2015 -Current"

Open Access Protocol

BMJ Open

Protocol for a scoping review study to identify and classify patient-centred quality indicators

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ABSTRACT

Introduction: The concept of patient-centred care (PCC) is changing the way healthcare is understood, accepted and delivered. The Institute of Medicine has defined PCC as 1 of its 6 aims to improve healthcare quality. However, in Canada, there are currently no nationwide standards in place for measuring and evaluating healthcare from a patient-centred approach. In this paper, we outline our scoping review protocol to systematically review published and unpublished literature specific to patient-centred quality indicators that have been implemented and evaluated across various care settings.

Methods and analysis: Arksey and O'Malley's scoping review methodology framework will guide the conduct of this scoping review. We will search electronic databases (MEDLINE, EMBASE, the Cochrane Library, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, Social Work Abstracts, Social Services Abstracts), grey literature sources and the reference lists of key studies to identify studies appropriate for inclusion. 2 reviewers will independently screen all abstracts and full-text studies for inclusion. We will include any study which focuses on quality indicators in the context of PCC. All bibliographic data, study characteristics and indicators will be collected and analysed using a tool developed through an iterative process by the research team. Indicators will be classified according to a predefined conceptual framework and categorised and described using qualitative content analysis.

Ethics and dissemination: The scoping review will synthesise patient-centred quality indicators and their characteristics as described in the literature. This review will be the first step to formally identify what quality indicators have been used to evaluate PCC across the healthcare continuum, and will be used to inform a stakeholder consensus process exploring the development of a generic set of patient-centred quality indicators applicable to multiple care settings. The results will be disseminated through a peer-reviewed publication, conference presentations and a one-day stakeholder meeting.

Strengths and limitations of this study

- This will be the first scoping review to identify quality indicators that are specific to patient-centred care across multiple different conditions and healthcare settings.
- The search strategy includes seven electronic databases with peer-reviewed literature, including article bibliographies and numerous conference proceedings, as well as a broad range of grey literature sources, including government and other organisation websites including quality improvement documents.
- Stakeholders including patient networks will be consulted and engaged throughout the study review process.
- Although this study will identify candidate indicators for further development, there will be no formal assessment of study quality or direct comparison of quality of the indicators.

BACKGROUND

The concept of patient-centred care is changing the way healthcare is understood, accepted and delivered. Traditionally, the quality of healthcare has been driven by policymakers and evaluated through the lens of healthcare professionals and management only, often excluding the patient perspective. Stakeholders from across the continuum of care have called for evidence-informed system improvements to foster innovation and improve the delivery of care; recent policy emphasises that patient views complement healthcare provider perspectives, as well as provide unique information about healthcare effectiveness.[1]

In its landmark report, *Crossing the Quality Chasm*, the Institute of Medicine (IOM) outlined six aims for quality improvement, which include the core need for healthcare to be patient-centred.[2] According to the IOM's definition, patient-centred care is care that aims to include the patients' values, needs and preferences in the healthcare system, ensuring that patient values guide all clinical decisions.[2] This concept of patient-centred care has carried into other healthcare improvement strategies. The Institute for Healthcare Improvement has incorporated the aim of improving the patient experience of care as one of its three dimensions in its 'Triple Aim', alongside improving the health of populations, and reducing per capita costs of healthcare.[3] Implementing a patient-centred approach is therefore necessary towards improving and achieving a high level of healthcare quality.

Although patient-centredness is changing the way healthcare systems around the world operate, healthcare performance measurement has yet to truly incorporate this patient-centred dimension of healthcare quality. The importance of systematic measurement and feedback to achieving patient-centred care is useful for monitoring and guiding improvement within organisations, as well as for holding organisations accountable for their results through public reporting.[4] Healthcare quality indicators provide information that can be used to assess the quality of care, and are essential to optimise healthcare quality, track improvements and establish quality of care benchmarks, leading to changes in the care provided.[5] The WHO has recently created the *WHO global strategy on people-centred and integrated health services*,[6] but has noted: 'as of yet there are no universally accepted indicators to measure progress in establishing integrated people-centred health services'.

For the most part, quality has been measured in terms of service and system performance without incorporating the patient perspective, needs or values. Healthcare quality indicators from and/or incorporating patient perspectives are lacking and have not been routinely integrated into the evaluation of healthcare system performance; rather, system performance measurement has traditionally relied on routinely collected administrative and clinical data to monitor procedures, drug and treatment interventions, and outcomes.[7–9] It has also been argued that patients lack the expertise to evaluate care received.[10 11] However, positive patient experiences have been linked to improved patient health status, while negative patient experiences have been shown to adversely affect health outcomes.[12–14]

The overall understanding of patient-centred care also varies from patients to providers to decision-makers. For instance, patients may value communication with healthcare providers, whereas providers may be more concerned about the effectiveness of treatment, and decision-makers may tend to focus on issues that affect the system, such as readmission rates and resource use. Thus, it is important to identify and implement measures that are relevant to patients and reflect their needs and values. It is also important to include the perspectives of family members and/or caregivers, who provide support to patients and may help to advocate on their behalf. In summary, in order to guide healthcare policy and implement practice change, healthcare systems need to develop and implement cost-effective and efficient ongoing mechanisms to measure and evaluate healthcare quality that incorporates all of these perspectives.

STUDY RATIONALE

Globally, healthcare policy and programmes have begun to promote patient-centred care models that could be implemented, measured and improved. The importance of measuring the effectiveness of patient-centred care has been identified as a need by multiple organisations[1–3 6] in the process of transitioning towards the implementation of a patient-centred care healthcare model. However, despite a large number of heterogeneous, disease and setting-specific indicators that have been proposed, it is unclear the extent to which these indicators have been tested, implemented or validated. Further, there is currently no single set of generic indicators that exist which can be implemented to measure patient-centred care across multiple disease groups or care settings. There is no existing published synthesis on patient-centred quality indicators (PC-QIs) that incorporates both the peer-reviewed and non-peer-reviewed literature.

STUDY OBJECTIVES

The objectives of this scoping review are to systematically scope the literature on PC-QIs, identify specific characteristics of these indicators and their definitions, and map indicators according to the thematic domains by which they can be classified. The indicators will be classified according to a predefined conceptual quality improvement framework adapted by the study team. Through this process, we will generate a comprehensive and well-defined list of unique indicators that may inform the adoption of standardised patient-centred care indicators. This work will constitute the first step in a multistep research programme aimed at the development of evidence-informed quality indicators to measure and evaluate the implementation and practice of patient-centred care across the continuum of care; the indicators determined through this review will subsequently be validated through a consensus review process. This information will allow healthcare organisations to assess the quality of patient-centred care being delivered, and provide outcome measurement data that can be used by healthcare system regulators and healthcare professionals to target efforts to improve care and service delivery that reflects what patients need and want.

METHODS AND ANALYSIS

Conceptual model

Our scoping review will use the Donabedian conceptual framework[15] for assessing the quality of care using *structure, process and outcome* components of quality, to map PC-QIs and categorise them according to relevant thematic domains. This framework will serve as a guide for synthesising the literature and determining how quality indicators can be classified. *Structure* in this context encompasses the physical setting and organisational characteristics in which healthcare is provided, including materials and health resources; *process* comprises the methods by which healthcare is provided, and is dependent on the structures to provide resources and mechanisms to carry out care, therefore directly resulting in and impacting patient outcomes; *outcomes* are the result of healthcare provided and include the health status and experiences of patients and communities. Although Donabedian's model does not take into account specific patient factors,[16] we have selected it because this model is perhaps the most widely used 'gold' standard for guiding quality improvement activities in healthcare. Specifically, this model has been used to outline the potential mechanisms of variation in quality and applied across a spectrum of healthcare settings and disease diagnoses, as well as being used to operationalise other types of healthcare quality measures (ie, Agency for Healthcare Research and Quality—Quality Indicators).[17]

A second dimension of indicator classification that will be applied, in conjunction with the Donabedian model, will include patient-centred care-relevant domains taken from existing frameworks and evidence of domains in patient-centred care, for instance (but not limited to) the Picker Institute's Eight Principles for Patient-Centred Care[18] and the British Columbia Patient-Centered Care Framework.[19] To illustrate how we will apply Donabedian's model and patient-centric domains, we have provided an example in table 1. For example, patient–provider communication is an important thematic domain for patient-centred care; for the Donabedian component structure, an indicator example would be the development of an electronic-health or 'e-health' information technology system to support the communication between patients and healthcare providers across the continuum of care.

Protocol design

Methods for this study were developed based on Arksey and O'Malley's[20] scoping review methodology, and Levac *et al*'s[21] methodological enhancement. According to this framework, there are six different stages in undertaking a scoping review: (1) identifying the research question; (2) identifying relevant studies; (3) selecting studies; (4) charting the data; (5) collating, summarising and reporting the results and (6) consulting with relevant stakeholders.

Stage 1: Identifying the research question

Through consultation with the research team and key stakeholders, the overall main research question developed is defined as: 'What are the quality indicators that have been implemented and evaluated across various points-of-care settings, processes of care and systems level proposed or currently in use to measure patient-centred care?'. For the purpose of this review, a quality indicator is 'an explicitly and measurable item which act as building blocks in the assessment of care'.[22]

Stage 2: Identifying relevant studies

Search strategy and information sources

Identification of studies relevant to this review will be achieved by searching electronic databases of the published literature which will include: MEDLINE, EMBASE, the Cochrane Library, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, Social Work Abstracts and Social Services Abstracts. (The proposed search strategy is shown in online supplementary appendix 1'.) We will also handsearch all reference lists of included studies to identify additional studies of relevance.

To ensure that all relevant information is captured, we will also search a variety of grey literature sources. We will search relevant grey literature databases (eg, Grey Literature Report, OpenGrey, Web of Science Conference Proceedings) to identify studies, reports and conference abstracts of relevance to this review. We will also conduct a targeted search of the grey literature in local, provincial, national and international organisations' websites and related health or scientific organisations including: Patients Canada,[23] the Patient-centered Outcomes Research Institute (PCORI).[24]

Search terms will be determined with input from the research team, research collaborators and knowledge users. The search strategy will be developed by an experienced research librarian and coauthor (DLL), and will be revised pending input from stakeholders. Specifically, our patient-partner will be consulted for contribution of specific search terms regarding patient-centred care for the aspects of measurement to search the grey literature, as we suspect there will be more relevant existing grey literature on this topic. To ensure that no bias occurs, the patient-partner will be blinded to the original search strategy developed by the research team. Database and other searches will combine terms from two themes: quality indicators (eg, quality indicators, QI, performance indicators) and patient-centred care (eg, patient centered, patient centred, patient centric, patient beliefs, culture, ethnicity). Terms will be searched as both

Table 1 Example of indicator classification using the Donabedian model and patient-centred care domains.

Example of PCC thematic domains	Donabedian framework of quality[11]		
	Structure	Process	Outcome
1. Patient–provider communication	Development of innovative e-health information technology to support and enhance patient–provider communication	Listening and responding to patients' concerns and expectations of care	Effective and timely access to care and consultation length

PCC, patient-centred care.

keywords in the title and/or abstract and subject headings (eg, MeSH, EMTREE) as appropriate. No language or date limits will be applied. Search results will be downloaded and imported into a custom-written Java software application called Synthesis,[25] specifically created for systematic and scoping literature reviews.

Stage 3: Study selection

The review process will consist of two levels of screening: (1) a title and abstract review and (2) full-text review. For the first level of screening, two investigators will independently screen the title and abstract of all retrieved citations for inclusion against a set of minimum inclusion criteria. The criteria will be tested on a sample of abstracts prior to beginning the abstract review to ensure that they are robust enough to capture any articles that may relate to PC-QIs. Any articles that are deemed relevant by either or both of the reviewers will be included in the full-text review. In the second step, the two investigators will then each independently assess the full-text articles to determine if they meet the inclusion/exclusion criteria. To determine inter-rater agreement, Cohen's κ statistic[26] will be calculated at both the title and abstract review stage and at the full article review stage. Any discordant full-text articles will be reviewed a second time and further disagreements about study eligibility at the full-text review stage will be resolved through discussion with a third investigator until full consensus is obtained.

Relevant studies will be included if they describe the concept of patient-centredness or patient-centred care, and describe quality measurement or indicators concerned with patient-centred care, which can be a single measure or a set of measures. These measures can include patient-reported outcome and patient-reported experience measures. Studies included can be on any of (a) development; (b) implementation; (c) evaluation; or (d) comparative validation of such measures. Any type of study design (eg, randomised control trials, case–control study, prospective or retrospective cohort study, quasi-experimental, qualitative) will be included. Studies will be excluded if they describe or evaluate quality improvement indicators in healthcare that are not patient-centric.

Stage 4: Data collection

A data collection instrument will be developed by the research team to confirm study relevance and to extract study characteristics. Study characteristics to be extracted will include, but not be limited to: publication year, publication type (eg, original research), study design, country, patient population characteristics, healthcare setting, patient-centered definition, description of quality indicators including definition, numerator, dominator, psychometrics of the indicators (face validity, reliability, construct validity, risk adjustment), and whether patients were involved in the development of the indicators. This form will be reviewed by the research team and pretested by all reviewers before implementation to ensure that the form is capturing the information accurately. Data abstraction will be conducted in duplicate with two reviewers independently extracting data from all included studies. To ensure accurate data collection, each reviewer's independent abstracted data will be compared and any discrepancies will be further discussed to ensure consistency between the reviewers. The data will be compiled in a single literature review software program, Synthesis, and then downloaded into a single excel spreadsheet in Microsoft Excel software for validation and coding.

Stage 5: Data summary and synthesis of results

Since a scoping review can be used to map the concepts underpinning a research area and the main sources and types of evidence available, the aggregated findings provide an overview of the research rather than an assessment of the quality of individual studies. For our scoping review, the quality indicators identified and extracted will be coded based on the Donabedian model and thematic dimensions of patient-centred care as discussed above. From this, a list of candidate quality indicators for further development and potential systematic reviews will be presented.

Stage 6: Consultation

Levac *et al*[21] suggest that the consultation stage provides opportunities for stakeholder involvement, providing insights beyond what is reported in the literature. To address the study's patient-centric approach, stakeholders, in particular a patient-partner, will be engaged throughout the study acting as a consultant and knowledge user. Specifically, she will provide input regarding the search strategy and grey literature search to integrate the patient voice in capturing what is important to a patient in addressing measurement. This targeted search will be informed by input from subject experts and our provincial, national and international collaborators in different jurisdictions at the national level with the Canadian Institute for Health Information, the provincial level with Health Quality Councils, and internationally consult with experts in patient-centred care and measurement in the UK, Australia and Sweden. In addition, our patient-partner will connect with patient networks to provide a summary of results.

DISSEMINATION AND ETHICS

This study will constitute the first step in a multistep research programme aimed at developing a set of evidence-based PC-QIs that can be used across the healthcare spectrum. The results from this scoping review will guide the next phase of a multifaceted research programme that will lead to development of a set of PC-QIs that can be implemented at the system level to measure and monitor patient-centred care.

Since the scoping review methodology consists of reviewing and collecting data from publicly available materials, this study does not require ethics approval. To facilitate knowledge translation activities, our research team will use an integrated approach involving consulting a patient-partner to guide the research objectives and presenting the findings to other key health system stakeholders.

Contributors MJS conceived of the idea, developed the research question and study methods and contributed meaningfully to the drafting and editing; she has also approved the final manuscript. RJJ, DLL, KM, ML and HQ aided in developing the research question and study methods, contributed meaningfully to the drafting and editing, and approved the final manuscript.

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Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement No additional data are available.

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Protocol for a scoping review study to identify and classify patient-centred quality indicators

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Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	4
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	4
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Supplemental file 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	5
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	N/A
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	6

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	6
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	7
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	N/A
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	7-11
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	13
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	14
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	14
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	15

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Measuring patient-centred system performance: A scoping review of patient-centred care quality indicators

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Measuring patient-centred system performance: A scoping review of patient-centred care quality indicators

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Abstract

Objectives: The shift to the patient-centred care model as a healthcare delivery paradigm calls for systematic measurement and evaluation. In an attempt to develop patient-centred quality indicators (PC-QIs), this study aimed to identify quality indicators that can be used to measure patient-centred care. The objective of this scoping review was to identify existing PC-QIs that have been developed and implemented across various care sectors.

Search Strategy: Studies were identified through searching 7 electronic databases and the grey literature. Search terms included: quality improvement, quality indicators, healthcare quality, patient-centred care. Articles were included if they mentioned development and/or implementation of PC-QIs.

Results: A total 184 full-text peer-reviewed articles were assessed for eligibility for inclusion; of these, nine articles were included in this review. From the non- peer-reviewed literature, eight documents met the criteria for inclusion in this study. This review revealed the heterogeneity describing and defining the nature of PC-QIs. Most PC-QIs were presented as patient-centred care (PCC) measures and identified as guidelines, surveys, or recommendations, and therefore cannot be classified as actual PC-QIs. Out of 502 ways to measure PCC, only 25 were considered to be actual PC-QIs. None of the identified articles implemented the quality indicators in care settings.

Conclusion: The identification of PC-QIs is a key first step in laying the groundwork to develop evidence-based PC-QIs. Research is needed to continue the development and implementation of PC-QIs for healthcare quality improvement.

Keywords: patient-centred care, quality indicator, healthcare quality, quality improvement

Strengths

- Transparent and rigorous search strategy
- Involvement of patient partner in the study
- Study informed by a previously published protocool[9]

Limitations

- Search strategy using only English terms
- We did not assess the quality of the measures and/or indicators identified

INTRODUCTION

Patient-centred care (PCC) is one of the six dimensions of healthcare and was formally described by the Institute of Medicine in 2001 as *"healthcare that respects and responds to the preferences, needs and values of the individual patients throughout all healthcare decisions"*.[1] PCC is an approach that has become central to policies and programming to improve healthcare efficiencies and address patient safety issues.[2]

PCC is a model in which healthcare providers are encouraged to partner with patients and families to design and deliver individualized care. PCC models have been linked to positive patient experiences and improved outcomes, such as increased adherence to care and treatment.[3-5] A PCC approach not only benefits patients, but also healthcare organizations in reducing costs, for instance through decreasing the length of hospital stays and readmission rates.[6 7] However, patient-centred care is conceptualized differently among different stakeholders, impacting effective implementation in care settings.[8] The adoption of a PCC model requires first, the identification of appropriate indicators to measure the quality of PCC, and second, the assessment of the impact of delivering PCC on healthcare system and patient outcomes.[9]

Quality indicators are tools that measure system performance and healthcare quality, and demonstrate the extent to which improvement efforts have led to desirable change, or contributed to unintended results.[10] As identified from the Agency for Healthcare Research and Quality (AHRQ), a quality indicator consists of: a specific aspect of quality being captured, and a method for how concepts of quality are captured (which includes: data source, measure type, observable event, specification and risk adjustment).[11] While various quality indicators have been developed to measure healthcare safety, effectiveness and access,[12] they typically do not incorporate the priorities and experiences of patients and family caregivers. To truly evaluate the impact of patient-centredness, indicators must reflect the patient and family caregiver perspective.

This scoping review aimed to synthesize existing literature on quality indicators used in the evaluation of patient-centred care. This review was guided by the questions: "What PC-QIs have been developed to measure patient centred care ?" "How are patient-centred quality indicators defined?" and "Have existing patient-centred quality indicators been implemented and evaluated across various points-of-care settings, processes of care, and at the systems level to measure patient-centred care?" The information gained from this study will inform the development of patient-centred care quality indicators that could be implemented to drive healthcare improvement valued by patients and families.

METHODS

We employed a scoping review protocol that was previously published,[13] using methodology based on Arksey and O'Malley's scoping review framework[14] and Levac *et al.*'s methodological enhancement.[15] We searched the peer-reviewed published and grey literature for either proposed or existing quality indicators that have been developed and/or implemented across various points-of-care settings to measure patient-centred care. For this scoping review, the Agency for Healthcare Research & Quality (AHRQ)[16] definition of a quality indicator was adapted to incorporate a patient and family focus. Specifically, a patient-centred quality indicator (PC-QI) was defined as the unit of measurement of healthcare system, organizational or individual performance, that quantify patients' and families' experiences with the care received and quantify the experience of any individual who needs to contact with healthcare services." In contrast, PCC measures are in the form of a survey, guideline, or recommendation.

Data sources and search strategy

In order to identify studies assessing quality indicators for patient-centred care, search strategies were developed that combined terms from two concepts: patient-centred care and quality indicators (supplemental file 1). The Cochrane Library, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), EMBASE, MEDLINE, PsycINFO, Social Services Abstracts, and Social Work Abstracts were searched from inception to January 2017. A search of the Google search engines, and the websites of relevant quality improvement and patient-centric organizations enabled the identification of relevant grey literature. Grey literature searches were conducted in duplicate by both a researcher and patient partner. The reference lists of included studies were also scanned to identify any other studies of relevance.

Citation management

All references were imported into a custom-written Java software application, Synthesis for reference management and data collection.[17] Duplicate citations were removed automatically by the software, with any mismatched duplicates removed manually if detected.

Study selection and data abstraction

To be eligible for inclusion, the study/article had to 1) identify quality indicators for PCC and/or 2) identify PC-QI in performance measurement (e.g., validation). The title and abstract of each citation identified was screened for eligibility independently by two reviewers (MJS, ML). The full-text of any abstract selected by either reviewer was retrieved and assessed for eligibility. Any full-text articles for which there was inter-rater discord were reviewed a second time, and final disagreements about study eligibility were resolved through discussion.

Data collection and Classification of Indicators

A data collection tool was developed and tested on a sample of papers to determine its practicality prior to the full review (supplemental file 2). Extracted data included study characteristics (country, year of publication, type of study/article), patients' inclusion in the development of indicators, and type of patient populations and point of care if applicable (e.g. in-patient, out-patient, primary care).

All extracted indicators were classified by two authors (MS, SA) according to a person-centred care framework[18] developed by the team and guided by the Donabedian model of quality of care.[19] This framework provides a roadmap for healthcare systems to implement and measure PCC at the level of structure (the health care system/organizational level); process (the patient-healthcare provider interaction level), and outcome (the patient-health care provider, healthcare systems interaction level).[18]

Patient Involvement

Levac et al, recommends the involvement of stakeholders in the scoping review methodology.[15] We worked closely with our patient-research partner (SZ) in the design of the study who also aided in the search strategy. Our patient research partner aided in the clarification of research questions as well. The involvement of patient research partners allows for suggestions of additional references as well as the provision of insights beyond those in the literature.[15] The involvement of patients is key to patient centred care, and therefore our patient-research partner was vital for this review.

RESULTS

A total of 36,643 citations were retrieved, and upon duplicate removal, a total of 16,173 citations were reviewed at the title and abstract stage for inclusion (Figure 1). A total 184 full-text peer-reviewed articles were assessed for eligibility for inclusion; of these, nine articles were included in this review (Figure 1). From the non- peer-reviewed literature, following the title and document review, eight documents met the criteria for inclusion in this study (Figure 1). The most common reason for excluding articles (n=15,905) was the absence of indicators for PCC.

Article Description

Table 1 presents the characteristics of the full text articles included in the study. The years of publication ranged from 1996 to 2015. Included studies were published in Belgium (n=1), United States of America (n=2), Canada (n=3), United Kingdom (n=4), the Netherlands (n=4), and three sources did not include a country of publication. Sources were varied and included original peer reviewed research (n=8), guest editorial (n=1), reports (n=4), discussion paper (n=1), working paper (n=1), literature review (n=1), and a website (n=1). The study populations varied in the peer reviewed literature (e.g., cancer, fertility care, HPN, etc.) and no specific populations were identified in the non-peer reviewed literature.

"What PC-QIs have been developed to measure patient centred care?"

From the sources included, a total of 502 ways of measuring PCC were explicitly identified as quality indicators by studies' authors. However only 25 were classified as actual indicators by our research team.

PCC measurement varied between articles. While all sources used the term ‘quality indicator’, not all were quantifiable and measurable. Most sources presented quality indicators as guidelines or recommendations for healthcare practitioners. Wensing *et al.* presented indicators as survey items, such as “Does the GP pay attention to patients' needs?”[20] Actual indicators were presented as percentages and proportions, and identified from six grey literature sources.[21-26] For instance, one study outlined an example of a structure indicator - “Percent of nurses attending education sessions (orientation, organization professional development opportunities) on client centred care.”[25]

Study populations included cancer patients (n=2), colonoscopy patients (n=1), home parenteral nutrition patients (HPN) (n=1), chronically ill (n=1), fertility care (n=1), and assisted living support patients (n=1) (Table 1). For the development of PCC measures, seven studies used focus groups, interviews, and/or consensus meetings, ten studies included patients and family caregivers in the development of PCC measures, and one article developed measures through the authors’ clinical and research work. Two sources developed ways to measure PCC from patient reported experience surveys,[24 27] and two studies used a framework.[25 28]

Some studies grouped ways to measure PCC according to domains of patient-centred care that were based on previously defined frameworks or through consensus (e.g., access to care, communication and information). Domains identified from the person-centred care framework are categorized according to structure, process, and outcome.[18] Table 2 presents examples of measuring PCC classified according to the person-centred care framework,[18] and Table 3 presents the actual indicators classified according to the same framework.[18]

Table 1. Characteristics of Articles on Patient-Centred Quality Indicators

Study identifier (first author)	**Country**	**Year**	**Study Type**	**Population**	**Patients involved**	**Number of Indicators & ways to measure PCC**
Peer reviewed literature (n=9)						
den Breejen et *al.*[29]	Netherlands	2013	Focus groups/interviews/ consensus meetings	Fertility care	Yes	34
Dreesen et *al.*[30]	Belgium	2014	Focus groups/interviews/ consensus meetings;	Home parenteral nutrition (HPN) patients	Yes	33
Ouwens et *al.*[31]	Netherlands	2010	Focus groups/interviews/ consensus meetings;	Cancer- Non-small cell lung carcinoma	Yes	54
Sewitch et *al.*[32]	Canada	2013	Focus groups/interviews/ consensus meetings; Surveys	Colonoscopy patients - adult	Yes	20

Uphoff et *al.*[33]	Netherlands	2012	Focus groups/interviews/ consensus meetings	Cancer	Yes	21
Wensing et *al.*[20]	Netherlands	1996	Focus groups/interviews/ consensus meetings; Surveys	Chronically ill patients (chronic obstructive pulmonary disease, diabetes, cardiovascular disease, migraine, chronic disease of locomotor system)	Yes	41
Zimmerman et *al.*[34]	USA	2014	Focus groups/interviews/ consensus meetings	Community-based, assisted living support patients	Yes	43
Cox et *al.* [35]	United Kingdom	2014	Guest editorial	-	-	4
Carinci et *al.* [28]	United Kingdom	2015	Modified Delphi approach/consensus meeting	-	-	12
non-peer reviewed Literature (n=8)						
Steven Lewis[26]	Canada	2009	Discussion paper	-	-	6
RNAO[25]	Canada	2002	Guidelines document/report	-	-	18
Silow-Carroll et *al.*[36]	USA	2006	Report	-	-	6
Kelley & Hurst (OECD)[24]	-	2006	Working papers	-	Yes	7
OECD[27]	-	2006	OECD website	-	Yes	8
Essence of Care- Patient Focused benchmarks for clinical governance (NHS)[22]	United Kingdom	2003	Report	-	Yes	116
Davies et *al.*[23]	United Kingdom	2009	Report	-	-	10
IAPO[21]	-	2012	Literature review	-	-	69

PCC, Patient-Centred Care
OECD, Organization for Economic Co-operation and Development
NHS, National Health Services
RNAO, Registered Nurses Association Ontario
IAPO, International Alliance of Patients' Organizations

Table 2. Examples of PCC measurement classified according to the person-centred care framework.[18]

PCC Measure Classification	Domain	Example of ways to measure PCC
Structure (n=80)	Supporting a workforce committed to Patient-Centred Care (PCC)	• The development needs of health care personnel are met by ongoing review through supervision, appraisal and individual development plans[22] • All staff and volunteers can articulate person-centred principles and practices applicable to their role(s) and demonstrate their implementation[34]
	Providing a supportive and accommodating PCC environment	• Residents have a choice of a private room[34] • Patient satisfaction survey translated into Spanish[35]
Process (n=343)	Cultivating Communication	• (Regular) doctor involving patients in decisions about care or treatment[27] • Making use of open-ended questions in a conversation with the patient[33] • Patient had the knowledge and support to make decisions[31] • Regular doctor providing easy-to-understand explanations[28]
	Respectful and compassionate care	• Patient received emotional support from nurses if needed[31] • Giving confidence to the patient[30] • Does the GP pay attention to patients' needs?[20]
Outcome (n=79)	Patient-Reported Outcomes (PROs)	• Measures are in place to assess and provide feedback on the interpersonal skills of health care personnel[22] • Regarding infertility treatment, patients would like to see all members of the infertility treatment team following the same policy[29]

Table 3. Identified Patient Centred Quality Indicators from the literature classified according to the person-centered care framework as actual indicators[18]

Type of Indicator	Domain	PCC Indicators (n=25)
Structure	Creating a PCC Culture	• An induction programme is in place which promotes the philosophy of care [22] • % of PHC organizations who currently have processes to involve community input for planning the organization's services (e.g. advisory committees, focus groups[21] • Clear policies are in place on how services are offered to patients[21]

	Supporting a workforce committed to PCC	• Percent of nurses attending education sessions (orientation, organization professional development opportunities) on client centred care[25] • Percent of non-nursing staff attending education sessions (orientation, organization professional development opportunities) on client centred care[25]
Process	Cultivating Communication	• % of patients with access to an on-line HER a) By region b) By practice[26] • Proportion of service users who stated that the district nurse provided health advice or information about his/her condition[23] • Proportion of service users who stated that they were involved as much as they wanted to be in decisions about their care and treatment[23]
	Respectful and compassionate care	• Proportion of service users who stated that their district nurse treated them with respect and dignity[23] • % of inpatients who said they were always treated with respect and dignity while in hospital/primary care[21]
	Engaging patients in managing their care	• % of PHC clients/patients, 18 years and over, with a chronic condition(s), who actively participated in the development of a treatment plan with their PHC provider over the past 12 months[21] • % of hospital patients who said they had been sufficiently involved in decisions about their care as much as they wanted to be[21] • Percent of nurses self-reporting: Adequate assessment of a client's perceived needs for care, adequate assessment of a client's goals for care, adequate documentation of a client's personal goals for care, sharing client's concerns/choices with other members of the health care team, discharge teaching guided by the client's goals for managing their care at home[25]
	Integration of Care	• % of hospital patients taking medicines home after discharge who were told completely about the purposes of the medicine in a way they could understand[21]
	Access to Care	• % of patients who can get all diagnostic work ordered by their primary care doctor done the same day in the same location (excluding certain

		high-technology procedures such as CT and MRI)[26] - Percentage of outpatients seen within 13 weeks of GP referral[24] - Percentage of those on waiting list waiting 12 months or more[24] - Proportion of service users who were able to contact a district nurse when needed, including outside of normal working hours[23] - The percentage of patients who, in the appropriate national survey, indicate that they were able to obtain a consultation with a GP or appropriate health care professional within 2 working days (NHS Confederation, UK)[21] - % of PHC clients/patients, 18 years and over, with a chronic condition(s), who had sufficient time in most visits to confide their health-related feelings, fears and concerns to their PHC provider[21]
Outcome	Patient-Reported Experiences (PREMs)	- Proportion of service users who stated that the district nurse had all the necessary information about the service user and his/ her health needs[23] - Proportion of service users who stated that the district nurse had all the equipment and dressings needed[23] - Proportion of service users who stated that the district nurse was knowledgeable and competent[23] - Proportion of service users who rated the district nurse service as very good or excellent[23] - Proportion of children whose parents routinely received all aspects of family centred care (Child and Adolescent Health Measurement Initiative)[21]

PHC, Primary Healthcare
HER, Health Electronic Record
CT, Computed Tomography
MRI, Magnetic Resonance Imaging
GP, General Practitioner
NHS, National Health Services
UK, United Kingdom

How are patient-centred quality indicators defined?

The definition of a PC-QI was not clearly articulated in the studies identified (Table 4). Ten of the included studies provided no such definition of a quality indicator (Table 4). Sources where the definition of a quality indicator was mentioned defined indicators as something to be measured, and developed through consensus (Table 4).[23 30 31 33] Of those four sources where the definition of a PC-QI was clear, two included actual indicators.[21]

[23] The National Health Services (2003) report described indicators as ‘items that patients, carers and professionals believed were important in achieving the benchmarks of best practice.” [22]

Have the existing patient-centred quality indicators been implemented and evaluated across various points-of-care settings, processes of care and at the system level to measure patient-centred care?

None of the articles mentioned actual implementation of indicators in the settings for which they were developed. Similarly, many of the sources (15/17) did not evaluate the indicators according to any set criteria. The two studies that did evaluate indicators, used two different approaches.[28 31] The study by Ouwens et *al.* assessed guidelines for psychometric characteristics and only 26 out of 56 guidelines were found to be reliable.[31] The study by Carinci et *al.* used a modified Delphi approach with expert Organization for Economic Co-operation and Development (OECD) members to rate the PCC measures, using validity, reliability, relevance, actionability, international feasibility, and international comparability as the criteria.[28] Uphoff et *al.*, recommended using the Gol & Grimshaw model for evaluating indicators,[33] while a future direction for Zimmerman et *al*. was the evaluation of the indicators.[34]The working paper by Kelley and Hurst presented criteria that can be used to select indicators.[24] These included the importance of what is being measured (which includes policy importance), scientific soundness, and feasibility of the measure.[24]

Table 4. Definition of quality indicator used by authors

Study Identifier (First Author, year)	**Definition of quality indicator used**
(den Breejen et *al*, 2013),[29] (Sewitch et *al*, 2013),[32] (Uphoff et *al*, 2012),[33] (Zimmerman et *al*, 2014),[34] (Cox et *al*, 2014),[35] (Lewis, 2009),[26] (RNAO, 2002),[25] (Silow-Carroll et *al*, 2006),[36] (Kelley & Hurst, 2006),[24] (OECD website, 2006),[27] (Carinci et *al*, 2015)[28]	Definition not included
(Dreesen et *al*, 2014)[30]	A quality indicator as a measurable element of practice performance for which there is evidence or consensus that it can be used to assess the quality of care, and hence change the care provided.[37]
(Ouwens et *al*, 2010)[31] (Uphoff et *al*, 2012)[33]	Quality indicators are ‘measurable elements of practice performance for which there is evidence or consensus that they can be used to assess the quality of care’[38]
(Davies et *al*, 2009)[23]	An explicit measureable statement of the quality of care given. Relates to a single

	outcome or process of medical care. Clearly defined and unambiguous.[38 39]
(NHS, 2003)[22]	Items that patients, carers and professionals believed were important in achieving the benchmarks of best practice.[22]
(IAPO, 2012)[21]	Can be measures of structure, process and outcome, either as generic measures relevant for all diseases, or disease-specific measures that describe quality of patient care related to a specific diagnosis.[40]

OECD, Organization for Economic Cooperation and Development
NHS, National Health Services
IAPO, International Alliance of Patients' Organizations

DISCUSSION

This review specifically examined existing patient centred care quality indicators in the academic and grey literature. Patient-centred care has been increasingly adopted by many jurisdictions, however this review revealed there to be gaps in the conceptualization of patient-centred quality indicators. Out of the 17 articles that met the inclusion criteria, only 9 were peer reviewed, and looked at specific conditions. Additionally, the heterogeneity of the PCC literature relates to the variety of definitions on PC-QIs, and a diverse type of indicators developed for different patient population and care-settings. For instance, all included articles in the review used the term 'indicator,' but not all presented actual indicators as defined by the Agency for Healthcare Research & Quality (AHRQ).[16]

The absence of a standard definition of what a PC-QI is in the literature has posed challenges in identifying the literature sources for inclusion in this review. 'Quality' means different things to different people, and despite the standard definition of PCC by the Institute of Medicine,[1] PCC continues to be operationalized and measured differently.[41] Most sources identified in the literature did not explicitly define what a quality indicator is, which may explain the differences in approaches to indicator development. The absence of a definition for quality indicators results in inconsistencies for how an indicator should be presented and also what makes for a good indicator. Previous reviews have also found variability in quality indicator definitions, such as indicators for hip fracture patient care.[42] The absence of a standard definition of PC-QIs poses concerns for standardized measurement of PCC, and for implementation of PC-QIs in healthcare settings.

In compliance with quality improvement agencies, quality councils and organizations such as the AHRQ, quality indicators should be presented as a unit of measurement - as a percentage or proportion.[16] Our review revealed inconsistencies in the definition of indicators. Only few sources in the non-peer reviewed literature included PC-QIs as quantifiable units, such as percentages, incorporating a numerator and denominator in the unit of measurement.[43] Most of the identified indicators were actually domains included in PCC measures and guidelines. The lack of defined units of measurement impedes comparisons across facilities, and benchmarking, and doesn't allow for longitudinal evaluation and overall measurement of care that is patient-centred. Without this unit of measurement for PC-QIs, it is difficult to target specific improvements needed for PCC.

The review revealed that when incorporating the patient and caregiver perspective in quality improvement, a difficulty exists in translating perceptions and subjective experiences into standardized objective indicators. Measures of well-being are both necessary and important to incorporating a PCC model of care. The study by Carr et *al.* suggests that perceptions of health and its meaning vary between individuals and across time, as do their experiences and expectations of healthcare.[44] In order to capture various perspectives on quality care, it is vital to include patients and families. Including the patient and family perspective is necessary to ensure quality patient-centred care.

Additionally, this review found large variances for domains to categorize approaches to measuring PCC. In an attempt to organize our findings and understand the ways of measuring PCC, we used a previously published person-centered care framework[18] to classify them into healthcare quality domains. From this classification, most strategies for measuring PCC were found to relate to domains associated with healthcare processes (e.g. cultivating communication). These findings are consistent with the current measurement landscape, for instance trauma indicators,[45] and AHRQ PC-QIs[46] which mainly assess processes and outcomes. For PCC, structures, such as policies and education programs can provide an important basis to improve PCC practice.[18 47] Structure indicators provide the necessary foundations for the assessment of process and outcome indicators, for instance through creating a PCC culture, supporting the workforce to deliver PCC, and providing an accommodating environment for patients.[18] In this review, structure indicators were lacking.

Finally, there is scarce evidence in the literature on how to implement indicators for PCC, and how to evaluate their implementation. PCC measurement has, to date, primarily focused on specific disease conditions and healthcare sectors. However, recent initiatives, (National Health Services) reveal a more generic approach to measurement (Family and Friend Test).[48] In order to create a standardized set of PC-QIs, indicators must be developed across the continuum of care. Santana & Stelfox. also found a lack of implementation of indicators in care settings in their review.[45] Before indicators are implemented, they must be evaluated according to standard set criteria. What constitutes as a good indicator has been outlined by health quality organizations, such as National Quality Forum. As outlined by the National Quality Forum, quality indicators should be evaluated through a set criteria including: importance, scientific acceptability, feasibility, and usability and use.[49] Our review did not identify any studies where such evaluations were implemented. In the development and implementation of quality indicators, the guideline set by the National Quality Forum should be adhered to.

The gaps identified in the literature for patient-centred quality indicators provide directions for future research. First, there needs to be consensus on a standard definition of patient-centred quality indicator to guide future measurement of patient-centred care. Second, there needs to be development of standard PC-QIs for all healthcare settings.

Third, PC-QIs need to be evaluated according to a set criteria. Lastly, PC-QIs need to be implemented across healthcare settings for monitoring and evaluation of PCC.

Strengths and Limitations

Our scoping review used robust and transparent methods guided by a protocol previously published,[13] and supported by a research librarian with expertise in knowledge synthesis and scoping reviews (DLL). We worked closely with our patient research partner (SZ) in the study design, research questions, search strategy and manuscript preparation.

This review may not have identified all relevant sources in the published and grey literature as we conducted the search using only English terms. As we are following the scoping review methodology, the quality of the studies was not assessed. Therefore, indicators from weak and strong studies is considered.

Conclusions

In summary, our review is the first to examine the literature pertaining to quality indicators that are patient-centric. Our findings will further the development of validated healthcare tools assessing healthcare quality from a patient-centred approach. Future research should focus on developing and refining PC-QIs that are ready to implement and evaluate following the criteria set forth by the National Quality Forum.[49]

Figure 1. Flow Diagram for study inclusion

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Details of contributors:
MJS conceived the study, and all authors identified key literature to be included in the review. MJS led the drafting of the manuscript and key discussion points with support from DL, RJJ, SA, ML and KM. SA managed the design of the tables (with feedback from all authors), and management of references. All authors provided important intellectual contribution and guidance throughout the development of the manuscript. HQ, DL, SZ, and ML provided guidance on the presentation of the findings and guidance on final revisions. All of the authors contributed to critical review and revisions to the manuscript, agreeing on the final version.

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All authors had access to the data (literature identified and tables) in the study and assume responsibility for the integrity of the data and the accuracy of the data analysis.

The lead author* affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

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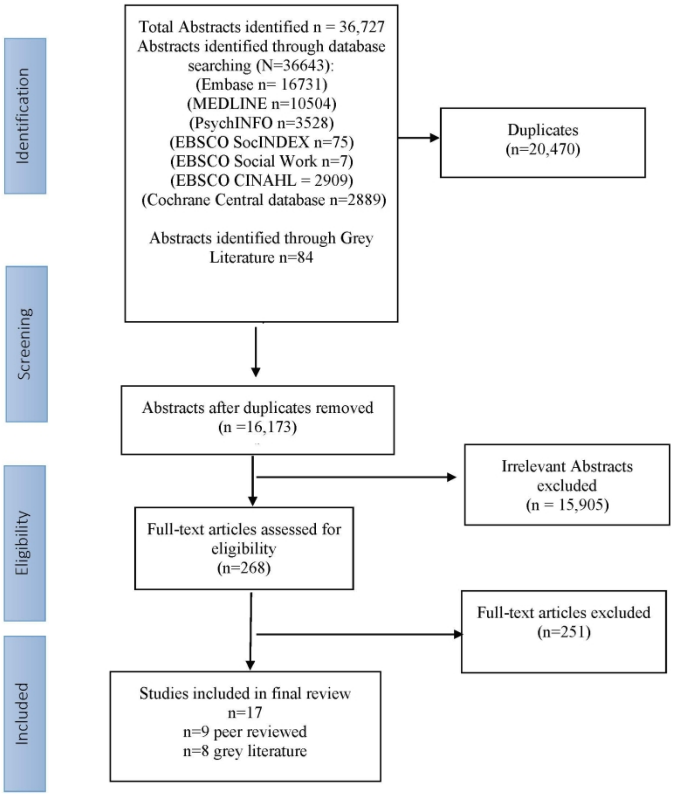
Figure 1- Flow Diagram for study inclusion



215x279mm (300 x 300 DPI)

CINAHL (EBSCO)- Patient Centered Quality Indicators Search Strategies

1. (MH "Patient Centered Care") OR (MH "Gender Specific Care") OR (MH "Transcultural Care") OR (MH "Cultural Competence") OR (MH "Transcultural Nursing") OR (MH "Family Centered Care") OR (MH "Patient Satisfaction") OR (MH "Patient Rights+") OR (MH "Patient Advocacy")
2. TI (((carer* or care giver* or caregiver* or culture* or cultural* or family or families or parents or patient* or person) N5 (centered* or centred* or focused) N5 (care or healthcare or nursing or medical or medicine))) OR AB (((carer* or care giver* or caregiver* or culture* or cultural* or family or families or parents or patient* or person) N5 (centered* or centred* or focused) N5 (care or healthcare or nursing or medical or medicine)))
3. TI (((carer* or care giver* or caregiver* or cultural* or culture* or family or families or parents or patient*) N5 (advocacy or autonomy or beliefs or choice or perspectives or preferences or rights or satisfaction or values or views) N5 (care or healthcare or nursing or medical or medicine))) OR AB (((carer* or care giver* or caregiver* or cultural* or culture* or family or families or parents or patient*) N5 (advocacy or autonomy or beliefs or choice or perspectives or preferences or rights or satisfaction or values or views) N5 (care or healthcare or nursing or medical or medicine)))
4. TI ((cultural competency or culturally competent care)) OR AB ((cultural competency or culturally competent care))
5. 1 or 2 or 3 or 4
6. (MH "Clinical Indicators") OR (MH "Benchmarking") OR (MH "Clinical Governance") OR (MH "Guideline Adherence") OR (MH "Performance Measurement Systems") OR (MH "Quality Assessment") OR (MH "Quality Patient Care Scale")) OR TI ((performance measure* or (healthcare N3 monitor*) or performance reporting or QI or PQI or (quality N3 criteria) or (quality N3 indicator*) or (quality N3 measure*) or (quality N3 scale*))) OR AB ((performance measure* or (healthcare N3 monitor*) or performance reporting or QI or PQI or (quality N3 criteria) or (quality N3 indicator*) or (quality N3 measure*) or (quality N3 scale*)))
7. 5 and 6

Patient Centered Quality Indicators Search Strategies

MEDLINE

1. exp patient-centered care/

2. Culturally Competent Care/ or exp ethnic groups/

3. ((carer* or care giver* or caregiver* or client* or culture* or cultural* or ethnic* or family or families or indigenous or parents or patient* or person or racial* or ethnocultural* or immigrant* or refugee* or migrant*) adj5 (centered* or centred* or focused) adj5 (care or healthcare or nursing or medical or medicine)).tw.kw.kf

4. cultural competency/ or patient satisfaction/ or patient preference/

5. exp Patient Rights/

6. ((carer* or care giver* or caregiver* or client* or cultural* or culture* or ethnic* or family or families or indigenous or parents or patient* or racial* or ethnocultural* or immigrant* or refugee* or migrant*) adj5 (advocacy or autonomy or beliefs or choice or perspectives or preferences or rights or satisfaction or values or views) adj5 (care or healthcare or nursing or medical or medicine)).tw.

7. ((cultural* or ethnic* or racial* or ethnocultural* or immigrant* or refugee* or migrant*) adj10 (competency or competent care)).tw.

8. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8

9. exp Quality Indicators, Health Care/

10. benchmarking/ or clinical audit/

11. (performance measure* or (healthcare adj3 monitor*) or performance reporting or QI or PQI or (quality adj3 criteria) or (quality adj3 indicator*) or (quality adj3 measure*) or (quality adj3 scale*)).tw,kw.

12. Guideline Adherence/

13. 10 or 11 or 12 or 13

14. 9 and 14

15. limit 15 to yr="1990 -Current"

16. limit 16 to yr="2015 -Current"

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	4
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	4
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Supplemental file 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	5
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	N/A
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	6

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	6
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	7
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	N/A
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	7-11
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	13
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	14
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	14
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	15

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

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BMJ Open

Measuring patient-centred system performance: A scoping review of patient-centred care quality indicators

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Secondary Subject Heading:	Health services research
Keywords:	Patient-centred care, Quality indicators, healthcare quality, quality improvement

Measuring patient-centred system performance: A scoping review of patient-centred care quality indicators

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Number of references: 49
Number of Figures: 1
Number of Tables: 4

Abstract

Objectives: The shift to the patient-centred care model as a healthcare delivery paradigm calls for systematic measurement and evaluation. In an attempt to develop patient-centred quality indicators (PC-QIs), this study aimed to identify quality indicators that can be used to measure patient-centred care.

Methods:
Design: Scoping review
Data Sources: Studies were identified through searching 7 electronic databases and the grey literature. Search terms included: quality improvement, quality indicators, healthcare quality, patient-centred care.
Eligibility Criteria: Articles were included if they mentioned development and/or implementation of PC-QIs.
Data Extraction & Synthesis: Extracted data included study characteristics (country, year of publication, type of study/article), patients' inclusion in the development of indicators, and type of patient populations and point of care if applicable (e.g. in-patient, out-patient, primary care)

Results: A total 184 full-text peer-reviewed articles were assessed for eligibility for inclusion; of these, nine articles were included in this review. From the non- peer-reviewed literature, eight documents met the criteria for inclusion in this study. This review revealed the heterogeneity describing and defining the nature of PC-QIs. Most PC-QIs were presented as patient-centred care (PCC) measures and identified as guidelines, surveys, or recommendations, and therefore cannot be classified as actual PC-QIs. Out of 502 ways to measure PCC, only 25 were considered to be actual PC-QIs. None of the identified articles implemented the quality indicators in care settings.

Conclusion: The identification of PC-QIs is a key first step in laying the groundwork to develop evidence-based PC-QIs. Research is needed to continue the development and implementation of PC-QIs for healthcare quality improvement.

Keywords: patient-centred care, quality indicator, healthcare quality, quality improvement

Strengths

- Transparent and rigorous search strategy
- Involvement of patient partner in the study
- Study informed by a previously published protocool[9]

Limitations

- Search strategy using only English terms
- We did not assess the quality of the measures and/or indicators identified

INTRODUCTION

Patient-centred care (PCC) is one of the six dimensions of healthcare and was formally described by the Institute of Medicine in 2001 as *"healthcare that respects and responds to the preferences, needs and values of the individual patients throughout all healthcare decisions"*.[1] PCC is an approach that has become central to policies and programming to improve healthcare efficiencies and address patient safety issues. [2]

PCC is a model in which healthcare providers are encouraged to partner with patients and families to design and deliver individualized care. PCC models have been linked to positive patient experiences and improved outcomes, such as increased adherence to care and treatment.[3-5] In the literature, a PCC approach has been found to not only benefits patients, but also healthcare organizations in reducing costs, for instance through decreasing the length of hospital stays and readmission rates.[6 7] However, patient-centred care is conceptualized differently among different stakeholders, impacting effective implementation in care settings.[8] The adoption of a PCC model requires first, the identification of appropriate indicators to measure the quality of PCC, and second, the assessment of the impact of delivering PCC on healthcare system and patient outcomes.[9]

Quality indicators are tools that measure system performance and healthcare quality, and demonstrate the extent to which improvement efforts have led to desirable change, or contributed to unintended results.[10] As identified from the Agency for Healthcare Research and Quality (AHRQ), a quality indicator consists of: a specific aspect of quality being captured, and a method for how concepts of quality are captured (which includes: data source, measure type, observable event, specification and risk adjustment).[11] While various quality indicators have been developed to measure healthcare safety, effectiveness and access,[12] they typically do not incorporate the priorities and experiences of patients and family caregivers. To truly evaluate the impact of patient-centredness, indicators must reflect the patient and family caregiver perspective.

This scoping review aimed to synthesize existing literature on quality indicators used in the evaluation of patient-centred care. This review was guided by the questions: "What PC-QIs have been developed to measure patient-centred care?" "How are patient-centred quality indicators defined?" and "Have existing PC-QIs been implemented and evaluated across various points-of-care settings, processes of care, and at the systems level to measure patient-centred care?" The information gained from this study will inform the development of patient-centred care quality indicators that could be implemented to drive healthcare improvement valued by patients and families.

METHODS

We employed a scoping review protocol that was previously published,[13] using methodology based on Arksey and O'Malley's scoping review framework[14] and Levac *et al.*'s methodological enhancement.[15] We searched the peer-reviewed published and grey literature for either proposed or existing quality indicators that have been developed and/or implemented across various points-of-care settings to measure patient-centred care. For this scoping review, the Agency for Healthcare Research & Quality (AHRQ)[16] definition of a quality indicator was adapted to incorporate a patient and family focus. Specifically, a patient-centred quality indicator (PC-QI) was defined as the unit of measurement of healthcare system, organizational or individual performance, that quantify patients' and families' experiences with the care received and quantify the experience of any individual who needs to contact with healthcare services." In contrast, PCC measures are in the form of a survey, guideline, or recommendation.

Data sources and search strategy

In order to identify studies assessing quality indicators for patient-centred care, search strategies were developed that combined terms from two concepts: patient-centred care and quality indicators (supplemental file 1). The Cochrane Library, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), EMBASE, MEDLINE, PsycINFO, Social Services Abstracts, and Social Work Abstracts were searched from inception to May 2017. A search of the Google search engines, and the websites of relevant quality improvement and patient-centric organizations enabled the identification of relevant grey literature. Grey literature searches were conducted in duplicate by both a researcher and patient partner. The reference lists of included studies were also scanned to identify any other studies of relevance.

Citation management

All references were imported into a custom-written Java software application, Synthesis for reference management and data collection.[17] Duplicate citations were removed automatically by the software, with any mismatched duplicates removed manually if detected.

Study selection and data abstraction

To be eligible for inclusion, the study/article had to 1) identify quality indicators for PCC and/or 2) identify PC-QI in performance measurement (e.g., validation). The title and abstract of each citation identified was screened for eligibility independently by two reviewers (MJS, ML). The full-text of any abstract selected by either reviewer was retrieved and assessed for eligibility. Any full-text articles for which there was inter-rater discord were reviewed a second time, and final disagreements about study eligibility were resolved through discussion.

Data collection and Classification of Indicators

A data collection tool was developed and tested on a sample of papers to determine its practicality prior to the full review (supplemental file 2). Extracted data included study characteristics (country, year of publication, type of study/article), patients' inclusion in the development of indicators, and type of patient populations and point of care if applicable (e.g. in-patient, out-patient, primary care).

All extracted indicators were classified collaboratively by two authors (MS, SA) according to a person-centred care framework[18] developed by the team and guided by the Donabedian model of quality of care.[19] This framework provides a roadmap for healthcare systems to implement and measure PCC at the level of structure (the health care system/organizational level); process (the patient-healthcare provider interaction level), and outcome (the patient-health care provider, healthcare systems interaction level).[18]

Patient Involvement

Levac et al, recommends the involvement of stakeholders in the scoping review methodology.[15] We worked closely with our patient-research partner (SZ) in the design of the study who also aided in the search strategy. Our patient research partner aided in the clarification of research questions as well. The involvement of patient research partners allows for suggestions of additional references as well as the provision of insights beyond those in the literature.[15]

RESULTS

A total of 36,643 citations were retrieved, and upon duplicate removal, a total of 16,173 citations were reviewed at the title and abstract stage for inclusion (Figure 1). A total 184 full-text peer-reviewed articles were assessed for eligibility for inclusion; of these, nine articles were included in this review (Figure 1). From the non- peer-reviewed literature, following the title and document review, eight documents met the criteria for inclusion in this study (Figure 1). The most common reason for excluding articles (n=15,905) was the absence of indicators for PCC.

Article Description

Table 1 presents the characteristics of the full text articles included in the study. The years of publication ranged from 1996 to 2015. Included studies were published in Belgium (n=1), United States of America (n=2), Canada (n=3), United Kingdom (n=4), the Netherlands (n=4), and three sources did not include a country of publication. Sources were varied and included original peer reviewed research (n=8), guest editorial (n=1), reports (n=4), discussion paper (n=1), working paper (n=1), literature review (n=1), and a website (n=1). The study populations varied in the peer reviewed literature (e.g., cancer, fertility care, HPN, etc.) and no specific populations were identified in the non-peer reviewed literature.

"What PC-QIs have been developed to measure patient centred care?"

From the sources included, a total of 502 ways of measuring PCC were explicitly identified as quality indicators by studies' authors. However only 25 were classified as actual indicators by our research team.

PCC measurement varied between articles. While all sources used the term 'quality indicator', not all were quantifiable and measurable. Most sources presented quality indicators as guidelines or recommendations for healthcare practitioners. Wensing *et al.* presented indicators as survey items, such as "Does the GP pay attention to patients' needs?"[20] Actual indicators were presented as percentages and proportions, and identified from six grey literature sources.[21-26] For instance, one study outlined an example of a structure indicator - "Percent of nurses attending education sessions (orientation, organization professional development opportunities) on client centred care."[25]

Study populations included cancer patients (n=2), colonoscopy patients (n=1), home parenteral nutrition patients (HPN) (n=1), chronically ill (n=1), fertility care (n=1), and assisted living support patients (n=1) (Table 1). For the development of PCC measures, seven studies used focus groups, interviews, and/or consensus meetings, ten studies included patients and family caregivers in the development of PCC measures, and one article developed measures through the authors' clinical and research work. Two sources developed ways to measure PCC from patient reported experience surveys,[24 27] and two studies used a framework.[25 28]

Some studies grouped ways to measure PCC according to domains of patient-centred care that were based on previously defined frameworks or through consensus (e.g., access to care, communication and information). Domains identified from the person-centred care framework are categorized according to structure, process, and outcome.[18] Table 2 presents examples of measuring PCC classified according to the person-centred care framework,[18] and Table 3 presents the actual indicators classified according to the same framework.[18]

Table 1. Characteristics of Articles on Patient-Centred Quality Indicators

Study identifier (first author)	**Country**	**Year**	**Study Type**	**Population**	**Patients involved**	**Number of Indicators & ways to measure PCC**
Peer reviewed literature (n=9)						
den Breejen et *al.*[29]	Netherlands	2013	Focus groups/interviews/ consensus meetings	Fertility care	Yes	34
Dreesen et *al.*[30]	Belgium	2014	Focus groups/interviews/ consensus meetings;	Home parenteral nutrition (HPN) patients	Yes	33
Ouwens et *al.*[31]	Netherlands	2010	Focus groups/interviews/ consensus meetings;	Cancer- Non-small cell lung carcinoma	Yes	54
Sewitch et *al.*[32]	Canada	2013	Focus groups/interviews/ consensus meetings; Surveys	Colonoscopy patients - adult	Yes	20

Uphoff et *al.*[33]	Netherlands	2012	Focus groups/interviews/ consensus meetings	Cancer	Yes	21
Wensing et *al.*[20]	Netherlands	1996	Focus groups/interviews/ consensus meetings; Surveys	Chronically ill patients (chronic obstructive pulmonary disease, diabetes, cardiovascular disease, migraine, chronic disease of locomotor system)	Yes	41
Zimmerman et *al.*[34]	USA	2014	Focus groups/interviews/ consensus meetings	Community-based, assisted living support patients	Yes	43
Cox et *al.* [35]	United Kingdom	2014	Guest editorial	-	-	4
Carinci et *al.* [28]	United Kingdom	2015	Modified Delphi approach/consensus meeting	-	-	12
non-peer reviewed Literature (n=8)						
Steven Lewis[26]	Canada	2009	Discussion paper	-	-	6
RNAO[25]	Canada	2002	Guidelines document/report	-	-	18
Silow-Carroll et *al.*[36]	USA	2006	Report	-	-	6
Kelley & Hurst (OECD)[24]	-	2006	Working papers	-	Yes	7
OECD[27]	-	2006	OECD website	-	Yes	8
Essence of Care- Patient Focused benchmarks for clinical governance (NHS)[22]	United Kingdom	2003	Report	-	Yes	116
Davies et *al.*[23]	United Kingdom	2009	Report	-	-	10
IAPO[21]	-	2012	Literature review	-	-	69

PCC, Patient-Centred Care
OECD, Organization for Economic Co-operation and Development
NHS, National Health Services
RNAO, Registered Nurses Association Ontario
IAPO, International Alliance of Patients' Organizations

Table 2. Examples of PCC measurement classified according to the person-centred care framework.[18]

PCC Measure Classification	Domain	Example of ways to measure PCC
Structure (n=80)	Supporting a workforce committed to Patient-Centred Care (PCC)	• The development needs of health care personnel are met by ongoing review through supervision, appraisal and individual development plans[22] • All staff and volunteers can articulate person-centred principles and practices applicable to their role(s) and demonstrate their implementation[34]
	Providing a supportive and accommodating PCC environment	• Residents have a choice of a private room[34] • Patient satisfaction survey translated into Spanish[35]
Process (n=343)	Cultivating Communication	• (Regular) doctor involving patients in decisions about care or treatment[27] • Making use of open-ended questions in a conversation with the patient[33] • Patient had the knowledge and support to make decisions[31] • Regular doctor providing easy-to-understand explanations[28]
	Respectful and compassionate care	• Patient received emotional support from nurses if needed[31] • Giving confidence to the patient[30] • Does the GP pay attention to patients' needs?[20]
Outcome (n=79)	Patient-Reported Outcomes (PROs)	• Measures are in place to assess and provide feedback on the interpersonal skills of health care personnel[22] • Regarding infertility treatment, patients would like to see all members of the infertility treatment team following the same policy[29]

Table 3. Identified Patient Centred Quality Indicators from the literature classified according to the person-centered care framework as actual indicators[18]

Type of Indicator	Domain	PCC Indicators (n=25)
Structure	Creating a PCC Culture	• An induction programme is in place which promotes the philosophy of care [22] • % of PHC organizations who currently have processes to involve community input for planning the organization’s services (e.g. advisory committees, focus groups[21]

		- Clear policies are in place on how services are offered to patients[21]
	Supporting a workforce committed to PCC	- Percent of nurses attending education sessions (orientation, organization professional development opportunities) on client centred care[25] - Percent of non-nursing staff attending education sessions (orientation, organization professional development opportunities) on client centred care[25]
Process	Cultivating Communication	- % of patients with access to an on-line HER a) By region b) By practice[26] - Proportion of service users who stated that the district nurse provided health advice or information about his/her condition[23] - Proportion of service users who stated that they were involved as much as they wanted to be in decisions about their care and treatment[23]
	Respectful and compassionate care	- Proportion of service users who stated that their district nurse treated them with respect and dignity[23] - % of inpatients who said they were always treated with respect and dignity while in hospital/primary care[21]
	Engaging patients in managing their care	- % of PHC clients/patients, 18 years and over, with a chronic condition(s), who actively participated in the development of a treatment plan with their PHC provider over the past 12 months[21] - % of hospital patients who said they had been sufficiently involved in decisions about their care as much as they wanted to be[21] - Percent of nurses self-reporting: Adequate assessment of a client's perceived needs for care, adequate assessment of a client's goals for care, adequate documentation of a client's personal goals for care, sharing client's concerns/choices with other members of the health care team, discharge teaching guided by the client's goals for managing their care at home[25]
	Integration of Care	- % of hospital patients taking medicines home after discharge who were told completely about the purposes of the medicine in a way they could understand[21]

	Access to Care	• % of patients who can get all diagnostic work ordered by their primary care doctor done the same day in the same location (excluding certain high-technology procedures such as CT and MRI)[26] • Percentage of outpatients seen within 13 weeks of GP referral[24] • Percentage of those on waiting list waiting 12 months or more[24] • Proportion of service users who were able to contact a district nurse when needed, including outside of normal working hours[23] • The percentage of patients who, in the appropriate national survey, indicate that they were able to obtain a consultation with a GP or appropriate health care professional within 2 working days (NHS Confederation, UK)[21] • % of PHC clients/patients, 18 years and over, with a chronic condition(s), who had sufficient time in most visits to confide their health-related feelings, fears and concerns to their PHC provider[21]
Outcome	Patient-Reported Experiences (PREMs)	• Proportion of service users who stated that the district nurse had all the necessary information about the service user and his/ her health needs[23] • Proportion of service users who stated that the district nurse had all the equipment and dressings needed[23] • Proportion of service users who stated that the district nurse was knowledgeable and competent[23] • Proportion of service users who rated the district nurse service as very good or excellent[23] • Proportion of children whose parents routinely received all aspects of family centred care (Child and Adolescent Health Measurement Initiative)[21]

PHC, Primary Healthcare
HER, Health Electronic Record
CT, Computed Tomography
MRI, Magnetic Resonance Imaging
GP, General Practitioner
NHS, National Health Services
UK, United Kingdom

How are patient-centred quality indicators defined?

The definition of a PC-QI was not clearly articulated in the studies identified (Table 4). Ten of the included studies provided no such definition of a quality indicator (Table 4). Sources where the definition of a quality indicator was mentioned defined indicators as something to be measured, and developed through consensus (Table 4).[23 30 31 33] Of those four sources where the definition of a PC-QI was clear, two included actual indicators.[21 23] The National Health Services (2003) report described indicators as 'items that patients, carers and professionals believed were important in achieving the benchmarks of best practice." [22]

Have the existing patient-centred quality indicators been implemented and evaluated across various points-of-care settings, processes of care and at the system level to measure patient-centred care?

None of the articles mentioned actual implementation of indicators in the settings for which they were developed. Similarly, many of the sources (15/17) did not evaluate the indicators according to any set criteria. The two studies that did evaluate indicators, used two different approaches.[28 31] The study by Ouwens et *al.* assessed guidelines for psychometric characteristics and only 26 out of 56 guidelines were found to be reliable.[31] The study by Carinci et *al.* used a modified Delphi approach with expert Organization for Economic Co-operation and Development (OECD) members to rate the PCC measures, using validity, reliability, relevance, actionability, international feasibility, and international comparability as the criteria.[28] Uphoff et *al.*, recommended using the Gol & Grimshaw model for evaluating indicators,[33] while a future direction for Zimmerman et *al*. was the evaluation of the indicators.[34] The working paper by Kelley and Hurst presented criteria that can be used to select indicators.[24] These included the importance of what is being measured (which includes policy importance), scientific soundness, and feasibility of the measure.[24]

Table 4. Definition of quality indicator used by authors

Study Identifier (First Author, year)	**Definition of quality indicator used**
(den Breejen et *al*, 2013),[29] (Sewitch et *al*, 2013),[32] (Uphoff et *al*, 2012),[33] (Zimmerman et *al*, 2014),[34] (Cox et *al*, 2014),[35] (Lewis, 2009),[26] (RNAO, 2002),[25] (Silow-Carroll et *al*, 2006),[36] (Kelley & Hurst, 2006),[24] (OECD website, 2006),[27] (Carinci et *al*, 2015)[28]	Definition not included
(Dreesen et *al*, 2014)[30]	A quality indicator as a measurable element of practice performance for which there is evidence or consensus that it can be used to assess the quality of care, and hence change the care provided.[37]
(Ouwens et *al*, 2010)[31] (Uphoff et *al*, 2012)[33]	Quality indicators are 'measurable elements of practice performance for which there is evidence or consensus that they can be used to assess the quality of care'[38]

(Davies et *al*, 2009)[23]	An explicit measureable statement of the quality of care given. Relates to a single outcome or process of medical care. Clearly defined and unambiguous.[38 39]
(NHS, 2003)[22]	Items that patients, caregivers and professionals believed were important in achieving the benchmarks of best practice.[22]
(IAPO, 2012)[21]	Can be measures of structure, process and outcome, either as generic measures relevant for all diseases, or disease-specific measures that describe quality of patient care related to a specific diagnosis.[40]

OECD, Organization for Economic Cooperation and Development
NHS, National Health Services
IAPO, International Alliance of Patients' Organizations

DISCUSSION

This review specifically examined existing PC-QIs in the academic and grey literature. Patient-centred care has been increasingly adopted by many jurisdictions, however this review revealed there to be gaps in the conceptualization of PC-QIs. Out of the 17 articles that met the inclusion criteria, only 9 were peer reviewed, and looked at specific conditions. Additionally, the heterogeneity of the PCC literature relates to the variety of definitions on PC-QIs, and a diverse type of indicators developed for different patient population and care-settings. For instance, all included articles in the review used the term 'indicator,' but not all presented actual indicators as defined by the Agency for Healthcare Research & Quality (AHRQ).[16]

The absence of a standard definition of what a PC-QI is in the literature has posed challenges in identifying the literature sources for inclusion in this review. 'Quality' means different things to different people, and despite the standard definition of PCC by the Institute of Medicine,[1] PCC continues to be operationalized and measured differently.[41] Most sources identified in the literature did not explicitly define what a quality indicator is, which may explain the differences in approaches to indicator development. The absence of a definition for quality indicators results in inconsistencies for how an indicator should be presented and also what makes for a good indicator. Previous reviews have also found variability in quality indicator definitions, such as indicators for hip fracture patient care.[42] The absence of a standard definition of PC-QIs poses concerns for standardized measurement of PCC, and for implementation of PC-QIs in healthcare settings.

In compliance with quality improvement agencies, quality councils and organizations such as the AHRQ, quality indicators should be presented as a unit of measurement - as a percentage or proportion.[16] Our review revealed inconsistencies in the definition of indicators. Only few sources in the non-peer reviewed literature included PC-QIs as quantifiable units, such as percentages, incorporating a numerator and denominator in the unit of measurement.[43] Most of the identified indicators were actually domains included in PCC measures and guidelines. The lack of defined units of measurement impedes comparisons across facilities, and benchmarking, and doesn't allow for longitudinal evaluation and overall measurement of care that is patient-centred. Without this unit of measurement for PC-QIs, it is difficult to target specific improvements needed for PCC.

The review revealed that when incorporating the patient and caregiver perspective in quality improvement, a difficulty exists in translating perceptions and subjective experiences into standardized objective indicators. Measures of well-being are both necessary and important to incorporating a PCC model of care. The study by Carr et *al.* suggests that perceptions of health and its meaning vary between individuals and across time, as do their experiences and expectations of healthcare.[44] In order to capture various perspectives on quality care, it is vital to include patients and families. Including the patient and family perspective is necessary to ensure quality patient-centred care.

Additionally, this review found large variances for domains to categorize approaches to measuring PCC. In an attempt to organize our findings and understand the ways of measuring PCC, we used a previously published person-centered care framework[18] to classify them into healthcare quality domains. From this classification, most strategies for measuring PCC were found to relate to domains associated with healthcare processes (e.g. cultivating communication). These findings are consistent with the current measurement landscape, for instance trauma indicators,[45] and AHRQ PC-QIs[46] which mainly assess processes and outcomes. For PCC, structures, such as policies and education programs can provide an important basis to improve PCC practice.[18 47] Structure indicators provide the necessary foundations for the assessment of process and outcome indicators, for instance through creating a PCC culture, supporting the workforce to deliver PCC, and providing an accommodating environment for patients.[18] In this review, structure indicators were lacking.

Finally, there is scarce evidence in the literature on how to implement indicators for PCC, and how to evaluate their implementation. PCC measurement has, to date, primarily focused on specific disease conditions and healthcare sectors. However, recent initiatives, (National Health Services) reveal a more generic approach to measurement (Family and Friend Test).[48] In order to create a standardized set of PC-QIs, indicators must be developed across the continuum of care. Santana & Stelfox. also found a lack of implementation of indicators in care settings in their review.[45] Before indicators are implemented, they must be evaluated according to standard set criteria. What constitutes as a good indicator has been outlined by health quality organizations, such as National Quality Forum. As outlined by the National Quality Forum, quality indicators should be evaluated through a set criterion including: importance, scientific acceptability, feasibility, and usability and use.[49] Our review did not identify any studies where such evaluations were implemented. In the development and implementation of quality indicators, the guideline set by the National Quality Forum should be adhered to.

The gaps identified in the literature for patient-centred quality indicators provide directions for future research. First, there needs to be consensus on a standard definition of patient-centred quality indicator to guide future measurement of patient-centred care. Second, there is a need to develop a standard set of PC-QIs that could be implemented in various healthcare settings. Third, PC-QIs need to be evaluated according to a set criteria. Lastly, PC-QIs need to be implemented across healthcare settings for monitoring and evaluation of PCC.

Strengths and Limitations

Our scoping review used robust and transparent methods guided by a protocol previously published,[13] and supported by a research librarian with expertise in knowledge synthesis and scoping reviews (DLL). We worked closely with our patient research partner (SZ) in the study design, research questions, search strategy and manuscript preparation.

This review may not have identified all relevant sources in the published and grey literature as we conducted the search using only English terms. As we are following the scoping review methodology, the quality of the studies was not assessed.

Conclusions

In summary, our review is the first to examine the literature pertaining to quality indicators that are patient-centric. Our findings will further the development of validated healthcare tools assessing healthcare quality from a patient-centred approach. Future research should focus on developing and refining PC-QIs that are ready to implement and evaluate following the criteria set forth by the National Quality Forum.[49]

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Details of contributors:

MJS conceived the study, and all authors identified key literature to be included in the review. MJS led the drafting of the manuscript and key discussion points with support from DL, RJJ, SA, ML and KM. SA managed the design of the tables (with feedback from all authors), and management of references. All authors provided important intellectual contribution and guidance throughout the development of the manuscript. HQ, DL, SZ, and ML provided guidance on the presentation of the findings and guidance on final revisions. All of the authors contributed to critical review and revisions to the manuscript, agreeing on the final version.

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All authors had access to the data (literature identified and tables) in the study and assume responsibility for the integrity of the data and the accuracy of the data analysis.

The lead author* affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

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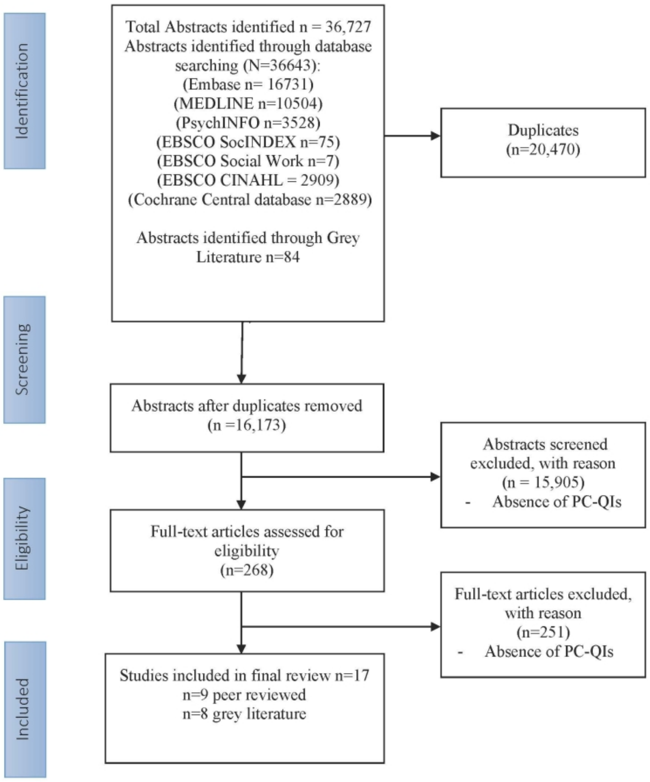
Figure 1. **Flow Diagram for study inclusion**

Figure 1- Flow Diagram for study inclusion



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Patient Centered Quality Indicators Search Strategies

MEDLINE

1. exp patient-centered care/

2. Culturally Competent Care/ or exp ethnic groups/

3. ((carer* or care giver* or caregiver* or client* or culture* or cultural* or ethnic* or family or families or indigenous or parents or patient* or person or racial* or ethnocultural* or immigrant* or refugee* or migrant*) adj5 (centered* or centred* or focused) adj5 (care or healthcare or nursing or medical or medicine)).tw.kw.kf

4. cultural competency/ or patient satisfaction/ or patient preference/

5. exp Patient Rights/

6. ((carer* or care giver* or caregiver* or client* or cultural* or culture* or ethnic* or family or families or indigenous or parents or patient* or racial* or ethnocultural* or immigrant* or refugee* or migrant*) adj5 (advocacy or autonomy or beliefs or choice or perspectives or preferences or rights or satisfaction or values or views) adj5 (care or healthcare or nursing or medical or medicine)).tw.

7. ((cultural* or ethnic* or racial* or ethnocultural* or immigrant* or refugee* or migrant*) adj10 (competency or competent care)).tw.

8. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8

9. exp Quality Indicators, Health Care/

10. benchmarking/ or clinical audit/

11. (performance measure* or (healthcare adj3 monitor*) or performance reporting or QI or PQI or (quality adj3 criteria) or (quality adj3 indicator*) or (quality adj3 measure*) or (quality adj3 scale*)).tw,kw.

12. Guideline Adherence/

13. 10 or 11 or 12 or 13

14. 9 and 14

15. limit 15 to yr="1990 -Current"

16. limit 16 to yr="2015 -Current"

CINAHL (EBSCO)- Patient Centered Quality Indicators Search Strategies

1. (MH "Patient Centered Care") OR (MH "Gender Specific Care") OR (MH "Transcultural Care") OR (MH "Cultural Competence") OR (MH "Transcultural Nursing") OR (MH "Family Centered Care") OR (MH "Patient Satisfaction") OR (MH "Patient Rights+") OR (MH "Patient Advocacy")
2. TI (((carer* or care giver* or caregiver* or culture* or cultural* or family or families or parents or patient* or person) N5 (centered* or centred* or focused) N5 (care or healthcare or nursing or medical or medicine))) OR AB (((carer* or care giver* or caregiver* or culture* or cultural* or family or families or parents or patient* or person) N5 (centered* or centred* or focused) N5 (care or healthcare or nursing or medical or medicine)))
3. TI (((carer* or care giver* or caregiver* or cultural* or culture* or family or families or parents or patient*) N5 (advocacy or autonomy or beliefs or choice or perspectives or preferences or rights or satisfaction or values or views) N5 (care or healthcare or nursing or medical or medicine))) OR AB (((carer* or care giver* or caregiver* or cultural* or culture* or family or families or parents or patient*) N5 (advocacy or autonomy or beliefs or choice or perspectives or preferences or rights or satisfaction or values or views) N5 (care or healthcare or nursing or medical or medicine)))
4. TI ((cultural competency or culturally competent care)) OR AB ((cultural competency or culturally competent care))
5. 1 or 2 or 3 or 4
6. (MH "Clinical Indicators") OR (MH "Benchmarking") OR (MH "Clinical Governance") OR (MH "Guideline Adherence") OR (MH "Performance Measurement Systems") OR (MH "Quality Assessment") OR (MH "Quality Patient Care Scale")) OR TI ((performance measure* or (healthcare N3 monitor*) or performance reporting or QI or PQI or (quality N3 criteria) or (quality N3 indicator*) or (quality N3 measure*) or (quality N3 scale*))) OR AB ((performance measure* or (healthcare N3 monitor*) or performance reporting or QI or PQI or (quality N3 criteria) or (quality N3 indicator*) or (quality N3 measure*) or (quality N3 scale*)))
7. 5 and 6

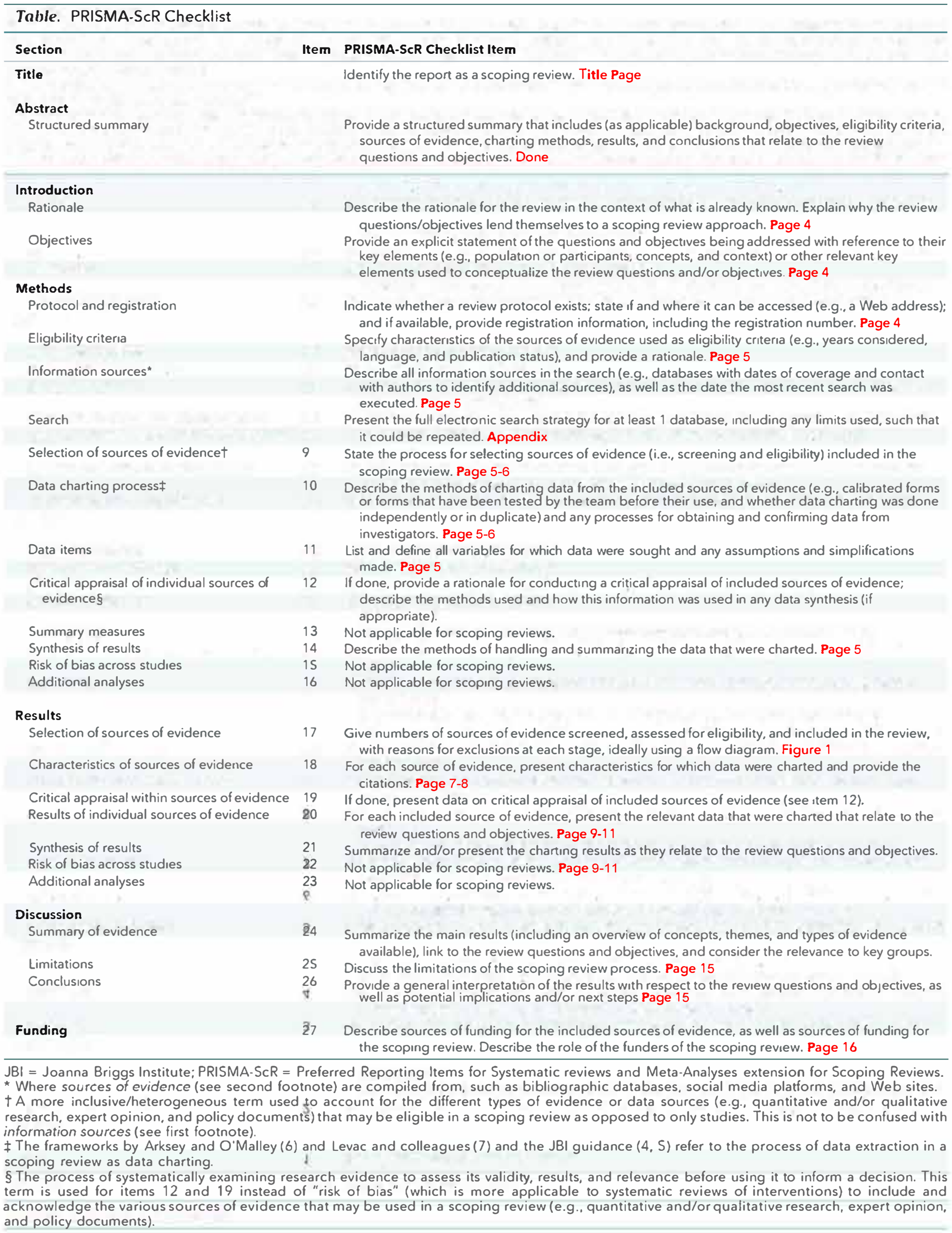

Table. PRISMA-ScR Checklist

Section	Item	PRISMA-ScR Checklist Item
Title		Identify the report as a scoping review. Title Page
Abstract		
Structured summary		Provide a structured summary that includes (as applicable) background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives. Done
Introduction		
Rationale		Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach. Page 4
Objectives		Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives. Page 4
Methods		
Protocol and registration		Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number. Page 4
Eligibility criteria		Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale. Page 5
Information sources*		Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed. Page 5
Search		Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated. Appendix
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review. Page 5-6
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators. Page 5-6
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made. Page 5
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).
Summary measures	13	Not applicable for scoping reviews.
Synthesis of results	14	Describe the methods of handling and summarizing the data that were charted. Page 5
Risk of bias across studies	15	Not applicable for scoping reviews.
Additional analyses	16	Not applicable for scoping reviews.
Results		
Selection of sources of evidence	17	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram. Figure 1
Characteristics of sources of evidence	18	For each source of evidence, present characteristics for which data were charted and provide the citations. Page 7-8
Critical appraisal within sources of evidence	19	If done, present data on critical appraisal of included sources of evidence (see item 12).
Results of individual sources of evidence	20	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives. Page 9-11
Synthesis of results	21	Summarize and/or present the charting results as they relate to the review questions and objectives.
Risk of bias across studies	22	Not applicable for scoping reviews. Page 9-11
Additional analyses	23	Not applicable for scoping reviews.
Discussion		
Summary of evidence	24	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.
Limitations	25	Discuss the limitations of the scoping review process. Page 15
Conclusions	26	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps Page 15
Funding	27	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review. Page 16

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy documents).